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THE PROMISE OF MENTAL HEALTH RESEARCH

HEARING

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDRED SECOND CONGRESS

SECOND SESSION

ON

EXAMINING MENTAL HEALTH RESEARCH ISSUES, FOCUSING ON THE TREATMENT OF SEVERE AND PERSISTENT MENTAL ILLNESS, AND RECENT RELATED REPORTS FROM THE OFFICE OF TECHNOLOGY ASSESSMENT AND THE NATIONAL ADVISORY MENTAL HEALTH COUNCIL

SEPTEMBER 15, 1992

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Tuesday, September 15, 1992

THE PROMISE OF MENTAL HEALTH RESEARCH

TUESDAY, SEPTEMBER 15, 1992

U.S. SENATE,
COMMITTEE ON LABOR AND HUMAN RESOURCES,
Washington, DC.

The committee met, pursuant to notice, at 11:13 a.m., in room SD–430, Dirksen Senate Office Building, Senator Edward M. Kennedy (chairman of the committee) presiding.

Present: Senators Kennedy, Pell, Simon, Bingaman, Wellstone, Hatch, Thurmond, and Durenberger.

OPENING STATEMENT OF SENATOR WELLSTONE

Senator WELLSTONE [presiding]. The Labor and Human Resources Committee will come to order.

Let me just announce at the beginning that Senator Kennedy will be here shortly; he is still down on the floor.

Today, we are going to be focusing on the promise of mental health research, and we will start out with four excellent panelists: Rod Steiger, the Academy Award-winning actor, who currently lives in California—we thank you very much for being here, Mr. Steiger—Eleanor Guzzio, from Chicago, IL; Eileen Trainor, from Melrose, MA, and Rebecca Viers, from Albuquerque, NM. Mrs. Viers is accompanied today by her daughter Jessica.

I would like to welcome each of the panelists. We'll start with Mr. Steiger. At this point, I would like to defer to the ranking minority member, Senator Orrin Hatch, from Utah.

OPENING STATEMENT OF SENATOR HATCH

Senator HATCH. Thank you, Senator Wellstone.

Senator Kennedy is over on the floor where he is managing S. 2, which is an education bill and a very important one at that, so that is why he is having difficulty getting here right now.

Mr. Chairman, for far too long, the ravages of mental illness have not been fully appreciated in our society. The hearing today marks the opportunity to draw the country's attention to the toll on families from these "hidden" disorders.

One in five Americans will suffer a mental disorder ranging from minor depression to full blown psychosis in his or her lifetime. Over 2 million individuals in this country are currently afflicted by a persistent or severely disabling mental disorder. A good example would be schizophrenia. And nearly 5 percent of Americans will suffer from major depression at one time or another during their lives.

Today we will hear the real life struggles of four individuals who have the courage, which I want to publicly applaud, to share their stories with our committee, and thus with the world.

The hope for these families, as well as for countless millions who suffer, is our Nation's investment in research. Mr. Chairman, we have recently taken a step toward strengthening our research efforts with passage of legislation reauthorizing Federal programs for both treatment and research. The chief focus for these important research endeavors is, of course, the National Institute of Mental Health, under the leadership of my good friend, Dr. Fred Goodwin, who I think is without peer in this field and is a great advocate for all of us.

A reorganization incorporating the NIMH into the National Institutes of Health means that the importance of research into the causes and treatment of mental health has been reaffirmed by Congress and the Bush administration and made an integral part of our Nation's biomedical research effort.

Such efforts will help destigmatize mental illness. Such disorders must be examined in the context with other diseases. Reports by the Office of Technology Assessment and the National Advisory Mental Health Council document the continuing stigma attached to mental illness. It is time for all of us Americans to get rid of that stigmatization and to realize that many, many millions of people suffer at one time or another from these difficulties and that they can be helped.

Mr. Chairman, I want to commend our Chairman, Senator Kennedy, you, and others on this committee for finding time in the waning moments of the 102nd Congress for today's hearing. The committee's examination of this health problem will help us and all Americans to better understand the effects of mental illness.

I am happy to welcome all of our witnesses this morning and appreciate their taking time to be here. I certainly look forward to the testimony of each and every one of you.

The first panel is especially important. We are really looking forward to hearing each one of your testimonies. I have met you, and I feel very good that you would take the time and have the courage to come here today and talk about these serious problems.

Mr. Steiger, I want you to know that I have long looked upon you as one of the truly greatest actors this country and this world has ever had, and from all I know, you are a great human being as well. So, for you to come and to be willing to discuss the problems that you suffer and that you were afflicted with, I think is a matter of great courage and great example on your part. There are millions of people who will benefit from the five of you testifying here today and the others who will testify. Millions of people will understand that people just like themselves can be afflicted with these problems and that they can get help.

So, your testimony is very important. I just want to personally thank each and every one of you for being here today.

Thank you, Mr. Chairman.

Senator WELLSTONE. Thank you, Senator Hatch.

We have two panels testifying today. If I could just add one word and then move on to Senator Thurmond, I appreciate what Senator Hatch said. I was at a gathering Saturday night which was in honor of Pete Domenici, held by the National Alliance for Mental Health. The interesting thing about that gathering was that it wasn't just to honor Senator Domenici, but there were probably several thousand people there. And I think what Senator Hatch said is very important, but of course, we have a long way to go. I mean, the stigma is there. There is the funding for research; there are also so many people who should not be incarcerated, but they are, and it is because of problems they have with mental illness; there are so many people who are street people, who should not be street people. And unfortunately, all too often when we debate health care policy, and we write health care legislation, we think that the mental health part is the icing on the cake, that it is somehow not really part of health care in this country. And from what we do with national insurance, or any kind of health reform bill, and what we do in terms of insurance regulation or insurance reform, I think this is an area where there is starting to be change. I think people are starting to speak out, I think people are starting to show a lot of courage, and I really believe that we are going to see some great changes, and I really appreciate your being here.

Senator Thurmond.

OPENING STATEMENT OF SENATOR THURMOND

Senator THURMOND. Thank you, Mr. Chairman.

Mr. Chairman, it is a pleasure to be here this morning to receive testimony on the promise of mental health research in this country.

I wish to also join the chairman in welcoming all the distinguished witnesses who appear before us today. I know their testimony will prove very valuable to the committee.

I especially want to take this opportunity to welcome to the committee a fellow South Carolinian, Mrs. Peatsy Hollings, a distinguished member of the National Advisory Mental Health Council and wife of Senator Hollings. I appreciate the fine work, Mrs. Hollings, that you and the other members of the council are doing in bringing attention to various mental health issues in this country. I know the council has worked hard in preparing this report on mental illness in America, and I am sure their findings and recommendations will be of great value to the committee.

Understanding the causes of mental illness and developing new and better ways to treat such illnesses is very important. It seems that one of the keys to understanding mental illness, like so many other things, is education. Certainly, the testimony received today will be a valuable part of this educational process.

Mr. Chairman, again, it is a pleasure for me to be here. I have another appointment; I must speak to a military group at 11:30, so I'll have to leave in a few minutes, but I will take care to read this testimony, and I want the witnesses to know I appreciate your coming today.

Thank you, Mr. Chairman.

Senator WELLSTONE. Thank you, Senator Thurmond.

We'll move along with some other quick statements so we can get to the panelists.

Senator Durenberger.

OPENING STATEMENT OF SENATOR DURENBERGER

Senator DURENBERGER. I will be quick, and I will ask unanimous consent that my statement be made part of the record. I must say publicly that the panelists aren't the only people who are going to be here today. There are literally hundreds of thousands of Americans who have been involved in the process that led to the report that is being released. About 500, as I recall, were involved at one time in our home State of Minnesota, out in Marshall, MN, which was one of the rural settings where the advisory council sought to gather information. What moved me was the wide variety of people whose own particular concerns for mental illness brought them to this small town in the middle of Minnesota.

The stories we heard that day from the Indian reservations of South Dakota to the most remote part of our communities are still with me, as are all of the personal experiences we've had.

My second observation is that there are a couple of Senators and Senators' spouses who are involved directly here today and there are many more who are involved in other ways. I don't know that it afflicts us peculiarly, as opposed to other professions, but there is something special about the commitment that the members and their families have made to dealing with this, which I think is important and, hopefully, will make a big, big difference.

Thank you, Mr. Chairman.

Senator WELLSTONE. Thank you, Senator Durenberger, for your very sensitive remarks. Your full statement will be included in the record without objection.

[The prepared statement of Senator Durenberger follows:]

PREPARED STATEMENT OF SENATOR DURENBERGER

Good morning, Mr. Chairman, and good morning, everyone.

I remember two and a half years ago being in Marshall, MN, to testify before the National Advisory Mental Health Council panel that wrote the report we will hear about today. We talked about tragedies: depression, teen suicide, the stigma that too many still attach to mental illness. What was remarkable was the attendance——300 to 400 people. And this was in a very rural part of western Minnesota, where in early April everybody's mind is on spring planting.

It was another reminder to me that mental illness is everywhere. So too is heart disease and cancer, but it's a lot easier to say "My wife has heart failure" than to say "My wife has schizophrenia." There's still so much stigma to mental illness, and it' so unnecessary, so unfair.

How we phrase things can be so revealing. Instead of saying "My wife has schizophrenia," many people would say "My wife *is* schizophrenic"——or manic depressive or compulsive or whatever. It's as if schizophrenia were her essential characteristic. We wouldn't say that about heart disease or cancer.

The testimony we will hear and the reports we will receive will help break down the ignorance and prejudice that people with mental illness face every day.

Our first panel of witnesses are brave, selfless people who are willing to share painful experiences in the hope that others will learn from them. The second panel comprises authors of reports that emphasize the biological nature of serious mental illness.

We have learned a lot in recent years about the origins and treatment of mental illness. When we look back at how we treated patients 30 years ago, we're appalled at how much we blamed the victims and their families and at how often the "treatment" amounted to warehousing in mental hospitals.

With assistance from people like those testifying today, attitudes will continue to improve——and I just hope it will happen faster in the next 30 years than it has in the last 30 years.

Now I look forward to learning from the testimony of our witnesses.

Thank you.

Senator WELLSTONE. Senator Simon.

OPENING STATEMENT OF SENATOR SIMON

Senator SIMON. Thank you, Mr. Chairman.

I want to thank the panel and everyone who has been participating. I go back to my years when I was a member of the Illinois General Assembly, when it was a different era, when higher education was getting all the money they wanted, and we were having a tough time getting money for mental hospitals. I remember the question was asked on the floor of the house why, and half in jest, half not in jest, someone responded that the universities have more active alumni associations.

One of the things that we need, and why I particularly appreciate this panel, is we need people to stand up. Why do we spend less on mental health research relative to every other disabling disease? Well, it is because if you or someone in your family has cancer, or arthritis or diabetes, we stand up. But there is still, unfortunately, a stigma with mental illness, and we don't stand up and demand what we should.

So I particularly appreciate what the members of this panel are doing, and I am proud to have Eleanor Guzzio from Illinois as one of the members of the panel. But to all of you and to your counterparts who more and more are standing up, I think that is absolutely essential, and I just want to commend you for doing so.

Thank you, Mr. Chairman.

Senator WELLSTONE. Thank you, Senator Simon.

Mr. Steiger.

STATEMENTS OF ROD STEIGER, MALIBU, CA; ELEANOR GUZZIO, EVANSTON, IL; REBECCA AND JESSICA VIERS, ALBUQUERQUE, NM; AND EILEEN TRAINOR, MELROSE, MA

Mr. STEIGER. Thank you, gentlemen.

I am here to try to take you on a little trip through an experience, and I hope you will indulge me. I am very flattered to be here, and I will begin.

I want to die. I don't want to move. I have no feeling for movement. To be left alone. To disappear. Not to be bothered with washing, shaving, talking, walking or going to the bathroom. Just to get out of this tunnel and the heavy darkness, the cold, the oily, the constantly pressing against my brain, and feeling the way that this scum, grease, tallow, pushes against my sides, crushing you. You, dead-eyed, gray-faced, unshaven, dirty of body, and empty of mind.

Acting—oh, what is so important about acting? The paralyzing fear of not remembering a line, projections, images, visions of failure. They are watching. They are watching. I can feel them on my body. I can feel their eyes all over my skin. And it is time to act. And the crew is watching. Thirty of them are watching. The director is watching. My partner in the scene is watching. A rat in the corner of the studio is watching. And I will not be able to do it. I will not be able to remember. And they are going to discover that I am inadequate, I am unable.

I must not scream. I must not scream in front of them. I must stay. I must not, I must not listen to my mind. I must not, I must not run off the set. I must not run. I must not run.

I know I'll break down. I'll break down, and they'll find out I am weak, and they will find out I am in pain. Oh God. What God? I will break down. I'll look like a fool, an idiot, and they'll find out I can't act. I can't act. I can't act at all.

End of vision—but there is a way out. My mind is telling me there is a way out. You get a gun, a nice, cool gun. And then—wait, now—you mustn't make a mess. I'm worried. I'm worried about the mess—the head half gone, the blood on the walls, the carpet, the flower, all over the cat—and I don't want my loved ones to walk in on that.

But there is a way. There is a way. I live by the beach. And they are waiting, the waves, ever moving, relentless ocean. I'll get a small rowboat while my wife is in town doing business, and my daughter is in Europe, so she won't know until later. I'll row out on the ocean. I'll lower myself over the side of the boat, holding tightly with my right hand to the boat, keeping my head and shoulders above the water, holding with my left hand, the gun, pointing toward God's sky. And then I will lower the gun, I'll take the barrel in my mouth and pull the trigger, and then, I rest. I rest. The boat floats away. My body floats away from it. There is no mess, no mess, just fish food.

It's strange—I am more worried about the mess than my life. I rest. I rest. Oh, yes, there is a way, there is a way.

My wife, Paula—oh, God, my poor wife, Paula—who, through 8 years of my twisting, freezing fog, heroically kept my head above the waters of insanity, tending me like a crippled child, never criticizing, never, never, never in frustration raising her voice, shouting or screaming with fury that comes with the fear of the unknown. Never has she tearfully begged or demanded her release or relief, saying, "How can you sit there like that? What's wrong with you? What kind of a man are you? How can you let yourself look like that?" Never. Always, with the never-ending stretching of patience, kindness, motherhood and maternity, she more than gently took care of me. Never, never, never reminded me of my illness, my chemical imbalance—chemical imbalance—isn't that the phrase that the doctors use? And that, Paula, that love, that patience, that preserving shield kept me from suicide one more time.

I sit in the squalor of myself. Movement is my enemy. I sit, staring at the sea, the sun. I sit, numb, drowning in self-pity. And maybe—maybe—I'll die. Oh, what if I die? Please, above all, let me not linger. Let it not be a long stretch of dying. Let me not linger. Let me, in the depth of my depressive sleep, never ending, let me in that darkness depart. Let me die simply. Not wake up. That's exciting. That's a goal. That would be an accomplishment.

Once again I feel the cold sheets of fear moving over my body. If I don't move, if I don't breathe, maybe they'll absorb me and bind me in a never-ending sleep, and I'll rest. I'll rest.

I am here, gentlemen, to ask for help—help in the form of funds for research and education; funds to keep the fighters, such as Dr. Goodwin and the National Institutes of Health, to give them more strength so that, through their science and intelligence, they can improve the lives of millions and destroy the stigma.

I will not have a human being condemned because of pain which is part of a God-given life. Unfortunately, every one of us in this world has to suffer at some time or another. I will not have them condemned as insane. I want to destroy that stigma, and I want it so that to suffer disease and bear its pain does not mean in any way are you insane.

I hope for more funds. I hope most of all for somehow in the educational system for some way to educate people as to what mental illness can be, and that these things can be cured.

I thank you. I am very honored to be here, and I thank you for your indulgence.

[The prepared statement of Mr. Steiger may be found in additional material.]

The CHAIRMAN [presiding]. Thank you very much, Mr. Steiger.

All of us are enormously moved by your testimony, and I think all of us are very mindful that it is never easy to talk about various mental and physical challenges that we face. These are matters of great privacy, and to open up your own soul with those extraordinary comments give us a reflection of the depths of the kind of depression that many of our fellow citizens feel. And I think the only way we can ever express our appreciation to you and to the others on the panel, who will each tell their own stories, is by following through on your recommendations regarding research in mental health and the wide variety of related undertakings in the NIH under the recent reorganization.

So I want you to know that we are—I certainly am—very moved and very grateful to you for your willingness to share your experiences with us and with the American people.

[The prepared statement of Senator Kennedy follows:]

PREPARED STATEMENT OF SENATOR KENNEDY

Today the Committee on Labor and Human Resources will examine the remarkable potential of mental health research.

Mental illness in America remains a disease of epidemic proportions. One in every five adults is afflicted with some degree of mental disorder. Twelve percent of all children suffer from a mental disorder. Two million Americans endure the living mightmare of schizophrenia. Another fifteen million will suffer a major depressive illness at some point in their lives.

Economists tell us that psychiatric illness costs society 130 billion dollars a year in medical expenses, lost productivity, and other direct and indirect economic costs. And the human cost of such illness is immeasurable.

Those who suffer from mental illness endure more than just the debilitating consequences of their disease. They also endure the stigma that society attaches to these disorders. Surveys show the widespread public misperception that mental illness is a moral failing or weakness, rather than an illness like any physical affliction. Too often the mentally ill are shunned and isolated. Regrettably, they are more often objects of fear or ridicule than compassion.

But there are signs of progress. In this Congress, Senator Hatch and I worked together to enact a major reform of the Federal research and treatment effort. The ADAMHA Reorganization Act of 1992 is one of the most significant pieces of mental health legislation to approved by Congress in nearly a decade. It transfers the NIMH and the ADAMHA research institutes to the NIH, and reauthorizes and improves existing Federal research activities. It also creates a Center for Mental Health Services, to administer a new childhood mental health initiative and other Federal service programs.

The transfer of research to the NIH was long overdue. We know enough about the nature, the origin and the biochemistry of mental illness to insist the NIMH deserves its seat as a full partner at the NIH table. The isolation of NIMH has contributed to the persistent stigma surrounding mental illness. Separate is not equal. Placing NIMH alongside the National Cancer Institute and the other NIH institutes is a timely pledge by Congress to bring the same degree of Federal commitment to mental illness that we bring to any other major illness. The days of second class status are ending.

Similarly, mental health service providers have cause to welcome the reorganization. The creation of a Federal agency with a clear mandate to support treatment and prevention services for the mentally ill is an important success——an overdue declaration of Federal responsibility for promoting mental health and treating mental illness in every community in the country.

