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RECOMMENDATIONS TO IMPROVE MENTAL HEALTH CARE IN AMERICA: REPORT FROM THE PRESIDENT'S NEW FREEDOM COMMISSION ON MENTAL HEALTH

HEARING

BEFORE THE

SUBCOMMITTEE ON SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES

OF THE

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS
UNITED STATES SENATE

ONE HUNDRED EIGHTH CONGRESS

FIRST SESSION

ON

EXAMINING THE REPORT FROM THE PRESIDENT'S NEW FREEDOM COMMISSION ON MENTAL HEALTH RELATING TO RECOMMENDATIONS TO IMPROVE MENTAL HEALTH CARE IN AMERICA

NOVEMBER 4, 2003

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RECOMMENDATIONS TO IMPROVE MENTAL HEALTH CARE IN AMERICA: REPORT FROM THE PRESIDENT'S NEW FREEDOM COMMISSION ON MENTAL HEALTH

TUESDAY, NOVEMBER 4, 2003

U.S. SENATE,
SUBCOMMITTEE ON SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES,
OF THE COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS,
Washington, DC.

The subcommittee met, pursuant to notice, at 10 a.m., in room SD–430, Dirksen Senate Office Building, Senator DeWine (chairman of the committee) presiding.

Present: Senators DeWine, Kennedy, Reed, Murray, and Clinton.

OPENING STATEMENT OF SENATOR DEWINE

Senator DEWINE. We welcome all of you today. I certainly welcome my colleague, Senator Kennedy, whom I look forward to working with closely on these issues particularly as we move forward on the reauthorization of the Substance Abuse and Mental Health Services Act.

Today we are meeting to talk about the report and recommendations made by the President's New Freedom Commission on Mental Health. The findings in this report are certainly very important but also very troubling.

Each year, approximately 5 to 7 percent of adults and 5 to 9 percent of children experience serious emotional disturbances or serious mental illness. These illnesses are a great impediment to their daily function. Mental health is fundamental to a person's overall physical health and well-being and is crucial to leading a productive and balanced life.

Mental illnesses such as depression and schizophrenia are illnesses as destructive as cancer or heart disease. Mental illness ranks first among illnesses that cause disabilities in the United States, Canada, and Western Europe.

The World Health Organization has reported that suicide worldwide causes more deaths each year than war or murder and is the leading cause of violent death.

Despite such staggering statistics, it is apparent that there continue to be barriers to treatment for a great number of those who suffer from mental illness. In a 1999 report by the Surgeon General on the topic of mental health, he said: "Research-based capacities

to identify, treat, and in some instances prevent mental disorders are outpacing the capacities of the service system the Nation has in place to deliver mental health care to all who could benefit from it."

Clearly, this leaves a great number of people with mental illness suffering.

We know that the monetary and emotional toll of mental illness is very high in this country. Annually, the indirect economic cost of mental illness is around $79 billion, $63 billion of which is due to lost productivity.

There is also a tremendous cost to the system for the incarceration of mentally ill offenders. Approximately $4 billion is lost in productivity for the incarcerated who have mental illnesses and for the lost time of those who provide family care.

The difficult issues surrounding the incarceration of mentally ill offenders are discussed in this report and are issues that have been of great concern to me for quite some time. In an effort to address this problem, I worked with my fellow Ohioan, Congressman Ted Strickland, to introduce the Mentally Ill Offender Treatment and Crime Reduction Act, which recently passed the Senate. This bill offers grants to create and expand mental health courts and also provides training for officers in criminal and juvenile justice agencies to help them properly identify offenders who may be mentally ill.

This bill also has received broad bipartisan support. I want to thank Senator Kennedy for his work on the bill. And I feel it is very important, both to public health and to public safety, that we continue to move forward on this bill.

The report that we are examining today will help us do even more here in Congress to help ease the suffering of the mentally ill. I look forward to hearing the goals and recommendations in this report as well as plans for implementation. This report has the potential to be a concrete starting point for the Federal Government, the States, and the mental health community in reforming the current system.

On our first panel this morning, I would like to introduce Dr. Stephen Mayberg and Administrator Charles Curie. Mr. Stephen Mayberg comes to us from the California Department of Mental Health, where he serves as director. Dr. Mayberg was appointed director in 1993 and was reappointed in 1999. Prior to his appointment, he served as director of the Yolo County Mental Health Program. He has served as president of the California Mental Health Directors Association, president of the National Association of State Mental Health Program Directors, and president of the NASMHPD Research Institute.

Administrator Curie is from the Substance Abuse and Mental Health Services Administration. He has been gracious enough to testify at two previous hearings of this subcommittee, and we thank him for doing that.

Prior to his confirmation as administrator in October 2001, Mr. Curie served as deputy secretary for mental health and substance abuse services for the Department of Public Welfare in Pennsylvania. During his tenure, he established and implemented a policy to reduce and ultimately eliminate the use of seclusion and re-

straint practices in the State hospital system. This program won the 2000 Innovations in American Government Award sponsored by the Harvard University John F. Kennedy School of Government, the Ford Foundation, and the Council on Excellence in Government.

Mr. Curie also served as president and CEO of the Helen H. Stevens Community Health Center in Carlisle, PA and executive director and CEO of the Sandusky Valley Center in Tiffin, OH.

Let me now turn to Senator Kennedy for introductions of our second panel.

OPENING STATEMENT OF SENATOR KENNEDY

Senator KENNEDY. Thank you very much, Mr. Chairman.

I might just make a brief opening comment, and I want to first thank Senator DeWine. He was really responsible for our committee developing this Subcommittee on Substance Abuse and Mental Health Services because of his long-time interest and strong commitment. We are hopeful that in this Congress not only will our committee be more involved and active but also that the Senate will in terms of our national debate and action. So I want to thank him very much for all that he has done in developing the subcommittee and also for calling this hearing today.

As the President's Commission reports, our mental health system is in crisis and is providing inadequate care. Too many people are falling through the cracks and not obtaining the care they need. Improving access to mental health care is one of the most important health issues facing the Nation. One of the saddest examples of the crisis is the emerging issue of families giving up custody of their children because mental health care and support are not available.

We have legislation with Senator Grassley and myself, cosponsored by more than 77 Members of the Senate, and the funding is already in the budget, so we are very hopeful that we can get that legislation passed before we adjourn this fall.

As the report makes clear, the mental health system needs far more than simple repair. A broad transformation is needed. Mental illness should be treated with the same urgency as other medical problems.

When the President announced the formation of the Commission, he urged Congress to enact legislation that would provide full parity in health insurance coverage of mental and physical illnesses. He emphasized that limits placed on benefits are a major barrier to mental health care. Yet the legislation needed to bring parity to mental health care is still far from enactment.

It has been 3 years since the "Mental Health Equitable Treatment Act" was first introduced by Senator Domenici and Senator Wellstone. In this Congress, it has broad bipartisan support, with 66 Senate cosponsors. The American people should not have to wait any longer for this help.

The bill brings first-class medicine to millions of citizens who have been second-class patients for too long. Passage of the Paul Wellstone Mental Health Equitable Treatment Act should be the first order of business in transforming the mental health system in the Nation.

The crisis in coverage has many harmful consequences. Private practitioners are withdrawing from managed care networks over concerns about adequate reimbursement, and patients are left struggling to find doctors who will treat them. Often, patients face a 50 percent copay for mental health services compared to the customary 20 percent for physician office visits. Many do not get the treatment they need for mental disorders because of the higher copayment.

The report also cites another key barrier—the shortage of mental health professionals trained to work with children and adolescents particularly in rural areas. Disparities like this in mental health services should be eliminated, and early mental health screening and assessment should be common practice.

The failure by a patient to obtain treatment can mean years of shattered dreams and unfulfilled potential. Americans with mental illness deserve health and happiness, too, just as those with physical illness.

One in five Americans will suffer some form of mental illness this year, but only one-third of them will receive treatment. Millions of our fellow citizens are unnecessarily enduring the pain and sadness of seeing a loved one or a friend battle illnesses that seize the mind and break the spirit.

Now is the time for Congress and the administration to take action to address the mental health crisis in our Nation. I look forward to the important testimony we will hear today and to working with my colleagues to achieve the reforms so clearly needed.

I might mention, Mr. Chairman, that we have excellent studies that go back to the Carter Administration. Rosalyn Carter appeared before this committee and was one of the first First Ladies to testify on mental health. She was very impressive then, and she continues to maintain a very high profile and a great interest in this issue, and I believe she was over in the House of Representatives testifying as well. She has done an extraordinary job.

Then, we had the 1999 Surgeon General's report, and now we have this report. So it is really coming down to whether we have the will to take action.

I think we have seen the documentation of what is necessary and what is needed, analyzing the challenges that we have out there in terms of the fragmentation and the failure to reach parity. But as we are looking at the failure to reach parity, we fail even in the Medicare system, the public system. We have not done our job even here in terms of making sure that that system is going to have full parity.

What we are finding out is that the longer we wait—and today we are going to hear some excellent testimony—it is getting more difficult to develop providers. The numbers are shrinking, reimbursement obviously is poor, the paperwork is exhaustive, and the gymnastics that doctors have to go through in order to treat their patients correctly in terms of getting proper treatment for them is wearing on the doctors as well as on the patients. Children and the elderly are the most vulnerable, and we see that and hear about it time and time again, and we have not done what is necessary.

So I want to thank the chairman. He is a man of resolution and determination, I know, and he works to try to see how we can work

across the span to try to get bipartisan support. We want to thank him very much for having this hearing, and we commit ourselves to working with the chair and all of the members of the committee.

Just briefly, I want to thank Paul Appelbaum, at the University of Massachusetts Medical School. It is a great pleasure. He is currently director of the Department of Psychiatry at the University of Massachusetts Medical School and has been a practicing psychiatrist for 20 years. I want to thank him for his commitment to treating the indigent and working poor. He has had an extraordinary commitment to that over the course of his life.

He is immediate past president of the American Psychiatric Association, where he highlighted the growing problems of persons with mental disorders in accessing needed psychiatric services both in terms of personnel and facilities. It is a very important message for us.

And I want to thank Ann Buchanan who will be telling us a human story. She is enormously courageous, and we look forward to her testimony.

Thank you, Mr. Chairman.

Senator DEWINE. Senator Kennedy, thank you very much.

Senator Reed?

OPENING STATEMENT OF SENATOR REED

Senator REED. Thank you very much, Mr. Chairman, and let me also commend you, not only for scheduling this hearing but for your consistent and determined advocacy for mental health issues and so many other issues in the U.S. Senate and the United States Congress.

I want to thank the witnesses for being here. The New Freedom Commission is another in a series of reports which suggest that our mental health care system is broken and needs significant reform. And policymakers at every level—national, State, and local—have to be concerned about this system.

I am particularly disappointed as we begin this hearing that we have yet to move on the Paul Wellstone Mental Health Parity Act. I think that measure alone would contribute significantly to improving the system of mental health care throughout the United States.

We have seen despite our initial efforts to achieve mental health parity, the insurance companies have found ways around it. What we want to do is find a way so that they can deliver care that meets the needs that we see out there in society.

I think indeed, one of the first steps we should take in this reform effort is to pass the pending Paul Wellstone Mental Health Parity Act, but as the Commission points out, that is not the only step that we can take and must take. In my own State of Rhode Island, we have a very, very active group of mental health practitioners and support systems, but we still have problems. One of the key problems is in the area of childhood and adolescent mental health services. We have a wonderful hospital, Bradley Hospital, the only psychiatric hospital in the Nation to exclusively treat children and adolescents with mental illness, and they do a remarkable job. Yet that hospital and that system of care for adolescents and children is under great pressure and great stress.

In many cases, we are failing the children of this Nation when it comes to providing effective mental health services, and that is a problem that we will not only regret, but suffer for many decades going forward as these children mature into adults.

Ann Buchanan, as Senator Kennedy pointed out, will tell the story of her son Rusty, who experienced the problem of "aging out" of the system, being in that awkward transition from an adolescent mental health care system into the adult system, and that transition is difficult and in some places impossible.

But again, I hope we can rally the support and, as Senator Kennedy said, the will to do what increasingly is clear that we must do, and that is to fix our mental health care system.

Thank you, Chairman DeWine.

Senator DEWINE. Thank you, Senator Reed, very much.

What we will do for all of our witnesses today is follow a 5-minute rule, and we would like you to condense your testimony to 5 minutes. We already have everyone's written testimony, so if you could just condense it to 5 minutes, that will give us an opportunity to ask some questions.

Dr. Mayberg, thank you for joining us.

STATEMENTS OF STEPHEN W. MAYBERG, COMMISSIONER, THE PRESIDENT'S NEW FREEDOM COMMISSION ON MENTAL HEALTH, SACRAMENTO, CA; AND CHARLES G. CURIE, ADMINISTRATOR, SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Mr. MAYBERG. Thank you, and good morning, Mr. Chairman and subcommittee members.

I am Stephen Mayberg. I have submitted written testimony, and I think all of you have clearly articulated many of the issues and what brings us to this position. I will speak to you from my position as a commissioner on President Bush's New Freedom Commission on Mental Health and as director of the California Department of Mental Health, arguably the largest public mental health system in the United States.

As you know, there were 15 commissioners on this committee, the first group representing States, elected officials, constituency groups, family members, and consumers. There were seven ex officio members and representatives from Health and Human Services as well as HUD, Labor, Education, and Veterans' Affairs.

We were charged with looking at the public and private mental health system and the issues that led to the failures in our system, or the system in shambles, as we reported in our annual report, looking at three particular issues—stigma, fragmentation, and the disparities in private insurance between health and mental health. We focused in on fragmentation.

The charge was to complete this in 1 year. We found that the work was overwhelming and was more than we could handle in a year, but that did not stop us from holding monthly meetings and having two field visits, one to Los Angeles and one to Chicago.

We discovered that the issues are tremendously complex and not easily articulated in a short period of time. We had feedback from the public, from written testimony, expert testimony, invited testi-

mony, as well as reading voluminous amounts of material. We broke into 16 subcommittees because we could not get a handle on that and focused on specific issues like children's services, older adult services, the interface with the criminal justice system and the interface with the physical health system, cultural competence, acute care—all kinds of things like that.

What we came up with after 6 months was that it was in our minds true that the system was broken and needed to be transformed, not reformed, that services were fragmented for children and for adults, and for older adults, services were almost nonexistent, and there was a disproportionate amount of burden on us in terms of disability and employment of persons with serious mental illness.

In July, we submitted our report with a series of goals and recommendations and a vision that mental health needs to be a higher priority, that there should be a time in our future when mental illness can be prevented or cured, but every American deserves access to adequate treatment and support.

Let me quickly discuss the key goals and recommendations that we have made. First, we found that if we are to transform mental health care, our programs, from the Federal level to the community level, must shift toward consumer and family-driven services. Consumer needs and preferences—not bureaucratic requirements—must drive the services that they receive. To achieve that goal, the Commission recommends specific changes in Federal programs and upgraded State responsibility for planning effective services.

Second, we observed that the members of minority groups and people in rural areas today have worse access to care. "Place and race" does matter. Further, they often receive services that are not responsive to their needs. As a result, the burden of mental illness is heavier for those individuals. The Commission urged a commitment, again, from the community up to the Federal level to services that are "culturally competent," acceptable to and effective for people of varied backgrounds.

The Commission's review further found that too often, mental illness is detected late, not early. As a result, services frequently focus on helping people live with considerable disability rather than on intervening early, which nearly always yields better outcomes, with less disability, and a better opportunity for meaningful life in the community.

Thus, we recommend a dynamic shift in care toward a model that emphasizes early intervention and disability prevention and, as our report stated, "Early detection, assessment, and linkage with treatment and supports can prevent mental health problems from compounding and poor life outcomes from accumulating."

Achieving this goal requires better and more extensive engagement in education of first-line health care providers, primary care practitioners, but also demands a greater focus on mental health care in institutions such as schools, child welfare programs, and the criminal and juvenile justice systems. The goal is a system of integrated community-based care that can screen, identify, and respond to problems early.

The Commission also noted that a majority of adults, even those with the most serious mental illness, want to work but are held

back by poor access to effective job supports, incentives to remain on disability status, and employment discrimination. That, too, can be changed.

We also recognize that there is a gap between what we know and what we do, and there is a 15- to 20-year science-to-service delivery gap. We need to move our system forward where we use what we have learned in practice rather than leaving it in the journals, and that means changing our incentives to pay for that but also changing our training programs to make sure that people are educated appropriately in the latest state-of-the-art, state-of-science, services.

Finally, we feel that it is incumbent upon us to move into the 21st century and use the power of information technology more appropriately. We need to look at how to use patient records in ways that both protect privacy but use technology so that people get appropriate and adequate care and do not have to reiterate their issues time and time again.

We understand that the majority of Americans go to the Internet to look up issues of their disease, and we need to be able to put that in a usable form for most people when they find out that someone in their family or they themselves are suffering from a mental illness.

With these recommendations, our work is done and the work of all the rest of our advocates, friends, and policymakers begins. We truly believe that we have a blueprint for change. We hope that through a series of hearings like this and through the advocacy of all those in the mental health community, we will be able to achieve that change.

Thank you very much.

Senator DEWINE. Dr. Mayberg, thank you very much.

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

Senator DEWINE. Mr. Curie?

Mr. CURIE. Thank you, Mr. Chairman, Senator Kennedy, Senator Reed. I am honored to present on the President's New Freedom Commission on Mental Health and the administration's activities to achieve the goals contained in the Commission report.

I would also like to request that my written statement be submitted for the record.

First, I want to thank my friend and colleague, Steve Mayberg, for his contributions to the Commission's work. He is a great leader in California, and he was a tremendous leader and member of the commission.

I also want to recognize the leadership demonstrated by Michael Hogan, the director for mental health from Ohio, who was unable to be with us today, but he was chairman of the President's Commission, and Mike's steadfast commitment to do what is right for people with mental illness steered the Commission through many tough decisions and ultimately led to the final report which we are here to discuss today.

An important context for our work in the Bush Administration and the recommendations developed by the Commission is the words of people in our service delivery systems working to obtain and sustain recovery. In particular, the first position I held as a

new master's of social work graduate in a branch office in Fostoria, OH was working as a therapist to help mental health consumers, individuals coming out of at that time Tiffin State Hospital to make the transition back into the community. This aftercare group included consumers who had spent over a decade in the hospital. I asked them the question what they needed to make their transition successful and what they needed to deal with and manage their illness. They never spoke in terms of programs, they did not speak in terms of needing a psychiatrist or even a social worker, but what they spoke of was that they needed a job, a home, and meaningful personal relationships—or, to use a direct quote, "I need a life, a real life; I need a job, a home, and a date on the weekend." They want a life, a real life with its rewards.

This is the very essence of the recommendations contained in the final report of the President's New Freedom Commission. It is a privilege to serve President Bush and work for Secretary Tommy Thompson, as this is an administration that knows treatment works and recovery is real.

As you may know, SAMHSA has been given the lead role to conduct a thorough review and assessment of the final report of the President's New Freedom Commission on Mental Health, with the goal of implementing appropriate steps to strengthen our mental health system.

The "Mental Health System Recovery Plan," if you will, will require the implementation of a "To Do List" currently being developed by SAMHSA on behalf of the Bush Administration. The "To Do List" will form an action agenda to achieve transformation of mental health care in America. And I am very fortunate to have a lead staff person whom I have asked to address this internally for developing this action agenda, and she is Kathryn Power. Kathryn recently joined SAMHSA as director of our Center for Mental Health Services—she is standing up behind me—I was going to say we stole Kathryn from Rhode Island, but it benefits us greatly, and it is going to benefit the Nation greatly. She is working to develop an agenda for transformation that is built around the six goals and 19 recommendations contained in the Commission's report.

To lead the effort, I have assembled a transformation task force. We are already working with relevant Federal agencies to determine ways to provide States the flexibility needed and the incentive to bring to bear the full force of the resources available to meet the needs of people with mental illness.

Our agenda must be consumer and family-driven, not bureaucratically bogged down. Consumers of mental health services and their families must stand at the center of the system of care. Consumer and family needs must drive the care and services that are provided. The result will be more of our family members, coworkers, neighbors and friends living that rewarding life in their communities that I talked about in the beginning of my remarks.

In closing, we all need to recognize the changes that need to be made will not happen overnight. But what we structure, what we begin to pull together to develop this "To Do List" must assure that we keep pressing onward. Developing and implementing the action agenda for transformation will be an ongoing process. Clearly, our success will depend on our ability to span all levels of government

and the private sector to align and bring to bear the full force of resources available. The strategy will be to keep our focus on the needs of adults with serious mental illnesses, children with serious emotional disturbances and their family members. The goal is to make recovery a reality for everyone.

Thank you for your time and interest in our work, and of course, we would be pleased to answer any questions you may have at this time.

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

Senator DEWINE. Mr. Curie, thank you very much.

The "To Do List" that you are working on, again, when do you think that will be completed, and give us some more ideas about what you are looking at.

Mr. CURIE. Sure. We have actually begun working on the "To Do List," and we anticipate having a first draft of the document which describes our activities and immediate plans within the next 60 days. And again, we will have ongoing discussions with the committee as we are in the process of developing that.

Senator DEWINE. And in 60 days, we will be able to see that?

