The President's New Freedom Commission on Mental Health: Transforming the Vision

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The Nineteenth Annual Rosalynn Carter
Symposium on Mental Health Policy

November 5 and 6, 2003

THE
CARTER CENTER

Waging Peace. Fighting Disease. Building Hope.

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New Freedom Commission on
Mental Health:
Transforming the Vision

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MENTAL HEALTH PROGRAM

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Opening Remarks

Rosalynn Carter
Chair, The Carter Center Mental Health Task Force

We all were thrilled when the president announced the New Freedom Commission on Mental Health. The commission was assigned a huge task: to study the whole public mental health system and report back to the president with recommendations. From my experiences with the Carter commission on mental health, I well understand the hours and hours of listening and discussion about what needed to be included in the report. It is not easy. I want the members of the commission to know that all of us in the mental health field are grateful to you.

Reading the final report brought back a lot of memories of our commission. What struck me most were the similarities in issues. We know so much more today, and yet the problems are still very much the same, with one exception: recovery. Twenty-five years ago, we did not dream that people might someday be able actually to recover from mental illnesses. Today it is a very real possibility. With our new knowledge of the brain and the advances in treatment quality, we can now shift our focus to recovery. For one who has worked on mental health issues as long as I have, this is a miraculous development and an answer to my prayers.

The commission has done its work. It is now up to us, the mental health community, to mobilize to implement the recommendations of the report. It is an enormous responsibility that is going to take all of us – advocates, professionals, researchers, consumers, and family members – working together. No single sector can do it alone.

There could not be a better time for us to come together, with so much that needs to be done and so much new knowledge. The mental health system is still in trouble in states and communities throughout our country. It is sad that all this new knowledge and these new recommendations come at a time when resources are scarce and mental health programs are being cut. I am concerned about being able to keep what we have now. We are at risk of losing the gains that we have made for people we care about and for whom we want better lives.

In the next two days, we have the opportunity to determine where we want to go from here and how we can best leverage and implement the recommendations of the president's commission. No doubt we will disagree on some of the details, but if we can go away from the symposium united and with a new sense of mission, I believe we can develop a more effective, efficient, just, and equitable system of care for people with mental illnesses.

Opening Remarks

Carter Administration – President's Commission on Mental Health

Thomas E. Bryant, M.D., J.D.
Non-Profit Management Associates, Inc.

A couple of observations occurred to me about the difference between the two commissions. First, we did not foresee the impact of Medicaid on mental health care. The vast majority of people who are supported by the public system are done so by Medicaid, and the vast majority of people with mental illnesses are in the public system.

Next, the field now knows a lot more in the way of biological science about how the brain works and how to treat certain mental illnesses. I think it is a fair statement today to say that while we have not cured mental illnesses, recovery is now possible. The word "recovery" was not even in our vernacular back then. There are now drugs and services like supported work and education that allow

> *I think it is a fair statement today to say that while we have not cured mental illness, recovery is now possible.*

people to function better and in a more normal environment. That boils down to the fact that people with mental illnesses are not just stuck in entry-level jobs mopping the floor but can go back to school and can get a degree or even an advanced degree. All of that has changed since we grappled with some of the same problems, and that is a watershed change.

One thing that remains absolutely true is that there still is not enough funding. Providing quality mental health services costs money. The commission came up with some genius recommendations about ways to spend money differently, more effectively, and efficiently. However, we still need more funding for mental health care in this country.

Keynote Address

Michael Hogan, Ph.D.

President's New Freedom Commission on Mental Health
Ohio Department of Mental Health

My remarks will attempt to give you a summary of our experience on the commission, as well as our thinking and recommendations about the changes needed in mental health care at this time.

In considering our work, one has to start with a basic question: Why did this president create this commission at this time? President Bush announced the commission, accompanied by Senator Pete Dominici, in a speech in Albuquerque at the end of April 2002. However, our clearest view of the president's intentions came in an informal gathering that same day. Before his prepared speech, the president met with about a dozen local people (providers, family members, and commission leaders) for a conversation about mental health and mental illness. This was an informal, unscripted conversation about problems and potential in mental health. The president led the conversation.

As the president was wrapping up the meeting, he said that the message he got growing up about these issues was to "suck it up" if you have personal problems. He went on to tell the story of a close personal friend who had developed a terrible clinical depression in mid-life. This friend got the treatment he needed and had a wonderful recovery. The president said that while watching his friend, it became clear this is a medical illness, and it is not right for us to treat some illnesses one way and other illnesses another. As it is with so many of our elected officials, I concluded it was a personal experience that led the president to his understanding of the poor way that we traditionally treat mental illnesses.

When the commission came together, we had to grapple with and try to understand what we were. We understood that opportunities like this are very rare. It had been a quarter of a century since the Carter commission. This led us to conclude that one important thing to do was not blow it. This meant that we had to comply with all of the rules and requirements; to be open and accessible, taking time to listen to people; and to collaborate with the advocates in the mental health community. We also were mindful of how commissions make recommendations and do not implement them. This is one reason why this opportunity for conversation and action provided by The Carter Center is so critical.

We determined that it was necessary to be "mindful of our master." In other words, we had a responsibility to write a report that would be acceptable to the administration, thereby increasing the likelihood of good follow-through. We also were mindful of the Carter commission's experience: Leaving behind a menu of opportunities that advocates could subsequently return to and leverage might be as important in the long run as actions by the current administration.

We were struck by how dramatically things have changed in mental health services since the time of the Carter commission. The federal role was very limited back then. The statutes underlying mental health care were evolving rapidly, whether in terms of the commitment laws, or the laws structuring state systems of care, or legislation setting standards for mental health coverage in health plans. Research was in its infancy; the first surgeon general's report on mental health was two decades away.

The major problems in mental health care, and society's view of these problems, also have shifted dramatically. If you had asked people 25 years ago to name the biggest thing wrong with mental health care, they would probably have said "those terrible state institutions." That is not the problem anymore. Indeed, by and large, the problems with mental illnesses people would cite today are problems in the prisons. If we look deeper, we see mental illness is a major challenge in juvenile justice, in child welfare, in schools, on the streets, and in both public and private disability programs. It is not just that the main problems in mental health care moved from hospitals to communities. These days, the biggest problems are outside the public mental health system. This creates much more complicated challenges for advocacy and for improving care.

In our interim report, as directed by the president, we focused on barriers to care. The first barrier we identified was that neither mental health nor suicide prevention was yet a national priority. The surgeon general had advanced awareness of suicide tremendously. The National Strategy for Suicide Prevention is now well-developed and ready to start moving forward. But the public has no idea, frankly, of the enormity of the impact of suicide or of the frequency of mental illnesses and their impact. Measuring the impact of suicide by the number of lives lost is the simplest and starkest way to understand the impact.

> *These days, the biggest problems are outside the public mental health system.*

The World Health Organization's data show that deaths from suicide worldwide are approximately equal to deaths from war and homicide put together. In this country, there are approximately 60 percent more deaths annually from suicide than homicide and twice as many deaths annually from suicide than from HIV/AIDS. And while we understand that suicide is driven and precipitated by mental illness and substance abuse disorders, we still do not acknowledge the impact of mental illnesses and suicide.

Our look at barriers to care caused us to look at the burden of disability caused by mental illnesses. Our failure to deliver the right care for people who end up on disability has an incredible impact. In fact, although Medicaid is the biggest payer for mental health treatment, the biggest federal expenditure for mental illness is over $20 billion annually in payments for SSI and SSDI combined. To put it bluntly, we are paying an increasing number of people a huge amount of money, but individually an inadequate amount – in effect to stay disabled, because of the work disincentives in the system. Recent WHO data looking at the impact of mental illnesses on disability show that mental illness is the greatest illness-related cause of disability, followed closely by alcohol and drug dependence, Alzheimer's, and dementia. Much lower levels of disability are attributable to illnesses like cancer, heart disease, or diabetes.

> *Care delivery has become increasingly complex in the last 25 years, and we expect people to navigate this complexity when they are ill and at their worst.*

Barriers to care also include gaps in care and fragmentation of care for both adults and children. Care delivery has become increasingly complex in the last 25 years. Our commission review found no fewer than 42 different federal programs that might be used at different times by children or adults. Often, obtaining services or coordinating these different programs – conducted by various agencies with different eligibility standards – must be coordinated by the consumer or family. And we expect people to navigate this complexity when they are ill and at their worst. This unintended complexity, coupled with real gaps in care, is a striking problem that led us to the blunt and perhaps controversial statement that "the system is in shambles."

Knowing the complexity of the mental health system, the commission realized that the incremental reform that has brought us to this point cannot move us forward. What is needed, we concluded, is a transformation in our approach to care. The "mental health mess" cannot be fixed via reorganization or by adding new programs – our conventional tools. The concept of transformation – implying many changes, at every level, over time – emerged as a necessity.

But there are also new possibilities in mental health care. Learning from testimony, from research, from the surgeon general's report, and also from Mrs. Carter, we determined that the idea or paradigm of recovery is a powerful force for change. When the commission talks about recovery, we do not mean a simplistic picture of complete wellness and remission for every person, immediately. Rather, we understand recovery to mean three things:

1. Recognition that some people – more than we have historically appreciated – do achieve complete recovery and remission.