This hearing will focus on the promise of research in treating severe and persistent mental illness. We will hear the personal experiences of four Americans who suffer from mental illness themselves, or who have family members with such illness. They will tell us how they have confronted the stigma surrounding their illnesses, and how advances in mental health research have improved the quality of their lives.

We will then hear from witnesses who will present two important reports. Three members of the National Advisory Mental Health Council will describe the public hearings that led to the publication of the Council's Report entitled "Mental Illness in America." In addition, we will hear about a new report prepared by the Office of Technology Assessment entitled "The Biology of Mental Disorders."

The witnesses presenting these two reports will give their recommendations for Federal action to expedite research and its applications in order to serve the mentally ill.

Thirty years ago, President Kennedy sent Congress a landmark message on mental illness and mental retardation. He challenged the American people with these words:

"For too long, the shabby treatment of the many millions of the mentally disabled in custodial institutions and in communities has been justified on grounds of inadequate funds, further studies, and future promises. We can procrastinate no more."

The groundbreaking research of recent years brings us closer to the fulfillment of our goal. Working together, researchers and service providers bring us closer to the day when citizens with mental illness will have the opportunity to lead lives of dignity, justice and achievement.

I look forward to the testimony of our witnesses.

The CHAIRMAN. Eleanor Guzzio, we'd be glad to hear from you.

Ms. GUZZIO. Today, I am at last a woman with a future. I am working on a master's degree in social work at Loyola, and I am happy—happier than I have ever been in my 48 years.

I am also a woman who suffers with chronic mental illness. I am here, despite the shame and fear I can still feel at times, to tell my story.

I was born in New Haven, CT, the third child of six. I grew up in an old, rambling house in the suburbs. My father was a successful businessman, and my mother the most respected politician in town. We went to church, and we took Sunday rights in my dad's 1949 black Buick with the overstuffed back seat. I remember summer days of tuna fish sandwiches and warm Koolaid on the porch, and the best neighborhood baseball games on our side lot.

My parents could not have been more devoted to their children. Higher education was expected. I earned a B.A. degree in history from Southern Connecticut and an M.A. degree in Latin American studies from the Catholic University of America.

I began my young career as a high school teacher. But long before that, things began to go terribly wrong for me. By outward appearance, my senior year in high school was enviable. I was president of my class and the outstanding athlete of the year. At the same time, I was experiencing unexplainable self-hate and hiding great emotional pain. I was cutting my hands with broken bottles, smashing my head against walls or the bathroom sink, and faking accidents in gym class.

I barely got through college. I was miserable, suicidal, and I spent as much time locked in my car as in class.

I know now that I suffer from a form of bipolar affective disorder, also known as manic-depressive illness. It is a mood disorder which in my case caused manic periods of euphoria, grandiosity, and also fluctuations into deep despair and hopelessness.

My illness was not so much a descent into hell as it was a 27-year sentence in purgatory. I can honestly say that I did not know a time free of struggle. My manic moods could last for hours or days or weeks at a time. During these times, I was expansive, powerful. My self-esteem was inflated. My thoughts raced. I was a woman who could be or do anything. My judgments were impaired. For example, I once wrote a 900-page manuscript, going weeks with little sleep, and then I decided to drop everything and move to Chicago to publish it.

I pursued jobs for which I was totally unsuited. I would run out, and I would spend a fortune on clothes, way beyond my means, for one job interview. With inflated confidence, I could sell myself to any CEO. I had seven different professional jobs, each in a different field.

In variably, I would start having problems at work, and repeatedly I was fired or had to quit because I wasn't functioning.

Unlike my shorter episodes of mania, my experiences of depression were like a heavy black cloud that enveloped me, holding me hostage, until it lifted of its own accord 6 months to a year later.

Depression was a very physical experience for me, as with the time I felt my heart break from loneliness. It is the terrible loneliness that many people feel with mental illness when they are isolated and stigmatized.

To be mentally ill for me meant to withdraw and to spend long periods of time without talking to another human being; to abuse alcohol as a form of self-medication; it is to be hospitalized and to feel myself a wild dog, growling and scratching a nurse, who threatens to put me in isolation; to crawl under porches and try to freeze myself to death in subzero Iowa winters; to be arrested for attacking police who tried to remove me from a building where my therapist's office was. I was very sick, and I was overwhelmed with fears. That night in jail was horrendous because, in my mind, being sick meant being a criminal.

To get well, I needed psychotherapy, medication and Thresholds rehab program. If any one of those important components had failed me, I would not be here today.

Finding the right medication to correct the chemical imbalance in my brain was a long and difficult task. I first saw a psychiatrist involuntarily in 1966 as a Peace Corps trainee. Since then, I have had four other psychiatrists. All prescribed medication which I eventually stopped taking because I either wanted to die, or the medicines didn't work, or I was too depressed to care.

I worked hard with my current doctor to find the right combination to stabilize me. My last hospitalization in July of 1988 provided enough revealing information to indicate that I needed lithium. Now, three times a day, I take some combination of lithium, Prozac and Xanax. I don't like to take medication, but I will probably have to for the rest of my life. It is a small price to pay to be free of torment.

In addition to therapy and medication, I needed Threshold's STAY program, a successful psychosocial rehab program in Chicago, where I went every day for a year. It was the most humbling experience of my life, but it also saved my life because there, in July of 1989, I, Eleanor Guzzio, began to get well—really well.

Thresholds provided structure and helped me gain self-esteem and the confidence I needed to return to work. But most of all, Thresholds cared deeply. Dr. Gerry Jenson, the executive director of Thresholds, was not too busy to be my caseworker. When I was ready, Gerry and I came up with the idea of applying for a staff position at Thresholds. For the next two and a half years, I was an outreach worker with Thresholds' mobile assessment team. I was respected by my coworkers, and I excelled at working with the homeless mentally ill. I recently left that job to return to studies.

Last September, I spoke as a consumer witness at the Chicago hearing on severe mental illness in America. The council's report on mental illness in America speaks correctly and directly to my needs and the needs of millions. Mental illness is a terrible disease made worse by ignorance and stigma. Yet we know that with more and better research, better community services as well as public education, millions of ordinary people like myself can recover from mental illness, work, and lead productive, happy lives.

Despite some obstacles, I have turned my illness into an asset. I am learning to accept my limitations and to use my strengths for the benefit of others. And that is why I am here. My story is only one, but I speak for many. Tragically, too many of us who suffer mental illness suffer unnecessarily. Here is one situation that the Senators of the United States are not powerless to hear the cry for help and to answer it.

Thank you.

[The prepared statement of Ms. Guzzio may be found in additional material.]

The CHAIRMAN. Thank you very much.

Eileen Trainor, we are glad to have you here.

Mrs. TRAINOR. I am Eileen Trainor, mother of a son suffering from major depression. I am a registered nurse who has worked in public health and school nursing.

Forty years ago, I took my psychiatric training at Danvers State Hospital. I was impressed then and felt that I might want to work 1 day with the mentally ill. However, my life took a different path, and I ended up working in public health and school nursing.

I currently work on a children's and adolescents' psychiatric unit. I served as president of my area and regional boards and am immediate past president of the Massachusetts Alliance for the Mentally Ill. I therefore have a unique perspective on care and treatment of mental illness.

I live in suburban Boston and am the mother of seven children. The family has all been affected by mental illness through the illness of my son.

In May 1979, my handsome, intelligent, outgoing son suddenly left maritime school 2 months prior to his graduation. In April, on a visit with his grandfather, he had held us spellbound as he enthusiastically described his experiences at sea, the foreign countries he visited, and his plans for a life onshore following 2 years in the maritime. The young man who came home in May of 1979 was not the same person we knew and loved. He hadn't been writing, and when we called, he would sound as though he had recently been sleeping. I chided him on this, but wasn't overly concerned.

He was distant, quiet and uncommunicative. My husband and I thought he needed time to unwind, and we didn't pressure him, not being sure of what had happened.

It is a long story, fraught with difficulty, trying to get him into treatment. It was eventually through a drunk driving accident that we were able to get him into treatment. As so often happens, he abused alcohol in trying to treat his symptoms.

We have experienced his leaving and not knowing for months where he was dead or alive. We have experienced totally inappropriate care from psychiatrists, misdiagnoses, overmedication, ill-advised suggestions that resulted in his living in his car for several days in front of our house, despite our repeated attempts to convince him to come into the house, manhandling and subject to foul language by police when we called for help. We paid hospital bills when he had no insurance. We have experienced State hospital treatment when we had to refuse to allow him to come home because he was so resistant to treatment.

We finally got him into a group home. He did well there until, despite the agreement of all the professionals that he wasn't ready, he was moved to a rooming house to make room for others waiting for housing at the State hospital. Perhaps you have heard of it—Danvers State Hospital, which has recently closed, but at that time was the most overcrowded in the country.

The rooming house, unknown to us, but well-known to the State system, had a reputation for alcohol and drug problems. He was placed there despite their knowledge of his prior problem with alcohol. Not surprisingly, he got into trouble, resulting in expulsion from the boarding house, difficulties with police and the court system—not unusual for families dealing with neurobiological disease, commonly called mental illness.

We spend hours in police stations, at the court, and bringing him to his appointments with aftercare. It was painful for the whole family, especially the younger members, but most difficult was experiencing the grief and sadness of having his and our expectations for him dashed, to see the pain he experienced with the illness, the symptoms, the side effects and the stigma.

He lost all his friends, couldn't take part in family events with any joy or happiness, as enthusiasm and motivation became strangers to him, and he became overwhelmed with his painful illness.

I have never completely lost hope, knowing that someday there would be a breakthrough, that research and advocacy would eventually bear fruit. I knew his illness was not as severe as others, and eventually we found a wonderful psychiatrist, Dr. Howard Stone from Ipswich, who has worked unceasingly to find the right medication and support to help him.

My son now is involved a Fountain House Model Clubhouse, where he found support, friends and, most importantly, work. He has experienced several types of work situations and is now currently working in a computer software business. He works 20 hours a week but would like to work full-time. Because SSDI puts limits on his Medicaid eligibility, he is unable to do this. He is currently on a spend-down of $1,400. He must pay for his own medication. Because of his meager earnings, he cannot afford housing even if it were available. His medical bills eat up most of his combined checks. Massachusetts Medicaid will not pay for the monitoring support of Clozaril, the wonderful drug which has helped him so much.

He also takes Pamelor, an antidepressant. The combined cost of medication alone is over $7,000 a year. He cannot afford to give up SSDI, even though it is a disincentive to his rehabilitation. There regulations must be changed.

My son desperately needs to be on his own, taking responsibility for his life and the management of his illness. He cannot, without housing.

In Massachusetts, I serve on a task force to research how Massachusetts Rehabilitation can accommodate our people as well as those with physical disabilities. Federal rehabilitation money needs to be targeted to this aim. Changes in commitment laws are needed to help those whose judgment is impaired by mental illness. Would we allow a person suffering a heart attack to remain on the street where he fell, untreated, because his illness hadn't been properly diagnosed, nor his symptoms, surely threatening his life?

Currently in Massachusetts, the administration of Governor Weld is implementing a privatized and consolidated agenda for mental health services. Three of our seven department of mental health hospitals are being closed. The Gabler Unit, the only State-operated inpatient unit for children and adolescents, is also being closed.

I see the pain every day that children from 4 to 12 who are hospitalized on my unit experience. Much of the rationale for these closings is based on the shaky ground of cost-shifting to Federal Medicaid reimbursement. While we have heard promises that persons affected by these closings will receive equal or better care, we have yet to see the proof that these promises are being kept. We fear the closing of State facilities in Massachusetts and across the country is tearing apart the already weakened safety net of public responsibility for some of our most vulnerable citizens who suffer from no-fault diseases of the brain.

We fear that managed care systems that are being implemented in Massachusetts and across the country should actually be called "managed cost systems."

We fear that the closing of State facilities is adding even greater stress to already inadequate community support and housing programs. If people are turned away from the hospital, they must have community support.

We know that the cracks in our mental health system are turning into gaping holes as more and more of our loved ones end up homeless and without treatment on our streets and in our shelters. Of even greater shame is the fact that most of our loved ones who are filling the country's jails and prisons should not be there. Should this be their only refuge?

We know and understand what state-of-the-art treatment is needed. We want more basic brain research and research on medication which will result in more effective relief of symptoms and alleviation of side effects. We want prices of medication in Canada and Europe to be made available to us. We want insurance coverage for neurobiological illness, the same as other illnesses such as cancer, heart diseases and AIDS.

We can alleviate the suffering of the ill in their families and show them that we care. This past week, 2,500 parents and family members gathered here in Washington, DC to advocate, educate and communicate our needs. We can erase the stigma, and we can help these people.

Thank you.

The CHAIRMAN. Thank you very much.

I had the opportunity to speak to the panel earlier, and found it to be very inspiring. They deserve our lot of commendation and respect. The panel members have been enormously constructive in helping the Congress better understand the realities of the stigma and the problems of being mentally ill. It was a very worthwhile meeting and conference.

We will now hear now from Rebecca Viers, of Albuquerque. Mrs. Viers is accompanied by her daughter, Jessica.

Do you want to add a word of welcome, Senator Bingaman?

Senator BINGAMAN. I compliment you on the hearing, Mr. Chairman, and welcome Rebecca and her daughter Jessica. I would also note that Nancy Domenici, who has been a real leader in our State and nationally on this issue, is here in the audience as well. This is a very important issue in our State, and Rebecca has been a leader, so we are very pleased to have her here.

Thank you, Mr. Chairman.

The CHAIRMAN. Very good.

Mrs. Viers.

Mrs. VIERS. Thank you.

We are here to talk to you today about stigma, because stigma is something that Jessica and I know intimately and painfully well. We want to share our story with you.

I celebrated the birth of my only child as any other young mother would. I was really thrilled. Jessica was beautiful and seemed to very healthy that day. It would be 13 very difficult years before we would learn that Jessica was born with a severely abnormal brain structure.

The first few months of her life seemed very normal, although she sometimes used to cry as an infant in a way that would make me think that her head hurt—mother's intuition, some might call that. Before Jessica's first birthday, she suffered her first major seizure in what would be diagnosed as "acute infantile hemiplegia with no known etiology."

By her second birthday, Jessica's behaviors became quite aggressive, noncompliant, and more difficult than any daycare staff cared to handle. She used to talk about "Satchuwa," an imaginary playmate that she held responsible for the deep scratches on her arms and the handfuls of hair that she would pull from her head.

I made an appointment with a pediatric specialist who would become the first in a long line of specialists across the country, looking for help and answers. The first team of professionals evaluated Jessica and determined that she in fact was fine; that it was her mother who needed help. And I won't pretend that I didn't need help. Her behaviors were becoming a greater struggle every day. No one had yet made the connection between those abnormal behaviors and the seizure disorder, both symptoms of a brain disorder.

Through all of this incredible depression and confusion and chaos, I kept telling myself that something was wrong with her brain. I became very depressed as I watched her slip further and further away form the normal developmental milestones that are expected of children her age.

By her fourth birthday, her father and I were divorced.

I thought public school was going to help, so at age 5, we anxiously went to public school. Jessica lasted less than a week in kindergarten. So I sought a private Christian preschool; I thought surely they would be more willing and understanding of a challenging 5 year-old. That was not the case. Jessica came home and told me that the teacher had set her in a circle of tape on the floor, and then she said, "Mommy, how did the devil get inside of me? My teacher says that's why I'm bad. I don't want to be bad."

We endured that year. Jessica was tested by public school and qualified for placement in a special education class for children with communication disorders. One month later, a special meeting was called by the psychologist, and we were told, "This child is totally dysfunctional, totally disorganized and cannot return to school here. She should be in a hospital."

I still remember the paralyzing feeling that shot through my body that Friday afternoon and how the tears burned my face. I thought I was being scolded for expecting the public school system to help me with my child. My world fell apart, and as I lay in bed, cradling Jessica in my arms that night, I thought for the first time that suicide might be the only way out.

A social worker from Jessica's school called on us the next day and told us about a place called the Children's Psychiatric Hospital. She told us that children "like Jessica" belonged there and could be helped. So we went and interviewed with the hospital staff, and after they carefully reviewed our insurance coverage, they decided that a court hearing was in order. The court hearing took place, and the court decided that Jessica should be committed to that hospital for 30 days. She was 5 years old.

That was a very sad day for Jessica and for me. But at last I thought she might get the kind of help she needed. I think it is very important to mention here that not one person had yet used the words, "seriously emotionally disturbed." No one had used the words, "mental illness." No one had used the words, "neurobiological disorder."

They also didn't tell me that I relinquished custody of my only child by placing her in that State-funded facility. They didn't tell me that my involvement with her in the future rested solely on their judgment of my "amenability" to parent treatment. I became completely emotionally exhausted, and sunk deeper into my own depression.

But somewhere in the depths of my soul, that material instinct kept whispering that I loved this little girl more than life itself, and no army of professionals or any system was going to take her away from me.

Jessica would be recommitted three more times, for a total of 10 months, and she would not have been released that last time, but I had become a good "patient," and I learned to say all the right things that the doctors wanted to hear—and I expect my insurance coverage had run out—and Jessica came home.

Then I found out about the National Alliance for the Mentally Ill, and I was finally freed of that prison of blame. That prison is very real. It feels dark and hopeless there. No parent should be trapped in that prison. No parent should be required to relinquish custody, and nobody should be blamed for biologically-based disorders. No parent should be dictated to about when and how often they can see their own child in a hospital setting. I hope that that is changing because people like you are listening.

Our story has a happy ending, believe it or not. Two years ago, Jessica qualified for neurosurgery at UCLA. The surgery was intended to remove the portion of her brain responsible for her seizures. There is an instrument called the PET scanner which looked at her brain before surgery, and that would indicate that her brain was much more abnormal than we knew, and the neurosurgeon would confirm that after an eight-hour surgery that resulted in a partial hemispherectomy.

Jessica has continued to have seizures, but she is getting better every day. She has never been to her high school football game, she has never been invited to a slumber party, but she is better, she is doing much better. And while we are disappointed that she still has seizures, we are elated that we now possess a pathology report from the UCLA lab that does in fact concur that what I always suspected was true—my beautiful little girl was born with an abnormal brain—and I quote: "severe cortical dysplasia, temporal and parietal; heterotrophic neuronal collections within subcortical white matter, and severe hippocampal sclerosis." My maternal instinct has now been validated by medical science and research.

