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DEINSTITUTIONALIZATION, MENTAL ILLNESS, AND MEDICATIONS

HEARING

BEFORE THE

COMMITTEE ON FINANCE
UNITED STATES SENATE

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SECOND SESSION

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COMMUNICATIONS

DEINSTITUTIONALIZATION, MENTAL ILLNESS, AND MEDICATIONS

THURSDAY, MAY 10, 1994

U.S. SENATE,
COMMITTEE ON FINANCE,
Washington, DC.

The hearing was convened, pursuant to notice, at 10:12 a.m., in room SD–215, Dirksen Senate Office Building, Hon. Daniel Patrick Moynihan, (chairman of the committee) presiding.

Also present: Senators Daschle, Packwood, Dole, Danforth, Chafee, Durenberger, Grassley, and Hatch.

[The press release announcing the hearing follows:]

[Press Release No. H–33, May 6, 1994]

FINANCE COMMITTEE SETS HEARING ON MENTAL ILLNESS, DEINSTITUTIONALIZATION, AND MEDICATIONS

WASHINGTON, DC.—Senator Daniel Patrick Moynihan (D–NY), Chairman of the Senate Committee on Finance, announced today that the Committee will continue its examination of health care issues with a hearing on mental illness, deinstitutionalization and medications.

The hearing will begin at *10:00 A.M. on Tuesday, May 10, 1994,* in room SD–215 of the Dirksen Senate Office Building.

"In 1955, there were 550,000 patients in state mental hospitals across the country," Senator Moynihan said. "A deinstitutionalization policy begun in 1963 had reduced that number to 180,000 by 1990. There was broad support for deinstitutionalization in the late 1950's and early 1960's. It seemed that by using effective, newly discovered drugs to control illness, patients could be let out of state hospitals where they had been 'warehoused'."

"We now recognize that the unintended consequences of this government mental health policy have been homelessness, drug addiction and immense human suffering. The Committee will explore the history of the deinstitutionalization and also examine the advances in the development of medications to treat mental illness and addiction," Senator Moynihan said.

OPENING STATEMENT OF HON. DANIEL PATRICK MOYNIHAN, A U.S. SENATOR FROM NEW YORK, CHAIRMAN, COMMITTEE ON FINANCE

The CHAIRMAN. A very good morning to our distinguished witnesses and our guests. This hearing begins the final week of hearings on the issues of health care that have been presented to us by the President and any number of Senators, including members of this committee.

I point out that if our attendance is somewhat spare this morning, it is because it is on the occasion of the establishment of a new government in South Africa. A large delegation is there and there will be no votes in the Senate until tomorrow afternoon. So in the way of the world, not everybody is in Washington.

This morning's subject is deinstitutionalization, mental illness and medications. We are honored with the presence of two of our finest colleagues who feel very strongly on this subject and have information about it.

I am going to take the liberty, if they will be patient with me for one minute, of saying that in our back room here I have posted an artifact, which for those who know about these things is a pen certificate. This is a certificate which reads, "This pen was used by President John F. Kennedy in signing Public Law Number 88–164, October 31, 1963," and presented to me.

This was the last public bill signing ceremony of the Kennedy Administration. It was held in the Cabinet Room. The title of the bill may be cited as The Mental Retardation Facilities and Community Mental Health Centers Construction Act of 1963.

That Act, on which I had been one of those working for some years from the very early days of the Kennedy Administration, proposed that deinstitutionalization of mental patients become national policy. That was then a much larger public issue than now, in the sense that the number of persons in mental hospitals was growing, and continued to grow in every State of the nation. In New York, for example, it had reached almost 100,000 persons.

But then, as is often the case, in the pattern that we have seen so much in medicine, a treatment emerged. Again, that treatment, as it happened, was in New York State. At Rockland State Hospital in the early 1950's, two doctors, Joseph Barsa and Nathan Kline, began using the alkaloid reserpine to treat psychotics. Reserpine had been developed by German organic chemists. In 1952, Munachutler and Bine isolated the active ingredient in the root of the plant rauwolfia serpentine or snake root, which had been used in Vedic medicine in India for thousands of years to calm down disturbed persons.

They reported on its use in Rockland State and found that the conclusions are reserpine is definitely of value in the treatment of chronically disturbed psychotic patients. Twenty-two percent of a group of 200 such patients improved sufficiently to be judged well enough to leave the hospital.

This appeared in the Journal of the American Medical Association in May of 1955. That was the month Governor Harriman, newly inaugurated, met with his newly appointed Commissioner of Mental Hygiene.

A very distinguished research psychiatrist, Paul Hoke, told the Governor of this development and proposed that what had been clinically tested be used system wide. The Governor agreed. The money was found. On that date New York had about 97,000 adults in mental institutions. Today it has fewer than 9,000.

Deinstitutionalization had begun. Now, it was soon enough clear that in order for this to work you could not just discharge persons, they had to be looked after. They had to have someone who knew who they were, where they were, how they were doing.

President Kennedy's bill specifically provided that we would build 2,000 community mental health centers by the year 1980, and thereafter build one per 100,000 population and keep it at that rate. But, we built about 400 and then forgot we had set out to do this.

The institutional memory got lost in the Congress, and in the Department of Health, Education and Welfare. Then we stopped, but the deinstitutionalization continued, or is more likely the case, people did not go into institutions. Then a generation went by and, low and behold, we have a problem called "the homeless," which in my State at least is defined as a problem that arises from the lack of affordable housing. It does nothing of the kind. It arises from a decision based on research to follow a particular strategy with respect to a particular illness, which I think we now know has a fairly steady incidence in any large population anywhere. The species has this problem.

We keep this pen certificate hanging in our back room as a reminder of the cost of good intentions. To make great changes casually and not pay very rigorous attention to what follows is to invite large disturbances. We would hope that we would be a lot more careful in this health legislation than we were a generation ago in mental health.

Having put our colleagues through this display, good morning, Senator Packwood. Perhaps you would like to welcome them as well.

Senator PACKWOOD. I welcome them and I think Mrs. Domenici is some place in the audience, is she not? I believe I see her.

The CHAIRMAN. Nancy, where are you? Good morning.

Senator PACKWOOD. Welcome.

The CHAIRMAN. Did you have to sit all the way back? There is room in the front. You can come up and sit at the table and tell us.

Mrs. DOMENICI. I think you have some wonderful experts up there.

Senator PACKWOOD. I have no opening statement, Mr. Chairman. Thank you for the excellent education.

The CHAIRMAN. Thank you, sir.

Senator Domenici, good morning and thank you for coming. You have an exhibit of some kind.

STATEMENT OF HON. PETE V. DOMENICI, A U.S. SENATOR FROM NEW MEXICO

Senator DOMENICI. Good morning, Mr. Chairman. I am going to just ring this bell and tell you what that means. In 1987 I got an award. This was the award. It was from the National Mental Health Association. Encrypted on this bell it says, "This is cast from the shackles which bound them. This bell shall ring out hope for the mentally ill and victory over mental illness."

Essentially, the mental health society in giving me this award brought me into a giant assembly, Mr. Chairman and Senator Packwood, and as they read the citation for services and extraordinary activities as they saw it on behalf of the mentally ill, they ring a giant bell.

It is about 50 times bigger than this and those words are written on it, and literally that bell is made from the prison bars that you have alluded to when deinstitutionalization occurred.

Now when Ronald Reagan was President in May of 1985 he wrote a letter to the nation calling for a mental health month. I just want to read one lengthy sentence and tell you why I am here.

"You have chosen for 1985 Ring Out Hope. That captures the spirit of our times," he said, "when these words were inscribed on a bell cast from the chains and shackles that once restrained the mentally ill they marked the end of an era of ignorance. Now they celebrate the beginning of an era of enlightenment."

Now, Mr. Chairman and Senator Packwood, friends here, you have alluded to a very significant event in history which was further supported by the United States Supreme Court, deinstitutionalization, with an opinion of theirs.

People point to that as a big event in history. You have alluded to it as a major event. You have almost alluded to it as an event where we might have made a big mistake. We did not follow through.

Now I want to make the point, Mr. Chairman and Senator Packwood, this committee and this Congress when they pass health care reform are sitting in a position to once again make a giant mistake. Much worse than the deinstitutionalization decision because we are enlightened today. We know so much more than that good mental hygienist that advised your Governor in New York knew. That it is almost incredible, the evidence about these dread diseases—schizophrenia, manic depression, bipolar illness and a number of others—the evidence about what they are is overwhelming and most of it is on the side that this is a disease.

We need not have any stigma attached to these diseases. They are not the result of bad parents or bad upbringing. You mentioned that we are now getting close to saying the species, to borrow a word from your opening remarks, the species human beings, obviously are beset with a certain number of these kinds of illnesses and this is now a truism. You can ask the distinguished doctor, one of those who will follow, you can ask them, they will tell you about it.

Now I come here because I know, Mr. Chairman and Senator Packwood, what it is for millions of American parents to have teenagers with one of these dread diseases. I tell you they almost literally wake up one day and find that their beautiful, delightful, intelligent, forthright child, male or female, is somehow or another behaving almost overnight, in some enormously strange way.

Whether it is the inability to make a decision at all, which you will find in young people as they are diagnosed as seriously depressive, whether it is just abhorrent behavior, hate, all kinds of things that you never would expect to come from the mouths and the activities of your 16-year-old daughter.

Well, Mr. Chairman and Senator Packwood, these dread elements led by schizophrenia, in particular let us allude to it, most of these symptoms come in the population between 16 and 25 years of age. So you might send your daughter off to college, Senator Packwood, at 18 years of age and everything has been normal. And you might get a call 2 months into that first term and your daughter may be talking strange.

And then a friend may call you and say something is amiss. And then they will say, well, too much pressure, why not give them one of these tranquilizers. They will soon find it does not work because it may very well be that that is the onset of one of these dread diseases.

Now that is the case. If we let health care reform go through and deal with those kind of dread elements any differently than we deal with the dread disease of cancer, shame on us. We will never get rid of the homeless in this country and we will never properly help the parents of hundreds of thousands of young people who loose their children during this period of these enormous episodes.

Incidentally, the deinstitutionalization has gone full circle. If you want to know where most of the mentally ill are institutionalized, look at the jails, city, county and State. It is now estimated that there are more incarcerated, schizophrenics, manic depressives, bipolars, in county, city jails and State jails across this country than go to hospitals for these diseases.

Because they steal trivial amounts, but they do it so many times, or they urinate in the street or they undress and eventually in our society today they are put into some kind of prisons or incarceration. And what has happened to the insurance coverage you must understand because you must change it.

An insurance company not too many years ago in their own economic interest—and I am not sure that I am critical today. Some people insist that when I testify I should tell you I am critical of them. But I do not know that I am. What they really did, Mr. Chairman, was to say we are going to dramatically limit the benefits for mental illness, mental health and severe mental illness. And so one major company does it, Senator Packwood, and says only so many visits; and, in fact, started a series of limitations such as $50,000 worth of coverage for your life.

Now there is no such limitation for cancer. There is no such limitation for kidney disease, for a myriad of medically necessary procedures and practices. Yet that caught on, that limitation caught on in the economic sense. One company followed the other in writing out mental health coverage, in particular the very expensive coverage for the severely mentally ill.

So we have no policies to speak of in the private sector which have similar coverage to what you have for the other dread diseases. If you happen to have a child, a relative or a friend who has schizophrenia, bipolar disease, manic depression or a myriad of others that are alluded to in a white paper that I have prepared explaining all of this. I would ask that it be made a part of the record for your staff to allude to.

The CHAIRMAN. Thank you for having done and it will be made.

[The paper appears in the appendix.]

Senator DOMENICI. Now, Mr. Chairman, I want to thank a number of people and proceed to other issues, to other explanations. First, Senator Wellstone is here on my left, where he properly belongs. [Laughter.]

The CHAIRMAN. See how the world changes. Instability everywhere.

Senator DOMENICI. And the National Alliance for the Mentally Ill, called NAMI, a very large organization that works at the grassroots. Senator Wellstone co-chairs with me the group, the Senate Working Group on Mental Health, that is trying to see that we do not make another mistake, that indeed when we finally took down all those bars and created these bells of hope that we do not let them down now as we move through health care reform.

The American Psychiatric Association, they have had a very, very important study done which I assume my friend Senator Wellstone will talk to that has to do with how much this program might cost with various definitions.

Dr. Torrey, who you are going to hear from, he would be good for you to exchange views with, Senator Moynihan, on the state of the art and what has actually happened since those heady days when New York lead this deinstitutionalization approach.

The United States will never rid itself of the scourge of homelessness unless and until the health care system of this country provides for coverage for the mentally ill and for the severely mentally ill in terms of covering them under the terminology of medical necessity with a definition of what it means in the field of mental illness and then leave it somewhat open for the science to evolve with further definitions.

Believe it or not, where you were talking of that discovery made in one of your research facilities with a 20 percent efficacy, what that the number you used, or 30?

The CHAIRMAN. 22 percent, yes, which on reflection it was——

Senator DOMENICI. We have attached to that paper I have submitted to you a very current total evaluation by the National Institute of Mental Health on the efficacy of treatment for the more severe mental illnesses and you will be astounded. The efficacy with treatment, drugs, pharmaceuticals and therapy is higher than the efficacy of angioplasty and many of the surgical interventions that we have today, which interestingly enough are not nearly as effective as one might think and we give you all those.

Now we cover them nonetheless and we do not say do not cover them because it is not so effective, stop doing them. So I am here to tell you that we have to make sure that in this health care bill we cover the severely and seriously mental ill.

This study also says, because you are going to be concerned about dollars, it says for this aspect of the coverage it will probably cost in the neighborhood of $6.5 billion.

The CHAIRMAN. In a 5-year period?

Senator DOMENICI. Per year.

The CHAIRMAN. Per year.

Senator DOMENICI. But I tell you, this probably is only a 1 percent increase over what is going on now. Now this is a different evaluation than he is going to give you because I am talking about a more narrow definition of the severely mentally.

Now I submit to you that if anybody says it costs too much that you have to ask is it as important as the other medical procedures and medical treatments that we are covering. And if it is, the answer should not be it costs too much, but rather we must pay for it or everybody should take a slight cut in what they get. Perhaps co-payments go up a tiny, tiny bit so that you add this to the coverage.

We are giving you a documentation that will tell you that there is significant efficacy of treatment that medically necessary care can be defined for the severely mentally ill. It can include hospital services in and out, health professional services, case management, intensive nonresidential treatment, and outpatient prescription drugs.

The time is now to make sure that we do not leave out the 5 million or so Americans who currently have these dreaded diseases. Now, frankly, there is so much more to talk about and I think you must know that I have been working about this for awhile and that I have a very, very special interest. I do and I have.

I believe we have given you from this vantage point a way to subscribe to this, to define it appropriately, and to see to it that with new science this is the decade of the brain and research is turning up incredible insights. I mean, the various scanning devices are beginning to pinpoint in the brain the exact location and situs for schizophrenia or manic depression.

And incidentally, for those of you who are steeped in history, you should know that manic depression, for instance, is the dread disease. But you should also know that some of the greatest, greatest figures in history had manic depression. There is no question that Abraham Lincoln did.

There is no question, Senator Moynihan, that Winston Churchill was a manic depressive. You know, those enormous ups and downs in his life, you read about them——

The CHAIRMAN. What he called black——

Senator DOMENICI. You got it. And then he would stay up 6 days in a row writing history with no sleep. That is the manic side of manic depression. The point of it is, some people can live with it, but for the most part it is hell, disabling and there are medications that are being brought into existence regularly.

But we need to make sure that we send the signal out to the parents of this country,the families of this country, that, indeed, with this new health care reform where we talk about insurance coverage, we are going to insist that this kind of illness be treated under medical necessity with a few words that prescribe it so that we get the same coverage we get for all other dread diseases.

I am pleased with the people that you are having come before you, and particularly your Commissioner. We know him. My wife knows him well. I think he is going to be here. He is a very, very enlightened person.

Dr. Torrey is doing some fantastic research and works with the National Alliance for the mentally ill and others, and he is on your list today. I hope some of you get to hear him. Thank you very much for listening. I appreciate it very much.

The CHAIRMAN. We thank you, Senator. Can I just, before you have to go, ask Dr. Hein what were the Koch postulates on disease? There are three. This would be about 1890. They think of it as infectious diseases mostly. There were those three specifics. One, that it has an identifiable cause; two, has a link between the cause and the disease; and, three, it implies that there is a treatment.

This is properly called disease and it has a stable incidence, I think. We will ask our medical witnesses. But you used the figure 5 million, which argues about a 2 percent incidence in the population, which is what I am familiar with.

Senator Domenici. It may not have changed from those days.

The CHAIRMAN. It ought not to have changed.

Senator Domenici. It might be the same.

The CHAIRMAN. If it is what we think it is, if it has that stable incidence within populations, it ought not to have changed.

Senator Domenici. But what has changed is that there are millions of them in a stabilized mode at this point, where before with the severe ones they were institutionalized with hardly any stability, other than the confinement.

The CHAIRMAN. That is exactly right. Then there are those in between who have no treatment and no institutionalization either. That is what we call our homeless.

Senator Domenici. No, I do not think so, Mr. Chairman. I think the homeless are treatable.

The CHAIRMAN. Oh, I did not say they were not treatable. I said they had no treatment.

Senator Domenici. Oh, great.

The CHAIRMAN. They are not getting any treatment.

Senator Domenici. And if you do establish the law that the country has decided we are going to start covering these people, you might not get the population of homeless people off the street, but you will certainly nip in the bud the huge addition to it, because many of those come about because parents cannot take care of them, run out of insurance, and they become street people.

Where you might stop that homeless surge if, indeed, there was coverage for that and it was available in a very broad sense.

The CHAIRMAN. Thank you very much, sir.

Senator Wellstone.

STATEMENT OF HON. PAUL WELLSTONE, A U.S. SENATOR FROM MINNESOTA

Senator WELLSTONE. Thank you, Mr. Chairman, and Senator Packwood, Senator Danforth, Senator Grassley, and Senator Hatch. First of all, let me just say that I am pleased to be here with my colleague, Senator Domenici, seated to my far right, where he properly belongs.

More to the point, it has been a real honor working with Senator Domenici and his wife, Nancy. Sometime ago we stepped forward to co-chair a working group on mental health and as each and everyone of you can tell from the kind of powerful words of Senator Domenici, this whole area of mental health and how we treat those that are struggling with mental illness is a very, very important issue to Senator Domenici. He has been a true champion, as has Nancy.

The interesting thing about this working group is that if you look at the Senators that have joined, it started out, Senator Domenici, with just a few of us, but it has really dramatically expanded. As you look at the Senators that have joined, there is one essential truth that is right there before you, which is that mental illness does not respect political parties. I mean, we have Senators across the board on both sides of the aisle that feel very, very strongly about this.

For my own part, it is interesting, I became involved here in Washington in the Senate on this issue coming to speak at a NAMI gathering honoring Senator Domenici. I spoke at that gathering and talked a little bit how as a teacher I always was impressed with the fact that so much of our viewpoint is shaped by our own

personal lives and what has happened to us. Sometimes it is the family, sometimes it is religion, sometimes it is community, sometimes it is a powerful personal experience.

What I did not speak about that night was my own brother because I had never asked my brother for permission as to whether or not he wanted me to speak about his own struggle with mental illness. Some 2 years after this gathering I went back to Minnesota and I talked with Steven and he said I am very proud of you and I want you to mention it. So in my case, too, from the time I was 11, which was sometime ago now, our family has really had to confront what has been quite a major struggle. My brother struggled with mental illness and this is an issue that is very near and dear to my heart.

I would say to each of you all as Senators that in some way serving in the U.S. Senate at this point in time is a dream come true for me, because it just might be that I might be a small part, working with you all, of helping to shape some legislation that really will do good, that really will make a difference in the lives of people.

That, to me, is ultimately what public policy should be about. As a former college professor, Mr. Chairman, I admire your scholarly approach to this issue. You did not say it today, but I can imagine your saying it sometime soon, how we conceptualize the problem has much to do with the solutions that we then propose.

There is much at stake here and we should not create hasty naive solutions to important problems that influence our society in so many ways. Part of what we are doing here today, and I feel like I am under instructions not to go into a specific discussion of a benefits package, but I take it that part of what we are trying to do here today is to answer the question, "what happened with the deinstitutionalization, and what lessons can we learn?"

Because clearly what we have seen is a staggering toll that this well-meaning but ultimately failed intervention of deinstitutionalization has exacted on people. Deinstitutionalization depended on the premise that the community and State systems would be well integrated and well funded and it raised all sorts of expectations. It did not happen.

As a matter of fact, Mr. Chairman, cost shifting or charge shifting, and we might also use the word dumping, we have seen a lot of that from private sector to public sector, part of what Senator Domenici talks about all the time is this issue of parity. That is to say, mental illness is diagnosable and treatable and so much has happened since the 1950's and the scholarly piece that you referred to Mr. Chairman. We do so much more through pharmacological treatment, so much more in terms of community based care.

There is so much potential. In fact, the success rate is really astounding. So the problem that we run into is when we have the artificial caps and we just simply say to people, you are out, whether it be inpatient care or if we have 50 percent co-pays and we do not enable people to be able to afford community based care, then they simply do not receive it.

I think, Mr. Chairman, that this is in many, many ways what we are talking about today. I think if we were going to talk about the cost, we ought to start first of all with the externalities and

what is not figured into the cost. The cost of those people who are right now, Senator Domenici, as you said in jail or in prison but should not be, the cost of those people who are in the streets—I have organized with homeless people, with street people. It is very interesting to see, once upon a time we thought it was "skidrow" people.

Now it is often people who are casualties of deinstitutionalization, because we did not follow through on the promise of President Kennedy's piece of legislation, and we see these people that are in the streets but need not be there. They just simply do not receive any care. They simply receive no care.

The premise is that people ought to be able to live in as near as normal of circumstances as possible at home with dignity and contribute to community, and people struggling with mental illness can do just that if given some support. But we have not provided that support.

The cost of children who could do well in school but do not or the cost of men and women who are not at work, who could contribute at work but are not able to because of just simply not receiving the care because there simply is not the coverage that they need.

So, Mr. Chairman, I feel as if we have an opportunity of a generation. I would just ask each and every one of you on this committee to please not miss this opportunity. I do not want us to put mental health or for that matter substance abuse in parenthesis. I want us to consider this to be a part of health care in the United States of America.

We pay a terrible price, Senator Danforth, in terms of denying people their very dignity by not providing decent coverage; and we also from a dollars and cents point of view pay a terrible price financially. We can have care that is comprehensive and flexible and we can do that in a cost effective way.

Mr. Chairman, one of the things I fear the most about this debate is that we are now on a fast track and as we now have to step up to the plate and mark up bills and write legislation, which I find to be on the one hand why we are here, but I also find to be by far the most challenging part of our work, is that I do not want us to essentially be unable to really come through with good legislation because of outdated data and outdated assumptions.

I would like to, Mr. Chairman, if possible have included as a part of the form record a study that was done that Senator Domenici talked about by Milliman & Roberts Associates, very well-known actuaries, very solid data. The reason that I want this study included in your record is that one of the issues that is raised all the time is well, yes, we agree, but can we really afford to do this.

Now I can make two arguments. One is, we cannot afford not to because of the terrible costs we pay. But the second argument I want to make—and I hope members of the committee or their staffs will have a chance to look at this very important study—is that as a matter of fact—and this, by the way, is premised on what many of the Fortune 500 companies do for anywhere between $185 and $224 per person. That is what we are talking about.

We can provide broad coverage in the mental health field, which would cover those that are persistently ill. Sometimes we run into problems with persistently ill.

Senator Domenici. For what period of time?

Senator WELLSTONE. Per year. What we are talking about is a continuum of care. One of the problems quite often is there is a fine line between those that we talk about as suffering from persistent mental illness and those that suffer from less than that, but are still very much in need of care.

The CHAIRMAN. Episodic.

Senator WELLSTONE. That is correct. So I hope that you will take a very close look at this study. We can do it in a cost effective way.

Mr. Chairman, I just would conclude this way. I offer my full cooperation. I have with the help of some wonderful people on my staff, working with Senator Domenici, and other Senators, and certainly working on markup in the Labor and Human Resources Committee devoted the last several years to this.

The last several years to this in terms of the policy part; the last several years, Senator Domenici, in terms of how we can deliver truly humane and dignified care. I put a very strong emphasis on community-based care. And also, I feel like the last half of the year just looking at the numbers, just making sure that we get the data, because once again I do not want us to look at data that is pre-1983. I do not want us tc do this on the basis of outdated assumptions when we have really got some solid data that I think presents us with a real opportunity to do well for people.

So I come here to support my colleague, those of us that are on this working group which now numbers over 20 Senators, are pleased to work closely with your committee, and I hope that we will be up for the job. This is the chance to do it.

If we do not do it well this time, I just think we will be waiting decades before we do. If I can just say this to you in a very personal way, there are a lot of citizens in this country. They are not the most politically powerful, but their hopes are high and they are counting on you.

The CHAIRMAN. We thank you for very powerful testimony. I think you have made your point. The last time the Presidency addressed this subject was October 31, 1963 and we have a lot of explaining to do about how we did not follow through. Obviously, there have been great advances in science on the subject and we must address the subject in this administration.

Senator Domenici. Mr. Chairman, could you let me just make sure that I call to your attention a couple of very specific things. I inserted in the record a letter of mine to each of you.

The CHAIRMAN. Yes.

Senator Domenici. A very simple document that a lot of people have worked on called "Health Care Coverage for Severe"——

The CHAIRMAN. Severe mental illnesses.

Senator Domenici. Yes. And under it the words that are really important are, "The case for parity of treatment."

About 2½ years ago in an appropriate bill, we directed that the National Institutes of Mental Health put an advisory group together and give us the efficacy and cost of treatment. You will find that as the second document that I attached. It is called "A Special Report." It is very simple. I do not think it has been refuted. It is startling information with reference to the effectiveness of treatment.

Then as you are going to hear from Dr. Torrey, we put in an Office of Technology Assessment summary which they put together called the biology of mental disorders. That is my third submission.

The CHAIRMAN. Oh, good.

Senator Domenici. I think you and your staff people will come to some conclusions that we are not talking about vague things. We are talking about real serious things that are tangible. We cannot call them diseases yet but we are very, very close. So we call them by other names. But we have begun to define them.

I might say to all of you as my friends, you might have suspected, as I described, the young lady going off to college, that was one of our eight that I was describing for you. It has been 14 years. She is better. But we understand and we have been privileged I must say to all of you to meet thousands of parents with severely mentally ill children.

I will tell you, if you want to go to a national meeting where you can hobnob from table to table and leave finding something out, go to a National Alliance for the Mentally Ill, national conference with 4,000 to 5,000 relatives, parents and friends.

I mean, these are people that you just cannot believe. They are great citizens. They are hardworking for the most part. They are well educated and they have this scourge in their families and it is something to be there and feel that. I think we must make sure that you all begin to feel some of that because we cannot let this one go by.

Thanks so much for your time.

The CHAIRMAN. Thank you.

Senator WELLSTONE. Mr. Chairman, we both could go on for hours. I will just take one final 10 seconds and say that what Senator Domenici said is so true about the National Alliance of the Mentally Ill. I can remember again from our own family's experience. There was such a long period of time, Senator Domenici, where family members were unwilling. You know, it was a stigma. People did not talk about it. That has all changed and for the better. That is why we are so hopeful.

Mr. Chairman, I also with your permission would like to submit to the committee, not in a sense of pretension, please believe me, but some of the sort of work that our office has been trying to do on how we would structure delivery of mental health services to people. I hope that would be all right, along with the actuary study. I would like to have that submitted to you. And look forward to working with you all. Thank you very much for having us.

The CHAIRMAN. Thank you both so very much. Thank you, Mrs. Domenici, for being there in the back of the room. Thanks, colleagues. And now we will go to the panel to which Senator Domenici so generously referred. We are going to hear from four professional witnesses in this, the next to last of our hearings.

First from Dr. Richard Surles, who is the Commissioner of Mental Health. Now, Dr. Surles, has that been changed?

Dr. SURLES. It is called the Office of Mental Health. The Department of Mental Hygiene in New York still exists, but it was broken into three different organizations.

The CHAIRMAN. Mental Hygiene is still the name.

Dr. SURLES. In the State Constitution it is still there.

The CHAIRMAN. Yes.

And, Dr. Fuller Torrey, who is with the National Institute of Mental Health Neuroscience Center at St. Elizabeths.

Charles O'Brien, who is Chief of Psychiatry at the Philadelphia Veterans Administration and Professor of Psychiatry at the University of Pennsylvania.

And finally, David Musto, who is Professor of Psychiatry and the History of Medicine at Yale University School of Medicine.

We welcome you all, Doctors. Just following the pattern in which these names appear, Dr. Surles, you are first. All statements will be placed in the record as if read. I would like to ask you to keep your statements fairly close to our appointed time so we have a chance to ask you questions. But we will not have any flashing lights.

Good morning, Dr. Surles.

STATEMENT OF RICHARD C. SURLES, PH.D., COMMISSIONER OF MENTAL HEALTH, STATE OF NEW YORK, ALBANY, NY

Dr. SURLES. Thank you, Mr. Chairman. I really appreciate being here, and to all the members. I actually was given an assignment to provide a brief history of deinstitutionalization and to try to bring it up to date of what has happened. I also wish to make some recommendations from a State government point of view of what might we do to improve the delivery and organization of care within this framework of national change.

First of all, the definition of deinstitutionalization generally describes the downsizing of the State operated psychiatric hospitals. In 1955 there were over 559,000 people in State operated facilities.

The CHAIRMAN. That was when the meeting took place in the Governor's office on the second floor of the State Capitol with Paul Hoke, Averill Hammond and this paper from that week's issue of the——

Dr. SURLES. That was the peak year. And after that year we started to see a reduction of the State hospital system. Until today, I think the last time I saw the estimate was only 85,000 people nationally belonging——

The CHAIRMAN. It was 85 percent of the total population, which was at least a third smaller. So you are down to about 15 percent of what you would have been in 1955.

Dr. SURLES. In New York State, as we frequently do, led the nation. As you mentioned earlier, the number of people in State facilities in New York exceeded 90,00 and today the adult population of State psychiatric hospital, we still have 20 hospitals, but that census is now down to about 9,000.

Deinstitutionalization, too, as the Senator mentioned was not only about downsizing the hospitals, but shifting the responsibility of care to community-based settings. Some have made an argument that what we got in the 1960's and 1970's was not really deinstitutionalization but transinstitutionalization. When you look at the people leaving those hospitals, especially in the 1960's and 1970's, people were placed in what I knew in North Carolina as rest homes. In New York State we call them adult care homes.

Patients were discharged from the hospital into adult care homes asthroughout the State. In urban areas a high use was made of

single room occupancy hotels. At one point in the 1970's we had over 100,000 single-room occupancy hotels in New York City alone. A third of those beds were occupied by people who had a severe mental illness.

We also discharge people to nursing homes. We made it economically possible through the Medicaid program to move people from State care into nursing care, in a State like New York, generally very elderly people. In some other States, people of all ages.

Finally, I think as many people know, that today many children or adult children are remaining at home, frequently untreated and lacking access to care. The history of mental health contains many examples of Federal programs that actually made possible some of this transinstitutionalization. For example, the Social Security Act for Disabled People in 1954, Medicaid and Medicare in 1968, the Community Health Centers Act of 1963, and Supplemental Security Income of 1972 are examples of major reforms which affected persons with severe illness.

The States also have played a major role in financing care for people with the most severe illnesses and disabilities. The National Institute of Mental Health last year published a study that showed that the States accounted for about one-third of all the money going to pay for mental health treatment, as compared to about 14 percent that the States were paying for other forms of health care services.

So States have remained a major payer. While they have been a diminished operator of care, they have continued to make funds available, either by matching the Medicaid program or State appropriation.

These changes during this period of transinstitutionalization and the fragmentation of the financial systems have really made for very unclear accountability. Who is responsible for trying to arrange care? Who is the responsible party that a family member should turn to when things do not work and when people are told that they are no longer eligible for care?

My professional struggle has been to find another way to organize care that would fit into some of the changing scene at the Federal level, not only in health care reform, but welfare reform. Most of the examples that I have mentioned are also welfare programs that have impacted upon deinstitutionalization. They need to be considered in light of the impact that they will have on someone's ability to not only retain their health status, but to live in the community setting.

I also want to focus on the most severely mentally ill. When we talk about the consequences of the institutionalization we frequently talk about homelessness and the mentally ill among the homeless. I actually see four populations that I am most concerned about.

I felt Senator Domenici made a very good point. I think that the creation of an accessible benefit has the potential to lessen in the long term the creation of more homelessness and disabled people who were undomicile, but in the interim a person like myself has to worry about the fact that we do have a large number of people both in the inner city and rural areas who remain either undomiciled or at some level of risk.

We in New York have given priority to people with major mental illness who we find in our city shelters. About 90 percent of the homeless are mentally ill in New York State living in New York City. We have had a major effort to get the homeless out of shelters and have placed over 4,000 people in some form of treatment setting. Among this population was a large number of veterans, actually younger veterans. About 25 percent of all of the homeless mentally ill that we have put into treatment in the last 3 years have been veterans.

Second, there is a high percentage of undomiciled, that is people on the streets, in public stations, that are also mentally ill. Because of the fear of the shelter system we find a surprisingly high percentage of women who are in public places who have either history of previous hospitalization or major mental illness.

Third, there is also a group of people who refuse care. Some of that is because they have come to fear the mental health system. But the refusal of care means that they frequently wait until there is an acute crisis before they try to seek services.

Then, fourth, there are those with multiple and complex conditions. We are seeing people more and more who are—there is almost no such thing anymore as a pure schizophrenic—that we are seeing people with multiple disorders. And especially in the areas in which there is a high rate of drug abuse, it is not uncommon to find people with a major mental illness self-medicating with street drugs. That has added to the complexity of trying to organize and provide a care system.

In my testimony that I submitted for the record, I suggest that as we examine reform we have a 30-some year history of creating some of these problems you now seek to resolve. As reform occurs, interim steps will be needed that might give us some hope that we can address some of our most serious problems quickly.

I am interested in redesigning the existing mental health system and to reallocate monies that we currently spend on mental health. It would make it much easier if in considering Federal health care reform we could look at the possibility that States might collaborate with the Federal Government in designing a plan which would co-mingle State funds and Federal funds from various resources to design a new benefit that would be targeted for a period of time, until health care reform takes full affect to people that are the most seriously ill and poorly served.

So it would be an idea of a negotiated approach in which we would target the population and that the States would agree to put State resources into a supplemental appropriation.

I think it is incredibly important to realize that in terms of trying to respond to the undomicile, to people with multiple illnesses, that we are going to have to offer more than people are accustomed to in a health care benefit. We have to blend good health care, mental health treatment, rehabilitation, case management, and for some people we are going to have to arrange a new form of supported residential living, some type, in some cases supervised residential living in others.

But we have to have for this most disabled group an ability to do those five things within some type of overall managed system of care.

I am really not here in any way to suggest that change does not need to occur. The current benefit system does not work, especially for the people that I am most concerned about. If a new approach can be taken which provides special assistance to the most disabled by pooling resources from a variety of governmental sources; substantial gains could be made for the most disabled while also lessening the overall financial risk associated with most open-ended entitlements or insurance benefit.

From our work in New York, on any given day there are about 80,000 people out of 18 million that would need this type of comprehensive benefit. If our past problem of creating an open-ended entitlement and then letting people like myself and others who provide care figure out how to game it, I think we have to call an end to those policies. If you take out the most expensive cases it really reduces the costs to every other person covered in whatever insurance type program that is developed.

In considering a new approach to respond to most severely disabled Americans suffering from mental disorders, I recommend a fundamentally restructuring of both the health and welfare systems within the following framework.

First, to provide an accessible basic mental health benefit for all covered persons in a universal health plan and include in this benefit the array of services proposed in the Health Security Act. In addition, what I am also suggesting is a targeted benefit for a limited number of persons with the most severe mental disorders, which is both comprehensive and managed.

It does not make any sense anymore to think that we can just do an open-ended go to the marketplace and purchase whatever you need. It has to be both comprehensive and managed.

To those targeted individuals——

The CHAIRMAN. That means somebody is responsible for it.

Dr. SURLES. Somebody is in charge. That it is very clear who is responsible for everything the person would need. This is not something we are unaccustomed to doing. We do this in rehabilitation, in the vocational rehabilitation program. We do it in the area of mental retardation. For the identified individual there is a unique plan of care developed and paid for, and that it is not shopping around.

For this targeted benefit program, permit States to develop rosters of those who should be considered for this supplemental benefit. Use a need base rather than an income based approach to eligibility. In other words, we should decide that people because of their medical condition and their disability need this benefit. If they have income,then they should contribute to the cost of their care.

Last, establish responsibility. Again, there are a variety of ways of doing this. Promoting outreach and support to enable the most severely ill to access care. And clearly assign leadership for the overall management of a plan of treatment and care.

It seems that for the population of people on the streets and in shelters, and people who wait for the crisis, an insurance type plan is too passive for that population. And at least for this small percentage of people that the system has not worked for, we need a much more aggressive, much more assertive approach.

But again, I think it is possible to limit the number of people, not the benefit, and then provide this additional wraparound service for this group of most in need individuals.

Thank you very much.

The CHAIRMAN. Thank you, Dr. Surles.

[The prepared statement of Dr. Surles appears in the appendix.]

The CHAIRMAN. Could I ask, and I hope this is not a question that cannot be answered, do you all work with some sense of what the incidence of mental illness is in a large population? I see you all agreeing. As you testify, could you let us know what you think that might be? Is it about 2 percent? Do I have that about right?

Dr. SURLES. We use a figure of about 1.8 percent.

The CHAIRMAN. Yes. And you are going to find that in Argentina?

Dr. TORREY. Not necessarily, sir.

The CHAIRMAN. Oh.

Dr. TORREY. The incidents around the world varies about 10-fold from the highest to the lowest. The United States is kind of upper median but not as high as some areas of the world. There are areas of the world where diseases like schizophrenia and manic depressive illness are remarkably rare.

The CHAIRMAN. Are remarkably rare?

Dr. TORREY. Rare. Yes, sir.

Senator PACKWOOD. Could I ask a quick question then?

The CHAIRMAN. Yes. There are a lot of people who would like to know where that place is. [Laughter.]

Senator CHAFEE. And vice versa, where they are most common.

Senator PACKWOOD. I was curious as to something Senator Domenici said, that these diseases are biological. If there is that degree of variance around the world and it is biological, and we know it is biological, why the difference?

Dr. TORREY. There are marked differences in the incidence of virtually every disease around the world. Not only cancers, but heart disease, diabetes, et cetera. The surprising thing would be if there were not differences, not that there are differences in incidence.

If I could tell you today exactly why these differences exist, we would not have this hearing. We could all go home. But we do have a lot of ideas.

The CHAIRMAN. Dr. Torrey.

STATEMENT OF E. FULLER TORREY, M.D., CLINICAL AND RESEARCH PSYCHIATRIST, AND GUEST RESEARCHER, NATIONAL INSTITUTE OF MENTAL HEALTH NEUROSCIENCE CENTER, ST. ELIZABETHS HOSPITAL, WASHINGTON, DC

Dr. TORREY. Thank you very much, Mr. Chairman and members of the Senate Finance Committee for the opportunity to testify today. I am a research psychiatrist specializing in schizophrenia and manic depressive illness, specifically research on viruses as a possible cause of these diseases. I am also an advocate for individuals with serious mental illnesses and I work with the National Alliance for the Mentally Ill, pro bono, as well as for the Public Citizen Health Research Group.

I have authored a book on the consequences of deinstitutionalization and specifically the consequences for the homeless population. For over 10 years I have run a clinic every other week for mentally

ill women who are homeless. And finally, but probably most importantly, I have a sister who has had schizophrenia for 37 years. For 30 of those years she has been hospitalized, mostly in the New York State hospitals before she was deinstitutionalized.

I wish to make four points this morning. Number one, deinstitutionalization is the largest social experiment in twentieth century America except for the New Deal. There were about 559,000 people at the maximum in the State hospitals in 1955. But based on the population today, if we had the same number of people in the hospitals today it would be 869,000.

There are, as Dr. Surles said, only 85,000 people left in the hospitals. That means we have effectively moved 785,000 people who would be today in the hospitals if we were in 1955, into the community in one form or another. That number of people is the same as the population of San Francisco or Baltimore. It is larger than the population of Washington, DC or Boston or Cleveland or Denver. This has been an enormous social experiment.

Number two, deinstitutionalization has worked for many people. It was a humane idea. It was basically a good idea. It was just carried out very, very poorly. For many, it has been a disaster and the disaster can be measured in a variety of ways.

One measure is the homeless mentally ill. At least a third of the homeless have schizophrenia or manic depressive illness. Depending on the total number of the homeless, even if we use a relatively conservative number of 450,000 total homeless in the United States, this means that today there are approximately 150,000 people with schizophrenia and manic depressive illness who are homeless on the streets or living in shelters.

Where these people came from is no mystery. In a study in Massachusetts of 187 patients, within 6 months 27 percent were homeless after being discharged from the State hospital. A similar study in Ohio showed that 36 percent were homeless within 6 months after being discharged from a State hospital.

I do not need to tell this committee about the situation of the homeless, mentally ill in New York which is now known as Calcutta West, or in San Francisco or in Miami. The Wall Street Journal carried a very instructive letter recently. It said, "A simple visit to the local elementary school, post office or grocery store can now be a daunting journey through the dark underside of our society."

Another measure of the failure of deinstitutionalization is the jailing of the seriously mentally ill. Senator Domenici also referred to this. We did a study 2 years ago of all the jails in the United States. We found almost 31,000 people on any given day with schizophrenia or a manic depressive illness in the jails in the United States.

There are probably twice that many in the nation's prisons. The Los Angeles County jail is de facto the largest mental institution in the United States today. The third measure of the failure of deinstitutionalization is suicides. The suicide rate among people with schizophrenia is 10 to 13 percent. The suicide rate for individuals with manic depressive illness is 15 to 17 percent. These rates are considerably higher than when deinstitutionalization was begun.

The fourth measure is acts of violence. There is no question now that there are increasing acts of violence by seriously mentally ill

individuals who are not treated—and I would emphasize the "not treated." People with these illnesses who are under treatment and receiving medications are no more dangerous than the general population. However, when they are not treated they do become more dangerous than the general population.

In your own State, Senator Moynihan there are two recent studies. One is of individuals who push people in front of subway trains. Three-quarters have been found to be psychotic. Another very important study done by Dr. Link, and others, at Columbia, showed that mentally ill people who are not receiving treatment and living in the community have a rate of violent episodes two to three times the rate in the general population.

The fifth measure is revolving door rehospitalization. It is common now to have people with schizophrenia and manic depressive illness being rehospitalized 100 times or more.

The sixth measure is transinstitutionalization. Both Senator Domenici and Senator Wellstone referred to this. Last week, for example, I was in Iowa and was in a residential care facility. It holds 38 mentally ill individuals. It is for all intents and purposes a nursing home. And many, many, many people who have been deinstitutionalized have been merely transinstitutionalized to nursing homes or nursing home equivalents.

This particular facility had not been inspected in 5 years. That is one of the problems; we transinstitutionalize people to places which are no longer being inspected.

Last week I was also in an institution for mental diseases, called an IMD, in California. There are now 35 IMDs in California, totalling over 3,500 beds. They are for all intents and purposes exactly like State mental hospitals, except they have a new name.

One of them, for example, which is run by a for-profit company called TeleCare, has even leased a building on the grounds of Metropolitan State Hospital. So you have an IMD using a hospital facility but it is no longer called a hospital.