2. Regardless of the seriousness of illness, a recovery-oriented approach expects and facilitates a meaningful and good life for each person despite living with an illness or disability.

3. The core and engine of recovery is hope – expectations for better outcomes on behalf of the person, their family, and professional.

It was this understanding of recovery that led the commission to propose a national vision for mental health in America – a future where recovery and resiliency are the expected outcomes.

Given the magnitude of this change and the complexity of transforming care, the commission proposes a set of national goals backed up by recommendations to achieve these goals. Our logic is: Implement the recommendations to achieve the goals, and if we can achieve these national goals, then transformation will be achieved. The six goals are expressed in terms of future expectations:

1. Americans will understand that mental health is essential to overall health.

2. Mental health care is consumer- and family-driven.

3. Disparities in mental health services are eliminated.

4. Early mental health screening, assessment, and referral to services are common practice.

5. Excellent mental health care is delivered, and research is accelerated.

6. Technology is used to access mental health care and information.

We know that we must and will see federal leadership in a number of different areas. One of the most complicated and intriguing recommendations that we have made is upgrading state responsibility for mental health, elevating responsibility for mental health to the governor's level on a collaborative basis with the federal government and others. This extends the state's responsibility for mental health beyond the block grant and the mental health agency, reflecting the need to think about mental illnesses in other sectors (e.g., prisons, schools, health care). This change is a tremendously complicated process that cannot be simply legislated; it might require shifts in Medicaid, vocational rehabilitation, Social Security, and housing programs. But change may be required in all these arenas. Some states have begun to think about the kind of transformation that is required; a number of states initiated state-level mental health commissions. We are greatly encouraged by advocacy and professional organizations coming together in Washington to create the Campaign for Mental Health Reform. Strong and well-aligned advocacy is essential to achieve the needed changes.

The commission also was mindful that much can be done without waiting for Washington to act. There are many areas where federal leadership might be helpful but is not essential. For example, I'd cite the goal of finally taking steps to reduce disparities in access to and quality of care, both with respect to race and place (especially in rural America). While some of the access questions require a broader approach, there is no reason that every mental health program in the country cannot be taking steps right now to better match our staffing with the people we serve and developing a welcoming attitude about people from diverse backgrounds.

Finally, if the work of the commission is to become real, all of us in the mental health community must embrace Gandhi's notion that "we must become that change that we seek in the world." We delivered a good body of work for all of us to advance together. Now this work is in your competent hands. We look forward to the collaboration that will make it real.

Q In thinking about the two commissions, the Carter commission and the New Freedom Commission, how would you characterize the most significant recommendation in the Freedom Commission that is different from the Carter Commission?

A Dr. Hogan: There are two. The first difference grows from the relatively new awareness that recovery is a realistic possibility for every individual if the right steps are taken with the right attitude. This means approaching the development of every individual service plan collaboratively and with optimism. It means new expectations about quality, such as consistent use of interventions that are scientifically proven. It means a focus on helping people achieve the changes they desire in their lives. Recovery and resiliency must become expectations, not ideals.

The second change that we see today compared to the time of the Carter commission is that there is a paradox in how our well-intended reforms have made things so much more complicated. The issue of mental illness is pervasive. It needs attention in the schools, in primary care, in the workplace, and in many other sectors. Fixing the relatively narrow and separate public mental health system alone is not sufficient. We have to work across the entire spectrum. This is more of an emerging idea than a recommendation. However, two major recommendations address it directly: the development of a more comprehensive state plan backed by federal flexibility and providing for comprehensive, crosscutting individual service plans that provider a higher degree of consumer choice and control.

Q Why didn't the commission address the connection between alcohol and drug addiction and mental illnesses? People should be trained in treating both illnesses, instead of treating them separately.

A Dr. Hogan: The commission said quite strongly that treatment, where there are co-occurring disorders, should always be integrated. It is the person who has to be treated, not the separate illnesses. We also need to use the skills of both consumers and families in the service delivery system and in the processes of recovery.

Panel 1: Implications of Mental Health Science for Society

Rodolfo Arredondo Jr., Ed.D.
President's New Freedom Commission on Mental Health
Texas Tech University Health Services Center

Recovery is at the center of all of the recommendations of the New Freedom Commission report. When we look at transformation of our mental health system to maximize recovery for adults with serious mental illnesses and children with serious emotional disturbances, it becomes very obvious that we need to develop policy to coordinate systemically the role and functions of numerous agencies at the state and local levels. This would increase access clinically and also maximize the quality of care.

Clinical services need to be coordinated and integrated. Mental health is part of overall health, as mental health, substance abuse, and physical illness frequently co-occur.

While science has contributed significantly to the development of new medications in the past two decades, we must continue to encourage strongly the development of new medications, not only for mental health but also in the area of substance abuse, as well as clinical and prevention research. I feel optimistic that with the strength of science and research, treatment will continue to improve and we will enhance recovery.

Research for Recovery: The National Institute of Mental Health Perspective

Thomas R. Insel, M.D.
National Institute of Mental Health (NIMH)

I want to focus on one of the goals of the transformed system: "excellent mental health care is delivered and research accelerated." I am particularly committed to establishing an evidence base of treatments and services that actually work. There have been numerous studies funded over the last decade from NIMH showcasing which treatments are effective in treating different mental illnesses. At this point in time, based on careful, rigorous studies, we know that there are numerous psychosocial treatments that work. For example, in comparing relapse rates of different treatments for people with schizophrenia, the combination of medication and family psycho-education has a 20 percent relapse rate, whereas medication alone has a 45 percent relapse rate. There is similar data showing the effectiveness of supported employment.

However, this evidence base is not enough. Even when we have the evidence, the dissemination of that evidence is too infrequent, or there is limited access to the treatments that we know work. So it is important to understand what barriers are impeding our ability to implement evidence-based treatment.

First, mental health needs are no longer in the traditional mental health system. NIMH recognizes that we must do research in the very places where the public health need is greatest, such as schools, nursing homes, and the criminal justice system. We now have a services research portfolio that has begun to look at a number of nontraditional settings for mental health research. We are learning how to do this effectively as we go. What we are trying to accomplish is the development of an evidence base of what works in these different settings. We also need to

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develop the science of how to make sure that something that works in the research setting can be disseminated and practiced in a jail or a school or in a homeless shelter.

What do we need from a research perspective to get to the point of recovery for the vast majority of people with mental disorders? Part of the need is to provide the evidence base for diverse settings and implement what we know. That is still not enough. We still need the fundamentals. We now recognize that mental illnesses are medical illnesses or, more specifically, brain illnesses. The problem is that we do not have the tools for mental illnesses that we have for most other medical illnesses. We do not have diagnostic tests that are reliable. We do not have an understanding of the risk architecture the way we do for heart disease or Alzheimer's disease. We do not have strategies for prevention based on understanding genetic risk. Also, we do not have treatments that are truly effective, safe, accessible, and targeted to individual needs.

> *We need to model ourselves after the way research is conducted in the rest of medicine.*

While we like to say that mental illnesses are real illnesses and that we have real treatments, the problem is that currently available real treatments do not work for many people with these real illnesses. So while there is an important argument to be made about how to implement the treatments we now have, it would be selling all of us far too short if we stopped with the currently available treatments. What we really need are treatments that are far more effective than current treatment options.

As an example, look at what happened with chronic lymphoid leukemia recently. Now we have a treatment that is more like a cure. Suddenly nobody talks about the problems with service delivery, because services are trumped by having a treatment that actually does away with the disorder. It is time for us to begin thinking about that as a model, how we now can begin to plan for the next generation of interventions that would do away

> *We now have the full sequence of the human genome.*

with some of these disorders and not simply turn an untreated chronic disorder into a partially treated chronic disorder.

We need to model ourselves after the way research is conducted in the rest of medicine. In cardiovascular medicine or cancer research, we identify molecular targets based on basic research. Then we employ biochemical assays to screen for small molecules that could be used as new treatments. We then develop animal models to find out whether the small molecule treatments are effective and safe. And ultimately, we go into human clinical trials. This is a process that used to take about 12-15 years but has now been condensed into a much shorter period of time. It is proven to work. This approach has worked in some cancers and it also has helped reduce the rate of heart attack and heart disease. This model is now being applied globally for developing interventions for Alzheimer's disease.

For mental disorders, however, the model of treatment development has been almost the opposite. We always have relied on chance clinical observations and then gone to clinical trials. We have used animal models but these are often not satisfying. We then attempt to identify molecular mechanisms, although generally, the mechanisms have more to do with the mechanisms of drug effects rather than the mechanism of the disease. Finally, we come up with essentially "me too" compounds, compounds that are not truly novel but developed based on something that already works. So perhaps it is no surprise that we do not have the kind of breakthroughs in this area that we have seen in other areas of medicine.

This is going to change. The first reason for the change is because we now have the full sequence of the human genome. This is a landmark event that will change everything that we do in biomedical science over the next several decades. We now know that there are 30,000 genes in the human genome. The genes only represent a very small part of all DNA, only around 1.5 percent, but a great number of these 30,000 genes are expressed in the brain; as many as 6,000 may be expressed only in the brain.