Mr. CURIE. Yes, yes. And in fact, what we will be doing in the meantime—at this point, some of the things that we are actually doing include conducting an inventory of those things that already are being implemented and being worked on within the Federal Government around the goals of the Commission. For example, there is a national suicide prevention plan that has been in the process of being developed over the past 3 to 4 years. We are looking to bring that into an action plan which would be relevant to achieving Goal 1, that mental health is essential to health and that we raise the awareness of mental health in this country, tying it to health, and have a real focus on suicide prevention and a multifaceted approach to raising the awareness of what mental illness really is and what society needs to be doing to begin to address that.

We are also pulling together a transformation task force in which we bring aboard the Federal agencies. Steve mentioned those agencies in his testimony. Not only, of course, will SAMHSA and HHS, with CMS, be involved with that, the National Institutes of Health, NIMH in particular, and ACF, Children and Families, within HHS and HRSA, but also HUD, Labor, Education.

Recovery is going to be framing this "To Do List." If we are looking at recovery, that is facilitating the process of helping people learn how to manage their illness and be able to manage their life and get that life. That is the end game.

Access to treatment is critical. Access to care is critical. Having the latest evidence-based practices and having incentives out there which will be part of this "To Do List" and how we work with financing and Medicaid to do that is going to be critical. But along with that, we also want to make sure that all the entities—and I did not mention Justice, but Justice will also be part of this task force—are helping people understand in general, particularly people with serious mental illness in their families, that we are here to help them build a life, because we also know that that prevents

relapse. We also know that ultimately, if you attain and sustain recovery, you are also overcoming that disability.

Senator DEWINE. Let me move if I could, because we do not have much time, to a follow-up to what Senator Reed said in his opening statement and that is an area that I think troubles all of us, and that is the whole problem with young people who have mental health problems. We are going to get into this further in this committee—in fact, we are going to hold at least one hearing on the whole issue of suicide among young people, and we are going to do that fairly shortly in this committee, and I think we will probably have another whole hearing just on mental health issues of young people—but let me ask both of you this. What is in this report that we should know about in the whole area of young people's mental health problems? Maybe another way of asking the question is, how are we doing as a country? How are we doing, what are we not doing, and what do we need to do? I am going to ask the second panel the same question.

Mr. MAYBERG. We are not doing very well, and the reason we are not doing very well is that first, the system is fragmented. Parents say to us time and time again, "We do not know where to get care. The system is opaque"——

Senator DEWINE. Where do I go.

Mr. MAYBERG [continuing]. Where do I go, whom to ask—and if I do ask somebody, they send me to somebody else, so that care is not coordinated.

We realize that our interventions with children are oftentimes many years after they have first exhibited symptoms, and by the time we intervene, many, many bad things have happened so that they have lost critical developmental milestones because they are struggling with the issues of their illness.

We have to provide more active outreach into the schools because children are in schools. Most kids are first seen by their primary care providers. We need to work out a system where our interface with primary care is much better. And we do a very, very poor job where our most disturbed kids are. We do not do the same kind of active outreach into the child welfare system and into the juvenile justice system like we should do.

So in summary, we are not treating the early end of it or the late end of it, and the system is opaque. So our recommendation is much more of a public health-type recommendation where we need to do earlier intervention, better identification, more empowerment of families to be able to move the system forward.

Senator Reed talked about issues of transition and where kids move out. We have two distinct systems. When someone graduates from our children's mental health system, a whole set of new rules and obligations occurs, and we lose them. We have invested lots of energy, and then they start all over again in the adult system.

Mr. CURIE. I could concur with everything Dr. Mayberg shared. Clearly, primary care linkage is critical because kids are seen there more frequently than in any mental health setting initially; also, school-based—and those are clear recommendations. Keeping the child with the family—you brought up earlier the issue around custody, and we need to address that. Parents should not have to give up custody of their children in order to receive mental health serv-

ices, and we need to address that as part of this action plan. It is unacceptable.

Also, a systems of care approach is important. We do have a track record through the Center for Mental Health Services of SAMHSA in which we have had over the past decade the establishment of systems of care which we see better outcomes—that is, making sure that all child care and child-serving agencies within a neighborhood are working to the benefit of a child. The reason that children's issues are so complex is because you are talking about multiple systems which engage children, and we need to make sure there is a consistent way of doing that.

One other example I would give of why early intervention and also applying what we know—and I think that with children, taking the science of what we know and making sure it is in the delivery system is critical. When we talk about people with co-occurring disorders, and we are seeing now that one out of every five adults with an addiction, according to our latest household survey, also has a serious mental illness, we now know that there is a window of opportunity in those teen years that when a mental illness is beginning to emerge, and kids begin experimenting with drugs, that is many times the beginning of a co-occurring disorder. We can intervene earlier and have a full assessment done. If a teenager, for example, is presenting himself because he is using drugs, make sure there is a full assessment done; is there an emotional disturbance or a mental illness involved in that situation? If you intervene in that window of opportunity in the teen years, you can give an individual years of a life in their twenties because you are treating them for the underlying disorder. We need to make sure that that is the expectation.

Senator DEWINE. Senator Kennedy?

Senator KENNEDY. Thank you.

I thank both of you for enormously powerful and distressing testimony. Just on this issue of what you call co-occurring disorders, what is SAMHSA doing now to try to deal with that?

Mr. CURIE. I am glad you asked that question, Senator. It is a top priority for SAMHSA. We submitted approximately a year ago a report to Congress on co-occurring disorders which offers a 5-year blueprint of how we can begin implementing a partnership with States, in particular, a structure which will bring the assessment of co-occurring disorders and treatment as part of the expectation of what we do.

We are in the process of awarding grants. This year, we are awarding grants to seven States, called our COSG grants, to Governors' offices, so that a Governor's office can bring together not only the mental health authority and the drug and alcohol authority, but the criminal justice authority because of the high rate of individuals in the criminal justice system with untreated co-occurring disorders.

We are also providing ongoing technical assistance. We have had a National Summit on Co-Occurring Disorders, and we are working very actively to raise it with the professional associations as well as the State mental health and drug and alcohol authorities. We are working in close partnership with the National Association of State Drug and Alcohol Directors as well as the National Associa-

tion of State Mental Health Program Directors to see to it that States have what they need to address this issue.

And I think for the first time, the most significant thing is that we have been able to quantify the issue. The household survey that we do each year now has a mental health component, and to be able to clearly show that one out of five people with an addiction or an abuse dependence problem has a serious mental illness—that is not just a mental health diagnosis, that is a functional assessment—tells us that it has got to be every door being the right door when you come to a treatment door, whether that be primary care, whether that be a mental health door or a substance abuse door.

Senator KENNEDY. Is this with regard to children; did the survey look at children, too?

Mr. CURIE. The household survey does include those 12 to 17, so we are able to capture the teenage population, yes.

Senator KENNEDY. Let me ask you, Dr. Mayberg, your Commission report strongly supports Federal legislation for mental health parity; is that correct?

Mr. MAYBERG. That is correct.

Senator KENNEDY. Do they also make a recommendation with regard to Medicare, that we ought to do something to address that issue?

Mr. MAYBERG. One of the important issues that we looked at was the whole issue of financing, and we did make a recommendation that any time there are discussions about Medicaid reform or Medicare reform, that mental health needs to be at the table and not be an afterthought. And there are some specific recommendations about particular issues that should be addressed when that discussion occurs, such as parity in Medicare, such as prescription drug costs.

Senator KENNEDY. Your earlier outline about the fragmentation and how families are trying to deal with this and are lost in trying to get a handle on it includes stories that we hear time and time again, and our failure to try to systematize this is one of the great public policy failures, I believe. And part of it is getting the framework and second is to get the resources out there.

How can we change the consumer-driven—most mental health services are controlled by managed care where choice is limited. We run up against this kind of challenge as well. How can we deal with this?

Mr. MAYBERG. We have several recommendations for how to deal with this. One, with the transformation, States need to take a more active role in developing a plan of care, and that means not just mental health, because mental health does not provide the majority of care for children or for adults, as it turns out, so we need to look at ways that States can plan the delivery of care, and there need to be some kind of incentives to be able to do that, to break down the silos.

Senator KENNEDY. Which States are doing that? Are any of them doing that now?

Mr. MAYBERG. None of them is doing that right now.

Senator KENNEDY. Well, this is the challenge you give us—to try to set an overall framework at the Federal level, but you want the flexibility within the States. I do not know what we are hearing

about how the States are going to use the flexibility to try to deal with the range of different issues and problems in terms of the prisons, child welfare. We have a great debate about health clinics in schools, and the basic reason that we do not have health clinics in schools is because people are concerned about the distribution of condoms. That is basically the reason. And we see what the loss is in terms of being able to work—some schools get around this, and I can tell you a dozen different schools in Massachusetts where it makes an enormous difference. They do have the health clinics, because they have worked the arrangements out with the local hospitals and so on, and it makes an enormous difference.

But what can you tell us about how we are going to as a society—is it resources, is it public policy? Here we are now. You have studied this thing. What are the real roadblocks in trying to get through this? We want you to knock hard on our door. Is it resources? Is it the willingness to deal with it? Is it the entrenched interests? Where does the responsibility lie—and if it is with us, we want to hear it.

Mr. MAYBERG. Senator, I will knock hard, and I think you addressed all of the issues. Part of it is a comfort with status quo. Part of it is a lack of knowledge. Part of it is bureaucratic silos that we have where there is an unwillingness to think about new ways of doing business. And part of what we really are looking at in our consumer and family-driven system is that the persons who are most disenfranchised are the recipients of service, and the more we can give them information and empower them, the more we can hope that there can be some pressures from a grassroots point of view to force these changes. I think that we make a mistake in our bureaucracies from not listening to that grassroots message. It certainly was true in California, not listening, that voters were feeling disenfranchised. And I think that consumers and family members are very disenfranchised right now. The more information we can give them, the more they can attack the bureaucratic and policy barriers that stop us from delivering quality care.

Senator KENNEDY. My time is up, but could I just ask you one question. We have a prescription drug bill that is in conference now. Can you make any kind of assessment about the people who know they have a problem, are trying to get prescription drugs for mental health and just cannot get them because of income limitations? Can you make a quick assessment? As I said, my time is up, but can you tell us now, or do you want to submit that?

Mr. MAYBERG. From a quick point of view from my perspective of analyzing the pharmacy debt in California, 70 percent of all prescriptions written are by primary care—they are not written in mental health. So if it is not covered on the formulary, they are not going to get the services.

Half the people that we see are not eligible for Medicaid coverage for their medication, and they do not get it on Medicare, so many, many people do not get needed medications because of insurance or formulary restrictions.

Senator KENNEDY. Thank you very much.

Thank you, Mr. Chairman.

Senator DEWINE. Senator Reed?

Senator REED. Thank you very much, Mr. Chairman, and thanks, Charles, for identifying Kathryn Power. I am working on one cup of decaffeinated coffee, so I did not recognize her—and you are right—you did in fact steal her from Rhode Island, but it was good for SAMHSA, and we in Rhode Island are making do without her. And Bill Emmett who is also here today is from Rhode Island, too. He is a long-time advocate for families with mental health issues. Thanks, Bill for your work.

Let me just address a question which you both alluded to based on the questions of the chairman and Senator Kennedy, and that is, the problem with transitions. In the juvenile justice system, you are getting care and then, suddenly, you are released, and the good news is that you are out of some type of incarceration, but there are no services. We just throw these young people, typically young male adults or teenagers, back into the same environment, with no support system, after they have made some progress. In fact, in a way, it is cruel, because they are beginning to learn to adjust and cope, and then they are out the door again.

There is another area of transition, and that is increasingly, college students, who may be getting support at home, may be receiving health care under the family plan, they go off to college, confront a whole different world, and we are seeing remarkable rates of suicide among college students.I know that NYU is not alone, but in the last several months, there have been three major incidents there.

It seems to me that one of the problems with the system—and you have alluded to it, and perhaps you can do more—is these transitional points and how do we address the transitional points where it seems to be really broken.

Dr. Mayberg first, and then Mr. Curie.

Mr. MAYBERG. Thank you, Senator.

Part of the difficulties we have in transition have to do with the silos that we talked about, the bureaucratic silos, and part of it has to do with regulatory and statutory limitations that contribute to that. For example, with children in the juvenile justice system, if you are "incarcerated," you lose your eligibility for Federal participation, so that oftentimes, mental health systems drop out and are not engaged in doing case management or care management. The person shows back up in the neighborhood, and the system is really clueless about what is happening.

The same thing is true in terms of rules that determine eligibility for children up to the age of 18, and when they move away and go to college, they lose their eligibility. Too often, our system becomes driven by funding streams rather than by consumer or family needs. So if we look at ways to deliver the services instead of following the dollar, we probably are going to do a better job.

Senator REED. Charles?

Mr. CURIE. I would also add, Senator, that transitions—and framing it that way, I think, is very helpful, because you are exactly right—that is where many people fall through a crack, where the system has failed individuals not only in your example of the young person going to college and that being a transition and is there going to be coverage for them and accessibility of care, but also in the public health sector, not only the juvenile justice sys-

tem, but also the children's mental health system. There are States that have very good children's mental health systems but still have not mastered the transition of that child going into an adult system of care.

I do believe that what the action agenda needs to address as far as the recommendations of the Commission is to assure that for the first time, we have a coherent, cross-systems mental health agenda at the Federal level, with all those departments and entities I mentioned earlier at the table in agreement that they are going to be giving a consistent message to their counterpart agencies at the State level and that we put incentives in working with the States and provide the assistance so that every State has a cross-systems mental health agenda and plan.

Right now, the only plan that States are required to submit around mental health is around the block grant. That is submitted from the State mental health authority to SAMHSA. Our block grant constitutes less than half a billion dollars across the States, while we have Medicaid that is in the mid-$20 billion, and we have a juvenile justice system and an adult justice system that is providing services within the walls and getting into mental health and behavioral health care.

If we can get that aligned and require a real plan from the States, that would be profound and I think set the stage to be able to deal with the silos and to be able to address transitions in ways that we have not been able to address them before.

Senator REED. Do you need additional statutory authority to prompt this comprehensive planning?

Mr. CURIE. We are examining that right now. We believe right now that if we use our State incentive grant model that we have used for substance abuse prevention and that we are using now for co-occurring disorders, award the dollars to the Governors' offices, and we are also discussing with NGA, that the Governors would be able to bring together those folks. Right now, the good news is that within the administration, all the agencies that I mentioned earlier have agreed to send not only principals but people who are going to roll up their sleeves and do the work for each of those agencies to hammer out such a plan.

So if we set the stage and get rolling with it, one goal will be how do you institutionalize that long-term.

Senator REED. Thank you very much, gentlemen. My time has expired.

Thank you, Mr. Chairman.

Senator DEWINE. Thank you, Senator Reed.

Senator Murray?

Senator MURRAY. Mr. Chairman, thank you very much for having this hearing and for all the work of the Commission. I think this provides a very good road map for ways that we can improve our country's mental health services, and I think it clearly identifies some of the significant gaps in access and coverage and quality outcomes, and I hope we can use this report as a call to action.

Mr. Chairman, I especially appreciate your focus on children, and Senator Reed and Senator Kennedy as well—I think all of us are deeply concerned about where that is going—and your commitment

to hold additional hearings on how we can address some of those inequities, and of course, the Commission's report as well.

Senator Reed and Senator Kennedy both mentioned mental health parity. It is an issue that has raised its head here a number of times. The Commission has addressed it. I think that is one of the reasons why young people have trouble getting access to mental health care as well, is the mental health parity, and if you could just reemphasize for all of us the importance of that, I would appreciate it.

Mr. CURIE. Absolutely. The Commission, of course, has some very strong statements in its findings that the issue of parity is going to be part of the fundamental transformation, that if a parity bill passes—and again, the Commission supported the President's position on endorsing and supporting parity—it will greatly help access, especially those employees who have coverage, to make sure that children who have emerging serious emotional disturbances can receive the treatment they need.

We think it is also tied to developing a system that can address in an early way interventions as well.

Also, there is the issue of the data. There are a variety of studies now that have come out that have demonstrated that those States that have adopted parity have done so in such a way that it has been at a minimal cost and yet the benefits, which we are still studying, are very encouraging.

So again, the Commission supports the President's position on parity, and we do believe that you pay for it sometime, I guess is another way of looking at it, and if you are not paying for it early on to do the right type of treatment, the costs are even greater economically, but most importantly, profoundly, the human cost is tremendous.

Senator MURRAY. Thank you, and I appreciate the recommendation on that.

I did want to ask this. The Commission's report does address the current geographic inequities in access, and it paints a pretty dim picture for our rural communities. I know that in my home State of Washington, almost every county has been deemed a mental health profession shortage area, so for patients, that means that even if we had mental health parity, getting access is almost impossible.

One of the Commission's recommendations is greater access or greater use of technology to reduce some of these access problems. In Washington, we are working to integrate telemedicine into rural communities to expand access to mental health treatment.

There are a lot of difficulties in implementing technology. One of them is reimbursement. I would like you to comment on how we are going to address that issue, because it seems to be one of the blocks that we have in trying to move forward on this.

Mr. CURIE. Goal 6, one of the six major goals, is technology, and the link to remote areas was made in terms of the use of telehealth. Clearly, as part of this action agenda that I described earlier, we are going to be looking at aligning financial incentives in a way to realize those goals, recognizing that in remote areas, we need to take a multifaceted approach. We need to look at technology not only in terms of linking professional help directly to con-

sumers and families but also the use of technology in individuals' lives so that individuals can have access to information and care. And we have not exploited that opportunity enough and need to do that in this process.

So a major focus will be the alignment of financial incentives to determine what are the types of interventions and what are the types of tools that individuals need to have available to them in order to attain and sustain recovery, so that will be a major focus.

The other thing I might mention is that when it comes to the issue of dealing with rural and remote areas, it is also a workforce development issue, and we need to look at how to give incentives to professionals to live in those areas, have partnerships with the academic institutions. It will be a multifaceted approach that we are going to have to take.

Senator MURRAY. Well, again, specifically, how do you recommend providers are reimbursed and host sites reimbursed for training and equipment? That seems to be one of the barriers to using technology in our rural communities.

Mr. CURIE. I think we need to examine how we begin to look at those as being real interventions in ways that we have not looked at them before and determine how they can be financed. I think we need to examine what are the barriers——

Senator MURRAY. So you are not ready to make recommendations?

Mr. CURIE. We are still in the process of examining just how those recommendations can look, but we are working—I cannot say enough good things about CMS and how they were at the table throughout the whole Commission, how they committed themselves through this action agenda—and we are examining ways in which we can align the financing and have the incentives in the right place to realize the goals of the Commission.

Senator MURRAY. Thank you very much, Mr. Chairman.

Senator DEWINE. Thank you.

Senator Kennedy—excuse me. Senator Clinton?

Senator CLINTON. I would be happy to listen to Senator Kennedy. [Laughter.]

I want to thank the chairman for this important hearing, and I do want to thank Senator Kennedy for his lifetime of commitment, along with his family, to many of these issues.

I also really want to congratulate and thank the Commission. I think this is a very significant piece of work, and my greatest fear is that nothing will come of it. We have been down this road before. We deinstitutionalized people. We created drug regimens. We have done a lot to try to deal with the problem on the margins and in the silos, and your report convincingly and movingly illustrates how far we have to go.

I would hope that you would use this committee, particularly people like the chairman and Senator Kennedy, my colleagues, Senator Reed and Senator Murray, who have both a wealth of experience and a real commitment to try to figure out what legislative, regulatory, and appropriations strategies will work, because otherwise, I am afraid that we will go down the path of sending a lot of money out to Governors' offices, telling them to get everybody together, asking them to please come up with results, and we

will be here 5 years or 6 years or 7 years, with not much to show for it, and the situation will continue to deteriorate.

So I really do urge you to be very forward-leaning in your efforts to try to get the support that you need, and perhaps even pick a couple of States and pour everything into them so that you can make them laboratories and we can look.

I know the work that Mr. Curie did on Medicaid managed care for substance abuse was excellent work in Pennsylvania, and partly because of funding cutbacks and budgetary pressures, a lot of that work is not going on elsewhere and has even been taking some hits in Pennsylvania. And I know the work that Dr. Mayberg did in California was really essential in trying to rationalize such a huge system.

But I can just see what is happening now—as State budgets are cut, a lot of the advances that individual States made in the nineties are being undercut.

There are a couple of startling findings or conclusions in your report, but one that just really got to me was that the very first goal and the very first point you make is about suicide and the fact that suicide ranks as the leading cause of violent deaths worldwide came as a surprise to me. Amidst all of the other priorities that you are talking about, the fact that you put that as number one I think says a lot. But what can we do—while we are looking at revamping the system, creating better transitions, providing better financial incentives, is there anything specifically that can be done to address suicide, or is it something that is just embedded in the whole range of problems, and we really cannot take it out and deal with it separately from everything else you are recommending?

Dr. Mayberg?

Mr. MAYBERG. We put that first because it is one that actually is something we can do something about. We were shocked by our benign neglect of this huge problem. Thirty thousand Americans a year die of suicide, and we do not address the issue. And clearly, when we focus in on suicide prevention programs, the results are dramatic.