Jessica's behavior and emotional problems had much more to do with her in utero development than it ever had to do with her home environment. We have mountains to move in this arena.

Thank you.

Miss VIERS. Our story is not unique. There are over 7 million children in the United States who suffer from these disorders. Most of us are receiving no services at all, and some of us are receiving inappropriate services.

We support the recommendations in this report to help people understand that brain disorders are no one's fault, and to give $200 million to the NIMH research budget.

Thank you.

[The prepared statement of Rebecca and Jessica Viers may be found in additional material.]

The CHAIRMAN. Well-done, Jessica. That was very simple and to-the-point. We're glad you are here. You have a wonderful mother; I'm sure you realize that.

The testimony from this panel has been very moving. I have some appreciation for these problems, since my mother faced many of these issues with my sister Rosemary, who is mentally retarded. Many of the observations I heard today are similar to the issues heard in my family for many years.

I think we have come a long way but we all understand we still have a long way to go. Please be reassured that part of the reason we've come so far is because of people like you who are willing to speak out on the issues. I think Mrs. Viers said it best when she said we are talking about chemical imbalances and medical disorders. Part of the great tragedy of mental illness is not only the illness itself but these extraordinary personal feelings of guilt, hopelessness, and frustration which accompany the disease. We must address this problem to the extent possible Rebecca. The statement in support of the Alliance that you gave, is about as powerful a commendation as any organization could receive. It is very clear the value it holds for you.

I would like to ask a very brief question, because we have another panel, and there are other Senators here as well.

As we heard at the Alliance this week—and have heard before—Senator Domenici has introduced resolutions to insure that when we address national health insurance we will make sure that the benefits of the program, will address the particular needs of the mentally challenged. I think we can all agree with that—I'll indicate for the record that all of the heads nodded yes.

Let me ask just one question. Why is the research in this area so important? I think we caught bits and pieces of the relevance of the research. I think all of us are very mindful of the extraordinary leadership Sil Conte provided in "the Year of the Brain," and we'll hear in the next panel about the OTA study. Perhaps you could just briefly tell us from your own experience why you think research in this area is so important.

Mr. Steiger.

Mr. STEIGER. Well, outside of the obvious hope that there would be an alleviation of pain, I think research will overcome the absence of knowledge. If there are breakthroughs—and they can only be with funding and research—they will become public knowledge through the media, television, what-have-you, this will probably get to the ear of the adverse public and gradually, like a huge, heavy cloud, it will begin to lift because of the progress made through research. And also, an other word for "research," as far as I'm concerned, and I think the members of this panel, is "hope." Research is hope for us. Research is hope that the stigma will be destroyed, and that the public will be more aware.

I know a person has to make his living, so he is not going to go crazy worrying about any one of us individually here, but I hope that through more knowledge, there will be less fear; through less fear, there will be less condemnation, and through less condemnation, there will be less stigma. That is my personal feeling.

The CHAIRMAN. Very good.

Mrs. Viers.

Mrs. VIERS. I think, aside from the-obvious, that we hope to find cures and eventually eradicate mental illness, what a change in our lives when we could prove with a CAT-scan or a PET scan a picture of Jessica's brain that something was wrong. That instantly alleviated a lot of blame and stigma, not only by her schoolteachers and friends, but family and the community. So it directly impacts stigma. And research, of course, ultimately lead to the cures for these disorders.

The CHAIRMAN. Jessica, would you like to comment?

Miss VIERS. I would also like to say that the psychiatric hospitals and all the psych doctors don't really know anything, especially psych hospitals, because the brain is an organ of the body like anything else. If someone has a kidney transplant or heart surgery or whatever, they don't need points and level systems and things like that—the psychiatric hospitals just make people more depressed and more confused, and they shouldn't exist.

The CHAIRMAN. Thank you.

Ms. Guzzio.

Ms. GUZZIO. America is a great country, and its people are a great people, so there are millions of people who needlessly suffer from mental illness who are bright, talented, who ought to be about the business of being good community people, good Americans, good citizens. So it is a tremendous, tremendous waste.

The other thing is that in addition to biomedical research, there is a lot of research that ought to be done in the service area—why is it that a 16 year-kid goes into a rehab program, and at 47, he still has problems, and nothing has gone right—and it isn't the medicine. So I'd like to see a lot more research in that service area.

The CHAIRMAN. Thank you.

Mrs. Trainor.

Mrs. TRAINOR. From my perspective, having worked as a student nurse in a psychiatric hospital years ago, before the medications that we have now were used, I certainly understand that even though we are far from there, that people with neurobiological illness today are a little bit better off than they were 40 years ago, when I first took care of them.

I now work on psychiatric units, both adult, children and addictions treatment units, and I know there is a connection. I know that we need more research to find out what the connections are. We need to find out what causes the illnesses and how many illnesses are grouped under the same term of "neurobiological illness." It is only through research that we can do that, and it is only through research that we can come up with better treatment and, hopefully, a cure.

Senator DURENBERGER. Mr. Chairman, could I just make one observation, please?

The CHAIRMAN. Senator Durenberger.

Senator DURENBERGER. This is a very, very difficult question to resolve—the interchange between your observation that everybody up here agrees that if we ever do national health insurance, we're automatically going to cover these services the same way we do other services, and what you just heard from these panelists. It is real agony for me to hear what Jessica said and to hear the description of her 13 years in this system.

I don't know that we are going to convince a lot of Americans that they ought to start writing automatic premium checks to cover that set of diagnostic and treatment services.

Now, having said that, it is not to say that we can't and shouldn't attend to the issue of financial access. America has suffered for almost a century from the medicalization of everything that goes on. It is really fun to see some doctor transplant a liver, or transplant a lung—and nobody cares about the $100,000 bill or the $200,000 bill that goes with it, because it is like man playing God. We have a system that guarantees a whole lot of people financial access to that sort of thing, but you don't have it in treatment of mental illness.

It isn't fair to say that we can't have it here because we don't know enough, when we have the tragedies that we have heard about today. But how to get to it, how to get to what the chairman said, we need to treat mental illness with the same financial commitment, the same research commitment, the same service, diagnostic, treatment, rehabilitation and so forth we do others is important for us to agree to. But whether or not it can be done, just like that, given the absence of concentrated national research in this area, is an agony that I have to live with.

I haven't sponsored Pete's bill yet because it is easy to say, but it is really hard to deliver on that. So it is an incredible challenge to all of us here, so that all of our heads will nod like this, and when they nod like that, we'll actually be able to do it.

Thank you.

The CHAIRMAN. Thank you, Senator Durenberger.

Mrs. TRAINOR. May I speak to Senator Durenberger's comments?

The CHAIRMAN. Yes.

Mrs. TRAINOR. My son is now on Clozaril. Without the research, we wouldn't have Clozaril. Clozaril is probably the most effective, cost-reducing medication that we have right now for schizophrenia and some of the affective disorders that are helped by it.

The cost of keeping people in hospitals and the cost of keeping them in day programs is so prohibitive, but if you can help people get back to wellness by helping them with the right medications and with education—and that is even education for the psychiatrists, who have not kept up on the current medications and the current research and knowledge.

We do know that a lot of our problems are political. A lot of our problems are coming from the fact that when we know we have good programs that work, such as the Clubhouse programs that have been mentioned by two of us here today, we can't get the funding for those because we have to advocate so strongly for programs that are good, and we still have ongoing programs that are not filling the bill.

The CHAIRMAN. Thank you.

Senator Hatch.

Senator HATCH. Thank you.

I want to tell how moving your testimonies have been. Mrs. Viers, the way I got into this was as a young lawyer, when a very courageous young mother and father named Eileen and Harvey Glick, in Pittsburgh, came to me. They had a son with autism, and he was treated just like an animal by the current medical environment. We fought for that young man, and there was some progress. But it dawned on me how we just cast people aside without really trying to find the answers—or, we did in some ways at that time, and we are still doing it today. So your testimony and Jessica's is very, very important here today.

Ms. Guzzio, I really enjoyed your testimony. If there is a good illustration of somebody who has really worked hard to be where you are today and who deserves the respect of everybody in America and the world, you've got to be it. It is just wonderful to have you here today.

Mrs. Trainor, you remind me of that valiant mother who fought for her autistic child every step of the way and is still doing so, without any real, solid answers. Now, Clozaril has been an answer, and we have had battles here trying to figure out what to do because it costs so much to develop these lifesaving drug-therapies or pharmacological therapies that a lot of companies aren't willing to do it unless there is the appropriate profit mechanism built into the system; and yet we want to keep costs down, and we have that problem, because of Medicaid, Medicare, Federal costs, State costs, and just private costs. It is a constant battle around here to try to get the incentives to find these pharmacological solutions to these neurobiological problems that we have in our society today, and many of them are neurobiological, and we know that—not all, but many of them. So you made a very compelling case.

I'd like to come to you now, Mr. Steiger, because I think you can speak for all of these folks—and please go ahead and say what you want to say before I ask you a couple questions.

Mr. STEIGER. I just would like to see—and I'm not an authority on this—I would like to see in the educational system, perhaps in the second year of high school, some opening up of the young minds who are going out into the world from high school to college, a little awareness made in them about mental illness and about how it is a disease and has nothing to do with insanity. I don't mean a course in it, but just a gradual awakening of the citizen who is going on to different schools and educations and then going out into the world, so they have more knowledge with which to judge people who are in this merciless type of pain.

Senator HATCH. I think that's a great statement, and all of us need to be more aware, more compassionate, more feeling, more tolerant and more understanding—I think understanding is probably the most important of those words.

The reason I want to ask you a few questions is because you rose to the top of your profession. You are an Academy Award winner, one of the truly all-time great actors, a person admired by people of all persuasions, and certainly in a wide variety of the arts as well. You indicated this morning on television that this really came to a culmination when you had open heart surgery—or, bypass surgery, I guess it was——

Mr. STEIGER. I was told that there is a large percentage of people who, after any major operation, not just bypass—because the citadel of your being, your mind, your brain and your heart, that's it if they start fooling around with that—that there is a tendency you might slip into a depression. And I guess because I am such a ham, I did a good job of it for the next 8 years, you know.

Senator HATCH. But you slipped right into depression?

Mr. STEIGER. Well, not right into it, but gradually it came into my life, yes.

Senator HATCH. And how did that affect your career?

Mr. STEIGER. Well, it affected my career in that it is impossible to act inside a large bowl of greasy jello, and nobody can hear you crying because of the density of the substance around you. And in Hollywood, where whispers and gossips and rumors—as well as in politics, unfortunately—can help destroy a person or sometimes elevate them, the actor evidently is supposed to go through life without ever being ill or ever having any problems, every getting a little drunk or ever doing whatever.

I remember my agent and my business manager, when this happened, tried to hush it up because the shadow of the word, "insanity," always lingered in the back—undependable, and what-have-you. Since I had 4 years of depression and then about a year and a half off and another 4 years back, my career came to kind of a screeching halt until I was beginning to sell my assets to pay my bills, and then I started to do little pictures in Argentina and so on, where if I could get through the day, I considered it a great performance in life, which is more important than film. I got through the day.

What happened was it took me out of the business, and I'll tell you if I have a chance just how it took me out of the business. What happens, when you are out of any business for about a decade, new people get into places of authority. Two years ago, I was invited to a studio to speak about a movie, and there was this young executive, 38 years of age, and he asked me, "Can you do a Southern accent?"

I said, "Well, I guess so. I won an Academy Award doing a Southern accent in a picture called,' In the Heat of the Night.' Did you see it?"

He said, "No." And I realized that I had to kind of start again with the generation who were now in—they only last about 2 months in Hollywood, anyway—but they are in a position of power there. It crippled my career to that extent.

I never and will never apologize for being ill. I don't think anyone should have to, and that is one of the main reasons that I am here today. It did hurt my career a great deal. But then, when I began to speak out about it—as I said, I am 67; if I don't say something, what the hell was my life worth? So let me get out and speak. If I were 40 years of age, I may not have been this brave. If my career were going great, I might just say, well, wait a minute, I don't want to go to Washington. They're going to say I'm nuts, and I won't be able to work. But I think it's the time for me, through the pain I have, to try to help prevent the pain in other people, and that's why we're all here.

Senator HATCH. Well, let me say you've made some of the most remarkably cogent and intelligent comments here today of anybody who has ever appeared before this committee. Nobody is going to think anything ill of you. I think they are going to love you and respect you a lot more because of what you have done today, and they should.

You indicated that your wife was that compassionate, kind, helpful, loving person——

Mr. STEIGER. My wife stopped me from killing myself more than once, yes. She was my shield, she was my protection. And the thing I will never get over is that I was never condemned. Now, had the positions been reversed, I don't have the patience that some people have, and I would have been screaming, "What the hell's the matter with you?" and there would have been divorce or something. I am much more selfish than that. So I was very lucky.

Senator HATCH. Let me just get to one last thing here. After this operation, you gradually slipped into this depression, where getting through each day was a major triumph for you——

Mr. STEIGER. Well, getting through a day that you didn't want to get through because you wished to God you'd died so you didn't have to wake up the next morning.

Senator HATCH. Yes. You suffered all of the stigma of wanting to commit suicide, of feeling like your life was over, your acting career was over—you couldn't read, you couldn't remember—you went through all of that. Were you able to get pharmaceutical therapy?

Mr. STEIGER. Just as the ladies at this table have indicated, you go through a ping-pong system. You are trying to find the right psychiatrist with the right pill that works for your chemical system. Everyone in this room is an instrument made up of different chemicals. So you are trying to find a medicine that works. That's why I would never mention the medicine I take because some poor person who is suffering would take the medicine, and it might kill them. It takes time to find the right person, the right analyst, and the right medicine.

Senator HATCH. And you tried a wide variety of therapies?

Mr. STEIGER. Oh, yes. I went through stuff that didn't work for me; I went through different opinions, yes.

Senator HATCH. But finally, you came to a point where you found the right medication——

Mr. STEIGER. Yes, but let me make a big point here, if I may, and I don't mean to interrupt. I was lucky enough to have some money to go looking. I was lucky enough to be able to go from doctor to doctor. There are millions of people who do not have that chance.

Senator HATCH. I'm going to get to that. What I want to get to right now is that you, by going to doctors and psychiatrists and pharmacological advisors, went from medication to medication until finally you were able to find medication that has worked well for you; right?

Mr. STEIGER. Right.

Senator HATCH. And it brought you into balance; right?

Mr. STEIGER. Right.

Senator HATCH. Biologically, you started to feel better; right?

Mr. STEIGER. Yes. I have to take this medicine for the rest of my life, but yes, absolutely.

Senator HATCH. The suicidal feelings went?

Mr. STEIGER. Only when I don't get a part—yes, they went. [Laughter.]

Senator HATCH. I understand that. But the fact is that you came back to normalcy.

Mr. STEIGER. Yes, sir.

Senator HATCH. And that it really came down in your case to good advice, loving care from a close person, consideration by others around you, tolerance, and medication?

Mr. STEIGER. Yes. I must point out that this was kind of a new medication, and had there been no funds for research, I never would have been able to find this medication.

Senator HATCH. Now we are getting into it. You had enough money because you have been a successful actor, et cetera——

Mr. STEIGER. Yes. I don't know how an average person who wasn't as lucky as I have been financially could go to work and pay the rent. I couldn't have done it. I would be a coward.

Senator HATCH. You had enough money to go from doctor to doctor and from therapy to therapy.

Mr. STEIGER. Yes, sir.

Senator HATCH. It took you 8 years——

Mr. STEIGER. Yes, sir.

Senator HATCH. Maybe longer, really, but eight intense years.

Mr. STEIGER. Yes, sir.

Senator HATCH. It took a lot of love from your wife and others—and a lot of money, I take it?

Mr. STEIGER. Yes, sir, I guess so.

Senator HATCH. So one of the points you are making here is that the average person in our society really doesn't have that luxury; is that right?

Mr. STEIGER. The average person in our society——

Senator HATCH. The average person, as well as the poor individual.

Mr. STEIGER. The average person would be lost, condemned, misunderstood and perhaps incarcerated.

Senator HATCH. What all of you seem to be saying to me here today—and I'm a conservative—is that all of the help in the world isn't going to help you if you can't afford it, if you can't get to it, if you can't get the advice, if you can't have some help. And it is apparent that it may not be in the private sector where you are going to get this help—it may be, but in most cases it just isn't going to be, unless you are wealthy enough to be able to go, as you did, from experiment to experiment, from trial to trial, from medication to medication, and from doctor to doctor.

So what you are saying, Mrs. Trainor—and I think it is very compelling—is that we can't give up here; we can't just ignore the fact that Government does have a role; that we are going to have to approach this in a very intelligent and good way. And that includes liberals and conservatives, Democrats, Independents, and Republicans, getting together, trying to conserve where the conservatives want to conserve, but also trying to get the services and research and rehabilitation where that has to be, and bring that all together so that it works.

I will tell you, the testimony of this panel has been as good as any panel we've ever had, at least in my 16 years before this committee, which is a very compassionate committee, run by a very compassionate chairman. And I have to tell you that your testimony here today has been very, very important.

We've spent over $1 billion over the last 2 years at NIMH just on research. We spent another $600 million on rehabilitation and so forth. But it is apparent that there are millions of people who are suffering. Thirty million people suffer from depression. Two million of them suffer from very serious mental illnesses such as schizophrenia, and Clozaril has now been able to help one-third of them if they can get the medication. Literally 5 percent of all American citizens suffer from some sort of mental illness during their lifetime.

So I want you to know your time has been well-spent here today. I think those of us on this committee have recognized some of this, if not a lot of it, and we have worked hard to try to get enough funds, and there aren't enough funds. And we are working hard to try to come up with a comprehensive national health approach that will be cost-effective, yet work, and provide the services that are needed.

And I just want to tell you that I am dedicated to helping to try to resolve these mental illness and other neuropsychological and psychiatric problems that exist in our society. But the most important thing that you have done here today—and all of that is important—is you have let the rest of the world know that, basically, there are answers and that we should not stigmatize people who suffer primarily, in many cases, from biological disturbances that might possibly be helped with the appropriate medication and therapy.

I am going to do, as I know the Senator from Massachusetts will, everything in our power to try to help people like yourselves and your families, and you, Mr. Steiger, so that we can approach these problems in a lot more humane and effective way.