With the sequencing of the genome, we can actually go after individual genes to find out whether they are involved in mental illnesses. We are beginning to discover that out of those

30,000 genes, there are many, at least 12 so far, that appear very important for susceptibility to schizophrenia. What is fascinating is that we had never heard of most of these genes before; some appear to be important for brain development, but many have functions that remain largely unknown. Research will need to explore how these various susceptibility genes confer risk for schizophrenia.

One remarkable example is a gene called COMT (catechol-o-methyltransferase). The COMT gene codes for an enzyme that is found in synapses where it breaks down dopamine, especially dopamine in the prefrontal cortex. Dopamine has been implicated in schizophrenia for the last 40 years. We know that there are subtle variations in the sequences of most genes. In the case of COMT, there are two major versions or "alleles" depending on whether the DNA sequence codes for the amino acid methionine or the amino acid valine. Sometimes such variations are unimportant, but in the case of COMT, this subtle change in sequence alters enzyme activity, resulting in more dopamine in the prefrontal cortex. People with one version of the COMT gene appear slightly more likely to develop schizophrenia. And, even more interesting, "unaffected" relatives of people with schizophrenia who have the same COMT genotype show many of the same abnormalities on physiological and cognitive testing even though they do not develop the disease. Apparently, the COMT gene variations bias cognition, but they may not specifically lead to the disorder of schizophrenia. NIMH is interested in this finding because the disability in people with schizophrenia is correlated more closely with cognitive deficits, such as problems with working memory or judgment, rather than delusions and hallucinations. Although problems with cognitive function may keep people with schizophrenia from being able to work and recover, we do not yet have a drug that targets the cognitive symptoms of this illness. By understanding the molecular basis of this deficit, we can begin to design a novel treatment.

The second major breakthrough that will permit research for recovery is the ability for the first time to look at the brain in-vivo, to see what the living brain is doing. We are no longer talking about a black box. Originally this was true for studying brain structure, but now we have gone beyond structure to look at brain function at very high resolution. We now can actually do in-vivo brain chemistry to look at neurotransmitter content in different parts of the cortex. Amazingly, just in the past two months, we have begun to visualize brain connectivity, providing an unprecedented opportunity to study how the brain develops in autism or schizophrenia.

New research with schizophrenia showcases the kind of work that will occur. For example, we can now follow changes in the brain for children with schizophrenia. Over the five years from about age 9 to age 14, there is a relatively profound change in the thickness of gray matter, but in people with schizophrenia, that goes out of control and they end up with up to 10 percent or greater deficits in the amount of gray matter in

The second major breakthrough that will permit research for recovery is the ability to look at the brain in-vivo.

some regions. These kinds of results suggest that this illness is not only neurodevelopmental but also neurodegenerative. The loss of connectivity, from either gray matter or white matter changes, may be very important to the pathophysiology of this disorder, particularly because the areas involved, like the dorso-lateral prefrontal cortex, appear important for the cognitive deficits of this illness.

By identifying the genes that are involved and understanding how the genes work to change brain function, we should be able to develop treatments as it is being done in the rest of medicine. Research is our best hope that, ultimately, every person with a serious mental disorder will be able to recover. Let there be no doubt, this is a long and difficult road with many blind alleys and many roadblocks. But we now have the tools to make progress at an unprecedented rate. While excellent mental health care needs to be delivered, this is also the time to accelerate research at a pace that can finally deliver the real promise of recovery for the large population of people with mental disorders who are not helped sufficiently by the treatments we have today.

The Connection Between Mental Health and General Health

David Satcher, M.D., Ph.D.

National Center for Primary Care, Morehouse School of Medicine

As assistant secretary for health, I had the responsibility and the opportunity for developing Healthy People 2010. Our first goal was based on the reality that our society is aging. While we have done a great job of increasing the number of years of life people live, there was a need for far more focus on quality of life. In the area of mental health, we see that some of the greatest challenges are in improving the quality of life. Our second goal was a commitment to work toward the elimination of disparities in health among different racial and ethnic groups. Those two goals also point out how critical mental health is, and our report on culture, race, and ethnicity relative to mental health pointed out that disparities in access were a barrier.

Our challenge is to find a way to get the American people to focus on strategies for action. We decided to come up with a set of leading health indicators similar to leading economic indicators. With the help of the Institute of Medicine, we came up with 10 leading health indicators. Each indicator has an objective or two associated with it, so there are measurable outcomes associated with each indicator. Mental health was listed as one of the 10 leading health indicators for Healthy People 2010, recognizing that in the context of general health challenges, mental health emerges as very critical.

I do not think that we talk about mental health enough as mental *health.* We talk about mental illnesses and mental disorders. Mental health should be defined as the successful performance of mental activities in such a way as to be productive in one's life and to develop positive relationships with other people. Additionally, mental health is the ability to adapt to changes in one's environment and to deal with adversity. When I look at that definition, it says two things that are very important. First, it says that there is a continuum between mental health and mental disorders. Second, it says that none of us can take our mental health for granted.

Mental health is fundamental to overall health and well-being. One cannot have good health without mental health. We have to treat it that way. It is amazing how far we are from that in terms of our policies, in access to mental health care, and in the need for comprehensive parity of access. Plato said, "The greatest mistake in the treatment of diseases is that there are physicians for the body and physicians for the soul, although the two cannot be separated." This was a cry for connection, for integrating mental health into overall health and well-being.

The fact that mental disorders are common is a big surprise to a lot of people. When you think about it, one in five Americans suffers from some form of mental disorder each year. That means that there is virtually no family who has not experienced mental disorders or who is not struggling with them everyday. That statistic means that 44 million adults and approximately 14 million children are experiencing mental disorders each year. Yet there are still so many people who do not appreciate the reality of mental disorders. They either attribute it to character weakness or, sometimes, spiritual disorders. We have to point to all of the outstanding brain research in the past several years showing the connection between mental disorders and changes in the brain.

Mental disorders are disabling. Research points out the disability associated with mental disorders. This research base continues to grow as we learn more every year about the tremendous impact of different mental disorders, such as depression, on our ability to be productive and to maintain positive relationships. There also is an association between depression and other chronic illnesses.

The relationship between depression, especially, and chronic disorders is an evolving science. I participated in the International Conference on Diabetes in the Caribbean back in April, and one commonality was the extent to which depression interferes with the ability to successfully treat and control diabetes. Several studies have shown how prevalent depression is in chronic diseases. Fifty percent of people who suffer from Parkinson's disease experience depression; more than 40 percent of cancer patients and about 30 percent of people with diabetes also have depression, according to some studies.

The connection between mental health and general health plays itself out in primary care settings. Approximately 30 percent of primary care patients are suffering from depression but are complaining of other illnesses, and depression is a major factor with many patients who have any type of chronic disorder. Recent studies show a dramatic impact of depression on patients with myocardial infarcts. We are learning more everyday about the role that mental disorders play in our general physical health.

There has been a lot of work on physical activity for prevention and health promotion relative to physical diseases but little attention paid on the impact of physical activity on mental health. Recent studies out of Duke University show that physical activity as a component of treatment for depression enhances recovery significantly.

The good news is that in many cases we have the ability to treat mental disorders. We have the ability to return people to productive lives and positive relationships, and hopefully that capability will improve. Tremendous research is going on that will greatly enhance our ability to diagnose mental disorders earlier and better treat mental disorders. The bad news is that so many people who suffer from mental disorders do not even seek treatment, and the people who do seek treatment often have trouble accessing care. So even though mental health is a major component of general health, people have a lot of difficulty in accessing quality mental health services.

Stigma is a critical issue in this country. Stigma has a tremendous impact not only on the individual but on the family and community, as well. It impacts policies at the local, state, and federal level. As we struggle to get Congress to act on legislation like the Domenici-Wellstone bill, stigma plays a major role.

Culture counts when it comes to diagnosis and treatment of mental disorders. How people manifest their diseases, how they cope, the type of stresses they experience, and whether they are willing to seek treatment are all impacted by culture. Stigma also is greatly influenced by culture. I visited a program in Seattle called the Asian Counseling and Referral Center, where they have targeted the cultural aspects of mental health in that community. As a result, they have bridged some major gaps in getting people into treatment, focusing on primary care, partnering with mental health specialists, and training people in the community who speak the language and understand the culture. This has allowed them to break down barriers inhibiting access.

Stigma is a critical issue in this country.

Professionals also are influenced by culture. Our culture impacts upon how we hear things when we talk to patients. It can interfere with our ability to make accurate diagnoses and can even impact our judgment about treatment. This is a major component of disparities in quality of care.

In conclusion, I would like to remind us of what Kay Redfield Jameson said in her book *Night Falls Fast.* She wrote, "The breech between what we know and what we do is lethal."

The Importance of New Epidemiological Findings for Policy

Ronald Kessler, Ph.D.
Harvard Medical School

The question aris-
es whether early
treatment while a
disorder was still

The past decade has seen major growth in psychiatric epidemiology due to the development of new assessment methods and the creation of a number of important cross-national collaborations that have allowed us to pool data and learn about subtle issues surrounding mental disorders. We now know, based on these studies, that mental disorders are very common, that they are seriously impairing, and that most serious mental disorders begin in childhood and adolescence.