My third point is that the principle reasons for failure are twofold. One is a misunderstanding of the causes of serious mental illnesses; and the other is a thought disordered funding system which guarantees failure.

At the time you began the planning for deinstitutionalization, Mr. Chairman, the causes of these disorders were thought to be things like bad parenting, early childhood traumas and the conditions in society. Those ideas have long since gone by the board.

We now know that schizophrenia and manic depressive illness are brain diseases. We can measure changes in brain structure and brain function. Appended to my testimony are pictures of MRI scans taken from people with schizophrenia. They came from our study of identical twins, which we recently completed. We studied 66 pairs of identical twins.

Also appended is a chart, which I will hold up, showing that using the MRI on identical twins in which one has schizophrenia and one is well, we can tell on the basis of one particular part of brain structure alone in 80 percent of the cases, which is the individual who is sick. We can now measure these things.

What this means is that schizophrenia and manic depressive illness are brain diseases in exactly the same sense that multiple

sclerosis, Parkinsons disease and Alzheimers disease are brain diseases.

The fact that they are brain diseases also complicates the treatment, because somewhere between 40 and 50 percent of people with these diseases do not have insight into the fact that they are sick and need medication. Therefore, we have to treat some people involuntarily who do not accept the fact that they need treatment because, like Alzheimers disease, they no longer have the ability to appreciate their own needs for medication.

The other principle reason for the failures of deinstitutionalization has been the thought disordered funding system. Dr. Surles referred to SSI, Medicaid, Medicare, SSDI, food stamps, and HUD 202 housing. Effectively what we did when we started deinstitutionalization, and you should remember at that time the Federal Government, in 1955, only was paying between 2 and 3 percent of the total bill for people with serious mental illnesses. The States were paying 96 percent.

The CHAIRMAN. Mental health care was concentrated in the Veterans Administration.

Dr. TORREY. Yes. That was the major Federal program at that time. What we have effectively done is shifted the cost from 96 percent from the States to less than 50 percent from the States. The Federal share of the cost has risen from 2 to 3 percent to, we had estimated, 38 percent in 1985. It almost certainly is over 50 percent today.

This has created a gigantic fiscal carrot, providing a huge incentive for the States to empty out their State mental hospitals and providing virtually no incentive for the States to then follow these people once they leave the hospital.

In most States today the single most important function of State Departments of Mental Health is to find additional ways to shift the cost from the State Government to the Federal Government. And in States like New York you have what looks like a three-way tag team wrestling match as the State, New York City, and the Federal Government try and shift the cost to each other. This has been a very important reason for the failure.

My fourth and final point is that the Senate Finance Committee today has the opportunity to correct both of these errors. Number one, you should ensure that health care reform covers brain diseases such as schizophrenia and manic depressive illness in exactly the same way it covers brain diseases such as multiple sclerosis and Parkinsons disease and Alzheimers disease. The brain is a single organ and it is both illogical and discriminating to provide full coverage for some diseases of the brain and not for other diseases of the brain.

It would be exactly like covering some diseases of the heart but not covering other diseases of the heart.

Secondly, the committee should ensure that the new financing system removes the fiscal incentives for States, counties and cities to continue dumping patients into the community without providing aftercare.

Dr. Surles referred to some mechanisms that can be utilized, like waivers and innovation. The financing system must be changed so the fiscal rewards come from providing care, not from failing to

provide care. As long as States are rewarded for dumping patients, they will continue to do so.

What is clear, Mr. Chairman, is that under the current financing system, services for individuals with serious mental illnesses are unlikely to improve and the failures of deinstitutionalization will continue to haunt us. Thank you.

The CHAIRMAN. Thank you, Dr. Torrey. That is very powerful testimony.

[The prepared statement of Dr. Torrey appears in the appendix.]

The CHAIRMAN. May I just interject that in 1963—I will not speak to 1955—when President Kennedy signed the Mental Health Center Construction Act, which was his last public bill signing, we did not have anything like the present tomography or brain scanning. But we assumed that the major disorders were diseases and that they would have a continued incidence that improving early childhood training or whatever was not going to make go away. This was a permanent condition, it had nothing to do with the sexual repression of middle class life in Vienna.

That is why I was surprised to learn that there are large differences in the incidence of these diseases around the world. But you say that is normal. Doctors find that to be expected. And Dr. O'Brien is nodding.

Dr. O'Brien, at the time of the deinstitutionalization measures, the decision to do so by President Kennedy was largely the initiative of the Veterans Administration which knew most about the subject, with some input from such places as New York, and a commission that the Congress had created at that time. So we welcome you, sir, and look forward to your testimony.

STATEMENT OF CHARLES P. O'BRIEN, CHIEF OF PSYCHIATRY, PHILADELPHIA VETERANS ADMINISTRATION MEDICAL CENTER, AND PROFESSOR AND VICE CHAIR OF PSYCHIATRY, SCHOOL OF MEDICINE, UNIVERSITY OF PENNSYLVANIA, PHILADELPHIA, PA

Dr. O'BRIEN. Thank you, Mr. Chairman, and good morning to members of the committee. My written testimony actually deals with the development of medications generally throughout psychiatry. And, in fact, since we had mentioned the Veterans Administration I will just point out that much of the research, especially in those early years in developing medications, beginning with the derivatives of the snake root plant and the various other drugs that were discovered really by serendipity originally, by astute clinicians who noticed these effects——

The CHAIRMAN. Well, those Vedic doctors have been fussing around for five millennia. They were smart enough, they knew something.

Dr. O'BRIEN. To pay attention to the folk medicine a little bit.

The CHAIRMAN. Yes.

Dr. O'BRIEN. But our medicines now are much more specific, less side effects and much more effective. I will focus my oral comments on the treatment of addictive disorders, because this is an area where there is still a great deal of misunderstanding about the success of treatment.

Almost everyone has a relative, neighbor or colleague who sufferers from dependence on alcohol, nicotine or an illegal drug. So everybody feels as though they are a little bit of an expert on this. These sufferers typically try to stop their drug taking and usually succeed for a short time. But then they relapse.

Once a person becomes addicted, the habit pattern etched in the brain as a memory trace, does not go away when they stop taking the drug. It persists for months and even years, and, therefore, treatment has to continue for months and years and sometimes many years.

Willpower alone just is not enough for most people. This is exactly the pattern we see in the treatment of chronic disorders such as asthma, hypertension or diabetes and we can show, and there actually have been very many cost effectiveness analyses, that the treatment of addictive disorders is just as effective, and in fact in many cases more so; and it is also cost effective. Because money invested in the treatment of addiction saves money elsewhere, both in the medical care system and also in the penal system.

For heroin addicts, for example, we have excellent medications that help them become drug free. But only a small minority of heroin addicts are able to remain abstinent. Since the 1960's, however, it has been known that heroin addicts can be stabilized on an opiate such as methadone or on the new medication called "LAAM." LAAM was developed by NIDA (National Institute on Drug Abuse) and it maintains former heroin addicts in a comfortable, functional state with only three doses per week. So it interferes less with their daily lives and they can function at a very high level.

These maintenance treatments are analogous to the hormone maintenance for people with adrenal gland insufficiency, or thyroid insufficiency or diabetes. Currently, about 125,000 of the approximately one million opiate addicts in the United States are treated in methadone programs.

Overall the success rate is approximately 60 percent, although results vary. Good programs that provide psycho—social rehabilitation in addition to methadone have higher success rates, while those that provide little more than the medication do less well.

Scientists funded by NIDA have discovered a great deal about how opiates affect the brain. This has led to another medication called naltrexone, that specifically blocks the receptors for opiates. While receiving this medication, the effects of heroin are prevented. Unfortunately, this treatment itself requires willpower and it is successful only for better educated and motivated opiate addicts. For example, physician addicts do extremely well on naltrexone.

Cocaine abuse and dependence are serious public health problems. Highly addictive crack cocaine sells for as little as $2 to $3 per dose. I have actually read in the New York Times that it is occasionally available for 75 cents in New York and it is available throughout the United States.

People seeking treatment of cocaine addiction are usually in desperate shape. Thus far, there are no medications that are consistently helpful in preventing relapse of the cocaine dependence.

There are, however, behavioral programs that have achieved significant success. For example, our VA program in Philadelphia recently published 7 months success rates of 68 percent for an out-

patient rehabilitation program and 51 percent for an inpatient program.

Clearly, we would like to improve these results. There is an intensive effort directed at finding a medication that would be helpful with this disorder.

Alcoholism is a form of drug dependence whose treatment has already benefited from advances in neuroscience. One of the most exciting developments is based on the finding that some of the reward or euphoria produced by alcohol is mediated by the endorphin system, the endegenous opiate system, the "heroin" that we all have.

Naltrexone, as I mentioned, is a drug that blocks receptors for endorphin and has been shown to significantly improve the results of treatment for alcoholics. Thus, a medication developed by NIDA researchers for the treatment of heroin addiction may turn out to help a far larger population of alcoholics.

The 40 years of increasing success for medications in the treatment of mental disorders has generally been achieved through the combined efforts of the private pharmaceutical industry and government funded scientists. An exception has been in the area of addictive disorders where relatively little pharmaceutical interest has been shown.

In 1992 the Congress asked the National Academy of Sciences to establish a committee of the Institute of Medicine to examine the incentives and disincentives for the development of anti-addiction medications. The first report of the committee, published recently, noted major disincentives, such as inadequate understanding of mechanisms of addiction and relapse at the neurochemical level, especially for cocaine dependence, an uncertain market environment restricted by FDA and DEA regulations, and legal liability during clinical trials.

The committee also noted that the medications development program at NIDA had been authorized funding for fiscal year 1994 at $95 million, but it was appropriated at only $36 million. The committee recommended high priority for full appropriation of medications development, both at the basic and at the clinical level. They suggested the special forfeiture fund as a possible source of increased support. This is managed by the Office of National Drug Control Policy.

The report recommended increased Federal leadership in assigning a high priority to the development of medications for drug abuse treatment. The exploration of special incentives, such as increased patent protection, tax incentives, and the streamlining of regulatory mechanisms.

In general, the IOM report concluded that there is a need for more basic information on the mechanisms of addiction and that there are great opportunities for building on neuroscience discoveries that are not being exploited because of inadequate resources.

It would appear that investment in the addiction area would have a high probability of deriving clinically important results.

Thank you for this opportunity to testify.

The CHAIRMAN. Thank you, indeed, Dr. O'Brien.

[The prepared statement of Dr. O'Brien appears in the appendix.]

The CHAIRMAN. We have a copy of the Institute of Medicine study, which the fact that it happened is an event in itself.

Dr. Musto is now going to wrap up our morning here. May I just say by way of preface, this one member of this committee, I gave the first Lindberg lecture a year ago I suppose at the Kennedy School, which I published under the title Iatrogenic Government on Social Policy and Drug Research and offered the proposition, it could be no more, that there has been a problem within the medical profession about addressing these particular issues.

It is not for nothing that they known as drugs. They are known as drugs because they used to be bought in drug stores and they began as medicines. Then the medicines turned out to be iatrogenic in a general sense.

I was speaking with the heads of three major pharmaceutical companies about a month ago and asked them, we all know that heroin is a trade name, right? No, they did not know that heroin was a trade name. They never heard that heroin was a trade name. They said that the people who made Bayer Aspirin developed it, tried it out on their employees, and made them feel hellish. Dr. Musto, from Yale, you can find advertisements for heroin in the Yale Alumni News in 1910.

Dr. MUSTO. Not recently. [Laughter.]

The CHAIRMAN. But we banned it. Our statute outlawing heroin outlaws it as a stimulant, which in fact it is not. It is a narcotic.

But I have just felt that there are a shelf load of Nobel Prizes awaiting those who make the first breakthroughs on AIDS. All that Vincent Dole got for developing methadone treatment was a hard time.

I do not know where the work is going on in the sort of brain research that would deal with crack cocaine, which was a mutant. Crack cocaine appeared in the Bahamas in 1983, date certain. There is a man trained at Yale, named Allen, I am sure you know him, who was running the Sandy Lands Clinic, which was the only psychiatric clinic down there.

A fellow showed up one day who the previous day had cut off the head of his dog and drank its blood and then stabbed his brother-in-law to death. I do not know how these things go, but I suppose Dr. Allen said, well, do you do this often, is this a regular weekend pattern with you or has anything happened lately that is different. I think that is the way you do it. Has anything changed in your behavior recently?

In due time, it did not take long, this mutant had appeared. He tried to tell us something was coming. Made speeches about an epidemic is heading your way and he got no attention at all. He finally published the work in Nature, but got no attention over here. The Centers for Disease Control paid little attention, indeed.

But I am not testifying. I am just rambling. Dr. Musto.

STATEMENT OF DAVID F. MUSTO, M.D., PROFESSOR OF PSYCHIATRY (CHILD STUDY CENTER) AND THE HISTORY OF MEDICINE, YALE UNIVERSITY SCHOOL OF MEDICINE, NEW HAVEN, CT

Dr. MUSTO. Thank you very much. I am going to say something about the history of drugs. You are quite right, it has not had a

high level of esteem among the medical profession, nor has the history of drugs had a high level among historians. Until very recently there has been very little serious work among historians.

I first got involved in this by accident back in the 1960's when I was special assistant to the director of the NIMH. He ordered me to look into the history of drugs. I had no interest in it whatsoever. It was Dr. Yolles, if you remember Dr. Yolles.

The CHAIRMAN. Yes, indeed.

Dr. MUSTO. He came in one morning and said, well, Musto I see you have done all this history. I said, yes. He said, well, I want you to find out why the AMA condemned heroin maintenance in 1919 because every time I bring maintenance up the FBN has that counter to it and I do not know how to respond.

I said, is there not something else? Maybe you would like me to look into mental health centers? He said, no, I want you to find this out. So I went downtown and did just what I think any student of history, a graduate student, maybe a junior in college would do if they studied a historical question. I discovered there were boxes and boxes of materials in the National Archives and also in the Library of Congress dealing with this topic that essentially had never been looked at by anybody involved in drug policy—well, at least, since they were put away.

It revealed that the United States started the world anti-narcotic movement and why we got the Harrison Act and all other sorts of things which people have been speculating upon but simply had not done what I call every day historical investigation.

Out of that I discovered a number of things—that my understanding of the history of drugs was not correct. I had adopted in medical school what I call the Public Health Service history of drugs. Then you also had the Federal Bureau of Narcotics history of drugs which was also inaccurate. They were both in a sense more like party platforms. And if you believed one you could not understand why anyone would disagree with you, that you were completely correct and the other side was completely wrong.

Well, I got involved in this. Let me just say something about the first cocaine epidemic because that in many ways illustrates the summary of the things I might say.

First of all, in this country we have had peaks of drug use that are separated usually by a lifetime, not by a generation but by a lifetime. So when it comes again, there is really nobody around who remembers the last peak of use.

The run up to these peaks is an era of drug toleration, a sense that there is nothing intrinsically wrong with a drug if you know how to use it properly. You should not use too much. No one ever recommended immoderate use of drugs. But if you understand it, you would achieve more than you could otherwise.

It is really a very American notion that you can use technology to reach the absolute maximum you could be. Cocaine was a wonderful example of this, cocaine became the official remedy of the United States Hay Fever Association. It was in Coca Cola until 1900 and people thought this was a wonderful substance that was very helpful.

The CHAIRMAN. Cocaine was in Coca Cola until 1900?

Dr. MUSTO. Until 1900. We know that from decisions in the Coca Cola case in Delaware a few years ago. There is a footnote there which is quite revealing. It does not have much cocaine in it. And, of course, if you were making a soft drink you would not want to put too much in. You would want them to have another drink. [Laughter.]

Dr. MUSTO. But it was there. It was removed in 1900 shortly before the Atlanta City Council passed an ordinance that no one could provide cocaine at a soda fountain unless by prescription. Then the Georgia State Legislature the next year, I believe it was the next year, passed a law that also said you could not obtain cocaine without a prescription.

The CHAIRMAN. It was a drug and you bought it in the drug store.

Dr. MUSTO. Well, yes. Within 1 year—cocaine actually appeared in 1884 in this country commercially. Within 1 year Parke-Davis and Company was providing cocaine in 14 different forms and it was quite legal. There were no laws against it. It was considered the ideal tonic for athletes or whatever one happens to be. It was at first considered harmless and experts reassured people that this was a wonderful substance.

So you have this tolerant phase in which you see drugs as useful if you understand how to use them: the technology of drug use. Then you reach a peak, when people start turning against it in the case of cocaine. Cocaine is particularly interesting because it became the most feared of all the drugs, from being seen as the ideal tonic to being the most feared drug.

So when the Harrison Act was passed by Congress in December of 1914 cocaine was the only substance that was totally outlawed. Even in 1914 you could still get heroin in cough medicine if it was a small amount. But cocaine was absolutely forbidden, except with a doctor's prescription.

So you have an interesting story with cocaine. One of the first major State laws against it was the Al Smith Anti-Cocaine Law of 1907. Mr. Smith had just entered the New York Assembly and by popular demand had enacted this law in 1907 which he continued to strengthen right up until the Harrison Act.

With this turn against cocaine it became linked with minorities in the United States, particularly African Americans.

The CHAIRMAN. I would just like to make a nice point from your testimony. Coca Cola entered the market in the 1880's as a temperance drink.

Dr. MUSTO. Yes, it was. Much of the cocaine was available in wines. There was Vin Mariani, which was a certain amount of cocaine in a Bordeaux wine. That was very popular. One of the people that sent an endorsement to them was Thomas Edison. I have often wondered, whenever they get things organized in East Orange, if they can find out just how much Vin Mariani he did order.

And Pope Leo XIII gave Mariani a gold medal and there was a discount to orphanages and clergy and so on and so forth. [Laughter.]

Dr. MUSTO. It was not considered bad. It was considered a tonic. And, in fact, that it was the first antidepressant so-called—it is not truly an antidepressant—that the medical profession had ever had.

And when Freud got the idea for using cocaine he got it from reading American medical journals.

The CHAIRMAN. His first publication was Über Coca, was it not?

Dr. MUSTO. Yes, that is correct; and he cites many American references. It was the Americans who felt it was a cure for morphine addiction and for alcohol addiction.

So we turned against cocaine. And over a long period of time, about oh I would say 10 or 15 years, cocaine gradually declined until the New York City's Mayor's Commission on addiction in 1930 said that it used to be a big problem, about 15 years ago, but now we do not really see so much problem with cocaine. So it was a very gradual decline.

I do not want to take any more time. I want to just say this one point which I think is very relevant to our own day. In the first drug epidemic, which included heroin as well as cocaine and morphine and smoking opium and so on, there were no laws against these drugs until people became alarmed by them and demanded that there be laws against them.

So the laws actually came after the peak of drug use. The laws appeared to be extraordinarily powerful because drugs were going down and we did have these severe laws. And the responsible people at that time, the policy makers, took the view in the 1930's, 1940's and 1950's that the laws were largely responsible for the decline in use.

So as there became a concern that this drug epidemic might occur again, the laws became more severe. We had more severe mandatory sentences. We had the death penalty by 1956, the Federal death penalty for anyone over 18 providing heroin to anyone under 18. That was an option for the jury. It was not required. Then we had the second drug epidemic.

So one of the interesting aspects is that many who have lived through all of this recently have much less confidence in criminal justice, although the Nation as a whole has turned to more severe penalties. But there are a large number of Americans who have questioned how effective are the laws because the current epidemic occurred in spite of having the most severe laws imaginable on the books.

I am sure you remember that much of the governmental activity in the 1960's was pulling back some of these severe laws until the 1970 Comprehensive Drug Abuse Act softened a great many, many of these, particularly the ones dealing with marijuana.

So I think we are in a difficult position. We cannot have the full confidence in criminal justice that our ancestors may have had. We are in a different situation than we were at that time. We cannot have the naive faith in laws that perhaps people in the 1930's and 1940's had.

That is one of the big differences in the way we look at it now, compared to how this problem was conceptualized prior to the current epidemic.

The CHAIRMAN. Thank you very much, Dr. Musto.

[The prepared statement of Dr. Musto appears in the appendix.]

The CHAIRMAN. Thank you all. I have been interrupting more than I normally do and more than I obviously ought. So why do we not go right to you, Senator Packwood.

Senator PACKWOOD. Well, as usual, Mr. Chairman, these panels are tremendously educational. I want to ask a question based upon Senator Domenici's statement. I want to preface it on what Oregon is trying to do with its so-called Medicaid waiver program where we have prioritized spending or tried to, and with some degree I think of intelligent prioritizing.

We got a waiver from the government concerning Medicaid spending. I might add, we have passed in Oregon an employer mandate that will go into effect in a few years and employers will have to provide the same level of benefits that Medicaid patients get. It is a minimum level, but you will have to provide it for employees. Unless we voluntarily get there before the trigger date and we may.

But in the program we really divided illnesses into three kinds and we listed them from one to about 700. We said we are not going to treat the ones we do not know how to treat. We are not going to treat the common cold anymore. We just do not know how to cure it. We are not going to treat muscle strains and muscle sprains and infertility. We just do not know how to treat them.

So they are at the bottom of the list and they are not at the bottom of the list because of cost. They are at the bottom of the list irrelevant of cost. We do not know how to treat them.

Then there are some which we said is just a matter of social policy. We are not going to do cosmetic surgery solely because you do not like your nose. If you are in an auto accident or you need it, we will do it; but we are just not going to do it at public expense just because you want to change your face.

Then we came to the tougher ones—illnesses that could be treated but we only had a limited amount of money. So on this list, let us say the cutoff is $500—it is not that, but let us say we cut it off at $500—we would say on some of them below the $500, if we had $1,000 to spend on a disease the chance of cure would be one in 100. And if we spent the $1,000 on something above the line, the chance of cure would be 50 in 100 and we would spend it on the 50 rather than the one.

That is simply a question of not having enough money to treat everything. Now with that, here is the question I want to ask. I want you, if I understood what Senator Domenici said, to divide what we called mental illnesses into two, those that have a biological base and we know how to treat or we think we know how to treat. I agree with you, that those ought to be covered unless we are going to get into an issue of where we do not have enough money to treat all diseases biologically oriented. But those should be covered.

Are there—I will call it—mental illnesses that we simply do not know how to treat and it is not a question of whether they are biological. They may or may not be but we do not know it. Are there those that we do not know how to treat and there is no point in spending money on and we find some other way to handle people that have these diseases, but we do not really try to treat them because we do not know how.

I will just start with Dr. Surles and ask the panel to answer.

Dr. SURLES. I think Dr. Torrey is really the authority on this. But, yes, I think there are things called mental illnesses that we

can describe, but that whether or not we can put together a treatment package that has efficacy should be debated.

I would add one note of caution though, that for people that present for treatment who do have psychotic symptoms, somebody is going to have to provide a response. I think that the question I would have is, do we have an access point to make sure that we know what we are dealing with? My concern would be the issue of someone presenting that may present a false positive of a symptom of emerging mental illness.

Frequently, and as Senator Domenici mentioned, you at the onset of an illness and you do not know what you are recognizing for a period of time. My cautionary note would be that we assure ourselves of having access to determine what we are dealing with before we do the disclaimer that this disease entity is, one, not a disease or we do not know how to treat it.

Senator PACKWOOD. Dr. Torrey?

Dr. TORREY. First of all, I want to comment Oregon for their innovative program. I think it is a very important thing and I think it is one of the more important things going on in American medicine right now and I think we should be doing more of that innovative work at the State level.

The answer to your question, Senator Packwood, is yes, indeed, we can make divisions within what we call mental illnesses on it. There is a series of mental diseases, schizophrenia, manic depressive illness being good examples for which we have inadequate treatment and which we know are brain diseases.

I would also put in that category—and incidentally, both of those are ranked high in the Oregon system. I would put in that category severe recurrent depression, excessive compulsive disorder and panic disorder. These are treatable. These are brain diseases. We know that now.

There is a whole series of other "mental diseases" and broadly defined by the American Psychiatric Association, many of which we do not know how to treat. Personality disorders are a very good example. I think it is incumbent on us at this time to make a division as Oregon has done and say it would be nice if we had the money to cover everything. We cannot cover everything. Therefore, let us cover those things for which we know there is a biological basis and for which we have an adequate treatment.

And if enough money is available down the line, let us cover the other things in exactly the same way Oregon has done.

Senator PACKWOOD. Thank you.

Dr. MUSTO. I do not have any specific information to add to that.

Dr. O'BRIEN. Actually, I, too, think that the Oregon plan is a very good common sense approach. I would just like to focus on the term that you use though is "cure," because, in fact, we learned in medical school that we cure very, very few things—infectious diseases, broken bones maybe.

So what are we talking about? We are talking about improving level of function. Most of the time physicians are trying to make people more comfortable, improve their quality of life, induce a remission in a chronic disorder and you hope that that remission will last a long time.

In fact, there are a lot of disorders. I am a neurologist as well as a psychiatrist, and there are a lot of disorders for the nervous system for which we do not really understand the ideology.

However, we do have evidence of treatment. We do control clinical trials where we randomly assign people to a control group, where they may get a placebo and an active medication and we can demonstrate improvement, not in terms of cure or not cure, but in terms of, for example, in the addiction area, which is a controversial area, whether they are able to reduce or stop their drug use, whether they are able to improve their liver function, go back to work, pay taxes, take care of their family and so forth.

If we do that and we get evidence that our treatments are effective, and more importantly cost effective and we can actual measure this and get the economists to agree—and they are a very hard-nosed group of people—if we can get the economists to agree that a treatment is cost effective, then I think it ought to be included.

Senator PACKWOOD. Thank you, Mr. Chairman.

The CHAIRMAN. Economists are hard-nosed people. They are softies. They are always coming around thinking about easy ways to get rich.

Dr. O'BRIEN. They want to see the bottom line and I think it is really important that in medicine——

The CHAIRMAN. Oh, you are talking about accountants. [Laughter.]

The CHAIRMAN. Oh, they are awful. We try to avoid them.

Senator Chafee?

Senator CHAFEE. Thank you, Mr. Chairman.

This hearing is involved with the health care reform bill. What I am seeking here is some assistance as we proceed to do something about health care reform across the nation.

Dr. Torrey makes the statement that he believes that the policies we mandate, and in the uniform benefit package, that brain diseases should be treated the same as other diseases.

Could you lead me through the specifics of that? Suppose we pass a bill and in the uniform benefit package, schizophrenia or manic depression is treated like breaking up. You are cared for. So you start with somebody out there in the community who is a homeless person. Could you lead me through what happens?

For example, as I understand in listening to your testimony, the key thing is that these individuals need supervision. If a medicine is prescribed, they have to take the medicine. Does that not lead to an institutionalization all over again? Maybe that is fine and maybe that is what we want.

At the same time in listening to this testimony, I hear it deplored that so many of these individuals are in something called an institution, now they are in a nursing home which is the same as an institution but has a different name to it. I am confused. Is that bad?

Dr. TORREY. Let me try and clarify it, Senator Chafee. No, it is not necessarily bad. Some of these people need to be in some kind of an institution. The point I was trying to make is that the institution they are in now as opposed to the institution they were in before is simply due to the way we have funded the system.

We have funded the system in such a way that we have encouraged the States to get the people out of the hospitals and not do it. In terms of the specific benefits, yes, I would suggest that people with brain diseases be covered in exactly the same whether they have Parkinsons disease or schizophrenia.

The current health plan as proposed by President Clinton discriminates against people with schizophrenia in that they are only eligible for a certain number of days of hospital, whereas people with Parkinsons disease do not have that limit. The people with schizophrenia have a higher co-payment, 50 percent of outpatient visits. People with Parkinsons disease do not have that.

There is a discrimination within brain diseases as it is now. Now, I am not saying the Senate Finance Committee can solve all of these problems. What you will do, if you fund brain diseases like schizophrenia and manic depressive illness at parity is you will then create a financial system which will give an incentive to the States to do something other than dump these people into the community, which is really their incentive now because you gain all of your money.

In Iowa you gain all of your money by discharging all of the people from Cherokee State Hospital and putting them over into an RCF. In California you gain the money at the State level by discharging them from the hospital and putting them in an IMD. And if they end up on the streets or homeless or whatever, then that is incidental on it.

Yes, many of these people do require a situation where they have to get involuntary medication, where they have to be followed up. We know how to do that. The financial system has no incentive to do so. We know how to treat people with schizophrenia. We know how to treat people like my sister who has no insight into her illness at all. She will take the medicine because she has to take the medicine.

But if you have a system that proposes to discharge people with following them, and that is what we have now, then these people are not followed and they end up on the streets, homeless, in jails, et cetera.

Senator CHAFEE. Well, I must say, by the way, in our bill, we do treat severe mental illness the same as many of the others—Parkinsons or whatever.

But I must say, in reading your testimony I was encouraged by what you had to say about the treatment and what can be achieved.

Dr. TORREY. Yes, sir.

Senator CHAFEE. I take it that the others agree with that. That is extremely encouraging.

Dr. TORREY. Yes.

Senator CHAFEE. Certainly with those with developmental disabilities, if you take a child who has got some severe problems at home, you get no help. But if the child goes into an institution, Medicaid covers it.

So the whole thrust is toward institutionalization. I am not sure. What is the thrust for deinstitutionalization for the type of patient that we are discussing here today. I cannot believe that these folks

are not covered by Medicaid, for example, when they are in a big central institution.

Dr. SURLES. They are not covered. In the area of mental retardation, the 1970 Developmental Disabilities Act and the combination of changes in Medicaid, if you are in a facility for people that are mentally retarded, you are fully covered.

Senator CHAFEE. By Medicaid?

Dr. SURLES. By Medicaid. In my State the State Department of Mental Retardation, 90 percent of its funds come from Medicaid. People with a diagnosis of a severe mental illness in a State hospital, one of the 20 adult hospitals I operate, if you are 21 to 64 there is zero Federal financial participation.

So the incentives are to try to find those places in which there is Federal financial participation—a nursing home.

Senator CHAFEE. Well, all right. Now let us say that the individual goes to a nursing home. What is the difference between the treatment there and in the mental hospital?

Dr. SURLES. Well, actually because of abuses in this system about 5 years ago, 6 years ago, Congress passed a law which makes it almost impossible now to discharge anyone with an active psychiatric illness to a nursing home.

So at this point in time the avenues that the States used in the 1960's and the 1970's to cost shift has been effectively blocked and only people who basically no longer have psychiatric symptoms can be transferred to skilled nursing care.

But in the past as I think Dr. Torrey was pointing out, in some cases we saw States that created these skilled nursing institutions for mental disease and there was very little active treatment. It basically was people being held there and maintained at a very low level of custodial care.

Senator CHAFEE. Well, you lost me there. You pointed out a problem that exists but then you indicated it has not existed recently. Tell us what you think we ought to do.

Dr. TORREY. In the State of Rhode Island if the person is in the State hospital in Rhode Island today they are not eligible for Federal Medicaid. If they are discharged from the State, and there have been large, large numbers, and put in any other kind of facility, virtually any other kind, then they are eligible for the Federal funds.

So that each time you discharge someone from the State hospital the State of Rhode Island saves money. Now most of us do not much care whether we pay for this care through our Federal or our State or our local taxes. But at the level of government you do want it. So you have set up a gaming system. That is what is going on, Senator Chafee, is the care is being driven, mostly by Medicaid and by eligibility for these Federal programs.

The quality of care and the clinical needs of the patient are incidental.

Senator CHAFEE. Well, I do not want to prolong this.

The CHAIRMAN. Well, why not?

Senator CHAFEE. Let me just continue this one moment if I might. First of all, let me just say, perhaps you know, I have been deeply involved in the developmental disability situation with the extension of Medicaid to community-based settings. So that in our

State, the large institution where most with mental retardation were—when I was Governor there were 1,200 residents of this institution. It is now closed.

This we consider is a magnificent step forward because these individuals now are in community-based settings where we have the homes for them. It might be 10 or 12, probably no more than that, where they are cared for and through a waiver Medicaid covers them.

Now under the situation you pose, where you are dealing with severe mental disability, let us say they are in a State institution in your State, Doctor. Now you are saying that Medicaid would not pay for them there.

Dr. TORREY. Right.

Senator CHAFEE. All right. So, therefore, they end up in a nursing home where Medicaid will pay for them. Now what is the difference as far as the individual goes? Not who bears it for the State. The State thinks it is wonderful because Medicaid is only 50 percent as opposed to 100 percent in the institution. But set that aside.

How about the care for the individual, is it better in the State hospital versus the nursing home? Is that your point?

Dr. SURLES. Let me use the example you are using because I think it is very helpful. The case of people with mental retardation, the benefit they get is comprehensive. It includes whatever they need to make it in the community.

The benefit for people with severe mental illness is very fragmented. That the benefit a person needs to make it in the community with a severe illness has to be uniquely designed for that person and our payment systems permit it for the mental retarded; they do not permit it for persons with severe mental disorders.

So if we send someone to a nursing home, we are sending them there because that is the only place we could find. But I certainly would not pretend in the case of somebody with a serious mental illness that that would be a place in which they are going to get the benefit package they would need to stabilize and potentially recover.

Senator CHAFEE. Well, it is your point that you have to have a plan for each individual. One individual might be better in the State hospital; one individual might be better in the community; and one individual might be better in the nursing home. Is that the point?

Dr. TORREY. There is an important distinction between the mentally retarded and the seriously mentally ill. That is, if someone is mentally retarded the quality of the living situation is what you want. And I think what you have accomplished in Rhode Island and other States has been magnificent for the mentally retarded.

People with serious mental illnesses like schizophrenia need treatment. And in a hospital, they may have been getting their medication. When you discharge them from the hospital and they are no longer getting the medication, that is when they relapse and they end up in jail or on the streets.

That fundamental difference when they do not receive treatment, that is the consequences of all the bad parts of deinstitutionalization.

The CHAIRMAN. The mentally retarded are not unstable normally.

Dr. TORREY. Correct.

The CHAIRMAN. In an earlier world they probably had very important functions. I mean, they looked after the sheep and things like that.

Senator CHAFEE. I think you are right. And, of course, the distortion is that Medicaid is looked on as a medical program and that is not what the mentally retarded need. They do not need a medical program. In most instances what they need is some supervision.

In our State in operating under the waiver, as I say, we have closed this institution that when I was Governor, as I say, they had 1,200 residents in it. But that is an entirely different situation from the group of those with severe mental illness.

Dr. TORREY. That is right.

Senator CHAFEE. Let me ask you one other quick question. What you were talking about here, about the developments in cures if you will, or maybe the word stabilization of schizophrenia and manic depression are pretty exciting. I know that in biotechnology they are working—all of us have heard testimony to this—on things like Alzheimers and, indeed, Parkinsons.

Now in biotechnology, is there much hope that we can make significant strides in these areas you all are discussing? Dr. Torrey?

Dr. TORREY. Yes. In fact, the research is very, very exciting. The largest single reason for that is Senator Domenici's leadership on the Hill, and the fact that this committee and other committees have provided the research funds within the last 10 years so that research is taking off. It is a very exciting time for those of us involved in the field on it.

I would caution you as Dr. O'Brien also said, we do not talk about cures; we talk about treatment in exactly the same sense as we talk about the treatment of diabetes. In diabetes we do not know what changes the beta cells in the pancreas. We know that the person needs the insulin.

So that by giving them the chemical that their body needs, we can stabilize them. We did exactly the same thing in schizophrenia and manic depressive illness, using drugs like lithium, frolixin and haldol and the others. That is simply stabilizing the chemistry in the body so the person does not have the symptoms. That is what allows them to lead a more normal life. That is a major difference also from the people with mental retardation who do not need this kind of chemical balance.

Senator CHAFEE. Well, Mr. Chairman, thank you. I want to report that I studied Dr. Torrey's charts and in my future incarnation I think I would be a disaster as a successful diagnostician. These charts all look the same to me. [Laughter.]

The well and the affected person, I tried covering the bottom up where it says well and affected, and I have missed every single time. So I had better stick with the profession I am in.

The CHAIRMAN. That speaks of itself.

Senator CHAFEE. But, Mr. Chairman, I want to say you have had a series of extraordinarily good panels here.

The CHAIRMAN. Haven't we?

Senator CHAFEE. And I know we have to come to a point of resolution. But this could go on for another couple of years. It would be rather pleasant.

The CHAIRMAN. We keep learning. Next week, as I said at the outset, next Thursday will be out last hearing which will be on malpractice and antitrust.

Could I just make a few questions? Before Senator Chafee leaves, I started out with the only show and tell that has been this last year of hearings. But I have in the back on the wall the pen that President Kennedy presented in October 31, 1963 when we began the deinstitutionalization movement as a formal policy of the Federal Government.

What Dr. Torrey says, you know, it was the largest social experiment in twentieth century America. And yet somehow it alludes us. In my State it has been redefined because you say it has been a success for many individuals in Rhode Island, but a tragic failure for many others.

Senator CHAFEE. Well, I cannot say in our State we are dealing with what you might call the easier group, if you would, the mentally retarded. As Senator Packwood and others have pointed out, these are——

The CHAIRMAN. But "primum non nocere" is what we are trying to think about here, as the third largest experiment will be what we are doing now.

Dr. Musto?

Dr. MUSTO. Just from a historical point of view, I do not want you to forget prohibition.

The CHAIRMAN. Prohibition, yes, that was a pretty good one. [Laughter.]

All right, then, you invited this question. We have got a certain number of treatments for drug addiction, these drugs that began as medicines and I take your point that when you go through this cycle it appears that the use is just peaking, well, research will decline because the need will seem to decline.

Dr. MUSTO. Well, yes, research has seemed to be pointless because all you have to do is separate the drug from the person. So what happens if they take it is not all that interesting.

I particularly wanted to call attention to the bad effect of the ups and downs for research money for drug abuse.

The CHAIRMAN. We have been through that.

Dr. MUSTO. I know you have. It is an amazing process. Because when it is a big political issue, more money goes there. Then it is pulled back. If you were a researcher, you would just go to some other field. You could not exist in a field that keeps going up and down. The whole important thing is to have not enormous amounts of money, but a steady amount, and not turn it off like happened last time.

The CHAIRMAN. But let me ask you since you mentioned prohibition and there is no reason we cannot ask and every reason we should. How do you feel about the present state of drug prohibition in the United States? Do you see it improving conditions? Do you think the alternatives are horrendous? Do you see anything different historically from what happened last time?

Dr. MUSTO. The success of prohibition of a substance depends on the degree to which the public feels that the drug is dangerous in itself, not for the cost it may have or the law enforcement problems. With alcohol prohibition, the peak opposition to alcohol in the 1920's may have been 50 percent. But you did have a large number of people who felt that way, at least a political majority that was able to put in prohibition.

I do not think people were tricked into prohibition. I think it had been coming for along time and they knew what they were getting into.

The CHAIRMAN. Almost a century old movement.

Dr. MUSTO. Yes, that is correct. And, in fact, alcohol had another peak of prohibition, the 1850's, just about a lifetime earlier and all of New England was prohibitionist in the 1850's.

So we have had this recurrently. But alcohol prohibition has always failed because you never really had an enormous percentage of people feeling against it. Now cocaine prohibition was existing at the same time as alcohol prohibition. And it in a sense was more successful because you had something like 95 plus percent agreement in the public that cocaine in itself is a dangerous substance.

So when I review the efforts of prohibition over our National history, it can be relatively successful if you have the vast majority of people feeling that a substance is dangerous in itself to take it. That is the category that heroin and cocaine fall into.

Now with cannabis, cannabis is more in the middle of this spectrum. It is much more used than cocaine or heroin. It is used less than alcohol. I am not sure how that will come out. I think one has to be very careful about using alcohol prohibition as a model to decide that you cannot prohibit anything.

We only remember prohibition because it failed. We just do not remember the success we actually had—eventually—with cocaine, for example, which started out legal and was very widespread.

The CHAIRMAN. But there certainly is an epidemic of crack cocaine.

Dr. MUSTO. Yes. But I was recently visiting the John Jay College of Criminal Justice and gave a talk there. The impression I get from people who were there——

The CHAIRMAN. That is in New York.

Dr. MUSTO. Yes, that is in New York City. The people who have been doing what you might call anthropological studies of crack and living in crack areas seem to think that crack use in those areas is going down.

The CHAIRMAN. Well, there is sort of a Darwinian pattern, is there not? I mean people who use it die.

Dr. MUSTO. Yes, many of them die. For some people their major contribution is their example because as other people see this, it causes them——

The CHAIRMAN. That is a pattern you have observed.

Dr. MUSTO. Yes, that people actually decide not to get involved in it because they have seen what happens to users. We have to give people credit for observing what use of the substance does to users.

It is very attractive but also it is very dangerous. And cocaine, as I said, in this country has had an eclipse previously. We never

were very successful in keeping cocaine from coming into the country and the coca bush is still——

The CHAIRMAN. That will never happen.

Dr. MUSTO. No, that is correct. And the coca bush still grew in Peru and Bolivia and yet cocaine use dropped way down in the United States.

The CHAIRMAN. Dr. O'Brien, did you——

Dr. O'BRIEN. I just would like to add to the discussion that when we speak of the question of legalizing the drugs that are now illegal, we should not do it in a blanket way but take them individually because pharmacologically they are very different.

So a discussion about possibly marijuana is very different from heroin and very different from cocaine.

We should also look carefully at experiments and try to learn from them that have been tried in other countries. For example, Italy which for a few years legalized personal use of heroin and Switzerland which has adopted a tolerant view in Holland. And then they have had a tendency to pull back because it seems to be accompanied by a great deal of increased use. And when you increase the use of a drug like cocaine, for example, you get a lot of other social problems.

Finally, I wanted to point out that our policy, in terms of prevention, has worked better than our policy in terms of interdiction. Because while the drugs have never been cheaper and more available on the street, which tells me that the billions we have been spending on Coast Guard cutters and balloons and all is pretty much wasted.

We have noticed improvement in our ability to prevent young people from getting into drugs. So that you had in some of the surveys, in the high school survey, you had the availability going up and the use going down as the kids saw what Dr. Musto pointed out, and also the complications. And also, they were exposed to the prevention programs.

So this to me ratifies some of our prevention efforts.

The CHAIRMAN. I thank you for that. If you are a New Yorker and you would like to see a monument to the efficacy of interdiction, there is nothing better than the Seagrams Building on Park Avenue, Miës van der Rohe's great architectural triumph and it just proves that Lake Ontario has two sides and boats can cross.

If that is too arcane a reference, I probably better leave it at that. We thank you very much. We are much in your debt. And as our next to last hearing concludes, it was first rate, said Senator Packwood. Doctors, all, thank you.

[Whereupon, at 12:22 p.m., the hearing was concluded.]

APPENDIX

ADDITIONAL MATERIAL SUBMITTED

PREPARED STATEMENT OF PETE V. DOMENICI

April 29, 1994.

Dear Colleague: Severe mental illnesses are some of the most crippling and disabling illnesses that can strike any person from any background. Illnesses such as schizophrenia, major depression, bipolar disorder, obsessive compulsive disorder, and panic disorder are, if not treated properly, severely disabling and life threatening.

Historically, people with severe mental illnesses have been subjected to discrimination and scorn largely because of ignorance and fear on the part of the public. People have seen the behavioral component of mental illness and assumed that these are not actually illnesses as much as a magnification of the problems of daily living.

Both public and private health insurance reflect these widespread misconceptions. Today, coverage for major illnesses is defined by medical necessity, but coverage for severe mental illnesses is defined by cost and time limitations. The limitations imposed by most insurance plans have no basis other than to limit costs arbitrarily. Rarely is this limited coverage adequate to provide the effective medical treatment these disorders require.

As we address health care reform, we are given a unique opportunity to set aside the misconceptions about severe mental illnesses, recognize the financial risk they pose to all Americans, affirm the medical necessity of their treatment, and provide equitable health coverage.