A recent study suggested that just having primary care providers asking a person, "Have you considered suicide?" reduces the suicide rate by 29 percent—one question.

The Air Force focused in on it and dropped their suicide rate by almost 50 percent.

So just putting it as a priority of our mental health system to focus in on this national tragedy—as you said, twice as many people die of suicide as of homicide.

Mr. CURIE. I would say the answers to your questions, can we do it directly or is it embedded, are "yes" and "yes." I think there are things that we can do directly, and I think Steve has described some of those efforts.

Also, when you take a look at the other roles—early intervention, the linkage to primary health care, having mental health programs available in the schools where we can interview early—all of these can play a role and have been demonstrated in an evidence-based way do play a role in reducing suicide.

But again, they are not systemic, they are not systemwide, and they are not the natural way we are doing things, and much of

what we need to be doing is making sure that we have early intervention available, we have access to care where people present themselves, particularly children and youth.

Also, it is going to take a public-private partnership. The private sector has come forward and foundations have come forward identifying this as an issue, and I think government and the private sector need to come together on both a national suicide prevention strategy as well as overall awareness of mental health and anticipate that that will be part of our action plan, getting that process rolling.

Also, health classes, education—if we can begin educating kids in the health classes about depression and mental illness early on, just as we educate them about having a healthy diet, I think that stressing that more is going to be another aspect.

Senator CLINTON. I certainly hope we can move on that. I am deeply concerned about it.

I also wanted to ask is it fair to say that in many ways, we desintitutionalized during the sixties and seventies, and we incarcerated during the eighties and nineties? In looking at the numbers just for New York, the Mental Health Association shared with me some very frightening statistics. In 1955, there were 550,000 people with mental illness in State mental hospitals. In 2000, there were 870,000 persons with mental illness incarcerated—three-tenths of the population in 1955, three-tenths of the population in 2000.

We shut down a lot of the mental health institutions for good reason, we never made good on the promise of community-based services, and we have essentially used our prisons as the mental health institution of last resort.

What can we do about the prison being the new back ward of the mental health system?

Mr. MAYBERG. We refer to this issue as "trans-institutionalization." We do not think that all of the people who went from the State hospital ended up in the criminal justice system, but clearly one of the contributing factors has been the increase in co-occurring disorders, that the use of substances and alcohol combined with mental illness does create a situation where we are more apt to come in contact with the criminal justice system. So part of it is doing better screening up front for co-occurring disorders and also looking at some of the incentives to institutionalize. It is a cost-shift in some ways. It is cheaper in many instances to put someone in prison than to put them in a State hospital.

Senator CLINTON. What is the difference in cost, because certainly in some of the high-cost States, it is $30,000 to $40,000 per prisoner. So what would be the comparable cost?

Mr. MAYBERG. The cost of one of my State hospital beds is $110,000 a year, so it is three times as much to be in a State hospital. And the cost of being on the street, homeless, when you look at all the costs of revolving doors and emergency rooms, revolving door and county jails, is probably $30,000 or $40,000, too.

Mr. CURIE. I would add that before I left Pennsylvania, we did a survey of the State prisons, and this has pretty much held up nationally with other prison systems. Eighty percent of the individuals in prison had a drug and/or alcohol issue. Over 50 percent were under the influence at the time of arrest. Twelve to 13 per-

cent met the definition of serious mental illness. Ninety percent of those individuals had a co-occurring substance abuse problem.

The individuals with mental illness typically are getting into trouble and arrested due to a substance abuse or use issue into the prisons. Also, we did a study of what we call our CHIPS program in Pennsylvania to try to derive real data based on what you just shared, Senator Clinton, the notion of are people coming out of State hospitals and going to prisons. We found that around one to two percent of the individuals who came out of State hospitals actually got in trouble with the law, but the mushrooming going on in the State prisons, the link seemed to be the enforcement of the drug laws, which does point out the need for us to be partnering with Justice to determine how we can assure access to treatment, because there have been many demonstration studies across this country that have shown that individuals receive treatment for their substance abuse, they recover, and they do not recommit a crime, they do not get in trouble with the law, and with the high percentage of co-occurring, the same is true—if they receive the appropriate treatment, they attain recovery.

So it is the nexus of public health and public safety, and definitely is a focus of the action agenda.

Senator CLINTON. Thank you.

Thank you, Mr. Chairman.

Senator DEWINE. Let me thank both of you very much, and to conclude on an observation, Dr. Mayberg, I was intrigued with your exchange with Senator Clinton and your statement that just asking the question, "Have you thought about or contemplated suicide?" will take that rate down is a phenomenal thing. It strikes me that the asking of that question by a primary care physician or by someone in the military really, though, is going beyond the mental health system, or at least in a sense is going beyond the mental health system, and maybe that is the key.

I am afraid that sometimes, a primary care physician may not think he or she is in the mental health system, and I think sometimes people in the military certainly would not think they were part of the mental health system. And maybe the key is for more people to think they are part of the mental health system, and if we can do that, maybe we can accomplish a lot more. It is just a thought; I do not know.

Mr. MAYBERG. That is why we put that goal first. We have made a fundamental mistake by separating the mind from the body; they are integrated, and we need to look at persons as a whole and not separate their behavioral health issues out from their physical health issues, and it is incumbent upon us as mental health professionals to work with the primary care system and the school system because they are the case-finders, they are the individuals who can make substantive differences for us.

So we really need to change our focus from the tail-end of the system to the beginning of the system.

Senator DEWINE. Thank you both very much. We appreciate it.

Mr. MAYBERG. Thank you, Mr. Chairman.

Mr. CURIE. Thank you.

Senator DEWINE. We look forward to working with both of you in the future.

Senator DEWINE. Let me ask our second panel to begin coming up now, if you will, and I will introduce the second panel as you are coming up.

Senator Kennedy has already introduced Dr. Paul Appelbaum. We appreciate you being here with us, Doctor.

Mr. Michael Faenza is the present CEO of the National Mental Health Association, which works to promote mental health and prevent mental disorders. He is a social worker by training and has spent the last decade on legislative advocacy to improve mental health services. He has also spent over 15 years providing direct service to children and adults with mental disorders. In addition to his service with the National Mental Health Association, he also serves on the National Assembly of Health and Human Services Organization's board of directors and the National Health Council board of directors. He was also a member of the planning board for the Surgeon General's Report on Mental Health.

Dr. Carlos Brandenburg is joining us today as a member of the NASMHPD and as the administrator of the Nevada Division of Mental Health and Developmental Services. Prior to joining the Nevada Division of Mental Health in 1995, Dr. Brandenburg served as director of forensic services at the Lakes Crossing Center for the Mentally Disordered Offender in Reno, NV and as a mental health consultant at the Sierra Nevada Job Corps Center.

Dr. Brandenburg has also served as a social worker and clinical psychologist.

Ann Buchanan, our final witness today, is from suburban Baltimore and will be sharing with us the story of her son, Rusty, who has struggled with depression since the age of 16. Her experiences in dealing with treatment centers, support systems, and payment plans place her in a unique position to comment on the New Freedom Commission's recommendations.

Mrs. Buchanan, you and your son should certainly be commended for your courageousness and perseverance in dealing with this debilitating disease, and we thank you for testifying today and for joining with us.

Thank you very much.

Dr. Appelbaum, we will start with you.

STATEMENTS OF DR. PAUL S. APPELBAUM, DEPARTMENT OF PSYCHIATRY, UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL, WORCESTER, MA; MICHAEL M. FAENZA, PRESIDENT AND CHIEF EXECUTIVE OFFICER, NATIONAL MENTAL HEALTH ASSOCIATION, WASHINGTON, DC, ON BEHALF OF THE CAMPAIGN FOR MENTAL HEALTH REFORM; CARLOS BRANDENBURG, ADMINISTRATOR, NEVADA DIVISION OF MENTAL HEALTH AND DEVELOPMENTAL SERVICES, CARSON CITY, NV; AND ANN BUCHANAN, COCKEYSVILLE, MD

Dr. APPELBAUM. Thank you, Mr. Chairman.

I am Paul Appelbaum, M.D., professor and chair of the Department of Psychiatry at the University of Massachusetts Medical School, where I oversee the largest mental health treatment system in central Massachusetts.

As immediate past president of the American Psychiatric Association, I have been deeply involved in efforts to reform the system of care for mental disorders and have followed the work of the Commission closely. When the Commission declared in its interim report that the mental health system is "fragmented and in disarray," it struck a chord with mental health professionals and persons with mental disorders and their families across the country.

Let me tell you about the troubling situation in my home State of Massachusetts.

Imagine that you live in Massachusetts and have become so depressed that you cannot work or care for those who rely on you, but you are fortunate enough to have health insurance and expect not to have trouble finding the treatment you need.

When you call a general hospital with a large outpatient clinic like mine, however, they explain that they must put you on a waiting list of weeks to months in duration. With insurers paying less than the actual cost of delivering outpatient treatment, hospitals have been reducing the size of their clinics or closing parts of them altogether, to the point where the need for services vast exceeds the supply.

Perhaps next, you try calling a list of private practitioners in the community who, your insurance company says, are part of their "network." But many of them tell you frankly that they can no longer accept insurance coverage because the rates are too low to allow them to survive. They can see you only if you pay out-of-pocket for the cost of your care. Other clinicians of course do still accept some patients with insurance, but they too have waiting lists; if you leave your name, they will call you back—when and if an opening appears.

With time passing and no treatment, your condition worsens. One morning, you cannot even get out of bed. A worried family member brings you to the nearest psychiatric emergency room, itself overwhelmed with people like you who have been unable to access timely care. Although it is clear by now that you need to be hospitalized, you wait 7 hours—about average, you later learn—for an empty bed to be found in a hospital 50 miles away. You are one of the lucky ones. Other patients, several of them adolescents, have been living in the emergency room for several days while waiting for a bed. It turns out that psychiatric units are notorious money losers in general hospitals, with insurers paying somewhere around 70 percent of the real costs, and that units have been closing around the State and indeed around the Nation for the last decade.

Your neighbor, with bipolar disorder, who works in a minimum wage job without insurance, is in an even tougher spot. Community mental health centers are no longer funded by the State or the Federal Government to care for uninsured patients and are now simply turning them away.

Since Massachusetts hospitals have to accept uninsured patients as a condition of participating in the Medicaid program, when your neighbor deteriorates to the point of needing to be hospitalized, at least a bed can be found. But as it becomes clear that she will need longer-term care in one of the few remaining State hospitals, she waits for more than a month before the transfer can take place. And once she is discharged into the community, the continuum of

services that she needs—housing, job training, treatment for substance abuse—is stretched so thin that there is no guarantee that she can access any of them.

If this were the situation only in Massachusetts, it would be a tragedy but might not warrant the attention of this committee and the whole Congress. But these scenarios are echoed in State after State. Given this, it is no surprise that the U.S. Surgeon General's Report on Mental Health cited data showing that only 20 percent of persons with mental disorders receive any treatment in a given year, and that includes fewer than half the persons with such severe disorders as schizophrenia and bipolar disorder.

Hence, the importance of the Commission's call for a "fundamental transformation" of our approach to mental health care.

The recommendations in the Commission's report are, without exception, helpful. But to be frank, they fall short of the fundamental transformation that is so clearly needed. As president of the American Psychiatric Association, I appointed a task force to develop a vision of what a genuine system of mental health care should be. That report, along with my presidential address that lays out some directions we can follow, has been provided to the committee.

In short, I suggest that we need to facilitate the integration of treatment for most mental disorders into the primary care medical system—a goal that faces numerous structural obstacles today. And for our citizens with severe and persistent mental disorder, we must reinvigorate the vision of President John F. Kennedy, whose Community Mental Health Act of 1963 marked the last attempt to construct a nationwide mental health system that could care for all of our citizens.

Finally, while the costs of such a program cannot be ignored, it can be funded in substantial part from money now spent on jails, homeless shelters, disability payments, and other efforts to compensate for the failing of our mental health system.

Thank you for your attention, and I would be pleased to respond to the committee's questions.

Senator DEWINE. Thank you very much, Dr. Appelbaum.

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

Senator DEWINE. Mr. Faenza?

Mr. FAENZA. Thank you, Mr. Chairman, and a special thanks to you, Senator, for your attention to the plight of adults with mental illness who are caught in our justice system and kids in our juvenile justice system. After 30 years in the field, I do not think anything is more important than that focus, frankly.

My name is Michael Faenza, and I am the president and CEO of the National Mental Health Association—I have been in that job for 10 years—and I am pleased to offer this testimony on behalf of the Campaign for Mental Health Reform.

We are very excited about this Campaign. It is an effort to advance new Federal policy to make access, recovery, and quality in mental health services the hallmarks of our Nation's mental health system, and that idea is to use the Commission report, which we are very excited about, as the baseline and the lever to do this work.

The Campaign represents a broad spectrum of mental health consumers, families, advocates, professionals, providers, States, counties, and communities, and it is rare that we in our community have this kind of solidarity with a single purpose. We share a commitment to the vision and goals of the President's Commission on Mental Health and are eager to work with this committee to advance needed reforms.

I want to say a special recognition for Bob Glover, with the National Association of State Mental Health Program Directors, whose vision created this Campaign.

Just a word about myself—I have worked within that 30 years for years in juvenile justice, public mental health services, vocational rehabilitation, and I have lived with mental health problems since childhood. Forty years ago, I was a kid who was moved from classroom to classroom and expelled from schools because of inability to pay attention, was not able to play well with others. I had a diagnosis of a bipolar disorder as an adult. But I have been blessed to have the same psychiatrist for 7 years, who found five medications that worked for me, and my 30 years in the field have not led with that fact, but I think it informs my testimony.

A true mental health system must bring many systems to the table, as has been noted—public health and primary care are so important, as Dr. Appelbaum said; health financing, child welfare, education, housing, criminal justice, rehabilitation, and employment, to name only the most obvious. And I believe that that will not happen without Federal legislation and without legislation in the States. It just will not come to be.

In calling for transformation of mental health care, the Commission has given us a vision that we believe truly can be reached because the science has transformed our understanding of mental illness, given us the tools to diagnose and treat most mental disorders. The Commission's message that we can build resilience in the recovery from mental illness is a realizable goal reflects another transformation in thinking about mental illness.

What is needed now is a policy and budgetary commitment to realize dramatic reform in mental health care.

We do appreciate that there are opportunities for mental health reform at all levels of government, and we recognize the importance of leadership from the Federal Government—the Federal Government—in advancing change administratively. But administrative action alone cannot align the inconsistent eligibility of requirements of many Federal programs that are critical to providing benefits, services, and supports needed by many people with mental illness. And administrative measures alone cannot overcome the limitations, for example, of Medicare mental health benefits, which fail to provide basic parity and fail to cover cost-effective services needed to treat chronic mental illness.

This committee in particular can play a vital role in crafting needed solutions by giving new policy direction to the Substance Abuse and Mental Health Services Administration. With revision of its statutory charter, SAMHSA can become a truly effective leader of mental health system transformation and more closely embrace the principles of public health.

We hope to work with this committee and provide concrete recommendations that will advance the Commission's goals and strengthen SAMHSA's hand in helping achieve them.

I would be remiss in not reinforcing what Senator Clinton said, that in my 30 years in the field, this is the worst time for mental health. The National Mental Health Association did a study several months ago, and there are 23 States that have cut back funding for public mental health services. We project that within the next few months, 45 States will cut mental health services. The numbers of kids with mental health problems in juvenile justice settings, adults with mental illness on our streets and in our jails—these are numbers that are increasing. There is a special irony in what we are talking about here today and what is actually happening for people at risk and with mental disorders.

Concretely, the Campaign wants to earmark a number of things that we think are important in legislation and action by this committee. The first is fostering new financing and planning mechanisms to provide effective community-based care to children and youth with mental health needs. People with mental illness are on the short end of the stick in terms of interventions for health status and quality of life in this country. Nothing in my experience is as grotesque as our neglect of children in this country; it is just shameful.

Second is fostering mental health promotion and early intervention services through school-based mental health care. As an example, the Safe Schools, Healthy Students Program is a collaboration between SAMHSA, Department of Education, and Department of Justice. It is underfunded. It is just pilot programs, but it is an example of the kind of integration that could happen at the Federal level.

We need to advance early detection and treatment for mental health problems across the age span.

We need to reduce fragmentation in mental health service delivery, including systems for care for children and their families. We need to make that more than a concept but real, through Federal leadership for the States.

As mentioned, we need to advance a national strategy for suicide; we need to foster integration of health and mental health care—that should be a huge priority for SAMHSA; and, as mentioned, we need to increase the integration of mental health and substance abuse.

As the President stated in announcing the establishment of the Commission, "Our country must make a commitment." That commitment will necessarily require, we think, dramatic reforms across a range of government programs. A national system in shambles requires national Federal leadership a little wary of the flexibility of the Sates. When we look at Medicaid reform down the road, we need to be sure that we do not pull the rug out from under 50 percent of the funding in community mental health services.

We believe it is critical that we embark on this path with an appreciation that mental health has long been dramatically underfunded relative to the impact of mental disorders on the individual

and, really, the overall health and quality of life of people in this country.

We urge Congress to make mental health and the transformation to a recovery-based system both a legislative and a funding priority.

Again, thank you so much, Mr. Chairman, and I will be pleased to answer any questions.

Senator DEWINE. Mr. Faenza, thank you very much.

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

Senator DEWINE. Dr. Brandenburg?

Dr. BRANDENBURG. Good morning, Mr. Chairman and members of the subcommittee.

My name is Carlos Brandenburg, and I am the administrator of the Division of Mental Health and Developmental Services in the State of Nevada.

I would like to extend my thanks to Chairman DeWine for inviting me to testify this morning regarding the State of Nevada's experience and efforts in trying to implement the President's New Freedom Commission on Mental Health.

By describing the poor State of the Nation's public mental health system, the President's New Freedom Commission provided an invaluable service not only for millions of people in this country with mental illness and their families, but also for those of us responsible for administering the programs that are in crisis.

Nevada, notwithstanding our successes, faces many challenges. At the same time, there has never been a more hopeful time to take on this challenge, and I am profoundly grateful for the opportunity to serve as my State's lead on this issue at this particular moment in time.

Why am I so hopeful? First, we have in the Federal Government a true partner. As you indicated this morning, Administrator Curie has worked hard within the administration to help the President form the Commission, to ensure that it was composed of extraordinary people, and to establish for it an ambitious and achievable mission.

Second, as you are hearing today, the advocates who stand up for the mental health community here in Washington, DC as well as nationwide are organized and prepared to work together like never before to help the policymakers make the Commission's vision a reality and see to it that the light shone on this issue is not dimmed.

Third, we are witnessing an unprecedented interest on the part of Congress, as evidenced by this hearing and the creation of this subcommittee.

Fourth is the good fortune of the State of Nevada itself. Nevada was honored that President Bush appointed Nevada State Senator Randolph Townsend to serve on the President's Mental Health Commission. In order to assist Senator Townsend on this, we held numerous task force and focus group meetings throughout the State to explore the range of problems and the gaps in mental health services in our State. This enabled Senator Townsend to bring to the Commission concrete recommendations for improvements that could be applied both locally and nationally.

Further, these meetings and focus groups allowed us to quantify the degree of unmet need in Nevada and to identify the barriers that impede care for people with severe mental illness.

During the 2003 State legislative session, Senator Townsend had the foresight to introduce Nevada State Senate Bill 301, a copy of which I am submitting along with my testimony. This State law created the Nevada Mental Health Plan Implementation Commission. The commission is charged explicitly with developing an action plan for implementing the recommendations and goals of the final report of the President's New Freedom Commission on Mental Health. The Nevada Commission must submit a report setting forth an action plan to Nevada's Interim Finance Committee, its Legislative Committee on Health Care, and to Governor Guinn on or before January 1, 2005.

In all of our deliberations, we are focused on specific recommendations, both policy and budgetary, that will turn the President's Commission's national goals into concrete, forward steps in Nevada.

The Nevada Commission, in addition to providing an organized mechanism to facilitate comprehensive State mental health planning and policy development, has also been an effective means of keeping the subject of mental health in the media cross the State and helping us reduce stigma and increase awareness.

During the course of our meetings, we have been struck by the fact that too many Nevadans do not know that mental illness can be treated and that recovery is possible. We have learned about the large barriers encountered by individuals waiting in emergency rooms up to 3 or 4 days before they can be hospitalized in our public mental health hospitals. We have tremendous work shortages in our rural areas; we are having a hard time recruiting and retaining mental health professionals to work in rural Nevada. In fact, all the psychiatrists in our rural areas are considered "tourists," working mainly out of Reno or Las Vegas.

And more important, we need to be more consumer-involved and consumer-friendly in the delivery of services. Nevada for the last decade has led the Nation in the rate of suicide. We are determined to develop a Statewide suicide prevention strategy to work on this problem.

The Nevada Commission's efforts have been greatly enhanced by generous technical support provided by the National Association of State Mental Health Program Directors, NASMHPD. In conjunction with a grant they received from the Federal Substance Abuse and Mental Health Services Administration, NASMHPD is enabling us to bring national experts, including members of the President's Commission, to our meetings. They are providing us with recommendations of best practices and programs in other areas of the country that can be implemented in Nevada. This assistance has been invaluable.