The last of the findings mentioned in the last paragraph, that most serious mental disorders begin in childhood or adolescence, should not be taken to imply that these disorders are always serious at the time they begin. Indeed, quite the opposite is true. Most of these disorders are relatively mild at first. A typical pattern might be a child having school phobia at the age of 4-5, social phobia beginning in early adolescence, major depression beginning in middle adolescence, and secondary alcohol or drug abuse to self-medicate the mood problems beginning in late adolescence. A young person with a profile of this sort often has secondary problems in developmental roles, such as becoming pregnant as a teen, dropping out of school, and becoming involved in a violent marriage that ends in divorce.

This kind of profile does not begin with a serious emotional disturbance (SED), but with a disorder (school phobia) that is usually considered mild. Indeed, the hypothetical young person in this example might not meet criteria for SED at any part of her childhood or adolescence, but only in early adulthood with the onset of substance dependence superimposed on anxious-depression. Epidemiological data show that a young person of this sort seldom seeks professional treatment until their disorder becomes severe. This could be many years after the first onset of their disorder in childhood.

The question arises whether early treatment while the disorder was still mild would help prevent progression to a serious disorder. We do not know the answer to this question because mild childhood mental disorders are seldom treated. No controlled study of treating mild

Questions & Answers

Q Dr. Satcher, how do you put legs on these federal reports so we can implement and make changes?

A Dr. Satcher: People have to take those reports and make sure they are communicated at every level of our society. We need to have meetings like this and talk about them. We also need meetings at the community level, in churches and groups, and we need to be involved in policy-making at the local, state, and federal levels. It begins by educating people at every level of society about the importance of mental health and the fact that recovery is possible.

Q Will these research findings actually change the delivery of care, or will they primarily be a background for new pharmaceutical research? And if they do change the care, how do you implement that type of paradigm shift? Is anybody directing their attention and goals toward that?

A Dr. Insel: The answer to the first question is that we will have to wait and see the extent to which these findings will play into new treatments. These findings might not impact treatment only but diagnosis as well. One of the things we talk a lot about is whether the genome era will allow us to begin to individualize treatment so we know which treatment is going to work for whom, and more importantly, which person may be particularly sensitive to adverse effects of drugs or other treatments. How that will take place depends partly on what the discoveries are.

How will it happen? It will happen through a number of different avenues, and one of the things that should be happening more in the future is to see more public-private partnerships. I have become concerned that in the last decade the NIH has given drug development to the pharmaceutical industry. It is time for us to take back some of that and begin to think about how we can develop drugs not with a profit motive but with a public health motive.

Q I would like to hear you talk about getting to the kids with mild disorders. In Philadelphia, we have 210,000 children in the public school system, and 60 percent of them have serious behavioral difficulties. We can identify at-risk children, but the unwillingness of the community and the government to address this issue is frustrating.

A Dr. Kessler: Yes, that is true. I am spending a lot of time lately conducting epidemiological surveys in the workplace showing the cost of mental illnesses. There has been a lot of argument in the last decade about how much it costs to treat mental illnesses, and my research is showcasing the cost of not treating it. We are now engaged in a very large demonstration project with some major corporations in America, screening over 100,000 workers, getting depressed workers into treatment, following them for two years, and documenting how much money it makes for the company. It is a human capital investment that makes corporations money.

I also am doing similar kinds of studies with children, but I cannot figure out who to talk to. With the employer it is very easy, because I have this dollar and cents impact. With the children, the school does not think it is their problem. So it is a real tough thing to figure out who to go to.

Dinner Address: Achieving the Mental Health System Transformation Together: SAMHSA's Action Agenda and Partnerships

Charles Curie, M.A., A.C.S.W.

Substance Abuse and Mental Health Services Administration (SAMHSA)

childhood disorders has ever followed subjects into adulthood to evaluate the long-term effects of treatment.

Even more disturbing than the pervasive delays in treating early-onset disorders is the fact that treatment quality is often quite poor when people with these disorders finally get into treatment. Demonstration projects have shown that treatment quality can be improved dramatically with relatively modest interventions. However, these model programs seldom are adopted by health plans due to a lack of willingness by largely institutional purchasers to pay the additional costs of these programs. This means that institutional will is needed to demand that these programs be put into place and to monitor the ongoing quality of these programs.

Little evidence exists that this institutional will is going to develop. Indeed, an opposite inclination appears to exist among the architects of the American Psychiatric Association's planned revision of the Diagnostic and Statistical Manual of Mental Disorders, who want to remove mild disorders from the diagnostic system. The thinking is that so many people meet criteria for a mental disorder that society cannot afford to provide treatment to all of them. Triage rules are needed, which the architects of the DSM propose to implement by focusing treatment efforts on individuals with serious disorders.

> *Too many Americans wait half their lifetime for someone to notice that their behavior was not simply a matter of poor choices but part of an illness.*

But this might be a mistake, as the cost-effectiveness of treating mild disorders could be high. We do not know whether this is the case because, as noted above, no systematic long-term research has been done to evaluate the long-term effects of treating early-onset disorders. We do know from longitudinal research, though, that a high proportion of mild cases among young people evolve into more serious cases over time.

A disturbing epidemiological pattern is that the earlier the disorder starts, the longer it takes to get into treatment. People who develop specific phobias as children, for example, often get into treatment only in their late 20s, whereas people who have acute onset phobias in their early 20s typically get into treatment by their mid-20s. This pattern is presumably due to a figure-ground problem: that people adapt to early-onset disorders and don't recognize them as being as much a problem once they reach adulthood as they do problems that have adult onsets. This is disturbing, especially because early-onset disorders often are more severe and persistent than later-onset disorders. This means that the people with the greatest need for early intervention are the ones who are likely to delay longest before seeking treatment.

Despite this disturbing picture, there are some positive trends. The epidemiological evidence is clear in showing that delays in initial treatment-seeking have decreased in recent years. This presumably reflects decreases in stigma and increases in public awareness that mental disorders can be effectively treated. Nonetheless, delays in initially seeking treatment are still pervasive, especially for early-onset disorders. We need to develop school-based early screening, outreach, and treatment programs to do something about this. We are not taking advantage of the opportunity for early intervention provided by school systems. As noted above, we do not know if early intervention works. As a result, research and demonstration projects are needed to develop, evaluate, and disseminate effective early treatments. Although these efforts might be seen

as diverting valuable resources away from research and treatment of more serious disorders, the public health implications of early interventions with mild cases could be profound.

It is a privilege to be here for a variety of reasons. One of those reasons is the fact that The Carter Center – and the Mental Health Program in particular – has been a true partner in helping us strive to build a system of care that embraces resilience for children and recovery for people with serious mental illnesses. The essential element to everything that The Carter Center does is hope, and I see building hope as being one of the major tenants of your mission. In the absence of hope, recovery is lost.

It is also a privilege to serve President Bush and Health and Human Services Secretary Tommy Thompson. They clearly know that treatment works and recovery is real! I also want to recognize the support SAMHSA has received from the White House and Secretary Thompson. Some have questioned whether we at SAMHSA will get the support we need to achieve our vision of a life in the community for everyone. Well, I am happy to say we already are.

When the president announced the commission and defined the scope of responsi-bility, he spoke frankly about the poor quality of mental health care in this country in terms of its fragmented delivery system. He drew upon the common example of a 14-year-old boy who suffered from severe depression and began experimenting with drugs, not realizing that he was self-medicating the depression to alleviate his symptoms. He was an honor student who began slipping in school and eventually got into trouble with the juvenile justice system.

This young man, like many Americans of all ages, slipped through the cracks. Was he put into rehabilitation programs? Yes. But he was treated for the drug abuse and not for the underlying issue of depression. And he ended up graduating into the adult criminal justice system in his 20s. He was not diagnosed until age 30 with bipolar disorder. Once diagnosed and receiving appropriate treatment, his symptoms were alleviated and he began to regain his life.

On one hand, some people describe this as a success story. But I can't help but think about the 16 lost years of his life and how the system failed. If he were diagnosed earlier and received the right treatment, perhaps he could have completed high school, gone to college, and at the age of 30, be raising a family and claiming a career instead of just starting to think about how he was going to fit in again once he had his symptoms under control.

Too many Americans wait half their lifetime for someone to notice that their behavior was not simply a matter of poor choices but part

> *Recovery needs to be defined in the terms of the consumers, family members, children, and parents who receive services from our system.*

of an illness, an illness that we can do something about.

Clearly, we have made progress and we will continue to make progress by pushing for what is right for the people we serve. The simple concept – doing what is right for the people we serve – is the concept that steered the New Freedom Commission through many tough decisions, leading ultimately to its final report.

Now, the White House and Secretary Thompson have given SAMHSA the lead role to conduct a thorough review and assessment of the final report. Our goal is to implement appropriate steps to strengthen our mental health system. The commission was asked to give the mental health system a physical, and they did it. The diagnosis: fragmentation and disarray. The commission report found the nation's mental health care system to be well beyond simple repair. It recommends a complete 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 will require the implementation of a to-do

list currently being developed by SAMHSA. The to-do list will form an action agenda to achieve transformation of mental health care in America. I recognize "transformation" is a term with different meanings to different people. Often, it is just a simple synonym for change. There is also a mathematical definition of transformation, the change into another form without altering the value. Our definition of transformation will simply be reconsidering, reshaping, and changing the ways in which the mental health system provides effective treatment and how consumers and families recover. We need to be thinking about how we operationalize recovery from the standpoint of public policy as well as public financing.