Attached you will find a white paper entitled "Health Care Coverage for Severe Mental Illnesses: The Case for Parity," which establishes the need for medically necessary coverage for these illnesses, and argues for the elimination of arbitrary limits in health coverage. You will also find guidance for drafting legislation that would provide parity coverage.

An historic opportunity exists to end a clear form of discrimination against persons suffering from illnesses over which they have no control. If you would like more information on this important issue please feel free to contact Mike Knapp of my staff at 224–6621.

Sincerely,

PETE V. DOMENICI, *United States Senator.*

Attachment.

HEALTH CARE COVERAGE FOR SEVERE MENTAL ILLNESSES: THE CASE FOR PARITY

SEVERE MENTAL ILLNESS: MISUNDERSTANDING AND DISCRIMINATION

Severe mental illnesses are some of the most crippling and disabling illnesses that can strike any person from any background. Illnesses such as schizophrenia, major depression, bipolar disorder, obsessive compulsive disorder and panic disorder—the minimum number of illnesses which fall into this classification—are, if not treated properly, severely disabling and life-threatening. Generally, these illnesses affect about 5 million Americans in any given year, or about 2.8% of the adult population.

Historically, people with severe mental illnesses have been subjected to discrimination and scorn largely because of ignorance and fear on the part of the public. The public has viewed the behavioral component of mental illness and assumed that these are not actually illnesses as much as a magnification of the problems of daily

living. Therefore, both public and private health insurance plans have set arbitrary limits on the amount of coverage a person suffering from severe mental illnesses can receive.

This discrimination has been understandable because very little was known about the brain and how it functioned. Today our knowledge of the brain, and these illnesses in particular, has vastly increased. Moreover, under both the public and private health insurance, the therapeutic options available to clinicians for treating these disorders have become more numerous, more specific, and more effective. But most Americans are unaware of these dramatic advances. As a result, public policy and insurance programs have yet to fully recognize that the treatment of these illnesses should fall within a traditional medical model of care and discrimination has continued against persons suffering from these illnesses.

Pamela Wagner, a Hartford, Connecticut-based freelance writer who suffers from schizophrenia, describes the frustration of many who suffer from severe mental illnesses in an article in the Hartford Courant (Aug. 22, 1993),

"Given the prevailing attitude and the resulting stigma against those with serious mental illness, I do not expect President Clinton's health care reform to change the present situation in which those of us with mental illness are penalized for our suffering because it is considered somehow not real, not significant or our own fault. If a person has an accident because of drunken driving, no one refuses to set his or her broken bones or charge enormous copayments. And yet this is precisely the case with mental illness, which is no more the patient's fault than arthritis, diabetes, or heart disease and may be just as chronically disabling."

There are a number of groups of mentally-impaired persons whose impairment could theoretically be categorized as a severe mental disorder, but for a number of reasons their disorders are treated differently. For example, at one time the severely mentally retarded were mixed indiscriminantly with people suffering from severe mental illnesses. However, the nature Of these two disorders and their impact on the brain require very different types of treatment and rehabilitation than severe mental illnesses. While severe mental illnesses can last a lifetime, they differ from disorders like retardation because they typically follow a cyclical course. Often people will achieve or return to extremely high levels of functioning during periods of remission. There are also differences for treating persons who are disabled with addictions, as their therapy and treatment must take into account the volitional aspect of the disorder. Each of these disorders, while similar, require a different type of intervention, thus making it difficult to place together in a broad category.

HEALTH CARE REFORM AND MEDICALLY NECESSARY COVERAGE

The primary purpose of health insurance is to spread the risk of major medical costs among a relatively large segment of the population. In recent years, our private health insurance system has not worked well for many Americans—particularly those working for small businesses—because health insurers have begun charging consumer premiums based on individual health risks instead of spreading risks more evenly across a larger group. Moreover, insurers have begun imposing limitations on coverage to hold down their costs, regardless of whether or not a patient still requires medically necessary care.

Clearly, a major reason that the Administration and Congress are moving toward health care reform is to correct these inequities and return to a system where the costs of providing expensive medical care is spread more evenly and fairly among everyone in a community.

But for such a system to work consumers must understand that all are at risk: if they do not participate, they—through no fault of their own—may face huge financial losses. In other words, consumers must see that they cannot fully avoid the risk of certain costs or illnesses through their own behavior, nor can they correct the medical problem without medically necessary care.

Coverage for major illnesses is defined by medical necessity. Coverage for severe mental illnesses is defined by cost and time limitations. The limitations imposed by most insurance plans are arbitrary and have no solid basis other than they obviously limit costs and they are accepted as a typical benefit. Rarely is this limited coverage adequate to provide effective medical treatment for severe mental disorders and they often result in denials of medically necessary treatment for those persons most in need.

These arbitrary limits do not give health care providers the incentive to adequately and effectively treat severe mental disorders. Typically, persons are treated only until their limits are reached and then they are shifted to the state public health systems. Thus, the increased burden is placed on families and taxpayers as patients with legitimate medical disorders are forced to seek care in less effective

settings. This process unnecessarily forces individuals and families to the brink of bankruptcy and often turns persons with medically treatable disorders out into the streets.

As we address health care reform, we are given a unique opportunity to set aside the inaccurate perceptions about severe mental illnesses, recognize the financial risk they pose to all Americans, and affirm the medical necessity of their treatment.

PUBLIC POLICY REACTIONS TO SCIENTIFIC ADVANCES

Across the nation we are beginning to see more frequent cases Of persons challenging the current discrimination against severe mental illnesses in both the courts and legislatures.

In the first case of its type, a father sued Arkansas Blue Cross and Blue Shield for increased coverage for the care of his daughter who was hospitalized for bipolar disorder (manic-depression). His insurance policy provided for extensive coverage for physical conditions, but limited coverage for "mental, psychiatric, or nervous" disorders. The plaintiff argued that bipolar disorder is a biological disorder and therefore should be considered "physical" under the terms of the policy. In this case, Arkansas Blue Cross and Blue Shield v. Doe, the courts ruled that bipolar disorder "is a physical condition within the meaning of the Blue Cross contract."

State legislatures have also begun to address the issue of providing equal treatment for severe mental disorders in Georgia, North Carolina, Alaska, New Hampshire, Texas, Maryland, Massachusetts, Idaho, Kentucky, Rhode Island, Vermont, Illinois, and Missouri. Clearly, the guidance to be found in these precedents is that covering medical services for disorders of the brain on any basis other than equal to coverage of medically necessary treatment for disease in any other part of the body is unfair and unjustified.

HOW DO WE BEGIN TO SOLVE THE PROBLEM?

Rather than set forth a specific benefit package that might not be suited to the particular legislative structure that may be developed in committee or floor debate, it is best to make more general recommendations regarding what services should be included on parity with services for other illnesses.

With the elimination of arbitrary limits, it becomes necessary to provide a starting point which defines the illnesses requiring medically necessary care, to include those disorders that are broadly understood through research to fall within the medical treatment model. The definition must be flexible enough to allow new diagnoses—resulting from scientific research—to fall within its parameters. This definition should include disorders generally characterized by psychosis, lengthy duration, and severe disability, which without medical care would result in worsening symptoms. Currently, such disorders include, but are not limited to, schizophrenia, schizo affective disorder, bipolar disorder, autism, as well as severe forms Of other disorders such as major depression, panic disorder, and obsessive compulsive disorder.

Once the definition is established, health care reform must make it clear through legislation that any standard or minimum package of health care coverage must not provide arbitrary limitations on medically necessary care for these illnesses. **In general, medically necessary care must include:**

(1) Hospital services (inpatient and outpatient);
(2) Health professional services (physician and other);
(3) Case management; .
(4) Intensive non-residential treatment; and
(5) Outpatient prescription drugs.

For children and young adults under the age of 21, it is often difficult to provide an accurate diagnosis. So for this population, it will also be critical to cover a broad array of prevention services which may influence a diagnosis in adulthood. Additionally, health care reform must provide services which would allow for the proper diagnosis of persons who suffer from one of these illnesses.

WILL NON-DISCRIMINATORY COVERAGE BE TOO COSTLY?

One of the primary issues addressed by health care reform will be the continued rising costs of health care. It is difficult to provide accurate cost information for equitable coverage of severe mental illnesses because there are very few examples of an equitable benefit currently in existence. Yet, some consideration must be given to the provision of equitable coverage not only as a new benefit, but also as an issue of eliminating discriminatory barriers.

The National Advisory Mental Health Council in its report, "Health Care Reform for Americans with Severe Mental Illnesses," has determined that the costs of providing commensurate coverage for both adults and children with severe mental dis-

orders would cost an extra $6.5 billion annually. This represents less than one percent of our nation's overall health expenditures. Additionally, this report indicates that equitable coverage would result in economic benefits in areas such as mortality and morbidity as a result of persons obtaining medically necessary treatment.

Some observers have raised the concern that providing equitable coverage for severe mental illnesses will induce dramatically higher utilization of health services by persons suffering from these disorders. Much of this concern is based on uncertainty and inadequate data. The lack of widespread private insurance coverage for severe mental illnesses, and the large component of public services for this population, makes it difficult to estimate the effect of insurance on utilization and cost. Moreover, as actuaries have been forced to turn to aggregate public program data for their information, they have produced widely varying estimates of use and cost.

Recent research on actual use of services by the uninsured indicates that these fears are not well founded. In one study, it was shown that persons previously not covered for these illnesses would, upon receiving insurance, increase their utilization of out-patient services to only 1% above the level of the currently insured, and would show no increase in their use of inpatient hospital services.

In addition, it must be noted that nearly every formulation of health care reform included strong incentives for insurers—or health plans—to manage the use of services wisely to control costs. Indeed, in recent years, some large employers have demonstrated that coverage of mental illnesses can be managed to increase overall access and still reduce costs.

Clearly, any aspects of health care reform that may increase costs should be examined with great scrutiny. However, there are also opportunities in the development of public policy when issues such as cost cannot be used to support discriminatory actions. The development Of a national health care reform plan with arbitrary limits on coverage for severe mental illnesses would amount to little more than federally-mandated discrimination. If the cost of parity coverage is projected to be more expensive than experts currently predict, then all health coverage should be uniformly affected, not just severe mental illnesses.

THE OPPORTUNITY TO END DISCRIMINATION

Persons suffering from severe mental illnesses have long made up the segments of society many people have chosen to ignore—persons housed in institutions, and much of the homeless population. This neglect was legitimized insofar as little was known about these disorders or how to treat them. The last 20 years of research on the brain gives policy makers a base of knowledge and Criteria which can be utilized to ensure that persons suffering from severe mental illnesses receive health care coverage that is commensurate to coverage for other illnesses requiring medically necessary care.

Attached you will find the summaries of two documents prepared by entities of the federal government, the National Advisory Mental Health Council and the U.S. Congress Office of Technology Assessment. These two reports summarize recent data regarding the scientific research on severe mental illnesses, as well as the prevalence, efficacy and effectiveness of treatment of these debilitating disorders. They demonstrate that it is possible to provide affordable, effective treatment for the severely mentally ill—information which should be helpful as the health care reform debate becomes more intense.

An historic opportunity exists to end a clear form of discrimination against persons suffering from illnesses over which they have no control.

General Legislative Framework for Equitable Coverage of Severe Mental Illnesses in Health Care Reform

Health care reform legislation must include at least the following elements to provide parity health insurance coverage for persons suffering from severe mental illnesses.

(1) DEFINITION OF SEVERE MENTAL ILLNESSES

Severe mental illness is defined through diagnosis, disability, and duration, and include disorders with psychotic symptoms such as schizophrenia, schizo-affective disorder, manic depressive disorder, autism, as well as severe forms of other disorders such as major depression, panic disorder, and obsessive compulsive disorder. For persons 21 years of age or younger, severe mental illnesses are also defined to include psychotic disorders, attention deficit hyperactivity disorder, autism and pervasive development disorder, severe childhood eating disorders, Tourette's syn-

drome, and any behavioral disorder that would result in conduct which may place the person or another person in danger of death or serious bodily injury.

(2) MEDICALLY NECESSARY SERVICES

(A) Hospital Services (inpatient and outpatient)
(B) Health Professional Services (physician and other)
(C) Case Management
(D) Intensive Non-Residential Treatment
(E) Outpatient Prescription Drugs

(3) SERVICES FOR DIAGNOSIS

Services necessary to properly diagnose a mental illness.

(4) PARITY COVERAGE

(A) All health insurance plans must provide coverage for medically necessary services for treatment of severe mental illnesses with parity to other illnesses, including parity cost-sharing for such services.

(B) If parity coverage would make health insurance more expensive than projected, then all health coverage should be uniformly affected to reduce cost.

Special Report

Health Care Reform for Americans With Severe Mental Illnesses: Report of the National Advisory Mental Health Council

This report was produced in response to a request by the Senate Committee on Appropriations that the National Advisory Mental Health Council prepare and submit a report on the cost of insurance coverage of medical treatment for severe mental illness commensurate with the coverage of other illnesses and an assessment of the efficacy of treatment of severe mental disorders.

About 5 million Americans (2.8% of the adult population) experience severe mental disorders in a 1-year period. Treating these disorders now costs the nation an estimated $20 billion a year (with an additional $7 billion a year in nursing home costs). These costs represent 4% of total U.S. direct health care costs. When the social costs are also included, severe mental disorders exact an annual financial toll of $74 billion. This total accounts for the dollar costs of shortened lives and lost productivity, as well as the costs incurred in the criminal justice and social service systems. However, it cannot begin to account in human terms for the enormous emotional cost and pain borne by Americans with severe mental illness and by their families.

Many myths and misunderstandings contribute to the stigmatization of persons with mental illness and to their often limited access to needed services. For example, millions of Americans and many policy makers are unaware that the efficacy of an extensive array of treatments for specific mental disorders has been systematically tested in controlled clinical trials; these studies demonstrate that mental disorders can now be diagnosed and treated as precisely and effectively as are other disorders in medicine.

The existence of effective treatments is only relevant to those who can obtain them. Far too many Americans with severe mental illness and their families find that appropriate treatment is inaccessible because they lack any insurance coverage or the coverage they have for mental illness is inequitable and inadequate. For example, private health insurance coverage for mental disorders is often limited to 30–60 inpatient days per year, compared with 120 days or unlimited days for physical illnesses. Similarly, the Medicare program requires 50% copayment for outpatient care of mental disorders, compared with 20% copayment for other medical outpatient treatment.

These inequities in both the public and private sectors can and should be overcome. Estimates based on studies of current coverage and utilization suggest that under health care reform, for an additional annual cost of $6.5 billion—representing approximately a 10% increase over current total direct costs of mental health care—the nation can provide coverage for adults and children with severe mental disorders commensurate with coverage for other disorders.

Commensurate coverage for Americans experiencing severe mental illness will yield both human and economic benefits. Millions of Americans will be able to participate more productively at home, at work, and in the community. Substantial numbers will no longer need to impoverish themselves to obtain coverage under Medicaid. The enormous but often hidden costs of untreated or undertreated severe mental illness, which are now borne by the general health care system and society at large, can be appreciably reduced. In addition, commensurate coverage for severe mental disorders can be expected to produce a 10% decrease in the use and cost of medical services for individuals with these conditions. The annual saving in indirect

costs and general medical services would amount to approximately $8.7 billion. This benefit would offset the cost of providing such coverage and would represent an estimated net economic benefit for the nation of $2.2 billion annually.

In summary, a solid body of research evidence supports the provision of commensurate coverage for persons with severe mental disorders. Greater access to treatments of demonstrated effectiveness will help these individuals function more productively. As a result, they, their families, and the nation as a whole will benefit. That benefit can be realized in the context of the actions by the President and the Congress on health care reform.

(Am J Psychiatry 1993; 150:1447–1465)

In its report to accompany the fiscal year 1993 appropriations bill for the Department of Health and Human Services, the Senate Committee on Appropriations stated:

> The Committee appreciates the report of the National Advisory Mental Health Council entitled, "Mental Illness in America: A Series of Public Hearings," which includes a special recommendation on the need to provide coverage for severely mentally ill Americans under national health care reform. The Committee requests that the Council prepare a report on the cost of covering medical treatment for severe mental illness commensurate with other illnesses and an assessment of the efficacy of treatment of severe mental illness.
>
> Severe mental illness is defined through diagnosis, disability, and duration, and includes disorders with psychotic symptoms such as schizophrenia, schizoaffective disorder, manic depressive disorder, autism, as well as severe forms of other disorders such as major depression, panic disorder, and obsessive compulsive disorder. The Committee requests further that this report be transmitted to the Committee prior to next year's hearings as authorized under section 406(g) of the Public Health Service Act. (Senate Report Number 102-397, p. 96)

The following report has been prepared by the National Advisory Mental Health Council in response to this request.

BACKGROUND

One of the key questions confronting the nation is how to provide affordable, appropriate health care for all Americans. As we rethink the structure and costs of health care in the United States, one essential goal must be to create a system that enables Americans with severe mental illnesses to obtain the care they need to function at their best. These individuals continue to suffer from misunderstanding, stigmatization, and inadequate societal resources—a cruel and unnecessary addition to the burden of illness.

Contrary to persistent myth, mental illnesses are both real and definable. Thanks to research advances, the diagnosis and treatment of mental disorders have undergone dramatic improvements in recent years, enabling millions of people to recover quickly and return to productive lives. Furthermore, the great majority of people can now be treated on an outpatient basis. Even those who once would have spent much of their lives disabled and hospitalized can now live successfully in the community.

Nevertheless, for many people, especially many of those with severe mental illness, these advances are irrelevant. As the care system and its financing are now structured, inequitable allocation of health resources places many severely mentally ill individuals at an extreme disadvantage: they simply cannot gain access to the services that would benefit them. We must do better in the coming years, and we can.

Improving the financial accessibility of mental health care, especially to those most in need of it, will yield both humane and economic benefits for our nation. Millions of Americans with severe mental disorders will be able to participate more productively at home, at work, and in the community. Substantial numbers will no longer face the prospect of impoverishment before becoming eligible for the only public coverage they might obtain for treatment, namely, Medicaid. And finally, the enormous but often hidden costs of untreated severe mental illness—which are now borne by the general health care system and society at large—can be appreciably reduced.

The creation of a more rational and effective health care system requires a solid empirical understanding of what service needs exist, what treatments work for whom, what those treatments cost when delivered appropriately, and which treatments reflect good, cost-effective care. For persons with mental disorders, much of this information already exists or is currently being developed through the research supported or conducted by the National Institute of Mental Health (NIMH). The National Advisory Mental Health Coun-

Received June 17, 1993; accepted June 18, 1993. From the National Advisory Mental Health Council: Frederick K. Goodwin, M.D., Chairperson; Dewitt C. Alfred, Jr., M.D., Joseph T. Coyle, M.D., Jeanne C. Fox, Ph.D., Rita L. Hollings, Ph.D.(Causa Honoris), James S. Jackson, Ph.D., Norma Lagomarsino, Joseph D. Matarazzo, Ph.D., James L. McGaugh, Ph.D., Dominick P. Purpura, M.D., Donald E. Shumway, M.A., and Gary J. Tucker, M.D. Ex officio members: Bernadine Healy, M.D., Richard T. Suchinsky, M.D., and James A. Scaramozzino, Ph.D. Address reprint requests to Public Inquiries, Room 7C-02, NIMH, 5600 Fishers Lane, Rockville, MD 20857.

Recommendations in this report do not necessarily reflect the views of the National Institute of Mental Health, the National Institutes of Health, the Public Health Service, or the Department of Health and Human Services.

cil has drawn upon these data in the preparation of this report.

What follows is a brief overview of key findings germane to the request of the Senate Committee on Appropriations (and, wherever possible, consistent with that committee's definition of severe mental illness), as developed through NIMH-supported research and data analyses (appendix 1). Most of these data pertain primarily to adults, although some data about the prevalence, treatment, and costs of severe mental disorders in children are presented as well.

THE NATURE OF SEVERE MENTAL ILLNESS

The term "severe mental illness" encompasses a group of discrete mental disorders that differ in cause, course, and treatment. Most of the disorders discussed in this report are long-lasting and produce significant levels of impairment, especially when optimal treatment is not available. (It is well to remember, however, that this toll continues to be diminished as scientific progress yields new clinical advances.)

No single image captures the functional meaning of severe mental disorders for those struggling with their consequences. The lives of individuals with schizophrenia, manic-depressive illness, or obsessive-compulsive disorder are as varied as their ages, family incomes, service needs, and responsiveness to treatment and rehabilitation. This population includes a relatively small group of individuals whose symptoms are largely untouched by current treatments or rehabilitative efforts and who require lifelong supervised living arrangements. (Included, as well, are some individuals—such as many homeless people with severe mental disorders—whose disability is exacerbated by long-term lack of treatment, physical illness, and/or substance abuse.) But the population of Americans with severe mental illness also includes many more individuals who, with appropriate diagnosis, treatment, and rehabilitation, can lead relatively normal, productive lives in the community.

PREVALENCE

During the past decade, our understanding of the epidemiology of mental disorders has taken a giant leap forward. The mental health field has developed increasingly explicit, research-based diagnostic criteria for identifying and classifying discrete mental disorders (e.g., DSM-III-R, the Research Diagnostic Criteria [1], and the World Health Organization's ICD-10). It has also seen the growth of new, systematic ways to quantify the severity of illness and the extent of impairment it produces (e.g., DSM-III-R, the Global Assessment Scale [2], and the Children's Global Assessment Scale [3]). These advances, coupled with important improvements in epidemiologic survey methodology (4, 5), have made it possible to develop increasingly reliable national data on the prevalence of a wide range of mental disorders in the United States (5, 6). The following data selectively focus on the severe end of the spectrum of mental disorders.

FIGURE 1. Percentages of the U.S. Adult Population With Mental Disorders and Severe Mental Disorders, Including Users of Mental Health Services, in 1 Year[a]

[a]Unpublished ECA data from the National Institute of Mental Health.

Adults

The major source of prevalence data on mental disorders in the adult U.S. population is the Epidemiologic Catchment Area (ECA) program, a large epidemiologic survey in 1980–1985 sponsored by NIMH (7). This database is unique in several respects. It is the first epidemiologic survey to yield reliable national estimates of discrete, diagnosable mental disorders. Because the ECA study incorporated a 1-year follow-up, it provides data on changes in mental health status over time. And because it also surveyed use of services, it offers a picture of which individuals, with which diagnoses, use which service providers and with what frequency.

Mental disorders affect 22% of the U.S. adult population in a 1-year period (6) (figure 1), a rate below or comparable to the rates for various groups of "physical" disorders, such as respiratory disorders (50%) (8) and cardiovascular disorders (20%) (9). Many of these mental disorders are relatively brief in duration; less than 7% of U.S. adults have mental disorders that persist at full diagnostic levels for 1 year or more (6). Other studies reveal that only 9% of adults report significant disability (defined as a Global Assessment Scale score of less than 70) associated with mental disorders (10).

Between 2% and 3% of U.S. adults are affected by *severe* mental disorders. Specifically, the ECA data re-

TABLE 1. Percentages of U.S. Adults With Severe Mental Disorders[a]

Diagnosis	Percentage of Adults (ages 18 years and above)
Schizophrenia	1.5
Manic-depressive illness (bipolar disorder)	1.0
Major depression	1.1
Panic disorder	0.4
Obsessive-compulsive disorder	0.6
Any of these diagnoses	2.8[b]

[a]Unpublished ECA data from the National Institute of Mental Health.
[b]A person may have more than one diagnosis at the same time. In this table these persons are counted once for each diagnosis and are included in more than one row. The percentages for each individual diagnosis cannot be added together to obtain the total percentage of the study population with any disorder.

TABLE 2. Percentages of Study Population Children and Adolescents With Severe Mental Disorders[a]

Diagnosis	Percentage of Children and Adolescents (ages 9–17 years)
Schizophrenia	1.2
Manic-depressive illness (bipolar disorder)	1.2
Major depression	1.2
Panic disorder	0.3
Obsessive-compulsive disorder	0.6
Any of these diagnoses	3.2[b]

[a]Unpublished data from the 1992 National Institute of Mental Health Cooperative Agreement for Methodologic Research for Multi-Site Epidemiologic Surveys of Mental Disorders in Child and Adolescent Populations.
[b]A person may have more than one diagnosis at the same time. In this table these persons are counted once for each diagnosis and are included in more than one row. The percentages for each individual diagnosis cannot be added together to obtain the total percentage of the study population with any disorder.

veal that in a 1-year period, 2.8% of the U.S. adult population—or approximately 5 million persons in 1990—would meet the criteria for severe mental illness outlined by the definition of the Senate Committee on Appropriations (unpublished data from NIMH) (table 1).

Although the ECA prevalence data were gathered almost a decade ago, they are in the same range as those from more recent studies. Thus, the 1992 NIMH-sponsored National Comorbidity Survey, directed by Ronald Kessler of the University of Michigan and based on a national sample of over 8,000 households (including all members 15–54 years old), estimated that severe mental disorders (defined in accord with the criteria of the Committee on Appropriations) affect 3.2% of this somewhat younger and more high-risk population (unpublished data from the National Survey of Health and Stress [National Comorbidity Survey]). In addition, in an NIMH-sponsored supplement to the Health Interview Survey, conducted in 1989 by the National Center for Health Statistics, 2.1%–2.6% of the U.S. adult population was identified as having "serious mental illness," as indicated by diagnosis and disability (11). (This study defined serious mental illness as "any psychiatric disorder present during the past year that seriously interfered with one or more aspects of a person's daily life.")

Another indicator of the size of the population with severe mental illness is provided by data from the Social Security Administration. The severely mentally ill population includes a core group of individuals so impaired that they qualify for Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). In 1991 0.5% of the national population (or about 1 million individuals) received support benefits because of severe mental disorders (12). This represents 18% of the severely mentally ill population. Among disabled workers receiving SSDI benefits, 24% did so on the basis of mental disorders, as did 27% of SSI recipients.

Children

Epidemiologic data on the prevalence of mental disorders in the United States are not yet as well developed for children as they are for adults (13). Nonetheless, unpublished, unweighted preliminary data from the 1992 NIMH Cooperative Agreement for Methodologic Research for Multi-Site Epidemiologic Surveys of Mental Disorders in Child and Adolescent Populations permit some estimates to be made, although they cannot be generalized to the population at large. These data indicate that 3.2% of the sampled population of children 9–17 years of age have a severe mental disorder (as defined by the criteria of the Senate Committee on Appropriations) in a 6-month period (table 2).

TREATMENT EFFICACY

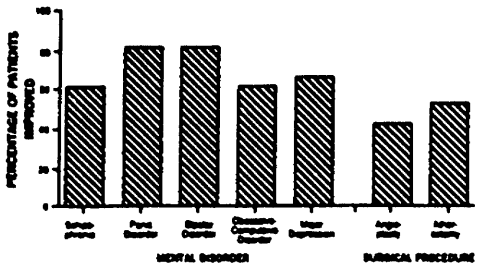
For persons with severe mental disorders, the chances of obtaining significant benefit through treatment have never been better. Millions of Americans, however, are largely unaware that over the past two decades, the therapeutic options available to clinicians for treating specific mental disorders have become more numerous, more specific, and more effective. Treatment alternatives for many severe mental disorders now exist.

Equally unknown by many outside the field is the fact that a growing body of research knowledge from clinical trials has verified the efficacy of these treatments for specific disorders and has provided a useful scientific basis for clinical decision making (figures 2 and 3). Indeed, of the available treatments for mental disorders, the majority are supported by evidence from extensive, controlled clinical trials. This compares very favorably with other areas of medicine.

Further, the efficacy of many treatments for severe mental disorders is comparable to that in other branches of medicine, including surgery. Note, for example, in figure 2 that the 6-month success rates for angioplasty and atherectomy are well below the rates for early response to treatments for most severe mental disorders.

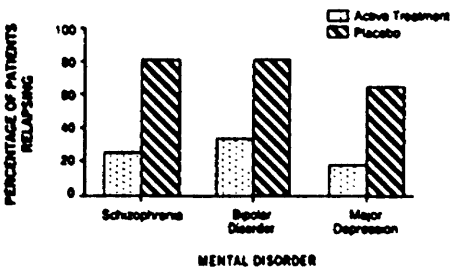
To aid in assessing this body of knowledge and in

FIGURE 2. Treatment Efficacy (Early Treatment Outcome) for Five Severe Mental Disorders and Two Cardiovascular Surgical Procedures[a]



[a]Unpublished data from scientific reports on treatment efficacy commissioned by the National Institute of Mental Health (see Acknowledgments).

FIGURE 3. Treatment Efficacy (Long-Term Outcome) for Three Severe Mental Disorders[a]



[a]Unpublished data from scientific reports on treatment efficacy commissioned by the National Institute of Mental Health (see Acknowledgments).

identifying new research directions, NIMH, at the request of the National Advisory Mental Health Council, recently commissioned a cluster of overviews of the treatment efficacy literature concerning the following major topics: schizophrenia, major depression, manic-depressive illness (bipolar disorder), panic disorder, obsessive-compulsive disorder, geropsychiatric disorders, disorders of childhood, and rehabilitation (see Acknowledgments for authors of these reports). What follows are the key findings pertinent to the request of the Committee on Appropriations. (The full reports will be published in *Psychopharmacology Bulletin*, 1993, vol. 29, no. 4.)

Schizophrenia

Established treatment efficacy. Schizophrenia is an illness beginning in late adolescence or early adulthood in which psychotic features (hallucinations, delusions, and disordered thinking) and lost capabilities (loss of will, pleasure, and emotional range) are predominant. Data from clinical trials in the past 30 years are in agreement that standard antipsychotic medications (e.g., chlorpromazine, trifluoperazine, and haloperidol) initially reduce psychotic symptoms in 60% of patients and in 70%–85% of those experiencing symptoms for the first time. However, even when medication is sustained, 60% of patients will subsequently relapse and require inpatient care. Adding specific psychosocial treatments to an active medication program can reduce the rehospitalization rate to 25%–30% in a 2-year period. Particularly effective are psychoeducational treatment programs that give families skills for managing a member's illness. Further, the context and service system in which treatment is delivered are particularly important for those suffering from a psychotic illness (see the section on Rehabilitation).

New developments. Although the antipsychotic medications and psychosocial treatments mentioned above can appreciably improve the lives of substantial numbers of persons with schizophrenia, for 10%–20% of all patients with this disorder, schizophrenia is a chronically deteriorating illness. New hope has arisen in the past 3 years with the availability of clozapine, a medication that is effective in nearly one-third of patients previously unresponsive to all treatments. However, clozapine requires close monitoring of patients for potentially life-threatening side effects (e.g., agranulocytosis). Additional medications (e.g., risperidone) that appear to have clozapine's beneficial effects without some of its serious side effects may well be introduced in the next year or two.

Manic-Depressive Illness (Bipolar Disorder)

Established treatment efficacy. Persons with manic-depressive illness experience cycling mood changes between extreme highs (mania) and extreme lows (depression). Episodes may recur within days, months, or years, with intermittent periods of normal mood. Many treatments now permit effective management of this severe and often persistent mental illness and enable persons with bipolar disorder to lead essentially normal lives.

In the treatment of acute episodes of mania, lithium has been shown to lessen symptoms within the first 10 days of illness; the addition of antipsychotic medications can hasten recovery. ECT is even more rapidly effective than lithium during early treatment, especially for severely manic patients and those with mixed (manic and depressive) states.

Lithium is also a well-established and effective treatment for preventing recurrence of manic and depressive episodes, and it remains the standard of treatment. Psychosocial interventions that emphasize compliance with medication regimens are also critically important. Studies have shown that patients maintained on a lithium regimen after the acute episode of illness are 28 times less likely to relapse in a given month than those not receiving the medication. For patients receiving lith-

ium who nonetheless have "breakthrough" episodes of mania or depression, other antimanic or antidepressant medications have been shown to be effective.

New developments. Because of the obvious success of lithium, for many years it was believed that the problem of treating bipolar disorder had been solved. For the majority of patients, this was true. But for others, particularly those who cycled rapidly between mania and depression, those with coexisting substance abuse, and those whose illness began in early adolescence, it was not. Special treatment approaches for these groups of patients are being explored, as are some psychosocial approaches that are demonstrably effective in encouraging patients to comply with their medication regimens.

For patients with an unsatisfactory or incomplete response to lithium, use of the anticonvulsant drugs carbamazepine and valproate provides a promising new approach. Both medications have been shown to be effective in controlled studies of individuals unresponsive to lithium.

Major Depression

Established treatment efficacy. Major depression, beyond affecting mood itself, contributes to loss of interest and pleasure, fatigue, feelings of worthlessness, suicidal ideation, and disturbances in bodily functioning, such as weight loss and insomnia. These symptoms are frequently all-pervasive and may last for long periods of time without treatment.

For the more severe forms of major depression, medication has been shown to be an essential component of treatment. Many therapeutic options are offered by three classes of antidepressant medication: tricyclic antidepressants, monoamine oxidase inhibitors (MAOIs), and the newer heterocyclic antidepressants. Between 60% and 65% of patients obtain relief from their depression upon initial treatment with antidepressants. This rate rises to 80%–85% with substitutions in medication or the addition of supplemental pharmacologic treatments. ECT remains a highly effective treatment for selected depressed patients who cannot tolerate or respond to antidepressant medication or for whom a rapid response is imperative.

A variety of depression-specific psychotherapies—cognitive therapy, behavior therapy, interpersonal psychotherapy, and brief dynamic psychotherapy—have demonstrated efficacy in less severe forms of depression. In addition, they have been shown to be useful as adjuncts to medication in treating the more severe forms of this disorder. Also, when combined with maintenance medication, psychotherapy may help delay or prevent recurrences of depression.

New developments. There is evidence that 65% of patients who do not respond to tricyclic antidepressants do respond to MAOIs. However, some have difficulty with the dietary restrictions required when using standard MAOIs (patients must eliminate all foods containing tyramine, such as beer, some red wines, fava beans, liver, and many aged cheeses). Clinical studies are now evaluating new MAOIs (e.g., moclobemide and brofaromine) that do not require these dietary restrictions.

The recent emergence of selective serotonin reuptake inhibitors (e.g., fluoxetine, sertraline, and paroxetine, a medication newly approved by the Food and Drug Administration), along with the chemically novel medication bupropion, provides a new approach to depression with fewer side effects. These medications also offer an alternative for patients previously unresponsive to treatment. New evidence is accumulating, as well, regarding the importance of maintaining the medication dosage levels that produced the initial response, in order to enhance prevention of relapse.

Panic Disorder

Established treatment efficacy. Often first seen in the family physician's office because of the sudden onset of feelings of impending death, individuals suffering from panic disorder experience discrete periods of intense fear or discomfort, accompanied by shortness of breath, dizziness, palpitations, sweating, choking, and chest pain. Frequently these symptoms assume such significance that persons experiencing them can pay attention to little else. The treatment of panic disorder is one of the major successes demonstrated through research on clinical treatment. Response rates of 70%–90% have been reported for antidepressant medications such as tricyclics and MAOIs, as well as the antianxiety, high-potency benzodiazepines. Further, some, but not all, studies have reported that behavioral interventions, such as cognitive restructuring (designed to alter a patient's perceptions of impending catastrophe), produce results comparable to those reported for medication.

New developments. Panic Control Treatment, a new behavioral approach, has produced response rates similar to those for medication and has demonstrated enduring effects over a 2-year follow-up. With this treatment, 50%–60% of patients attain high overall functioning. Clinical trials are now underway to examine the efficacy of this treatment in combination with medication.

Obsessive-Compulsive Disorder

Established treatment efficacy. For many years, persons suffering from obsessive-compulsive disorder had very little hope of relief from their crippling rituals and obsessive thinking patterns. They were besieged by intrusive, senseless ideas and uncontrollable, repetitive behaviors driven by their own minds. Clinical studies report that only about 5% of patients have spontaneous recovery and that others (up to 75% initially) may recover somewhat with behavioral treatments, but as they try to return to normal life patterns, their symptoms recur more often than not.

New developments. For patients with obsessive-compulsive disorder, the prospect of improvement has brightened through the recent introduction of the tricyclic antidepressant clomipramine as well as the selective

serotonin reuptake inhibitors (e.g., fluoxetine, sertraline, and paroxetine), all of which are now under study. With evidence that 80% of patients with obsessive-compulsive disorder show some response to clomipramine, that 60% show at least a moderate response, and that the addition of behavioral therapy provides relief from rituals (particularly when additional booster sessions are given), these severely ill individuals have new grounds for hope.

Late-Life Depression

Established treatment efficacy. Extensive research with clinical trials provides evidence that antidepressants are effective in treating acute depression in elderly patients. Approximately 60% of these patients improve clinically with antidepressants, although many significant symptoms remain. When these medications are combined with interpersonal psychotherapy or cognitive-behavioral therapy, the success rate rises to between 70% and 80%, as it does in other age groups. ECT has also been established as the treatment of choice for severely immobilizing depression. High success rates (80%) have been reported for antidepressant maintenance treatment over a period of 1½ years.

New developments. The side effects of the commonly used and effective tricyclic antidepressants (e.g., urinary retention, weight gain, constipation, and hypotension) are of particular concern in an older patient population. Thus, considerable interest has been generated in new medications that are virtually free of these side effects, such as bupropion and the serotonin reuptake inhibitors, and results from clinical trials look quite promising.

Late-Life Psychosis

Established treatment efficacy. Neuroleptic (antipsychotic) medications are the most effective treatment for both early- and late-onset psychosis and are consistently used in older patients (see preceding section on Schizophrenia).

New developments. The role of clozapine in the treatment of older patients has not been completely established, but work is underway to examine its efficacy in this group.

Disorders of Childhood and Adolescence

Established treatment efficacy. Establishing effective treatments for the developmental, emotional, and behavioral symptoms of childhood mental disorders is an urgent task. These disorders have relatively high prevalence rates among children and adolescents, and the great majority of adult mental disorders—many of which often co-occur with substance abuse—originate in childhood or adolescence.

Many demonstrably effective treatments for these disorders are available or under development. For bipolar disorder in children and adolescents, the use of medication (lithium along with supplemental antidepressants for breakthrough episodes of depression and antipsychotics for breakthrough episodes of mania) together with psychotherapeutic intervention is essential to restore normal functioning. For anxiety disorders (e.g., separation anxiety disorder and obsessive-compulsive disorder), psychotherapies, such as behavior therapy that involves the child and the family, as well as specific medications (clomipramine and fluoxetine) are effective. For autism, antipsychotics (haloperidol, thioridazine, and chlorpromazine) markedly reduce symptoms, while behavioral treatments enhance day-to-day functioning.

New developments. Because developmental factors have a special impact on juvenile depression, research studies have attempted to clarify how this severe mental disorder resembles or differs from adult depression. Unfortunately, the response to tricyclic antidepressants has not been as positive in children as in adults. Other therapies (selective serotonin reuptake inhibitors, bupropion, MAOIs, and cognitive therapies) are just now beginning to be investigated, with promising early results. For the most severe forms of aggression and conduct disorder, there are encouraging studies evaluating early psychosocial interventions as well as the use of medications for some individuals.

Research has revealed the benefits of psychotherapeutic interventions for many disorders of childhood and adolescence. However, there is still a challenge to pinpoint further how well these treatments work, how they are best administered, how they compare to and combine with specific medications, and how to achieve the best match between treatments and the individual needs of children and adolescents with severe mental illness.

Rehabilitation

The goals of treatment for individuals with severe mental illness must extend beyond remission of symptoms to rehabilitation. The lives of many such individuals are significantly disrupted at a time when they are trying to complete important developmental tasks such as advancing their education and initiating a career. As with impairments produced by some physical illnesses, those produced by some severe mental illnesses may require extended rehabilitation. Programs that have focused on the full range of rehabilitation, from skills training to comprehensive community programs, have repeatedly demonstrated the necessity for ongoing availability of rehabilitation resources for this population.

Another critical principle, as noted in the section on Schizophrenia, is the integration of the components of treatment and the context in which treatment is delivered. This principle is successfully illustrated by the Program of Assertive Community Treatment model, which uses an intensively focused, multimodality treatment team to offer crisis intervention, formal education, community resource management, direct skills training, and employment assistance. Outcomes for patients treated according

TABLE 3. Percentages of U.S. Adults With Severe Mental Disorders in Treatment in 1 Year[a]

Service Sector	Percentage of Adults With Diagnosis[b]					
	Any Severe Mental Disorder	Schizophrenia	Bipolar Disorder	Major Depression	Panic Disorder	Obsessive-Compulsive Disorder
Specialty mental health	43.6	45.6	39.8	64.5	55.0	39.0
General medical	32.6	33.7	40.6	34.2	50.5	28.1
Health care system total	62.4	64.5	79.1	79.8	54.1	

[a]Unpublished ECA data from the National Institute of Mental Health.
[b]A person may have more than one diagnosis at the same time and may receive treatment in either the specialty mental health or general medical sector or both. The percentages for each diagnosis within each service sector cannot be added together to obtain the total percentage of the population in the total health care system.

to this model have included lower rates of hospitalization; increased independent living, employment, and social interactions; and greater satisfaction with life. These advances are maintained, however, only when the program is continuously available.

Cost-benefit analyses have shown that the Program of Assertive Community Treatment provides both additional benefits and additional costs in comparison with conventional hospital-based treatment. However, the benefits (e.g., sheltered-workshop income and/or other earnings) considerably outweigh the costs of providing treatment. The Program of Assertive Community Treatment model has now been implemented on a statewide basis in Delaware, Michigan, Rhode Island, Wisconsin, and Ohio; an additional 20 states have implemented at least several treatment teams on the basis of this model.

Current research efforts are exploring ways to identify subgroups of patients who are particularly likely to respond to specific rehabilitative techniques. In addition, work continues on delineating clear, standardized methods for teaching skills and developing better assessment methods in order to improve treatment decisions.

In summary, the treatments available for severe mental illnesses are effective for most patients and can be delivered in a cost-efficient manner. As we extend our scientific database into the future, we can expect the development of treatments that will further reduce symptoms and return functioning.

UTILIZATION OF SERVICES

Health care for Americans with mental disorders is offered by a complex array of providers and organizations, public and private, on both an inpatient and an outpatient basis (14, 15). The ECA study, which provides a description of the use of health services by adults with severe mental disorders, reveals that, as with other types of illness, not all persons with these disorders seek care, as illustrated by the following findings (see also table 3).

Severely Mentally Ill Adults

During a 1-year period, approximately 60% of the adult population with severe mental disorders (about 3 million persons) sought *outpatient* care for those disorders in the health care system, either in the specialty mental health sector or in the general medical sector (6 and unpublished NIMH data). (Components of these sectors are described in appendix 1.) Of adults with severe mental illness, 17% (about 850,000 persons) received some kind of *inpatient* care in the health care system in 1 year (14 and unpublished NIMH data).

Severely Mentally Ill Children

The previously mentioned Methodologic Research for Multi-Site Epidemiologic Surveys of Mental Disorders in Child and Adolescent Populations revealed that during a 1-year period, 29% of the children and adolescents in this population who had severe mental disorders used *outpatient* mental health services, and 10% used *inpatient* services (unpublished NIMH data).

SOCIAL COSTS AND TREATMENT COSTS

An NIMH-sponsored study by Dorothy P. Rice of the Institute for Health and Aging, University of California, San Francisco, provides the most recent available data on the indirect and direct costs of mental illness (16, 17, and unpublished data of D.P. Rice and L.S. Miller). Key data from this study, focused on adults and children with severe mental disorders, are presented below (see also table 4).

In 1990 the core *indirect* cost of severe mental illness in the United States was conservatively estimated at approximately $44 billion. This cost to society includes lost productivity and lost earnings due to illness, as well as lost earnings due to premature death.