Ultimately, our Commission will show Nevada how to change the fragmented nature of our mental health delivery system.

This is the last point that I would like to leave with the subcommittee. The ultimate goal of the President's Commission and, in turn, the Nevada Commission is ambitious and attainable. Indeed, it is calling for system transformation. The report of the New

Freedom Commission on Mental Health identifies the fragmentation of services and financing as central barriers to the effective delivery of comprehensive mental health services and has called on all levels of government to correct this problem by ultimately establishing in each "an extensive and coordinated State system of services and supports that work to foster consumer independence and their ability to live, work, learn, and participate fully in their communities."

You have heard about Nevada's commitment in making this happen, but neither Nevada nor any other State can do this without significant assistance on the part of the Federal Government. Specifically, we require Federal assistance to both engage in the type of planning envisioned by the Commission and to implement those plans, enabling us to fill the tremendous gaps in our service delivery systems for those individuals who are severely mentally ill.

Even in Nevada, where we have been uniquely fortunate to begin the transformation process, we will not be able to do this without Federal funding. We hope that the subcommittee, presumably as it begins its efforts to reauthorize SAMHSA and its programs, will work closely with the States and the Campaign for Mental Health Reform to devise a bold program that will provide the support needed to ensure that the vision of transformation is realized.

Thank you.

Senator DEWINE. Thank you.

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

Senator DEWINE. Mrs. Buchanan, thank you very much for joining us.

Mrs. BUCHANAN. Good morning, Chairman DeWine and members of the subcommittee.

I am Ann Buchanan of Cockeysville, MD, and I am proud to be here this morning to share with you the story of my son's struggle with mental illness and offer some perspectives on President Bush's New Freedom Commission on Mental Health. I would like to thank you for convening this important hearing and inviting the unique perspectives of individuals living with mental illness and their families.

I want to begin by sharing with you the story of my family's struggle with mental illness. The story is about my 22-year-old son, Russell, or Rusty, as we call him. Today Rusty is doing better and slowly moving on the difficult but uncertain path of recovery. He has a diagnosis of schizophrenia. He lives in a residential program at Keypoint in Dundalk, MD.

As a child, Rusty was quite calm, quiet, and a loving child with no signs of aggression at all. Today he is participating in a program that will help him acquire skills to begin working soon. He is making slow but sure progress in his recovery. However, it has been a long way back from 4 years ago when Rusty turned 18.

In 1997, our family suffered a devastating loss when my husband lost his battle with cancer. Rusty was 16. Shortly thereafter, Rusty began showing signs of anger—probably normal for a teenager coping with the death of a parent. However, these symptoms grew worse and resulted in attacks on me. We reached a turning point

that eventually resulted in Rusty being admitted to an inpatient unit.

Within a one-year period of time, he was hospitalized three times. Things worsened to the point that Rusty had to leave high school and eventually was placed at Maryland's Regional Institute for Children and Adolescents, RICA, in Baltimore. He spent much of 1998 and 1999 at RICA.

In March of 1999, he was about to turn 18 and was moving toward getting his high school diploma. The staff at RICA made clear that once Rusty turned 18, he would be an adult and would legally have the right to make his own decisions. More important, they made clear that once he turned 18, he would no longer meet the age criteria, and he would have to transition to the adult mental health system.

Unfortunately, most of the staff at RICA was not familiar with how to make this transition. It fell on me to do research and make contacts with residential programs in the area. What I found was that most programs had long waiting lists for housing and residential programs. Those without long waiting lists refused to accept him because of his history of aggressive behavior. At this point, I was afraid he was going to be sent back home to me, which I was very worried about because of his prior attacks on me.

Throughout this period in the spring and summer of 1999, I grew increasingly anxious. More important, this uncertainty put enormous stress on Rusty and compounded his symptoms. During a period when he was trying to finish his high school studies in July 1999, just before returning to RICA after a weekend visit at home, Rusty attempted suicide by drinking gasoline. This resulted in his hospitalization, first in the hospital for his medical care, and then to Shepherd Pratt, and eventually a 3-month stay at Spring Grove Hospital. This is how he entered the adult mental health system.

I remain convinced that had Rusty been able to seamlessly transition to a housing program, with a treatment plan coordinated by the adult mental health system, many of these problems in 1999 could have been avoided. However, we were left on our own to manage this transition, not because the staff at RICA was uncaring but rather, our struggle stemmed from the fact that neither the child and adolescent system nor the adult system is held accountable for ensuring that young adults can make the transition.

The sad reality is that thousands of families every year face the enormous challenge of having their child "age out" of adolescent treatment and service programs.

It should not come as a surprise to anyone that the course of mental illness does not magically shift once a child turns 18, 19, or 20. The symptoms they experience, be it anxiety, depression, mania, psychosis or paranoia, do not change to fit our mental health system's preexisting definitions about what are child and adolescent services versus what are adult services.

In my view, it is disturbing that the separate child-adolescent and adult systems struggle so mightily to help adolescents make the transition into adulthood. This is especially the case with children and adolescents with more severe mental illnesses who are much more likely to see diagnoses of illness stay with them into adulthood.

Why is the transition so difficult? Children acquire certain legal rights when they reach age 18, legal rights that can limit the ability of parents and families to get their children the help they need. Rules governing eligibility for SSI, SSDI, and Medicare and Medicaid shift once a child reaches the age of 18, and eligibility for certain treatment and residential programs may be compromised once an adolescent turns age 18.

These problems are compounded by complicated and confusing rules such as Medicaid spend-down. It is rare to find a public agency, whether in the adult or the child system, which will pay for case management and other wraparound services that can ease this transition for families.

What must be done to address the complicated issues faced by consumers and families dealing with the transition from the child-adolescent system to the adult system?

The White House Commission Report offers some important findings and recommendations. As this report notes, funding and accountability in our Nation's public mental health system is needlessly fragmented and complicated. The Federal Government has to begin working with States and localities to provide more flexibility while insisting on more accountability for achieving outcomes that are tied to recovery. Individualized treatment plans for consumers and their families, as proposed by this report, would be a major step forward in helping families put in place the treatment and support their children need before they turn 18 and become adults.

Better systemwide planning, as this report proposes, is critically important and should involve not just public mental health agencies but also affordable housing, education, and job training.

Finally, I want to comment on findings and recommendations in the report calling for consumers and families to have greater control over their own care. While this goal is laudable, it will never be achieved without expansion of family education and peer support programs to help consumers and families learn more about mental illness, treatment system, and how to advocate for themselves.

I am a graduate of the NAMI Family-to-Family Education Program. I found it to be enormously helpful in preparing me to cope with my son's illness and become an advocate both for his recovery and for improvements in the service system in our community. I attended the Family-to-Family class when Rusty was hospitalized the first time, and it helped me understand and make contacts to get me started learning about this illness.

Thank you for the opportunity to talk today.

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

Senator DEWINE. Mrs. Buchanan, thank you very much. Yours is a very, very compelling story and I think a story that is very instructive for us.

Senator Kennedy really wanted to be here to hear your testimony, and he had another commitment, but he did leave a question which I am going to ask on his behalf for you. This is Senator Kennedy's question: "We know that far too many children and adolescents, like your son, who need mental health services do not receive them. One reason for this is that public schools do not do a good

job of supporting mental health. In your own experience, your son Rusty was forced to withdraw from his high school. How could Rusty's school have done a better job of helping him so he could have remained in school?"

Mrs. BUCHANAN. Actually, Rusty was always in the special education system of public education, and each year, he would have an individual IEP plan drawn up. After he was hospitalized, each time he returned to Towson High School, he had to go through a review board to see if they felt he was safe to return, and they accepted him. One day, he made a verbal threat to a student, and then they really questioned him. They did psychological testing on him, and Rusty felt that he could no longer attend, so they did provide home tutoring for him until he could be placed at Hannah Moore School, which is for emotionally disturbed children. This was just prior to going to RICA. But Hannah Moore was not equipped to handle his problems, either, so he went to RICA.

So more psychological testing and attention—at first, we thought Rusty's behavior was typical teenage behavior, being argumentative and so on, but it led to much more than that; it was deeper. After his father died, he was first treated with major depression, but as time went on, I could see that it was not just from his father's death, it was more deep-rooted than that.

Senator DEWINE. Thank you very much. Senator Kennedy has a second question, and I think it does make a good follow-up: "From your own experience, what advice do you have for the Senate and today's panel about how to help more people like your son by successful and have positive outcomes?"

You have already touched on that a little bit, but is there anything else you would like to add?

Mrs. BUCHANAN. More education on mental illness needs to be addressed. Like many illnesses, people do not want to talk about mental illness, but it needs to be brought forth so that people are aware of it before it gets too far advanced.

Senator DEWINE. Thank you very much. Your testimony has been very, very helpful and certainly has outlined for us in very human terms a lot of the problems that we do have.

Dr. Brandenburg, in your State, how do you currently address children's mental health issues, and what kind of help would make the most difference for your State? What additional help do you need?

Dr. BRANDENBURG. The State of Nevada right now has a Division of Child and Family Services that provides mental health services for children in our State. Like other States, our services for children are fragmented. We are having a hard time providing mental health services to those individuals who are in the child welfare system, those individuals who are in the juvenile justice system. So what we are trying to do is get a handle on that through a legislative subcommittee, trying to find out how to break those various silos.

Just like Mr. Curie and the subcommittee indicated earlier, at the Federal level, you have many different funding streams. You have SAMHSA, you have NIMH, you have Justice, all providing funds at a different area for different programs. That translates itself down to the State level, where we have our various silos.

So what we are trying to do at the State level is break down those silos and break down the fragmentation of services, because kids are falling through the cracks in our State between the time that they go either from juvenile justice into the mental health system or from the children's mental health services into the adult system.

Senator DEWINE. Thank you.

Mr. Faenza, you have outlined in your written testimony as well as in your oral testimony that "Among the important issues we urge this committee to take up and on which we are developing legislative proposals are the following," and then you give a very brief summary of a number of different proposals.

I take it you are going to develop those further and come forward to this committee and Congress with very specific legislative proposals; is that correct?

Mr. FAENZA. That is correct. The Campaign partners are determined to bring a lot more flesh to the bones of these concepts and to very candidly bring those forward. We will also be looking with a lot of anticipation to Director Power's game plan to respond to the Commission report under SAMHSA. But they will be very specific, and there will be a lot of solidarity in the community behind those recommendations.

Senator DEWINE. We look forward to reviewing your very specific proposals, so we welcome that. We want to encourage that.

Mr. FAENZA. Thank you.

Senator DEWINE. When you bring them to the committee and to the Congress, we certainly want to take a look at them.

Mr. FAENZA. We will be anxious to do that. Thank you, Senator.

Senator DEWINE. Very good.

Dr. Appelbaum, in your written testimony you state: "The recommendations in the Commission's report are, without exception, helpful, but to be frank, they fall short of the fundamental transformation that is so clearly needed." And then you continue on.

Do you want to give us the highlights of what you are talking about? What is lacking?

Dr. APPELBAUM. Senator, the track record of mental health policy in this country for the last 25 to 30 years has been to address problems of high salience in a piecemeal fashion for a short period of time, so we become interested in youth suicide or substance abuse by pregnant women or the problems of the elderly; we develop a few model programs, we fund them for an initial period, and 5 years later, when the focus has shifted elsewhere, we allow those programs to be resorbed into the residual mental health system.

The result has been a system that has contracted over time and failed to provide a comprehensive approach to mental health care.

What I was suggesting in that comment was that merely to continue with a model programs approach such as we have been doing condemns us to being, as Senator Clinton suggested, in the same place 5 years from now or 10 or 20 years from now.

The last time we really thought systemically about what it would take to address the mental health needs of the American people as a whole was in the early 1960's, and we came up with what was not a bad plan. We divided the country by State, and each area of each State was assigned a catchment area. There was a community

mental health center designed to be responsible within that catchment area for the mental health needs of every person who lived there.

So the question of where you went when you had a mental health problem was a nonquestion. You went to the mental health center, and it had the responsibility of integrating you into the system of care.

Moreover, when you transitioned from being a child to being an adult, there was a place—it was the mental health center—that had responsibility for making sure that you bridged that gap. They were responsible for you when you were 17, and they were responsible for you when you were 19.

It was a terrific concept. In part, the problems that it had were problems derived from inadequate funding in the first place. The notion was that the Federal Government would provide funds to build these centers and then would taper its support over a number of years, and that the States or someone would pick up the difference. Well, the Federal support indeed was tapered and ultimately transitioned to the block grant system in roughly 1980, but the State tapered their support simultaneously, and nobody picked up the difference.

So we have a vestige in some areas of the country of this community mental health system, but the reality is it is only a shell of what it once was.

Maybe a revitalization of that system is what we need now. Maybe there is some other equally comprehensive and integrated approach. But it is that kind of thinking that I was suggesting we need to engage in.

Senator DEWINE. So, Doctor, if you took a snapshot of where we were 10 years ago, 20 years ago, are you saying that we have actually regressed?

Dr. APPELBAUM. I am saying that we have actually regressed.

Senator DEWINE. I am seeing a nodding of "yes" from Dr. Brandenburg, Mr. Faenza, and of course, Dr. Appelbaum. Would that be correct? OK.

Dr. APPELBAUM. I was speaking last week, Senator, to a team from Summit County in Ohio that had just won a national award for an innovative mental health program. I visited Summit County 2 years ago and frankly, I thought that in my travels around the country, it was one of the finest integrated community mental health center-based programs I had seen—the kind of model that we could expand around the country. But when I talked to the director of mental health services and the medical director last week and told them how impressed I had been 2 years ago on my visit, they said, "Well, you might feel differently if you came back today," that even this model program is facing extreme economic stress, and they are watching important pieces of it no longer be able to be supported.

So the answer to your question is clearly "yes."

Senator DEWINE. That testimony is very troubling, and this hearing has been very troubling—but very instructive and, we hope, very helpful.

Are there any additional comments from any of the witnesses?

[No response.]

Senator DEWINE. We thank you all very much.
The hearing is adjourned.
[Additional material follows.]

ADDITIONAL MATERIAL

PREPARED STATEMENT OF STEPHEN W. MAYBERG

Good morning Mr. Chairman and Members of the Subcommittee. I am Dr. Stephen W. Mayberg, Director of the California Department of Mental Health. I was privileged and honored to have been named by President Bush to serve as a member of his 15-member New Freedom Commission on Mental Health, under the chairmanship of Ohio Mental Health Commissioner Mike Hogan.

My position as the Director of the California Department of Mental Health, the largest State mental health system with a public sector budget at almost $3.4 billion and 8,500 employees, gives me a broad perspective of the issues and problems facing our public mental health system. Even more important, I suspect that a factor in my selection to the Commission was my long time advocacy for an accountable, state of science and user-friendly mental health system that is responsive to the people we serve. I have frequently spoken of a system that produces outcomes and is about services, not bureaucracies.

The public members of the Commission included not only representatives of State Government such as I, but also representatives from the judicial branch, from mental health services providers, and from the ranks of mental health advocates. We were joined by seven ex officio Federal members representing not only agencies and offices of HHS, but also the Departments of Education, Labor, HUD, and Veterans Affairs.

One of those ex officio members, SAMSHA Administrator Charles Curie, is testifying here with me today. He and his agency have been charged by the Administration to assess the work of the Commission and to lead the transformation of mental health care that its recommendations help guide. With his expertise that spans Federal, State and local mental health—and his highly effective leadership style—evidenced in his remarkable work in Pennsylvania State Government to change how mental health services are done there—I feel confident that we can accomplish the transformation of today's mental health care system And, with your help, we can do it in ways that benefit the people the system was intended to serve first and foremost—men and women, teens and children and their families living today with mental illnesses.

Quoting the Executive Order that created the Commission, the charge to the Commission was "to recommend improvements [in the U.S. mental health system] to enable adults with serious mental illnesses and children with severe emotional disturbances to live, work, learn, and participate fully in their communities." To do so we were asked to conduct a comprehensive examination of the U.S. mental health system today.

The challenge was to accomplish that mission within a year. And so we have. In July, the result of our work was submitted to the President, and to the Nation.

Why The Commission Was Created

In any given year, about 5–7 percent of adults have a serious mental illness. In 2002, for example, SAMHSA's National Survey on Drug Use and Health reports that an estimated 17.5 million adults age 18 or older, 8.3 percent of all adults, had serious mental illnesses (SMI). A similar percentage of children and youth, from 5–9 percent, have a serious emotional disturbance in any one year. I'm referring to illnesses that not only meet the diagnostic criteria for mental illnesses found in the Diagnostic and Statistical Manual of Psychiatry, Fourth Edition (the DSM–IV), but illnesses that also substantially hinder one or more life's activities like holding a job, getting dressed, learning at school, or participating in community activities. These are illnesses that rank first among the leading causes of disability in the United States, Canada and Western Europe. They also are the leading cause of suicide, causing more deaths each year worldwide than homicide and war together.

Mental illnesses cost the Nation an estimated $79 billion annually. And the vast majority of that total ($63 billion) reflects loss of productivity as a result of these illnesses and another $12 billion in mortality costs resulting from premature death. In human terms, the losses are nearly incalculable, spanning lost families and homes, lost education, lost livelihood, and most of all—lost opportunities.

Yet, despite the prevalence, the costs, and the clear public health imperative, people with these disorders often are untreated or under-treated. Mental illnesses often have been under reported. Compounding the problem, countless individuals in need of services cannot or do not receive them. Again, according to the SAMHSA Household Survey, in 2002, among adults with serious mental illnesses, 30.5 percent perceived they had an unmet need for treatment in the past 12 months.

Too many Americans including policymakers and administrators, program officials and health care providers, for too long did not recognize the full public health implications of these devastating disorders. And for too long, any efforts to address mental illnesses in America have been piecemeal, patchwork affairs.

President Bush created the Commission because, first and foremost, as he stated, "Americans with mental illness deserve our respect . . . and they deserve excellent care." He recognized that millions of Americans of all ages, both male and female, and of all races and ethnicities experience mental illnesses.

President Bush created the Commission because he recognized that mental illnesses, like other chronic illnesses, can be treated successfully and that people with mental illnesses can and do recover.

Perhaps most critically, he recognized, as do an ever-growing number of those of us working in the field, that three key obstacles keep people with mental illnesses from getting the services they want and need:

1. The stigma that still surrounds these illnesses;
2. The fragmented mental health care service system; and
3. Existing treatment and dollar limits for mental health care in private health insurance.

The Commission the President established was asked to address the second issue—the fragmented mental health care service delivery system, to identify ways to respond and models that work to respond, and to make solid recommendations for all levels of government and public and private sectors to take action.

The Report's Findings

To do so, the Commission developed a format to receive public comment, hear expert testimony, and to conduct field visits. We assessed existing reports and documentation addressing a wide range of issues and reached out to experts in science, policy, program development, and those experiencing mental illnesses themselves. Our open meetings generated voluminous content as well as input from the 1,000,000 hits on our website.

The scope of information and issues was, at times, staggering and to provide focus we identified 16 areas of concern. Subcommittees of the Commission looked at, for example, diverse issues such as interfaces between physical health and mental health, criminal justice issues, children's and older adult issues, issues of culture, and co-occurring disorders, as well as numerous other topics.

The work was prodigious; the information gathered extensive. An interim Report issued at the 6-month point in our work helped inform the field about where our deliberations were headed and generated still further comment and discussion. That interim report clearly stated the "system is in a shambles", care is fragmented for adults and children, older adults do not receive adequate care, and we have unacceptably high levels of unemployment and disability for persons with serious mental illness.

With tremendous diligence, dedication and work, the Commission crafted the Final Report of the President's New Freedom Commission on Mental Health. Titled *Achieving the Promise: Transforming Mental Health Care in America*, the report presents the Commission's vision for a transformed mental health system for America and provides a roadmap for that transformation. The destination is recovery—the essentials for living, working, learning, and participating fully in the community—what SAMHSA Administrator Curie likes to call "a life in the community for everyone."

It's a vision that we must realize. During our work, we disclosed that today's mental health system unintentionally is focused on managing the disabilities associated with mental illnesses rather than fostering recovery. That limited approach is a product of fragmentation, gaps in care and uneven quality of care when it occurs. These system problems frustrate the work of dedicated staff and make it much harder for people with mental illnesses and their families to access needed care.

We would reweave today's patchwork system into whole cloth—strengthened by a focus on resilience and recovery. The approach we have recommended will move children, youth, adults and older Americans with mental illnesses toward full community participation, instead of school failure, institutionalization, long-term disability and homelessness.

The roadmap we have charted focuses on six goals and a series of specific recommendations for Federal agencies, States, communities, and providers nationwide. Together, working through both the public and private sectors, the recommendations leverage resources to their utmost to achieve the needed transformation of mental health care.

The data I have already shared with you underscore the importance and urgency of meeting the goals and implementing the recommendations the Commission has

proposed. As I've already observed, these goals and recommendations are drawn not from the Commission members alone, but from the experiences of clinicians and administrators, consumers and families, policymakers and community-based services programs.

The Goals and Recommendations

Let me discuss some of the key goals and the recommendations we have made to reach them.