Mr. Steiger, I just want you to know that I don't have any doubt in my mind that you are going to win the Academy Award again. I have no doubt in my mind you have won it here today. If there is an Academy Award that should be given for telling the truth, and telling it through compelling testimony that helps millions of people to understand how terrible it is to stigmatize people who have biological disturbances, you have won it here today in my heart and in my eyes, and you will have my respect the rest of my life—as will each of you. Each of you have won an Academy Award here today for truth and for discussion and for helping the rest of us to understand this just a little bit better.

And you as a mother, I can't tell you how much I admire you and appreciate the way you have hung in there with your daughter. Each of you deserves a lot of commendation.

I am sorry to have taken so long, but I wanted to get this across because a lot of people just think that mental illness is something they shouldn't be concerned about, when really, millions of us suffer from it, and a lot of good people who function every day, but who have the same feelings that some of you have expressed here today.

Thank you. I'm sorry, Mr. Chairman, for taking so long.

The CHAIRMAN. Thank you, Senator Hatch.

Senator Simon.

Senator SIMON. Thank you, Mr. Chairman.

I join other members in thanking the panel. You have just been superb.

I also want to thank our colleague, Senator Domenici, who has really been a leader in this area, and we all appreciate it.

It is worthwhile as a group of political leaders here to recall that Abraham Lincoln was a manic-depressive and, in his early 30s, almost committed suicide. What a loss that would have been to this Nation had he done so. And how many Abraham Lincolns have we lost in the process? We don't know.

Senator Hatch went into the financial side a little bit with Mr. Steiger and, Mrs. Viers, you talked about going to a hospital, and your phrase is, "after carefully reviewing our insurance policies," they provided help.

If I may ask the other three of you—Jessica, I'll leave you out on this one, but we are very happy to have you here—how do finances play a role in this whole thing, because we have people—you heard our colleague, Senator Durenberger, and he is sincere in this—there are people who aren't sure as we develop a health program that is going to be for everyone whether we should include assistance for mental health.

Mrs. VIERS. I believe that there are many facilities serving children and adolescents particularly now, with names like "adolescent stress center" and things like that, where placement in those facilities are determined often by what kind of insurance coverage you have. We have a joke among some of us young parents in the NAMI organization support group, and new parents will come, and their children are in the hospital, and they will ask, "When will my child get well?" And our response is, "Didn't you know—when your insurance runs out."

It does, unfortunately, tend to work that way some of the time. Many, many families that don't have insurance have limited opportunities, limited facilities that will take children, unless they are on Medicaid.

Senator SIMON. What if you had not had that insurance?

Mrs. VIERS. Jessica may have been committed. Again, the State would have paid for it, taking all custody. She could have then been placed in a foster home. We have calculated that over $1.5 million have been spent by our insurance companies. And I have been fortunate in that I have been able to switch jobs often enough and switch insurance policies at least five times, and two marriages, so insurance policies with those husbands. So she has actually gone through eight lifetime insurance policies, and she is 16 years old.

I would just like to say that we don't have the answers. Research is going to bring us that. We have some treatments that are helping, and we are certainly grateful that we were in a position to look for those kinds of treatments. But we don't have all the answers yet.

Senator SIMON. Ms. Guzzio.

Ms. GUZZIO. It has been very mixed, but actually, I used to be very, very afraid that I wasn't going to get through the day and that I was going to kill myself. Now my fear is that I'm not going to be able to get the medication that I need, and part of that problem is pre-existing condition.

So, for example, in 1990, a year ago, I was employed with what would be considered in this country, or at least around the Illinois area, a fairly good health insurance policy. I was only making $17,000 a year; that was my income. And because of my pre-existing condition, I wasn't able to get medication—and Prozac is $1.50 a pill, and I was taking two each day, plus other medication. So that year for therapy and medication, I spent something like $8,000 out of my pocket because I couldn't get an insurance policy to pay for that cost.

So it scares me because I don't know, for example, how I am going to function, and I don't know what's going to happen, for example, when I finish school, and I have this pre-existing condition.

Senator SIMON. What if you had not had that $8,000?

Ms. GUZZIO. Oh, I'd be in trouble. If I didn't have it, I would be my client. I could be homeless—well, I have friends, and they would probably help out a little bit—but I would not be able to provide for myself, because without the medication, I could be psychotic. I could just get into all kinds of problems. So it is a very scary feeling not to know that that medication or those therapeutic services are going to be there. That's scary.

The other thing, tragically, is that when I worked with the homeless mentally ill, to see the people and to hear their stories and to say, this should not be in America. This should not be—because this man is bright, and this man can work, this man can have a no life. And no insurance, no health care. It is tragic.

So, it is significant, major significant, in my life, and I certainly know in the lives of a lot of people.

Senator SIMON. Mrs. Trainor.

Mrs. TRAINOR. I would agree with what Eleanor said, because I know what a problem it is. My son has not had insurance. He was a student and not covered. Also, you need education about insurance when the illness first occurs. I think that we might have gotten some coverage on my husband's insurance had we understood it at the time.

We had to put down cash, a couple thousands dollars in cash, before he was even admitted to the hospital for diagnostic tests, and then we had to pick up the balance of his hospital bills. He has been on Medicare, and he has been on Medicaid. As I mentioned, the spend-down is a problem because if he is going to take the medication and pay for the medication that Medicaid does not pay for, he doesn't have money enough to be able to pay rent and to live on his own. So we have had to help with that right through his illness.

Also, working in a hospital, what has concerned us greatly is the short time stays in hospitalization now because of insurance regulations and cutting off of the hospital stay from what used to be a 30-day cure period to now a 10-day period.

And in the Alliance in Massachusetts, we feel that 10 days may be enough to stabilize a person, or it may not be, and that that should be judged on the individual's needs. And if the community services are there, then hospitalizations are not going to be as necessary, and if a person can be stabilized because they've stopped taking their medication by having a respite place to go for a week while they get back on their medication and are helped to find the services they need, then we won't need the expensive hospitalizations that we have needed in the past.

And I want to say here that some of the public programs, the State programs that we have had in Massachusetts, have been much more of a help to people than people who have been in private care and have not been referred to after-care, because the after-care after a hospitalization is just as important as the hospitalization care.

Senator SIMON. Mr. Steiger, you have never been more powerful than you were in that opening statement today. It was tremendous.

Mr. STEIGER. Thank you. I'd like to say that 1 day when I was depressed, I spoke that into a tape recorder, and then later on, I wrote it down. I have been trying to get people to know what it feels like, and if I have some gift that helps emotionally, I am very pleased. So thank you very much.

Senator SIMON. But you said one thing, that your agents when talking about your illness, tried to hush it up.

Mr. STEIGER. Yes. It would endanger my career.

Senator SIMON. I understand. What would your advice be today to someone who is an actor, who is a journalist—any profession—should you hush it up, or should we——

Mr. STEIGER. Well, I have to get down to the bitterness of reality, then. I would have to ask this person how much do you make a week, and can you put food on the table. If they have enough, then you can go out and open your mouth. I can open my mouth now because I can retire. I'm not great hero. But to a 40 year-old person, working, that's a hard question. If they have babies to diaper and feed, I'd probably say keep your mouth shut. You'd have to keep your mouth shut. You may get crucified and lose the roof that's over your head.

I was lucky. I made a lot of money early, and I could run around from doctor to doctor. As I said before, if I were 40, and my career was hot, I probably wouldn't be sitting here. I'd be too much of a coward. I think the average person is heroic that they get to work from nine to five and pay the rent under the burden of depression. I don't think I could have done it. But they will be destroyed if the word gets around in the office. It's not just Hollywood—if it gets around anywhere—it will not help them, that's for sure.

Senator SIMON. Which means we have a long way to go yet.

Mr. STEIGER. Which means—and I'm glad to see it indicated in the conversation here—that pain has no political party of its own. I was glad to hear that, that there is going to be a working camaraderie. A country is responsible for the mental health as well as the physical health, in my opinion, each one of us in our own way. I was very heartened to hear that—and I don't know anything about politics—but the groups intend to work together. That makes me feel pretty good.

Senator SIMON. I thank all of you again.

Thank you, Mr. Chairman.

The CHAIRMAN. Senator Bingaman.

Senator BINGAMAN. Mr. Chairman, I have no questions. I am honored to be here to hear this testimony, and I compliment again you and Senator Domenici and the others who have been working on this for so long. I hope that as we get on to serious consideration of national health care reform and enactment of comprehensive health care, we can give this the priority it deserves.

Thank you.

The CHAIRMAN. Thank you.

Thank you all very much.

We have a second panel of witnesses consisting of four nationally recognized experts in the field of mental illness.

Dr. James Jackson, a noted psychologist and researcher, recently served as associate dean of the University of Michigan School of Graduate Studies.

Rita Hollings is a teacher, education leader, former president of the National Council of Social Studies, and wife of our distinguished colleague from South Carolina, Senator Fritz Hollings.

David Kupfer is chair of the Department of Psychiatry at the University of Pittsburgh Medical School.

And Laura Hall is an analyst with the Office of Technology Assessment. OTA is an independent agency that provides Congress with information about the implications of new and developing technologies, including medical technology.

I think we are very fortunate that, as I mentioned, Senator Domenici and Mrs. Domenici have been very active, along with Peatsy Hollings, who we know not only as the wife of our colleague, but who has established a very distinguished reputation on her own as a teacher and education leader in the area of social studies and has been a leader in this area.

We have Mrs. Norman Lagomarsino, wife of Congressman Bob Lagomarsino, from California here today, and we're delighted to have her join us in the audience today as well.

Dr. Jackson, we'll start with you. As you probably know, we are very squeezed on time and I am sorry. We had an unfortunate and unavoidable delay in getting started this morning, with a filibuster on an education bill. We found out, after we went through two votes and about a two-hour delay, that we finally got the appointment of conferees on S. 2, without objection, at about 11:45. So we do apologize to the witnesses, and we will include all of your complete statements in the record. If you could summarize your comments, we would appreciate it very much.

Dr. Jackson.

STATEMENTS OF JAMES S. JACKSON, ASSOCIATE DEAN OF GRADUATE STUDIES, UNIVERSITY OF MICHIGAN, ANN ARBOR, MI; RITA L. HOLLINGS, MEMBER, NATIONAL ADVISORY MENTAL HEALTH COUNCIL, CHARLESTON, SC; LAURA HALL, STUDY DIRECTOR, OFFICE OF TECHNOLOGY ASSESSMENT, U.S. CONGRESS, WASHINGTON, DC; AND DR. DAVID J. KUPFER, CHAIRMAN, DEPARTMENT OF PSYCHIATRY, WESTERN PSYCHIATRIC INSTITUTE AND CLINIC, PITTSBURGH, PA

Mr. JACKSON. Thank you, Senator.

I am also a member of the National Advisory Mental Health Council, in addition to your introductory remarks, and I was a member of the council's subcommittee that authored the report, "Mental Illness in America: A Series of Public Hearings."

For myself, and for my esteemed colleagues, Mrs. Hollings and Dr. Kupfer, we thank you for the opportunity to testify on this report.

My purpose here today is to present to you the history behind the report—briefly, of course. Following my testimony, Mrs. Hollings will speak to the findings and recommendations of that report, and Dr. Kupfer will address issues for the future that emerge from the findings and recommendations.

Let me mention two organizations that sponsored the series of public hearings upon which the report is based. The National Advisory Mental Health Council is a 12-member body consisting of eminent researchers, mental health professionals, and laypersons active in the mental health field. The council provides guidance to the National Institute of Mental Health on mental health policy issues and mental health research issues.

The National Mental Health Leadership Forum is a coalition of 40 national professional, scientific and consumer organizations concerned with mentally ill Americans and the important mental health issues facing the Nation.

In its report on the fiscal year 1992 budget for the Department of Health and Human Services, the Senate Committee on Appropriations requested a report on the ongoing work of the council and forum. It was really in response to this particular request that the council formed a subcommittee composed of myself, Mrs. Hollings, Dr. Joseph Matarazzo, Mrs. Norma Lagomarsino, who you just mentioned—and, by the way, she contributed indirectly to this hearing, since she had an original idea about trying to hold a seminar around these particular issues. I should also mention Ms. Patt Franciosi. This panel was chaired by Dr. Kupfer.

The council transmitted this report to the National Institute of Mental Health through the Department of Health and Human Services. The report reached Congress earlier this year.

I know that you and members of this committee, Mr. Chairman, are aware, but most Americans are not, that one in five Americans will suffer a mental illness at some point in their lives, and that only 20 percent of the adults who suffer a mental disorder receive any type of care; that the annual cost of mental illness is a staggering $129 billion per year; that few psychiatrists, psychologists and other mental health professionals are available in rural areas, and that specialists in specific mental disorders are practically nonexistent.

Most Americans are unaware, Mr. Chairman, that an astonishing 7.5 million Americans under the age of 18 have a diagnosable mental illness, and that 80 percent of them do not receive treatment. It is estimated that as many as 25 percent of severely mentally ill Americans will be incarcerated, sometimes repeatedly, and that one-third of the homeless persons in America, an estimated 200,000 individuals, suffer from mental disorders.

It is horrifying statistics such as these that led the council and the forum to initiate the series of national public hearings described in this report. Our purpose was to reach out to America and to hear first-hand the problems and barriers, as well as the opportunities and possible solutions to enhancing our knowledge and improving care for persons suffering from mental illness.

It was intended that holding these hearings in a public forum would serve to help raise the national awareness of the pain and cost of mental illness in the United States and to contribute to removing the stigma associated with these devastating disorders.

The hearings took place in Marshall, MN, Los Angeles, CA, and Chicago, IL during 1990 and 1991. They focused on, respectively, mental illness in rural America, child and adolescent mental disorders, and severe mental illness and homelessness.

Although the programmatic content of the three hearings differed, they shared a common format. Panel presentations by patients, service providers, researchers, and others offered them the opportunity to provide testimony to the council and the forum. As you have heard here today, through the moving testimony of the previous panel, the hearing officers heard powerful and informative testimony that was at times shocking, heart-wrenching, terrifying and, yes, hopeful.

In light of the council and forum's goal to reduce stigma associated with mental illness and to increase public awareness about these disorders, the hearings received extensive press and media coverage. It is estimated that over 100 million Americans viewed the coverage of these hearings.

The decision by the council and forum members to make mental illness in rural America the first hearing stemmed in part from congressional requests to expand research efforts in rural mental health. The hearing occurred on April 12, 1990, at Southwest State University in Marshall, MN, then and still America's most rural congressional district.

Dr. Douglas Treadway, president of Southwest State University, opened the hearing. Senator David Durenberger, distinguished member of this committee, delivered eloquent testimony pointing out that we cannot separate mental health from physical health. Insightful testimony by Congressman Vin Weber, in whose district the hearing was conducted, and by two world class scientists from the executive branch—Frederick Goodwin, then administrator of ADAMHA, and Dr. Lewis Judd, then NIMH Director—set the stage. These were followed by four panels, with testimony from 30 witnesses. Then there were an additional 75 witnesses who offered testimony to the council and to the forum and to the 350 other attendees who were interested in these issues.

The focus of the second hearing was on the status of research and services concerning mental disorders in children and adolescents, and on steps that must be taken to free our youth of the costly, tragic burdens of mental illness.

The opening session of the hearing, entitled, "Faces of Mental Illness," consisted of personal stories intended to reveal the human dimensions of child and adolescent mental disorders. It was co-chaired by actress Patty Duke and Dr. Lewis Judd.

Children suffering from mental illness and from all walks of American life and members of their families described the effects of these disorders. They related success stories of winning the battle to overcome mental illness as well as tragedies in the difficult search for effective treatment.

This session was followed by four panels that addressed risk factors, depression and suicide, service systems, and financing issues.

Severe mental illness and homelessness was the theme of the third hearing. The hearing explored the medical, behavioral, sociological, and financial issues associated with severe mental illness. Actor Rod Steiger, whom you heard from today, and nationally-syndicated columnist Ann Landers, served as honorary guest speakers. Leading national experts in the field of mental health, as well as local and State political and religious leaders, also addressed the audience of over 1,000 people.

At the end of the main plenary session, the hearing divided into five concurrent panels. One hundred twenty witnesses addressed new treatments, homelessness, service system issues, criminal justice, and insurance concerns.

I served as a hearing officer in both Los Angeles and Chicago, and I can tell you that the hearings were sobering. As hearing officers, we heard about the difficulties rural Americans face in gaining access to and receiving appropriate mental health care, and about how stigma acts as a barrier to many in rural areas in seeking help. We heard about the devastation of young lives by mental illness that develop much earlier in life than previously thought, and that depression, even though it is a largely treatable disorder, is one of the leading causes of suicide in children and adolescents.

We heard about the grossly inadequate treatment of severely mentally ill individuals in the criminal justice system. We heard about the double tragedy of being homeless and of suffering from a mental disorder and how one young man, afflicted with depression, lived for some time with an Irish setter in a dog house, because that was the only place he could find shelter.

However, we also heard about success and hope—success in terms of mentally ill individuals receiving appropriate psychopharmacologic and psychotherapeutic care, and how they returned to full, functioning lives; hope in terms of findings from basic, clinical, and services mental health research providing new, more effective treatments for mental illness, and better, more efficient ways to organize, deliver and finance care for the mentally ill.

The ultimate goal of the National Mental Health Council is to harness and direct the creative energies of this Nation in ways to end unnecessary suffering for those with mental illness who can be helped now, and to assure that remaining barriers to effective treatment are removed. The findings and recommendations of this series of hearings which are represented in the report which we present to you, and which Mrs. Hollings will enumerate in more detail, are indispensable steps toward this end.

Thank you.

[The prepared statement of Mr. Jackson may be found in additional material.]

Senator WELLSTONE [presiding]. Thank you very much, Dr. Jackson.

Rita Hollings.

Mrs. HOLLINGS. Thank you, Senator.

I am Peatsy Hollings, a member of the National Advisory Mental Health Council, and I was also on the subcommittee that helped draft this report, "Mental Illness in America: A Series of Public Hearings." My purpose here today is to outline the content of this publication.

I know that time is short, and much of the information really came out in the previous panel's testimony. But there were basically five major themes that ran through these three hearings. The first was stigma, which was discussed in great detail. The second was the need for better research in the areas of biochemical, behavioral, and in the service industry. Third, the infrastructure. Just as we need better roads and more bridges in this country, we need better services, and we need some repairs within the delivery system. We need to retain more researchers in every field, from child and adolescent, work with the elderly, with those in rural areas, and those who are involved in the criminal justice system, as well as a number of the homeless who are also mentally ill.