> *As a compassionate nation, we cannot afford to lose the opportunity to offer hope to those fighting for their lives to obtain and sustain recovery.*

How we first define "recovery" is critical. Recovery needs to be defined in the terms of the consumers, family members, children, and parents who receive services from our system. My first professional position included running an aftercare group. The goal of that aftercare group was to help those individuals coming out of the psychiatric hospital adjust to the community. I remember asking them what they needed to deal with their mental illness. What was important to them? It was interesting to hear their reaction, because they did not say they needed a psychiatrist. They did not say they needed a psychologist or a caseworker. They did not just say they needed a program. They defined what they needed in terms of what they wanted in their life. They wanted a job. They wanted meaningful daily activity that helped give them an identity. They wanted a place of their own in the community. They wanted standing in the community, to be part of a neighborhood and a community. They wanted a safe, decent place to live. Finally, they wanted connectedness. They wanted to have a relationship with family and friends.

When you think about your own life and what you want for those of us who are not mentally ill, for those of us who have not struggled with that disease, those are the things all people want: a job, a home, and people who are important to us. This gives us an idea of what we need to begin doing in our service delivery system to help people truly attain recovery.

I am a little concerned that there has been some criticism that recovery was not the right thing for the president's commission to emphasize in our final report. Some say we are offering false hope, because not everybody with a mental illness will fully recover from their disease. Well, of course, some will not fully recover. The disease can be very severe, chronic, and disabling. But recovery is both an outcome and a process. We need to define the process of recovery and what we are doing in the system to help that process, because in the process of recovering, people learn how to manage their illness and manage their life. That is what we are talking about. People will be emerging and arriving at different levels and at different stages of the process. It is not

false hope. It is finally realizing hope and understanding how hope moves the process along.

This transformation will require a shift in the beliefs of most Americans. It will require the nation to expand its paradigm of public and personal health care. Everyone from public policy-makers to consumers and family members must come to understand that mental health is a vital, 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. We are talking about a societal change here, one that has to begin with the professions, with government, and in academia. It has to be in the groundwater of our society.

The report also challenges us to close the 15- to 20-year lag it takes for new research findings to become part of day-to-day services for people with mental illnesses. Waiting for research to make its journey down an already clogged pipeline equates to losing a generation of people while we transition from what we know to what we do. Many Americans 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 also 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 also challenges 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 illnesses are treatable and recovery can be the expectation. As a compassionate nation, we cannot afford to lose the opportunity to offer hope to those fighting for their lives to obtain and sustain recovery.

To lead that effort, we have assembled a transformation task force. We already are working with relevant federal agencies to determine ways to improve the flexibility

required by the states and develop the incentives to bring the full force of 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. States are where the action is when it comes to mental health and thus states have an awesome responsibility. We know that the new state agendas must be consumer- and family-driven rather than bureaucratically bogged down. Consumers of mental health services and their families must stand at the center of the system of care and drive care. We have talked about consumer- and family-centered care for years, but we don't really know what that means. When we begin to say the consumer and their families must drive the care and drive the system, that begins to strengthen and clarify their role. The result should be more of our family members, co-workers, neighbors, and friends living a rewarding life in their communities.

This commission report gives us the opportunity to find common ground.

Over time, with strong leadership, enough people will be thinking of new ways and doing things differently. The new will become the norm.

We need to be careful not to rush toward change frantically, grabbing at what we can. We need to be strategic while pressing onward. We need to have careful planning. I refer to a quote by Dr. Gary Tisler, who was on the Carter commission. Dr. Tisler made an observation that many of the recommendations of the two commissions are similar. It is troubling that after 25 years we still

Panel 2: Moving Science to Services

Larke N. Huang, Ph. D.
President's New Freedom Commission on Mental Health
Georgetown University Child Development Center

The challenge for us today is to harness the personal and the collective responsibility for the strategic implementation of this report. To paraphrase a probably overused phrase, it will take a village to transform a system that has been in shambles. And this village must be built on collaborations and on relationships. I think we may anticipate that some of the relationships will be uneasy relationships; nevertheless, we must build on them to promote better outcomes for people with mental health disorders.

> *We know it takes about 15 to 20 years between the discovery of effective treatments and the implementation of these treatments into routine practice.*

We heard earlier about "transforming" concepts in the commission report, such as recovery and resiliency as an expected goal of mental health care and the need for care to be consumer- and family-driven. We heard of the urgency to provide mental health care in other service systems such as child welfare, juvenile justice, and primary health care where we see a burgeoning of mental health problems.

Today we are going to speak about goal five of the commission report – excellent care is delivered and research is accelerated. This is another transforming concept. Research has yielded critical advances in our understanding of human development and behavior; research has been fundamental to the development of effective treatments and services. Yet we know it takes about 15 to 20 years between the discovery of effective treatments and the implementation of these treatments into routine practice. While we have generated considerable knowledge regarding effective services and supports, we are moving these practices into service delivery far too slowly.

This panel will address the challenges of transporting research to practice. They will examine the science-to-services gap and the parallel gap from services to science. They will look at the concepts of evidence-based practice and practice-based evidence. Structural issues such as financing, human resource development, or organizational inertia that impede change will be touched upon as well as strategies for how to work with local communities and providers to develop services that better meet the needs of these communities. The successful dissemination and implementation of effective treatments, services, and supports is essential to the provision of high-quality mental health care.

Evidence and Transformation

Benjamin Druss, M.D., M.P.H.
Rollins School of Public Health, Emory University

This symposium is really about each of us looking within ourselves to answer a fundamental question, which is what can we do to bring about the transformation called for in the president's commission report. As a researcher, I will talk about evidence, both what it can and cannot do in bringing about change in mental health policy. I will focus on the gap between how the research community and the rest of the world understands and uses evidence and how we might use the symposium as a step toward bridging that gap.

The executive order establishing the President's New Freedom Commission on Mental Health in 2002 placed evidence in a central role in how the commission should approach its charge. This notion of grounding the report in evidence is actually quite extraordinary. It reflects recognition that we are finally beginning to develop a science base that is broad and deep enough to support clinical and policy decisions.

Evidence also plays a central role within the report itself. Each of the subcommittees commissioned a background paper from a research expert, and these papers both help inform and bolster the recommendations of the final report.

This issue of translating science to practice has been a major focus in recent years in a number of major federal agencies. However, this gap between evidence and practice has been far easier to identify than it has been to close. Why is this the case? I think it is important to look at how we have been thinking about what translation actually is to understand the problem. To date, translation has been thought of as a top-down process, moving from research to practice, policy, and communities. We researchers feel like we keep speaking, but no one seems to be listening. So we look for a way to make our voices louder. Translation becomes a megaphone through which we hope to be heard among the din of competing demands faced by clinicians, managers, and policy-makers.

But being at The Carter Center brings another metaphor to mind. This is the notion of translation as a dialogue between those who do research and those who use the findings. This is translation in the most concrete sense of the word. It is the process of interpreting between languages and between the cultures of research and practice. Most of the rest of my talk will seek to understand how these two different worlds think about evidence.

Let's start with a few terms. What is evidence? The answer to this question will vary considerably depending on whom you ask. The researcher thinks of evidence primarily in terms of its level of truth or validity. Courses in evidence-based medicine teach about the hierarchy of evidence, with randomized control trials as the gold standard of truth.

Most of the rest of the world views evidence in a much more pragmatic manner. As found in the American Heritage Dictionary, evidence is simply a thing or things useful in forming a judgment. The key operational term here is *useful*. It

> *We are finally beginning to develop a science base that is broad and deep enough to support clinical and policy decisions.*

doesn't have to be perfect. It doesn't have to be supported by randomized trials. It just has to help us to make the best decisions we can make.

How do we decide which evidence is significant? Anyone who has ever read a scientific article knows that results are statistically significant if P is less than .05, which means that there is less than a 1-in-20 likelihood that the findings were simply a result of chance. This cutoff point, which was first proposed by the statistician R. A. Fisher in 1925, is actually an arbitrary convention. However, this point has become a very convenient way for the researcher to sort between what needs to be paid attention to and what can be ignored. The fact that it is called "significant" tends to give us the impression that it is the same as clinical

importance. In reality, statistical significance and clinical importance are not one and the same thing.

The rest of the world cannot afford such certainty. In our daily lives we need to make decisions under conditions of varying and often high levels of uncertainty. Most of us spend our days making the best decisions that we can under imperfect conditions. Our critical P value is not P less than .05, but P less than .5. In other words, is this decision more or less likely to give us the outcome that we are looking for? If I check the weather in the morning and see there is a 60 percent chance of rain, even though I am a researcher, that is good enough for me to bring my umbrella. I do not need 95 percent certainty to have the sense to come in out of the rain.

Reinvention is a form of learning, and in its own way, it is an act of both creativity and courage.