The *direct* cost of treating severe mental illness was estimated at about $20 billion, with almost $7 billion more for long-term nursing home care. These costs occurred in a context of $67 billion in direct costs for treatment of all mental illness (unpublished data of D.P. Rice), which represents 10% of the total $670 billion direct cost of all health care in the United States in 1990 (18).

The *other, related* costs of severe mental illness, which include those for social welfare administration, criminal justice, and family caregiving, were estimated at about $4 billion. Other sources (specifically, studies

TABLE 4. Estimated Treatment and Social Costs of Severe Mental Disorders in 1990[a]

Type of Cost	Amount (millions of dollars)
Direct	26,551
Mental health organizations	7,921
Federal providers	696
State and county psychiatric hospitals	3,766
Private psychiatric hospitals	2,476
Other[b]	983
General medical hospitals	6,862
Office-based physicians	729
Other professional services	1,317
Nursing homes	6,585
Drugs	1,095
Support	2,042
Indirect	43,473
Morbidity	33,488
Noninstitutionalized population	31,266
Institutionalized population	2,222
Mortality[c]	9,985
Other, related	3,460
Criminal justice system	649
Social welfare administration	335
Family caregiving	2,476
Total	73,484

[a]Unpublished data of D.P. Rice and L.S. Miller.
[b]Includes residential treatment centers for emotionally disturbed children, freestanding alcohol, drug, and mental health care organizations, multiservice mental health organizations, and correctional facilities.
[c]Discounted at 6%.

TABLE 5. Health Care Expenditures in 1990 for Total U.S. Population and for Persons With Mental Disorders

Source of Expenditure	Percentage of Group		
	U.S. Population[a]	All Persons With Mental Disorders[b,c]	Persons With Severe Mental Disorders[d,e]
Government programs	42	54	57
Federal		26	26
State and local		28	31
Private	58	46	44

[a]Data from Levit et al. (18).
[b]Data from Rice et al. (16).
[c]All persons with mental disorders who use specialty or general medical mental health services in 1 year constitute 9%–10% of the total population in 1 year (6 and unpublished data from the National Comorbidity Survey).
[d]Unpublished data of D.P. Rice and L.S. Miller.
[e]All persons with severe mental disorders who use specialty or general medical mental health services in 1 year constitute 1.7% of the population in 1 year (6).

TABLE 6. Insurance Coverage for Total U.S. Population and for Persons With Mental Disorders

Source of Coverage	Percentage of Group		
	U.S. Population[a]	All Persons With Mental Disorders[b,c,d]	Persons With Severe Mental Disorders[b,e]
Private insurance	64	73	64
Government programs[f]	22	8	18
No insurance	14	18	18

[a]Estimates based on data from the U.S. Bureau of the Census (20).
[b]Unpublished data from the National Comorbidity Survey.
[c]All persons with mental disorders constitute 20%–22% of the total population in 1 year (6 and unpublished data from the National Comorbidity Survey).
[d]Column does not total 100% because 1% of persons with mental disorders do not know whether they have insurance coverage.
[e]All persons with severe mental disorders constitute 2%–3% of the total population in 1 year (6 and unpublished data from the National Comorbidity Survey).
[f]Includes Medicare, Medicaid, and other public programs.

conducted from a public finance perspective) indicate that about one-fourth of all SSDI payments are for individuals with severe mental disorders (12, 19).

The *total* cost (core costs—direct and indirect—plus other, related costs) of *severe* mental illness in 1990 was estimated to be nearly $74 billion. For *all* mental disorders, the total cost was $148 billion (unpublished data of D.P. Rice), in contrast to $159 billion in the same year for all cardiovascular system diseases (unpublished data from the National Heart, Lung, and Blood Institute) (see also appendix 2).

As noted in the section on Utilization of Services, only 60% of persons with severe mental illness now obtain treatment within the health care system in a 1-year period. Presumably, a substantial proportion of the indirect cost of severe mental disorders can be attributed to the relatively large population that is now untreated. Given the effectiveness of current treatments for these disorders, it seems likely that improved access to treatment would decrease indirect costs, possibly offsetting increases in direct costs (see section on Benefits of Commensurate Coverage).

FUNDING SOURCES FOR MENTAL HEALTH CARE

Within the overall health care delivery system, the mental health care system relies on an unusually high proportion of funds from state and local governments. In the overall health care system, only 14% of total expenditures are derived from state, local, and other (non-Medicaid or non-Medicare) government sources (18). In contrast, as shown in table 5, these sources represent 28% of all funding sources for mental health care (16).

As shown in table 6, among persons with *severe* mental disorders, 64% have some private insurance, and only 18% have Medicaid or other government coverage (unpublished data from the National Survey of Health and Stress [National Comorbidity Survey]). However, as shown in table 5, state and local government programs account for 31% of expenditures for persons who seek care for their severe mental disorders, and Medicare and other federal programs account for 26%; combined they represent a public share of 57% (unpublished data of D.P. Rice and L.S. Miller), compared to 42% of all health care costs.

CURRENT INEQUITIES IN INSURANCE COVERAGE

Research studies have revealed a key characteristic of the mental health service system and its financing: health insurance coverage for the diagnosis and treatment of mental disorders is usually not comparable to coverage for other disorders (21–25). Some examples follow.

Private Insurance Coverage

A wide variety of plans provide employer-based private insurance coverage for the treatment of mental disorders. The following findings, based on data from the mid-1980s from the Bureau of Labor Statistics, are illustrative.

Of employees in large and medium-size firms, roughly 79% of participants in plans with any mental health benefits had more restrictive hospital coverage for mental illness than for other types of illness. For about one-half of the participants, coverage for hospitalization was limited to 30–60 days per year for mental illness, compared with 120 days or unlimited days for physical illness. About 38% of all participants belonged to plans that impose an additional or separate lower maximum on annual expenses, such as a lifetime maximum of $50,000 on all mental health benefits.

Coverage of outpatient psychiatric care was limited in 95% of the health insurance plans surveyed. Among participants, 34% had fewer outpatient visits covered annually for mental disorders than for other disorders, and 66% had special maximum annual payment limits imposed on mental health visits.

Managed-care settings also place discriminatory limits on treatment of mental disorders, as indicated by a 1985 NIMH-sponsored survey of 473 health maintenance organizations (HMOs) (26). For example, the average inpatient mental health benefit was 34 days per year; the outpatient mental health benefit was 21 visits per benefit period. These restrictions generally were not applied to other health care offered in HMOs.

Public Coverage

Among persons with severe mental disorders who use services for their mental health care, public insurance programs account for an estimated 18% of all coverage (table 6). Key among these are the Medicare and Medicaid programs; their mental health coverage provisions and state mental health authority programs are described in appendix 3. As with private insurance, these public programs also place more limitations on mental health care than on other health care.

The federal government has incorporated lower coverage levels for mental health services than for other health services in the design of the Medicare program (27). Although recent legislation has improved the situation somewhat, there are still remnants of discriminatory mental health coverage. For example, outpatient treatment of mental disorders requires 50% copayment by the patient, compared with 20% copayment for other medical outpatient treatment (28).

The Medicaid program maintains a historical exclusion in which individuals aged 22–64 years who are in an "institution for mental disease" may not receive federal funding for any psychiatric or other medical care (29).

COSTS OF COMMENSURATE COVERAGE

In response to the request of the Senate Committee on Appropriations for information on the cost of covering medical treatment for severe mental illness commensurate with that for other illness, the National Advisory Mental Health Council requested that NIMH commission and perform special economic analyses that would permit such cost estimates to be obtained.

In developing an estimate of the total cost of "commensurate" coverage for persons with severe mental disorders, the NIMH staff assumed that the total cost would include both persons insured by the private insurance sector and those insured by the public sector. Analyses were based on studies of service utilization and costs, with the use of data from both private and public sources of funding. (The sources and methodologies for developing all data presented in this section are discussed in appendix 1.)

Unpublished data from the National Comorbidity Survey indicate that 64% of persons with severe mental disorders have private insurance. As noted above, these private insurance plans rarely adequately cover treatment for mental disorders, but under proposed health care reform, these plans would have to cover such treatment commensurate with coverage of other illnesses. This change would shift the cost of treatment for mental disorders from the public sector or out-of-pocket payments to the private system.

Analyses of MEDSTAT data on private insurance costs and utilization were conducted by an economic research group at The Johns Hopkins University. These studies show that the average expenditure under a full-coverage private insurance plan during 1 year (1990) for each person with a severe mental disorder was $7,462 (unpublished data of R.G. Frank from the MEDSTAT data set). Thus, assuming that approximately 3.3 million persons (64% of the 5.1 million with severe mental disorders) would be covered by an expanded private insurance plan, the direct cost of commensurate coverage for them would be $24.6 billion.

Unpublished data from the National Comorbidity Survey reveal that the remaining 36% of persons with severe mental disorders are potentially covered by the public sector. As a basis for estimating the cost of commensurate coverage for this segment of the population, a public insurance plan providing full coverage (during the mid-1980s)—the Michigan Medicaid program—was chosen. An analysis of this program at the Health Care Financing Administration (30) showed that the average annual expenditure for each person with a severe mental disorder was $3,528 (inflated to 1990 figures). Thus, assuming that 1.8 million persons (36%

of the 5.1 million with severe mental disorders) would be covered by an expanded public insurance plan, the direct cost for these individuals would be $6.4 billion.

If one combines the two costs just described (i.e., the direct costs for expanded private and public insurance coverage), then the total cost of commensurate coverage for adults with severe mental disorders would be $31 billion. However, this estimate assumes, incorrectly, that the total population covered would use the system during the year. Currently, 60% of persons with severe mental disorders use services during a given year; this number would probably increase to about 80% with full coverage. (The 80% estimate is based on data from the RAND Health Insurance Experiment [31], which suggests an increase in utilization of approximately 20% under the type of coverage estimated in this report. This more closely approximates the 80% yearly utilization rate now seen for persons with cardiovascular disorders.) Thus, the *direct* cost of commensurate coverage for *adults* should be approximately *$24.8 billion* in 1 year (80%×$31 billion).

The cost of commensurate coverage for children with severe mental disorders is more difficult to estimate (see appendix 1 for the methodology). Estimates of expenditures for care of this population and the treatment settings used by children vary widely. Therefore, cost estimates for this segment of the population were based on assumptions used for the adult population. The *direct* cost of commensurate coverage for *children* would be *$1.7 billion*.

On the basis of these estimates, the *direct* cost of commensurate coverage for *both* adults and children with severe mental disorders would be *$26.5 billion*. Given current (1990) expenditures excluding nursing homes, this would represent an extra $6.5 billion needed each year to provide such coverage. It is important to note that if private insurance plans were required to provide commensurate coverage as assumed here, most of this increase would be borne by the private sector.

BENEFITS OF COMMENSURATE COVERAGE

In addition to the humanitarian benefits of providing commensurate coverage, there would also be economic benefits. The indirect costs, such as those for mortality and morbidity, should be reduced if people are able to obtain treatment. In addition, the costs of administration of social welfare payments and use of the criminal justice system should decline.

Assumptions applied in calculating the economic benefits were adopted or derived from various cost-benefit evaluations of pharmaceutical interventions, therapies, treatment settings, and treatment packages (32–43 and an unpublished 1992 paper by R.G. Frank). As shown in appendix 1, the annual savings in indirect costs would amount to approximately $7.5 billion. In addition, savings in general health care costs as a result of treatment of mental disorders were also estimated on the basis of empirical data from a large-scale medical offset study (44). The expectable 10% reduction in general health care costs would result in a potential saving of $1.2 billion.

The total annual saving in indirect costs and general medical services would amount to approximately $8.7 billion. This would represent a net economic benefit of approximately $2.2 billion ($8.7 billion minus $6.5 billion).

In summary, a solid body of research evidence supports the provision of commensurate coverage for persons with severe mental illness. Greater access to treatments of demonstrated effectiveness will help these individuals function more productively. As a result, they, their families, and our nation as a whole will benefit. That benefit can be realized in the context of the actions by the President and the Congress on health care reform.

APPENDIX 1. Definitions and Method

EPIDEMIOLOGIC DATA

Operationalizing "Severe Mental Disorders"

The population of adults and children with severe mental disorders described in this report reflects the language of the request of the Senate Committee on Appropriations to the National Advisory Mental Health Council. The mental disorders included here are those commonly accompanied by psychotic symptoms—schizophrenia, schizoaffective disorder, manic-depressive disorder (bipolar mood disorder), and autism—and the severe forms of major depression, panic disorder, and obsessive-compulsive disorder. Manic-depressive disorder is known in DSM-III-R as bipolar disorder. For the purposes of this report, bipolar disorder was subcategorized into type 1 and type 2. Bipolar disorder, type 1, is characterized by the occurrence of a manic episode; bipolar disorder, type 2, is characterized by the occurrence of a hypomanic episode, which by definition produces less impairment than a manic episode. Whenever possible, criteria set forth in DSM-III-R were used as the basis for making diagnoses. Corresponding diagnoses from ICD-9 were used as necessary. Severity criteria were defined in the domains of recent treatment, symptoms, and social/occupational/school functioning. Diagnostic information and criteria for severity were applied to five data sets in the following way.

For individuals who were diagnosed as having schizophrenia, schizoaffective disorder, bipolar disorder, type 1, or autism within the year before the study's data collection, no additional indicator of severity was required to designate them as severely mentally ill. The DSM-III-R criteria for schizophrenia, bipolar disorder, type 1, autistic disorder, and, by inference, schizoaffective disorder, require marked disturbance in functioning during an active episode of illness.

For individuals who had received a diagnosis of schizophrenia, bipolar disorder, schizoaffective disorder, or autistic disorder at some other point during their lives but who did not meet the diagnostic criteria during the past year, further evidence was required to ensure their appropriate inclusion in

the group with severe mental disorders. For this group, evidence of severity included at least one of the following within the past year: any inpatient psychiatric hospitalization or nursing home placement; any outpatient mental health treatment in a specialty mental health or general medical setting; psychotic symptoms (criterion A for DSM-III-R schizophrenia); use of antipsychotic medication; or a Global Assessment of Functioning (GAF) scale rating of 50 or less (i.e., functioning at or below the level of "serious symptoms . . . or any serious impairment in social, occupational, or school functioning") (DSM-III-R, p. 12).

Individuals diagnosed as having major depression, bipolar disorder, type 2, panic disorder, or obsessive-compulsive disorder during the previous year (or at any point in their lifetime for persons with bipolar disorder, type 2) were considered severely mentally ill if there was evidence of severity in the past year. Evidence of severity for this group included inpatient psychiatric hospitalization, psychotic symptoms, use of antipsychotic medication, or a GAF scale rating of 50 or less.

The definition of severe mental disorders in children and adolescents required one modification when it was applied to epidemiologic data sets. Recent research has shown that accurate psychiatric diagnoses of children in community surveys require an assessment of the level of impairment resulting from the reported symptoms (45). This is especially important for the psychotic disorders, for which standardized measurement in the community is still relatively unrefined. Therefore, for children and adolescents who reported symptoms consistent with a history of schizophrenia, bipolar disorder, schizoaffective disorder, or autism in the past year, severity criteria were also applied.

This definition of severe mental disorders in adults and children and the method by which it was put into operation were intended to include individuals with severe mental disorders as specified by the request from Congress. The definition and method are not intended to designate eligibility for coverage under health care reform programs.

SERVICE UTILIZATION DATA

Persons with severe mental disorders seek both inpatient and outpatient care for those disorders within the health care system. As a group, for that care they use general health care facilities and practitioners as well as specialized mental health facilities. In the development of the service utilization data presented in this report, the following components of the health care system were examined (4, 6, 14).

Components of the Ambulatory Mental Health Care System

Specialty mental health sector
- Psychiatric hospital outpatient clinics
- Mental health center outpatient clinics
- General hospital outpatient clinics
- Veterans Affairs hospital outpatient clinics
- Alcohol and drug treatment outpatient clinics
- Mental health specialists in health plans or family clinics
- Mental health specialists in private practice
- Crisis centers

General medical sector
- General hospital emergency departments
- General medical (nonpsychiatrist) physicians

Components of the Inpatient Mental Health Care System

General hospitals (psychiatric units and scatter-beds)
State and county mental hospitals (includes residential supportive care)
Community mental health centers
Private mental hospitals
Veterans Affairs hospital psychiatric units
Alcohol and drug treatment units
Nursing homes

COST DATA

Private Insurance Coverage

In response to the request of the Committee on Appropriations for information on "the cost of covering medical treatment for severe mental illness commensurate with other illnesses," the council requested that NIMH commission and conduct special economic analyses that permit a variety of such cost estimates to be developed. One such analysis is based on a broader NIMH-funded study by Richard Frank of The Johns Hopkins University, who is creating simulations of mental health service utilization and costs under various benefit packages (including those providing inpatient and outpatient coverage for mental disorders comparable to coverage for other disorders). The simulations have adopted a set of principles that were developed after review of the scientific research literature on the demand for and supply of mental health services (46). The simulation model was calibrated by McGuire (47).

The simulations are based on analysis of mental health service utilization and costs in a large database: 1.5 million individuals who are associated with 25 middle-size to large firms throughout the United States whose private health insurance is part of the MEDSTAT claims-processing system. This population represents approximately 40% of the employed U.S. population and their dependents who have insurance coverage—approximately 100 million individuals.

Important broad goals of this study include identifying the costs of a benefit for severe mental disorders in both the public and private sectors, examining the interaction of these sectors, and helping to redefine the role of the public sector.

An initial set of estimates has been developed that focuses solely on *private-sector* coverage of *severe* mental disorders. It examines insurance plan costs of severe mental illness as defined by the Committee on Appropriations. The costs of several very simple benefit options for coverage of mental health care are determined.

Full coverage (baseline). In the MEDSTAT data, the average copayment level for outpatient care is 20%, while average inpatient coverage generally involves no cost sharing and unlimited days paid under a negotiated per diem limit.

Limited coverage. Outpatient coverage is defined as requiring a 50% copayment, but there are no limits on visits or expenditures. Inpatient coverage consists of no copayments or deductibles, but there is a 30-day limit per year on duration of hospital stay.

Mixed coverage. This alternative calls for full coverage of the severely mentally ill population and limited coverage of all other beneficiaries.

Costs of Commensurate Coverage

In developing the costs of commensurate coverage for persons with severe mental disorders, the following calculations were made.

Adults. Of 184 million U.S. adults, 2.8% (N=5.1 million) have severe mental disorders; 64% (N=3.3 million) of these would be covered by private insurance, and 36% (N=1.8 million) would be covered by the public sector. Private costs=3.3 million×$7,462 per person per year, or $24.6 billion; public costs=1.8 million×$3,528 per person per year, or $6.4 billion; total direct cost=$31.0 billion. This assumes 100% utilization during a year. A more reasonable estimate of use with full

coverage would be 80%. Thus, the total direct cost would be approximately *$24.8 billion* (0.80×$31.0 billion.)

Children. Of 31 million U.S. children aged 9–17 years, 3.2% (N=992,000) have severe mental disorders; 64% (N=635,000) of these would be covered by private insurance, and 36% (N=357,000) would be covered by the public sector. Private costs=635,000×$7,462 per person per year, or $4.7 billion; public costs=357,000×$3,528 per person per year, or $1.3 billion; total direct cost=$6.0 billion. This assumes 100% utilization during a year. However, studies show very low utilization by children; a recent study showed a figure of around 29% (unpublished NIMH data). Thus, the total direct cost would be *$1.7 billion* (0.29×$6.0 billion).

The total direct cost (for adults and children) would therefore be *$26.5 billion*. Current direct treatment expenditures are approximately $20 billion (excluding nursing home costs). Thus, it would require another $6.5 billion to provide commensurate coverage for adults and children with severe mental disorders.

Several caveats should be noted regarding the estimates presented here. First, in the calculations of public-sector costs, expenditures from state budgets were not factored into the estimate of costs for patients in the public sector. Those expenditures are already part of current expenditures, and there is no current plan to shift state expenditures into federal programs such as Medicaid. However, if commensurate coverage is mandated for persons having *private* insurance plans, a large part of the costs currently provided in the public sector will shift to the private sector for those persons.

Second, the direct cost estimate does not include the cost of treating children under age 9 who have severe mental disorders. There are no current data to indicate the size of this population. Among the severe mental disorders under consideration in this report, the only one likely to be found in this youngest age group is autism. Because the prevalence of that disorder is low, the added cost would probably be very small relative to costs for the other age groups.

Economic Benefit of Commensurate Coverage

Reduction in mortality costs. Premature death due to severe mental illness is the ultimate loss; the cost is estimated as the current monetary value of future output lost due to premature death. In the case of severe mental illness, the majority of deaths are suicides. In assessing the benefits of an equitable benefit package that allows the treatment of additional patients and/or provides more adequate treatment of patients who already have contact with the care delivery system, it is assumed that one-third of the individuals treated will be treatment resistant, while the other two-thirds will be treated successfully, thus avoiding premature death. Therefore, two-thirds of deaths related to mental illness—primarily suicides—will be avoided, averting about 12,800 premature deaths in a year and restoring about $5.2 billion in lost *lifetime* earnings to the national economy.

The average number of productive years lost due to premature death is estimated to be 30, given that one-third of suicides occur in the relatively young age group of 25–44 years. (It is noteworthy, however, that death related to severe mental illness does occur in all age groups, including children under the age of 15 years and the elderly. These individuals are reflected in calculating the cost of mortality.) Averting 12,800 deaths *in a given year* restores about $0.2 billion in each year to the economy in the form of earnings.

Reduction in morbidity costs. In the cost-of-illness studies based on a human capital approach, morbidity costs are the value of goods and services not produced in a given year because of the illness. The following morbidity cost calculations are based on ECA data (unpublished NIMH data).

It is estimated that the average annual wage loss per person with a severe mental illness is $6,442. Of the 5.1 million individuals with severe mental disorders, it is also assumed that 20% will not receive treatment, resulting in a morbidity cost of $6.4 billion for 1 million untreated individuals. Assuming that one-third of the remaining 4.1 million persons with severe mental disorders will not be successfully treated, the morbidity cost will be $9.0 billion for those 1.4 million persons. Half (or 1.4 million) of the remaining 2.8 million individuals will be treated successfully, resulting in a $9.0 million reduction in morbidity costs, and half of that gain ($4.5 million) will be realized during the first year of treatment. The remaining 1.4 million individuals will be partially successfully treated, and their annual average wage loss per person will be reduced by 50%, resulting in a $4.5 billion reduction in morbidity costs over a 2-year period. Of that saving, $2.3 billion will be realized in the first year.

The effect of commensurate coverage on morbidity due to severe mental disorders is an increase in individuals' productive capacity and a reduction of $6.8 billion per year.

Reduction in criminal justice system costs. When individuals with severe mental disorders receive adequate treatment, it can be assumed that the crime-related costs of these disorders will be reduced by 50%. Crime-related costs include private and public expenditures for police protection, legal and judicial services, and correctional institutions. The 50% reduction will result in annual savings of $246 million (or $0.2 billion). This figure assumes that 80% of persons with severe mental disorders will seek treatment and that two-thirds of those individuals will be treated successfully.

Reduction in social welfare administration costs. The assumptions described above are made in estimating cost savings in social welfare administration. These assumptions permit a reduction in costs of another $0.2 billion.

Reduction in incarceration costs. The loss of productivity for individuals incarcerated as a result of convictions for crimes related to their severe mental disorders is also estimated as 50%. With commensurate coverage, the cost reduction is estimated to be $0.1 billion.

Reduction in general medical care. Reduction in general medical care is expected to result as a cost offset of providing appropriate and adequate mental health treatment, thus reducing the amount of physical health care required. The calculation is based on empirical findings derived from a study by Strain et al. (44) that reported a 10% reduction in general health care costs as a result of mental health treatment. The average health care expenditure per capita in the United States in 1990 was $2,800. By multiplying this amount by the 4.1 million persons with severe mental disorders who are expected to receive treatment, and by the 10% cost offset, the resulting reduction in costs of general medical care is estimated to be $1.2 billion.

The tabulation of the total annual cost savings (including the savings in indirect costs) of commensurate coverage, using the conservative assumptions described, is as follows:

Reduction in mortality costs	$0.2 billion
Reduction in morbidity costs	6.8 billion
Reduction in criminal justice system costs	0.2 billion
Reduction in social welfare costs	0.2 billion
Reduction in incarceration costs	0.1 billion
Reduction in general medical costs	1.2 billion
Total savings	$8.7 billion

APPENDIX 2. Comparable Medical Illnesses

While the total economic cost of mental illness seems large, it must be viewed in the context of the economic costs of other illnesses. The division of diseases into medical and mental types becomes more arbitrary with every new study of the physical causes of mental illness. There is good evidence for biochemical and structural etiologies for schizophrenia, affective disorders, anxiety disorders, and other mental disorders as well as behavioral risk factors for many physical disorders. Comparing some physical illnesses with mental disorders may help to clarify the similarities.

About 50% of the U.S. noninstitutionalized population has a respiratory condition in any 1 year. This figure includes both acute and chronic respiratory conditions. About 15% of individuals with respiratory conditions seek ambulatory health care for their illness (8). Mental disorders are also classified as either acute or chronic, and, like respiratory illnesses, most mental illnesses are acute. In any 1 year, about 25% of individuals with mental disorders seek care within the health system. The total economic cost of respiratory diseases was estimated to be $99 billion in 1990 (unpublished data from the National Heart, Lung, and Blood Institute).

Cardiovascular diseases include a broad spectrum of conditions that are in many respects similar to those included in mental illness. Both types of conditions tend to affect a large portion of the population and are usually treated with medications. Like mental disorders, cardiovascular diseases are rarely "cured" but usually can be controlled, and they have a variety of effects on patients, ranging from the less severe to the life threatening.

In 1990 about 18% of the population had a cardiovascular disease, while 22% had a mental illness. In contrast to the 25% of the mentally ill who seek care in the health system in a year, 60%–80% of persons with cardiovascular diseases are seen by a physician in any one year (9). The direct and indirect costs of cardiovascular diseases were estimated to be $160 billion in 1990 (unpublished data from the National Heart, Lung, and Blood Institute). In the same year, mental disorders were estimated to have economic costs of $148 billion (unpublished 1992 paper by D.P. Rice and L.S. Miller). While there are differences among these conditions in the treatment modalities and the ways in which illnesses are defined, these figures place the cost of mental disorders in a context that allows comparison with other medical conditions. Table 7 shows the costs of mental illness, cardiovascular disease, and respiratory disease in 1990.

The direct costs of an illness represent the resources needed to treat the person affected by the illness. They include hospitalization costs, payments to physicians and other health care personnel, the costs of medications, and other costs. Indirect costs are the costs imposed on society because of the missed productivity of those who are ill or die prematurely. For mental illness, there are also other costs, mainly related to the criminal justice system and family caregiving, that are not relevant for other types of illness. The direct costs of cardiovascular and respiratory diseases constitute more than one-half of the total cost of these illnesses (53% and 57%, respectively), while the direct costs of mental disorders constitute less than one-half of the total cost of these conditions (47%).

To display better the similarity of mental illness to medical illness, it is useful to examine one particular disease in each classification. Severe diabetes and schizophrenia share many characteristics. Severe diabetes affects about one-third of the 6.2 million Americans with diabetes (if a "severe" illness is defined as one for which the patient has required hospitalization). Thus, 2.5% of the population have diabetes, and about 0.83% (2.0 million) have severe diabetes (48, 49).

TABLE 7. Costs of Respiratory Disease, Cardiovascular Disease, and Mental Illness in 1990

Type of Cost	Amount (billions of dollars)		
	Respiratory Disease[a]	Cardiovascular Disease[a]	Mental Illness[b]
Direct	57	85	67
Indirect	42	75	75
Other, related	0	0	6
Total	99	160	148

[a]Unpublished data from the National Heart, Lung, and Blood Institute.
[b]Unpublished 1992 paper by D.P. Rice and L.S. Miller.

Of the U.S. population aged 18–64 years, about 2.5 million currently experience schizophrenia (unpublished 1992 paper by D.P. Rice and L.S. Miller). Both severe diabetes and schizophrenia can involve loss of some of the abilities to support and care for oneself. Most treatments for these illnesses are with medications or counseling.

THE ECONOMIC IMPACT OF DIABETES

Diabetes is a chronic condition that causes significant disability among the persons it affects. The disease imposes not only considerable costs for the care of patients but also costs to our society for the loss of the productivity of those who have diabetes. Good, current cost data for all types of diabetes do not exist, but a recent study examined the economic impact of non-insulin-dependent (type II) diabetes (50). Since about 93% of all persons with diabetes have type II, this study provides a substantial guide to the cost of diabetic illness. The other types of diabetes include insulin-dependent (or type I) diabetes, gestational diabetes, and other, rarer types that are caused by chemical exposure or pancreatic disease. All cost data for the type II diabetes group were used to represent the costs of the other types of diabetes because data are not available for the latter.

To use data from this study, certain assumptions about the costs of severe diabetes are necessary. It is assumed that all hospital costs, all nursing home costs, all disability costs, and all mortality costs incurred as a result of diabetes are due to severe diabetic illness. Because diabetes leads to other medical conditions such as circulatory disorders, visual disorders, neuropathies, nephropathies, and skin ulcers, the costs of these related medical conditions must be taken into account. The other costs attributable to diabetes were apportioned to the severe group according to their part of the entire diabetic population (33%). Table 8 summarizes the estimates of the economic impact of all diabetic patients and those severely affected by the disease in 1990. Almost 93% of the entire cost of diabetes can be attributed the 2.0 million Americans with severe diabetic disease.

THE ECONOMIC IMPACT OF SCHIZOPHRENIA

Schizophrenia is a chronic mental illness characterized by disordered thinking, hallucinations, delusions, and impaired functioning. Like diabetes, schizophrenia imposes costs on our society for direct treatment and for reduced or lost pro-

TABLE 8. Cost of Diabetes in 1990[a]

Type of Cost	Amount (billions of dollars)	
	All Patients With Diabetes	Patients With Severe Diabetes
Direct	17	15
Hospitalization	4	4
Nursing home	3	3
Related medical conditions	7	7
Other	3	1
Indirect	10	10
Disability	3	3
Mortality	7	7
Total	27	25

[a]Data from Huse et al. (50).

ductivity. In 1992 Dorothy P. Rice and Leonard S. Miller estimated the economic cost of schizophrenia in 1990 as $32.5 billion (unpublished paper). The method used to make this estimate is similar to the method used to estimate the costs of severe diabetes in that it includes direct costs of patient care and indirect costs of morbidity and mortality.

Other costs are associated with schizophrenia that are not usually associated with severe diabetes. Many individuals with schizophrenia are unable to care for themselves, since they are not in touch with reality. Because their judgment is markedly impaired, some individuals may be involved in crimes and may be incarcerated. Rice and Miller included the related costs of this illness, such as social welfare administration, criminal justice administration, and family caregiving. Table 9 summarizes the economic costs of schizophrenia.

Although the estimates for the total costs of schizophrenia exceed those for severe diabetes by about $7 billion, the per capita cost estimates are much closer. For each of the 2.5 million individuals with schizophrenia, the total economic cost is about $13,000, while the total economic cost for each person with severe diabetes is $12,632.

TABLE 9. Cost of Schizophrenia (1990 Estimates)[a]

Type of Cost	Amount (billions of dollars)
Direct	18
Patient care	17
Related	1
Indirect	15
Morbidity	11
Mortality	1
Other	3
Total	33

[a]Unpublished 1992 paper by D.P. Rice and L.S. Miller.

Also of importance is the difference in direct and indirect costs between the two diseases. Direct costs reflect the outlays needed to treat patients affected by these illnesses. Indirect costs are the costs to society because these people are unable to work or die prematurely because of their disease. In 1990 the direct costs made up about 61% of the total cost of severe diabetes and 55% of the total cost of schizophrenia. The total direct cost of treating each person with schizophrenia was $7,158, while the direct cost of treating each person with severe diabetes was $7,725. This means that per patient, severe diabetes imposes more costs for treatment than does schizophrenia. It also means that the potential gains—in terms of reducing morbidity and mortality costs through treatment—are greater for schizophrenia.

CONCLUSIONS

Both severe diabetes and schizophrenia are chronic illnesses that impose significant costs on our society. While cost estimation techniques differ and certainly contain some errors, the estimated total economic cost of schizophrenia is within $500 per patient of the cost of severe diabetes. In addition, the per capita direct cost of treating schizophrenia is less than that of treating severe diabetes. This analysis provides a reasonable context for evaluating the economic impact of this severe mental illness.

APPENDIX 3. Current Coverage for Mental Disorders in Public Programs

OVERVIEW

Historically, state mental hospitals, which were publicly financed and operated, dominated the care for individuals with severe mental illness. In the 1960s Medicaid was introduced as the major public health assistance program to increase access to health care for the poor, including mentally disabled individuals residing in the community. The largest of other public health care programs covering other segments of the population is Medicare, a federally administered program for the elderly and for the disabled in the SSDI program.

Employment-related private health insurance grew rapidly in the 1950s and 1960s in the United States to cover the majority of the working population and their dependents. Coverage in these health insurance packages was restricted, however, emphasizing inpatient care in acute general hospital settings and offering limited outpatient care. Thus, public programs have continued to play a significant role in funding care for persons with severe mental disorders (25).

MEDICARE

Eligibility

Medicare covers all persons aged 65 years and over who are eligible for Social Security, have been receiving SSDI payments for at least 2 years, or have end-stage renal disease (24).

Covered Mental Health Services

Medicare coverage includes hospital insurance (part A) and medical insurance (part B) (28).

Hospital insurance (part A). The coverage by Medicare hospital insurance for general hospitals is the same for physical and mental disorders: 90 days per benefit period. A new benefit period begins once a beneficiary has been out of the hospital or skilled nursing facility for 60 consecutive days. A beneficiary has an additional 60 "lifetime reserve days" that can be used only once. Freestanding public and private psychiatric hospitals have a lifetime limit of 190 days.

The structure of the benefits for hospital insurance is the same for both mental and physical disorders. It includes a deductible of $652 per benefit period. Coinsurance is required for days 61–90 at $163 per day (daily coinsurance calculated as one-fourth of the part A deductible). Lifetime reserve days are calculated at $326 per day (daily coinsurance calculated as one-half of the medical insurance deductible).

Medical insurance (part B). Medical insurance includes payment for physicians' services, outpatient hospital services, durable medical equipment, and some other services. Services of physicians (and other professional providers, including psychologists, clinical social workers, and certain other therapists who are employed by or supervised by a psychiatrist or psychologist) are covered in psychiatric and general hospitals and skilled nursing facilities. They are also covered in the following outpatient settings: private offices, community mental health centers, comprehensive outpatient rehabilitation facilities, rural health clinics, HMOs, partial hospitalization psychiatric programs, and home health agencies. Outpatient prescriptions, including psychotropic drugs, are excluded from coverage.

Reimbursements

Under part A, specialty psychiatric providers (all public and private freestanding psychiatric hospitals) are reimbursed under the 1982 Tax Equity and Fiscal Responsibility Act rules, while the treatment of patients in scatter-beds of general hospitals is reimbursed under prospective payment system rules. Most psychiatric units in general hospitals are reimbursed under Tax Equity and Fiscal Responsibility Act rules, but some are paid under prospective payment system rules.

Under part B, providers are paid "customary, usual, or prevailing fees" for treating both mental and physical disorders. Medical insurance includes a $100 deductible per year, coinsurance, and a feature called "balancing bills" for fees above what Medicare will pay. A 20% coinsurance is required for inpatient services in hospitals and skilled nursing facilities, initial diagnostic evaluation, medical management of psychotropic drugs, treatment of Alzheimer's disease (except psychotherapy), and partial-hospitalization psychiatric programs. A 50% coinsurance is required for therapeutic outpatient services, follow-up diagnostic services, and all other outpatient mental health services. About 3% of the Medicare dollar is spent on mental health care (24).

MEDICAID

Eligibility

Medicaid is a joint federal-state government program that pays medical bills for low-income persons. These recipients become eligible for Medicaid mainly because they receive federal income assistance through two programs: Aid to Families with Dependent Children and SSI for the blind, aged, and disabled, including those disabled by mental disorders. Medicaid may be the most important legal entitlement program for low-income persons with mental disorders for both their mental health and medical care (29).

Covered Mental Health Services

The law does not establish a consistent, national program of services offered by Medicaid. Instead, it requires that each state offer nine specified services and then allows the states the option of offering additional services. Through Medicaid all states provide the following:

- Inpatient hospital services other than services in an institution for mental diseases
- Outpatient hospital services
- Physician and dentist services
- Laboratory and X-ray services
- Skilled nursing facility care for persons over age 21 other than care in an institution for mental diseases
- Early and periodic screening, diagnosis, and treatment services for persons under age 21
- Family planning services and supplies
- Rural health clinic services
- Nurse-midwife services

As of 1988, each state has the option of offering any of the following 12 services through Medicaid:

- Medical or remedial care recognized under state law and furnished by licensed practitioners
- Home health services, which may include some mental health services
- Dental services
- Physical therapy, occupational therapy, and services for individuals with speech, hearing, and language disorders
- Prescribed drugs, dentures, prosthetic devices, and eyeglasses
- Diagnostic, screening, preventive, and rehabilitative services
- Inpatient hospital, skilled nursing facility, and intermediate care facility services for individuals aged 65 years or older in an institution for mental diseases
- Intermediate care facility services for mentally retarded individuals or those with related conditions
- Inpatient psychiatric hospital services for individuals under age 21
- Case management, personal health, and respite care services
- Any other medical or remedial care recognized under state law and specified by the Secretary of the U.S. Department of Health and Human Services
- Clinic services in a facility not part of a hospital

Each state determines the exact program of Medicaid benefits it will offer, within broad federal guidelines. Limitations in the Medicaid program for persons with mental disorders include such restrictions as requiring Medicaid coverage of psychiatric hospital care only for patients younger than 22 years and older than 65 years.

Medicaid does not discriminate coverage or restrict services on the basis of diagnosis. However, limitations imposed by the states on the amount, duration, and scope of services that each will cover effectively restrict access to services needed by individuals with severe mental disorders. Furthermore, because Medicaid covers limited outpatient care, a "perverse incentive" is created for using inpatient rather than outpatient services as the "usual" source of care (27).

Reimbursements

Payments for covered services are made directly to the service provider for the covered individual. To participate in the Medicaid program, a provider must agree to accept Medicaid reimbursement as payment in full, although some states require copayments under certain circumstances. Because state Medicaid plans vary widely with respect to whom they cover and what services they reimburse, the amounts spent also vary widely among the states. Medicaid per capita spending in 1984 ranged from $382 in New York to $52 in Wyoming. Nationally, the average per capita Medicaid spending in that year was $148. Crude estimates suggest that about 15% of Medicaid dollars are spent on persons with mental disorders, primarily for skilled nursing facilities, state psychiatric hospi-

tal care, and general hospital psychiatric care. The remainder is spent on community-based care (23).

STATE MENTAL HEALTH AUTHORITY PROGRAMS

Eligibility

Approximately 1.5 million adults, aged 18–64 years, defined as having a "persistent and severe" mental disorder are considered to be the priority population by state mental health programs. While definitions of persistent and severe mental disorders vary from state to state, they are generally characterized by a diagnosis of schizophrenia, psychosis, major affective disorder, anxiety, or phobia and a resulting disability of such magnitude that self-care is not possible (51).

Mental Health Services

Services provided or funded by state mental health authorities are categorized as residential services, community-based services, and specialized services. Because state programming and criteria for eligibility vary, not all of the following services are available to all persons, in all communities or in all states. (Furthermore, not all of the services are available to, or necessarily appropriate for, persons with severe mental disorders.)

The residential services provided by the states include the following types:

Publicly operated institutions
Nursing home care
Group homes
Assisted living programs
Adult foster care
Congregate living programs
Supervised apartment living
Supported living programs
Domiciliary care

State-run or state-supported community-based services include the following:

Homemaker services
Personal care
Day habilitation programs
Transportation
Vocational training services
Supported employment
Attendant care
Case management
Home modifications
Adult day care
Nutritional programs
Information and referral
Companion programs
Recreational services
Financial management assistance
Community support services
Self-advocacy

Specialized services may include the following:

Medication monitoring
Skilled nursing care
Psychological/psychiatric services
Home health services
Family counseling and support
Communication devices
Adaptive devices
Preadmission screening
Crisis management services
Early intervention programs
Behavior modification services
Therapies (e.g., speech, physical)
Emergency response systems
Legal assistance
Special education

Expenditures/Reimbursements

Public expenditures, controlled by the state mental health authorities for mental health services, were approximately $12.2 billion in 1990. The states contributed 80% of these dollars, and the federal government, 15%. Local governments contributed 2%, and all other sources, 3%. The average annual expenditure per state was $234 million.

The programs supported by these expenditures included the following: state psychiatric hospitals (total=$7 billion; state average=$135 million); other hospitals (total=$100 million; state average=$2 million); community-based programs (total=$4.5 billion; state average=$88 million); prevention, research, and training (total=$107.5 million; state average=$2.7 million); and the administration of the state mental health authorities (total=$336.7 million; state average=$6.6 million). State mental health authority annual per capita spending on mental health programs ranged from $268 in Delaware to $17 in Iowa (51).

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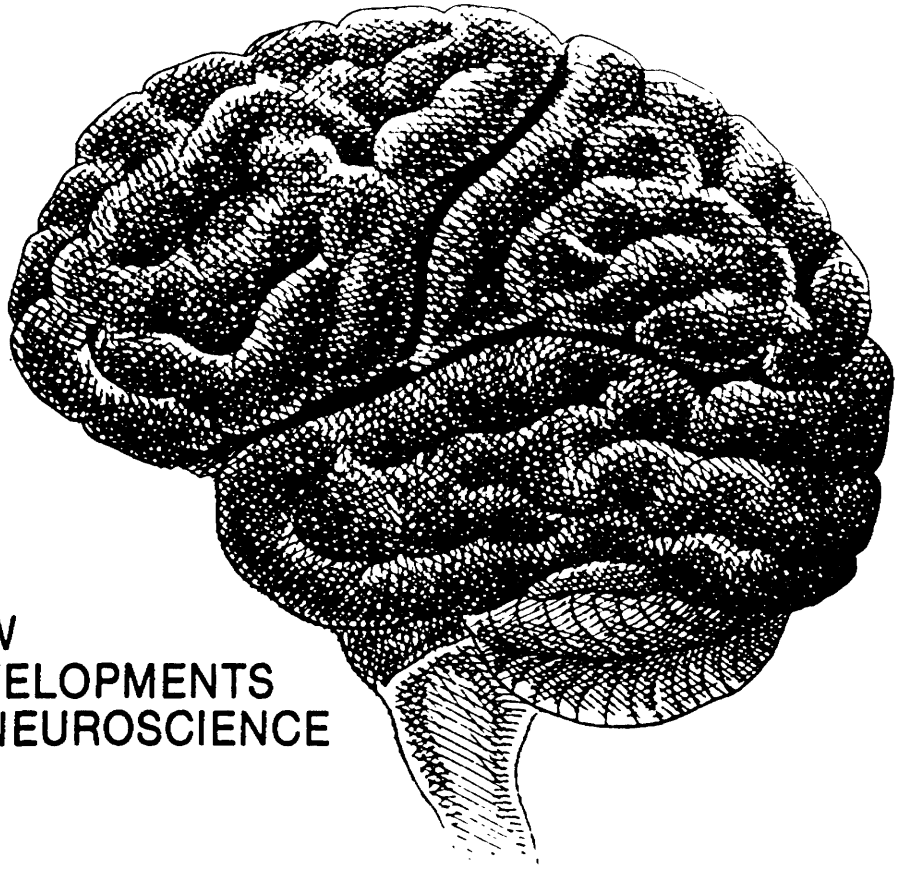
The Biology of Mental Disorders



NEW DEVELOPMENTS IN NEUROSCIENCE

CONGRESS OF THE UNITED STATES OFFICE OF TECHNOLOGY ASSESSMENT

Chapter 1

Summary, Policy Issues, and Options for Congressional Action

Mental disorders can strike with savage cruelty, producing nightmarish hallucinations, crippling paranoia, unrelenting depression, a choking sense of panic, or inescapable obsessions. The sheer number of Americans with mental disorders transforms this personal tragedy into a widespread public health problem. Nearly one in three American adults will experience a mental disorder during his or her lifetime, whether one of the disorders considered in this report [schizophrenia, bipolar disorder (commonly known as manic depression), major depression, obsessive-compulsive disorder, and panic disorder; table 1-1], or one of a variety of other conditions, including cognitive impairment (as in Alzheimer's disease), substance abuse or dependence, phobias, and antisocial personality disorder. Moreover, approximately 1.7 to 2.4 million Americans currently suffer from a persistent and severely disabling mental disorder, such as schizophrenia or bipolar disorder.