Then, we have problems with the delivery system because we are working at different levels—private, local, State and national facilities—and these have got to be better organized, as we got the message, again, from some of the people on the previous panel.

And finally, there is a special need for special populations. As you know, this country is made up of a number of different ethnic groups, and their approach to the subject of mental illness is different from others, and we must take these into consideration.

So the advisory panel also recommends that when you on this committee and in the U.S. Senate consider any kind of national health care or a national health insurance program, that mental illness be given consideration, along with the other illnesses that are and will be covered. We know, again, from the previous discussion that there have to be some limitations, and there have to be some investigations before this can really be decided.

Now, there are a lot of things that have been discussed in these hearings that could be improved, and they are listed in my testimony, but I would like to mention two things that we really need to work a little more on. One is brain imaging techniques. For the young lady on the previous panel, this solved her problem—not totally, but at least it puts her back into society. Then, second, we need extended tests for new and better psychotherapeutic agents, and then we need to find ways to transfer these drugs into the clinical practice both safely and economically.

Our council has considered all of these things, the themes and some of the solutions, and we have put forth strategic programs. There are four of them; they have been published. Again, these four are listed in my written testimony.

The mentally ill in America have been really denied many of the comforts that those of us who do not have these problems take for granted every day, and we need to help elevate this problem, as Jessica Viers mentioned, and thus the National Advisory Council would like to recommend that $200 million additional be put into research in the Federal budget for fiscal year 1993.

This committee, led by Senator Kennedy and Senator Hatch, helped to enact the ADAMHA Reorganization Act, and this put the National Institute of Mental Health back into the National Institutes of Health. This in itself, we hope and feel, will strengthen our research capabilities.

I wanted to say to Senator Kennedy, so that we could draw an analysis and show that there is some hope in this field, that when he first came here to this committee and was chairman of the subcommittee on health and scientific research, 21 years ago, he introduced a piece of legislation known as "the War on Cancer." At that time, there were thousands and thousands of young people and older people who were suffering and dying unnecessarily because cancer was stigmatized. And by the recognition of the Federal Government, and the establishment of the institute on cancer, more and more people are now taking preventive measures, they are getting treatment, and they are living longer.

We talk about the stigma, Senator Wellstone—20 years ago, a member of this body, Tom Eagleton, was forced to withdraw as a vice presidential candidate because it became known that he had a mental illness. And just 2 years ago, another former member of this body, Lawton Chiles, from Florida, knowingly and admittedly suffered from depression and was on medication, and—I shouldn't say without a problem, because there are always political problems—but he was elected Governor of Florida.

So we have made progress, but we need more progress, and the stigma has got to be done away with, it must be met, and it cannot be swept under the rug.

Thank you.

[The prepared statement of Mrs. Hollings may be found in additional material.]

Senator **WELLSTONE**. Peatsy Hollings, thank you very much for your testimony.

I imagine everybody in the room knows this—and Peatsy talked about the time constraint—I just want everyone to know that what we have bumped up against is two caucuses that are meeting right now. So it is not a lack of interest or commitment. The testimony is important, and I wanted to stay, so that is where Senator Kennedy has gone.

We will also, by the way, if it is all right with all of you, submit written questions to you.

Dr. Hall.

Ms. **HALL**. Good afternoon, Senator Wellstone, Senator Simon.

My name is Laura Hall, and I'm an analyst with the Congressional Office of Technology Assessment, and I appreciate this opportunity to talk about our report briefly today, a study that I directed, "The Biology of Mental Disorders."

This study was requested by and endorsed by several members of Congress, including Senator Kennedy.

Briefly, let me just tell you about one important part of our report. That is, we tried to quite simply answer the question: What do we know about the biological underpinnings of mental disorders?

I believe I can best relay the essence of our findings by talking about some information concerning a particular disorder we looked at, obsessive-compulsive disorder, or OCD for short. As its name suggests, OCD is characterized by repeated and irresistible if unwanted thoughts, like the feeling of being dirty, and compulsive actions, stereotypic actions, such as repeated handwashing, that may be repeated hundreds of times a day and thus can be quite disabling.

Fifteen or 20 years ago, experts considered OCD to be a very rare condition that was perhaps produced by repressed fear or guilt, and if a person with this disorder sought treatment, generally, they would receive psychoanalysis, which unfortunately was not very effective usually.

We have learned a great deal about OCD in the last 20 years. For example, we know that it is not rare at all. In fact, more than 2 percent of Americans will suffer from this condition during their lifetimes.

We also know that it bears some relationship to another condition, Tourette's Syndrome, a neurological disorder characterized by involuntary vocalization and motor tics.

Perhaps most importantly, we now have treatments, medication, and behavioral therapy that are effective for many people with OCD. We are even unveiling regions of the brain that subserve the symptoms of this disorder.

So I think you can see that in a span of 20 years or less, we have gone from thinking about this condition, OCD, as very rare, as being psychologically produced and being virtually untreatable, to understanding it to be a very prevalent, often treatable, disorder for which we understand, or at least are beginning to understand, the regions of the brain involved.

I could relate similar advances for all of the disorders that we considered in our report—schizophrenia, bipolar disorder or manic depression, major depression, and panic disorder.

We concluded in our analysis at OTA that indeed there have been major advances in understanding the biology of these conditions. Further, given these advances and the opportunities for future research, we conclude that brain and behavioral research will be a linchpin for understanding and improving our understanding of these conditions.

Just to conclude my comments, let me outline the issues that we discuss in the report that are relevant to Congress. The first has to do with support for research. We discuss a couple of options in this regard—obviously, support for NIMH is the most important—and we find that given the advances that have occurred so far, the important public health implications of mental disorders, and the promise of future research, that maintained if not increased support for research is warranted.

The second issue we discuss has to do with the implications of research. As with all scientific advances, there are ethical, legal, social, and economic questions that arise from new knowledge about mental disorders, and we provide some options for congressional action in this regard.

Finally, we identify the dissemination of new information as a key issue stemming from this research—and I think that echoes the earlier panel. On the one hand, we have seen the rapid accrual of new information about mental disorders and their treatment. On the other hand, ignorance about mental illness abounds in our society, creating a fertile environment for the stigma attached to these conditions.

So we have delineated several options to get information on mental illness to the people who need it—the public at-large, including patients and their families; care providers, and policymakers.

Thank you for this opportunity to talk about our report.

[The prepared statement of Ms. Hall may be found in additional material.]

[Due to the high cost of printing, the publication entitled "The Biology of Mental Disorders," supplied by Laura Lee Hall, is retained in the files of the committee, and is on sale at the U.S. Government Printing Office.]

Senator WELLSTONE. Thank you.

Dr. Kupfer.

Dr. KUPFER. Thank you, Senator.

I am a former member of the National Advisory Mental Health Council, and I chaired the council's subcommittee that authored the report that you have in hand now.

What I would like to do, very, very briefly, is to focus on how council believes it is possible to implement the recommendations made in our report.

As Peatsy Hollings has already explained, the specific recommendations in this report really pertain to the NIMH. These recommendations call for increased research in basic and clinical sciences as well as services research concerned with mental disorders.

All the specific recommendations that are described, such as what we heard earlier and as heard from some of the panelists in the second group, concerning stigma and things like that, which are very important—the delivery of effective treatments and ways to provide appropriate mental health care to very special populations—all of them depend on increased research endeavors.

We are in the midst of the 1990's, the Decade of the Brain. We have learned more about the brain and the nervous system in the last 10 years than throughout the rest of our history. Progress during the remainder of the Decade of the Brain promises to be spectacular. Unprecedented effort and progress in brain and behavioral sciences are making it possible to effect much needed changes on behalf of mentally ill individuals.

The convergence of the opportunities offered by the Decade of the Brain, the recommendations in our reports, and the legislative leadership provided by members of your committee have now resulted in the return of NIMH to NIH. And it could not have come at a better time.

It is apparent to us that significant increase in resources will be required to implement the recommendations that have emanated from the three national hearings contained in those reports and also the four national research plans.

As you have already heard, our review of the major and critical recommendations from the hearings indicates the need for a $200 million increase in the research budget of the NIMH. This number may very well raise some eyebrows, but let us put it in some perspective. NIMH-sponsored research has been disadvantaged over a long period of time, primarily due to an erosion of constant dollars in our research, which has limited opportunities to push back these frontiers.

For example, even in 1991, the per capita Federal research expenditure on mental illness was only $1.90, while for cancer it was $6.40.

In order for the NIMH to take advantage of the phenomenal opportunities that exist as a result of the explosive growth in science and technology, and which will exist for the remainder of the Decade of the Brain, playing catch-up ball will not work. It is imperative that the gap of constant dollars between the NIH and the NIMH be closed, especially now since we are an institute of NIH. Closing that gap is really one way that we can measure the extent to which we intend to deliver on the promissory note that S.1306 represents.

We need to increase our award rate substantially. This resultant increase will be then hopefully in the range that will advance the goal of equity for mental health research compared to other areas of biomedical research. Without such equity, crucial areas of research will be abandoned by young scientists who are attempting to begin research careers in an extraordinarily competitive environment.

Senator, there is one other set of additional points I would like to make as I close. I need to convey to you our concern that the implementation of your legislation as it affects NIMH is in jeopardy. At the time the House Appropriations subcommittee was deliberating the NIMH appropriation, the reorganization legislation had not yet been enacted. Thus, the NIMH was not considered to be part of the NIH and was therefore treated less favorably. Had the NIMH budget been considered part of NIH, as your legislation requires, the appropriations for NIMH would have been higher by over $5 million.

In addition, the House action did not allow for added program costs which the NIMH must absorb as a result of the new legislation. Examples of that include services research, previously funded by the block grant set-aside, continuation of prevention research demonstration projects, and the establishment of a new office of rural mental health research.

Those mandated absorptions alone will reduce what is available for ongoing NIMH research by almost $13 million. Thus, the House action reduced the program in real terms.

Unfortunately, as we now know, the Senate Appropriations Committee last week did not resolve that problem. Although NIMH was considered part of NIH, the committee added only $1.4 million to the House recommendation.

Thus, the responsibilities mandated by the new legislation, the budgetary shortfall that now exists, or could exist, will reduce the success rate of new applications to approximately 16 percent. This would be the lowest in NIMH history.

Surely, we can all agree that the first step in implementing this new law should not be a step backward. We would like to urge you and your distinguished colleagues on this committee to urge the Senate to amend the appropriations bill by adding at least $21 million to the NIMH appropriation for fiscal year93, and also to sustain this increase in conference with the House.

It simply does not make sense to begin the process of implementing this new and important law, that holds so much promise for the millions of Americans who suffer from serious mental illness such as depression, schizophrenia and other areas that you have heard about today. We need your help, and as you have heard, we need it now.

Thank you.

[The prepared statement of Dr. Kupfer may be found in additional material.]

Senator WELLSTONE. Thank you, Dr. Kupfer.

I'm going to hand this over to Senator Simon, who wants to say a few things. Very, very quickly, I wanted to thank each of you, and also the first panel, and we will put questions to you in writing.

Personally—I am just speaking for myself, Dr. Kupfer—I am absolutely delighted that you ended your testimony on that note. I am new to the Senate, but it seems to me that all too often, we have these hearings, and everybody talks about it, and it becomes kind of symbolic, and then staring us right in the face is a test case. I think that's what you've laid out for us in terms of something that we need to deal with here and now. So I'm glad you just laid that out. I think you were very direct, and I think you were right on the mark. And I certainly want to be a part of making that change, and I make my own personal commitment, and I think we'll have others; we'll see what happens.

Thank you for laying that out right on the line.

Dr. KUPFER. Thank you, Senator.

Senator SIMON. I want to thank you as well. Unfortunately, I have a matter that is going to be brought up in the caucus very shortly, and I have to get over there. But I appreciate your testimony. I have to say I looked at the list today, and it said, "Rita" Hollings, and I didn't know who "Rita" Hollings was.

And in connection with the research, there was one little statistic I heard Senator Harkin use the other day. In the last 7 years, we have spent as much on military research as we have spent from the beginning of the century on health-related research. We have to do better, and I think we can do better, and I appreciate the leadership that all of you have shown.

Senator WELLSTONE. And why don't I just take advantage of being chair here and just mention that Senator Harkin has a transfer amendment which actually transfers $50 million to NIMH, which I think is very much in order for the times. We'll see what happens.

[Additional material follows.]

PREPARED STATEMENT OF ROD STEIGER

I want to thank you Mr. Chairman for giving me the opportunity to testify about ten very frightening years I have had to live with depression both before and during the time that I was receiving successful treatment, and the battles I have had to fight since receiving such treatment.

It was in the early 1980s that I became aware that something was terribly wrong. I was always tired yet did not sleep well, and I began to overeat. I was easily irritated. "What's bothering me," I thought. I told myself to "calm down." I tried telling myself that I'm just nervous about when I will be offered a contract for my next film. But for reasons unknown to me at that time, all I felt inside was a strong sense of impending doom. I was unaware of the early warning signs of depression that were beginning to surface and would last for ten awful years.

My thought patterns were also changing. All the positive feelings and thoughts I had about myself throughout my life were quickly vanishing. I was plagued with such thoughts as, "I can't think straight." Everyone will find out what a horrible person I am. My life is a joke. My memory is failing me and I'll never be able to memorize another line for the rest of my life."

I knew even then that something was wrong. But I never knew that I was suffering from a Depressive Illness--and most importantly, I never knew that it was treatable.

I began to think how I would tell my family, my agent, friends and colleagues in the industry. My symptoms of depression only intensified after I thought about what I might do and whom I could trust to tell about this terrible nightmare.

Weeks lapsed with little sleep. I became terribly ashamed of myself and soon came to believe that I was unworthy of ever having a happy family, a successful career, or a peaceful life. I was slipping deeper and deeper into a bottomless pit of hell.

The anxiety that I felt every night as I struggled for some rest or to decide how I would tell others about my plight became unbearable. As I lay awake, I could hear my heart pounding. I remember thinking, "I am going to have a heart attack. Great! I just want it all to end."

Unknown to me at that time, my shame and guilt--resulting from the STIGMA attached to this and all other mental illnesses were only exacerbating the depression. The STIGMA that comes with being mentally ill conjures up such negative ideas as deficiency disordered thinking, and psychological deficits. STIGMA against mental illness often keeps people who have a mental illness from acknowledging it and from seeking treatment. I was no exception.

I worked very hard at trying to hide this living nightmare from everybody. This additional frenzy completely exhausted and overwhelmed me. I knew that I needed to talk to someone and get some kind of help. But, who could I trust? I was unable to let anyone in--to see the shame and ugliness. They would think I was CRAZY. STIGMA. I know it well. STIGMA delayed my call for help until I was in a severe crisis.

I tried to sound as upbeat as possible around the house so my family would not see my "ugliness." I became obsessed with attempting to portray the "usual" image. Even my family was not allowed to see my pain. I increasingly isolated my friends and colleagues, and even phone calls were kept to a minimum.

I longed to tell someone--about the sleepless nights, the overwhelming panic filled with thoughts of wanting to end it all. "What would my wife think of me? Would she think I was crazy?" Hell, maybe I was, I thought, "a total basketcase." Would they take me away and lock me up? What the hell was wrong with me? And my acting career suddenly became a joke to me. My colleagues would never even touch someone like me!

Slowly, word by word, I opened up to my wife and family about what was really going on--believing that she had never noticed the pain on my face, the rejection of many close and longtime friends, and my despair which grew deeper and deeper by the day. When I finally asked for help, I remember feeling so ashamed of that neediness. My thoughts were consumed with the painful belief that this disease was my destiny and that my life would never be the same again.

I had not made a film in years, and was at an age where any "normal" person would begin to wonder what will happen to their career. But in addition to having a very painful disease, I was also internalizing the very powerful STIGMA "that automatically goes with the territory." I thought of myself as crazy-undeserving of anything good in my life. I believed everyone was talking about me and laughing at me. I believed I could NEVER tell my colleagues because they would not accept me and I would never work again. Looking back now on those times, I realize that many of those thoughts were my own paranoia-despite evidence to the contrary. I also realize that the STIGMA I was experiencing was also real in many instances.

I finally, somehow, got myself to the point where reality overtook my denial of the situation and I obtained professional treatment. I hated myself for needing so much help and feeling dependent on so many people. I was successfully treated, with medication, and gradually the depression began to lift. Eventually, with close friends and my physician, I was able to talk openly about my pain, the terrible sadness in my life. The illness did not go away as fast as it seemed to initially appear. I continued the treatment, even though there were many days that my depression and pain seemed to grow worse. Many times the pain was so great that I had to put on my "well image" in the hope that I would feel better. This fooled no one and only dampened my progress toward recovery.

I finally recognized that my only hope for recovery was to aggressively seek treatment and that meant focusing on the matters associated with my depression, including the personal and professional stress emanating from the STIGMA. The safe environment of the hospital allowed me the opportunity to fully realize the devastation of my illness. I had suffered for several years an unrecognized mental disorder. Finally, I was beginning to get some very real and effective help. When I was discharged from my final stay at the hospital, I was given a firm reminder that my work was not over.

I returned home and continued my treatment. The antidepressant medication would need to be adjusted to an appropriate therapeutic level. I continued psychotherapy with a professional, and received incredible support from my family and friends. I began to feel significant relief in the coming year. Only then was I able to confront some of my most trusted professional colleagues about my illness. The combination of all these different activities has been invaluable in my recovery from depression.

A crucial aspect of my recovery was also confronting the STIGMA which exists in my profession regarding mental illness. In the acting business, where individuals do not have the anonymity found in many other careers, the effects of STIGMA are particularly evident. When I finally became strong and confident enough to talk to my colleagues about my ordeal, I was both very scared and yet relieved to have "gone public." This presented enormous professional and business concerns for me. Many questions arose. Was I not getting some roles because I was seen as too big a business risk? Was the person chosen more appropriate? Would I ever work again?

I then became determined to prove to members of my profession that "I was not a cooke, crazy, weird" or any of the many destigmatising words too frequently used to label individuals with mental disorders. To overcome the STIGMA, I took bit parts, took roles in movies that at one time I would have never considered. Gradually I was regaining a sense of confidence and independence. I started to renew old friendships and began to believe that there was new hope afterall.