The research process is slow, methodical, and conservative. And this is a great strength. It provides multiple safeguards that keep researchers from drawing conclusions that may be incorrect or dangerous. However, the rest of the world does not have the luxury to wait 17 years to make decisions. A recent study found that policy-makers overwhelmingly identify timeliness and relevance as the most important qualities that would lead them to use information in their decisions. A chief executive officer's time horizon is about a year, and chief financial officers' time horizon is typically the next fiscal quarter. Consumers impatient with the slow pace of the research process are increasingly using the Internet to learn about and discuss new innovations that will not be published in literature for many years.

Science itself warns us that evidence is only the first step in transporting policies and practices.

When researchers think about moving evidence into practice, our usual goal is to transplant the innovation into the real world with as few changes as possible. We call this notion "fidelity." But in real-world health and mental health settings, perfect fidelity is rarely practical, and I would argue that it also is not desirable.

In a recent *Journal of the American Medical Association (JAMA)* article about disseminating health interventions into routine settings, Don Berwick suggests that we substitute the notion of diffusion with the term "reinvention." To work, he says, changes must not only be adopted locally but adapted locally. Reinvention is a form of learning, and, in its own way, it is an act of both creativity and courage. "For reinvention to occur when we researchers develop an intervention, we need not only to expect but actively to encourage local sites to streamline the model and tailor it to their local environments."

Let me give you an example. An enormous amount of work has been done in the area of translation in the treatment of depression in primary care. More than a dozen randomized trials demonstrated that team-based, patient-centered approaches known as collaborative care improve the quality of medical outcomes and treatment for depressed patients. And yet the models have yet to be widely adopted. Even in the settings in which the studies are conducted, these models are not sustained after the research process ends. I think one of the challenges in helping these models be used more broadly is to demystify them by deemphasizing fidelity and encouraging more local experimentation. We need to help local leaders read the collaborative care literature with an eye toward what is most relevant to their own organizations. We must allow them to make incremental changes rather than simply offer them an all-or-none deal.

When researchers publish a study, we are convinced about the validity and importance of the findings. The need for action often seems self-evident to us. We are then often surprised and disappointed that the articles do not have the impact that we would hope. However, science itself warns us that evidence is only the first step in transporting policies and practices. Everett Rogers, who is a professor of communications at the University of New Mexico, has described the many determinants of how new innovations are widely adopted in society. He notes that the characteristics of the innovation are only part of the story. How they diffuse or are reinvented is highly dependent on the nature of the potential adopters and the broader system into which they are being introduced.

In a recent article in the journal *Health Affairs*, political scientists Rogan Kersh and Jim Morone examined the common elements of public health policy movements across a range of issues such as smoking and national policies on alcohol and illegal drugs. They describe a series of what they termed "triggers" that need to be tripped before change can occur. Medical science is only one of these triggers. Others include development of consumer groups, politically active interest groups, and increased awareness and interest in the general public. As you hear these, think about the parallels of mental health with the growth of the consumer movement. I believe the environment is becoming increasingly ready for the sort of major transformation we have seen, for instance, in national tobacco policies. We researchers need to make sure that as these policy triggers are tripped, we have the right evidence at hand for fostering constructive policy change.

If translation is a dialogue, then we from the research community can use this symposium to listen to all of you to learn how to better develop evidence that is useful, timely, and relevant to your needs.

But we need to do more than just give you evidence. We need to allow you to develop and use your own data more effectively. Examples of this might include helping a mental health clinic study its claims data to better understand its clients. It could be guiding policy-makers doing an informed survey of the literature on key issues. It can be teaching a consumer to more effectively use the Internet to understand his or her own condition. This is the sort of homegrown evidence that actually will be used to improve care, because it is addressing needs that are, by definition, timely and relevant. It also will be sustainable because done right, it can be continued locally even after we researchers go home. Largely what I am talking about here is an exercise in power-sharing in which we researchers must be willing to surrender our monopoly on producing and understanding evidence.

Finally, I want to challenge those outside the research community to think about ways of adopting and adapting evidence in your day-to-day work. How can you work toward goal number five of the New Freedom Commission report, which advocates advancing the use of evidence-based practices? And more generally, how can you use evidence as a tool in achieving the other goals outlined in this report? Evidence may not be the only step needed for change in our mental health system, but used properly, it can be a powerful tool for such a transformation.

I challenge those outside the research community to think about ways of adopting and adapting evidence in day-to-day work.

Readiness for Evidence-based Practice in Child and Adolescent Mental Health

Barbara J. Burns, Ph.D.
Duke University Medical Center

Historically, it has been a challenge to convince the public that children and families have real problems and an even greater challenge to get people to believe that we actually have some answers. What the work on the surgeon general's report did for me was to help me glean these messages of hope for kids. With that hope, we can translate our research findings into real-world clinical practice.

Mental disorders are prevalent in youth. In North Carolina, we have followed youth from ages 9 through 16 and found that 37 percent have had a psychiatric diagnosis. We also now know from an ongoing national survey of 6,000 kids that in the child welfare system at least 50 percent of those youth need clinical treatment. Also, almost two-thirds of those in the juvenile justice system have clinical needs.

> *Unfortunately, there is still a reliance on institutional care for children.*

So what are we doing about getting kids into care? In the last 25 years, we have moved from about 3 percent of children being seen in mental health services up to around 8 percent. We also have moved from an average of three visits per treatment episode to 11 visits. However, even with this progress, there is still a lot of unmet need. There also are racial disparities in obtaining treatment, with Hispanic youth being the ethnic group least likely to receive services. In addition, there is wide variation in the rates of children receiving care across states.

Evidence shows that we have a choice of effective interventions for four of the most common disorders in youth: depression, attention deficit hyperactivity disorder, anxiety, and disruptive behavior. This evidence has influenced service delivery. For example, psychoanalytic approaches are waning and behavioral approaches have gained popularity. Ecological models are commonly applied for youth with severe emotional disorders where multiple systems are needed to work together and intervene. We also have respectable evidence for the effectiveness of community-based programs.

We find that specific interventions are effective for specific disorders. For example, cognitive behavior therapy is an effective treatment option for depression, anxiety, and trauma, and behavioral approaches directed at parents and teachers work with children with ADHD and disruptive behaviors. The real question is how many of these interventions are being taught in graduate schools and continuing education? Are there even materials for adequate instruction?

Unfortunately, there is still a reliance on institutional care for children, such as hospitals, residential treatment programs, boot camps, and detention centers. This is in spite of evidence that suggests that institutional care is not effective for many childhood mental disorders. Until the community-based alternatives are truly in place, we will continue to see a significant number of our youth being sent away at great cost and minimal effectiveness.

With all the different types of treatment options available, is there any way to simplify? A very clever psychologist in Hawaii by the name of Bruce Chorpita and his colleagues looked at all the evidence-based literature for common disorders and identified core components for numerous types of interventions. He came up with 26 core components of effective treatment (e.g., tangible rewards, communication skills, limit setting, and maintenance). This could mean there are only 26 kinds of techniques that service providers have to learn. However, it is another matter to put them together appropriately. An approach to tailoring interventions to the child on a component-based approach is currently being tested in Hawaii.

How do these interventions spread? Let's take the example of family preservation. There were promising findings from uncontrolled studies, and based on them, family preservation became federal legislation. Then controlled research was conducted, and the results were not very positive. It is very hard to undo federal legislation, so family preservation prevailed long after it was known to be ineffective.

A little different lesson comes from treatment in foster care. The people at the Oregon Social Learning Center did a great job with the efficacy studies. Professional parents are paid about $30,000 a year to take in a fairly disturbed child and work together with the natural family to avoid placement in an institution or out of the community. The treatment spread and standards were developed for implementation. Yet there is a large gap between the promise of treatment foster care and the reality. We have just conducted an observational study in North Carolina and found that treatment foster parents were reactive to crises. They were not adequately trained in proactive approaches to preventing behavioral problems. The implications here are that quality monitoring and proper training are required.

As a final example, let's look at eye movement desensitization and reprocessing (EMDR). The use of EMDR spread like wildfire; however, there was little evidence for the technique. Very little formal training was required, and it was easy to learn, thus accounting for its spread.

According to Backer, the principles of facilitating the dissemination of interventions are:

1. **User-friendly communication.** We need readable training materials that are interactive and utilize electronic capabilities, such as the Internet.

2. **User-friendly evaluations.** Keep the researchers at some distance until you know what outcomes you want and you have a sense of an approach to monitoring quality. Quality monitoring is essential, but do not let the research weigh the intervention down.

3. **Resource adequacy.** We need enough policy support and enough funds to provide the treatment, to provide the training, and to conduct the evaluation. I see examples where all three are neglected. Neglecting any one of them is a risk for failure.

4. **Addressing the complex human dynamics of change.** Change is not easy, and many providers may resist change. Change makes people anxious, especially if they are already comfortable with the way things currently work. It is important to communicate clearly the benefits of change and provide an environment in which staff can successfully change.