What are the costs of this public health problem? The most recent and comprehensive estimate of the total costs of mental disorders—for fiscal year 1985—added up to $103.7 billion (figure 1-1) (box 1-A). When adjusted for inflation, this figure reaches $136.1 billion in 1991. However, dollar figures alone, no matter how large, do not convey the toll mental disorders take. These disorders can be extremely disabling, significantly compromising productivity and the ability to work. It has been estimated that individuals with mental disorders fill 25 percent of all hospital beds and, further, that one-third of these persons suffer from schizophrenia. Mental disorders account for an even larger percentage of hospital beds in Department of Veterans Affairs (VA) hospitals: Fully 40 percent of all VA inpatient care is for persons with mental disorders. Perhaps most tragically, approximately one-third of homeless single adults and 10 to 15 percent of individuals who are incarcerated in jails and prisons have a severe mental disorder such as schizophrenia or bipolar disorder.

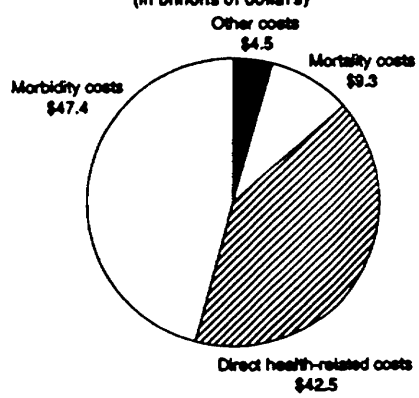
Table 1-1—Prevalence of Severe Mental Disorders

Disorder	Adults diagnosed with disorder during their lifetimes (%)
Schizophrenia	1.0
Bipolar disorder	0.8
Major depression	4.9
Obsessive-compulsive disorder	2.6
Panic disorder	1.6

SOURCE: L.N. Robins and D.A. Regier, *Psychiatric Disorders in America, The Epidemiologic Catchment Area Study* (New York, NY: Free Press, 1991).

One of the most powerful factors affecting people with mental disorders and their families is the stigma often attached to these conditions. While the public's attitudes and knowledge about mental disorders have improved during the last 30 years, negative attitudes toward and ignorance of these disorders still abound. A sizable number of people continue to be frightened by the notion of mental illness. The public fears that people with mental disorders are violent and dangerous and perceives them to be dirty and unattractive, therefore often treating them with disrespect, if not rejecting them outright. Furthermore, despite gains in knowledge about specific

Figure 1-1—The Cost of Mental Disorders, 1985 (in billions of dollars)



In 1985, mental disorders cost the United States more than $103 billion. Approximately 41 percent of that cost—$42.5 billion—stemmed from hospital care, medication costs, and other treatment costs. Nearly half of the costs of mental disorders—$47.4 billion—derives from lost productivity.

SOURCE: D.P. Rice, S. Kelman, L.S. Miller, et al., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness*, report submitted to the Office of Financing and Coverage Policy, Alcohol, Drug Abuse, and Mental Health Administration, U.S. Department of Health and Human Services (San Francisco, CA: Institute for Health and Aging, University of California, 1990).

Box 1-A—The Cost of Mental Disorders

How big a problem do mental disorders present to our Nation? What priority should these disorders receive in the outlay of government funds for research and services? The answers to these questions are often sought in terms of a dollar figure. However, estimating the toll of mental disorders, or any illness, in economic terms is no easy or straightforward task. Everything from the cost of hospitalization, which is relatively easy to estimate, to the cost of reduced productivity, which is more difficult to assess, may be evaluated. And while rarely included in studies, the psychological and social tolls on an individual's life are substantial, though not easily quantified.

During the last 40 years, studies have reported that mental disorders cost the Nation from $3.6 billion to more than $100 billion each year. The variation in estimates reflects changes over time as well as the use of different methods of calculation and sources of data. Dorothy Rice and colleagues have derived the most comprehensive estimate, based on the most recently available survey data. They estimate the total costs of mental disorders—including schizophrenia, major depression, bipolar disorder (manic-depressive illness), anxiety disorders, somatization disorder, antisocial personality disorder, and cognitive impairment—to be $103.7 billion for the year 1985. When adjusted for inflation, this figure reaches $136.1 billion in 1991.

These costs include health-related, or core, costs—that is, the expenditures made and resources lost as a consequence of having a mental disorder. Such costs make up 96 percent of the total estimated costs for 1985, or $99.2 billion. Health-related costs can be broken down further into direct and indirect costs.

Direct health-related costs—$42.5 billion in 1985 and more than $58 billion in 1991—include all expenditures related to the treatment and support of persons with mental disorders. The vast majority of these direct costs—92 percent—are related to treatment and involve expenditures on hospital and nursing home care, physician and other professional services, and drugs (figure 1-1). More than 50 percent of the treatment costs—almost $22 billion in 1985—were spent on care in institutional or hospital settings, such as Department of Veterans Affairs (VA) hospitals, State and county psychiatric hospitals, private psychiatric hospitals, residential treatment centers for emotionally disturbed children, and short-stay (general) hospitals. The costs of care provided by office-based physicians, psychologists, and social workers amounted to approximately $5.7 billion in 1985. Approximately $1.5 billion was spent on prescription drugs, including minor tranquilizers, antidepressants, and antipsychotics. The estimate reached more than $2.2 billion in 1991, when adjusted for inflation. Support costs, which equaled approximately $3.2 billion in 1985, include expenditures for research, physician and nurse training, and program administration (as for health insurance).

Indirect health-related costs estimate the burden of increased morbidity and mortality that accompanies mental disorders. These estimates, which are based on the National Institute of Mental Health's Epidemiologic Catchment Area prevalence data, include the value of lost output caused by decreased productivity, lost work days, or premature death. Rice and colleagues do not include measures of the psychological and social effects of mental disorders on the individual's life. Morbidity and mortality costs were estimated at $47.4 billion and $9.3 billion, respectively, in 1985. For 1991, estimates were $60.0 billion for morbidity costs and $11.7 billion for mortality costs. Thus, according to these data, lost or diminished productivity is the most costly outcome of mental disorders, with morbidity accounting for nearly 50 percent of the total costs of mental disorders. Furthermore, the cost of morbidity is not primarily due to institutionalization. Additional analysis, which considers such factors as the prevalence of mental disorders in various demographic groups, the type of disorder, and income levels, shows that a very large share of the morbidity costs—$44.1 billion in 1985 and $55.8 billion in 1991—derives from noninstitutionalized individuals.

Mental disorders have other, nonhealth-related effects that impose a cost on society. Nonhealth effects lead to public and private expenditures on crime control and social welfare administration, the sum of which was estimated at $1.7 billion by Rice and colleagues. Furthermore, the value of reductions or losses in productivity due to either incarceration for a criminal offense or time spent to care for a family member with a mental disorder exacts a price, estimated at approximately $2.8 billion.

SOURCES: D.P. Rice, S. Kelman, L.S. Miller, et al., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness: 1985*, report submitted to the Office of Financing and Coverage Policy, Alcohol, Drug Abuse, and Mental Health Administration, U.S. Department of Health and Human Services (San Francisco, CA: Institute for Health and Aging, University of California, 1990); The National Foundation for Brain Research, *The Costs of Disorders of the Brain* (Washington, DC: 1992).

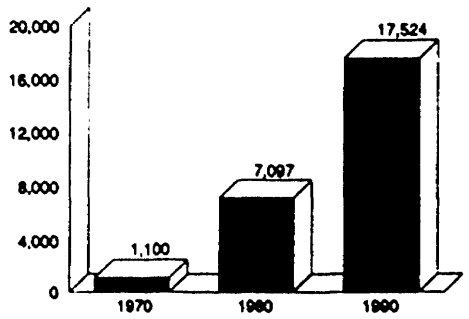
disorders and their treatment, considerable public ignorance about mental disorders persists. Although the stigma attached to mental disorders is complex in its makeup and effects, negative attitudes and ignorance have contributed to discrimination in research support, treatment availability, funding of mental health care, housing, and employment.

The reality of mental disorders—their symptoms, prevalence, costs, and associated stigma—commands the Federal Government's attention. Despite the fact that Federal, State, and local governments spend more than $20 billion each year on mental health services, with approximately 40 percent of these public funds derived from Federal sources, the consensus is that mental health policy is fragmented and mental health services often deficient. Fundamental to improving the Nation's efforts on behalf of people with mental disorders is increasing public understanding of these conditions. More than a decade ago the President's Commission on Mental Health wrote, "Expanding our understanding of the functioning of the mind, the causes of mental and emotional illness, and the efficacy of various treatments is crucial to future progress in mental health." This report from the Office of Technology Assessment (OTA) offers an appraisal of current knowledge about biological factors in severe mental disorders—schizophrenia, bipolar disorder, major depression, obsessive-compulsive disorder, and panic disorder.[1] It also reviews support for that research and considers some of the social implications of data from biological research into mental disorders.

DECADE OF THE BRAIN

An atmosphere of enthusiasm surrounds neuroscience—an area of interdisciplinary research focused on how the nervous system works and how it is affected by disease. Neuroscience is a rapidly growing field, as reflected in the membership of the Society for Neuroscience: This professional organization grew from 1,100 members at its inception in 1970 to more than 17,000 in 1990 (figure 1-2). The 1980s saw a nearly 70 percent increase in the number of papers published in neuroscience and behavioral research. At least 20 Federal organizations support research devoted to brain and behavioral research (figure 1-3), with total Federal expenditures just exceeding $1 billion in 1990.

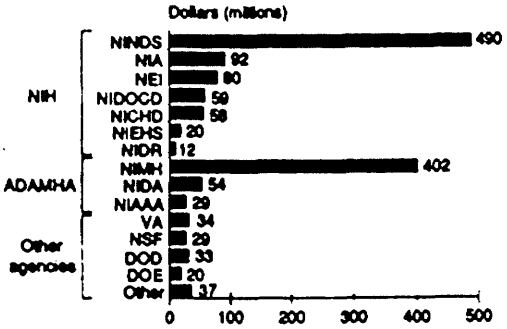
Figure 1-2—Membership in the Society for Neuroscience



Membership in the Society for Neuroscience has grown dramatically since its inception in 1970.

SOURCE: Society for Neuroscience, 1991.

Figure 1-3—Distribution of Federal Support of Neuroscience Research, Fiscal Year 1990



Funding of neuroscience research by various Federal agencies.

KEY: NIH = National Institutes of Health; ADAMHA = Alcohol, Drug Abuse, and Mental Health Administration; NINDS = National Institute of Neurological Disorders and Stroke; NIA = National Institute on Aging; NEI = National Eye Institute; NIDOCD = National Institute on Deafness and Other Communication Disorders; NICHD = National Institute on Child Health and Human Development; NIEHS = National Institute on Environmental Health Sciences; NIDR = National Institute of Dental Research; NIMH = National Institute of Mental Health; NIDA = National Institute on Drug Abuse; NIAAA = National Institute on Alcohol Abuse and Alcoholism; VA = U.S. Department of Veterans Affairs; NSF = National Science Foundation; DOD = U.S. Department of Defense; DOE = U.S. Department of Energy; Other = National Institute on Disability and Rehabilitation Research, National Aeronautics and Space Administration, Environmental Protection Agency, U.S. Department of Agriculture, Centers for Disease Control, and U.S. Food and Drug Administration.

[a]Fiscal year 1991.

SOURCE: Office of Technology Assessment, adapted from E. Pennisi and D. Morgan, "Brain Decade Scientists Court Support," *The Scientist* 4:8, 1990.

[1] Addictive disorders, Alzheimer's disease, and developmental disorders such as autism have been or are being discussed in other OTA reports, and therefore are not considered in this report.

Advances in scientific methods and techniques have fueled the dramatic increase in neuroscience research during the last 15 years. Improved methods for staining nerve cells have made it possible to pinpoint their precise location in the brain. The electrical activity of a single channel in a nerve cell's membrane—less than one-trillionth of an inch in diameter—can be measured. Advances in computing, microscopy, and especially imaging technology underlie the spectacular ability to observe living brain tissue—from single nerve cells to the intact human brain. The development of psychological tests has enabled researchers to correlate observed brain activity with specific behaviors and thought processes. And molecular biology has revolutionized the study of the brain, producing monoclonal antibodies that allow labeling of specific nerve cells, the cloning of proteins involved in brain function, and the search for specific genes.

The rapid growth and productivity of neuroscience spearheads, in large measure, the general interest in the biology of mental disorders and Congress' request for this study. Modern neuroscience research is an important part of the contemporary effort to expose the causes of mental disorders. The National Institute of Mental Health (NIMH), the primary source of Federal funding for research into mental disorders, has focused a major portion of its research plan on the basis of developments in neuroscience. By strongly supporting neuroscience research, NIMH aims to "understand the workings of the human brain in sufficient detail to effectively treat or prevent the broad variety of behavioral disorders and mental illnesses." The spectacular growth of neuroscience also distinguishes the current focus on the biology of mental disorders from that of previous eras. While biological models of mental disorders have been emphasized time and again in the past, today's research into the brain's functions in mental disorders is supported in a qualitatively and quantitatively new way by an expanding base of knowledge about the brain and behavior.

SCHIZOPHRENIA

Schizophrenia "is arguably the worst disease affecting mankind."[2] It is not, as commonly misconstrued, split personality. Although important questions remain about its classification, its characteristic symptoms are well defined. Positive symptoms, which typify psychosis, include hallucinations and delusions, as well as bizarre behaviors and dissociated or fragmented thoughts. Negative symptoms include impaired emotional responsiveness, loss of motivation, general loss of interest, and social withdrawal.

Credit: Copyright © 1992 Bill Lee. Reprinted with permission.

This cartoon, provided by O. Wahl, illustrates the commonly held misperception that schizophrenia is multiple personalities.

Schizophrenia is a common disorder, with approximately one in every 100 persons developing it during the course of his or her lifetime; approximately 1.2 million people have schizophrenia in the United States at the present time. While schizophrenia does not invariably follow a deteriorating course, there are substantial and enduring consequences for many people with this condition. Its onset typically occurs during the late teens and early 20s, with a generally younger age of onset and worse prognosis in men. The expressed symptoms of schizophrenia may combine in various ways, their severity and duration fluctuating over time. Schizophrenia is associated with an increased risk of suicide; approx-

[2] *Nature*, editorial, 336 95, 1988

Box 1-B—The Final Symptom: Mental Disorder and Suicide

In 1987, 11.7 people in every 100,000—more than 30,000 people—killed themselves in the United States, making it the eighth leading cause of death in the nation. While many factors are associated with suicide, including medical illness, availability of firearms, or stressful events such as a divorce or loss of a job, data indicate that mental disorders are a significant antecedent to many suicides in the United States. About 50 percent of all suicide victims may have suffered a mood disorder, and an estimated 5 to 10 percent of suicide victims suffered from schizophrenia.

Among people with schizophrenia, suicide is the number one cause of premature death, with the estimated age-adjusted suicide rate averaging 90 per 100,000 women with schizophrenia and 210 per 100,000 men with the disorder; 10 to 15 percent of individuals with schizophrenia commit suicide. The higher rate of suicide among men versus women with schizophrenia not only mirrors the suicide statistics in the general population, but also reflects the more severe symptoms that men usually suffer. Some people with schizophrenia may commit suicide as a result of a psychotic episode—in response to a hallucinatory command. More commonly, however, people with this condition take their lives early in the course of the illness during a relatively stable period following a recent hospitalization.

Approximately 15 percent of people with mood disorders will commit suicide, with the suicide rates for men and women with major mood disorders averaging 400 and 180 per 100,000, respectively, 30 times higher than the rate in the general population. The link between mood disorders and suicide is well recognized, with recurrent thoughts of suicide or a suicide attempt being one diagnostic criterion for these conditions. Other mental disorders, such as panic disorder, also appear to be correlated with suicide. Although there is little information available concerning the number of people with panic disorder who actually commit suicide, survey data show that approximately 20 percent of people with this condition will attempt suicide during their lifetime.

High rates of suicide among individuals with major mental disorders like schizophrenia or major depression provide chilling evidence of the distressing nature of mental disorders. Furthermore, the strong correlation between mental disorders and suicide indicates that general suicide prevention efforts must include strategies to improve the treatment of mental disorders.

SOURCES: C.B. Caldwell and I.I. Gottesman, "Schizophrenics Kill Themselves Too: A Review of Risk Factors for Suicide," *Schizophrenia Bulletin* 16(4):571-589, 1990; F.K. Goodwin and K.R. Jamison, *Manic-Depressive Illness* (New York, NY: The Oxford University Press, 1990); J. Johnson, M.M. Weissman, and G.L. Klerman, "Panic Disorder, Comorbidity, and Suicide Attempts," *Archives of General Psychiatry* 47:805-808, 1990; E.E. Moscicki, chief, Prevention Research Branch, National Institute of Mental Health, U.S. Department of Health and Human Services, personal communication, Apr. 30, 1991; U.S. Department of Health and Human Services, Public Health Services, National Center for Health Statistics, *Monthly Vital Statistics Report* 40(8 suppl. 2), 1992.

imately 10 to 15 percent of individuals with this disorder take their own lives (box 1-B).

Currently, there is no way to prevent or cure schizophrenia; however, treatments that control some of its symptoms are available. The optimal treatment generally integrates antipsychotic drugs and supportive psychosocial treatment. Individuals acutely ill with schizophrenia may require hospitalization. Furthermore, rehabilitation is generally necessary to enhance social and occupational outcomes.

The complexity of expressed symptoms and the likelihood that the disorder encompasses various subtypes, which are not yet reliably distinguishable, have slowed progress in understanding schizophrenia. Nonetheless, converging research data point to the alteration of specific brain chemicals and regions as the biological substrate of the schizophrenias.

Investigators have examined the possible role of several brain chemicals in schizophrenia, including serotonin, norepinephrine, various neuropeptides, and, most recently, glutamate. The most venerable theory concerning the chemistry of schizophrenia implicates the brain chemical dopamine. Dopamine-releasing drugs, such as amphetamines, can induce a psychotic state, and drugs reducing dopamine function have antipsychotic effects. However, studies looking for simple changes in dopamine levels in the brain have provided inconsistent results. Thus, even though there is a consensus that dopamine plays a role in schizophrenia, the specifics of this brain chemical's action remain unknown.

Various studies of the function and structure of the brain in schizophrenia point to the involvement of two specific areas, namely, the frontal cortex and

the limbic system (figure 1-4). The limbic system seems to be involved in the positive symptoms and the frontal cortex in the negative symptoms of schizophrenia. The precise interaction between these specific brain regions, as well as the possible involvement of other areas of the brain, still need to be clarified.

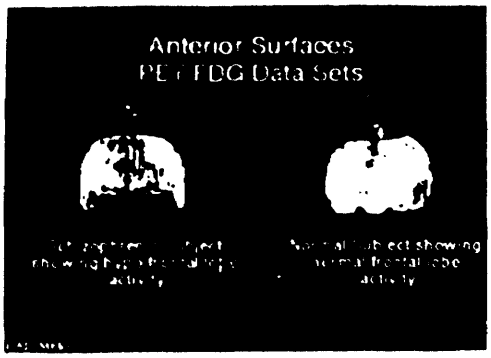
In addition to pinpointing the regions and chemicals in the brain that underlie the symptoms of schizophrenia, researchers have put forward several hypotheses concerning the cause or causes of this disorder. Information about the course of schizophrenia, its epidemiology, and specific biological measures suggests that a virus or immune system problem is a possible culprit. Another hypothesis asserts that injury to the brain early in life is the critical factor. Support for this viewpoint stems from various observations, including the higher rate of birth complications among individuals with schizophrenia and subtle deviations in neurological and psychological functions that sometimes precede the full expression of schizophrenia. Evaluation of the prevalence and pattern of schizophrenia among related individuals shows that genetic factors contribute to this disorder; however, the inheritance of schizophrenia is quite complicated, and nongenetic factors also play a role. The location of specific genes involved in schizophrenia remains unknown.

MOOD DISORDERS: MAJOR DEPRESSION AND BIPOLAR DISORDER

Mood disorders, which are also referred to as affective disorders, are characterized by extreme or prolonged disturbances of mood, such as sadness, apathy, or elation. These disorders can be divided into two major groups: bipolar and depressive disorders. The occurrence of manic symptoms distinguishes bipolar disorders from depressive, or unipolar, disorders.

The most severe depressive disorder is major depression. While it has proven difficult to discern whether depression is a single disorder or a collection of disorders, its expression is well characterized. Box 1-C is a personal account of the symptoms of depression. Various psychological and somatic symptoms accompany episodes of depression, including profoundly depressed mood, the complete loss of interest or pleasure in activities, weight gain or loss, insomnia or excessive sleepiness, slowed or

Figure 1-4—PET Scan of an Individual With Schizophrenia



Brain activity in an individual who does not have schizophrenia (right) and a person who does (left). The frontal cortex shows more activity in schizophrenia (white areas).

SOURCE: W Carpenter, Maryland Psychiatric Research Center and H. Loats, Loats Associates, Inc.

agitated movement, diminished energy, intense feelings of guilt or worthlessness, a diminished ability to concentrate, and recurrent thoughts of death or suicide (see box 1-B).

Major depression is a prevalent disorder: Nearly 5 percent of the population will develop it and the risk is twice as great for women as for men. Furthermore, its occurrence seems to be increasing among young people. Major depression typically has its onset in the late 20s, although it can emerge at any age. More than 50 percent of patients will have more than one bout of depression, the average being five or six episodes during a lifetime. Approximately 15 percent of persons suffering from the symptoms of depression will die by suicide.

Major advances have taken place in the pharmacological treatment of depression during the last decade. Various forms of psychotherapy—either alone or as an adjunct to medication—are also important to treatment. Severe cases may require hospitalization; electroconvulsive therapy may be used in severe cases. In depression that recurs each fall and winter, known as seasonal affective disorder, or SAD, light therapy can be useful.

Bipolar disorder is a severe mood disorder characterized by manic and depressive episodes. Although its symptoms are quite well known, questions remain about how it relates to other disorders, such

Box 1-C—Darkness Visible—A Personal Account of Depression

Depression is a disorder of mood, so mysteriously painful and elusive in the way it becomes known to the self—to the mediating intellect—as to verge close to being beyond description. It thus remains nearly incomprehensible to those who have not experienced it in its extreme mode, although the gloom, 'the blues' which people go through occasionally and associate with the general hassle of everyday existence are of such prevalence that they do give many individuals a hint of the illness in its catastrophic form. But at the time of which I write I had descended far past those familiar, manageable doldrums. . . .

It was not really alarming at first, since the change was subtle, but I did notice that my surroundings took on a different tone at certain times: the shadows of nightfall seemed more somber, my mornings were less buoyant, walks in the woods became less zestful, and there was a moment during my working hours in the late afternoon when a kind of panic and anxiety overtook me, just for a few minutes, accompanied by a visceral queasiness—such a seizure was at least slightly alarming, after all. . . .

I felt a kind of numbness, an enervation, but more particularly an odd fragility—as if my body had actually become frail, hypersensitive and somehow disjointed and clumsy, lacking normal coordination. And soon I was in the throes of a pervasive hypochondria. Nothing felt quite right with my corporeal self; there were twitches and pains, sometimes intermittent, often seemingly constant, that seemed to presage all sorts of dire infirmities. . . .

It was October, and one of the unforgettable features of this stage of my disorder was the way in which my own farmhouse, my beloved home for 30 years, took on for me at that point when my spirits regularly sank to their nadir an almost palpable quality of ominousness. The fading evening light—akin to that famous 'slant of light' of Emily Dickinson's, which spoke to her of death, of chill extinction—had none of its familiar autumnal loveliness, but ensnared me in a suffocating gloom. . . . That fall, as the disorder gradually took full possession of my system, I began to conceive that my mind itself was like one of those outmoded small-town telephone exchanges, being gradually inundated by flood waters: one by one, the normal circuits began to drown, causing some of the functions of the body and nearly all of those of instinct and intellect to slowly disconnect. . . .

What I had begun to discover is that, mysteriously and in ways that are totally remote from normal experience, the gray drizzle of horror induced by depression takes on the quality of physical pain. But it is not an immediately identifiable pain, like that of a broken limb. It may be more accurate to say that despair, owing to some evil trick played upon the sick brain by the inhabiting psyche, comes to resemble the diabolical discomfort of being imprisoned in a fiercely overheated room. And because no breeze stirs this cauldron, because there is no escape from this smothering confinement, it is entirely natural that the victim begins to think ceaselessly of oblivion.

SOURCE: Quoted from W. Styron, *Darkness Visible* (New York, NY: Random House, 1990). Copyright © 1990 by William Styron. Reprinted by permission of Random House, Inc.

as major depression and schizophrenia. The depressive episodes in bipolar disorder are similar to those seen in major depression. During a manic episode, an individual's mood is extremely elevated, expansive, or even irritable, and his or her self-esteem is elevated. There is diminished need for sleep, energy abounds, and thoughts race. Individuals are extremely talkative and distractible and stereotypically indulge in unrestrained buying sprees or sexual activity. Psychotic features (i.e., delusions and hallucinations) are not uncommon during a manic episode.

Bipolar disorder afflicts approximately 0.8 percent of the population, with men and women being affected equally. It emerges relatively early in life, usually during the mid-20s. Episodes of mania or depression occur every several months to every year or more, with periods of recovery typically separating the mood swings. This disorder continues throughout an individual's lifetime.

Treatment for bipolar disorder is aimed at ending a manic or depressive episode and preventing its recurrence. Medication is typically required, and hospitalization may be required for acute episodes. The specific symptoms are treated: depressive episodes with antidepressant drugs; psychosis with antipsychotic medication; and manic symptoms and relapses with lithium, or, less frequently, carbamazepine. Supportive psychotherapy is generally required to help patients understand and deal with the symptoms of bipolar disorder.

The typical symptoms and course of major mood disorders have led to their being conceptualized as

biologically based conditions. Since the discovery of clinically useful mood-altering medications 30 to 40 years ago, research has focused intensely on the biology of these conditions. Although the causes of these disorders remain obscure, studies of brain chemistry and function, other physical correlates, and genetic research provide clues about the biology of major mood disorders. The most consistent of these observations are discussed below.

A number of different brain chemicals appear to be involved in mood disorders. The most prominent hypotheses have focused on a group of brain chemicals called monoamines, especially norepinephrine and serotonin, because clinically effective antidepressant medications influence the levels of these chemicals. While neither depression nor mania seems to result from a simple decrease or increase of these chemicals, there is sufficient evidence to implicate monoamines in mood disorders.

Hormonal abnormalities are common in depression. Many of the symptoms associated with mood disorders—changes in appetite, sleep patterns, and sex drive—may be related to these hormonal changes. One of the most consistent findings in this regard is an elevation of cortisol in severely depressed individuals. Also, altered mood sometimes accompanies reproductive events in women—menstruation, pregnancy, childbirth, menopause—suggesting an association between reproductive hormonal alterations and mood disorders.

Individuals with mood disorders typically have sleep disturbances. Insomnia or excessive sleeping often occurs in depression, with REM sleep, during which dreaming occurs, frequently disrupted. The sleep of individuals with bipolar disorder is often affected; during depressive episodes, people may sleep excessively, and when manic, little or not at all.

Other functions that cycle over time may be disrupted in mood disorders. For example, many people with depression exhibit daily and seasonal fluctuations in mood. Some data suggest that circadian rhythms—biological and behavioral functions that repeat roughly every 24 hours—are disrupted in mood disorders. Furthermore, animal studies indicate that some antidepressant medications have an effect on the organization of circadian rhythms.

Episodes of mania and depression increase in frequency over time. And while environmental factors appear to be important in triggering periods of altered mood in the early stages of bipolar disorder, mood swings become automatic later on. The increasingly frequent and spontaneous nature of mood cycling has led to the development of a hypothesis about the recurrent nature of bipolar disorder: the kindling and sensitization hypothesis. Kindling refers to an experimental model for epilepsy, in which spontaneous seizures occur after repeated stimulation of a particular region of the brain. Behavioral sensitization refers to an increasing behavioral response to the same dosage of a drug following repeated administration. It is possible that similar brain mechanisms underlie mood swings. While additional information is needed to confirm this hypothesis, it is interesting to note that the medications used to treat bipolar disorder—carbamazepine and lithium—can block kindling and behavioral sensitization.

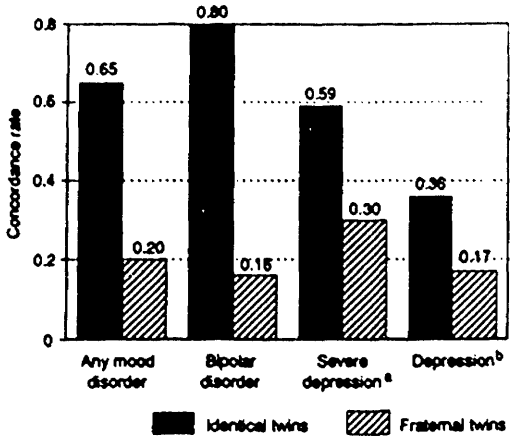
The most clearly established biological observation about mood disorders, and especially bipolar disorder, is that genetic factors play a role. Identical twins more frequently share mood disorders than do fraternal twins (figure 1-5). Also, parents, siblings, and children of individuals with bipolar disorder or major depression more commonly develop these conditions. Family and twin studies support a genetic link between depression and bipolar disorder, although the genetic overlap is not complete.

Clearly, genetic factors are important in both bipolar disorder and major depression. However, studies do not reveal a simple pattern of inheritance, nor do they necessarily implicate the action of a single gene. Data also indicate that nongenetic factors must play a role. While many studies have attempted to locate specific genes that lead to mood disorders, some with positive results, no strong evidence fixes a gene for mood disorders to a specific location.

ANXIETY DISORDERS: OBSESSIVE-COMPULSIVE DISORDER AND PANIC DISORDER

Anxiety is a normal human emotion, familiar to us all. However, anxiety can become extreme, leading to a disabling feeling of panic, a constant sense of apprehensiveness, or unrelenting worry about a possible mishap or accident. The current diagnostic system for mental disorders distinguishes several specific anxiety disorders, including panic disorder,

Figure 1-5—Mood Disorders Among Twins



Graphically depicted data were derived from evaluation of 110 pairs of twins. Identical twins shared mood disorders, and especially bipolar disorder, more frequently than fraternal twins.

[a]Three or more episodes of depression.
[b]Less than three episodes of depression.

SOURCE: Adapted from A. Bertelsen, B. Harvald, and M. Hauge, "A Danish Twin Study of Manic-Depressive Disorders," *British Journal of Psychiatry* 130:330-351, 1977.

phobias, obsessive-compulsive disorder, posttraumatic stress disorder, and generalized anxiety disorder. This report considers two of these conditions—obsessive-compulsive disorder and panic disorder—in which the role of biological factors has been more fully explored.

Obsessive-compulsive disorder (OCD) is characterized by the presence of recurrent and persistent thoughts, images, or ideas that are experienced by the afflicted individual as intrusive and senseless (obsessions) and stereotypical, repetitive, and purposeful actions perceived as unnecessary (compulsions) (table 1-2). A common manifestation of this disorder is the obsessional feeling of being dirty or contaminated, which leads to the compulsion of repeated hand washing. Many individuals with OCD have another diagnosis, most often depression. Other problems that may be associated with OCD include other anxiety disorders, eating disorders, alcohol abuse, and Tourette's syndrome.

Once thought to be quite rare, OCD has been found by more recent epidemiological studies to affect approximately 2 to 3 percent of the U.S. population. Males and females appear to be afflicted equally. The symptoms of OCD begin in childhood or adolescence in one-third to one-half of all individuals who develop the disorder; the average age of onset is 20. Although the symptoms of OCD sometimes recede completely with time, most patients suffer chronically from OCD, with a waxing and waning course.

Currently there are two primary treatment approaches for OCD: behavioral therapy and medication. Behavioral therapy entails repeated exposure of the patient to the stimulus that sets off ritualistic acts. For example, if an individual has a compulsion that causes him to wash his hands 20 or 30 times a day, his hands may be deliberately dirtied, after which he is prevented from washing them. Medications affecting the brain chemical serotonin have proven effective, with clomipramine (Anafranil) being commonly used to treat OCD.

As with the other mental disorders considered in this report, biological factors appear to have a role in OCD. The fact that drugs which act on the brain chemical serotonin are sometimes effective in treating OCD implicates biological factors. Studies have not, however, uncovered a specific abnormality in serotonin metabolism or activity. Other studies implicate a genetic component in OCD.

Several lines of evidence indicate that a specific region of the brain—the basal ganglia—mediates the symptoms of OCD. Damage to the basal ganglia can lead to compulsive behavior. And OCD is sometimes associated with Tourette's syndrome, which also involves this region of the brain. These observations, coupled with data from studies that show increased activity in the basal ganglia and in another region of the brain, the orbital system in the frontal cortex, have led to the hypothesis that OCD results from the abnormal interaction of these two regions of the brain (figure 1-6). According to this hypothesis, the basal ganglia and frontal cortex, which normally modulate actions based on thoughts or impulses, do not work properly in OCD.

While controversy remains as to whether panic disorder is a distinct entity, clinicians have long recognized panic attacks and the extensive morbidity associated with them. The hallmark symptoms of a panic attack include a sudden and inexplicable bout of intense fear associated with strong bodily symptoms. A panic attack typically unfolds quite

Table 1-2—Obsessions and Compulsions

Obsessions	Reported symptom at initial interview[a] (no.)	(%)
Concern with dirt, germs, or environmental toxins	28	(40)
Something terrible happening (fire, death, or illness of self or loved one)	17	(24)
Symmetry, order, or exactness	12	(17)
Scrupulosity (religious obsessions)	9	(13)
Concern or disgust with bodily wastes or secretions (urine, stool, saliva)	6	(8)
Lucky or unlucky numbers	6	(8)
Forbidden, aggressive or perverse sexual thoughts, images, or impulses	3	(4)
Fear might harm others or oneself	3	(4)
Concern with household items	2	(3)
Intrusive nonsense sounds, words, or music	1	(1)

Compulsions	Reported symptom at initial interview (no.)	(%)
Excessive or ritualized hand washing, showering bathing, tooth brushing, or grooming	60	(85)
Repeating rituals (going in or out of a door, up or down from a chair)	36	(51)
Checking (doors, locks, stove, appliances, emergency brake on car, paper route, homework)	32	(46)
Rituals to remove contact with contaminants	16	(23)
Touching	14	(20)
Measures to prevent harm to self or others	11	(16)
Ordering or arranging	12	(17)
Counting	13	(18)
Hoarding or collecting rituals	8	(11)
Rituals of cleaning household or inanimate objects	4	(6)
Miscellaneous rituals (such as writing, moving, speaking)	18	(26)

[a]The most frequent obsessions and compulsions among 70 children and adolescents who were diagnosed as having OCD by the author and her colleagues at the National Institute of Mental Health. The proportions total more than 100 percent because many sufferers have more than one symptom.

SOURCE: J.L. Rapoport, "The Biology of Obsessions and Compulsions," *Scientific American* 260(3):83-89, 1990.

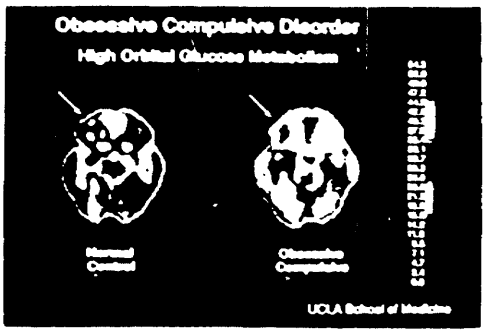
rapidly; in just a few minutes an extreme sense of fear overtakes an individual, his or her heart begins racing, the individual begins to perspire, sometimes profusely, and he or she has trouble breathing. A single attack is short-lived, lasting 20 minutes to an hour, on average. These symptoms often leave a person believing that he or she is suffering from a heart attack or is losing his or her mind. In fact, many individuals with panic disorder seek general medical care at an increased rate. Panic attacks occur, on average, about two times a week, although the frequency varies considerably among individuals. People with panic disorder often exhibit other disorders as well. They may fear being in a public place from which escape is difficult—agoraphobia. Depression and substance abuse are also common among individuals with panic disorder.

Data show that approximately one to two persons in every hundred will develop panic disorder during their lifetimes, with women being twice as likely as men to develop the disorder. The disorder usually first appears during young adulthood, with an average age of onset of 24 years. Data suggest that many patients suffer chronically from this condition.

Panic disorder is treated with medication and/or psychotherapy. Antidepressant drugs and antianxiety agents, such as the benzodiazepine alprazolam, are used with some effectiveness in panic disorder; behavioral or cognitive therapy may prove useful in diminishing the severity or frequency, or both, of panic attacks.

There are several psychological and biological theories about the origin of panic disorder. For example, one cognitive theory posits that individuals may misinterpret normal physiological changes, such as an increase in heart rate, as dangerous, thus inducing anxiety and precipitating a panic attack. Several observations are consistent with a role for biological factors in panic disorder. Data from

Figure 1-6—PET Scan of an Individual With Obsessive-Compulsive Disorder



Brain activity in the brain of a person with OCD (right) and the brain of a person without OCD (left). In OCD, there is increased activity in a region of the brain called the frontal cortex.

SOURCE: L. Baxter, UCLA Center for Health Sciences, Los Angeles, CA.

genetic studies indicate that panic disorder may, in part, be inherited. The action of antianxiety medications has led to hypotheses that naturally occurring anxiety-provoking chemicals underlie panic disorder or, conversely, that a deficit of natural anxiety-blockers is at the root of the disorder. To date, however, no such substances have been identified. Research data have also implicated a particular region of the brain, the limbic system, in anxiety and possibly panic disorder.

Whatever the cause, several lines of evidence point to the role of a particular brain region (the locus ceruleus) and a specific chemical (norepinephrine) in mediating panic attacks. Antidepressant drugs, which act on norepinephrine, are an effective treatment for panic disorder. Various drugs and other substances that stimulate the locus ceruleus and increase norepinephrine production can also trigger panic attacks. Continuing research is aimed at clarifying what role the locus ceruleus plays in panic disorder, how it might relate to the limbic system (which is involved in anxiety), and what other chemicals and regions of the brain may be involved.

A SYNTHESIS: UNDERSTANDING THE ROLE OF BIOLOGY

What can we conclude about the role of biology in mental disorders? In its review of research, OTA found the following evidence that biological factors are involved in schizophrenia, bipolar disorder, major depression, OCD, and panic disorder:

- Medications can suppress symptoms associated with these disorders.
- Specific mental disorders can often be typified by distinguishable clinical features, such as age of onset, symptoms, and course.
- These disorders may have associated "physical" symptoms, such as altered sleep patterns in depression.
- Known physical agents and drugs can produce some symptoms of mental disorders, demonstrating that biological factors can in fact be causative.
- Genetic studies show that the disorders are influenced by inheritance.
- Other areas of research provide evidence about correlated biological factors and suggest testable hypotheses as to causation.

Some researchers and advocates conclude from this evidence that biological factors are the predominant cause of severe mental disorders and that the medical model is the best way to conceive of them. In contrast, others deplore the talk of "brain disease," citing the incomplete state of our knowledge about what causes these conditions and even how best to categorize them. The majority of experts and interested parties—and OTA—recognize that research data increasingly show that biological factors play an important role in these disorders. Furthermore, OTA concludes that advances in biological research will serve as the linchpin in improving our understanding of these conditions.

Biological research has not ruled out a role for psychosocial factors in the mental disorders considered in this report. In fact, it is clear that mental disorders cannot be understood or treated in biological terms only. Nor does biological research necessarily implicate biological treatments. Environment, education, and culture exert powerful influences, and psychological interventions are important for treatment. Experts increasingly recognize the essential error of discussions that pit biology against psychosocial factors: The two are obviously and inextricably interrelated. Sorting out their relative roles and how they interact in different conditions will be critical for the development of research and treatment strategies.

Many questions remain about the biology of mental disorders. In fact, research has yet to identify

specific biological causes for any of these disorders. Why do we not know more about the biological causes and correlates of these conditions? One reason stems from the complexity of these disorders and the difficulty of categorizing them. Individuals often exhibit symptoms that reach across categories of disorders. And a single diagnostic category may encompass multiple conditions. Furthermore, we do not completely understand the relationship among different disorders.

Another reason is our incomplete understanding of the brain. The brain and behavior are immensely complicated, and our knowledge of them is still scant in comparison to what we have yet to learn. With advancing knowledge about the brain, more sophisticated hypotheses about mental disorders—involving how the many chemicals in the brain work, and how nerve cells and discrete regions of the brain interact—will be propounded. Given our nascent understanding of the brain, it will be necessary to stay the course in what is likely to be a slow unveiling of the biology of mental disorders.

The search for specific genes involved in mental disorders has also proven a difficult task. Attempts to locate specific genes have alternately produced acclaimed reports of success and contradictory data followed by the withdrawal of results. While these events impugn the theory of a simple relationship between one gene and a particular mental disorder, they do not rule out the need for further genetic studies: Evidence from many sources clearly indicates that mental disorders have a genetic component. Nor do past problems necessarily rule out the action of a major gene in the development of a mental disorder, at least in some cases. Like the investigations of other common diseases with complex genetics (e.g., Alzheimer's disease, diabetes mellitus), future studies must take into account the complicated pattern of inheritance, the likely role of more than one gene operating within different families and individuals, questions as to what is inherited, and the undeniable role of nongenetic factors.

THE RESEARCH ENTERPRISE

The pursuit of knowledge about the biological aspects of mental disorders rests upon an adequate research capacity, which in turn is subserved by a complex enterprise that makes funds available, sets research priorities, attends to relevant ethical and policy issues, outfits researchers with equipment and other resource needs, and provides for education and training. The answers to three questions shed light on factors that influence this research enterprise: What level of public concern motivates research into mental disorders? What is the level of research support? What factors form barriers to research?

What Level of Public Concern Motivates Research Into Mental Disorders?

Several studies and mental health advocates have claimed that research into mental disorders is underfunded, attributing the deficiency to the low priority assigned to these conditions by the public and policymakers. This assertion stems from three observations: 1) the Federal investment, as reflected in the NIMH budgets, declined significantly between the late 1960s and early 1980s; 2) Federal support for research on mental disorders is comparatively less than its support of other areas of health research; and 3) there are limited nonFederal sources of funding, especially from private foundations.