First, we found that if we are to transform mental health care, our programs—from the Federal level to the community level—must shift toward consumer and family-driven services. Consumers' needs and preferences, not bureaucratic requirements, must drive the services they receive. To achieve that goal, the commission recommended specific changes in Federal programs and upgraded State responsibility for planning effective services. Most critically, we stressed the importance of placing consumers and their families at the center of service decisions.

Second, we observed that members of minority groups and people in rural areas today have worse access to care. Further, they often receive services that are not responsive to their needs. As a result, the burden of mental illness is heavier for these individuals. The Commission urged a commitment, again, from community up to the Federal level, to services that are "culturally competent"—acceptable to and effective for people of varied backgrounds.

The Commission's review further found that, too often, mental illness is detected late, not early. As a result, services frequently focus on helping people live with considerable disability, rather than on intervening early, which nearly always yields better outcomes—less disability, and a better opportunity for a meaningful life in the community. Thus, we recommended a dynamic shift in care, toward a model that emphasizes early intervention and disability prevention. As our report stated, "early detection, assessment, and linkage with treatment and supports can prevent mental health problems from compounding and poor life outcomes from accumulating . . ."

Achieving this goal requires better and more extensive engagement and education of first-line health care providers—primary care practitioners. It also demands a greater focus on mental health care in institutions such as schools, child welfare programs, and the criminal and juvenile justice systems. The goal is a system of integrated, community-based care that can screen, identify, and respond to problems early. The Commission also noted that a majority of adults—even those with the most serious mental illness—want to work, but are held back by poor access to effective job supports, incentives to remain on disability status, and employment discrimination. That, too, can be changed with thoughtfully designed community-based programs, incentives to employers. Most critically, it can be changed by instilling in community leaders, employers and educators the knowledge that people with mental illnesses can and do recover and that they can be good students, workers, and members of their families and communities.

Acknowledging significant progress in research on mental illnesses, the panel urged the elimination of the 15–20 year lag between the discovery of effective treatments and their wide use in routine patient care. We underscored the need for accelerated and relevant research to promote recovery and, ultimately, to cure and prevent mental illnesses We also found that while we have gleaned considerable new insights into what services and supports are most effective in helping people achieve recovery and resilience, these practices find their way into community-based care far too slowly. Thus, we called for a more effective process to make "evidence-based practices" the bedrock of service delivery. This will require that payers of mental health care reimburse such practices, that universities and professional groups support training and continuing education in research-validated interventions.

Finally, we recommended that the mental health system needs to move more effectively to harness the power of communications and computer technology to improve access to information and to care, and to improve quality and accountability. With strong protections for privacy, these technologies can improve care in rural areas, help prevent medical errors, improve quality and reduce paperwork.

Throughout the report, the Commission identified private and public sector model programs as exemplars of how aspects of mental health care have been transformed in selected communities.

These examples of innovation—across America, across the age span, and addressing many needs—illuminate how dramatic change is possible, and serve as beacons for the broader improvements recommended by the Commission.

In Closing

With the transmission of our Report, the work of the Commission ended. Your work, the work of lawmakers, policymakers, program developers, administrators and citizens is just beginning. The challenge before you is to move today from the principles we have espoused to policy that will guide the transformation of mental health care today. It's a challenge to move from paper to practice in the community. Change is not easy; but the Commission has provided models and pointed the way. It's a challenge that will take thought, resources and resolve. But most critically, it's a challenge that must be accepted not only here at the Federal level, but also in States and communities as well as families and individuals.

I hope your role as Federal legislators, is to lead by example—to lead in breaking through the stigma of mental illnesses, to lead in breaking down the silos that keep policy and programs for working toward shared solutions, and to lead in the knowledge that, with a system that works for them, people with mental illnesses can and will recover to lead healthy, contributing lives in their communities as parents and partners, workers and students, taxpayers and concerned citizens of their Nation.

I am convinced that, together, we can undertake and realize the wholesale transformation of mental health care in America that will be measured not in the bureaucratic terms of dollars and cents, but rather in outcomes that improve the quality of the lives of people with mental illnesses, lives that can and should be lived with dignity, productivity and the pursuit of happiness that the founding Fathers envisioned for us all.

Thank you, Mr. Chairman and Members of the Subcommittee, for the opportunity to be here and to explore with you what the Commission has found and recommended.

PREPARED STATEMENT OF CHARLES G. CURIE

Mr. Chairman and Members of the Subcommittee, I am honored to present on the President's New Freedom Commission on Mental Health and the Administration's activities to achieve the goals contained in the Commission's final report. First, I want to thank my friend and colleague Steve Mayberg for his kind words and his contributions to the Commission's work. I also want to recognize the leadership demonstrated by Michael Hogan as the Chair of the President's Commission. Mike's is steadfast commitment to do what is right for people with mental illness steered the commission through many tough decisions and ultimately led to the final report which we are here today to discuss.

An important context for our work in the Bush Administration and the recommendations developed by the commission is the words of people in our service delivery systems working to obtain and sustain recovery. In particular, the first position I held, as a new MSW graduate, was working as a therapist to help mental health service consumers make the transition from in-patient care in State hospitals back into the community.

This aftercare group included consumers that had spent over a decade in the hospital. I asked them what they needed to make their transition successful. They didn't say they needed a psychiatrist. They didn't say they needed a psychologist. They didn't even say they needed a social worker. They didn't say they needed a comprehensive service delivery system or evidenced-based practices. They said they need a job, a home and meaningful personal relationships or to use a direct quote . . ."I need a life—a real life . . . I need a job, a home and a date on the weekends."

People seeking or in recovery from mental illness need most to feel connected. They want a life, a real life with all of its rewards. This is the very essence of the recommendations contained in the final report of the President's New Freedom Commission on Mental Health.

It is a privilege to serve President Bush and work for Tommy Thompson, our Secretary of the U.S. Department of Health and Human Services. This is an Administration that knows treatment works and recovery is real!

In the words of our President, "Political leaders, health care professionals, and all Americans must understand and send this message: mental disability is not a scandal—it is an illness. And like physical illness, it is treatable, especially when the treatment comes early." As you have heard the President charged the Commission to study the problems and gaps in our current system of treatment, and to make concrete recommendations for immediate improvements that will be implemented . . . by the federal government, the state government, local agencies, as well as public and private health care providers.

I will not spend a lot of time on the details of the report because you have already heard from Steve Mayberg. Instead, I will share a little of the "why" and the "what

now" perspectives with you. Currently, numerous Federal, State and local government entities oversee mental health programs. In fact, the Commission identified over 40 Federal programs alone.

One of the largest Federal programs that supports people with mental illnesses is not even a health services program. The Social Security Administration's (SSA) Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) programs paid approximately $27 billion in disability payments in 2002 to beneficiaries with mental impairments (excluding mental retardation). Persons with mental illness represent the fast growing group of persons determined to be disabled by SSA.

At the same time employment is an essential tool for persons with mental illnesses to fully participate in their communities. The majority of adults with serious mental illness want to work and many can work with help. However, many seek disability status to get health coverage and to do so, the must either end or limit their employment. As a result, many consumers with serious mental illness continue to rely on Federal assistance payments in order to have health care coverage, even when they have a strong desire to be employed.

Few mental health planning or Medicaid planning requirements ensure States work across State agencies or with mental health constituencies to form a single comprehensive mental health plan for the State. Consequently, the goals and desired outcomes, the service definitions and provider qualifications, and the payment mechanisms and organization of mental health care can be very different, depending on whether Medicaid, general fund appropriations, or other sources, such as schools, Temporary Assistance for Needy Families, local public mental health authorities, or juvenile justice systems are the payers of services.

Clearly, more efficient organization and better coordination of services and funding streams will assist providers in making sure effective treatment is received and that recovery can be realized. And, Federal funding sources should be aligned and provide consistent direction to States in their planning efforts, taking into account the multiple missions of the various funding streams and programs.

When the President announced the Commission and defined the scope of responsibility, he spoke frankly about the poor quality of mental health care in this country in terms of its fragmented delivery system. He talked about the many points of contact we have with people with mental illnesses—all too often this being homeless shelters, criminal justice system or welfare system. He talked about missed opportunities to diagnosis and treat individuals suffering from mental disorders. And, he also acknowledged the difficulty of achieving a diagnosis and providing the state of the art care we know can be delivered.

He spoke of the many Americans who fall through the cracks of our current service delivery system and equated that failure with years of lost living and of lives entirely lost before help is given—if it is ever, in fact, even offered.

President Bush drew upon the all too often common example of a 14-year old boy who suffered from severe depression and began experimenting with drugs to self-medicate and alleviate his symptoms. You are all well too familiar with the shameful scenario of the honor student turned drug addict. This young man, like many Americans of all ages, slipped through the cracks. And just like him, he wasn't diagnosed until age 30 with a bipolar disorder, they wait half their lifetime for someone to notice that their behavior wasn't simply a matter of poor choices.

As you may know, SAMHSA has been given the lead role to conduct a thorough review and assessment of the final report of the President's New Freedom Commission on Mental Health with the goal of implementing appropriate steps to strengthen our mental health system. In short, President Bush asked the Commission to give the mental health system a physical . . . they did. The diagnosis is "fragmentation and disarray." The Commission report found the nation's mental health care system to be well beyond simple repair. It recommends a wholesale transformation that involves consumers and providers, policymakers at all levels of government, and both the public and private sectors.

The "Mental Health System Recovery Plan" if you will, will require the implementation of the "To Do List" currently being developed by SAMHSA on behalf of the Bush Administration. The "To Do List" will form an action agenda to achieve transformation of mental health care in America. My lead staff person for developing this action agenda is Kathryn Power. Kathryn recently joined SAMHSA as the Director of our Center for Mental Health Services. She is working to develop an agenda for transformation that is built around the 6 goals and 19 recommendations contained in the Commission's Report.

This transformation will require a shift in the beliefs of most Americans and will require the nation to expand its paradigm of public and personal health care. Everyone from public policymakers to consumers and family members must come to un-

derstand that mental health is a vital an integral part of overall health. Along with this new way of thinking, Americans must learn to address mental health disorders with the same urgency as other medical problems.

The report also challenges us to close the 15-20 year lag time it takes for new research findings to become part of day-to-day services for people with mental illnesses. Waiting for the research to make its journey down an already clogged pipeline equates to generations lost in the process. Too many Americans are already under-served and many more are done a disservice when their quality of life remains poor while they wait for the latest research to crawl into their communities.

The report challenges us to harness the power of health information technology to improve the quality of care for people with mental illnesses, to improve access to services, and to promote sound decision-making by consumers, families, providers, administrators and policymakers. And it challenge us to identify better ways to work together at the federal, state and local levels to leverage our human and economic resources and put them to their best use for children and adults living with—or at risk for—mental illnesses. Most of all, the report reminds us that mental illness is a treatable illness and that recovery is the expectation. As a compassionate nation, we cannot afford to lose the opportunity to offer hope to those people fighting for their lives to obtain and sustain recovery.

To lead the effort I have assembled a transformation taskforce. We are already working with relevant Federal agencies—to determine ways—to provide States the flexibility needed and the incentive—to bring to bear the full force of the resources available to meet the needs of people with mental illnesses. I am counting on the relationship that SAMHSA and other Federal Agencies have with our State partners. As we move forward, we will work with States to develop an Action Agenda of their own. A few states have already begun—Texas, Nevada, Nebraska—to name a few.

The new state agendas must be consumer and family driven—not bureaucratically bogged-down. Consumers of mental health services and their family members must stand at the center of the system of care. Consumer and family needs must drive the care and services that are provided. The result will be more of our family members, co-workers, neighbors and friends living that rewarding life in their communities that I talked about in the beginning of my remarks.

In closing, we all need to recognize the changes that need to be made will not happen over night. Developing and implementing the Action Agenda for Transformation will be an ongoing process. Clearly, our success will depend on our ability to span all levels of government and the private sector to align and bring to bear the full force of resources available. The strategy will be to keep our focus on the needs of adults with serious mental illnesses, children with serious emotional disturbances and their family members. The goal is to make recovery a reality for everyone.

Thank you for your time and interest is our work. I would be pleased to answer any questions you may have at this time.

PREPARED STATEMENT OF PAUL S. APPELBAUM, M.D.

Mr. Chairman and members of the Committee, I am Paul Appelbaum, MD, Professor and Chair of the Department of Psychiatry at the University of Massachusetts Medical School, where I oversee the largest mental health treatment system in Central Massachusetts. As the immediate past president of the American Psychiatric Association, I have been deeply involved in efforts to reform the system of care for mental disorders, and have followed the work of the Commission closely.

When the Commission declared in its Interim Report that "the mental health delivery system is fragmented and in disarray . . .," it struck a chord with mental health professionals, persons with mental disorders and their family members, across the country. After three decades of neglect and progressive defunding, the mental health system finds itself mired in crisis. Let me tell you about the troubling situation in my home state of Massachusetts.

Imagine that you live in Massachusetts and have become so depressed that you cannot work or care for those who rely on you, or so stricken with anxiety that you can no longer leave your house. But you are fortunate enough to have health insurance and expect not to have trouble finding the treatment you need. When you call a general hospital with a large outpatient clinic like mine, however, they explain that they will need to put you on a waiting list of weeks to months in duration. With insurers paying less than the actual cost of delivering outpatient treatment, hospitals have been reducing the size of their clinics or closing parts of them altogether, to the point where the need for services vastly exceeds the supply.

Perhaps next you try calling a list of private practitioners in the community who, your insurance company says, are part of their "network." But many of them tell you frankly that they no longer accept insurance coverage, because the rates are too low to allow them to survive. They can see you only if you pay out of pocket for the costs of your care. Other clinicians, of course, do still accept some patients with insurance, but they too have waiting lists. If you leave your name, they will call you back when—and if—an opening appears.

With time passing and no treatment, your condition worsens. One morning, you cannot even get out of bed. A worried family member brings you to the nearest psychiatric emergency room, itself overwhelmed with people like you who have been unable to access timely outpatient care. Although it's clear by now that you need to be hospitalized, you wait 7 hours—about average you learn—for an empty bed to be found in a hospital 50 miles away. In the emergency room, you are one of the lucky ones. Other patients, several of them adolescents, have been living there for several days while waiting for a bed. It turns out that psychiatric units are notorious money—losers in general hospitals, with insurers paying somewhere around 70% of the real costs, and that units have been closing around the state for the last decade.

Your neighbor, with bipolar disorder, who works in a minimum wage job without insurance, is in an even tougher spot. Community mental health centers are no longer funded by the state to care for uninsured patients and are now simply turning them away. Since Massachusetts hospitals have to accept uninsured patients at the hospital's expense as a condition of participating in the Medicaid program, when she deteriorates to the point of needing to be hospitalized, a bed can be found. But as it becomes clear that she'll need longer-term care in one of the few remaining state hospitals, she waits for more than a month before the transfer can take place. And once she's discharged into the community, the continuum of services that she needs—housing, job training, treatment for substance abuse—is stretched so thin that there is no guarantee that she can access any of them.

If this were the situation only in Massachusetts, it would be a tragedy, but might not warrant the attention of this Committee and all of Congress. But these scenarios are echoed in state after state. Given this, it is no surprise that the US Surgeon General's Report on Mental Health cited data showing that only 20% of persons with mental disorders receive any treatment in a given year, and that includes fewer than half the persons with such severe disorders as schizophrenia and bipolar disorder. Hence, the importance of Commissioner Hogan's call in the transmittal letter for the Commission's report, for a "fundamental transformation" of our approach to mental health care.

The recommendations in the Commission's report are, without exception, helpful. But to be frank, they fall short of the fundamental transformation that is so clearly needed. As president of the American Psychiatric Association, I appointed a task force to develop a vision of what a genuine system of mental health care should be. That report, along with my presidential address that lays out some directions we can follow, has been provided to the Committee. In short, I suggest that we need to facilitate the integration of treatment for most mental disorders into the primary care medical system—a goal that faces numerous structural obstacles today. And for our citizens with severe and persistent mental disorders, we must reinvigorate the vision of President John F. Kennedy, whose Community Mental Health Act of 1963 marked the last attempt to construct a nationwide mental health system that could care for all our of our citizens. And while the costs of such a program cannot be ignored, it is likely that they can be funded in substantial part from money now spent on jails, homeless shelters, disability payments and other efforts to compensate for the failings of our mental health system.

Thank you for your attention and I would be pleased to respond to the Committee's questions.

American Psychiatric Association, 1000 Wilson Blvd. Suite 1825, Arlington, VA 22209

The American Psychiatric Association
Presents

A Vision for the Mental Health System

April 3, 2003

Prepared by APA Task Force for a Vision for the Mental Health System

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April 3, 2003

American Psychiatric Association

Presents

A Vision for the Mental Health System

A 15-year-old girl with severe substance abuse, depression, and suicidal intent and plan remains stuck in an emergency room for more than four days because there are no psychiatric beds available within a 250-mile radius. A 40-year-old man with a 20-year history of paranoid schizophrenia is picked up by the police for vagrancy and shoplifting shortly after his discharge from a psychiatric unit of a general hospital, and is discovered hallucinating in his jail cell after making a suicide attempt. A 35-year-old unemployed stock broker with symptoms of severe panic disorder is unable to find a psychiatrist for a timely appointment after calling ten physicians on a panel provided by his managed care company. A patient with schizoaffective disorder has had five different inpatient and outpatient psychiatrists in the space of six months having been re-hospitalized three times and discharged to day and outpatient programs. An 80-year-old patient with moderate dementia and major depression is hospitalized after the community mental health center that provided home visits and psychiatric care is forced to cut back community outreach services.

"America's mental health service delivery system is in shambles." [1] At a time when treatment for psychiatric illness has never been more effective, access to that care is fragmented, discontinuous, sporadic, and often totally unavailable. The numbers of individuals with serious and persistent mental illness (SPMI) who are incarcerated or homeless and without support have reached epidemic proportions.[2] The shortage of psychiatric hospital beds is endemic in many states across the country, and growing gridlock in our emergency rooms extends for days at a time as adults and children wait for an available psychiatric bed.[3] Outpatients struggle with a list of approved psychiatric physicians from their managed care company, unable to find one who can make a timely appointment for an initial visit.[4] In underserved and rural areas, it is often difficult for patients and families to find a clinician who can diagnose and treat. There is a nearly total disconnect between substance abuse and mental health treatment, and many disincentives for integration of psychiatric and medical services at the primary care level.[5] What should the mental health system look like in 21st century America? What are the values that guide advocacy for a genuine, responsive mental health system?

The Right to Quality Psychiatric Care

Every American with significant psychiatric symptoms should have access to an expert evaluation leading to *accurate and comprehensive diagnosis* which results in an *individualized treatment plan that is delivered at the right time and place, in the right amount, and with appropriate supports such as adequate housing, rehabilitation, and case management when needed. Care should be based on continuous healing relationships and engagement with the*

whole person rather than a narrow, symptom-focused perspective. Timely access to care and *continuity of care* remain today cornerstones for quality even as a *continuum of services* is built that encourages maximum independence and quality of life for psychiatric patients.

The *physician-patient relationship* is central to any reform of the health system. It encompasses confidentiality, continuity of care, and the ethical responsibility always to put the patient's needs first. Physicians need adequate time to complete an individualized evaluation of the patient that includes not only the medical and psychiatric clinical status but also the patient's personality, social and family circumstances, and immediate environmental needs. Such comprehensive evaluations may require obtaining information from other medical, mental health, and social service specialties to integrate with the psychiatric evaluation.

Confidentiality in the doctor-patient relationship and privacy are cornerstones of psychiatric values and a special challenge in today's complex communications environment utilizing always-changing medical information technology. Patients will not come for treatment if their information is shared without their explicit permission.

Psychiatric illness encompasses a broad spectrum of problems from the depressed child to a relapsed alcoholic to the anxious executive and the chronically ill patient with schizophrenia. Accordingly, proper care entails a wide range of options that can be tailored to individual needs. *Multiple modes of access* must be maintained in the system of the future. *Evidence-based care* must be encouraged and utilized. Proactive *diversion from jails, prisons, and the streets* must be planned and implemented. Acute inpatient care for most of those who need it and long-term residential care for a few must be available now and in the future. *Homelessness* among the mentally ill must be addressed and eliminated. Comprehensive and integrated approaches with multiple medical and mental health providers and social service agencies must join together to overcome the current fragmented, wasteful, and ineffective non-system we have today.

The Olmstead decision of the U.S. Supreme Court asserts that mental disabilities are true disabilities and establishes that institutionalization of persons with mental disabilities can constitute discrimination when that person could be reasonably accommodated in an integrated community setting. All persons with disabling mental illnesses should be able to receive individualized psychiatric evaluation and treatment that allows maximum independence and productivity.

The fragmentation and disintegration of care are the real challenges in developing a genuine mental health system. A genuine mental health system is more than the asylum movement of the 19th century or the community mental health centers in the mid-20th century or the more recent debacle of excessive utilization management that has forced patients prematurely out of hospital settings, split psychotherapy from psychopharmacology, separated primary care and specialty psychiatry, and focused on cost savings to the detriment of the physician-patient relationship.

Payments and Costs

Payment for care should be nondiscriminatory and *cost containment principles such as utilization review should be identically applied to health and mental health*, that is, in a nondiscriminatory fashion. *The budget for dealing with psychiatric illness should be interpreted*

broadly to account for all the cost shifts that occur today from mental health to the criminal justice, general health, welfare, and disability systems across the political landscape.