An elaborate initiative by SAMHSA in the adult arena for effectively spreading treatment innovations was the development of implementation resource kits. This involved creating a state-level infrastructure for training in conjunction with training materials that are user-friendly and comprehensive. The kits took about two years to develop with a lot of input from all the stakeholder groups. They include a video to introduce the intervention, a video to train the clinician, a manual for the administrator, and a manual for the clinicians. In one state, another local approach is mentoring utilized for ongoing training, where established community treatment programs act as a mentor to new ones. It is my great hope that we will be able to utilize the above model to engage in similar work for selected evidence-based child interventions in the near future.

To conclude, here are the big future questions:

- Can consensus be achieved about appropriate and effective clinical practice?

- Can necessary and effective training be integrated into graduate and continuing education?

- Will critical stakeholders support the implementation of evidence-based practice?

- Can we create a better balance between internal and external validity in treatment development research?

I do not have the answers. I do hope we can come up with them together.

Recovery-based Innovation

Larry Fricks
Georgia Department of Human Resources

If you believe that we can and do recover from mental illnesses, everything changes. You shift from a system founded on symptom reduction and custodial care to a strength-based system. And you call forth a potential of self-directed recovery and services such as supported employment to replace institutions that promote hopelessness.

An outgrowth of the 1999 Surgeon General's Report on Mental Health has been the realization of the value of peer-to-peer support in the acquisition of real recovery. Certified peer specialists (CPSs) provide hope and model that possibility to every consumer they serve. The role of the CPS is to transition ownership of recovery into the hands of the consumers.

Dr. Jim Saben, in his article about strengthening the consumer voice in managed care published in the April 2003 edition of *Psychiatric Services* says, "The primary responsibility of the certified peer specialist is to provide direct services designed to assist consumers in regaining control over

their own lives and control over their recovery processes. Peer specialists are expected to model competence in the possibility of recovery and to assist consumers in developing the perspective and skills of facilitated recovery." He goes on to say, "The aim of peer support is to provide an opportunity for consumers to direct their own recovery and advocacy process and to teach and support each other in the acquisition and exercise of skills needed for management of symptoms and the utilization of natural resources within the community."

The program started with leadership from the consumers. We were fully at the table when we rewrote our Medicaid service plan under the rehabilitation option. It was the consumers who asked that we go after a Medicaid billable service called peer support and created a new provider called a certified peer specialist, a recovery agent who helps consumers develop the potential to manage their own recovery.

Here is how we developed Georgia certified peer specialists:

1. **Training and certification.** First we had to develop the training certification and a code of ethics. Our certified peer specialists sign a code of ethics, and if they are accused of an alleged ethics violation, they go in front of a tribunal of peers to decide whether or not their certification gets pulled.

2. **Technology.** The certified peer specialists have their own Web site where they can go online and support each other, sharing information and best practices across the state.

3. **Recovery mediation.** One of the things that we are about to begin is recovery mediation. We are in the process of bringing in mediation training from the University of South Florida, so we peer specialists can be trained as recovery mediators to go in and help traditional staff and consumers work together toward recovery.

4. **Continuing education.** We have continuing education every three months.

5. **Values.** You need leadership that stands behind the program, believes in it, and says we are going to do this, we are going to make changes and grow. You have got to have that kind of commitment from the top down when starting something new like this.

I went out to talk with many of our mental health providers and review the individual service plans of the consumers they serve. You cannot believe how far removed those written plans were from what consumers say they want for their real recovery goals. We are training our certified peer specialists how to determine what the consumer is most dissatisfied with in his or her life and, therefore, what they want to change most. We then flip that into recovery goals and tie them back to the treatment plan.

Peer support is 55 percent cheaper than other forms of day support services and more effective. Currently, we have 163 certified peer specialists who serve 2,500 consumers with this new Medicaid service. The billing this year for peer support will be $5.5 million, and we have been doing this for three years. Preliminary outcome data for 500 patients, ages 18 to 55 with schizophrenia and bipolar illness, found a 5 percent greater improvement for those serviced by peer supports than other day services in three areas: skills, functioning, and resources.

The National Mental Health Association came out about a month ago with a national policy to support peer support as a recovery service. In their policy, they say that every state should provide adequate funding to develop this new recovery service. Where else but at The Carter Center should we kick off a national recovery initiative that calls forth the potential and resilience of consumers to lead us to higher ground? This is where the dreams of hope are born, right here at The Carter Center and where the human spirit is unbound to soar.

Questions & Answers

Q Larry, I wonder if you would comment on how the ideas that you've been able to actualize in Georgia shift that culture away from symptom management and toward really genuine recovery. How do you see that occurring in other states, and what role do you see consumers, advocates, and family members playing in that sort of shift?

is going on in the mental health services delivery community. Then what is required is the same kind of transformation in terms of how researchers see what they are doing as needed in the mental health system. The issue is how you change a system that is stuck in its conservative ways.

A Mr. Fricks: I am aware that there is a shift in some states. We have had nine states send people to our training certification, and South Carolina now has Medicaid-billable peer support. The shift is coming. This recovery stuff is going to change the system.

Q We have been struggling for 20 or 30 years to implement practices such as supported employment and other kinds of recovery support services but constantly come across huge barriers. No one is responsible for identifying those barriers, whether it is funding silos, regulations, stigma, staff turnover, or training. We need that dialogue happening at federal, state, and local levels. Do you think assigning responsibility for that is something we could ever make happen?

A Dr. Druss: I think your point is on target and well-taken. There certainly are efforts from the research community within the National Institute of Mental Health to try to be more applied and attempt to identify and think about barriers to dissemination. But I think what you are saying is that there are problems within the research communities, issues that kind of parallel what

Panel 3: Strategic Implementation

Norwood W. Knight-Richardson, M.D., M.B.A.
President's New Freedom Commission on Mental Health
Richardson Group

The treatment and cure of mental diseases at times appears quixotic at best, for stigma and shame inhibit proselytes to our cause. And ignorance and fear foster discrimination, which acts as a deterrent to progress at all levels of our effort.

I choose this field of care because it involves the brain, the most complicated and demanding of human organs. The brain holds sway over functions from heartbeat to our sense of well-being. It mediates our perceptions of reality and negotiates our social interactions. When its processes are off, we are off indeed.

In the field of mental health, there is no wasted or superfluous knowledge. All that we can know must be brought to bear in the discovery and implementation of palliatives and cures for this devastating spectrum of illnesses.

President Bush commissioned us to explore new solutions and bring to light existing solutions. At the end of the day, when the commission had sunsetted, we put forth 19 well-considered and thoroughly debated recommendations, believed to be essential for achieving some of those solutions. Nonetheless, as in the biblical quote, faith without works is dead; so it is that recommendations without implementation are dead. We now embark upon the implementation phase of our work. This will be the most difficult and frustrating part, requiring determination, stamina, tolerance, political dexterity, cooperation, and partnership, as well as a large volume of interfaith prayer, in order to achieve even partial successes.

In another life, before I became a psychiatric physician, I was an international banker and financial analyst. I viewed work through a different set of lenses, which I sometimes find useful to put on again. As an international banker, I came to understand the financial processes underlying most of the infrastructures that support a complicated and interdependent modern global society.

One of the financial mechanisms used when there is a need for large-scaled, multilayered financing is called project financing. Simplified, in this arrangement the suppliers of operating capital and funds evaluate the project's concept, organizational structure, economic viability, credit worthiness, and financing requirements. This evaluation requires that the financiers, under the guidance of a lead institution, not only review the integrity of the goals of the project but also consider whether those goals can meet the needs of a targeted market or consumers. Failure to meet the consumer's needs invariably leads to financial failure.

During the finance stage, financiers have significant influence over the eventual scope, structure, goals, and roll out of the project. It is important to understand that many projects fail due to a key financial participant pulling out for various reasons, often because they could not insert requirements they wanted. To minimize this type of risk, the financiers meet and discuss terms they want in the financing agreement. As each institution brings to the table its own set of requirements, there is an attempt to minimize the risk of conflicting covenants, which may cause an inadvertent breach in the agreement and, consequently, trigger a default. Such a default can trigger a cascade of defaults in other agreements. When this happens, the project can be seriously jeopardized.

They also meet to ensure that their covenants or terms of participation do not put undue stress on the project by requiring conflicting accounting or reporting forms and procedures or over-burdensome interference in the management of the project. There is a process of continued review and evaluation that ensures that the finances remain in synchronization.

While I am very cognizant of the fact that not all of the challenges we face in improving mental health and curing mental illnesses in America are related to finances, one cannot, in a capitalist economy, argue the relevance of the adage "no

pay, no play." For too many decades, we have had too little pay to play well. When we consider the financing of mental health, we discover conflicting covenants and requirements of participation that often burden the consumer with layers of bureaucracy and which inhibit their obtaining and even knowing about available services. We also discover covenants that create huge service gaps, as are found in services to children and families and in the juvenile and criminal justice systems. The conflicting covenants also place service providers at risk of breaking a rule. The sheer complexity of the rules fosters a fragmented system. It inhibits development of new services, especially in communities of color and rural areas where there is already a dearth of providers. Complexity may drive fledgling or developing service providers out of the field altogether.