I still have to deal with both the illness and the related STIGMA of my depression. However, I am committed to my treatment and taking care of myself and my family, because there is no other realistic alternative. I am also very determined to share my story with others so that my experiences--from both the disease and the accompanying STIGMA--and my subsequent recovery may help others suffering from a mental illness. I want everyone to know that there are very successful treatments available for many who are suffering; and, that we must continue to allocate significant resources to discover treatments so that all those suffering from a mental disorder have an equal chance to receive appropriate available care. We must also aggressively educate the public--and yes many health professionals--about the equally devastating consequences of STIGMA for those attempting to overcome such debilitating diseases.

I closing, I wholeheartedly urge you to allocate the necessary resources to implement the recommendations derived from five major themes which emerged from the testimony at the three hearings on Mental Illness in America. We must continue to combat STIGMA. This means educating the public, health professionals, the insurance industry, educators, and public officials about the psychobiological bases of mental illnesses and the availability of effective treatments and therapies. There is a need for more and better biomedical, behavioral, and services research in order to provide even more effective treatments and delivery of services to mentally ill individuals. We must expand and improve the mental health research and service delivery infrastructure. We need to find ways to more effectively organize, finance, and deliver care. And, we must gain new knowledge about the effects of cultural factors on the etiology and persistence of mental illness so we can more effectively treat mentally ill individuals in special populations.

Thus, I urge you to support the National Advisory Mental Health Council's recommendation for a $200,000,000 increase in the research budget for the NIMH for FY 1993 to advance significantly new knowledge which will give new hope to millions of mentally ill Americans.

PREPARED STATEMENT OF ELEANOR GUZZIO

Mr. Chairman, my name is Eleanor Guzzio. I served as a consumer witness on the Knowledge Development and Dissemination and New Treatments Panel at the Chicago hearing on Severe Mental Illness and Homelessness co-sponsored by the National Advisory Mental Health Council and the National Mental Health Leadership Forum. I am here to tell you about the inaccurate diagnosis of severe depression I initially received, and, more accurately, the bi-polar or manic depressive disorder I've suffered from most of my life; the accompanying self-destructiveness I have struggled with; and finally, how biomedical research, medication, and psychosocial rehabilitation have made a significant difference in the quality of my life.

Today, I am a woman with hope and a future. I recently worked at Thresholds (a psychosocial rehab agency) for two and a half years assisting the homeless mentally ill in Chicago. Unlike the past, I feel very good about my professional accomplishments. I've taken a leave of absence from my work to complete a Masters of Social Work degree at Loyola University. I now want to tell you about what my life was like before successful treatment.

For twenty-six years, I thought and my doctors thought that I was suffering from chronic severe depression. Not surprisingly, I had been very difficult to appropriately and effectively treat.

Four years ago, I found out why. After 26 years of inappropriate diagnosis and treatment, I was accurately diagnosed as having bipolar disorder - a manic-depressive illness. My friends used to look at me and say, "You don't look like you have a manic-depressive illness. But, frequently it is not something one can see. More about this later.

At about age 25, I sensed that something was very wrong with me. I was having severe mood swings and frequently became very depressed. The first time I saw a psychiatrist was involuntarily as a Peace Corp Trainee in 1966. Based on a number of written tests and my daily performance, I was diagnosed by the psychiatrist as having severe depression. I was summarily dismissed from the Peace Corp--without any medication and with no suggestions for treatment or what to expect from the illness.

Although there were intermittent successes in my life during these 30 painful years, much of my life has been marked by torment, lack of pleasure, wide mood swings, poor judgment, violence, extreme behaviors, instability, depression, hypomania, severe anxiety, inability to sleep, daunting insecurity, and ongoing unemployment problems.

I guess the above covers just about anything that could go wrong with one's life. Recognizing this at some level of consciousness, in May, 1977 I admitted myself to a hospital for care. The first medication prescribed was Trivil 2-10. This did not help me very much. I came to believe that I was one of the many unfortunate individuals whose system did not fully respond to a variety of medications over the next 11 years. I was very difficult to treat for many other reasons, such as:

- During the 1960s and 70s there was an incredible ignorance about mental illness which confused and discouraged me from really committing myself to a treatment regimen. "Depression" was badly misunderstood, socially unacceptable (STIGMATIZED), something my family, and many others, disapproved of, and generally was seen as "something you need to get over by yourself." People would discourage me from seeking treatment. But you don't encourage a diabetic or anyone with any kind of severe illness not to seek care. It was not until 1987 that I understood that I had a MEDICAL PROBLEM!!!

- Even then, I opposed taking any medication because I thought it would be "mind altering" and would "control me."

- Many times I remained noncompliant because either I did not expect the medications to be effective, I actually believed they were not working, or I was so depressed that I personally did not feel that I was worth saving.

- Instead of seeking proper medical attention, I self-medicated myself on large amounts of food, alcohol, and work. All three only contributed to my feelings of depression and lack of well being. I generally denied my problems and drove myself beyond any reasonable endurance that could be expected of an individual.

- My illness manifested itself in various physical ways and I naively placed an emphasis on attaining medical instead of mental health specialty care. I had frequent headaches, was weak and constantly fatigued, had gastro-intestinal pain and related symptoms, a spastic colon, and frequent problems with sleep. These problems only exacerbated high job absenteeism, withdrawal from family and friends, poor diet and lack of exercise. Feeling the depression was even worse. When the depression hit me, it was never gradual. It was like being on an elevator, having the wires cut and instantly plunging to the bottom. Without warning, I would be so depressed that I could not function. And, as mentioned above, I would not even want to get out of bed, I ate sporadically and not very well. I didn't care if I didn't comb my hair, leave my room or even go outside the house. The world had no colors for me--everything was grey. I couldn't even carry on an intelligent conversation--I was a prisoner inside my own mind and body.

- I unknowingly and repeatedly sought unnecessary and inappropriate medical care for these symptoms from general internists and other medical specialists--rather than mental health specialists. I spent a small fortune on the wrong care. I can imagine the enormous cost that I and many others are adding to our escalating health care bill by utilizing inappropriate treatments. Looking back on this period of my life, I recognize that had I received a correct mental health diagnosis and treatment much of my pain and suffering as well as unnecessary and inappropriate medical care/expenses could have been avoided.

- I then began taking such medications as Benadryl, Dalmane and Halcion prescribed by my primary care physician. I then decided to see a psychiatrist who prescribed Trivil 2-10 again.

- Other physicians continued to prescribe Trivil 2-10 which proved to be very ineffective for me because (we believed at that time) it was entirely too much tranquilizer and not enough antidepressant.

- Not knowing any better, I faithfully took the TRIVIL (subsequently changed to 4-10) for 19 months!!! I frequently told my psychiatrist that the Trivil 4-10 was also not working and he then prescribed Elavil, Desyrel, and Librium.

- After all these medications, I again expressed concern to my psychiatrist in May, 1987. I then was prescribed and tried Norpramin, pamelor, xanax, and prozac.

- In July 1988, I made the first and last attempt to take my life. This event finally ended the denial about my illness that I had been living with all my life. This attempt to take my life led to my last hospitalization--also in July 1988. This provided the key to what was biomedically missing---lithium. My psychiatrist and the hospital psychiatrist agreed that for all of these years, I had been suffering from bi-polar disorder--not just depression. Looking back now, I recall the manic moments of my life too. I remember the days when I felt very energetic and functioned at an incredibly-high level. Then, without any warning, I would hit rock bottom.

- My problem was further complicated by somatization--i.e., hypothyroidism, PMS, high blood pressure, poor diet, weight gain, and no exercise. These and many more physical problems manifested themselves before I obtained appropriate mental health treatment. When I first began to stabilize in June, 1989, I was also using estrogen, progesterone, synthroid, and cardizem.

- While somewhat more stable, I was still in very poor shape after 30 years of either no treatment, inappropriate treatment, or treatment which my system would simply not respond to. I was angry and very hurt because I didn't want to take my medication. I thought that I needed someone to talk to. Many times professionals think all one needs is to be medicated. They see you acting in a certain way and assume you are psychotic. I just wanted someone to ask me what's wrong and talk to me--all too frequently that did not happen. I was still experiencing suicide ideation, unable to find employment, depressed and often unable to get out of bed. That's when my friends literally pushed me into Thresholds which helped me turn my life completely around -- along with regular compliance with my medication.

- After 1 year as a resident of Thresholds and 2 1/2 subsequent years as an outreach worker, I am doing very well because of a very enlightened, integrated, and comprehensive treatment plan that includes: Psychiatric care that is appropriate for me; a positive living environment that includes family and friends; a terrific psychosocial rehab program that gave me the confidence to self-activate and do what is best for me; and a very caring and supportive caseworker at Thresholds . They educated me and that helped a great deal. You need someone to tell you what is going on, because there are several degrees of severity of mental illness. And frequently patients are treated in hospitals without this variability factor in mind. Some people can function at very high levels, and some can be very sick and hardly function at all--I've been at all of those levels.

In conclusion, I want to emphasize that both appropriate medication, psychosocial rehabilitation, and psychotherapy are essential to my full recovery. I want to suggest that many mental health consumers are interested in mental health careers and have very unique insights into how to assist patients. Grants and loans should be made available to this group to support their education and research. In addition, much more money needs to be made available to basic, clinical, and services researchers to expand our knowledge base. This is essential in order to more effectively diagnose, treat, finance and deliver appropriate care to the mentally ill. Finally, destigmatizing mental illness, and providing more education to the public and policy makers should be a national priority.

I am very pleased with the findings and recommendations that resulted from the testimony of hundreds of grass roots individuals, that now form the basis for the National Advisory Mental Health Council's report, Mental Illness in America: A Series of Public Hearings. It is essential that we implement the recommendations concerning: (1) the need for more and better biomedical, behavioral, and services research on mental illness; (2) expanding the number of mental health researchers, increase training opportunities, and encourage professionals to serve special populations; (3) gaining new knowledge to better organize, finance, and deliver care more effectively; and (4) reducing the STIGMA associated with mental illness which results in needless additional suffering by mentally ill individuals. I, therefore, strongly urge you to support the Council's recommendations to add a $200 million increase in the NIMH research budget to implement these recommendations.

PREPARED STATEMENT OF REBECCA AND JESSICA VIERS

Mr. Chairman, My name is Rebecca Viers and this is my daughter Jessica. I testified at the Hearing on Child and Adolescent Mental Disorders in Los Angeles about STIGMA and its impact on children and adolescents.

STIGMA. I know it all too well. I know it in my work as an early intervention specialist for the Bureau of Indian Affairs serving Native American infants and toddlers with disabilities. I know about it as the Chairperson of the National Alliance for the Mentally Ill--Children and Adolescent Network (NAMI CAN). I know it as founder of New Mexico's sole statewide voice for families--Parents for Behaviorally Different Children. But most importantly, I know STIGMA intimately and painfully as the mother of a sixteen year old daughter with a severe brain disorder. This testimony emanates from my experiences in each of the above roles.

I celebrated the birth of my only child as any other young mother would. Jessica was so beautiful and looked so healthy that day. It would, however, be thirteen difficult years before I learned that Jessica was born with a severely abnormal brain structure. I recall the first days of her life seeming "normal" although I also remember telling my husband that she sometimes cried as if her head hurt. Mother's intuition, some might say.

At ten months, Jessica suffered her first seizure. This was described to us as "acute, infantile, hemiplegia with no known etiology." I was naive enough at that time to believe that this disorder would be the most difficult obstacle that Jessica and our family would have to face.

By age two, Jessica's behavior had become quite aggressive, non-compliant, and more difficult than any daycare staff cared to handle. She began to talk of "Satchuwa" --an imaginary playmate that she held responsible for the deep scratches on her arms and the handfuls of hair pulled from her head. I made an appointment with a pediatric specialist in what would become a long line of specialists we would meet with from across the country.

A team of professionals evaluated Jessica and declared that she, aside from her seizures , was fine--it was her mother that needed help. I was well aware that I also needed some help by now--my daughter's behavior was becoming more of a struggle each day leaving the family drained of its energy. None of the professionals made any connection between uncontrolled seizures and her "abnormal" behavior. The message was that I was not properly socializing my child, and both my personal and professional esteem began to degenerate.

Over the next year, I tried every behavior management plan known to man--all with little success. I became DEPRESSED as I watched my beautiful little daughter slip further and further away from the normal developmental milestones for her age. My husband also became distant and depressed. By Jessica's fourth birthday, we were divorced.

Through all of this incredible depression, confusion, and chaos, I kept telling myself that something must be wrong with her brain. I hoped that a new and less combative environment would help somewhat to calm her. Her behavior did not improve--it steadily deteriorated. I was not only financially burdened but emotionally spent from trying to work and raise Jessica by myself. Babysitters did not last long, the seizures kept occurring, and I felt more depressed and hopeless.

By Jessica's fifth birthday, I too was convinced that I was responsible for her behavior but I also wanted to move to a larger city where I might get more accurate professional advice. Jessica had just been expelled from several daycare centers, and I hoped that public school would be able to help her.

She lasted less than one week in kindergarten. I found a private, Christian pre-school. Surely, they would be more understanding and willing to work with a challenging five year old. That did not happen. Jessica came home and told me that her teacher put her in a circle of tape on the floor for the day and then she asked, "Mommy, did the devil get inside me? My teacher said that's why I'm bad. I don't want to be bad."

We endured that year, and I then had her tested before school began the next fall. Based on the test results, she was placed in a special education program for children with "communication disorders." One month later, an emergency meeting was called by the school psychologist and on that Friday afternoon I was told, "Your child is totally dysfunctional and disorganized and cannot return to school here. She needs to be in a hospital." I can still remember the paralyzing feeling that shot through my body and how the tears burned my face as they rolled down my cheeks.

I felt I was being scolded for expecting the public school system to educate my "monster" of a child. My world fell apart and as I lay in bed cradling Jessica in my arms that night, I thought for the first time that suicide might be the only noble way out.

A social worker from Jessica's program called me the next day and made arrangements for Jessica and I to visit the Children's Psychiatric Hospital in Albuquerque. She told me that children "like Jessica" belonged there and could be helped. We went through the interview process and met the hospital staff. After carefully reviewing our insurance coverage, a representative of the hospital decided that a court hearing was in order. Innocently, I took Jessica with me to the hearing as I had been instructed to do. Then, I listened in horror as the "professionals" read aloud accounts of Jessica's behavior. They said things like, "she threatened to stab her teacher's eyes out" and "she almost pushed another child off the top of a slide." The court, decided that Jessica should be placed in the children's hospital for 30 days.

It was a sad day for Jessica and I, but at last, I thought, she might get the kind of help she needed. I think it is important to mention here that not one person had yet used the term "seriously emotionally disturbed" to me. The professionals also didn't tell me that I had relinquished custody of my only child and that my involvement with her in the future rested solely on their judgment of my "amenability" to parent treatment! I was enraged and completely emotionally exhausted. I sunk deeper into my depression and the idea of suicide seemed comforting once again.

Somewhere in the depths of my soul, that "maternal instinct" kept whispering that I loved this little girl more than life itself. She was my life and no ARMY of professionals or "system" was going to take her away form me. I will never forget the psychologist assigned to us. She acted, and therefore began to look to me very much like "Nurse Cratchet" in ONE FLEW OVER THE

CUCKOO'S NEST. During our first session together, she informed me that Jessica's problems were a result of my own behavior stemming from my relationship with my mother and life "stressors"; furthermore, she concluded that her behavior had nothing to do with her neurological make-up.

I proceeded to find out what the literature concluded about known etiologies of "acute, infantile hemiplegia." My thoughts were confirmed and I dropped dime after dime in the library xerox machine so that I might enlighten our Nurse Cratchet. My efforts were in vain. She discounted the recent medical research findings by explaining that research could be found to document anything.

I began to seriously question the motive of this system called "mental health" when I discovered a harsh reality. I was not going to be allowed to even speak to my daughter on the telephone until I became a compliant "patient." All efforts to attain protection against my unfair treatment ended in dead ends. I heard answers like, "that's the way the system works" and "there's nothing we can do." I even went to this woman's supervisor (at her suggestion) only to learn that "Nurse Cratchet" was his wife! I was told that if I didn't stop writing letters and causing trouble, perhaps there just might not be a bed available for Jessica at the hospital. I pleaded desperately with the hospital administrator and asked him what my options were. He replied with a smirk, "Oh, I don't now Mrs. Viers, why don't you move to Texas?"

Jessica was to be re-committed three more times--for a total of 10 months. The hospital did not want to release her the last time and the discharge summary read, "against hospital recommendations." But I had become a "good patient" (and I expect my insurance coverage had run out) and I had learned to say everything "Nurse Cratchet" wanted to hear. Jessica came home.

By now, I had become obsessed with the medical library. I found more and more articles discussing the relationship between brain dysfunction and abnormal behavior. I enrolled in graduate school, remarried, and graduated third in my class in Special Education-Behavioral Disorders. I felt good about myself for the first time in a long time and my appetite for information regarding brain disorders and families of children with disabilities grew stronger.

I began searching for other parents who had similar experiences with their children and then I attended a conference that was to change my life. Portland Research and Training Center, funded by the Children and Adolescent Service System Program (CASSP) of NIMH, sponsored the first "Families As Allies" Conference in Portland in 1986. As I sat in that room and listened to the parents and professionals speak about how families were not responsible for these illnesses and how families have a valuable role in planning the treatment for their children, once again tears streamed down my face. But this time, they were tears of liberation. Finally, I had been freed of my guilt and my pain.

I clearly remember an older farmer from Idaho, dressed in denim overalls, who was very moved by the conference experience. He stood for the first time in his life to tell the crowd about his daughter that became ill with schizophrenia at the age of sixteen. He described the pain and guilt that he and his wife had endured all of these years. One at a time, parent after parent stood to share their "war stories" and my spirit soared with renewed pride and self-esteem.

My maternal instinct and unconditional love for Jessica had been right all along. The conference was a spiritual event for many parents who were also there. When I left, I knew that nothing could stop me from telling the world about NAMI and the "family movement" for change.

I have found great healing in my advocacy work and in assisting other parents rid themselves from self blame. That prison is real. It is dark and it feels hopeless. No parent in this country should be trapped in that prison. No parent in this country should be required to relinquish custody of their child in order to attain services. No parent in this country should be blamed for these biologically-based disorders. No parent in this country should be isolated and dictated to about when and how they can interact with their own child. That is changing ... because people like you are listening.

My story has a somewhat happy ending that I want to share with you. About two years ago, Jessica qualified for neurosurgery at UCLA. The surgery was intended to remove the portion of her brain responsible for her disorder. The PET scan prior to the surgery indicated that perhaps her brain structure was more abnormal than we knew. The surgeon would confirm these findings after 8 hours of surgery that resulted in a partial hemispherectomy. Jessica has continued to have seizures, but she grows emotionally stronger everyday as is evident by two separate letters attached to this testimony-one written before the surgery with no hope and one written since.