A seminal report from the Institute of Medicine concluded in 1984 that the:

> . . . real buying power of research funding for mental disorders has dropped sharply during the past 15 years, even as available personnel and basic knowledge about brain function have expanded dramatically.[3]

OTA evaluated the NIMH research budget since 1980, to gauge recent Federal support (figure 1-7). Between 1980 and 1992,[4] NIMH funding of research, including funding of extramural basic and clinical research, intramural research, and research training, increased by 6.7 percent annually.[5] The rate of growth from 1986 to 1992 was substantially higher, at 11.5 percent.[6]

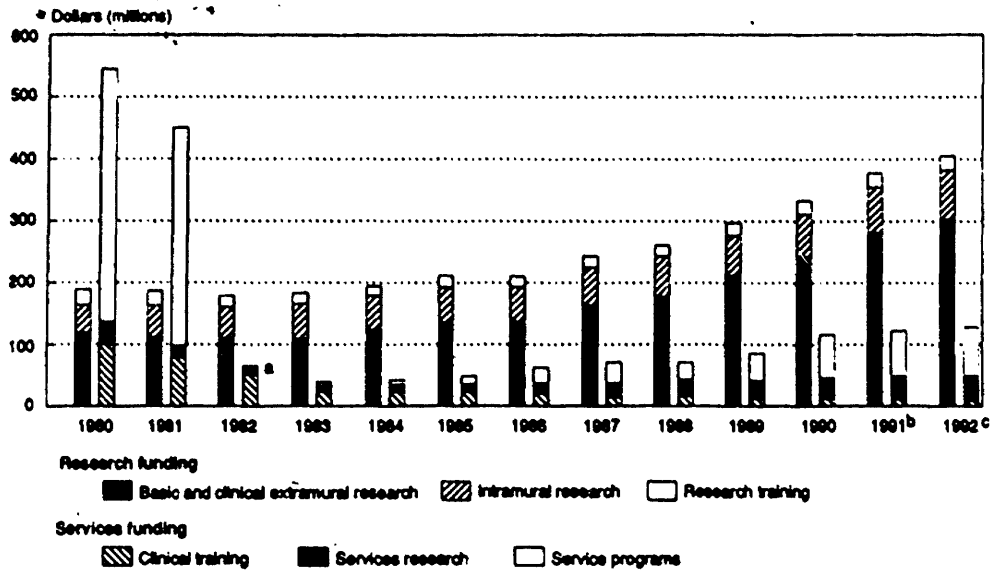
[3] Institute of Medicine, *Research on Mental Illness and Addictive Disorders: Progress and Prospects* (Washington, DC: National Academy Press, 1984)

[4] Fiscal years are indicated.

[5] This is the average annual real rate of increase, determined by converting the NIMH budget in current dollars into constant 1987 dollars, using the gross domestic product deflator as the price index.

[6] Based on estimates, the increase in NIMH's research budget slowed to 7.7 percent between 1991 and 1992.

Figure 1-7—NIMH Budget, Fiscal Years 1980-92



Funding of the components of the research and services budgets of NIMH.

NOTE: Figures converted to constant 1987 dollars using the 1992 gross domestic product deflator.
[a]Decrease reflects inflation of State block grants.
[b]1991 and 1992 figures are estimates.
[c]1992 figures based on assumption of constant price index.
SOURCE: Office of Technology Assessment from figures supplied by National Institute of Mental Health, 1992.

Despite the increases, various measures indicate that during the 1980s the relative investment in research on mental disorders was considerably less than that for other diseases. OTA compared the relative support for research to the total costs of mental disorders, cancer, and heart disease (table 1-3).[7] For every $100 of costs imposed by mental disorders, $0.30 was spent on research. In comparison, for every $100 of costs of heart disease and cancer, $0.73 and $1.63, respectively, were spent on research. It is of interest to note, however, that the Federal Government's purchasing power for mental disorders research increased faster in the 1980s than did its purchasing power for cancer research.

Previous studies have also called attention to the historic neglect of research into mental disorders by private foundations and voluntary health agencies, which currently form a relatively small, but important source of support for biomedical research. The 1980s did witness new sources of private support for research into the biology of severe mental disorders, with the formation of the National Alliance for Research on Schizophrenia and Depression (NARSAD) in 1986 and the establishment of the National Alliance for the Mentally Ill's (NAMI's) Stanley Awards Program. Still, support from such organizations for mental disorder-related research stands at a much lower level than private foundation support for other diseases. For example, in fiscal year 1991, the American Cancer Society spent nearly $91 million dollars on research, compared to NARSAD's $3.3 million.

What can we conclude about the level of public concern that surrounds mental disorders, as meas-

[7]The analysis used the most comparable and recent data, which stemmed from 1985.

Table 1-3—Comparison of Costs and Research Funding, Fiscal Year 1985

Illness	Costs[a] ($ millions)	Total budget of principal Federal institution[b] ($ millions)	Dollars spent on research per $100 of cost to society
Mental disorders	103,691[c]	310[d]	0.30
Cancer (malignant neoplasms only)	72,494	1,184	1.63
Heart disease	69,000	501	0.73

[a]D.P. Rice, S. Kelman, L.S. Miller, et al., *The Economic Costs of Alcohol and Drug Abuse and Mental Illness: 1985*, report submitted to the Office of Financing and Coverage Policy, Alcohol, Drug Abuse, and Mental Health Administration, U.S. Department of Health and Human Services (San Francisco, CA: Institute for Health and Aging, University of California, 1990); D.P. Rice, T.A. Hodgson, and F. Capell, "The Economic Burden of Cancer, 1985: United States and California," *Cancer Care and Cost. DRGs and Beyond*, R.M. Scheffler and N.C. Andrews (eds.) (Ann Arbor, MI: Health Administration Press Perspectives, 1989); T. Thom, Health Statistician, Division of Epidemiology and Clinical Application, National Heart, Lung, and Blood Institute, National Institutes of Health, personal communication, 1991.

[b]National Institute of Mental Health, National Cancer Institute, and National Heart, Lung, and Blood Institute budgets.

[c]Costs of mental disorders include costs of dementia.

[d]Figure includes $29 million for funding of dementia research by the National Institute on Aging.

SOURCE: Office of Technology Assessment, 1992.

ured by research support? As others have noted, the historical lack of support for this research was reversed somewhat in the 1980s: Federal funding for research into mental disorders increased significantly, and new private sources of funding developed. Even with the increased funding of the 1980s, however, support for research into mental disorders falls short of that for other conditions in relation to their cost to society.

What Is the Level of Research Support?

How much of NIMH's increasing funding goes to support the areas of research considered in this report? OTA examined extramural research funding in two major divisions of NIMH: the Division of Basic Brain and Behavioral Sciences (DBBBS) and the Division of Clinical Research (DCR). In 1991, these divisions accounted for 74 percent of the extramural research budget—some $287.2 million.

As indicated by its name, DBBBS supports basic research aimed at furthering the understanding of basic brain mechanisms and behavior related to mental disorders. Over the last few years, DBBBS has received increasing support, with its research budget reaching $117.6 million in 1991 (figure 1-8). Specific areas of neuroscience, including molecular and cellular biology, cognitive neuroscience, neuroimaging, and psychopharmacology research, have been particularly favored. The annual rate of increase in its budget was 14.5 percent between 1988 and 1992.

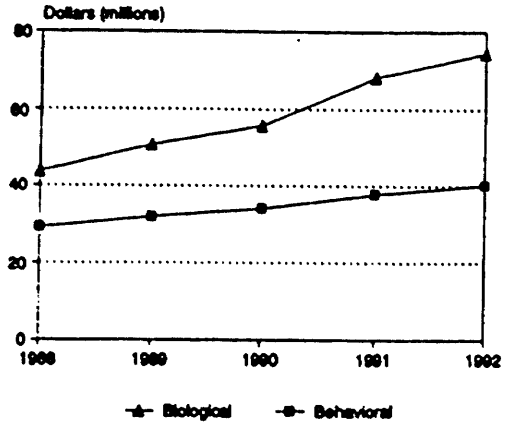
DCR consists of six research-oriented branches; its total research budget in 1991 was $169.6 million. Two branches—the Schizophrenia Research Branch and the Mood, Anxiety, and Personality Disorders Research Branch—target the disorders considered in this report and receive 50.3 percent of DCR's research budget. Between 1986 and 1992, both of these branches experienced above average funding increases (figure 1-9). The DCR's emphasis on schizophrenia and mood disorders is further reflected in the fact that 16 of its 23 research centers focus on these disorders.

What Factors Create Barriers to Research?

Funding is not the sole determinant of research capacity. Various other factors, ranging from the availability of animals to the number of trained researchers, influence the success of the research enterprise. OTA has identified several areas that, if neglected, can create barriers to research.

Several issues common to all biomedical research come to bear on research into mental disorders. For instance, support for facilities and equipment affects mental disorders research. Efforts to contain healthcare costs also affect clinical research, since third-party payers typically cover the costs of clinical care in research. Another general issue for mental disorders research centers around the representation of all members of society in research, regardless of age, sex, race, or ethnic group; concerns about fairness and the ultimate implications for health and the advancement of knowledge have driven congressional and executive branch action. Finally, because the use of animals, especially nonhuman primates, is critical for neuroscience and research into mental

Figure 1-8—Funding of the Division of Basic Brain and Behavioral Sciences, Fiscal Years 1988-92



The funding of the Division of Basic Brain and Behavioral Sciences broken down into biological and behavioral research (see text).

NOTE: Figures converted to constant 1987 dollars using the 1992 gross domestic product deflator.

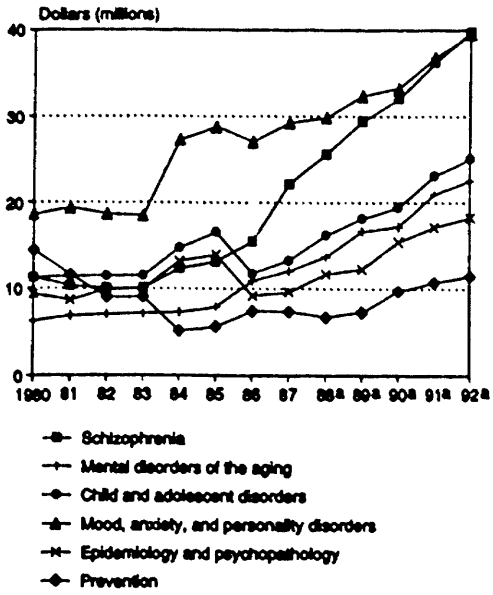
SOURCE: Office of Technology Assessment from figures supplied by National Institute of Mental Health, 1992.

disorders, developments concerning the use of animals in research, including tightening regulations and increased cost, raise concern.

The fact that mental disorders disrupt human cognitive, emotional, and social capabilities presents special challenges for researchers. For example, how can these complicated effects be studied or modeled in animals? Also, the unique nature of mental disorders raises ethical concerns in clinical research, requiring a careful balancing of individuals' needs and interests and the need for continued research. While these issues cannot be eliminated, investigators can devise ways of dealing with them effectively. Finally, the stigma attached to and the ignorance surrounding mental disorders influence research in a variety of ways, from hindering recruitment of subjects to amplifying privacy concerns.

OTA considered, in some detail, three issues identified as significant obstacles to research on mental disorders: the difficulty of obtaining postmortem brain tissue, the cost of hospitalization, and the number of clinician-researchers.

Figure 1-9—Funding of the Division of Clinical Research, Fiscal Years 1980-92



Funding of the six research branches of the Division of Clinical Research.

NOTE: Figures converted to constant 1987 dollars using the 1992 gross domestic product deflator.

[a]Figures include research training.

SOURCE: Office of Technology Assessment from figures supplied by National Institute of Mental Health, 1992.

The expansion of biological research into mental disorders makes the availability of postmortem brain tissue increasingly important. While there are two federally sponsored brain bank centers in the United States, as well as an informal supply, the amount of tissue available for research is simply inadequate. Improving the banking of brains requires consideration of several factors: funding, standardization of tissue retrieval and handling methods, attracting tissue donors, the need for complete medical histories, and safeguarding confidentiality. In an effort to improve the acquisition process and to better disseminate information about the availability of sources of brain tissue from various centers, NIMH has created a task force to make recommendations on how to coordinate these efforts. A number of suggestions are under consideration, including the use of a private institution under contract to NIMH

as a clearinghouse for the collection and distribution of brain tissue. The NIMH task force is also identifying other needs related to the collection of brains for research. These include designing systems to address the problem of the limited samples of tissue available from persons with specific disorders, and the pressing need for tissue from normal individuals that can be used as experimental controls.

Studies of subjects who have mental disorders and who are not taking medications are critical in investigating the underlying biology of a disorder and in establishing the effectiveness of new treatments. While several issues influence this research, the cost of care for medication-free research subjects—who generally require hospitalization—is a major obstacle to clinical research. The cost of each hospital day can range from $300 to over $1,000; thus, the cost of supporting a single research bed for a year can range from $109,500 to $365,000. NIMH funding can be used to support bed costs, but generally this is not a realistic option, since it would divert an enormous proportion of funds from other research activities.

Many experts and organizations have drawn attention to the apparent shortage of clinician-researchers—namely, psychiatrists and psychologists—in the United States. Recently, NIMH convened a task force to make specific recommendations about the recruitment of investigators into clinical research careers. While the need for clinician-researchers is not peculiar to mental health research, some factors make the situation particularly acute in this field. Few students in mental health professional training programs receive formal exposure to research. And financial issues, including expected salary levels and the need to pay off medical and/or graduate school debts, tend to forestall the choice of a research career.

IMPLICATIONS OF BIOLOGY

Support for neuroscience research, in general and as it is applied to the study of mental disorders, stems from a palpable enthusiasm for advances in understanding the human brain. Support for research into the biology of severe mental disorders is also intimately linked to the hope for improved treatments for these disorders. While treatments exist, they are not effective in all cases, and side effects, some of which are serious, are common. Although a detailed analysis of the development of new treatments lies outside the purview of this report, OTA finds that the development of new drugs to treat mental disorders is one of the greatest promises that biological research holds. History bears out this potential, as does the number of drugs being developed and tested (table 1-4). The increasing and more precise understanding of the action of chemicals in the brain has facilitated and will continue to facilitate the development of new medications for mental disorders. At the same time, important issues that cannot be overlooked—cost, side effects, forced treatment—accompany the development and use of psychoactive medication.

The zeal associated with the current focus on the biology of mental disorders may benefit from some tempering. Scientific advances can lead to better treatment, diagnostic tests, cures, and preventive measures. However, most new treatments will reflect incremental advances: Significant improvements in the understanding and treatment of mental disorders are likely to require years, even decades, to unfold. Some observers have noted that fostering expectations of rapid progress in discerning the biological underpinnings of mental disorders or developing new treatments may provoke impatience, disappointment, or even a backlash against this research. Perhaps most important, exclusive emphasis on biological factors could divert resources from other important areas of research and the provision of care for people currently suffering from these conditions.

Biological research into mental disorders has influenced the mental health care finance debate, as exemplified by recent court cases and State laws. Coverage for mental health care in both the public and private sectors is generally lower than coverage for "physical" illnesses. In order to gain parity in insurance coverage and to help defray the costs of these chronic and often severe disorders, some advocates have emphasized the biological basis of certain mental disorders, thus invoking the traditional medical model of illness as the most appropriate one for treatment. Also, emphasizing the biological basis of a disorder underlines the fact that the disorder is outside the control of the individual and invokes society's perceived responsibility for providing care. Biological research may also help insurers in objectively determining an insurable event, by identifying biological markers for certain mental disorders, along with effective treatments.

Table 1-4—Drugs in Development for Mental Disorders

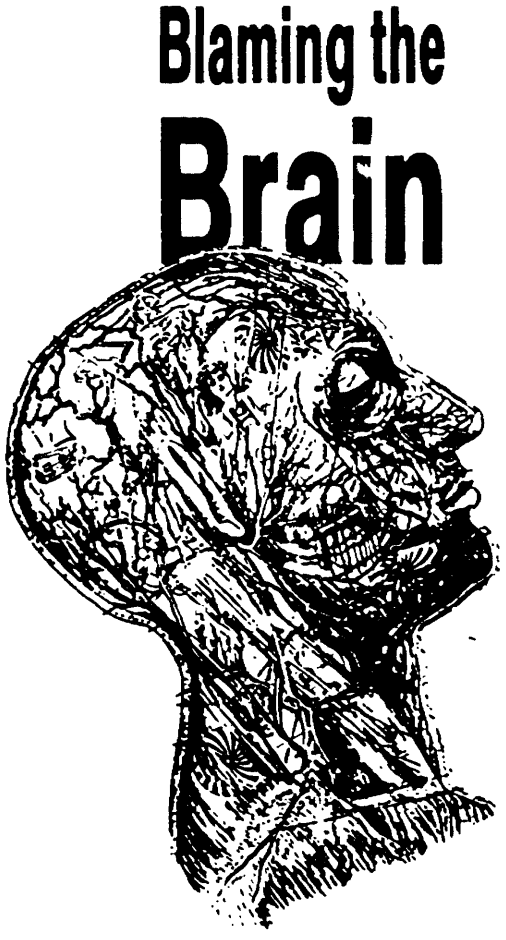
Disorder	United States	Other countries
Schizophrenia	76	42
Mood disorders	83	61
Anxiety disorders	91	46

SOURCE: PJB Publications, *Pharmaprojects* (Surrey, England: PJB Publications, 1992).

Data from research point increasingly to the importance of biological factors in certain mental disorders. This has given rise to other concerns, however, including coverage of "nonbiological" disorders or interventions. Furthermore, there is heightened concern about the cost of health care. Given the public health problem that severe mental disorders present and the complex issues involved in health care finance, the way in which care for persons with these disorders is financed warrants full evaluation.

OTA has identified ways in which information from research into the biology of mental disorders is used to counter the ignorance and negative attitudes that have long been attached to these conditions. Mental disorders have often been and continue to be perceived as a sign of moral or personal weakness. Biological explanations for mental disorders are used to counter the view that these conditions are based in moral turpitude, thus exculpating individuals whose disorders may lead to unusual, erratic, or frightening behavior. Also, the assertion that biological factors contribute to the development of mental disorders refutes the once-reigning and stigmatizing notion that bad parenting is the essential, causative factor. Despite the fact that little or no scientific evidence supports theories of bad parenting as a sufficient or necessary cause of severe mental disorders considered in this report, these theories continue to shape the attitudes of the public and even some experts.

The increased emphasis on biological aspects of mental disorders, while helpful in dismantling some negative attitudes, is not without limitations. Perceptions of what causes mental disorders are not the sole source of stigma; other factors, such as personal experiences and media portrayals (box 1-D), influence public attitudes as well. Also, with the increased publicity given biological research data, questions and worries may arise among individuals with mental disorders and their families. For example, many family members who have heard about genetic studies of mental disorders may overestimate their risk for these conditions. Furthermore, the perception that mental disorders are inherited could instill guilt among parents, who fear they might transmit "flaws" to their progeny. While our current understanding of the genetics of mental disorders makes unlikely the development of a single, highly



Credit: Illustration by Robin Applestein, reprinted by permission of R. Applestein and The Washington Times.

Findings that biological factors underpin certain mental disorders help relieve individuals and their families from feelings of guilt.

Box 1-D—Media Portrayals of Mental Disorders

Since the late 1950s and early 1960s, studies have consistently revealed a high incidence of media attention to mental disorders. While media attention contributed significantly to the end of mass warehousing of patients, often in cruel conditions, much of the information it provided about mental disorders was negative and inaccurate. Recent studies have shown that although there has been an increase in the frequency of portrayals of individuals with mental disorders, there has not necessarily been an increase in the accuracy of such portrayals. Surveys of images of mental disorders on prime-time television conducted in the 1980s found that between 17 and 29 percent of the shows had some portrayal of mental disorders. Unfortunately, much of that information concerning mental disorders is inaccurate and stigmatizing.

One of the most persistent and damaging inaccuracies conveyed by the media is the characterization of individuals with severe mental disorders as violent despite the fact that individuals with severe mental disorders are more likely to be withdrawn and frightened than violent and are more frequently victims than perpetrators of violent acts. Violence occurs on television at the rate of approximately six incidents per hour in prime time and 25 incidents per hour in children's daytime programming; a disproportionate number of these occurrences are either perpetuated by or against individuals identified as mentally disordered. In fact, characters labeled mentally disordered in television dramas are almost twice as likely as other characters to kill or be killed, to be violent or fall victim to violence. Efforts to combat this image are confounded by the fact that some individuals with mental disorders—particularly when untreated—are at risk of committing violent acts against themselves or others, or both. Perhaps more troubling is the fact that the stigmatizing equation of severe mental disorder with violence is not limited to fictional entertainment media. News stories and headlines identifying violent criminals on the basis of their mental health history, such as the recent Associated Press headline "Woman Who Shot at Restaurant Previously Committed to Mental Hospital," saturate the news media, while stories of successful recovery are rare. Such news stories are damaging to individuals with mental disorders because they suggest both an inescapable connection between mental disorders and violence and the incurability of mental disorder (that is, even *former*, treated mental patients remain prone to violence).

Do these inaccurate and negative depictions of individuals with mental disorders adversely affect public attitudes? Research has shown that television is able to influence viewers' attitudes in subtle ways, through the repetition of images not necessarily labeled as factual. Knowledge specifically concerning the impact of media depictions of mental disorders on public opinions is limited. Some studies have revealed that programming intended to increase knowledge of and improve attitudes toward individuals with mental disorders has a positive impact. However, data indicate that the damaging effects of negative portrayals overwhelm the benefits of the media's positive efforts. Negative mass media portrayals of persons with mental disorders generate negative attitudes among viewers, and corrective information, or disclaimers, has been shown to be largely ineffectual.

Advocacy groups are working to reduce inaccurate and stigmatizing depictions of individuals with mental disorders in the mass media. For example, the Alliance for the Mentally Ill of New York State operates a Stigma Clearinghouse that records and responds to inaccurate or stigmatizing media depictions of individuals with mental disorders, and the National Alliance for the Mentally Ill may soon launch a similar program nationwide. In addition, the Carter Center in Atlanta, Georgia, has held two conferences addressing the problems of stigma and mental disorders and the role of the mass media and has subsequently launched a media initiative to address these issues.

SOURCES: *Stigma and the Mentally Ill. Proceedings of the First International Rosalynn Carter Symposium on Mental Health Policy*, Nov. 15, 1985 (Atlanta, GA: Carter Center, 1985); L.R. Marcos, "Media Power and Public Mental Health Policy," *American Journal of Psychiatry* 146:1185-1189, 1989; A. Mayer and D. Barry, "Working With the Media To Destigmatize Mental Illness," *Hospital and Community Psychiatry* 43:77-78, 1992; Robert Wood Johnson Foundation, Program on Chronic Mental Illness, "Public Attitudes Toward People With Chronic Mental Illness," April 1990; O. Wahl, "Mental Illness in the Media: An Unhealthy Condition," *The Community Imperative*, R.C. Baron, L.D. Rutman, and B. Kliczynska (eds.) (Philadelphia, PA: Horizon House Institute, 1980); O. Wahl, Professor, George Mason University, personal communication, February 1992; O. Wahl and J.Y. Lefkowitz, "Impact of a Television Film on Attitudes Toward Mental Illness," *American Journal of Community Psychology* 17(4) 521-528, 1989; O. Wahl and R. Roth, "Television Images of Mental Illness: Results of a Metropolitan Washington Media Watch," *Journal of Broadcasting* 28:599-605, 1982.

predictive genetic test that would be useful across the general population, the future possibility of genetic testing—even the perception that mental disorders are inherited—raises additional concerns about possible discrimination.

Biological data also may be simplified or misinterpreted. Attributing behavior to biological, especially genetic, factors may lead to the perception that human actions are predetermined. Thus, biological explanations of behavior encroach uncomfortably on our sense of free will and moral agency. Furthermore, some observers fear that biological theories of mental functions reduce human behavior to the output of the gray mass in our craniums, thus robbing human thought and emotion of meaning and import. Individuals with mental disorders may be especially vulnerable in a society seduced by notions of biological determinism and reductionism; in this case, not only are mental functions just the reflection of brain function, but the brain function is diseased. The meaning attached to a person's thoughts and actions, and the extent to which he or she is responsible for them, are complex issues requiring the consideration of biological as well as social, philosophical, legal, and moral issues, which are beyond the scope of this report. Nevertheless, it is important to debunk some of the myths that surround these issues. Biological theories of causation are not necessarily more damaging to the person afflicted with a mental disorder than other theories; one need only be reminded of the cruel and stigmatizing concepts of family causation. Nor is it true that a biological underpinning is immutable and an environmental one malleable. Recent advances in neuroscience do not suggest that our brains are biologically fixed; rather, results increasingly show the dynamic nature of nervous tissue and its responsiveness to environmental cues throughout life.

POLICY ISSUES AND OPTIONS FOR CONGRESSIONAL ACTION

The findings of this study attest to the recent growth of the neurosciences and to a corresponding surge of interest in the biology of mental disorders. Researchers have partially uncovered the biological substrates of some mental disorders and have propounded testable hypotheses about causes. The upshot of the scientific advances is expanded research opportunities, potential treatments, and new questions regarding how this knowledge is used. The potential consequences of biological research into mental disorders raise several policy issues of congressional interest:

- Federal support for research,
- implications of scientific advances, and
- dissemination of new information.

The following section covers each of these policy issues and sets forth several options for congressional action. Some options require direct congressional action, while others involve indirect efforts, such as oversight or direction of the executive branch. OTA has fashioned a list of reasonable responses to the policy issues that emerged during the course of this study. No priority is set nor course recommended; rather, an analysis of each option and its likely result is presented.

ISSUE 1: Federal Support for Research

Congress is faced with the question, *How should we support research on mental disorders?* The most important congressional response to this question is given annually, in the allocation to NIMH; several observations and results from this study may assist Congress with its funding decision.

Option 1: Support research at NIMH.

It is no exaggeration to state that advances in neuroscience have revolutionized the study of mental disorders. While the causes of mental disorders remain unknown, data from various and diverse studies illuminate the role of biological factors in schizophrenia, bipolar disorder, major depression, OCD, and panic disorder. Furthermore, the intense efforts and rapid progress in neuroscience portend increased knowledge about these disorders in the years to come. New technologies enable scientists to probe more thoroughly everything from the tiniest molecules to the interaction of large collections of nerve cells, giving us insights into the more than 100 billion nerve cells that together make up the brain. This confluence of technological advances, rapidly accruing knowledge in the neurosciences, and considerable excitement among researchers calls for, at the very least, a sustained level of funding for biological research into mental disorders; undoubtedly, this research enterprise could effectively use even higher levels of funding. To reduce funding would be to ignore the opportunities that exist at this time, thus failing to capitalize on the investment and gains to date.

While this report does not detail the research and development of specific treatments for mental disorders, OTA finds that one of the greatest promises of research into the biology of mental disorders is the development of more effective medications. The need for and promise of better medications also argue for continued or enhanced funding. New drugs resulting from the investment in research could more than pay for their development costs by offsetting some of the tremendous burden now borne by society. For example, it is estimated that the 1969 introduction of lithium to treat bipolar disorder resulted in average yearly savings in treatment costs of $290 million in the United States. It was also estimated that $92 million in lost wages was regained in the first year following the introduction of lithium. It is important to note, however, that the translation of new scientific findings into new treatments will probably take place over a period of years, if not decades. Therefore, this must be viewed as a long-term investment.

Although the social burden of mental disorders is difficult to compare with that of other types of illness, it is generally of the same magnitude as cancer and heart disease. Mental disorders lead to considerable suffering, disability, and death. These conditions take a large toll on society, afflicting millions of Americans and costing the nation more than $100 billion each year. Yet based on the costs of the disorders, research spending for mental disorders is lower than that for cancer or heart disease. Increased allocation of funds for mental disorders research would redress this inequity in funding and demonstrate the priority given to mental disorders by the Federal Government. The relative cost of a health problem cannot be the sole determinant of research funding; however, together with the fact that significant research opportunities exist in this field, it serves as a strong argument for increased funds.

It is apparent that several factors argue for continued, if not increased, funding of mental disorders research, but Congress must weigh the relative importance and need for this investment of Federal dollars against a host of competing programs. It is also important to note that additional funding would certainly enable researchers to pursue more scientific opportunities and would yield fruitful gains, but it would also enlarge the system and increase the number of deserving competitors for Federal support. Scientific research budgets, including that of the NIMH, have fared well during the past years of fiscal constraints; however, the growing Federal debt and mechanisms enacted to address it have sharpened the competition among federally financed programs. While a main conclusion of this report is that continued support for research into the biology of mental disorders is necessary in order to reap the potential benefits, this study did not assess the state of knowledge, relative promise, or warranted priority of other programs or fields of inquiry.

Whatever the level of support for mental disorders research, it is critical that funding go to the highest quality research. Given the state of knowledge and existing research opportunities, how are Federal monies best invested, with the highest likelihood of return? OTA finds that maintaining a broad portfolio of research is the key. Continued investment in basic research is central to this effort, given the rudimentary, if rapidly growing, state of our knowledge concerning the brain and its functioning. Basic neuroscience research will produce more sophisticated hypotheses and methods of analysis, which are essential to understanding the complex manifestations of mental disorders.

Disorder-targeted funding is also necessary. This report notes many areas that are prime for research and that are likely to improve public health. Various viable hypotheses have been put forth concerning the causes of mental disorders, but further information is needed concerning the specific manifestations of these conditions and their pattern of inheritance. Advances in molecular biology and imaging technologies make possible more detailed examination of brain function and structure in these disorders.

Support for disorder-targeted research encompasses clinical studies. Congressional support for clinical research can be shown in various ways, among them additional funding for NIMH. The options that follow are also means of supporting clinical research.

Option 2: Support clinical research by the VA.

Since the costs of medical care in clinical investigations at VA hospitals are charged to health care delivery funds rather than research dollars, a modest increase in research appropriations could significantly increase clinical research. Thus, Congress could enhance clinical research by increasing the VA's research budget. Furthermore, to foster

mental disorders research, Congress could direct the VA to move forward on a recommendation from the VA Advisory Committee for Health Research Policy, which recommended the creation of a Health Research Advisory Council to identify and prioritize those areas with the greatest promise of enhancing VA health care. The council could be a useful mechanism for redressing the disparity between VA medical research expenditures for mental disorders and their clinical costs.

Option 3: Convene a task force to delineate mechanisms for underwriting bed costs.

Rapidly rising bed costs threaten clinical studies, which often require hospitalization of subjects during trials, as well as other persons who are free of medication. Bed costs can be included in the NIMH funding made available to the Clinical Research Centers. Yet few center directors choose to use funds in this fashion, since it would divert an enormous proportion of their total funding away from other priorities. The pharmaceutical industry has recently recognized the obstacle created by increasing bed costs; and while some companies have begun providing support, it is difficult to document the extent of such support. NIMH has not taken any direct action in regard to bed costs. In the absence of congressional action, it is unclear whether NIMH will address this issue. Thus, this acute need may go unmet.

Some virtually untapped resources exist to help defray the expense of bed costs in clinical research. In an effort to deal with the issue of bed costs, Congress could direct that a task force be established. The task force could include representatives of all parties who have a stake in this research and who can contribute to the solution: clinical investigators, NIMH, health insurance companies, private foundations, advocacy groups, pharmaceutical companies, State mental hospitals, the VA hospital system, and general and private hospitals. While it might be difficult for the many different parties involved to form a consensus, together they could devise a workable plan that would take advantage of existing and unutilized resources (e.g., VA hospitals, State hospitals). In addition to considering cost issues, the task force could explore research approaches that might be less expensive (e.g., day hospitals and partial-care centers). NIMH can be directed to follow the findings and recommendations of the task force.

Option 4: Fund the training of clinician-researchers.

The limited availability of researchers trained as clinicians has a continuing impact on the quality and quantity of clinical research. Professionals and policymakers acknowledge this problem, and NIMH is poised to address it by enhancing exposure to research for psychiatrists and psychologists during training. Support for research centers, which bring together clinicians and researchers with various skills to work together on research projects, also addresses the need for the clinician's expertise in studies.

Congress could, however, further respond to the need for clinician-researchers. Congress established the National Research Service Awards (NRSA) to provide for the training of clinician-researchers, but its appropriations for NRSA have not increased in the last 12 years. When adjusted for inflation, the 1991 training budget of $26.9 million is $2 million less than the 1980 budget. Increasing total funding and increases in the maximum salary for individual investigators could make this program more effective. Earmarked funds could also be directed to Research Career Awards and Scientist Development Award for Clinicians programs, which are generally considered successful, although underfunded. Simply providing additional training funds is not the whole solution, or even the most efficient mechanism for dealing with the problem. For example, forgiveness of medical school debt would be a powerful incentive. Congress may, therefore, want to link increased funds to such programmatic issues.

ISSUE 2: Implications of Scientific Advances

Advances in biomedical research during the latter part of the 20th century have raised new and difficult ethical, legal, and social questions; research into the biology of mental disorders is no different. In this study, OTA considered issues raised both by the conduct of research and by new findings.

Issues of informed consent and confidentiality inevitably emerge during the conduct of mental disorders research. While these issues are neither new nor entirely unique to the study of mental disorders, there are special concerns deriving from the nature of mental illness, its impact on the mind, and the associated stigma. Furthermore, scientific advances may add a new twist to these issues. For example, the process of gathering clinical informa-

tion for genetic studies poses questions about what to tell relatives of individuals with mental disorders who are contacted for this research. Existing guidelines specify that an Institutional Review Board (IRB) review the medical, legal, and ethical aspects of proposed research projects that will involve human subjects.

The results of research into the biology of mental disorders also have ethical, legal, and social implications. For example, findings concerning the biology of mental disorders have become an issue in the mental health care financing debate. The development of new medication interfaces with ongoing concerns about the right to refuse treatment. Increased understanding of the genetics of mental disorders raises the specter of a new age of discrimination against individuals with mental disorders (box 1-E). Advances in brain research challenge our very conceptualization of the human mind, affecting such issues as personal responsibility and free will. Researchers, clinicians, advocates, policymakers, ethicists, and lawyers have addressed some of the implications of research findings. However, NIMH pays little formal attention to the ethical, legal, and social implications of the results of the research they sponsor.

Option 1: Direct NIMH to formalize consideration of ethical, legal, and social issues.

Congress could stipulate that NIMH devise a systematic plan to deal with the ethical, legal, and social implications of both the conduct and the results of mental disorders research. By mandating such a program and providing funds for it, Congress would draw attention to these issues and create a process of anticipating the social impact of research results. The structure of a program devoted to such issues could take various forms. It could be modeled after the National Institutes of Health-Department of Energy program that considers such implications of the Human Genome Project: the Ethical, Legal, and Social Implications, or ELSI, program. Like the ELSI program, it might fund research into the likely implications and conduct of biological research into mental disorders. The NIMH program would foster the development of knowledge upon which consideration of these issues can be based and would increase the number of professionals with expertise in this area.

Such a program is not without potential problems. Forecasting the impact of scientific advances is difficult. Also, without a specific focus and a specific charge, the program might be ineffectual. The ethical, legal, and social issues raised by research are complex and sometimes emotionally charged; they lie at the interface of scientific knowledge and social values and beliefs. Forming a consensus about these complex and sensitive issues is often hard, if not impossible. The resolution of these issues may be more properly dealt with, in a democratic society, by a political process such as in the U.S. Congress rather than an academic or bureaucratic one.

Option 2: Request topic-specific studies as issues arise.

Rather than erecting a bureaucratic structure to handle the ethical, legal, and social implications of research, Congress could request individual studies from various governmental or nongovernmental organizations. This strategy would permit timely identification of topics for consideration, and the issues and charges of the study could be clearly elucidated and circumscribed. While this mechanism would give Congress more direct control over individual studies and would serve to focus the studies, it could lead to a piecemeal approach that does not provide the continuity and comprehensiveness of a permanent program.

Option 3: Establish an advisory commission on the ethical, legal, and social implications of mental disorders research.

Individuals with various backgrounds and expertise who are not normally a formal part of the policymaking process have important insights into the ethical, legal, and social issues raised by mental disorders research. Furthermore, such persons have a stake in how the issues are addressed. In order to tap into the expertise and interests of these groups, Congress could establish an advisory commission to study and make recommendations on aspects of policy related to the implications of mental disorders research sponsored by the Federal Government. Such bodies, including the ongoing Advisory Panel on Alzheimer's Disease, have proven useful.

A successful panel would be composed of distinguished and expert representatives from biomedical research, the social sciences, the legal profession, care-providing professions, law enforcement, consumers, families, and relevant organizations and businesses. It is important that membership on the

Box 1-E—Eugenics and Mental Disorders

In Nazi Germany and the United States during the earlier part of this century, people with mental disorders were among the initial targets of eugenic policies. People with mental disorders were subjected to immigration restrictions, involuntary sterilization, and extermination. While moderns deny that such practices could be repeated, the record of eugenics and its historical link to mental disorders raise uncomfortable questions: Is the new age of genetics a harbinger of a new age of eugenics? Are people with mental disorders especially vulnerable?

Eugenics enjoys a long, well-bred intellectual pedigree, with the cousin of Charles Darwin, Sir Francis Galton, as its modern forefather. Galton coined the term "eugenics" in 1883, christening the scientific pursuit of improved inborn human qualities through judicious matings: positive eugenics. Prior to Galton, eugenic notions can be traced back as far as Plato's *Republic*, wherein the philosopher also proposes positive eugenic practices. Of course, the human genetic pool can be distilled by other means. Negative eugenics refers to the systematic attempt to minimize the passing of deleterious genes by reducing or preventing the reproduction of individuals carrying such genes.

A number of scientific discoveries planted the seeds of eugenic policies in the 19th and 20th centuries. Galton himself observed that many accomplished men of his day were linked by blood lines, which led to his belief that proper matings could produce a race with enhanced intellectual, behavioral, and physical characteristics. In addition, Galton, as well as others, developed statistical techniques that permitted the quantitative analysis of inherited traits.

While these and other scientific advances were the seeds of eugenics, they were not solely responsible for such policies in the United States. Social, political, and economic factors of the late 19th and early 20th centuries fertilized the growth of the eugenics movement. National attention was increasingly focused on social issues of unemployment, criminality, prostitution, and chronic alcoholism. Also, concerns arose that increased immigration from southern and eastern Europe was drawing the United States away from its "Anglo-Saxon superiority."

At the Federal level, eugenic policies took the form of increasingly restrictive immigration laws. Eugenicists, asserting the simple inheritance of such traits as lunacy, epilepsy, alcoholism, pauperism, criminality, and feeblemindedness, proffered scientific rationales for excluding individuals from entry to the United States. It is important to note that while authentic advances in genetics seeded the eugenics movement, they provided no evidence for the simple inheritance of the traits mentioned above.

Eugenic considerations also prompted States to enact laws regarding compulsory sterilization. In 1907, Indiana passed the first law legalizing the compulsory sterilization of inmates at the State reformatory; by 1931, 30 States had passed compulsory sterilization laws applying to individuals categorized as feebleminded, alcoholic, epileptic, sexually deviant, or mentally ill. Individuals with mental disorders made up half of the 64,000 persons in this country sterilized for eugenic reasons between 1907 and 1964. When eugenic sterilization laws were challenged in 1927, the Supreme Court ruled the practice was constitutional.

What is the current status of eugenic policies in the United States? While immigration laws still restrict the entry of people with mental disorders, denial of entry is not based on eugenic principles, but rather on concerns about whether behavior associated with a disorder poses a threat. State sterilization laws still stand, as does the 1927 Supreme Court ruling upholding them. As of 1987, compulsory sterilization laws remained on the books in 22 States; however, these laws are rarely invoked.

The current application of immigration and compulsory sterilization laws suggests that eugenics is not a major concern at this time. Furthermore, the understanding that mental disorders do not have a simple genetic basis and that nongenetic factors play an important role would seem to limit the potential of eugenic policies. Perhaps most important, Americans repulsion by the Nazi legacy and the emphasis in this country on individual reproductive rights also make State-determined eugenic policies unlikely. But indirect pressure not to have children may well come to bear on individuals seen to have a greater genetic risk of mental disorders; society may brand them irresponsible or immoral for transmitting disorders to their children. Given the financial strain posed by mental disorders today and the stigma attached to them, in conjunction with scientific advances, it is possible that these factors could unlock what some call a backdoor to eugenics.

SOURCES: T. Duster, *Backdoor to Eugenics* (New York, NY: Routledge, 1990); K.L. Garver and B. Garver, "Eugenics: Past, Present, and Future," *American Journal of Human Genetics* 49:1109-1118, 1991; I.I. Gottesman, *Schizophrenia Genesis: The Origins of Madness* (New York, NY: W.H. Freeman, 1991); D.J. Kevles, *In the Name of Eugenics* (New York, NY: Knopf, 1985); D. Suzuki and P. Knudtson, *Genethics: The Clash Between the New Genetics and Human Values* (Cambridge, MA: Harvard University Press, 1989); N.A. Holtzman, *Proceed with Caution: Predicting Genetic Risks in the Recombinant DNA Era* (Baltimore, MD: The Johns Hopkins University Press, 1989).

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commission be balanced in terms of the points of view represented, something rarely achieved in mental health policy. This advisory commission could be established by the Secretary of Health and Human Services, or Congress itself, and could be assigned specific issues to address every year or two. The commission could then study the issue, identify the problems of concern, develop a consensus on how such problems can best be met, and present recommendations for legislation to the Congress and the States; the commission could also recommend executive branch regulations, activities, and other programs.

ISSUE 3: Dissemination of New Information

The Federal Government does not support research into the biology of mental disorders merely to gain new knowledge. Rather, Federal funds for this research reflect in large measure a desire for improved medications as well as for improved public perceptions of mental disorders and of individuals with these disorders.

The enthusiasm for and considerable gains in information about the brain and mental disorders that have accrued during the last several years speak to the potential gains in treatment and social handling of persons with mental disorders. However, to effect better treatment, care, and consideration of such individuals, the knowledge gained from biological research must be transferred to the public at large, including individuals with mental disorders and their families, as well as mental health professionals and policymakers.

There are many indications that the transfer of new knowledge to those who need and can act upon it is inadequate. Studies show that providers of mental health care are sometimes inadequately informed about the diagnosis and treatment of mental disorders or that they harbor some negative feelings about their patients. As noted earlier, the public at large commonly holds negative attitudes toward people with mental disorders or are ignorant about the prevalence, manifestation, or cause of these disorders. Such ignorance and attitudes have adverse consequences beyond stigmatizing people with mental disorders and their families. They also interfere with successful treatment: Individuals with

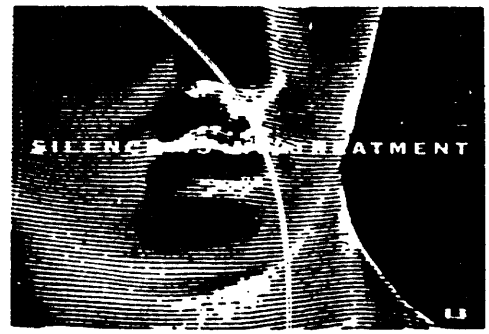

Photo credit: Courtesy of the American Psychiatric Association, 1982.

A recent public education campaign, sponsored by the American Psychiatric Association, highlighted the negative impact of stigma on treatment-seeking.

a mental disorder may avoid seeking treatment in order to avoid the associated stigma. Perhaps of most importance to Congress is the fact that uninformed and negative attitudes contribute to discriminatory public policies. A recent report by the Interagency Task Force on Homelessness and Severe Mental Illness highlights the malignant consequences of negative attitudes on public policy:

> Stigmatization, fear, and mistrust regarding people with severe mental illnesses. . .are commonplace in our Nation. Such reactions influence both the direct responses of community members to these individuals as well as the development of local, State, and Federal policies affecting them.