It is an unrealistic expectation that any changes in the funding of the mental health system should be "budget neutral." Reduced funding for treatment in the public and private systems has created the current crisis in which we find ourselves.

Many of our most resource-intensive patients have moved to other arenas of social policy, and a true budget must consider the cost offsets in general health, welfare, and criminal justice that would be remedied by devoting more funds to accessibility of quality diagnosis and treatment. Employers especially need to appreciate that failure to fund mental health care leads to costs in other dimensions, including lower productivity, higher absenteeism, and loss of valuable employees. Our advocacy must extend to dramatically improving the funding for treatments of psychiatric illness in both government-financed and employer-financed health systems. Employer-based private insurance mental health expenditures have dropped from 7.2 percent of total health spending in 1992 to 5.1 percent of total spending in 1999.[6]

A System for the Seriously and Persistently Mentally Ill*

For those with serious and persistent mental illness (SPMI), what we need in a genuine mental health system is:

- Full access to treatment, rehabilitation, and support services in a coordinated and comprehensive system of care that is culturally competent;
- Continuity of care;
- Treatment that meets standards of care that are supported by best practice research;
- Pharmacological intervention based primarily on efficacy and total cost rather than short-term costs;
- Treatment in the least restrictive setting that is consistent with both safety and reasonable expectations of benefit;
- Financial support adequate to meet basic human needs;
- Safe, supportive housing with the ultimate goal being housing as independent as possible;
- Daily activity that is meaningful, productive, and life-enhancing;
- Social opportunities and collegiality within a community;
- Support services that assist attaining this quality of life.

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* This section derives from an APA Assembly Task Force on SPMI which reported in November 2002 and was approved by the APA Board of Trustees in March 2003.

Mandatory Treatment

What about the SPMI patients who deny that they are ill, are hospitalized multiple times, and are potentially dangerous if not in treatment? Psychiatric care differs from general medical treatment due to the fact that psychiatrists treat some patients who are not able to appreciate that they need treatment. With the twin movements of de-institutionalization and managed care, there is less available funding for inpatient treatment. Involuntary hospitalizations occur in every state based on criteria that emphasize dangerous to self or others or grave disability. Sadly, involuntary hospitalization is often not available for patients who are not dangerous but who urgently need comprehensive evaluation and intensive treatment that is not possible outside a hospital. After patients are initially stabilized, they are often discharged and some are repeatedly noncompliant with outpatient care. Mandatory outpatient treatment is a useful tool and a preventive intervention for those who may not presently meet criteria for inpatient commitment but need treatment to prevent relapse or deterioration that would predictably and rapidly lead to their qualifying for admission. More than 40 states and the District of Columbia have commitment statutes permitting mandatory outpatient treatment, and studies of such treatment have been linked to improved patient outcomes such as reduced hospitalization rates and decreased violent behavior. Any humane and comprehensive quality mental health treatment system must make provision for both inpatient and outpatient involuntary treatment for those severely and/or persistently mentally ill who can benefit from such approaches

A System of Care for Children, Adolescents, and Families

The crisis of access to child and adolescent mental health services is particularly acute. According to the Surgeon General's Report on Mental Health, one child in five suffers from a psychiatric or substance abuse disorder.[8] However, research consistently demonstrates that the majority of these children are not receiving effective and appropriate treatment.

Children and adolescents with psychiatric illnesses have certain unique needs which must be addressed in the design, development, and implementation of any comprehensive system of care. Child and adolescent mental health services should be community-based and family-centered, with a focus on existing strengths and resources. Emphasis should also be placed on:

- < Identifying children with emotional and behavioral problems as early as possible;
- < Ensuring access to a comprehensive continuum of clinical services including emergency/crisis, outpatient, inpatient, and intermediate-level programs (e.g., day hospital, respite, residential treatment, and home-based services), with sufficient time to evaluate fully and address the clinical state, family and social situation, emotional and cognitive development, and personality of the child;
- < Facilitating access to services through school-based and primary care settings;
- < Improving coordination between mental health, substance abuse, education, social services, and juvenile justice at the local, state, and federal levels.

We must also achieve an adequate and appropriate number of well-trained mental health professionals to evaluate and treat children and adolescents with psychiatric illnesses.

To do so, our training programs must expand and prioritize recruitment into the seriously underserved subspecialty of child and adolescent psychiatry. Additionally, enhanced funding for research into the etiology, treatment, and prevention of child and adolescent psychiatric disorders must be an urgent priority.

The good news is that we can help most children and adolescents who suffer from psychiatric disorders. The real tragedy is that so many young people still do not receive the comprehensive treatment they need and deserve.

Access to Care for the Older Adult and for Ethnic and Racial Minorities

Mental illness in older adults is under-diagnosed and under-treated. There are considerable barriers for the elderly in accessing psychiatric treatment. As the population ages, it has been estimated in the Surgeon General's Report that the number of adults over age 65 with major psychiatric illness will more than double from 7 to 15 million individuals by 2020.[8] Medicare continues to discriminate against treatment for mental illness by requiring a 50 percent co-pay for psychiatrists in contrast to a 20 percent co-pay for other physicians. Parity for mental health care under Medicare is a long overdue and urgent priority.

Furthermore, many other individuals who need treatment do not receive it. This is especially true in rural areas and for ethnic and racial minority groups. The Surgeon General's Supplemental Report[9] underscored these disparities in access to care for ethnic and racial minorities as compared to the general population. The report found that racial and ethnic minorities bear a greater burden from unmet mental health needs and thus suffer a greater loss to their overall health and productivity. Most minority groups are less likely than whites to use services, and they receive poorer quality mental health care despite having similar community rates of mental disorders. In addition, the IOM report[10] released in March 2002 also highlights the racial disparities that result in decreased access and increased disability burden. Further, minorities are overrepresented among the nation's vulnerable, high-need groups such as homeless and incarcerated persons. These subpopulations have higher rates of mental disorders than do people living in the community. Taken together, the evidence suggests that the disability burden from unmet mental health needs is disproportionately high for racial and ethnic minorities relative to whites.

A Conceptual Foundation for the Design of a Rational Mental Health System

The Interim Report of the New Freedom Commission on Mental Health emphasizes a "recovery" approach for the treatment of the seriously mentally ill.[11] Although not incompatible with a biomedical and public health approach, the "recovery" model is based on rehabilitative and psychosocial concepts. Another approach which should be pursued is based on the biomedical and public health perspective and is a powerful and forward-looking conceptual foundation for designing a rational mental health system is the "global burden of disease model" jointly developed by the World Health Organization and the World Bank.[12] The Surgeon General's Report on Mental Health (1999) describes this model in some detail. Its major strength is a common approach across all medical, surgical, and psychiatric illnesses defined as disability adjusted life years (DALYS). This combines years of life lost (YLLs) as a result of premature death with years of life lived with disabilities (YLDs). The latter approach is calculated as the product of the prevalence of these disorders with duration of disabling symptoms and the severity of the disability. Chronic diseases with high levels of disability,

such as major depression, bipolar disorder, schizophrenia, are among the illness with high prevalence and high morbidity that contribute to years of disability. The new NIMH Director, Thomas Insel, has announced that one of the major public health goals of NIMH is to reduce YLDs associated with major depression by ten percent by the year 2010.[13]

There is clearly great disparity between the funding of treatment for psychiatric care and medical/surgical illnesses. In the U.S., the burden for disease accounted for by mental disorders is 20 percent, whereas only 5-7 percent of all health expenditures are directed toward treatment of these disorders.[14] Based on a relatively high prevalence rate and level of associated disability, major depression is the leading cause of disability in the United States for all disorders. Since we now have excellent epidemiological information on the prevalence rates of all mental disorders in the United States, there is a quantitative basis for determining DALYS associated with specific disorders. It is clear that additional funds are warranted to bring funding more in line with the 20 percent of DALYS associated with mental disorders. This approach lends itself to the monitoring of prevalence rates, the treatment costs of these disorders, and the cost benefit in reducing DALYS associated the allocation of resources.[15] This is an evidence-based approach to reformulate budgetary priorities at a time of scarcity to provide a rationale for increased funding for treatment of mental disorders.[16]

Introduction of nondiscriminatory insurance coverage ("parity") for mental disorders is one significant step in making those additional resources available. Many individuals with disabling anxiety and mood disorders predominantly belong to insured population groups, and any reduction of YLDs associated with depression, for example, will come as the result of improved access to appropriate treatment. Increased ability to access insurance benefits that provide reasonable coverage for mental illness (including private, Medicaid, and Medicare) would increase patient choice of mental health provider and reduce the burden on the public system. Reductions in state funding have resulted in a massive cost shift of care to the criminal justice system; incarceration is a costly, ineffective, and inhumane method for dealing with individuals with severe mental disorders. Reallocation of criminal justice funds to treatment for mental disorders would address the source of the problem by providing an evidence-based strategy to reduce DALYs associated with low prevalence severe disorders and all other disorders treated in the public system. Such a comprehensive health and human service reform would result in allocating resources more in line with the 20 percent of DALYS associated with mental disorders.

Progress in Opportunities for Effective Treatment

Within the last quarter century, a number of significant if not revolutionary medical treatments and psychosocial techniques have been developed. These have demonstrated good outcomes, dramatically enhancing treatment success for virtually every psychiatric illness. We have become more reliable in our diagnostic abilities through the scientific advancement of the *Diagnostic and Statistical Manual* (DSM), now in its fourth edition, supported by the American Psychiatric Association.[17] Our emerging science base and sophistication regarding specific treatments for specific conditions, including a new generation of effective medications and psychosocial treatments, augment recovery and raise hopes of "cure." Electronic technology for recording and communicating medical information, with stringent safeguards to protect privacy (particularly sensitive psychotherapy material), can facilitate continuity of care when multiple clinicians and facilities must be involved in the care of

a patient. Adopting evidence-based approaches in the emerging trend among psychiatrists and other clinicians provides a very compelling rationale for expanding the funding of treatments outlined above. Persons with psychiatric illness throughout our country should have the opportunity to access expert clinicians with the knowledge and ability to provide effective treatment.

In the Institute of Medicine's report, *Crossing the Quality Chasm: A New Health System for the 21st Century*[18] six general principles of health care services are elucidated that have strong application in the design of a mental health system. These services must be:

- < safe – avoiding injuries to patients from care that is intended to help them;
- < effective – providing services based on scientific knowledge to all who can benefit and refraining from providing services to those not likely to benefit. This must be applied with caution to avoid depriving very seriously ill persons of all hope of improvement or recovery of function. New treatments have brought great benefit to many SPMI who would previously have been considered beyond any effective treatment.
- < patient-centered – providing care that is respectful of and responsive to individual patient preferences, needs, and values;
- < timely – reducing wait and sometimes harmful delays for both those who receive and those who give care;
- < efficient – avoiding waste; and
- < equitable – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

This report also emphasized that care should be based "on a continuous healing relationship." This is probably the most critical problem facing the mental health system today. The current system does not provide this continuing healing relationship for many, if not most, of those who need care and treatment.

Who Is Responsible?

Today, there is an increasing blurring of the boundaries between public and private delivery of services. Much of the care delivered in private office and hospital settings is financed by the public sector (Medicare and Medicaid as well as state and county mental health funds), and the public sector remains a critical component in the design of a mental health system of the future. *State government* must be the ultimate locus of accountability as it is responsible for those patients who fall through the cracks of our non-system. *The federal government* must lead the way towards non-discriminatory mental health care by eliminating those discriminatory aspects in Medicare such as the 50 percent co-pay and the exclusion of Institutions for Mental Diseases (IMDs) from full Medicare coverage. We need national legislation to require all employer-based insurance to include mental health and substance abuse in parity with other medical conditions.

Employers are presently responsible for the funding of care for the workforce and should embrace early intervention, expert diagnosis and treatment, and non-discriminatory funding of care. Our fragmented system of health care has been decimated further by the managed care marketplace that carves out mental health care from general health care, discourages integrated psychotherapy and medication management by psychiatrists, denies

payment for long-term treatment of severe illness in favor of less effective episodic acute care, and disrupts continuity of physician-patient relationships as employers change from one MCO to another and then yet another. Employers can play a major role in demanding an end to these detrimental practices, and this is consistent with their own economic self-interest.

In summary, APA advocates the following:

Twelve Principles for a Vision for Our Nation's Mental Health System

1. Every American with psychiatric symptoms has the *right* to a comprehensive *evaluation* and an accurate *diagnosis* which leads to an appropriate, individualized plan of treatment.

2. Mental health care should be *patient and family centered*, community based, culturally sensitive, and easily accessible without discriminatory administrative or financial barriers or obstacles.

3. Mental health care should be *readily available* for patients of all ages, with particular attention to the specialized needs of children, adolescents, and the elderly. Unmet needs of ethnic and racial minorities require urgent attention.

4. *Access* to mental health care should be provided *across numerous settings*, including the workplace, schools, and correctional facilities. An emphasis should also be placed on the early recognition and treatment of mental illness.

5. Patients deserve to be treated with *dignity and respect*. When they are clinically able, they are entitled to choose their physician or community-based agency and to make decisions regarding their care. When they are incapable to do so, they should receive the treatment they need and when able, they should choose future care.

6. Patients deserve to receive care in the *least restrictive setting possible* that encourages maximum independence with access to a full continuum of clinical services, including emergency/crisis, acute inpatient, outpatient, intermediate level, and long-term residential programs.

7. Since mental illness and substance abuse occur together so frequently, mental health care should be fully *integrated* with the *treatment of substance abuse* disorders and with primary care and other general medical services.

8. Support must expand for *research* into the etiology and prevention of mental illness and into the ongoing development of safe and effective treatment interventions.

9. Efforts must be intensified to combat and *overcome the stigma* historically associated with mental illness through enhanced public understanding and awareness.

10. *Health benefits*, access to effective services, and utilization management must be the *same* for people with *mental* illness as for *other medical* illnesses, preferably funded by integrated financing systems. Although states are the ultimate locus of responsibility for the public safety net, the federal government and the private sector employers must also support an increased investment in the mental health of Americans.

11. *Funding* for care should be *commensurate with the level of disability* caused by a psychiatric illness. Disability occurs both in the severely and persistently mentally ill and in patients with other unforeseen psychiatric conditions who suffer despite having previously been productive and functional.
12. *More resources* should be devoted to *treatment* and to *training* an adequate supply of psychiatrists, *especially child* psychiatrists, to meet the current and future needs of the population.

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The 'Quiet' Crisis In Mental Health Services

Adequate reimbursement to providers of mental health services is the key to sustaining a viable care system.

by Paul S. Appelbaum

ABSTRACT: The failure of insurers and managed care organizations to reimburse providers of mental health services for the costs of care has led to a crisis in access to these services. Using the situation in Massachusetts as a case example, this paper explores the impact of this defunding. Unable to sustain continued losses, hospitals are closing psychiatric units, and outpatient services are contracting or closing altogether. The situation has been compounded by the withdrawal of many practitioners from managed care networks and cuts in public-sector mental health services. Unless purchasers demand effective coverage of mental health treatment, mental health services will likely continue to wither away.

WHAT WAS THE PRECISE MEANING of the President's New Freedom Commission on Mental Health declaration in the fall of 2002 that the mental health system was "fragmented and in disarray" and in need of "dramatic reform?"[1] As chair of a large academic department of psychiatry, I found no mystery in the commission's pronouncement. Over a little more than a decade, I have witnessed the progressive and systematic defunding of psychiatric services in Massachusetts and—despite some regional variation—in the United States as a whole. As a result, provision of mental health treatment in organized settings such as hospitals and clinics has often become a money-losing proposition. With inpatient units and outpatient clinics driven by the inexorable economics of the situation to downsize or close, people in need of treatment are finding it more difficult, if not impossible, to get care. The situation is compounded by the flight of private practitioners from managed care networks, leaving insured patients struggling to find clinicians who will accept their coverage, and by the continuing retreat of the states from their historical role as providers of last resort for psychiatric care.

I am generally cautious in my use of the word "crisis," but as best I can tell, the current situation in the mental health system qualifies for that label. When I talk to colleagues and mental health professionals around the country, I find that they agree. Rather than attempting here to review the situation in the entire country, I

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present a case example of the current crisis from Massachusetts, with some evidence to suggest that by no means does it stand alone in confronting this serious situation. I conclude that unless steps are taken to remedy the current "disarray," we are likely to witness the slow implosion of mental health services in many parts of the United States.

Organization Of Mental Health Care In Massachusetts

To understand this account, one needs to know a bit about the organization of mental health care in Massachusetts. Almost all insurance coverage for mental health treatment in the state is administered by managed behavioral health care organizations (MBHOs) or directly by a health maintenance organization (HMO); except for most Medicare patients, traditional indemnity coverage is all but nonexistent. Outpatient care is provided by a mix of private practitioners, clinics (both for-profit and nonprofit), community mental health centers (CMHCs, mostly private nonprofit, although a few state-operated centers remain), and general hospital outpatient departments. The primary payer for indigent patients is Medicaid, with the state's Department of Mental Health providing almost no direct support for outpatient services. Hence, there has been a major effort to enroll all qualified indigent patients in Medicaid. Except for the minority of patients who are enrolled in Medicaid HMOs, all Medicaid mental health benefits are provided through a contract with a large, for-profit MBHO in a "carve-out" arrangement. There is no payer of last resort for uninsured patients; the costs are assumed by the general hospitals and CMHCs where the care is provided.

Acute inpatient care in Massachusetts, except for the few state-run CMHCs, is provided entirely in the private sector. State hospitals no longer have any acute inpatient units. As with outpatient care, Medicaid is the payer for most indigent patients who require hospital admission. Uninsured patients who are not on the Medicaid rolls, either because they do not qualify for the program (a group that has been increasing in number as the eligibility criteria have been tightened) or because they simply have never enrolled, must be admitted by any hospital unit that has a Medicaid contract as a condition of participation in the program. Essentially, the costs of hospitalizing the uninsured have been shifted to the hospitals; a fraction of the Medicaid day rate may be reimbursed to hospitals through a state-run free-care pool, but the bulk of the funds available in the pool come from contributions by those same hospitals.

Continuing care for patients who cannot be discharged to the community after an acute hospitalization is still provided in a dwindling number of state hospitals. (One state hospital closed in the past year, and another was threatened with closure this year.) Beds for these patients are scarce, however, and patients can wait up to several months to be admitted to the state hospital after applying for transfer. Once such application is made, private payers consider patients awaiting transfer as no longer in need of acute care and thus pay the hospital and physicians

nothing, although the patients continue to occupy beds on acute units. The Medicaid carve-out plan reimburses their care at an "administrative day" rate—one-third less than the usual inpatient rate. Most residential and community support services are funded by state contracts with providers, largely nonprofit entities.

The Nature Of The Current Crisis: Outpatient Treatment

■ **Trying to cover the costs of care.** When managed care entered Massachusetts in the early 1990s, contracts were negotiated with practitioners and facilities to provide care at rates 30–50 percent below the prevailing rate of payment. In retrospect, one can question the wisdom of providers' entering into such contracts. At the time, however, there was a sense that retaining market share was an important survival mechanism and that as the weaker providers fell by the wayside, the survivors would be able to demand higher reimbursement. Beyond strategic considerations, however, providers—whether private practitioners or facilities—did not relish the thought of losing a substantial segment (sometimes 20 or 30 percent) of their patients by virtue of refusing to agree to any company's proffered terms. Although the particulars of their rates differed, the managed care companies that were flocking into the state all demanded substantial discounts from the prevailing payment levels, leaving most providers with no option but to agree to their terms.

In the decade or so since, the rates paid by most payers have edged up only marginally, as costs have continued to rise. Shortage professions, such as nursing, command premium salaries (in some cases exceeding those paid to physicians), and most other salaries have risen as well. In addition, the introduction of managed care itself resulted in an increase in costs, as clinical time was diverted and additional clerical personnel hired to obtain advance authorizations, collect copayments, monitor the number of authorized sessions, negotiate approval for additional sessions, meet increased documentation requirements for billing, and track and resubmit the growing numbers of bills denied—often for what seemed to be trivial reasons (such as an incorrect middle initial for a patient whose other identifying information was all correct).

As a result, outpatient clinics, whether based in general hospitals or CMHCs, receive payment at rates that do not come close to covering the costs of care. To personalize the situation, every time we see a patient at our university medical center–based outpatient clinic, we lose money. If patients are seen instead at the CMHC that is part of our system, the loss is less, but even this tightly run operation loses money on every outpatient visit. There is nothing unusual about our programs; the same is true at comparable programs throughout the state. As a result, clinics have been closing or scaling back services to the point where demand far exceeds supply. Early this year a major academic medical center in the western part of the state announced the closure of its psychiatric outpatient clinic.[2] At our clinic, which receives approximately 48,000 visits per year, we have largely restricted our flow of new patients to referrals from clinicians at our medical center.

"Some patients who are unable to obtain timely outpatient care deteriorate to the point where urgent intervention is required."

When other clinicians or patients call us directly, we make every effort to refer them somewhere else; we cannot justify the increased losses that would result from hiring additional clinical staff to meet the demand. If clinicians leave our system, we encourage them to take their patients with them—behavior that once would have been considered idiosyncratic but that is now adaptive.