I will not say that we "all lived happily ever after" because Jessica will never be perfectly whole, but she is getting better. She does not attend her high school football game, nor does she get invited to the teenage slumber party down the street; but she is better. She feels better about herself and is beginning to have greater internal control over her emotions. The future is brighter for Jessica and also for us as her loving family.

While I am disappointed that the surgery may not have been totally effective in controlling her disorder. I am elated that we now possess a pathology report from the UCLA lab which does in fact confirm what I always suspected. My beautiful little girl was BORN with a brain that (and I quote) has "severe cortical dysplasia, temporal and parietal; heterotopic neuronal collections within subcortical white matter; and severe hippocampal sclerosis." Yes, my maternal instinct, has now been validated by medical science and technology! Jessica's behavioral and emotional problems had more to do with her "in utero" environment than it ever had to do with her home environment. We have mountains to move in this arena!

My story is not unique. We know that there are over 7.5 million children in the United States today with mental disorders and we know that only about one third of them are receiving any kind of services at all. This is deplorable and cannot be accepted. Of those that are receiving services, many are receiving inappropriate or limited services.

I find it ironic that in my professional career I work as a service coordinator, or "case manager" yet no one wants to be thought of as a "case" and no one wants to be "managed." At any rate, in my job working with Native American parents of young children with disabilities, the "professional" enters the home as a family advocate from the day the child is dismissed from the hospital or from the day the child received a diagnosis. Today, our program model is "family centered" with families determining the kinds and amounts of services needed for their child. Parents are always considered to be the "expert" concerning their children and we are there as consultants to the parents in their journey to attain culturally sensitive, appropriate services by their standards. I have to wonder how different these past fourteen years might have been for Jessica and I, had such a program and philosophy been available to us.

I am further gratified by the findings from the national public hearings and their recommendations contained in the report, Mental Illness in America: a Series of Public Hearings. I strongly urge that you support the recommendations concerning: (1) the need for more and better biomedical, behavioral, and services research on mental illness; (2) expanding the number of mental health researchers, increasing training opportunities, and encouraging professionals to serve special populations; (3) gaining new knowledge to better organize, finance, and deliver care more effectively; and (4) reducing the STIGMA associated with mental illness which results in needless additional suffering by mentally ill individuals. I also strongly urge you to support the Council's recommendations to add a $200,000,000 increase in the NIMH research budget to implement these recommendations.

PREPARED STATEMENT OF JAMES JACKSON

Mr. Chairman, my name is James Jackson. I am Associate Dean of the Rackham School of Graduate Studies at the University of Michigan. I am also a member of the National Advisory Mental Health Council and was a member of the Council subcommittee that authored the report *Mental Illness in America: A Series of Public Hearings*. For myself, and for my esteemed colleagues Mrs. Hollings and Dr. Kupfer, thank you for this opportunity to testify on this report.

My purpose here today is to present to you the history behind the report. Following my testimony, Mrs. Hollings will speak to the findings and recommendations of the report, and Dr. Kupfer then will address issues for the future stemming from those findings and recommendations.

Let me start by describing the two organizations which sponsored the series of public hearings upon which the report is based. The National Advisory Mental Health Council is a 12-member body consisting of eminent researchers in the behavioral and biological sciences and the neurosciences, mental health professionals, and laypersons active in the mental health field. The Council provides guidance to the National Institute of Mental Health (NIMH) on mental health policy and mental health research issues.

The National Mental Health Leadership Forum is a coalition of 40 national, professional, scientific, and consumer organizations concerned with mentally ill Americans and the important mental health issues facing the nation. The Forum's primary goal is to establish mental illness as one of the nation's central health care concerns.

In its report on the FY 1992 budget for the Department of Health and Human Services, the Senate Committee on Appropriations requested a report on the ongoing work of the Council and the Forum. In response to that request, Council formed a subcommittee composed of myself, Mrs. Hollings, Dr. Joseph Matarazzo, Mrs. Norma Lagomarsino, Ms. Patt Franciosi, and chaired by Dr. Kupfer, to prepare this report, *Mental Illness in America: A Series of Public Hearings*. After approval by the full Council, our subcommittee transmitted the report to NIMH for submission through the Department of Health and Human Services to Congress. The report reached Congress earlier this year.

Mr. Chairman, I know that you are aware, but most Americans are not: that one in five Americans will suffer a mental illness at some point in their lives and that only 20% of the adults who suffer a mental disorder receive any type of care; that the annual dollar cost of mental illness is a staggering $129 billion; that few psychiatrists, psychologists and other mental health professionals are available in rural areas, and that specialists in specific mental disorders are practically nonexistent.

Most Americans are unaware, Mr. Chairman, that: an astonishing 7.5 million Americans under the age of 18 have a diagnosable mental illness and that 80% of them do not receive treatment; that it is estimated that as many as 25% of severely mentally ill Americans will be incarcerated, sometimes repeatedly; and, that an estimated 1/3 of the homeless persons in America, that is 200,000 individuals, suffer from severe mental disorders.

It is horrifying statistics such as these that led the Council and the Forum, in 1989, to initiate the series of national public hearings described in this report. Their purpose, to reach out to America and to hear firsthand, the problems and barriers, as well as the opportunities and possible solutions to enhancing our knowledge and improving care for persons suffering from mental illness. Additionally, it was intended that holding these hearings in a public forum would serve to help raise the awareness of mental illnesses to a level commensurate with their prevalence throughout the United States, and to contribute towards removing the stigma associated with these devastating disorders.

Present at that Forum meeting were two members of the Council at that time, Ms. Patt Franciosi and Mr. Dennis Jones, who suggested that making the hearings a collaborative effort between the Forum and the Council would provide a powerful mental health expertise upon which to draw. The entire Council subsequently approved the joint venture in November 1989. Thus, this extraordinary hearing project was born.

The hearings took place in Marshall, Minnesota, Los Angeles, California, and Chicago, Illinois during 1990 and 1991, and focused on, respectively, mental illness in rural America, child and adolescent mental disorders, and severe mental illness and homelessness.

Although the programmatic content of the three hearings differed, they shared a common format. Panel presentations allowed patients, service providers, health insurance experts, businessmen, researchers, church leaders, state and local officials, and legislators from across the country to offer testimony to members of the Council and the Forum. As you've seen here today with the testimony of the previous witnesses, the hearing officers heard powerful, poignant, and informative testimony that was at times shocking, heart-wrenching, terrifying, and, yes, hopeful.

In light of the Council and Forum's goal to reduce stigma associated with mental illness and to increase public awareness about these disorders, the hearings received extensive press coverage, including all three major network TV stations, CNN, PBS, regional affiliates, morning news talk shows, radio and print. It is estimated that more than 100 million Americans viewed coverage of our hearings, including, Mr. Chairman, a piece by Margie Reedy of WHDH, your CBS affiliate in Boston.

The decision by Council and Forum members to make mental illness in rural America the first hearing stemmed, in part, from a request by Congress, in its FY 1990 Senate Appropriations Committee report, to the National Institute of Mental Health, and thus to the entire field, to expand research efforts in the area of rural mental health. The hearing occurred on April 12, 1990 at Southwest State University in Marshall, Minnesota, then, and still, America's most rural Congressional district.

Dr. Douglas Treadway, President of Southwest State University opened the hearing. Senator David Durenberger, distinguished member of this Committee, delivered eloquent testimony pointing out that we cannot separate mental health from physical health. Insightful testimony by Congressman Vin Weber, in whose district the hearing was conducted, and by two world-class scientists from the Executive branch, Dr. Frederick Goodwin as Administrator of the Alcohol, Drug Abuse and Mental Health Administration and, Dr. Lewis Judd as NIMH Director and Chairman of the Forum set the stage. These were followed by four panels, with testimony from 30 witnesses, addressing overall rural mental health and the specific issues of depression, teenage suicide, and stigma. The panels were followed by a completely unstructured, open town meeting where an additional 75 witnesses offered testimony to Council and Forum members and to 350 other attendees interested in mental illness in rural America.

The focus of the second hearing was on the status of research and services concerning mental disorders in children and adolescents, and on steps that must be taken to free our youth of the costly, tragic burdens of mental illness.

The opening plenary session of the hearing, entitled "Faces of Mental Illness," consisted of personal stories intended to reveal the human face of child and adolescent mental disorders. It was co-chaired by actress Patty Duke and Dr. Lewis Judd. Children suffering from mental illness and from all walks of American life and members of their families described the effects of these disorders from personal, family, and financial perspectives. They related success stories of winning the battle to overcome mental illness, as well as tragedies of death at the end of a difficult search for effective treatment.

The plenary session was followed by four panels meeting concurrently: Risk Factors for Mental Disorders in Children and Adolescents; a two-part panel covering depression and suicide in children and adolescents and stigma and its impact on children and adolescents; Service Systems for Children and Adolescents with Mental Disorders; and, an at-large public hearing covering a wide range of service and financing issues.

Severe mental illness and homelessness was chosen as a theme for the third hearing because of the tragic and growing public health problem confronting this nation in its quest to develop improved methods of treating and caring for the severely mentally ill. The hearing explored the medical, behavioral, sociological and financial issues associated with severe mental illness. Mr. Steiger and nationally syndicated columnist Ann Landers served as honorary guest speakers. Leading national experts in the field of mental health as well as local and state political and religious leaders, including Chicago Mayor Richard Daley, and His Eminence Joseph Cardinal Bernardin, also addressed the audience of over 1,000 people.

Following this opening session, witnesses in a special panel entitled "Faces of Severe Mental Illness and Homelessness" presented testimony describing their own personal battles with these devastating disorders. The speakers told how these illnesses affect families, friends, and careers; they spoke of the successes and failures of treatment. The audience repeatedly heard that these illnesses affect people regardless of social class, ethnic background, gender, or age.

At the end of the main plenary session, the hearing divided into five concurrent panels: Knowledge Development and Dissemination and New Treatments; Severe Mental Illness and Homelessness; Treatment Delivery Systems; Criminal Justice Issues and Insurance Issues; and, Successful Programs and Advocacy. Approximately 120 witnesses presented testimony in Chicago.

Mr. Chairman and distinguished Committee members, I served as a hearing officer in both Los Angeles and Chicago, and I must tell you that the hearings were sobering. As hearing officers we heard about the difficulties rural Americans face in gaining access to and receiving appropriate mental health care, and about how stigma acts as a barrier to many in rural areas in seeking help. We heard about the devastation of young lives by mental illnesses that develop much earlier in life than previously thought, and that depression, even though it is a largely treatable disorder, is one of the leading causes of suicide in children and adolescents. We heard about the grossly inadequate treatment of severely mentally ill individuals in the criminal justice system. We heard about the double tragedy of being homeless and of suffering from a mental disorder, and how one young man, afflicted with depression, lived for some time with an Irish setter in a dog house because that was the only place he could find shelter. He expressed gratitude to the dog for letting him stay with her.

However, we also heard about success and hope. Success in terms of mentally ill individuals receiving appropriate psychopharmacologic and psychotherapeutic care and returning to full, functioning lives. Hope in terms of findings from basic, clinical, and services mental health research providing new, more effective treatments for mental illnesses and better, more efficient ways to organize, deliver and finance care for the mentally ill.

The ultimate goal of the Council is to harness and direct the creative energies of this Nation in ways to end unnecessary suffering for those with mental illness who can be helped now, and to assure that remaining barriers to effective treatment are removed. The findings and recommendations of this series of hearings which are presented in the report, and which Mrs. Hollings will enumerate in more detail, are indispensable steps toward this end.

PREPARED STATEMENT OF PEATSY HOLLINGS

Mr. Chairman, I am Peatsy Hollings, a member of the National Advisory Mental Health Council. I also served as a member of Council's subcommittee that authored the report *Mental Illness in America: A Series of Public Hearings.*

I would like to utilize my time today to describe the findings and recommendations outlined in the report. Specific recommendations in the report derive from five major themes which emerged from the testimony and discussion at the hearings.

Stigma associated with mental illness results in needless suffering by mentally ill individuals. Because of stigma, many are afraid to seek treatment. Insurance coverage and reimbursement for mental disorders are both inadequate. The best weapon against stigma is knowledge. Recent years have seen a surge of scientific discovery which has generated new knowledge about mental illness. The public, health professionals, the insurance industry, educators, public officials, and the media must be educated about the true, major psychobiological bases of mental illnesses and, most importantly, about the broad availability of effective treatments and therapies.

In order to provide even more effective treatments and delivery of services to mentally ill individuals, there is a need for more and better biomedical, behavioral, and services research on mental illnesses. Necessary efforts include basic and clinical neurosciences and behavioral sciences research, and research on the organization, financing, and delivery of mental health care.

There has been much discussion of late concerning the urgent need to rebuild America's physical infrastructure -- roads, bridges, and the like. We all recognize that that job will require public investment. Similarly, the mental health research and service delivery infrastructure is badly in need of expansion and improvement. Today, the federal investment in research on mental illness is less than 1% of the costs of treating these disorders. Areas of the mental health infrastructure requiring attention include: increasing numbers of mental health researchers (especially in child and adolescent mental health) and research training opportunities; expanding the facilities and equipment for mental health research; and, encouraging and retaining mental health professionals to serve special populations including ethnic groups, rural areas, children and adolescents, the severely mentally ill, the elderly, and the homeless mentally ill.

There are severe problems associated with the fragmentation of the mental health service delivery system. Ways must be found to improve availability of and access to services for individuals suffering from mental illnesses by enhancing the organization, delivery, and financing of these services. Integration of service delivery is critically important for all persons suffering from mental disorders, but is especially vital for children and adolescents, severely mentally ill persons, mentally ill individuals caught up in the criminal justice system, and the homeless mentally ill.

Efforts to improve the quality of care available to mentally ill individuals depend on research to provide more precise information than now available about their characteristics and environments. Such data are critical to understand how mental illnesses affect various special populations and where mental health services of different types are most critically needed. There is a need both for increased cultural awareness and for increased understanding of the effects of cultural factors on the etiology and persistence of mental illnesses. Also important is new knowledge about the impact of cultural and ethnic issues on the treatment of and service delivery to special populations.

Findings from the three hearings address a broad array of issues of prime relevance to state and local governments, the public and private insurance industry, the criminal justice system, clinicians in practice, and academia.

In our respect, Council made a <u>special</u> recommendation concerning the need for the inclusion in any forthcoming national healthcare reform package or national health insurance program, of adequate coverage for individuals suffering from mental illness. The Council believes it is urgently necessary for the Nation to take advantage of the resurgence of momentum toward the enactment of a national health insurance program by urging the President and the Congress to take steps in assuring that the program include rather than exclude adequate coverage for mentally ill Americans and their families.

Since the Council is principally advisory to the National Institute of Mental Health, it chose to focus all of its <u>specific</u>

recommendations on issues more directly within the substantive purview of the NIMH. These specific recommendations include the following:

- Increase research efforts on the basic neurobiology of severe mental illness including: identification of the genes implicated in these disorders; understanding the mechanisms of action of psychopharmacological agents; clarifying the impact of cultural, environmental, and behavioral factors on the etiology and persistence of severe mental illnesses.

- Enhance research efforts to clarify the impact of cultural factors in the etiology and persistence of mental disorders across the lifespan, and the mechanisms that mediate these effects.

- Expand research utilizing sophisticated, accurate, and non-invasive methods of brain-imaging techniques, and develop more refined imaging methods to study the highest cognitive functions of the intact human brain.

- Expand testing of new and better psychotherapeutic agents and also test ways to transfer newer drugs into clinical practice safely, economically, and efficiently.

- Expand research on the service needs of individuals with severe mental disorders and substance abuse disorders (dually diagnosed). These individuals represent an increasing segment of the population requiring care. Many of these individuals are homeless as well, and the hearing made clear that there have been very few studies of the service needs of this group. More effort is needed in order to determine the most effective methods for delivering services to homeless mentally ill persons.

- Conduct research on the financing of care for individuals with severe mental illness. This area needs extensive study based on an understanding of the unique characteristics of this population.

- Design and implement a major national public education campaign to reduce and eliminate the pervasive stigma associated with severe mental illness.

We increasingly recognize that adult mental illnesses have their roots in development during childhood and adolescence. Thus, research and education efforts must emphasize and focus on these developmental periods. As such, the following recommendations were made in the report:

- Expand basic neuroscience and behavioral science research focused on understanding the underpinnings of child and adolescent mental disorders, including especially longitudinal studies to understand better the developmental trajectory of mental disorders.

- Undertake a major new initiative to expand research on the efficacy of psychosocial treatment of children.

- Strengthen clinical and services systems research to focus on treatment, organization, financing, delivery, and outcomes of care for children and adolescents. System integration should include the educational and justice systems, as well as the health care and mental health systems.

- Increase research on youth suicide to determine risk factors and to seek effective, appropriate, and safe interventions.

- Expand research training efforts in child and adolescent mental health.

- Develop a program of awareness, recognition, and treatment of children's mental disorders modeled after the NIMH D/ART Program in order to decrease stigma.

Some recommendations in the report refer to special populations:

- Conduct additional research on mental illness among various ethnic and racial groups, to improve our understanding of the etiology of major disorders and the effects of existing services on the treatment of these disorders.

- Undertake research to analyze factors affecting supply and distribution of mental health providers, and examine more effective methods of recruiting and retaining psychiatrists and other mental health professionals in rural areas.

- Conduct research on various organizational, financing, and service-delivery approaches needed for different subgroups of mentally ill persons in rural areas.

- Strengthen research to discover strategies to prevent or reduce severe mental and emotional disorders in rural areas.

- Enhance the ability of research institutions in rural areas, especially land grant colleges and state universities, to compete more successfully for research and research training support.

- Increase efforts to disseminate information regarding mental illness throughout rural America and its institutions. Such information will combat the stigma inhibiting individuals from seeking care and creating barriers to the delivery of effective mental health care. Utilize the NIMH D/ART program model or other community-developed programs where appropriate.

- Conduct more research on mental health service needs of jail and prison inmates with a high prevalence of mental disorders.