One conclusion that OTA draws from this analysis is that advances in knowledge about mental disorders do not in themselves ensure better diagnosis, care, or prevention; nor do they guarantee that public policy keeps abreast of research and development. Those improvements and informed policy also depend on the dissemination of accurate information about mental disorders.

The current excitement about brain research, already recognized by Congress' declaration of the 1990s as the Decade of the Brain, can provide both an impetus to and a focus for information dissemination efforts, which began in 1983. That year and every year since, Congress has passed legislation that designates one week as Mental Illness Awareness Week.[8] More recently, several members of the

[8] The first legislation, in 1983, authorized a National Mental Health Week. All subsequent resolutions fell under the designation of Mental Illness Awareness Week.

House of Representatives, who formed a working group on mental illness, see as one of their first tasks the education of the "Congress and the American people about the *causes* of mental illness and about *new breakthroughs* in research and treatment modalities, and to eliminate the *ignorance and stigma* surrounding mental illness" (emphasis added).

OTA identifies several options for congressional action to improve the publics', providers', and policymakers' understanding of mental disorders. These options are not mutually exclusive; in fact, a combination of them may best serve the ultimate goal of facilitating the transfer of accurate information to the various parties who affect mental health care and policy.

These options focus on Federal programs, but they can also influence other dissemination activities. OTA knows full well that there are many other sources of information about mental disorders. The media, which often provide a skewed or inaccurate view of mental disorders, are far and away the public's primary source of information about mental disorders (see box 1-D). Furthermore, virtually every major national mental health organization and organizations promoting research (e.g., the National Institute for Brain Research, the Society for Neuroscience) direct educational materials toward the public. All of these activities may benefit from improvements in Federal programs that pay attention to recent advances in research and the promise of more to come.

Option 1: Build upon existing and planned educational efforts on mental disorders supported by the Federal Government.

The primary Federal source of information on mental disorders is NIMH. While NIMH has supported an assortment of educational activities, the centerpiece of its educational effort is the DEPRESSION Awareness, Recognition and Treatment (D/ART) campaign, which was launched in 1986 (box 1-F). Only last year, NIMH announced a new and similar program on panic disorder.

Congress can build upon existing and planned Federal activities, namely the D/ART program, the panic disorder campaign, and the recommendations of the Interagency Task Force on Homelessness and Severe Mental Illness, to capitalize upon the strengths of programs already in place. For example, the use of multimedia presentations, the collaboration with various private organizations, and the targeting of specific audiences (e.g., care providers) are all strong points of the D/ART program that could form a solid foundation for future educational efforts.

Expanding congressional support for ongoing Federal educational activities could take several forms. At the most basic level, Congress could augment the modest funding for these programs ($8.5 million for D/ART since 1986, or less than $2 million annually). Additional funds could ensure the expansion of existing programs and the full implementation of planned ones. Of particular importance to a successful public education campaign are evaluations of "outcomes." There has been less than adequate evaluation of the D/ART program's effectiveness, due at least in part to the expense of such research.

Money is not the only issue. To date, the entire D/ART program has been managed by only one and one-half full-time professional staff persons. Thus, Congress could urge NIMH to give a higher priority to educational activities in order to maximize the effectiveness of such programs.

Without establishing any new functions, Congress could direct NIMH to centralize all educational campaigns within a single office, thus improving the efficiency of the programs. At present, the panic disorder campaign, for example, will be administered separately from the D/ART program, even though both have similar goals and objectives: increased recognition and treatment of a disorder.

Option 2: Target educational activities at secondary schools.

Currently, students in junior high school and high school learn little, if anything, about mental disorders, despite the fact that adolescents are especially interested in the topics of health and human behavior. The Department of Education recognizes the importance of such instructional opportunities and includes some mental health information as part of the health curriculum. That information targets mental health in the context of family violence, rape, other emotional crises, the prevention of drug abuse, stress management, and assertiveness training rather than specific mental illnesses. Congress could direct the Department of Education, alone or in conjunction with NIMH, to initiate a grants program to develop model supplemental curricula on advances

Box 1-F—Educating the Public About Depression

Of the 15 million people who experience a major depressive disorder each year, four-fifths can be treated successfully; yet, only one-third of them seek treatment. Even when people seek treatment, symptoms of a depressive disorder are often unrecognized or inappropriately treated by health professionals. Given this level of ignorance, as well as the negative attitudes that surround mental disorders, the Federal Government sponsored its first major health education program about a specific mental disorder in 1986, with the initiation of the National Institute of Mental Health's (NIMH's) DEPRESSION Awareness, Recognition and Treatment (D/ART) program. The D/ART seeks to: 1) increase public knowledge of the symptoms of depressive disorders and the availability of effective treatment, 2) change public attitudes about depression so that there is greater acceptance of depression as a disorder rather than a weakness, 3) encourage changes in help-seeking behavior to reduce the number of untreated and inappropriately treated individuals, and 4) provide information to primary care physicians, mental health specialists, and medical students about advances in diagnosing and treating depressive disorders. The D/ART program will extend over a decade and consists of three components: a professional training program, a public education campaign, and a national worksite program.

For fiscal years 1986 to 1991, the D/ART program expended $4.5 million to train health professionals about recent advances in diagnosis and treatment of depressive disorders (table 1-5). Short-term training courses, developed for this purpose, have been used to train more than 11,000 primary care physicians, mental health professionals, and medical students about depressive disorders. In addition, the D/ART program sponsors continuing education programs in collaboration with professional associations.

In 1988, the D/ART program launched a two-part public education campaign consisting of a multimedia component to publicize messages about depressive disorders and a community partnership program to extend and reinforce the media messages at the local level. First, D/ART staff conducted 20 focus groups in nine geographically dispersed cities and contracted for a survey of 500 people in two cities (Indianapolis, IN and Sacramento, CA) to find out what people knew about depressive disorders. Furthermore, in the early stages of campaign development, the D/ART program organized a group of 45 campaign consultant organizations to advise about public education strategies. The group—comprised of representatives from the major mental health and medical professional associations as well as health and mental health organizations, businesses, labor, religious, and educational groups, mental health advocacy groups, foundations, and other Federal agencies—continues to provide advice on campaign policy matters and to disseminate information on depression.

The D/ART Public Education Campaign has expended $3.6 million in the past 5 years (table 1-5) to develop educational materials. For example, a total of 16 flyers, brochures, and booklets have been produced and distributed to more than 13 million people, with some of the publications geared toward the general audience and some to specific groups, such teenagers, college students, young African-Americans, and older people; some have been published in Spanish and five Asian languages. Also, close to 1,000 television and 9,000 radio stations have broadcast public service announcements (PSAs) about depression to as many as two-thirds of households nationwide. A number of the initial PSAs featured celebrity spokespersons to introduce the campaign.

A critical component of the D/ART program is its community partnership strategy. The Community Partnership Program consists of 32 mental health groups, mostly "Mental Health Association" and "Alliance for the Mentally Ill" organizations, located in 24 States and the District of Columbia. Community partners reproduce and distribute copies of print materials on depression; conduct public forums, worksite programs, and professional

Table 1-5—DEPRESSION Awareness, Recognition, and Treatment Program, Fiscal Years 1986-91

	($ thousands)						Total
Area	FY 86	FY 87	FY 88	FY 89	FY 90	FY 91	FY 86-91
Training	142	520	646	824	1,146	1,250	4,528 (53%)
Public education	292	924	447	745	616	631	3,655 (43%)
Worksite	N/A	N/A	50	50	100	100	300 (4%)
Total	434	1,444	1,143	1,619	1,862	1,981	8,483

SOURCE: I. Davidoff, Director, D/ART Campaign, National Institute of Mental Health, Rockville, MD, personal communication, Feb. 28, 1992.

seminars; develop videos; appear on television and radio talk shows; sponsor support groups and telephone hotlines, and carry out other varied educational activities, including brochure translations in five Asian languages. In 1990, the total dollar value of the programs that were offered and the partners' direct and in-kind contributions was estimated at nearly $1.3 million, about ten times the Federal investment in the Community Partnership Program. D/ART also recently initiated a Professional Partnership Program, through which depression-related community education activities similar to those offered by Community Partners will be developed by universities, foundations, and professional organizations.

In 1988, the D/ART program established a National Worksite Program as a collaborative effort between NIMH and the Washington Business Group on Health, a nonprofit health policy group composed of Fortune 500 employers. To date, $300,000 has been expended on this program component. The purpose of the worksite initiative is to assist employers in reducing the impact of depression on productivity, on health and disability costs, and on employees and their families. The program disseminates information about depressive disorders to employers and encourages corporate policies and programs that promote early recognition, quality cost-effective care, and on-the-job support for individuals experiencing depressive illnesses. The program has developed a "Management of Depression" model program and published a report based on the experience of seven large U.S. companies that contributed to development of the model. In 1992, the program will produce a training program for management personnel and occupational health professionals to improve early recognition and referral to appropriate care for depression.

Preliminary data suggest that the D/ART program has had some positive effects. For example, prior to the dissemination of any information, NIMH funded a 1987 telephone survey by the University of Michigan Institute of Social Research of 500 people (250 in Indianapolis, IN, and 250 in Sacramento, CA) to determine the extent of their knowledge about depression. The survey found that most people believed that depressed persons could get better on their own rather than by seeking treatment. In 1990, the American Medical Association conducted a followup survey of the same group of 500 people. A total of 210 of the original group responded; 40 percent of the respondees in Indianapolis and 25 percent of the respondees in Sacramento said they knew more about depression because of the D/ART campaign. AMA also surveyed a new group of 500 people (250 people from each of the two cities). Of this group, 34 percent of those in Indianapolis and 30 percent of those in Sacramento said they were aware of the D/ART campaign and its messages. Another survey in North Dakota found that the number of adults treated for depressive disorders increased 1.5 times and the number of children treated increased 3 times in Human Service Centers (akin to Community Mental Health Centers) for fiscal years 1986 to 1991. The increase was attributed in part to the D/ART public and professional education programs and to a State program to develop treatment teams specifically for children within the Human Service Centers.

Has the D/ART program been a success? While the limited data on the effectiveness of the D/ART program preclude a quantitatively based answer to this question, several aspects of the program clearly deserve commendation. With limited resources and personnel (the entire D/ART program is managed by one-and one-half full-time Federal professional staff persons), the D/ART program established an educational campaign that is solidly rooted in research advances; the D/ART program carefully devises the messages to be relayed, uses diverse media to disseminate the messages, and coordinates its efforts with people in the community. D/ART has also trained substantial numbers of health and mental health care providers through its own efforts and through collaborations with public and private organizations. Advancement of this pioneering educational effort on a mental disorder by the Federal Government—via further study of its effect on the level of awareness, prevalence and treatment changes, expansion of the program into other communities, and adapting its techniques for educating the public about other conditions—will require some combination of increased funds and personnel, as well as highlighting this activity as a priority at the NIMH.

SOURCES: J.E. Barbara, Mental Health Consultant, personal communication, May 4, 1992; R. Brown, Senior Scientist, Department of Mental Health, American Medical Association, personal communication, June 23, 1992; L. Davidoff, Director, D/ART Campaign, National Institute of Mental Health, Rockville, MD, personal communication, June 1992; R. Kessler, Institute for Social Research, University of Michigan, personal communication, June 23, 1992; A. Koss, coordinator of State D/ART Program, Division of Mental Health, Department of Human Services, Bismarck, ND, personal communication, June 22, 1992; D.A. Regier, M.A. Hirschfeld, F.K. Goodwin, et al., "The NIMH Depression Awareness, Recognition, and Treatment Program: Structure, Aims, and Scientific Basis," *American Journal of Psychiatry* 145:1351-1357, 1988; D. Regier, Director, Division of Clinical Research, National Institute of Mental Health, personal communication, May 1992; U.S. Department of Health and Human Services, Public Health Service, Alcohol Drug Abuse and Mental Health Administration, National Institute of Mental Health, *Depression, Awareness, Recognition, and Treatment (D/ART) Fact Sheet*, DHHS Pub. No. (ADM) 90-1680 (Rockville, MD: U.S. DHHS, 1990).

in neuroscience and mental disorders. Outstanding materials, capturing the excitement and complexity of a scientific area, have been developed on other topics, including a recent supplement on the genome project and the ethical issues it poses.

It is important to note that model supplemental curricula do have some limitations. While they can be distributed to school districts nationwide, the law prohibits mandating the use of such materials. Also, supplemental materials may not be the most fruitful approach, given the need for comprehensive curriculum development in science education and the large number of competing supplements now available in the sciences and in health education.

Option 3: Direct the Federal Government to play a role in coordinating the training and level of knowledge of persons caring for individuals with mental disorders.

Optimal care for individuals with mental disorders relies on providers having accurate, up-to-date information. Yet, providers face a widening pool of knowledge from basic, clinical, and rehabilitative research. Furthermore, the extent to which this information is included in academic and training programs remains a matter of institutional choice. This report did not evaluate in detail the extent of provider knowledge about mental disorders; however, it did note research evidence that some providers have less than adequate knowledge about diagnosing and treating these conditions. As a first step toward ensuring that providers receive current and accurate information about mental disorders, Congress could commission a study on the level of knowledge of providers and the way in which these professionals are trained and licensed. Furthermore, Congress could request that such a study devise mechanisms for improving the transfer of knowledge to providers.

Option 4: Formalize a mechanism for improving information transfer and communication among Federal agencies concerned with mental disorders.

One goal of giving the public information about mental disorders is to make it easier to develop public policies that will help people with these conditions. While such efforts can be important in shaping the political will needed to bring about successful policy initiatives, public education is unlikely to solve many of the problems people with mental disorders face, at least in the near term. Indeed, the mechanisms by which Federal policies on mental disorders are formed and implemented erect barriers to a rational problem-solving process. No single agency is primarily responsible for the issues that affect people with mental disorders; rather, it is scattered among various agencies, including several offices and institutes within the Departments of Health and Human Services (NIMH, Health Care Financing Administration, and others), Veterans Affairs, Justice, Labor, Education, Housing and Urban Development, and others. While NIMH has sometimes offered Federal leadership on policy issues related to mental disorders, there is clearly a need for better dissemination of new research findings, better communication about areas needing research, and better coordination of policy planning. This need is likely to become more acute with the reorganization of the Alcohol, Drug Abuse, and Mental Health Administration and separation of NIMH and the newly formed services agency, SAMHSA, Substance Abuse and Mental Health Services Administration.

NIMH, recognizing the need for information transfer, has set out to develop methods and a system by which knowledge exchange can proceed. Congress could build upon these plans and ensure the involvement of high-level officials in other Federal agencies and institutions, so as to create a mechanism for the exchange of information and development of policies and programs, by creating an Interagency Task Force or Council on Mental Disorders that would include representatives from all relevant agencies in the Federal Government. It could be directed to coordinate research and policy issues concerning mental disorders and to establish a mechanism for sharing information among all officers and employees of the departments carrying out programs that concern people with mental disorders.

Some mechanism for facilitating talk among Federal agencies is needed, given that no single agency has the jurisdiction or expertise to address thoroughly the issues associated with mental disorders. The composition of the task force is the single most important key to its success. Representatives from every relevant agency should be included. In addition, task force members should have adequate experience, expertise, and authority to devise and help implement policies and programs. The chair of the task force is also important; ideally, this person

would bring personal dedication and sufficient authority to help drive the group's efforts. A clear charge is necessary to focus the work of the group. Congress could specify topics for study every year or two and request that a report be made at the end of that time. The report would elucidate the topic and provide for policy initiatives.

One topic could be consideration of the financing of mental health care. Research advances, whether the development of new treatments or changing conceptualizations of the causes of mental disorders, clearly have influenced and will continue to influence the issue of mental health care financing. A study involving NIMH and other agencies in the Federal Government with expertise in and jurisdiction over the financing of health care and the provision of services could review the relevant factors and issues and develop a cohesive Federal policy. A final point should be made: Even in the event of a successful effort on the part of the task force, certain policy and program suggestions may be forestalled until adequate funds are provided.

PREPARED STATEMENT OF HON. ORRIN G. HATCH

Thank you Mr. Chairman.

I welcome our panel of distinguished witnesses to today's hearing, and certainly appreciate the benefit of their views about deinstitutionalization, mental disorders, and drugs in the context of health care reform. These are important issues.

I hope that the Committee will pay heed to Dr. Torrey's wise counsel in his testimony about deinstitutionalization.

The issue of health care reform is among the most complicated of issues to come before the Congress, and it has profound ramifications.

The situation with deinstitutionalization in the last half of this century can provide us some valuable lessons, as the Chairman has indicated. Let us not make conditions worse by diagnosing the wrong problem, and prescribing the wrong remedy.

Let me just take this opportunity to highlight one special interest of mine which, I believe, Dr. O'Brien will cite in his testimony.

As Dr. O'Brien has said, a relatively neglected area in pharmaceutical research has been treatment for addictive disorders, such as methadone for heroin. We had a hearing on this issue in the Judiciary Committee last month, and it was quite interesting.

The fact is that if we want to be serious about our war on drugs, we have to do more to encourage development of these so-called "pharmacotherapeutic drugs," or a term you might prefer, Mr. Chairman, is "anti-addiction drugs."

These drugs are simply not being developed at the pace we would like. The reasons for this are many: the approval process at the Food and Drug Administration-which is quite expensive and lengthy; the "stigma" attached to these drugs; the potentially small customer base for pharmacotherapeutic drugs which would not allow manufacturers to recoup research and development costs; and the many difficulties inherent in distributing these medications.

We have been looking at options to address this problem, and as Dr. O'Brien mentioned, tax incentives are one possibility. I look forward to pursuing this with you further during our question and answer period.

Thank you, Mr. Chairman.

PREPARED STATEMENT OF DAVID F. MUSTO, M.D.

Thank you for your invitation to say something about the history of America's drug problem. It has a long history, a fact that contradicts our frequently held belief that the drug problem began in he 1960s. For almost a century Congress has struggled with the control of heroin and cocaine, of smoking opium and cannabis. History builds a framework, often revealing a perspective that raises unexpected questions and calls attention to the American way of social control spanning the entire history of our nation. There is something to be gleaned from history if we do not allow extreme viewpoints to distort its shape. History, however, is not a hitherto secret path to a forgotten solution of the problem. The drug area is a good example of Richard Hofstadter's view that "history forces us to be aware . . . of complexity, . . . of defeat and failure; it tends to deny that high sense of expectation, that hope of ultimate and glorious triumph, that sustains good combatants." Yet, as Hofstadter concluded, "there may be comfort in it still. '

The first point to make is that we have had more than one great wave of drug use. The previous drug "epidemic" peaked about the turn of the century and consisted of cocaine, morphine, heroin and opium use that alarmed the public. One could quote on this topic another great American historian, one, in fact, that Hofstadter thought was the greatest of them all, Henry Adams. Writing here in Washington in 1911 Adams lamented "America cannot get flatter. There is nothing in it! .. .nothing but drugs." A year earlier the President had sent a message to Congress declaring the cocaine problem to be the most serious drug problem the nation had ever faced. Within four years of Adam's dismal pronouncement heroin would surpass morphine as the chief cause of addiction admissions to New York's Bellevue Hospital. Within a decade, Dr. Royal S. Copeland, then New York City's Health Commissioner, later a United States Senator, declared that heroin addiction among youth had become an "American disease."

Knowledge of that earlier era is important not only because it is a forgotten part of American social history on an important subject, but also because that history has lessons for our own day—even the suppression in the 1930s of that controversial past gives an important clue to the American style of cultural conflict.

When I briefly review the history of drugs over the last century I will draw upon statements I have prepared in the past for Congressional committees.

The history of cocaine in America began in 1884 when cocaine entered the commercial market. Cocaine was sniffed, swallowed, sprinkled, inhaled and injected without any legal restriction. Coca-Cola entered the market in the 1880s as a temperance drink: you got the tonic advantage of the Peruvian coca plant while avoiding the alcohol of other tonics. Cocaine was initially hailed by medical experts as the ideal American stimulant. Initially seen as harmless—as well as the first effective treatment for hay fever—cocaine changed in public and medical perception to a fearful drug that ought to be controlled. To take New York State as an example, after cocaine's introduction about twenty years passed before the first statewide legal restriction was enacted: the 1907 anti-cocaine law introduced by Assemblyman Al Smith. This first stage of cocaine control limited cocaine availability to the judgment of a physician. To restrict a medicine to the health professions and their wisdom is an understandable first step. This strategy, however, did not seem to contain the problem. An illicit street market coexisted and gauged by the purchasing power of the money the street cost in 1910 was apparently greater than illicit cocaine in New York in the 1980s.

The easy availability of cocaine persisted for years but public opinion gradually came to perceive cocaine as an almost totally evil substance, the worst among dangerous drugs. With considerable ingenuity a federal law, the Harrison Act of 1914, was enacted that severely limited legal access to cocaine nationwide and eliminated cocaine from over-the-counter, non-prescription remedies. It is significant that the Harrison Act still allowed heroin to be present in cough medicines purchased without a prescription, but allowed no exception when it came to cocaine. With some ups and downs, cocaine faded until by the 1930s it was much reduced in use.

As drug use declined—both opiates as well as cocaine—the penalties for drug possession increased until the maximum penalties were reached in 1956, a period of low opiate and even lower cocaine use.

As we know, the extreme penalties, including provision of the death penalty, did not prevent a second drug epidemic.

The rise in penalties was possible because so few Americans were involved in drugs. Those affected were anonymous individuals on the fringe of society. When, however, drug use again attracted mainstream young Americans, extreme penalties both failed to deter and were seen as excessive and inappropriate. An additional problem arose from a second deterrence strategy adopted by the government in the 1930s: gross exaggeration of drug effects so that young persons would not be tempted to experiment. Yet when drug use returned, the combination of extreme penalties and exaggerated warnings led to a loss of the government's credibility. Clearly, credibility of official statements is important in any war, including a war on drugs, and its loss at the beginning of the present wave of drug use severely damaged our ability to respond persuasively.

The wide swing from toleration and touting of drug use in the 1880s to the extraordinary measures to prevent a recurrence adopted in the 1950s is certainly an American phenomenon. We maintain our interest in achieving the most we can, but we change our minds on what are the best instruments to achieve individual and cultural progress. One major problem with our sincere and powerful changes of attitude toward drugs is that the high water mark of rejection and draconian penalties has ill-prepared our nation for a recurrence of drug toleration and availability. The ideal drug policy is one that can endure through changes in attitude and maintain credibility in the face of renewed fantasies about the value and harmlessness of, say, cocaine. Given that our drug policies in the decline phase mirror public fear and loathing of drugs, the achievement of a steady, durable policy is extremely difficult.

Linked to exaggeration in the 1930s was an even stronger desire by anti-drug strategists to draw a curtain across the existence of drugs, again to discourage use by keeping the problem out of sight. The Motion Picture Association of America's 1934 prohibition against showing any drug use in their movies is an example of this determination to make drugs invisible.

When we consider these three strategies—extreme punishment and silence punctuated by gross exaggeration—we can say that we understand the commendable motivation for these policies, and still admit that these policies were not adaptable to a later change in attitude and availability of drugs. Sadly, we can even suspect that these well-intentioned policies helped set the stage for and fueled a counter-revolution in attitude.

So when I think about the future, I am looking beyond a victory over drugs to the time afterwards. One is reminded of President Franklin Roosevelt's decision early in World War Two, when the outlook was extremely bleak, to establish a task force to consider the problems that would be faced after victory. We should keep in mind the great importance of establishing policies which are viable both in times

of anti-drug fervor as well as in later generations when drugs may be less familiar and those who have learned the hard lessons of the last decades are few in number. We must keep these concerns in mind, because no other countervailing forces in a era of anti-drug sentiment will prevent the most severe laws from being enacted with a sense of confident righteousness.

Of the various widely-used mood-altering substances, cocaine undergoes the greatest shift in popular attitude. When the slide begins, it goes all the way. This does reduce demand for cocaine, support increasingly severe penalties and improve suppression of cocaine use by reducing the niches in society where cocaine is tolerated or not reported.

One hazard of this extreme rejection is that cocaine achieves tremendous power as a symbol of social disorder. Cocaine can become perceived as the primary cause of social problems that are more correctly attributed to complex reasons such as inadequate education, lack of opportunity and alienation. Cocaine can also be linked in a simple way with minorities such as African-Americans and Hispanics, as did happen in the case of African-Americans around 1900. This kind of linkage with minorities confirms negative public attitudes toward the people in the inner cities and reduces support for the brave people there who are risking their lives to rid their neighborhoods of drugs. In other words, the change in attitude toward cocaine presents problems while at the same' time it supports a greatly desired improvement in the level of drug use—and this we know from history.

Just as knowledge of our drug history suggests warnings where we might anticipate only success, it also indicates opportunities. One opportunity today is due to the reduction of Cold War tensions. There is now a much greater likelihood of cooperative action against opium growing areas along the cold war border, the trail of poppies from Turkey to Vietnam. Such an opportunity for broad international cooperation has not existed since 1914.

One thing historical perspective is not well-equipped to provide is specific formulae. To take the issue of international cooperation, I can't provide a text for a treaty. I can, however, show how rare has been the chance for real progress between 1914 and the present and that such windows of opportunity are fleeting. Long-term goals may elude our vision when we are so deeply engaged with the day to day battle against drugs. For example, study of the past reveals the importance of drug education which should maintain accuracy even when social pressures would promote exaggeration. Moreover, such education should continue even when the crisis has passed. What precisely should be in that recipe for an educational package, unfortunately, is not provided by history, although I certainly believe history should be a part of that package.

Finally, there was in the decline phase of the previous "epidemic, a silent and generally unmourned casualty. I am referring to scientific research. As we become more punitive and sharply negative in our attitude toward drugs, interest in research fades. It is not a direct rebuff, it is even more negligent: research just drops off the horizon during the decline phase because the details of drug interaction are unimportant when your only goal and solution is to separate persons from drugs. The United States since the 1960s has gradually built up a highly competent cadre of researchers and their discoveries may aid greatly the response to drug craving. Research does not need an extraordinarily high level of funding, but it does need steady funding that rides out the violent swings in public and political attitudes toward drugs.

Again, I want to thank you for this opportunity to discuss the history of our drug problem.

PREPARED STATEMENT OF CHARLES P. O'BRIEN, M.D., PH.D.

Good Morning Chairman Moynihan and Members of the Senate Committee on Finance. It is a pleasure to appear before you today to discuss the modern treatment of mental disorders including addictions, and in particular to discuss the recent report on the development of medications for addictions prepared by a Committee of the Institute of Medicine of the National Academy of Sciences. In my lifetime there have been great strides in the treatment of disorders of the mind. I was born during an era when doctors had little more than morphine to use in the treatment of an acute heart attack and antibiotics were just beginning to be used for infections. The treatment of severe mental disorders was largely limited to custodial care and shock therapy. The modern treatment of mental disorders with medications had its origins in the early 1950's with some astute observations by alert clinicians. For example, alkaloid drugs derived from the snake root plant of India, Rauwolfia Serpentina, used primarily for blood pressure lowering effects were noted to reduce psychotic

symptoms. In France a sedative called chlorpromazine used in surgery was noted to improve the symptoms of schizophrenic patients who, by chance, needed surgery. An anti-tuberculous drug, isoniazid, was noted to relieve the symptoms of depression in tuberculosis patients who happened to be depressed.

These serendipitous observations led to studies in mental patients focused on psychiatric symptoms. Early clinical studies demonstrated for the first time that there were medications that could consistently relieve the signs and symptoms of mental disorders. The science of psycho-pharmacology was born as the medications discovered in the clinic were tried in various animal models in the laboratory. The animal models that were sensitive to the clinically effective drugs were then used to screen many new compounds and thus, to discover drugs that were more specific with fewer side effects and greater efficacy.

The animal models also permitted scientists to develop hypotheses for the mechanisms of mental disorders. This interaction between the laboratory and the clinic has also produced greater understanding of how the mind works. Researchers have compared the effects of drugs in the clinic with their effects in the laboratory, both on animal behavior and on biochemical mechanisms. It has been learned that drugs act at specific receptors in the brain and many of the receptors have been identified. We can now develop new medications not just by chance discoveries in the clinic, but by deliberate design based on molecular models of drug and receptor interactions.

The growth of neuroscience as a basic medical science has been spectacular and with it, our knowledge of normal brain function. The 90s have been declared The Decade of the Brain in recognition of this great progress and the challenges for the future. Some of the best minds have been attracted to this field. For example, scientists supported by the National Institute on Drug Abuse (NIDA) discovered brain receptors for heroin and other opiates in the early 1970s. Two years later other NIDA funded scientists discovered hormone-like substances that have effects similar to heroin and are normally present in our brains. Research on these endogenous opioids or endorphins has already had an impact on our understanding of hemorrhagic shock, spinal injury, endocrinology, gastroenterology and, of course, brain functions such as the normal adaptation to pain. Since the discovery of endorphins, dozens of additional brain messengers or neurotransmitters have been discovered, some of them in relation to studies on drugs of abuse. For example, receptors for phencyclidine or "angel dust" and receptors for marijuana have been discovered. The receptors for cocaine, heroin and marijuana have now been identified and cloned. Very recently there have been reports of a marijuana-like substance present in normal brains that may eventually explain still more about brain function.

Over the past three decades the treatment of mental disorders has continued to improve. There have been advancements both in medications and in psychotherapeutic techniques. Studies generally show that a combination of psychotherapy and pharmacotherapy is more effective than either alone. It must be pointed out that severe mental disorders tend to be chronic and relapsing. Our treatments are not curative. We learn early in medical school that relatively few illnesses treated by physicians are cured and that most physicians treat chronic disorders. Psychiatric physicians measure success by improvement in symptoms, in ability to function in society, and in improved quality of life. Our success rates in psychiatry are similar to those for other chronic disorders such as diabetes, arthritis, heart disease, and hypertension. Treatment for these chronic disorders must be continued throughout life but the treatment success rates are impressive. For example, patients with manic depressive illness (Bi-Polar Disorder) treated with a combination of lithium and supportive psychotherapy have a 75 to 80% probability of leading essentially normal lives. It has been estimated that lithium has saved the US economy $40 billion since 1970. The treatment of panic disorder has an 80% success rate while the treatment of major depression has a 65% success rate.

TREATMENT OF ADDICTIVE DISORDERS

Of all mental disorders, there is perhaps the greatest misunderstanding about the success of treatment for addictive disorders. Almost everyone has a relative, neighbor, or colleague who suffers from dependence on alcohol, nicotine, or an illegal drug. These sufferers typically try to stop their drug taking and usually succeed for a short time, but then they relapse. Even after going through a treatment program, relapse is common. Once a person becomes addicted, the habit pattern, etched in the brain as a memory trace, doesn't go away simply because the user stops taking the drug. "Willpower" is just not enough for most people. It is easy to tell these people to "just say no," but an addict has by definition lost control of his will where drug-taking is concerned. Treatment on an outpatient basis must be continued for

months or years. Relapses can be expected and they are not a sign of treatment failure. Relapse is a symptom of this chronic disorder and it tells the therapist that we must try to find the reason for the relapse and reduce the probability that it will occur again. This is exactly the pattern that we see in the treatment of other chronic disorders that also include a behavioral component. These include asthma, hypertension, and insulin dependent diabetes.

We have different types of treatments for different kinds of drug dependent patients and for different kinds and combinations of drugs. Our treatments for addiction must be flexible and tailored to individual patient needs. Most of the time we are not treating "pure" addiction, but rather a complex social dysfunctional syndrome complicated by drug addiction. This is illustrated by two cocaine addicts recently presenting for treatment in our program. One was a young physician with heavy cocaine use but no significant medical, social, legal, psychological, or occupational problems. Based on prior experience, this type of patient is unusually "pure" and we estimate an 85 to 90% probability for successful treatment over the next two years. Another recent patient, a teenager who had just given birth to a baby, was actually using less cocaine than the physician. But she had serious medical, social, family, legal, and psychiatric problems. The probability of her achieving stable abstinence from cocaine in the next two years is far less than that of the physician.

HEROIN ADDICTION

Our treatment of addictive disorders is helped by medications specific to the type of addiction. For the treatment of heroin addiction, we have excellent medications that help an addict detoxify or clear the opiate from the body. Once back to the drug-free state, however, heroin addicts continue to suffer from cravings and long-term physiological disturbances because of adjustments that their body has made during years of heroin taking. Research has shown that heroin is more like a hormone than a drug because it acts on receptors used by natural substances or endorphins. Thus, even with the best psychotherapeutic treatments, only a small minority of heroin addicts are able to achieve stable long-term abstinence. Since the 1960s, however, it has been known that heroin addicts can be stabilized on an opioid such as methadone or on the new medication called LAAM. LAAM is a medication developed by NIDA that maintains former heroin addicts in a comfortable, functional state with only three doses per week. These maintenance treatments are analogous to the way that people with adrenal gland insufficiency (Addison's disease) are maintained on synthetic steroids or people with thyroid insufficiency are maintained on thyroid hormone or people with diabetes are maintained on insulin. Even though scientifically, these analogies are accurate, there is controversy over opiate substitution treatment because some people believe that all addicts should be treated in drug-free programs. Currently about 125,000 of the approximately one million opiate addicts in the US are treated in methadone programs. Overall the success rate is approximately 60% although results vary. Good programs that provide psychosocial rehabilitation in addition to methadone have higher success rates while those that provide little more than the medication methadone by itself have lower success rates.

Neuroscientists funded by NIDA have discovered a great deal about the mechanisms of opiate addiction and this has led to a medication called naltrexone that specifically blocks opiate receptors. While receiving this medication the effects of heroin and other opiates are prevented. Unfortunately, this treatment itself requires some willpower to continue it and it is successful only for better educated and motivated opiate addicts.

NICOTINE DEPENDENCE

The treatment of nicotine dependence is a high priority because of the approximately 450,000 deaths and untold suffering produced each year by this addiction. As with other addictions, there are different types of nicotine dependent patients. Some are able to stop on their own. Of those who fail on their own and are forced to seek professional help, only about 15 to 20% succeed at the end of one year. The development of nicotine substitution therapy, somewhat like methadone substitution therapy, has improved the treatment results to the level of perhaps 25 to 30% at the end of one year. There is a great need to improve the treatment of this addiction still further and to find ways to prevent the development of nicotine dependence in the youth of our country.

COCAINE DEPENDENCE

Cocaine abuse and dependence are serious public health problems. Highly addictive crack cocaine sells for as little as $2 to $3 per dose and is widely available

throughout the United States. The number of heavy cocaine users is estimated at around 2 million in the United States. Patients desiring treatment of cocaine addiction are usually in desperate shape. Stopping the drug for a short time is relatively easy because the withdrawal syndrome is usually mild. However, there are strong tendencies to restart a cocaine binge when the former user returns to the environment where he or she has used drugs or encounters friends with whom she associates cocaine use. Thus far there are no medications that are consistently helpful in preventing relapse to cocaine dependence. There are, however, effective behavioral and psychotherapeutic rehabilitation programs that have achieved significant success. For example, our Department of Veterans Affairs Program in Philadelphia recently published seven month success rates of 68% for an outpatient rehabilitation program and 51% for an inpatient rehabilitation program. Clearly, we would like to improve these results and there is an intensive effort directed at finding a medication that will enhance our behavioral treatments for this disorder.

ALCOHOLISM

Alcoholism is a form of drug dependence whose treatment has benefited from advances in neuroscience. We have excellent medications to treat acute alcohol withdrawal. There are also effective behavioral techniques to prevent relapse and a well-developed, worldwide network of self-help programs involving the 12-step movement started by Alcoholics Anonymous that has become a mainstay of treatment for this disorder. But relapse to alcoholic drinking is still too common even with the best psychotherapeutic, behavioral and self-help programs. Advancements in understanding how alcohol affects the brain have led to the development of several different kinds of medications. One of the most exciting developments is based on the finding that in animals and human subjects, some of the reward or euphoria produced by alcohol is mediated via the endogenous opioid system. This is the system discovered by NIDA funded scientists that is specifically excited by opiates such as heroin. Naltrexone, a drug that blocks opiate receptors, has been shown to significantly improve the results of good psychosocial rehabilitation programs for alcoholics. Thus, a medication developed by NIDA researchers for the treatment of heroin addiction may turn out to help a far larger population of alcohol dependent patients.

INSTITUTE OF MEDICINE REPORT

The forty years of increasing success for medications in the treatment of mental disorders has generally been achieved through the combined efforts of the private pharmaceutical industry and government funded scientists. An exception has been the development of medications for addictive disorders where relatively little pharmaceutical industry interest has been shown. In 1992 as a stipulation of the ADAMHA Reorganization Act, the Congress asked the National Academy of Sciences to establish a committee of the Institute of Medicine to examine the incentives and disincentives for the development of anti-addiction medications. The Committee chaired by Dr. Laurence Earley recently released its first report. This multidisciplinary committee of which I am one of fourteen members, strongly endorsed the support of the development of medications for the treatment of addictive disorders. The Committee took note of advancements in neuroscience in general, but noted that more basic research is needed on the actual mechanisms of addiction. Thus, the development of medications particularly in the area of cocaine dependence requires more emphasis on basic research. The Committee noted that the development of anti-addiction medications requires Federal commitment and the overcoming of a variety of scientific, marketing and regulatory hurdles. The major disincentives cited by the pharmaceutical industry are an inadequate science base on addiction and relapse especially for cocaine dependence; an uncertain market environment which includes such issues as Food and Drug Administration (FDA) and Drug Enforcement Administration (DEA) regulations; size of the market; pricing; reimbursement; legal liability during clinical trials and difficulties in conducting clinical research. The Committee noted that the Medications Development Division of the National Institute on Drug Abuse had been authorized funding for FY94 at $95 million but it was appropriated at only $36 million. The Committee recommended high priority for full appropriation for medications development at the basic and clinical levels and suggested the Office on National Drug Control Policy (ONDCP) Special Forfeiture Fund as a possible source for increased support.

The Committee recommended that NIDA fund a series of national drug abuse research centers, subject to congressional appropriations, for the purpose of interdisciplinary research relating to drug abuse and other biomedical, behavioral, and social issues involved in the public health problem of drug abuse. These centers would be engaged in and would coordinate all aspects of drugs abuse research,

treatment and education. The committee made specific recommendations for speeding the FDA review process for anti-addiction medications and for removing the adverse effects of DEA requirements under the Controlled Substances Act on clinical research investigations involving controlled substances.

An important finding of the report was the need to create incentives for pharmaceutical industry activity in the anti-addiction area. Possible incentives will be detailed in a subsequent report from this IOM Committee. The incentives include increased Federal leadership in assigning a high priority to the development of medications for drug abuse treatment, increased patent protection for medications in this area, possible tax incentives and streamlining of the regulatory mechanisms that influence the difficulties of clinical research in this area.

In general, the IOM Report concluded that there is a need for more basic information on the mechanisms of addiction and that there are great opportunities for following scientific leads and clues that are not being exploited because of inadequate resources. It would appear that because of major advances in basic neuroscience, investments in the addiction area would have a high probability of clinically important payoff.

In summary Mr. Chairman, the modern history of the treatment of mental disorders began about 40 years ago and the pace of progress has been accelerating during the past two decades. This acceleration is largely attributed to the explosion of basic neuroscience information. A relatively neglected area is that of the addictive disorders. We should give adequate attention to this area by increased Federal funding and incentives for private industry involvement. Thank you very much for the opportunity to present this testimony.

PREPARED STATEMENT OF RICHARD C. SURLES

I appreciate the opportunity to testify today. My testimony will attempt to briefly review the recent history of trends in the treatment of persons with the most severe mental disorders. I will also suggest that current efforts at health and welfare reform have the potential to either improve or to make worse the current national dilemma of little access and treatment for the most severely disabled—especially those who are both mentally ill and homeless.

Widespread support for the social policy of deinstitutionalization of those with mental disorders emerged in the decades following World War II, as new psychotropic medications were introduced and many mental health professionals became convinced that people with severe mental illness could be successfully treated in community programs. A series of social reforms in the 60's and 70's were based on this belief, including the "bold new approach" of the federal Community Mental Health Centers (CMHC) Construction Act of 1963, the introduction of Medicaid in the mid-60's, followed by Supplemental Security Income (SSI) in 1974. Together, these social reforms allowed large numbers of people to leave institutions or to remain in community settings.

The history of reform in mental health has been marked by great enthusiasm for new ideas and new technologies, but has often proceeded without a full recognition of the degree to which the lives of people with severe mental illness are affected by public policy decisions. Similarly, reformers have often shown a lack of understanding about the nature of severe mental illness or the treatment and supports needed for rehabilitation and recovery. As David Mechanic observed in 1987:

> many dedicated professionals and reformers lost touch with the heterogeneity of mental health problems and the tough realities of designing and implementing effective programs appropriate for the most seriously mentally ill.

Unfortunately, many of the lessons learned about the potential negative impact of large-scale social reform on people with severe mental illness have been lost in the last decade. Sensitivity to the problems and unintended consequences of previous reform efforts may help us to avoid repeating the same mistakes.

Nationally, the census of state hospitals peaked in 1955, and declined steadily during the 60's and 70's. This decline in census was largely attributed to shorter lengths of state hospitalization. However, admissions to state hospitals continued to increase during this period, reflecting, at least in part, the fact that the necessary components for community care were not yet in place. The CMHC program initiated in 1963 grew considerably during this period. The number of operating federally approved CMHC's increased from 104 in 1966 to 758 in 1981; the percentage of the U.S. population covered by CMHC's grew from 7% in 1966 to 53% in 1980; and the number of patients served by CMHC's increased from an estimated 156,000 to more than three million over the same period.

However, the development of CMHC's never came close to the estimated 1500–2000 centers needed to cover the U.S. population; nor, in general, did CMHC's develop the types of support systems needed by people with severe mental illness. Some of the failures of the CMHC legislation are quite understandable, in retrospect. In addition to being underfunded in general, the legislation reflected an inherent tension between those who were most interested in consultation and education (prevention) and those whose primary concern was rehabilitation of the severely mentally ill. For example, rehabilitation services, which are an essential component of a system of care for those with severe mental illness, were an optional service, while preventive services for the community at large were mandated. As a result, the legislation promoted the selection of providers who had little expertise with serious mental illness. In addition, the CMHC legislation attempted to integrate the severely mentally ill into mainstream programs without targeting resources for their care; underestimated the expanding demand for mental health services; and had no adequate evaluation.

The last major social policy initiative to target people with severe mental illness—President Carter's Mental Health Systems Act of 1980—was repealed in 1981. Its successor, the Omnibus Reconciliation Action of 1981, cut federal funds for mental health services by 25% and replaced various categorical grant programs with block grants to the states.

It can be argued, however, that other social reforms of the 1980's had an even greater impact on people with severe mental disorders. For example:

- The Supplemental Security Income program, while designed for people with disabilities, never developed the outreach or case management capacity to assist people being discharged from inpatient care, or to follow up on those who are otherwise disconnected from treatment services. Moreover, beginning in 1981, the Reagan Administration ordered administrators of the SSI program to review the continued eligibility of disabled beneficiaries. The review had a disproportionate—although apparently unintentional—impact on people with severe mental illness.
- Financial incentives in Medicaid contributed to the inappropriate placement of large numbers of people with severe mental illness in nursing homes, by providing low-interest loans to operators and by subsidizing the costs of nursing home care.
- Gentrification of low-income housing in urban areas, particularly Single Room Occupancy Hotels (SRO's), had a significant negative impact on low-income people with severe mental illness. While this low-income housing was frequently inadequate, nearly one million SRO hotel rooms were destroyed between 1970 and 1982 as part of urban renewal efforts. Roughly 33% of these rooms had been rented to people with severe mental illness. No policy was developed for replacing this capacity or upgrading care for those displaced. Thus eliminating, however inadequate, any affordable place to live for the displaced tenants.