■ **Impact on access.** Of course, since the situation is the same in the rest of the state, the patients we cannot treat have an extremely difficult time gaining access to care anywhere else—unless, of course, they are able and willing to seek treatment from one of the growing number of practitioners who limit their practices to people who pay directly for their care. There was a time when patients who could not find treatment anywhere else could go to a CMHC. I trained in such a facility in the late 1970s, when we were the locus of care for all who were excluded from every other system. Direct state support of the center allowed such treatment to be provided. Today, however, the state provides no funding to CMHCs for outpatient care, so no funds are available to pay for treatment of the uninsured. As a result, CMHCs are turning away uninsured patients, since even they have to limit the losses incurred in rendering outpatient treatment. As a member of the board of our CMHC for more than a decade, I have experienced repeated agonizing discussions about how much longer we can afford to operate an outpatient service altogether, at the risk of dragging the entire center down. Even limiting outpatient care, our CMHC projects a margin of less than one-third of 1 percent of its budget, an amount that could easily be wiped out by unexpectedly high costs for snow removal.

■ **Sicker adults and children.** The consequences of this situation in the outpatient setting are not difficult to imagine. Some number of patients who are unable to obtain timely outpatient care deteriorate to the point where urgent intervention is required. Emergency rooms are seeing a steady increase in the number of patients coming in for psychiatric evaluations. Clinicians in those settings have the impression that the increase in numbers is paralleled by a rise in the level of psychopathology and degree of acuity. As bad as the situation is for adults, it appears to be even worse for children. They cost more to treat, since clinicians have to spend unreimbursed collateral time meeting with parents, teachers, and others as part of the evaluation and treatment process. Our emergency room is seeing children in numbers we have never seen before: From the last six months of 2001 to the first six months of 2002, the number of children coming to our emergency service rose 30 percent.

■ **The situation elsewhere.** Were this only a Massachusetts problem, its implications would be dire but of limited extent. However, there is every reason to believe that the situation I have described reaches much beyond the borders of our state. The *Washington Post*, reporting on the gap between the costs of outpatient care and

the rates at which it is reimbursed, noted that in Montgomery County, Maryland, private insurers pay $52 for an hour of psychotherapy that costs a clinic $83 to provide. Similar discrepancies exist for other outpatient services.[3] Hence, it was no surprise when the *Post* subsequently featured a story about a mother in Maryland who called thirty clinicians to set up an appointment for her teenage daughter and found no one who would accept the fees paid by the MBHO that was managing her mental health insurance benefit.[4]

A report by the Minnesota Psychiatric Society noted that one organization in the state closed six of its nine outpatient clinics because of inadequate payments and that waits for initial appointments can be as long as six months.[5] It could be that this is a problem that only affects states beginning with the letter "M," but I don't think so.

The Nature Of The Current Crisis: Inpatient Treatment

■ **Private hospitals.** The situation is equally bad, perhaps even worse, when it comes to acute inpatient treatment. In Massachusetts our public and private payers typically cover about 50–60 percent of the total costs (direct and indirect) of a day of inpatient care in a general hospital unit (which account for the vast majority of hospital days). These rates dropped by roughly half at the time of managed care's initial penetration of the state, and they have only inched up marginally since. Costs continue to rise, as health care inflation exceeds the general rate of inflation, and units need to hire special staff just to deal with the demands of managed care companies, which puts these units into a progressively deeper deficit. As long as the units cover their direct costs and make some incremental contribution to the margin, there is some economic basis for their retention. But as hospitals' overall economic situation deteriorates (two-thirds of hospitals in Massachusetts lost money on operations in 2002), units that do not come close to covering their full cost allocations look like prime targets for replacement by more profitable services.

Consequently, the number of acute psychiatric inpatient beds in the state has decreased steadily over the past decade. Indeed, as more Medicaid cuts were announced recently, the *Boston Globe* reported, "Hospitals said they are considering hiring freezes, layoffs, and closures of money-losing programs such as psychiatric and addiction treatment services."[6]

The response has become almost reflexive; no other area is targeted as automatically. And the results are predictable. Patients requiring admission back up in our emergency rooms as staff spend hours trying to find facilities that can and will accept them. Some unlucky patients are kept in holding beds in the emergency room for days while beds are sought. When a bed becomes available, many patients and their families must travel halfway across the state to reach it.

■ **The situation elsewhere.** Once more, Massachusetts is more typical than atypical of other states, and I am not even sure that it is among those most drastically affected. Psychiatrists in Lansing, Michigan, report that closures of hospital

units force child and adolescent patients to travel an hour or more to the nearest inpatient units. The major general hospital in Columbia, South Carolina, has thirteen to fifteen psychiatric patients in its emergency room at any point in time, simply waiting for an inpatient bed.[7] Psychiatric beds in the Twin Cities area in Minnesota are in such short supply that patients are often forced to travel out of state for hospital care. Why don't hospitals build new units to meet the demand? A St. Cloud, Minnesota, hospital that built a new adolescent unit in 1998 in response to community concerns reported four years later that it expected to lose nearly $6 million on mental health services.[8] In an informal survey, members of the American Psychiatric Association (APA) reported bed shortages in sixteen states.[9]

■ **Public facilities.** In the public sector, where continuing care beds and residential and support services are funded, the current state budget crisis in Massachusetts has led to cuts in an already inadequate state budget. With patients already waiting up to several months for transfer to chronic care units in state hospitals, another state hospital is being readied for closure. The inevitable result will be to increase the bed squeeze and the fiscal pressure on acute care units, where patients in need of chronic care beds will back up. Meanwhile, at residential programs in the community, many staff members are paid only $20,000 a year for their work with extremely difficult patients. It is not uncommon for such workers to leave their jobs to take employment at fast-food outlets so they can earn something closer to a living wage. As with private hospitals, this situation is echoed around the country, as states from California to Florida continue to close state hospital beds despite the effects of such closures on the rest of the mental health care system.

Where Do We Go From Here?

As I traveled the country talking about these issues in my role as APA president, I found that I was not bringing any news to people working in the mental health system. They were well aware of the situation I have described and of the forces that have brought it about. But I found little awareness of the severity of the problem on the part of political leaders, public administrators, insurers, business leaders, and others who could actually bring about some of the needed changes. In part, I think this is attributable to the slowly progressive nature of the problem. Instead of a sudden cataclysm, the mental health system has undergone steady attrition of available services and a corresponding diminution in access for people needing care. Such a situation does not lend itself to the dramatic media coverage that seems to be essential to mobilizing support for major policy changes. Even the mental health services research community seems largely not to be paying attention to the crisis, perhaps because the aggregate data on which so many of their analyses depend have not yet caught up to the present dilemma, or perhaps because the variables on which they have focused are not those that would reveal the nature of the current problem.

The shape of a solution to the slow starvation of the mental health system is not

obscure. Adequate funding needs to be made available to cover the costs of care. Whatever gains can be achieved by greater efficiencies were obtained several years ago. In many parts of the country, Massachusetts being one, the care system is dominated by not-for-profit entities. They are not looking to return sizable funds to their shareholders; they have no shareholders. Rather, they are looking for the costs of providing mental health care to be covered. The greatest leverage in accomplishing that goal probably rests with the real purchasers of care: employers and the states. These purchasers believe that they are providing effective insurance coverage for mental health services to their employees and indigent citizens. But when the MBHOs to which they have carved out mental health care pay rates below the costs of delivering care, these purchasers are being shortchanged. The people they believe they are covering are often unable to get access to care, and the structure of the current system guarantees that the situation will only become worse. Purchasers must learn to demand adequate payment rates, sufficiently large networks to ensure access to care when needed, and an end to the petty harassment that has driven so many practitioners away from dealing with the managed care industry.

The U.S. surgeon general's report on mental health resulted in widespread attention to data from the National Comorbidity Survey, which indicated that only 20 percent of Americans with mental disorders—and fewer than half of people with severe mental disorders—receive any treatment for their conditions in a given year.[10] It is difficult to imagine the situation getting much worse than that. But barring effective intervention by those in a position to demand that things change, we are likely to witness an even more unpleasant reality for people with mental illness.

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Presidential Paper

Presidential Address: Re-Envisioning a Mental Health System for the United States

Paul S. Appelbaum, M.D.

Mental Health Services in Crisis: The Defunding of a System

Last year in Philadelphia, I stood before you to describe the crisis in our mental health system (1). The genesis of that crisis lies in the uniformly inadequate resources allocated for the delivery of psychiatric care in America today. So poorly are psychiatrists, clinics, and hospitals compensated for the treatment they render that relying on insurance payments for patients' care is often literally a losing proposition. As a result, hospitals are closing psychiatric inpatient units, clinics are cutting back on services, and psychiatrists and other mental health professionals are finding that insurance reimbursements can no longer sustain their practices. The situation is compounded by the extraordinary additional costs imposed by the managed care industry, whose utilization review and other procedures often seemed designed primarily to discourage patients from pursuing treatment and psychiatrists from providing it.

The inevitable result of this situation, as I demonstrated for you starkly 1 year ago, is a critical inability of patients to access needed psychiatric care. Hospital beds are routinely unavailable in many parts of the country, forcing severely ill patients to wait for days in emergency rooms or to travel hours from their homes to find a hospital that can accept them. When outpatient care is required, patients who must rely on insurance coverage for their treatment face waiting lists of weeks to months in many hospital or community clinics, and they often find that those private practitioners who are listed on their managed care companies' panels are unable to accept any new patients at managed care rates. Simultaneously, they discover that what was once the safety net of the public mental health system, having been steadily drained of resources for decades, can no longer offer them even minimal treatment.

In the year since we spoke of these developments, which I characterized as the consequences of the "systematic defunding" of the American mental health system, things have become even worse. There has been no meaningful improvement in reimbursement for psychiatric treatment by the for-profit managed care companies that dominate the field. Indeed, the largest of these companies, Magellan, which covers in excess of 60 million Americans, has itself gone into bankruptcy (2). As most specialties saw their Medicare payments increase, psychiatry's actually decreased, based on a badly flawed formula that continues to favor procedure-oriented specialties (3).

Medicaid, which pays for more than 20% of all psychiatric care in this country (4), has been hit particularly hard. Faced by unprecedented budget deficits, states are simply slashing what they will pay for psychiatric treatment across the board, imposing counterproductive restrictions on access to psychiatric medications and, in the worst cases, dropping tens or hundreds of thousands of indigent people from the Medicaid rolls (5). Oregon is this year's poster child for discriminatory treatment of Medicaid enrollees with mental illness, depriving 100,000 persons of coverage for psychiatric treatment, while retaining coverage of every other kind of medical care (6). At the same time, funding is being reduced for state departments of mental health, with yet more state hospitals closing (7) and still more patients discharged to community services that are inadequately funded even to care for their current caseloads.

By now, you know what comes next. With the costs of providing care continuing to rise—take spiraling malpractice insurance rates as just one example—the availability of psychiatric services is steadily declining. Hospital inpatient units continue to close. Not long ago I received an anguished call from a psychiatrist in the Northeast whose hospital CEO had just told him that the excellent 20-bed psychiatric unit that he oversaw would be replaced by medical/surgical beds. The reason? The hospital needed the extra income that medical/surgical beds would provide. So long as psychiatry remains the poor sister of medicine, such stories will continue to proliferate (8). And an identical process is going on in community and hospital-based outpatient clinics (9). In a country in which only 20% of persons with a mental disorder receive any treatment in a given year, even more people are having trouble accessing care than was the case a year ago.

Re-Envisioning the Mental Health System

As important as it is to call attention to the crisis in access to and reimbursement for psychiatric care, merely sounding the alarm—as I urged you to join me in doing last year—is not enough. Psychiatrists work every day to overcome the obstacles placed before us and our patients by the current nonsystem of care. Hence, we are in the best position not merely to critique the ongoing muddle, but—even more important—to set out a vision for a genuine system of care. Toward this end, I appointed a special APA task force, chaired by our Vice-President Steve Sharfstein, M.D., to develop a vision statement for the mental health care system. The task force worked through the winter, producing an excellent document titled "A Vision for the Mental Health System" (10), which was endorsed by APA's Board of Trustees at its March 2003 meeting. Members of the media and government decision makers have already told me how useful they have found this document, which creates a set of benchmarks against which progress toward meaningful mental health system reform can be measured. I encourage you to access and read this report on APA's web site (10).

Today, I want to share parts of the "Vision" report with you, using it as a starting point to suggest some key directions in which we must begin to move, if we are to create a genuine system of mental health care.

I begin with what I consider to be the cornerstone of the task force's vision:

> Every American with significant psychiatric symptoms should have access to an expert evaluation leading to *accurate and comprehensive diagnosis* which results in an *individualized treatment plan that is delivered at the right time and place, in the right amount, and with appropriate supports such as adequate housing, rehabilitation, and case management when needed. Care should be based on continuous healing relationships and engagement with the whole person rather than a narrow, symptom-focused perspective. Timely access to care and continuity of care* remain today cornerstones for quality, even as a *continuum of services* is built that encourages maximum independence and quality of life for psychiatric patients. (10, pp. 1–2, italics in the original)

What would a system that could achieve these goals look like? Here I use the "Vision" report as a starting point but move beyond its specific recommendations.

For most people with mental disorders, I submit to you, care is best delivered in the context of the general health system. As many patients already receive treatment for mental disorders from their internists and family practitioners as they do from psychiatrists (11, 12). Primary care specialists write the majority of prescriptions for psychotropic medications (13). Rather than seeing this as a less-than-optimal situation, we ought to consider the involvement of primary care physicians in the treatment of mental disorders as a potential strength of a future, integrated system of care. Not only are patients likelier to have ready access to primary care physicians, but there are simply not enough psychiatrists to treat every person with a mental disorder. I remind you again of the National Comorbidity Study finding that 80% of persons with mental disorders receive no care in a given year, including more than 50% of persons with such major psychiatric disorders as schizophrenia and bipolar disorder (14). Meeting this demand requires more access to medical expertise than psychiatrists themselves can provide.

But this is not a task that all primary care physicians can fulfill right now. Many of them need additional training in the recognition and treatment of mental disorders as an important component of primary care. Nor can they do this on their own. Psychiatrists should be available to every primary care setting for consultation—preferably on-site—and treatment of the more challenging cases, of which there will be no shortage. Collaborative management of psychiatric disorders is the essential component

of an effective primary-care-based system. Far from excluding psychiatrists from the treatment of most patients, it will tap their knowledge and skills to a much greater extent than is possible today. And no discipline without medical training can possibly substitute for the needed medical expertise.

Today, of course, there are multiple systemic obstacles in the way of widespread implementation of such an approach, although model programs organized along these lines have long existed (15, 16). When insurance coverage for psychiatric treatment is carved out from general health care—as is typical today—primary care physicians often cannot get reimbursed for dealing with psychiatric problems. Moreover, almost no insurer compensates psychiatrists (or other physicians) for consultation on patients whom they do not examine directly. This undercuts the most efficient model of psychiatric consultation in primary care and other general medical settings. Often described somewhat pejoratively as "curbside consults," these brief contacts can be all that is needed to assist nonpsychiatric physicians in managing cases or appropriately referring patients for psychiatric evaluation. In addition, when nonpsychiatric physicians are precluded from making direct referrals to psychiatrists—as they frequently are today—the relationships on which a consultative model depends can never develop. All of these self-defeating aspects of the current system need to be changed, a process that will be facilitated immensely by "carving" mental health coverage back into general health insurance plans.

It goes without saying that no primary-care-based system can succeed without every person having health insurance coverage. APA has long supported universal health insurance, a reform that is more crucial today than ever. Whatever universal insurance plan is adopted should cover treatment of psychiatric disorders on a nondiscriminatory basis compared with other forms of medical care. Nondiscrimination must go beyond benefits on paper to encompass the mechanisms of review for authorizing care. And, of course, the rates paid for treatment of psychiatric disorders must take into account the real costs of delivering such care. That is not the case today but is essential for both primary care and psychiatric physicians to be able to deliver effective treatment in this model.

As the task force recognized, for people with severe and persistent mental illness, special considerations come into play. Many of these patients can best be treated in the specialty psychiatric sector, where additional expertise and adjunctive services are available. They may require case management, social reintegration, employment training, assistance with housing, and other services that cannot be supplied in the primary care setting. For this extremely vulnerable group of patients, the most logical locus of care is a revitalized community mental health center (CMHC) network.

The Community Mental Health Centers Act of 1963 was the closest this country has ever come to acknowledging its responsibility to provide quality care for all persons with mental disorders (17). We can all point to problems in the implementation of the CMHC act. But its conceptual foundation was rock-solid: proactive efforts to provide mental health care are facilitated by assigning responsibility for a defined population in a circumscribed catchment area. No part of the country should be without such a facility. Refocused on the severely and persistently ill population, supported by ongoing allocations of state and federal funding (especially important for services that are not easily funded on a fee-for-service basis—e.g., case finding), given the flexibility to manage funding streams across the usual human services boundaries, emphasizing continuity of care, and evaluated by measurable outcome criteria, CMHCs would become the linchpin for serving people with long-term and severe psychiatric disorders. As a complement to this outpatient-oriented system, adequate numbers of beds should be available for acute and longer-term hospitalization when needed.

Funding a New System of Care

It is one thing, of course, to sketch the outline of a genuine system of psychiatric care—and it is only the barest outline that I have been able to present here today—and quite another to persuade the public and our political leaders to provide the necessary funding to make this vision a reality. Here, once more, the report of the "Vision" task force points the way. As the task force suggests, a methodology now exists for quantifying the impact of mental illness in our society, relying on the concept of the "burden of disease." A common metric—disability-adjusted life years—allows comparisons to be made across all medical disorders, in terms of both years of life lost and years lived with disabilities. When mental illness is looked at in this way, it becomes clear that psychiatric care is grossly underfunded. Mental disorders account for 20% of the total burden of disease in the United States, while only 5.7% of all health expenditures go to their treatment (18). Enlightened self-interest alone would suggest that this country should be investing a much greater proportion of its health care dollars in psychiatric care.

Beyond this, we need to make it perfectly obvious to decision makers at the federal and state levels that mental illness ignored does not simply disappear. The costs of untreated mental illness are shifted elsewhere in our society: to the correctional system, which may now house and treat more people with mental illness than our public mental health facilities; to the health care system, which covers the costs of emergency, inpatient, and often outpatient care for those without insurance coverage; to our social welfare system, which provides welfare and disability payments to persons who, with adequate treatment, might be self-supporting; and to patients' families, who often substitute for an ineffective mental health system and bear the staggering costs. Were the financial resources now being con-

sumed to compensate for the deficiencies of the current mental health nonsystem utilized to provide quality psychiatric care, we could afford to implement the vision of a genuine system of care.

The value of a vision is that it creates a "big picture" into which each of our incremental efforts can fit. Once we know what we need to do, it remains to muster the courage to do it. When the task seems too difficult, the outcome uncertain, our efforts unappreciated or ignored, we can draw inspiration in this quest from our patients, who often struggle to overcome precisely these feelings as they make their way through life. So I leave you with the words of the early 19-century Chassidic master Rav Nachman of Bratzlav, who himself suffered from recurrent, intense depressive episodes. Rav Nachman would say to his followers, "*Kol ha'olom kulo, gesher tsar m'od*" ("The world in its entirety is a very narrow bridge"); "*v'halkar lo lefacheid klal*" ("and the most important thing is to have no fear").

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PREPARED STATEMENT OF THE CAMPAIGN FOR MENTAL HEALTH REFORM

Mr. Chairman and Members of the Subcommittee, I am Michael Faenza, President and CEO of the National Mental Health Association and I am pleased to offer this testimony on behalf of the Campaign for Mental Health Reform.

The Campaign for Mental Health Reform has been organized to advance Federal policies to make access, recovery, coherence, and quality in mental health services the hallmarks of our nation's mental health system. The organizations making up the Campaign represent mental health consumers, families, advocates, professionals, providers, States, counties, and communities and are dedicated to improving the lives of people with mental illnesses and children with mental, emotional or behavioral disorders. We welcome the opportunity to provide testimony regarding the recommendations of the New Freedom Commission on Mental Health. Sharing a common commitment to advancing the Commission's vision and goals, we are eager to work with this committee to advance needed reforms.

The Commission report and its recommendations represent an important milestone to guide policymakers. Building on the 1999 Report of the Surgeon General on Mental Health, the Commission's work offers a compelling vision and recommendations on how our nation must address mental health that finds broad support in the mental health community. We view the Commission's report as a call to action, and applaud the commissioners' efforts to beam a national spotlight—albeit for a brief year—on a subject that is too often neglected: the needs of adults and children with or at risk of mental illness.