How are these recommendations to be addressed? Council believes that the specific research recommendations I've just enumerated are consistent with and will be addressed by implementation of the Institute's four related strategic research plans: *Approaching the 21st Century: Opportunities for NIMH Neuroscience Research*; the *National Plan for Schizophrenia Research*; the *National Plan for Research on Child and Adolescent Disorders*; and the newest plan, *Caring for People with Severe Mental Disorders: A National Plan of Research to Improve Services.*

Mentally ill Americans and their families have been denied the full lives most of the rest of us take for granted. Until recently, a compassionate nation could do little more than lament that reality, but no more. New knowledge, generated by tremendous scientific advances, has led to new and more effective treatments. The availability of those treatments has spawned hope among those who have heretofore suffered without hope. Realistic hope will eradicate stigma, just as the quickening pace of discovery will assure the development of even more effective therapies for those suffering mental illness, especially for those resistant to current treatments and for those who cease responding to treatment. Thus, the National Advisory Mental Health Council's report recommends a $200 million increase in the research budget for the NIMH for FY 1993 to advance significantly the pace of discovery needed to fulfill that hope.

As an additional note, I would like to thank you Mr. Chairman, and your colleague Senator Hatch, for your efforts in the enactment of S. 1306, the ADAMHA Reorganization Act. Moving the NIMH back to NIH is a crucial step to strengthen our research efforts towards understanding mental illness. As you said Mr.

Chairman, in your speech to the American Psychiatric Association earlier this year, "Mental health researchers will enjoy the greater prominence that derives from association with the National Institutes of Health. There is a dynamic interaction among the NIH Institutes -- a climate of scientific excellence that promotes the best in cooperation and ingenuity. The placement of NIMH alongside the National Cancer Institute and the NIH Institutes is a timely pledge by Congress to bring the same degree of federal commitment to mental illness as we bring to any other major illness." Mr. Chairman, I could not agree more.

Finally, Senator Kennedy, I must digress here for just a moment. I want to draw our attention to one of the first and finest things you turned your attention to as the incoming Chairman of the Senate Subcommittee on Health and Scientific Research 21 years ago. You were the principal author of S. 34, the War on Cancer legislation, that became law just before Christmas in 1971. You knew then that millions of Americans were suffering and dying prematurely because cancer was such a stigmatized disease that people were afraid and ashamed to speak openly about it; to seek early treatment. You have changed that. The stigma of cancer has been swept away and the nation is in your debt for your insight and perseverance at that-time. Now Senator Kennedy, a new challenge of the same kind, of the same magnitude, confronts the nation -- the stigma of mental illness. No less irrational than the stigma of cancer. No less corrosive in its impact on our national well being. It too can, and must, be swept away.

PREPARED STATEMENT OF LAURA LEE HALL

Good morning Mr. Chairman and Members of the Committee. My name is Laura Lee Hall and I am an analyst with the Congressional Office of Technology Assessment. I am pleased to appear before you with information on research into serious mental disorders. My testimony is based on a study that I have directed, The Biology of Mental Disorders; it is be released today. This study is the fourth and final one in a series of neuroscience reports, a project overseen by David Liskowsky; the series was requested and endorsed by several members of Congress, including Senator Kennedy, as well as the House Committees on Appropriations; Energy and Commerce; Science, Space, and Technology; Veteran Affairs; and the Senate Subcommittee on Science, Technology, and Space of the Committee on Commerce, Science, and Transportation.

A primary objective of this study was to answer the question: *What do we know about the biological underpinnings of mental disorders?* I believe that I can best relay the essence of our findings by briefly describing some of the research into one specific disorder - obsessive-compulsive disorder, or OCD for short. As the name suggests, OCD is characterized by recurrent and irresistible if unwanted thoughts--such as the feeling of being dirty--and stereotypic actions - compulsions - such as hand-washing, that may be repeated 100s of times each day.

Fifteen years ago, OCD was thought to be a very rare condition, caused by repressed fear or guilt. If an individual with this disorder sought treatment, he or she would often receive traditional psychoanalysis, which unfortunately was not very effective.

Research during the last decade or so has provided a great deal of new information about OCD, often contradicting what was previously thought to be true. For example, it is now known that OCD is not rare at all. Rather, more than 2 percent of the American population will suffer from the condition at sometime during their lives. Data indicate that witnessed during the last decade or so and the rich opportunities for further research, we conclude that biological research will serve as a linchpin in improving our understanding and treatment of these disorders.

I should make clear to you what we did not find. First, we do not know for certain the cause of any of these severe mental disorders. Secondly, given the complexity of the brain and mental disorders, advances are likely to be incremental, taking many years to achieve. Finally, while we find good reasons to be enthusiastic about research into the biology of mental disorders, we do not conclude that mental illness can be understood in biological terms alone - psychological and social factors are obviously important for a complete picture of mental disorders and for their treatment.

Let me conclude by sharing our thoughts on what this means for Congress. First, and most obviously, the question arises concerning support for this research. We discuss, in some detail, funding for this research at the National Institute of Mental Health, obviously the most important consideration when it comes to support for this research. Current research opportunities, the magnitude of the public health problem posed by mental disorders, and the promise of research advances argue for maintained or increased support for this research. Of course, you must balance competing demands on the Federal budget. Given concerns about the Federal budget deficit, we have also advanced some examples of specific mechanisms, such as increasing support for clinical research at the VA, to better clinical studies with modest increases in appropriations.

The second general issue that we discuss relates to the implications of research. As with many scientific advances, new information about the biology of mental disorders poses ethical, philosophical, legal, economic, and social questions. We note that little formal attention has been given to these concerns by the Federal government. OTA offers several options for congressional action concerning these issues.

Finally, we identify the dissemination of new information as a key issue stemming from this research. On one hand, we see the rapid accrual of new information about mental disorders and their treatment. On the other hand, ignorance about mental illness abounds in our society. This impairs the treatment of these conditions and creates a fertile environment for negative attitudes toward mental disorders, a subject we considered in some detail in the report. We provide several options for congressional action aimed at improving the relay of information about mental disorder to those who need it - patients, family members, care-providers, the public-at-large, and policy-makers.

Let me thank you once again for this opportunity to discuss the OTA report, The Biology of Mental Disorders. I would be happy to answer any questions you may have.

PREPARED STATEMENT OF DR. DAVID KUPFER

Mr. Chairman, my name is David Kupfer. I am Chairman of the Department of Psychiatry, University of Pittsburgh and Director of Research at the Western Psychiatric Institute and Clinic. I am a former member of the National Advisory Mental Health Council and chaired the Council's subcommittee that authored the report *Mental Illness in America: A Series of Public Hearings.*

My colleagues have previously discussed the background of the Hearings and the subsequent findings and recommendations of the Council's report to Congress. Today I will focus on how Council believes it will be possible to implement the recommendations made in the report.

As Mrs. Hollings has already explained, the specific recommendations in the report pertain to the National Institute of Mental Health (NIMH). These recommendations call for increased research endeavors in the basic and clinical sciences, and services research concerned with mental disorders. Reducing stigma; providing more effective treatments and delivery of services to mentally ill individuals; finding ways to provide appropriate mental health care to special populations; and, improving the mental health research and service delivery infrastructure all depend on these increased research endeavors.

As I present this testimony, the NIMH is being reorganized into the NIH structure. This is one of the significant outcomes of the enactment of S. 1306, the ADAMHA Reorganization Act hallmark legislation that emanated from this Committee under your able leadership Mr. Chairman. This legislation returns NIMH -- the lead Federal agency for research regarding mental illness and the foremost provider of support for mental health-related research in the world -- to the NIH -- the mainstream of biomedical and behavioral research -- an environment eminently suited to implementation of the recommendations of our national hearings.

Additionally, we are in the midst of the 1990's, the Decade of the Brain. We have learned more about the brain and the nervous system during the last ten years than throughout all of history, and progress during the Decade of the Brain promises to be spectacular. Significant efforts and unprecedented progress in brain and behavioral sciences are making it possible to effect needed changes on behalf of mentally ill individuals.

It is now clear that mental illnesses are brain-related disorders resulting from the combined influences of biological and psychosocial factors. The technological revolution occurring in the brain sciences, including the development of powerful microscopes and sophisticated brain imaging devices, new and better animal models, and major advances in the study of genetics, has brought us to a threshold as important and as promising as the first launch into space. For the first time, scientists can view, study and treat the intact, functioning brain, which previously has been inaccessible. The compelling message of the Decade of the Brain is that the brain and behavioral sciences are rich with the scientific means and opportunities to expand our knowledge, produce new, high-level technological innovations for industry, and reduce the personal and financial burden of brain-related disorders for the nation.

Advancing our capability to understand and effectively treat the many brain and behavioral disorders, whether genetic or environmental in origin, will improve our nation's well-being. Many brain disorders could be prevented, cured or alleviated inexpensively if research opportunities were fully exploited. Further progress depends on a broad-based research effort using the newly developed technologies that have already given promise of success.

Mr. Chairman, the convergence of the opportunities offered by the Decade of the Brain, the recommendations in our report, and your legislative leadership resulting in the return of the NIMH to the NIH could not be more fortuitous.

The wide prevalence and costs of mental disorders -- for individuals, for their families and for society -- demand a strategic approach to expanding the knowledge about these illnesses. A disorganized or strictly reactive approach just will not provide answers quickly enough. Therefore, NIMH has, over the past few years, developed four major strategic research plans that, taken together, will continue to provide the framework for the Institute's programs for years to come. This strategic planning has moved the Institute toward the development of crosscutting and broad-based research initiatives and programs that not only express the mission emphasis, but also will lead more expeditiously toward achieving the overarching goal of conquering mental disorders.

Mr. Chairman, we know what to do. We have the strategic plans in place to capitalize on the expanding research horizon and to implement the recommendations which grew out of the national hearings. These plans will enable us to commit our human and economic resources in a way which will put them to work for the millions of Americans afflicted by mental illness.

It is apparent to us that significant increases in resources will be required to implement the recommendations that emanated from our three national hearings and those contained in the four NIMH national research plans. Council's review of the hearings' major and critical recommendations indicates the need for a $200 million increase in the research budget of the NIMH.

This number may raise some eyebrows, but let's put it into perspective. NIMH sponsored research has been disadvantaged over a long period of time, <u>not</u> because there has not been superb science to support, but because an erosion of constant dollars for our research has severely limited our opportunity to push back the frontier of the unknown in our science for the benefit of those suffering from mental illness. Since 1970, funding for the NIH, in constant dollars, has increased significantly, while funding for NIMH has not. Over this time period funds for NIH research increased 55 percent, while NIMH research funds increased by only 11 percent (See Attached Chart). In 1991 the per capita federal research expenditure on mental illness was only $1.90, while that for cancer was $6.40. The federal investment in research on mental illness is less than 1% of the costs of treating these disorders, compared to an average of 1.7% for NIH. There is no doubt about it. The removal of NIMH from the NIH did real and considerable harm to the nation's research enterprise regarding mental illness.

Thus, in order for the NIMH to take advantage of the phenomenal opportunities that exist as a result of the explosive growth in science and technology, and which will exist during the remainder of the Decade of the Brain, playing rhetorical catch-up ball <u>will</u>

not do. It is imperative that the gap of constant dollars between the NIH and the NIMH be closed, especially now that NIMH is an institute of NIH. Closing that gap is one of the ways we can measure the extent to which we intend to deliver on the promissory note that S. 1306 represents.
The $200 million dollar increment would allow the NIMH to increase its award rate for new and competing research project grants from an estimated 24% in FY 1993 to approximately 40% in FY 1994. The total number of funded research project grants under the opportunity budget would increase from 1236 currently to approximately 1510 in FY 1994. The resultant success rate will then be in the range that will advance the goal of equity for mental health research compared to other areas of biomedical research. Without this equity, crucial areas of research will be abandoned by young scientists attempting to begin research careers in an extraordinarily competitive environment.

As a result of this increase, it will also be possible to:

- Complete initiation of the National Plan of Research to Improve Care for Severe Mental Disorders, including the funding of two new services research centers;

- Advance to the next phase of the National Plan for Research on Child and Adolescent Mental Disorders, including support of two new child research centers;

- Maintain momentum and progress toward full implementation of the Decade of the Brain and Schizophrenia National Research Plans;

- Fund two new integrated basic and clinical research centers focusing on the neurosciences and severe mental disorders;

- Fund two additional Regional Positron Emission Tomography (PET) Imaging Centers toward the goal of ultimately establishing a national network of 10 Regional PET Imaging Centers;

- Launch a major initiative to accelerate the search for treatments for mental disorders, with a focus on medications, psychosocial treatments, and combined approaches;

- Allow for increased research on the neuroscience of bipolar disorders and the development of treatments in addition to lithium;

- Develop a network of clinical psychopharmacology research sites to develop new and more efficacious and effective treatments for individuals with severe mental illness who either do not respond or cease responding to traditional treatments.

Council's $200 million recommended increase of resources will substantially accelerate the search for treatments for mental disorders, focusing on new medications, innovative psychosocial treatments and combined approaches. These additional funds would allow the Institute to:

- Expand studies on the mechanisms of action of antipsychotic agents, antidepressants, and antianxiety agents. Develop new medications and calculate new dose strategies to reduce side effects to help those individuals with severe mental disorders who do not respond or cease responding to traditional therapies;

- Increase research on combined treatments, specifically pharmacotherapy, behavior therapy, and cognitive therapy. These treatments are likely to be complementary in their effects.

Additionally, the strategic planning process has identified infrastructure development, research training and career development, and research environment enrichment as immediate and major needs for the future of research. The increase would allow NIMH to help expand the Nation's capability to do clinical research on mental disorders, to increase the number and quality of researchers in the field, and successful in securing Federal grant support.

As our national public hearings on mental illness in America have revealed, it is essential these recommendations be implemented. The entire mental health field is ripe with research opportunities--from basic neuroscience and behavioral science to health care systems. Our obligation is to recognize the magnitude of these opportunities and to find the resolve as a nation to seize them--now.

Mr. Chairman, in closing I again wish to thank you, Senator Hatch, and the entire Committee for your outstanding efforts leading to the enactment of P.L. 102-321. However, I also need to convey to you my concern that the implementation of your legislation as it affects the NIMH is in jeopardy. At the time the House Appropriations Subcommittee was deliberating the NIMH appropriations, the reorganization legislation had not yet been enacted. Thus, the NIMH was not considered to be part of the NIH and was, therefore, treated less favorably than NIH institutes. The House increase for NIMH was 1.2% over FY 1992 as opposed to an average NIH increase of 2.1%. Therefore, had NIMH's budget been considered as a part of the NIH, as your legislation requires, the appropriation for NIMH would have been higher by $5.1 million.

In addition, the House action did <u>not</u> allow for added program costs which the NIMH must absorb as a result of the new legislation. Examples include, services research previously funded by the block grant set-aside, continuation of prevention research demonstration projects, and the establishment of a new office of rural mental health research. These mandated absorptions will reduce funds available for ongoing NIMH research by at least $12.7 million. Thus, the House action reduce~~s~~ the program in real terms. Accordingly, the appropriation would need to be increased $17.8 million over the House allowance in order to maintain the status quo and treat NIMH as an institute of NIH, as P.L. 102-321 requires. Surely, we can all agree that the first step in implementing this new law should not be a step backward.

Mr. Chairman, as the author of P.L. 102-321, I urge you and your distinguished colleagues on this Committee to urge Senator Harkin and his colleagues on the Labor, Health and Human Services Appropriations Subcommittee to rectify this inequity in the NIMH appropriation for FY 1993 either in his Committee, on the Senate floor, or in conference with the House on the bill if necessary. It simply does not make sense to begin the process of implementing this new law, that holds so much promise for the millions of Americans who suffer from mental illness, in this way. We need your help, Mr. Chairman. And we need it now.

Mr. Chairman, this concludes our testimony. We will be pleased, of course, to answer any questions you or other members of the Committee may have.

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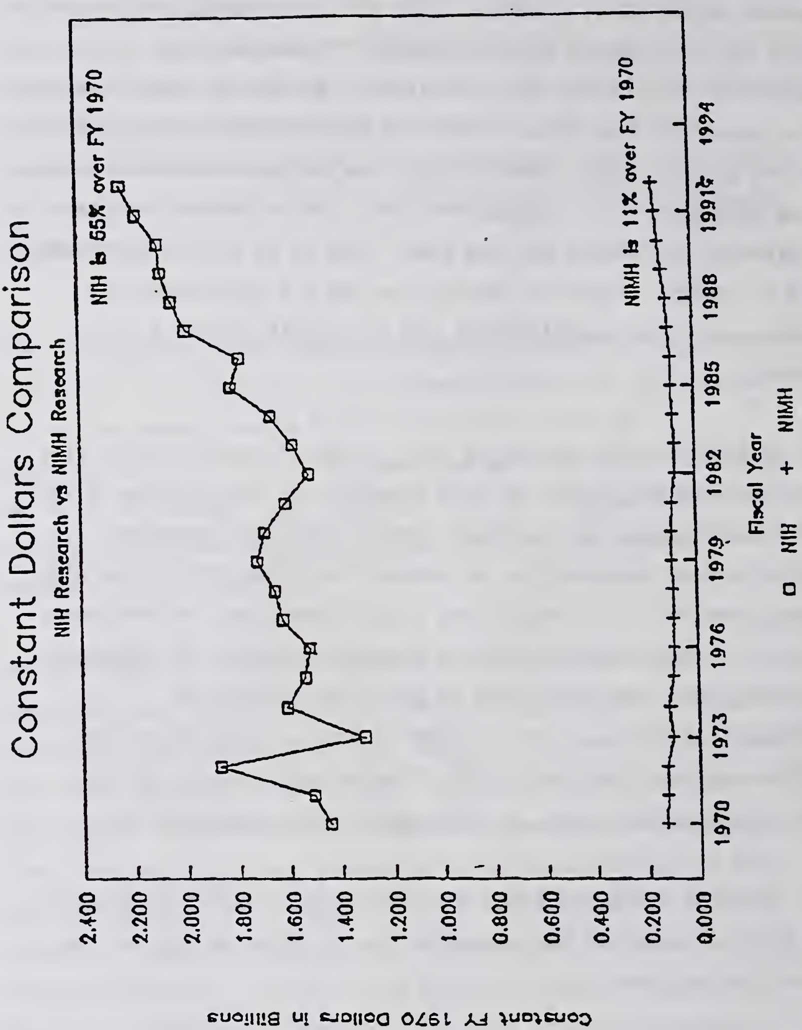

Thank you very much. We appreciate it.
The committee stands in adjournment.
[Whereupon, at 1:15 p.m., the committee was adjourned.]

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