These social policies contributed to the emergence in the 1980's and 1990's of several highly visible "special populations," including people who are homeless and mentally ill. Some are repeatedly hospitalized and use emergency rooms as their primary locus of treatment. In New York City, we have recently recognized the presence of a high percentage of younger disabled veterans among the new group of homeless mentally ill. We also now recognize that children and adolescents who are at risk of exclusion from home and school may become the next generation of "chronic mental patients."

A major risk in our current policy discussion about health and welfare reform is that we may repeat our past mistakes and, in fact, we may make things worse for people with severe mental illness. But there is also significant opportunity to address and correct major social and health problems.

First, the needs of the severely mentally ill are not yet fully addressed by any proposed plan for national health care reform. President Clinton's plan gets high marks for recognizing the importance of case management and rehabilitation. With some changes, a more comprehensive benefit could be designed to respond to the needs of the most severely mentally ill. We have learned in the last two decades that the severely mentally ill *can* live meaningful lives in the community when services are available which give equal priority to *health care, mental health treatment, case management, residential support* and, when necessary, *periods of hospitalization.* Without such a comprehensive benefit package, reform will have little meaning for people with the most severe forms of mental disabilities—continuing the cycle of homelessness and utter despair.

Second, a plan is needed which confronts the difficulty in assuring adequate access to care and treatment for people with severe mental illness—especially the homeless. There is a danger that we could effectively deny care by discouraging ac-

cess through an overuse of co-payments, co-insurance and absolute caps on essential services. There is a need to address the issue of outreach and for ensuring that people are assisted after discharge from public institutions and psychiatric inpatient care. We must also consider the problem posed by severely ill people who choose not to use services. As one of the primary architects of President Clinton's health plan, Alan Enthoven noted in 1989:

> There will always be some—homeless, undocumented aliens and others whose lifestyle does not include enrollment in a health plan, carrying a membership card and making regular payments—whose needs will have to be addressed by public providers of last resort.

Third, there is substantial risk that, once again, those who have little knowledge or understanding about severe mental illness will be put in charge. Managed health and behavioral health care organizations have shown little interest in the severely mentally ill, other than to have special rates for coverage of disabled persons included in the insurance fund. In fact, a recent edition of *Behavioral Healthcare Tomorrow* (March/April 1994), lists seven criteria for "terminating private benefits for chronically mentally ill patients." The seven are:

(1) Base-line chronic psychosis
(2) Medication non-compliant chronic patients
(3) Treatment resistant and chronically suicidal patients with major depressive illness
(4) Severe chronic personality-disordered patients
(5) Organic brain syndrome patients
(6) Conduct-disordered patients
(7) Treatment resistant chemically dependent/alcoholic patients

Taken together, the seven criteria accurately describe the traditional public mental health population. Moreover, managed health and behavioral health organizations are organized around financial rather than community considerations, and lack the range of community connections necessary for effective treatment of the severely mentally ill.

Fourth, health or welfare reform which is based on an insurance model or private market competition will place the most disabled at substantial risk. There is simply no reason to believe that organized care systems will have any more incentive to serve difficult and costly clients than did the CMHC's of the 60's and 70's. As one person with severe mental illness struggling with a new managed care system put it, "If you're outside the norm, you're outside the system."

Nevertheless, change in the existing health and welfare systems needs to occur. If a new approach can be taken which provides special assistance to the most disabled by pooling resources for a variety of government sources, substantial gains could be made for the most disabled while also lessening the overall financial risk associated with most open-ended entitlement or insurance benefits. For example, by enrolling extreme risk groups in a special health plan, the overall insurance premium for other covered groups would be lower.

In considering a new approach to respond to the most severely disabled Americans suffering from mental disorders, I recommend a fundamental restructuring of both the health and welfare systems within the following framework:

(1) Provide an accessible "basic" mental health benefit for all those covered in a universal health plan, and include in this benefit the array of services proposed in the Health Security Act.
(2) Provide a "targeted" benefit for a limited number of persons with the most severe mental disorders which is comprehensive and managed to the benefit of the individual. (Such benefit should merge health, mental health and social supports into one managed plan).
(3) For this targeted benefit program, permit states to:
    a. Develop rosters of persons who should be considered for the supplemental benefit.
    b. Use "needs based" eligibility criteria as the standard for considering enrollment with co-insurance for those at higher income levels.
    c. Establish responsibility for promoting outreach and support to enable the most severely ill to access care and for overall management of the plan of treatment and care.

Mental disorder, homelessness and deinstitutionalization are often discussed as if one is a product of the other. I contend that the negative stereotypes of all three result from poorly considered social and medical policies of the past 40 years. I hope there will be a willingness to recognize the potential for correcting many unintended consequences of past policies as we move to redesign both the national health and welfare system.

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PREPARED STATEMENT OF E. FULLER TORREY

Thank you for the invitation to address the Senate Finance committee on this important subject. I am a research psychiatrist specializing in research on schizophrenia and manic-depressive illness (also known as bipolar disorder) and am affiliated with the National Institute of Mental Health (NIMH) Neuroscience Center as a Guest Researcher. I am also an advocate for individuals with serious mental illnesses and work pro bono with the National Alliance for the Mentally Ill (NAMI) and with the Public Citizen Health Research Group. In this capacity I have been the primary author on several studies concerning deinstitutionalization, including one report on seriously mentally ill persons in the nation's jails (Criminalizing the Seriously Mentally Ill: The Abuse of Jails as Mental Hospitals, 1992), and three reports on public services for individuals with serious mental illnesses in each state (Care of the Seriously Mentally Ill: A Rating of State Programs, 1986, 1988, and 1990). I also have authored a book about the homeless mentally ill and their relationship to deinstitutionalization (Nowhere to Go: The Tragic Odyssey of the Homeless Mentally Ill, Harper and Row, 1988).

Perhaps my most important qualification for appearing before you today, however, is the fact that I have a sister who has had schizophrenia for 37 years. For almost 30 of these years, she was hospitalized in New York State hospitals before being deinstitutionalized.

I wish to make four points this morning regarding deinstitutionalization.

1. Deinstitutionalization has been the largest social experiment in 20th century America, exceeded only by the New Deal.

2. Deinstitutionalization has been a success for many, but a tragic failure for many others.

3. The principal reasons for the failures have been (a) misunderstanding the causes of serious mental illnesses, and (b) a thought-disordered funding system which guarantees failures.

4. The Senate Finance Committee has the opportunity to correct both these errors, specifically by (a) ensuring that health care reform covers brain diseases such as schizophrenia and

manic-depressive illness in the same manner as it covers brain diseases such as multiple sclerosis, Parkinson's disease, and Alzheimer's disease; and (b) ensuring that the financing system removes the fiscal incentives for states and counties to dump patients into the community without providing adequate aftercare.

1. Deinstitutionalization has been the largest social experiment in 20th century America, exceeded only by the social programs of the New Deal.

It is important to realize the magnitude of deinstitutionalization. In 1955 there were 559,000 seriously mentally ill individuals residing in state psychiatric hospitals. If there were a proportionate number of individuals in state psychiatric hospitals today based on population, that number would be 869,000. In fact there are less than 89,000 individuals remaining in these hospitals. That means that approximately 780,000 individuals who would have been in the hospitals in 1955 are today living outside of those hospitals. This is approximately the same number of people as live in Baltimore or San Francisco and more than the number who live in Washington, D.C., Boston, Cleveland, or Denver. In New York State it is the equivalent of the populations of Buffalo, Rochester, Syracuse, and Utica combined.

2. Deinstitutionalization has been a success for many individuals, but a tragic failure for many others.

Deinstitutionalization was fundamentally a humane and reasonable idea. It has been clearly proven that the majority of individuals who resided in state psychiatric hospitals in 1955 can, and should, live in less restrictive and more homelike settings in the community.

However for many others, deinstitutionalization has been a tragic failure. Evidence of such failure include the following:

a. Homeless seriously mentally ill: Several studies have found that approximately one-third of homeless individuals have schizophrenia or manic-depressive illness. Among homeless women

the proportion in some cities is as high as two-thirds. Among homeless individuals living on streets, not just in shelters, the proportion with schizophrenia and manic-depressive illness is also more than one-third. Depending on what estimate of the total homeless population one accepts, this means that there are at least 150,000 homeless individuals with schizophrenia and manic-depressive illness. Some of them also have secondary problems with substance abuse but their primary problem is their mental illness.

b. Jailed seriously mentally ill: The 1992 survey of the nation's jails which we carried out found that a minimum of 7.2 percent of all inmates have schizophrenia or manic-depressive illness. Given the fact that there were over 426,000 individuals in jail on any given day in 1991, this means that approximately 30,700 of them had schizophrenia or manic-depressive illness. The number in prisons is approximately twice that number. Most of them are incarcerated for misdemeanors such as trespassing, shoplifting, or being a public nuisance. A minority of them have no charges against them and are merely being held in jail pending the availability of a public psychiatric bed. In fact, 29 percent of jails in the United States reported holding mentally ill persons against whom no charges were pending. Sixty-nine percent of jail administrators reported that the proportion of seriously mentally ill individuals in jail has increased in the past five years.

c. Suicides: Suicide is an increasingly common outcome of failed deinstitutionalization. Recent studies of individuals with schizophrenia have reported that between 10 and 13 percent of individuals with schizophrenia kill themselves. Previous studies have reported the suicide rate for manic-depressive illness as 15 to 17 percent. The suicide rate in the general population is one percent.

d. Acts of Violence: It was said for many years that individuals with serious mental illnesses are not more violent than the general population. That, it turns out, is true only for seriously mentally ill individuals who are receiving medications and other treatment. Recent studies have shown conclusively that seriously mentally ill individuals who are not receiving medications and other treatment are more dangerous than the general population and that such acts of violence are

increasing (Torrey, E.F., "Violent Behavior by Individuals with Serious Mental Illnesses," accepted for publication in Hospital and Community Psychiatry).

e. Revolving door reshospitalizations: Seriously mentally ill individuals for whom deinstitutionalization has failed are increasingly re-admitted to hospitals. It is no longer unusual to find individuals who have been admitted to hospitals 100 times or more (Geller, J.L., "A Report on the Worst State Hospitals Recidivists in the U.S.," Hospital and Community Psychiatry 43: 904-908, 1992). Many of these individuals migrate from hospitals to shelters to the streets to jails and back to hospitals again, a 20th century migration reminiscent of the 16th century ships of fools which sailed from port to port never allowing their mentally ill passengers to disembark.

f. Transinstitutionalization: Many mentally ill individuals who have been said to be deinstitutionalized were in fact not deinstitutionalized but merely transinstitutionalized. For example, last week I visited a residential care facility (RCF) in northwestern Iowa. It holds 38 mentally ill and mentally retarded individuals. It looks and functions exactly like a nursing home except that there is virtually no monitoring of it. The facility is not subject to federal inspection because it is not an Intermediate Care facility (ICF). It is theoretically subject to state inspections but the state had not inspected it in over five years because it claims it does not have the funds for such inspections. There are 6,683 individuals in 183 RCFs in Iowa today, the largest has 216 beds, which is larger than three of the four state psychiatric hospitals.

Last week I also visited an Institution for Mental Diseases (IMD) in California. IMDs have up to 240 seriously mentally ill individuals. California has 35 IMDs with about 3,500 total beds. I have visited three, and all of them looked and functioned exactly like a state psychiatric hospital. Many are operated by for-profit corporate chains. One IMD on the grounds of Metropolitan State Hospital in Los Angeles has actually leased a building from the hospital. Some of the same patients who where in that building when it was part of the state hospital are in it again today, perhaps even in the same beds, when it is called an IMD. This is true transinstitutionalization.

3. The principal reasons for the failures of deinstitutionalization have been (a) misunderstanding the causes of serious mental illnesses and (b) a thought-disordered funding system which guarantees failures.

Thirty years ago, when deinstitutionalization was being planned, we did not understand the nature of schizophrenia and manic-depressive illness. Many people thought that they were caused by bad parenting, early childhood traumas, or by conditions in society. We no longer believe such theories. Rather, studies have conclusively shown that schizophrenia and manic-depressive illness are diseases of the brain.

We can now measure differences in brain structure and brain function in such individuals. For example, in a recent study of identical twins in which one has schizophrenia or manic-depressive illness and the co-twin is completely well, we were able to identify the sick twin on the basis of brain structure alone in a high percentage of cases (E. F. Torrey, et al., Schizophrenia and Manic-Depressive Illness, Basic Books, 1994). Attached to this testimony are pictures of such twins, pictures of differences in brain ventricular size, and a graph showing that differences in the size of the hippocampus and amygdala distinguished the sick twin 80 percent of the time. We know that these brain changes are not the result of medications taken by the sick individuals because the same brain changes have been found in other studies in which individuals with schizophrenia and manic-depressive illness had never received medications.

What these findings mean is that schizophrenia and manic-depressive illness are brain diseases, exactly as multiple sclerosis, Parkinson's disease, and Alzheimer's disease are brain diseases. In all these diseases we can measure structural and functional changes in the brain. And in all of them we do not yet know precisely what causes the changes, although research is focusing on such things as genes, viruses, neurochemical changes, and biological brain insults at specific periods of brain developments.

The other principal reason for the failure of deinstitutionalization has been the thought-disordered funding system. One of the symptoms of schizophrenia is a thought disorder in which the

individuals can no longer think logically. The thought disorder found in schizophrenia is minimal compared to the thought disorder in the funding system for services for such individuals.

Prior to 1965, 96 percent of the cost of public services for individuals with serious mental illnesses was borne by state governments. However, when deinstitutionalization was begun, individuals who were discharged from the hospitals were made eligible for a variety of federal support programs, including Medicaid, Medicare, SSI, SSDI, food stamps, HUD-202 housing vouchers, etc. What this effectively did was to create a gigantic fiscal carrot, encouraging states to discharge patients as a means of shifting the cost of care from the state government to the federal government. States have little fiscal incentive to ensure that discharged patients receive medications or aftercare. If such individuals relapse, they are often referred to psychiatric wards in general hospitals where Medicaid will cover much of the cost.

In recent years this fiscal buck-passing has become even more complicated as some states have also shifted fiscal responsibility to counties or cities. In states like New York, the fiscal buck-passing between the federal, state, and New York City government has taken on the character of a three-way tag team wrestling match. The losers in this match are individuals with serious mental illnesses.

In most states today the single most important function of state departments of mental health is to find additional ways to shift the cost of psychiatric care from state government to the federal government. This is the main reason why nursing homes, residential care facilities, IMDs, and similar institutions in other states have supplanted state psychiatric hospitals. It is also an important reason why aftercare of discharged patients is so disjointed and ineffective resulting in homelessness, jailings, suicides, acts of violence, and the revolving door of rehospitalization. In 1988, I estimated that the federal share of the cost of services for seriously mentally ill individuals had increased from four percent in 1965 to 38 percent in 1985. Today I would estimate that the federal share has increased to between 50 and 60 percent of the total and is still rising.

4. The Senate Finance Committee has the opportunity to correct both these errors, specifically by:

a. Ensuring that health care reform covers brain diseases such as schizophrenia and manic-depressive illness in the same manner as it covers brain diseases such as multiple sclerosis, Parkinson's' disease, and Alzheimer's disease. The brain is a single organ. It is both illogical and discriminating to provide full coverage for a disease like multiple sclerosis but only partial coverage (e.g. limited hospital days, higher co-payment for outpatient visits) for a disease like schizophrenia. This is analogous to providing full coverage for some heart diseases but only partial coverage for other heart diseases.

Schizophrenia and manic-depressive illness should be covered under any health care plan at parity with other diseases. A few other psychiatric diseases for which there is also strong evidence that they are brain diseases should also be covered: these would include severe recurrent depression, obsessive-compulsive disorder, panic disorder, anorexia and bulimia, childhood onset pervasive developmental disorder, and Tourette's syndrome. I personally do not believe that it is necessary, or fiscally feasible, to cover all "mental disorders" as defined by the standard diagnostic manual of the American Psychiatric Association. For the majority of these disorders, there is no evidence that they are brain diseases.

b. Ensuring that the financing system removes the fiscal incentives for states, counties and cities to dump patients into the community without providing adequate aftercare. As long as states are rewarded for dumping patients, they will continue to do so. The financing system must be changed so that the fiscal rewards come from providing care, not in failing to provide it. This might include a variety of financial strategies including giving federal Medicaid waivers to states to encourage creative approaches to services and block granting the Medicaid dollars for psychiatric services to the states and then monitoring the services.

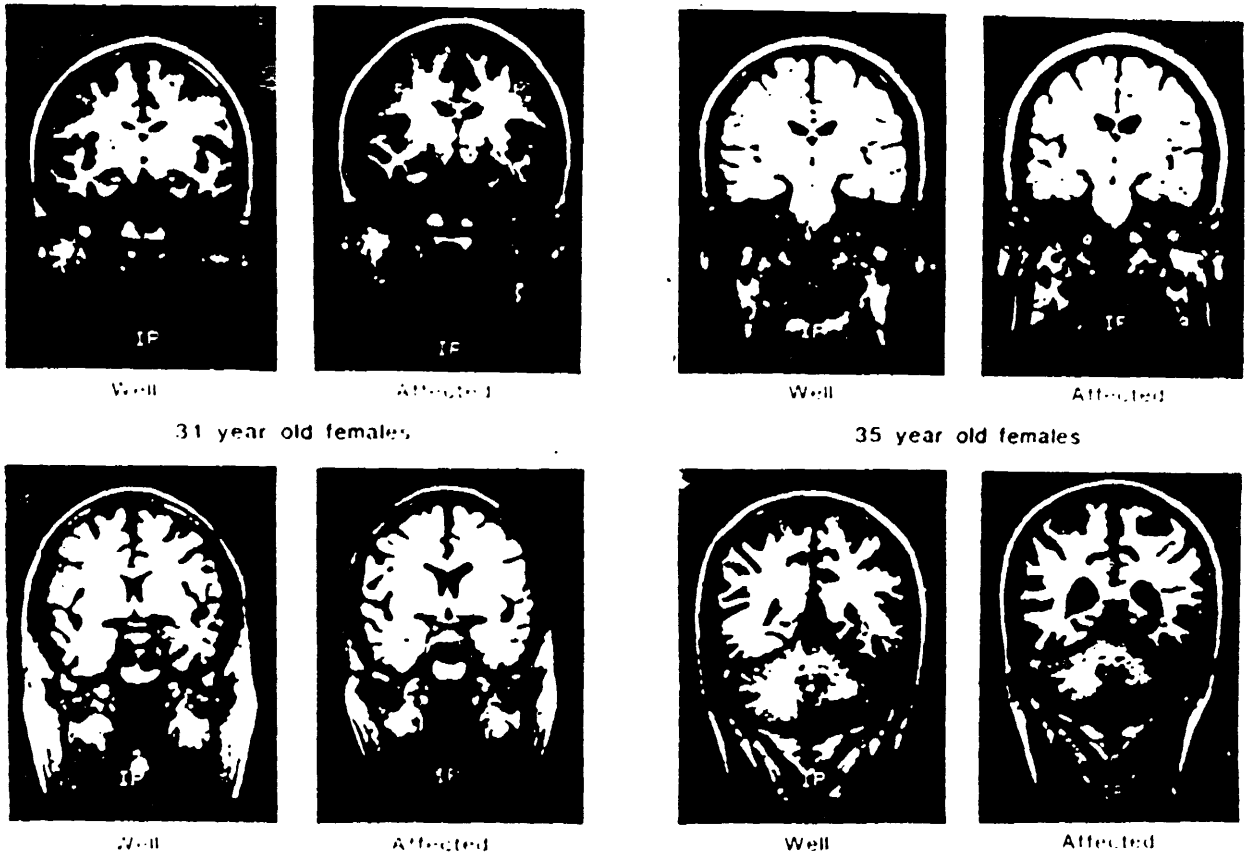
What is clear is that under the current financing system, services for individuals with serious mental illnesses are unlikely to improve, and the failures of deinstitutionalization will continue to haunt us.

Identical twins, now age 30, in which the twin on the left has remained well and the one on the right developed manic-depressive disorder at age 24.

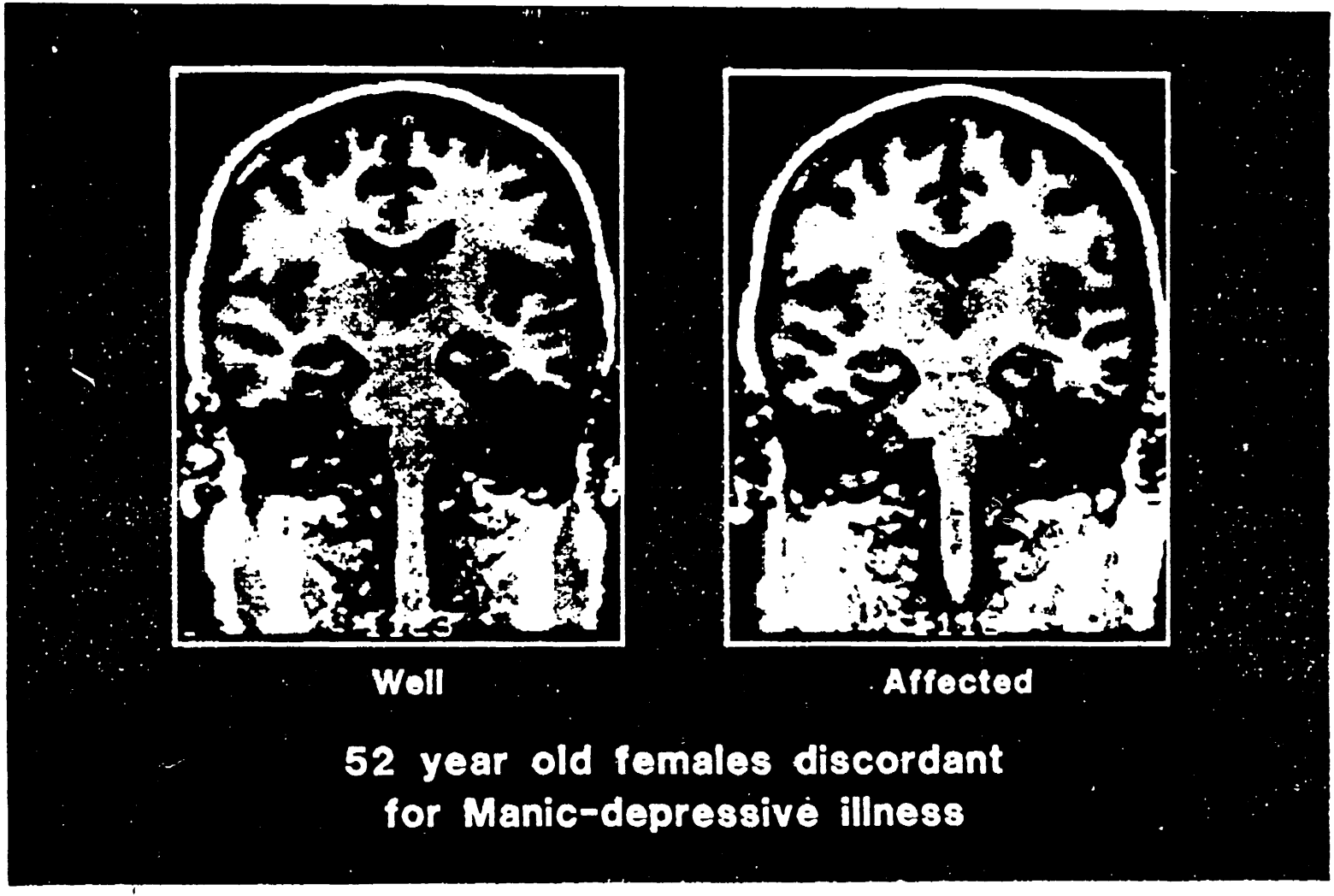
Identical twins, now age 24, in which the twin on the left has remained well and the one on the right developed manic-depressive disorder at age 17

Identical twins, now age 31, in which the twin on the right has remained well and the one on the left developed schizophrenia at age 20.

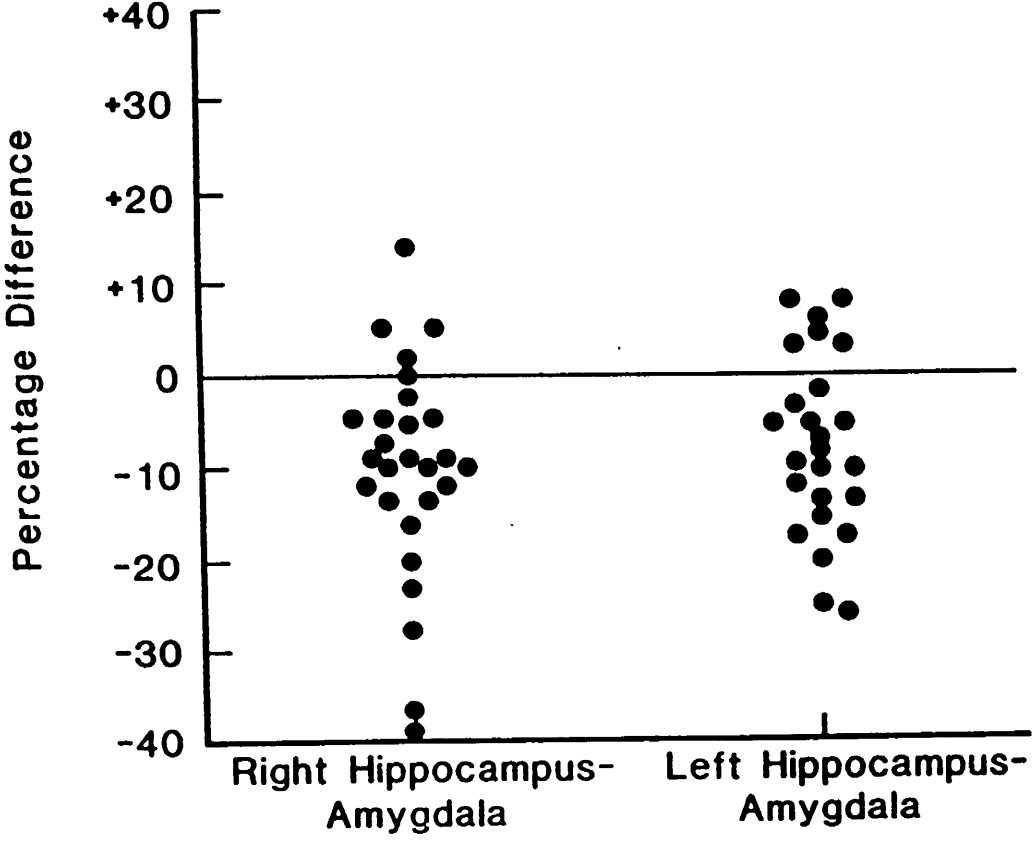
Identical twins, now age 29, in which the twin on the left has remained well and the one on the right developed schizophrenia at age 22.



MRI Scans from 4 identical twin pairs discordant for schizophrenia showing varying degrees of increased ventricular dilatation in the affected twin compared to the well twin.


Well
Affected
52 year old females discordant
for Manic-depressive illness

Hippocampus-amygdala size in identical twins discordant for schizophrenia: Percentage difference of affected twin minus well twin.



COMMUNICATIONS

STATEMENT MEDCO BEHAVIORAL CARE CORPORATION

Chairman Moynihan and Members of the Committee: We appreciate the opportunity to present our views and recommendations on mental health care issues, especially the importance of managed care arrangements for treatment of mental illness. We cannot tackle the domestic issues of health, welfare, homelessness and crime without addressing mental health coverage. If we do not include treatment of mental illness in our domestic agenda today, our children will pay for our mistake tomorrow.

Medco Behavioral Care Corporation is the nation's largest manager of behavioral health care. Medco Behavioral Care manages the cost, quality and access to psychiatric and chemical dependency treatment for over 12 million people.

Managed behavioral health care specializes in managing the cost and quality of psychiatric and chemical dependency treatment on behalf of a payer. Managed behavioral health care arrangements utilize a combination of individualized case management conducted by specialists, individually selected caregivers, and quality assurance and utilization review to achieve the most effective care. The success of a managed behavioral health care program is related to the added value to a patient and a payer.

We have devoted years to planning and operating efficient behavioral treatment programs for private insurers, HMOs, PPOs, employers and unions, as well as for government payers including state employee health benefit programs, Medicare and Medicaid.

It is from that perspective that we have arrived at these conclusions:

1. Treatment of mental illness and chemical dependency can be cost-effective;
2. Improved patient access to appropriate services and cost containment have only been achieved as a result of specialty managed behavioral care arrangements;
3. Managed behavioral health care can save billions of dollars in current spending for physical and mental well-being; and
4. Specialized managed behavioral care arrangements, whether by internal resources or by contract with independent expertise, should be used by the health plans used under any national health reform.

STUDIES BASED ON ACTUAL DATA

There has been a flurry of hypothetical economic models, including utilization assumption and cost estimates for mental illness and chemical dependency treatment under various benefit plans and for varying populations. However, instead of relying on such theoretical numbers, Congress should know that actual data do exist.

Managed behavioral health care companies have years of experience in managing the psychiatric and chemical dependency health care delivery system and now manage the mental health care for payers covering over one-third of Americans. With this experience, behavioral health care managers can achieve net savings of 25-40 percent over traditional open-ended, fee-for-service coverage. Typically, this result is achieved by saving 25-30 percent through more appropriate utilization (e.g., greater use of outpatient services and crisis intervention) and an additional 15-20 percent through decreased costs per unit of service, with a 10-15 percent increase to administer the program.

We would like to summarize the results of three new studies that analyze actual data on the cost, quality and access to treatment of mental illness under managed care arrangements. These studies were independently conducted for the American Managed Behavioral Healthcare Association (AMBHA), of which we are a member.

One AMBHA study, conducted by the leading actuarial consulting firm Milliman & Robertson, measured the cost of providing treatment with the benefits as pro-

posed in President Clinton's Health Security Act (HSA). With those benefits, in an employed population covering over 35 million lives, the actual cost of providing the treatment was $139 per person per year in a managed indemnity plan which is equivalent to the high option benefit in the HSA plan, $64 in a preferred provider organization (PPO) plan which is equivalent to the blended option in the HSA plan, and $41 in a health maintenance organization (HMO) which is equivalent to the low option plan in the HSA plan. These results based on actual experience contrast sharply with various economists' estimates that call mental health care costs "uncontrollable."

Just as dramatic, the rate of annual cost increases is favorably affected by the intensity of managed care. Specifically, the study demonstrated that in the past two years costs increased by 1 percent per year, less than the cost-of-living, for coverage in HMOs and PPOs, but 9.5 percent for managed indemnity plans.

The second study analyzed the costs of treatment not only among the employed population, but among Medicaid enrollees, the uninsured and the seriously and chronically mentally ill. In an unprecedented cooperation between the public and private sectors, AMBHA members and the National Association of State Mental Health Program Directors (NASMHPD) collaborated in this study. Milliman and Robertson were again contracted to collect the data and analyze them. This report is to be released on May 19. The study will demonstrate that the costs of treating all segments of society, if the care is managed, is significantly less than almost all published estimates to date.

Of course, some say costs are controllable, but at the loss of access and quality. Yet in the third study which will be released May 11, Foster Higgins dramatically found that access more than doubled in managed behavioral care settings and quality was sustained.

If costs can be decreased and controlled and access to quality care can be improved, why not include the requirement in any health care reform package that all psychiatric and chemical dependency treatment programs be managed by specialty managed behavioral care systems?

PRINCIPLES OF MENTAL HEALTH MANAGED CARE AND HEALTH REFORM

We strongly recommend adoption of following principles to provide for the foundation of a mental health and substance abuse benefit in health care reform:

1. Treatment of mental illness and chemical dependency is a necessary component of any health care benefit package.
2. Establishing parity for behavioral health care benefits with physical health care benefits is essential to health care reform.
3. The goals of improved access, cost-effectiveness and quality require a broad, flexible continuum of treatment alternatives offered and managed on an individual case management basis.
4. Effective health care requires the coordinated efforts of general medical and managed behavioral health care professionals within an integrated system. The behavioral health care managers' experience, specialized knowledge, comprehensive data systems, and ability to measure and improve treatment outcomes are fundamental in achieving the goals of health care reform.
5. Managed behavioral health care is proven effective in terms of access, cost and quality. This approach results in delivery of care that is medically necessary and appropriate to the patient's needs, optimizes treatment outcome, utilizes resources in the most efficient manner, assures continuity of care, and emphasizes collaborative efforts with patients and their families.

CONCLUSION

Mental illness and substance abuse affects millions of individuals at an annual price tag estimated at over $300 billion in direct and indirect costs. Comprehensive managed behavioral health care benefits are imperative if we are to conquer the rising health care costs that we are currently experiencing. We recommend this Committee enact a managed mental health care benefit as an integral part of national health reform.

We appreciate the opportunity to bring you up to date with the latest findings based on actual data and experience and look forward to working with you on behalf of Americans with mental illness.

STATEMENT OF JERRY RICHARDS

This testimony is based on direct personal experience, and is a recommendation for parity in health care coverage between mental and physical illnesses. My experience is with the treatment of my own mental condition, which has a specific, well established diagnosis of bipolar disorder, also known as manic-depressive illness.

In a hearing on May 10 of this year, the Committee was provided with expert medical testimony showing that, through use of brain imaging techniques, bipolar disorder, as well as other mental disorders such as schizophrenia, are physical diseases of the brain[1]. Other medical testimony you received on May 10 indicated a high rate of effectiveness for current treatment procedures[2].

That testimony is consistent with my personal experience. In 1982, after over two decades of my assuming I had various "life adjustment problems," and of wasting considerable money on psychological counseling, as well as on medication not specifically effective for bipolar disorder, a diagnosis based on both indirect and direct observations of my brain chemical function led to my receiving the most effective and economical treatment of my disorder.

This result was achieved because I could afford proper medical care. Without it I do not believe I would be here today. Even if I had survived inferior treatment, I doubt I would be able to make this testimony.

Now I am concerned about those who, because they could not pay enough out of their own pockets for necessary treatment of their mental illnesses, have not been as fortunate. I want you to feel that same concern, and to recognize what you can do to help.

First, consider how arbitrary it is for an insurance plan to impose limits of coverage on the basis of specific medical diagnoses. For example, for treatment of my bipolar disorder, the disease located in my brain, I have a prescription for the drug Nardil. For treatment of my Wolf-Parkinson-White syndrome, a disease located in my heart, I have a prescription for Tambocor, an equally expensive medication. One of the best, most comprehensive health plans I ever had, administered by Aetna, would pay the full cost of my heart medication, but only half the cost of my brain medication.

It is difficult for me to accept the idea that a private insurance company should presume to decide which organ of my body is more worthy of health coverage. For the federal government to endorse or mandate continuation of disparities in levels of coverage on the basis of disease category would only deepen the stigma already marking a vulnerable, sizable class of people still viewed by courts as too amorphous, too diverse in our characteristics to fall within an Equal Protection Clause.

We, as persons with mental illnesses, have yet to be regarded as meeting the legal definition of a discreet and insular group, but as our specific biological characteristics continue to be better understood by medical science, the vague generalizations are falling away. As this is happening, inferior coverage for treatment of our disorders is becoming as unacceptable as giving less coverage to blacks than to whites.

In the last decade I have been heartened by the rapid progress in the understanding of mental illness. I know from personal experience that mental disease, when acknowledged and understood, is responsive to treatment that is far more economical than the obsolete practices which in the past gave insurance companies an excuse to limit our coverage.

That excuse is outdated. The disparity between coverage of physical and mental disorders represents an increasingly suspect classification of those of us who have a need and a right to health care that is as valid as the claims presented by persons with disorders diagnosed as physical.

It is time for a legislative initiative which recognizes the emergence of a more rational understanding of actual mental illnesses warranting medical attention, in contrast to other behaviorally expressed difficulties in which the medical necessity of insured health care cannot be shown.

The economic boundaries of a health plan are best drawn along the line of medical necessity, and today, we have the diagnostic tools to discern reasonably well which specific mental difficulties deserve medical coverage. Many do not. Thus the distinction should not be between mental and physical, but between what is necessary to treat medically and what is not.

REFERENCES

1. Torrey, E. Fuller, M.D., "Deinstitutionalization," p. 5.
2. O'Brian, Charles P., M.D., Ph.D., testimony, p. 5.

STATEMENT OF THE VOICE OF THE RETARDED

(BY POLLY SPARE)

Mr. Chairman, thank you for the opportunity to present a written statement for the Finance Committee hearings on health care reform. We look forward to assisting you and members of the Committee as you continue to deliberate these important issues.

Voice of the Retarded (VOR) is a national, volunteer non-profit corporation with organizational and individual members in 48 states. It was incorporated in 1983 by a group of concerned Illinois parents in response to proposed federal legislation designed to phase out institutions for persons with mental retardation by withdrawing Medicaid support. VOR's charter was amended in 1992, expanding the scope of its activity and electing a nationally representative board of directors. I serve as President of VOR.

VOR provides information, support and advocacy services to individuals or groups as needed. We support alternatives in residential living and rehabilitation systems which provide for the special needs of persons with mental retardation and meets with the approval of his/her family or guardian. We endorse team planning that includes consumers, families, and people most familiar with the individual.

VOR does not provide proprietary services. We receive no public funding. Memberships and contributions support our activity. We are recognized as an information resource for related health care data, state and federal court actions, as well as legislation. VOR's primary focus is on continuity in high quality Long-Term Care programs for persons with mental retardation. In many cases, this means lifetime care (birth to death). Faced with finite state/federal financial resources, an ever-expanding need for service, and a large unserved/underserved community population, we are justifiably concerned about the direction of health care legislation for a cognitively impaired population too often incapable of self-determination and independence.

Senator Moynihan, we appreciated your remarks expressed in a Washington Post March 5, 1994 article entitled "A Cautionary Tale: the effects of government on health care. The Community Mental Health Center Construction Act of 1963 proved disastrous, because it was too ambitious an undertaking with too little knowledge and experience (as well as funding) with a population that could not always respond to our expectations. Homelessness could have been prevented if total deinstitutionalization had not been an absolute goal. You were correct in stating that "It's been absolutely catastrophic, a tribute to ignorance and all that is wrong." In spite of that disastrous experience, institutions today are still targeted for closure through lengthy and costly litigation involving Settlement Agreements, limited due process and repeated returns to the Courts. Plaintiff action more often than not is bought by publicly-funded advocates with an anti-institutional bias who seek expanded Medicaid support to implement what they believe to be the latest state-of-the-art philosophy. Just ten years ago, the argument was. small community residences are more normalizing and appropriate for everyone. Today's paradigm looks to independence, a home of his/her own and gainful employment. Some people with mental retardation will benefit, but many others—like my son and daughter with mental ages under 18 months, and who are chronologically over 38 years old, and neurologically impaired, osteoporotic, non-verbal, one blind-deaf, one with severe scoliosis—*their future cannot include independence.* Philosophy without reality should not dictate misdirected policy.

VOR is the only national organization that supports a full continuum of residential care options, including large specialized facilities for persons with mental retardation who need intensive support. Some states have excellent models that provide a continuum with inclusion of community resources that operate interchangeably. Montana and Utah have innovative community-based plans: a Main Street U.S.A. design that will accommodate all levels of disabilities and citizens. Individual states must be allowed flexibility with Federal guidelines to accommodate these different needs.

The VOR Executive Committee has approved the following Statement of Principles for consideration in any legislative proposal. They are based on the experience and knowledge of parents and professionals familiar with mental retardation.

HEALTH CARE PRINCIPLES VITAL TO VOR

(1) Provide Long-Term active treatment (birth to death) for citizens with mental retardation through home, community, institution or other large specialized setting.

(2) Provide retirement programs for senior citizens with mental retardation in a continuum of care in settings of all sizes.

(3) Require that states maintain one or more large specialized facilities for evaluation, training, centralized information, and residential treatment to support people with severe/profound disabilities.

(4) Support pharmaceutical and technological research into prevention and treatment of disease and disability to enhance quality of life, make outpatient care more feasible, reduce dependence on inpatient care and—reduce expenditures for Medicare and Medicaid.

(5) Create national quality assurance standards, including Long-Term care, for persons with Mental Retardation. Enforce and enhance state quality assurance activity and establish penalties for non-compliance.

(6) Combat health care fraud and abuse. Address violations and assure appropriate remedies.

(7) Continue Medicaid program for funding care options, including ICFs/MR.

(8) Continue Federal contributions to each state's Medicaid program at a single rate so that no preference is given to one choice of setting over another.

(9) Encourage the development of public and private sector Long-Term care insurance coverage, with portability, guaranteed renewability and no exclusion for pre-existing conditions.

(10) Offer unlimited choice of health care providers.

(11) Permit purchase (without penalty) of supplemental health coverage by consumers who choose it.

(12) Reduce health care overhead by simplifying and standardizing benefit administration nationally, and by establishing a secure health care database to expedite processing.

(13) Repeal authorization for DOJ Civil Rights (CRIPA) investigations and enforcement insofar as related to health care.

(14) Representation of Individuals with mental health retardation shall be defined as including, but not limited to, immediate family members and legal guardians.

(15) Provide tort reforms and limitations on malpractice awards.

The above points have been drafted as working guides by the executive committee and will be addressed by the VOR Board of Directors at the next meeting this month. As the Senate Finance Committee cannot wait in its deliberations for the more specific recommendations from VOR, I am submitting them now. A number of the points do invite further clarification. For example, our recommendations about the CRIPA statute and its enforcement derive from our experiences. The Department of Justice investigations and actions have resulted in downsizing and closure of large facilities—(often to the consternation of many parents), although the ostensible objectives have been improved conditions for residents. DOJ civil rights initiatives under CRIPA have become a part of the deinstitutionalization movement. Paradoxically, DOJ has little or no statutory authority to follow-up by investigating home or community conditions.

VOR supports retention of Medicaid as a funding option for mental retardation services. We support universal health care coverage, but recommend separation of acute and Long-Term care, which would significantly reduce Medicaid outlays and the cost to the federal government. Acute care for persons without health coverage who frequent hospitals' emergency rooms for routine treatment creates the most expensive form of health coverage. Acute care should be provided through an "Alliance."

We endorse an equal federal rate of reimbursement for all residential alternatives, HCB, ICF/MR and Waiver. The differential rate proposed for HCB programs (up to 90%) would create a severe anti-institutional bias. This negative effect would have unpredictable consequences to those citizens who require institutional care. Furthermore, all states have, for several years, sought increased federal financial participation to support new programs and are now dependent on these sources. Given the option for 90% as opposed to 60% they would elect the highest federal contribution, thereby arbitrarily jeopardizing institutions. Programs for persons with mental retardation should be unified, not treated separately.

Home and community are not always the most cost effective approach to care. According to our experience, and testimony provided by the Consortium for Citizens with Disabilities' Long-Term Services and Support Task Force, before the Senate Committee on Labor and Human Resources April 11, 1994, the funding and continuity of services are not adequate. The C.C.D. presenter was an Intellectually competent quadriplegic, a recipient of two hours per day of paid support, dependent on six additional volunteer hours by family and friends. At $10 per hour for an 8 hour day, an individual without volunteer assistance would need $29,200 per year, exclusive of costs for rehabilitation, health care, transportation, special equipment, room/board, and so forth. A cognitively impaired person with severe disability requiring 24-hour coverage would require a basic $90,000 per year plus all the above addi-

tional expense. This reveals not only the cost involved, but the problems associated with staffing and the realization that volunteer family and friends are not guaranteed for a lifetime. Institutions are a necessary back up service in situations such as this.

Thank you for the opportunity to present this written testimony. We look forward to working with you on health care reform. We would be happy to provide you with additional information.