We share a belief that there is a desperate need to transform mental health care in the United States. Mental illness takes a devastating toll on millions of individuals and their families. It is the second leading cause of disability and premature death in our country. However, as a country, we have yet to make mental health a real priority commensurate with its prevalence, morbidity and mortality. Mental health and the state of our public mental health delivery system should be matters of real societal concern. Consider, for example, that untreated mental illness im-

poses a cost of some $79 billion on our economy. As the Commission reported, one of every two people who need mental health treatment in our country do not receive it. Mr. Chairman, as you know from your years of work on this issue, some 16 percent of those in our nation's prisons and jails have a mental illness. And as many as 80 percent of the young people in our juvenile justice system have a mental or substance use disorder. Thirty-thousand Americans die by suicide each year, with mental disorders a factor in 90 percent of those instances. The suicide rate exceeded the homicide rate this past year as it has for the last 100 years. Like mental health problems generally, suicide strikes across the age span. Suicide is the third leading cause of death among those between 10 and 24. Older Americans have the highest rate of suicide of any population in the United States, and the suicide rate of that population increases with age, with those 65 and older accounting for 20 percent of all suicide deaths, while comprising only 13 percent of the population. The rate of suicide among Native Americans is about 1.7 times the rate of the nation as a whole. Shocking as they are, these statistics alone mask the crushing pain that mental health problems cause individuals, their families, and communities. They also represent a stark reflection of our failure to make mental health a real priority. The Commission "got it right," in our view, when it said last year that our nation's failure to prioritize mental health is a national tragedy."

In fact, government has both underfunded mental health programs and failed to address mental health as a cross-cutting issue. As the Commission ably documents in highlighting the paralyzing fragmentation in mental health service-delivery, mental health is an issue of public health, health financing, child welfare, education, housing, criminal justice, rehabilitation, and employment, to name only the most obvious.

In its report, the President's Commission called for a transformation of mental health care in America. The goal of transformation might seem a novel concept or overblown rhetoric. But there is a compelling logic to this vision. Science has transformed both our understanding of mental illness, and the tools to diagnose and treat most mental illnesses. The Commission's recognition that we can build resilience and that recovery from mental illness is a realizable goal reflects another transformation in thinking about mental illness. But public understanding and attitudes about mental illness are still shaped by old stereotypes and stigma. And, with rare exception, State and local governments have not been able to bring together the needed tools to enable people with mental illnesses to live and participate fully in their communities. Although the Commission has provided a compelling vision of the elements of a transformed mental health system, it has not laid out a roadmap for how the transformation it prescribes might be realized.

The Commission left it to policymakers to answer the question, how do we proceed down a road toward real transformation? Administration officials have described a process aimed at developing administrative measures that would advance the Commission's goals. Mental health advocates have been invited to offer recommendations. We welcome that invitation and have initiated efforts to meet with pertinent agency officials.

We appreciate that there are opportunities for mental health reform at all levels of government and we recognize the importance of leadership from the Federal Government in advancing change. But it is difficult to conceive that administrative action alone can transform a system described as "in shambles." Administrative measures cannot align the inconsistent eligibility requirements of the disparate Federal programs so critical to meeting the array of benefits, services and supports needed by many people with mental illness. Administrative measures will not address the anomaly that by law, Medicaid, the largest payer of mental health services in the country, treats mental health care as an optional service. And administrative measures will not alter the fact that Medicare mental health benefits fail to provide basic parity between mental health care and care for any other illness and fail to cover important, effective services needed to treat chronic illness.

Congress must be a leader in changing a "system" that, in the Commission's words, "does not adequately serve millions of people who need care." The problems pinpointed by the Commission span a range of challenges—including scattered and sometimes ineffective programs, uncoordinated funding streams, and unmet need—but this committee can play a vital role in crafting needed solutions. Importantly, this committee's leadership in reauthorizing and giving new policy direction to the Substance Abuse and Mental Health Services Administration can establish a framework for powerful change.

We hope to work with this committee and provide concrete recommendations for legislation that will advance the Commission's goals and strengthen SAMHSA's hand in helping achieve them.

Among the important issues we urge this committee to take up, and on which we are developing legislative proposals, are the following:

• Fostering new financing and planning mechanisms to provide effective, family-driven community-based care to children and youth with mental health needs;

• Fostering mental health promotion and early intervention services through school-based mental health care;

• Advancing early detection and treatment across the age span for mental health problems, including co-occurring mental illnesses and substance use disorders;

• Reducing fragmentation in mental health service delivery, including support and systems of care for children and their families;

• Developing mechanisms to expand, implement, and monitor the progress of the national strategy for suicide prevention;

• Fostering greater integration of health and mental health care;

• Fully involving mental health consumers and families in orienting the mental health care system toward a recovery orientation;

• Developing targeted programs to expand and improve the effectiveness of the mental health workforce, including the training of racial and ethnic minority mental health professionals to meet the needs of increasingly diverse populations; and

• Fostering diversion of juveniles and adults from justice systems to improved community-based mental health care systems.

As this committee moves toward reauthorization efforts, we also look forward to working with you, and with the agency, on a significant revision in the role of the Substance Abuse and Mental Health Services Administration (SAMHSA) within the Federal government. With appropriate revision of its statutory "charter", SAMHGA can become an even more effective focal point for leadership on many of these and other important mental health issues, as well as provide leadership to States and communities.

As the President stated in announcing the establishment of a mental health commission, "our country must make a commitment." That commitment will necessarily require dramatic reforms across a range of government programs—among them, Medicaid, Medicare, housing, Social Security income support, vocational rehabilitation, education, child welfare, and justice. In some instances, we believe Federal programs give insufficient attention to the needs of people with or at risk of mental illness; most, however, provide important assistance, but with their differing objectives, eligibility requirements, and financing structures, contribute to the widespread fragmentation in mental health service-delivery that is too often both inefficient and ineffective. We applaud this subcommittee for giving the Commission's recommendations early consideration. But we also hope, Mr. Chairman, that as you review the challenges facing children and adults with or at risk of mental illness that you will consider urging other committee chairmen to make mental health reform a priority that moves us toward cross-system coordination and integration, and ultimately the kind of transformation the Commission envisioned.

Finally, Mr. Chairman, it is critical that we embark on this path with an appreciation that mental health has long been dramatically underfunded relative to the impact mental disorders have on the individual, his or her family, the community, and the economy. In short, we urge Congress to make mental health and the transformation to a recovery-based system both a legislative and a funding priority.

PREPARED STATEMENT OF CARLOS BRANDENBURG

Mr. Chairman and Members of the Subcommittee: My name is Carlos Brandenburg, and I am the Administrator of the Division of Mental Health and Developmental Services in Nevada's Department of Human Resources. I would like to extend my thanks and appreciation to Chairman DeWine and the Subcommittee for inviting me to testify this morning regarding the State of Nevada's experience and efforts pertaining to the final report of the President's New Freedom Commission on Mental Health.

By describing the poor state of the nation's public mental health system, the President's New Freedom Commission on Mental Health provided an invaluable service not only for the millions of people in this country with mental illness and their family members, but also for those of us responsible for administering the programs that are in crisis. Indeed, the mental health system in Nevada, notwithstanding our successes, faces extraordinary difficulties. At the same time, there has never been a more hopeful time to take on this challenge, and I am profoundly grateful for the opportunity to serve as my State's lead on this issue and at this particular point in time.

Why am I so hopeful?

Much has already been said about the significance of the goals stated by the President's Commission itself, its recommendation that mental health be transformed, and its commitment to recovery. The value of the Commission's work cannot be overstated, but let me identify other critical factors.

First, we have in the Federal government a true partner. Administrator Curie worked hard within the Administration to help the President form the Commission, to ensure that it was composed of extraordinary people, and to establish for it an ambitious but achievable mission.

Second, as you are hearing today, the advocates who stand up for the mental health community in Washington, D.C., are organized and prepared to work together like never before. The Campaign for Mental Health Reform—today being represented by Mike Faenza of the National Mental Health Association—can help policy-makers make the Commission's vision a reality and see to it that the light shone on this issue is not dimmed.

Third, we are witnessing unprecedented interest on the part of Congress, as evidenced by this hearing and the creation of this Subcommittee.

And, fourth, is the good fortune of the State of Nevada itself. Nevada was honored that President Bush appointed Nevada State Senator Randolph J. Townsend to serve on the President's Mental Health Commission. The Commission's only elected official, Senator Townsend has long been a proponent of mental health care. His recent work with the Commission has served as a great catalyst for Nevada's current efforts to transform mental health in our state.

In order to assist Senator Townsend in carrying out his duties and responsibilities as a commissioner, we held numerous town hall and focus group meetings to explore the range of problems and gaps in mental health care for Nevadans. This enabled him to bring to the Commission concrete recommendations for improvement that could apply both locally and nationally. Further, these meetings and focus groups allowed us to quantify the degree of unmet need in Nevada and identify the barriers that impede care for people with mental illness and prepare us for our work ahead—after the work of the Commission was done.

During the 2003 state legislative session, Senator Townsend had the foresight to introduce Nevada State Senate Bill 301, a copy of which I am submitting along with my testimony. This state law created the Nevada Mental Health Plan Implementation Commission. The commission is charged explicitly with developing an action plan for implementing the recommendations and goals of the final report of the President's New Freedom Commission on Mental Health in Nevada.

The Nevada Commission must submit a report setting forth the action plan to Nevada's Interim Finance Committee, its Legislative Committee on Health Care, and to Governor Guinn on or before January 1, 2005.

The Nevada Commission members elected Senator Townsend to serve as its Chair. Other members include six state legislators, four state agency heads (including myself). The Commission also provides for extensive public involvement, including participation by consumers, family members, and providers. Our fourth meeting is being held as we speak. Needless to say, my colleagues gave me leave to speak with you all today. Each meeting is focused on one of the six goals of the final report of the presidential commission. Today's meeting is focused on ensuring early assessment and treatment of mental disorders, improving school-based mental health programs, and the need to provide integrated treatment for those with co-occurring mental health and substance abuse disorders. In all our deliberations, we focus on specific recommendations, both policy and budgetary, that will turn the President's Commission's national goals into concrete forward steps in Nevada.

The Nevada Commission, in addition to providing an organized mechanism to facilitate comprehensive state mental health planning and policy development, has also been an effective means of keeping the subject of mental health in the media across the state and helping to raise awareness and hopefully reduce stigma. During the course of our meetings, we have been struck by the fact that too many Nevadans do not know that mental illness can be treated and that recovery is possible. We have learned about the large barriers encountered by individuals with mental illness who are chronically homeless. We have heard compelling testimony about the need for consumer involvement in care and the success of various consumer model programs around the country, and we have learned some strategies used by other states and locales in improving the nearly nonexistent mental health care in rural areas of the nation—of course, an issue of particular concern in Nevada.

The Nevada Commission's efforts have been greatly enhanced by generous technical support provided by the National Association of State Mental Health Program Directors (NASMHPD) in conjunction with a contract with the federal Substance Abuse and Mental Health Services Administration (SAMHSA). NASMHPD is enabling us to bring national experts, including members of the President's Commis-

sion, to our meetings. They who are providing us with recommendations of best practices and programs in other areas of the country that can be implemented in Nevada. This assistance has been invaluable.

Ultimately our Commission will show Nevada how to change the fragmented nature of our mental health delivery system. There are some preliminary findings that I can report here today. For example, enhanced education about mental illness would greatly improve the general public perception of mental illness and also increase the understanding that mental illness impacts overall health and that mental illness is treatable and recovery is possible. Nevada will also focus on implementing a state strategy for suicide prevention.

But here is the last point I would like to leave with the Subcommittee. The ultimate goal of the President's Commission and, in turn, the Nevada Commission, is ambitious—attainable, but ambitious. Indeed, it is calling for system transformation. The report of the New Freedom Commission on Mental Health identifies the fragmentation of services and financing as central barriers to the effective delivery of comprehensive mental health services and has called on all levels of government to correct this problem by ultimately establishing in each "an extensive and coordinated State system of services and supports that work to foster consumer independence and their ability to live, work, learn, and participate fully in their communities." (Recommendation 2.4). You have heard about Nevada's commitment in making this happen. But neither Nevada nor any other state can do this without significant assistance on the part of the federal government.

Specifically, we require federal assistance to both engage in the type of planning envisioned by the Commission and to implement those plans, enabling us to fill the enormous gaps in care for people with mental illnesses. Even in Nevada, where we have been uniquely fortunate to begin the transformation process, we will not be able to do it without federal funding. We hope that the Subcommittee, presumably as it begins its effort to reauthorize SAMHSA and its programs, will work closely with the states and the Campaign for Mental Health Reform to devise a bold program that will provide the support needed to ensure that the vision of transformation is realized.

Thank you again for inviting me to speak today. I am happy to entertain any questions at this time.

PREPARED STATEMENT OF ANN BUCHANAN

Chairman DeWine, Senator Kennedy and members of the Subcommittee, I am Ann Buchanan of Cockeysville, Maryland. I am proud to be here this morning to share with you the story of my son's struggle with mental illness and offer some perspectives on President Bush's New Freedom Commission on Mental Health. At the outset I would like to thank you for convening this important hearing and inviting the unique perspectives of individuals living with mental illness and their families.

Before commenting on the final report of the White House Commission on Mental Health, I would like to first tell you and members of this Subcommittee a little about myself and my family's experience with mental illness—a saga that continues to this very day. My son is Rusty is now 22 years-old. When Rusty was age 16, he and I suffered catastrophic event when his father, my husband, lost his battle with cancer. Shortly thereafter, Rusty was diagnosed with depression—probably not uncommon for a teenage boy coping with the trauma of the loss of a father. In 1997, Rusty was hospitalized twice at Shepperd-Pratt. During this period, Rusty was growing increasingly agitated and angry and he physically attacked me twice. Shortly thereafter, he was forced to withdraw from Towson High School at age 17 and was enrolled at Hannah Moore—a school for troubled adolescents.

After only three months at Hannah Moore, he was sent to the Regional Institute for Children and Adolescents (RICA) in Baltimore. RICA is a treatment facility that is part of the Maryland Department of Health and Mental Hygene. It includes both residential programs and day treatment for adolescents with serious emotional disturbances and other mental illnesses. It offers a range of services including psychiatric treatment, crisis intervention, behavior modification, special education and rehabilitative services.

After arriving at RICA, Rusty stayed for over a year, and with the help of the staff and a supportive environment, graduated high school in 1999. While this would normally be an occasion for celebration and accomplishment for most families, it was a source of enormous stress for Rusty, myself and many of the staff at RICA. Tragically for us the spring and summer of 1999 were filled with anxiety and uncertainty as Rusty approached his 18th birthday and high school graduation. The sad reality is that as he approached what would normally be a period of great optimism

and promise for most adolescents and their families, Rusty and I were dealing with the fact that he was "aging out" of the child and adolescent mental health system with very little planning and stability about the adult system of care he would be entering.

While the staff at RICA were very caring and responsive, the sad reality is that it was rare for them to deal with a young person such as Rusty who was receiving a high school diploma. We all knew that a date certain was coming when Rusty would no longer be eligible to receive services at RICA—again, because of he was rapidly approaching the point at which he had "aged out" of Maryland's child and adolescent system. The stress this placed on Rusty was enormous and in the summer of 1999 he attempted suicide.

I want to reiterate that the staff at RICA were helpful. However, I was forced to do most of the work to find a residential placement for Rusty. Waiting lists were long and finding a residential placement was enormously difficult. All across Maryland, psychiatric hospitals and residential programs have been cutting beds and shrinking programs. I made applications to 3-4 residential programs. Each had either a long waiting list or were unwilling to take him because of his history of abusive behavior—the result of his mental illness.

This period was filled with tremendous anxiety for Rusty and myself. RICA said that he had to leave and I felt strongly that it was not safe for him to return to my home. He was being denied placement in residential programs that could meet his needs or was going to be placed on a waiting list that could take months if not years. Eventually, he began receiving services from the adult system only after the suicide attempt in July 1999 and an involuntary admission to Spring Grove Hospital. In other words, only after his symptoms and condition had deteriorated to the point that he was a threat to himself (and most certainly others) was he able to get the treatment he needed from the adult system.

While our story may be unique, I doubt it is. The sad reality is that thousands of families every year face the enormous challenge of having their child "age out" of adolescent treatment and service programs. It should not come as no surprise to anyone that the course of mental illness does not magically shift once a child turns 18, 19 or 20. The symptoms they experience—be it anxiety, depression, mania, psychosis or paranoia—do not change to fit our mental health system's pre-existing definitions about what are children and adolescent services v. what are adult services. In my view, it is disturbing that the separate child-adolescent and adult systems struggle so mightily to help adolescents make the transition in to adulthood. This is especially the case with children and adolescents with more severe mental illnesses who are much more likely to see their diagnosis and illness stay with them into adulthood.

What must be done to ensure that meaningful transitional services become a reality? First, we need to recognize the shift in legal relationships that occurs when the law deems an adolescent to be an adult with full legal rights in our society. Rusty acquired specific rights once he became an adult. This included certain rights relative to his mental illness treatment that did not exist when he was an adolescent. At the same time, the genesis of these legal rights should in no way obscure the obligation of child-adolescent programs to be assertive in ensuring that young people are fully able to access to mental illness treatment and services. More importantly, they should have an affirmative obligation to ensure that the adult system—whether a public mental health authority or a CMHC—is aware of, and is prepared to meet the treatment needs of adolescents reaching adult age.

The child-adolescent and adult mental health systems are necessarily separate—on the basis of clinical and legal rationale. However, this separation should not extinguish the obligation for both to develop a cooperative and collaborative relationship that can foster a seamless transition.

One major challenge for us—and for providers such as RICA—is the shift in eligibility for income support and health care entitlements that can occur as adolescent becomes a legal adult. In our case, Rusty qualified for certain Social Security survivor benefits from his late father. Many other adolescents with severe mental illnesses qualify for SSI before their 18th birthday. In either case, their access to certain programs may often be driven by what Medicare and Medicaid will pay for.

More importantly, for most families, this transition is rarely smooth and can involve months, and even years, of uncertainty as to which programs they qualify for—this is especially the case with respect to state Medicaid "spend down" requirements. Moreover, in many states eligibility for Medicaid can be tied to participation in a specific program. For example, Rusty's eligibility for Medicaid currently depends on his continuing to be served in the residential program where he lives. If he were to leave (or were forced out), he would almost certainly lose eligibility for Medicaid and be left with no coverage for prescription medications and only limited

coverage for outpatient therapy. Note—he would still be able eligible for Medicare; however, Medicare does not cover prescription medications and has a 50% co-payment requirement for outpatient mental health services. Clearly more needs to be done to address the fragmentation in both funding streams and eligibility standards for these very complicated programs.

Our struggle with mental illness continues. Rusty has been diagnosed with schizophrenia. Since 1999, he has been in several different programs in Maryland, including Alliance in Essex. Currently, he resides at Keypoint in Dundalk, in a 3-bedrrom apartment he shares with two other consumers. He slowly gaining more independence and has begun to ride the MTA on his own. He has also been participating in a day treatment program. As part of this, he has begin working in the greenhouse at Keypoint in hopes of acquiring skills that will allow him to participate in a work program at the local Home Depot.

THE WHITE HOUSE MENTAL HEALTH COMMISSION REPORT

I would like to make a few brief observations about President Bush's New Freedom Mental Health Commission Report as it relates to my own family's experience with mental illness. First, it is important to note this report does not contain any specific findings or recommendations with respect to services designed to address the transition from the child-adolescent system to the adult system. At the same time, this report does document the enormous fragmentation that remains a serious problem in our public mental health system.

The report also calls for development of an individualized plan of care for both children and adults with mental illness (Recommendation 2.1). Specifically, the report recommends that such plans should be designed to improve service coordination, allow for informed choices and help achieve and sustain recovery. I have little doubt that had such a plan been in place, Rusty would have been able to make a more productive transition into adulthood.

On a more macro-level, Recommendation 2.2 calls for greater involvement of consumers and families in fully orienting the mental health system toward recovery. This includes a plea for greater engagement of consumers and families in the planning and evaluation of services. This is certainly a laudable goal and would certainly help make providers (and more importantly) public officials more aware of the struggles that adolescents and their families experience when children become adults.

The report also contains a heavy focus on the need for more comprehensive state planning (Recommendation 2.4). This is a very positive step toward making the transition between the child-adolescent and adult system more seamless. As the report notes, such comprehensive state planning should allow for more creativity and flexibility with respect to eligibility requirements for federal programs, insist on more accountability at the state and local level (especially to consumers and families) and expand the array of available services. Among the requirements that could be an integral part of this new era of comprehensive state planning is accountability for ensuring that adolescents aging into the adult system (and their families) receive assistance in making this often difficult transition. Such transition services should include intensive case management and benefit planning.

Finally, I also want to comment on findings and recommendations in the report calling for consumes and families to have a greater control over their own care. While this goal is laudable, it will never be achieved without expansion of family education and peer support programs to help consumers and families learn more about mental illness, treatment system and how to advocate for themselves. I am a graduate of the NAMI "Family-to-Family" Education program. I found it to be enormously helpful in preparing me to cope with my son's illness and become an advocate both for his recovery and for improvements in the service system in our community.

Likewise, numerous peer support and psycho-education programs for both consumers and families have a proven track record of effectiveness in promoting recovery real change at the community level. As you and your colleagues on this Subcommittee move forward in implementing this report, I would urge you to consider the enormous value of programs such as "Family-to-Family" in moving toward the goals articulated by the White House Commission.

CONCLUSION

Chairman DeWine and members of the Subcommittee that you for the opportunity to offer this testimony on behalf of myself and millions of families living everyday with mental illness.

[Whereupon, at 11:48 a.m., the subcommittee was adjourned.]

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