> *Conflicting covenants and requirements of participation often burden the consumer with layers of bureaucracy and create huge service gaps.*

In view of this reality, I suggest a modest proposal, that federal, state, and local governments convene a meeting much like that of a project financier to discuss not only the elimination of conflicting rules of participation where they exist, but to evaluate ways they can better facilitate the provision of services to consumers and their families. There should be an interagency, transgovernmental council on mental health financing that meets biannually. I believe this level of coordination and cooperation is a cornerstone of our success in achieving further progress in mental health. Let us then pull together toward this goal of financial cooperation and revision and enhancement of covenants of participation. Let us pull together in the halls of our federal Congress. Let us pull together in the offices of our federal bureaus and our statehouses and governors' offices and our foundations and other nongovernmental agencies and among ourselves in whatever role we play in this vital undertaking.

Financing Mental Health Services in the Future

Glenn Stanton
Center for Medicare and Medicaid Services

Medicaid is a very flexible program that supports services for persons who have mental illnesses. There are, however, 50-plus different Medicaid programs. So, if you have seen one Medicaid program, you have seen…one Medicaid program. Georgia actually developed this peer support program model. No other state in the country has done it. That does not mean it is not possible. It just means that each state drives its own Medicaid program.

Medicaid is unique in that it is a federal program in which federal dollars simply follow where the state wants to go. The state defines what is in the state plan. The state decides what the rates are within broad federal parameters. Many of the recommendations included in the report to the president are not solely federal recommendations but state and local issues as well.

But it is not only a federal, state, or a local issue. It is also a matter of public versus private financing. If we want the commission's recommendations to be implemented, there has got to be a dialogue with the purchasers. As you move forward with implementation, I encourage you to talk not only about the gap between science and service but from science to service and financing.

In the future:

- Financing will have to come from multiple sources.

- Financing will support evidence-based services.

- Financing will support the achievement of personal and private outcomes.

- The individual will direct health care purchasing more frequently.

One of the quotes from the report that I use frequently when I speak about this is: "To be effective and comprehensive, mental health care must rely on many sources of financing. Flexible, accountable financing that pays for treatment and services that work and result in recovery is an essential aspect of transforming mental health care in America."

Currently, 57 percent of mental health care in this country is funded in the public sector. Medicaid and the states pick up the largest portion of that tab. We estimate that the federal share of mental health care payments was approximately $32 million in 2000.

This morning I want to talk about financing strategies. And I am going to spend most of the time talking about those that can be done immediately. There are those that are midterm, and these include demonstration approaches for new financing mechanisms in service delivery approaches. And then there has to be fundamental long-term reform.

Immediate Financing Strategies.

Medicaid Eligibility Maintenance. One of the key issues around mental health treatment and support, particularly for persons with serious mental illnesses, is that many people have their Medicaid eligibility linked to their Social Security income (SSI). If that person goes into a public institution like an institute for mental disease, after a certain period of time – 30 days – they can lose their SSI eligibility. Therefore, many states have taken the approach that once you go into an institution, they discontinue your Medicaid eligibility. You do not need to do that.

There is a great deal of confusion surrounding eligibility maintenance. Therefore, one of the things we will be doing this year in technical assistance is a reminder to the state Medicaid agency that you do not need to revoke someone's Medicaid eligibility when they go into public institutions, particularly for short periods of time.

Medicaid Buy-in Provisions. In 1997, Congress granted the ability for people who returned to work to have a state option, or the state could create the ability for someone to buy into the Medicaid program. There are now 28 states in the country that have the Medicaid buy-in option and more than 50,000 people in the country who are participating. It is somewhat disappointing that some states that have implemented the Medicaid buy-in option have done it in a way that it either had a very slow take-up rate or it was developed in such a way to be fairly limited in its application. This is a tool that is out there, and it is going to take working with the states to try and take advantage of this particular option.

TEFRA Eligibility Option. Switching topics to a children's issue that was discussed by the commission in the report is the tragedy of child custody relinquishment. There is often a confusion that child custody relinquishment is a problem within the Medicaid program. In fact, people are relinquishing their custody to get access to public services that Medicaid provides. There is an option that only 18 states have taken advantage of called the TEFRA option. It is not as broad-based as what is probably needed across the country, but it is a limited option where kids

who need an institutional level of care can have their eligibility up to 300 percent of the federal poverty level. So families can in fact keep their kids at home and get access to Medicaid services.

Utilization of Existing Sources to Support Evidence-based and Emerging Practices. We are currently developing technical assistance to the states on how you can support evidence-based practices such as medication management, supported employment, and family psycho-education. Available options include managed care options in 1915(b) programs where states can use the savings they have accrued through a managed care approach to provide services that would not normally be covered with a state plan.

The basic parameters that Medicaid asks of any service are:

- It must be a medical service that is nonduplicative. Therefore, the service cannot replace the responsibility of another federal agency.

- The service must be provided to a Medicaid-eligible person.

- There has to be evidence of a free choice of qualified providers.

- The service has to be in an amount, duration, and scope sufficient to achieve its purpose.

- There has to be comparability of services across populations.

- There has to be a reimbursement methodology that is consistent with the economy, the efficiencies, and the quality of care.

Based on the above criteria, the question is whether Medicaid will pay for evidence-based practices? The answer is maybe. Here's a look at some of the issues for some practices:

- **Assertive community treatment** is a well-established model with more than 30 states conducting programs. At least 23 of these states are using the Medicaid program to fund it in some way. States took numerous approaches to obtaining funding. Some have obtained funding under the rehabilitation option, while others have combined other state plan options such as clinic services and targeted case management.

- **Medication management.** The description of the practice says that nonphysicians conduct some monitoring activities. Under Medicaid programs, we need to know who is doing that monitoring and whether or not that practice is within your own state practice act.

- **Family psycho-education.** We have to be sure the Medicaid beneficiary is the primary target for the intervention. The point at which family psycho-education treatment for a family member who is not Medicaid-eligible begins to become an issue. This is a big issue in children's services. For example, when does the treatment of the family unit become a substance abuse treatment for dad, who is not Medicaid eligible?

- **Supportive employment.** We do not pay for training, but we can pay for the supports around it.

- **Integrated treatment of co-occurring disorders.** This is a good example of where clinical practice and insuring coverage policy do not match very well. The practice of delivering treatment for multiple, co-occurring disorders in a single site is outside of the Medicaid parameter. So the coverage policy based on clinical practice is sometimes quite tricky to figure out.

Mid-term Financing Strategies.

Demonstrations in the President's 2004 Budget. There are a number of Medicaid demonstrations specifically referenced in the president's budget:

- The "money follows the person" initiative, where Medicaid would pay at 100 percent of the slots per person for one year as long as the state would pick up that cost on an ongoing basis in the subsequent years.

- Respite care for children and adults.

- Alternatives for residential treatment facilities for children.

- Maintaining independence within the work provisions, which we are trying to find a way to apply to the mental health population.

Demonstrations in the President's Commission Report. There are currently two proposed demonstrations. The first is a demonstration over five or 10 years that would look at building a community-based system for persons in institutes of mental disease where the money being spent can follow the individual. I am not sure exactly what model we will eventually try to develop and propose. But I do have to note that whatever the model or method, it has to be a true demonstration and not one that simply cost-shifts what is currently being spent by the state to the federal government.

There also is a demonstration proposed for self-directed supports and services. Hopefully we can find a way to give individuals with mental illnesses more control over the resources available. One example is looking at the rehabilitation option as an alternative to day treatment. For example, under a demonstration proposal, you could cost funds that otherwise could not be matched and take the money that Medicaid is currently spending on day treatment to allow individuals to self-direct their rehabilitation benefit.

Long-term Financing Options.

What is really going to be required for us to move the mental health agenda and the recommendations of the report is the way the financing is done. The commission had two strong recommendations here:

1. As part of the national debate and dialogue on Medicare/Medicaid reform, issues of importance to the mental health community must be incorporated. Within care reform, we need a distinction between acute medical care and long-term care. In the long-term care process, we need to get away from trying to medicalize the process so that if you want to, for example, develop a peer support model, you do not have to develop five layers of sign-off in order for it to occur.

2. Medicaid and Medicare, as well as private insurance programs, must address the delivery of mental health care. Medicare or Medicare and public funding cannot do it alone. Hopefully, as we have this continued dialogue, we can get to a place where we have agreements on the covenants of financial participation to support the service delivery system for people with mental illnesses.

Implications for Implementing the Final Report's Recommendations for Systems Transformation

A. Kathryn Power, M.Ed.
Center for Mental Health Services

The New Freedom Commission's final report presented us with the vision of a national mental health care system for adults with serious mental illnesses and children with emotional disturbances that is unified, consumer-driven, and focused on recovery. This is a beautiful vision embraced as a necessity by all of us here. Our challenge and the theme of this symposium are transforming this vision into reality.

The first step in the process is to understand what transformation means. We are engaged in transforming our capabilities to better conquer mental illnesses through increased treatment as well as strategic and tactical crusades for prevention. According to current research, transformation is a continuous process without end. It is meant to create or anticipate the future. Transformation is not accomplished through change on the margin, but instead through very profound changes in kind and in degree. These changes result in new behaviors and new competencies. Thus in transformation, we look at what we can do now that we were unable to do before. Transformation was meant to identify, to leverage, and even to create new underlying principles for the way things are done. Transformation is meant to identify and leverage new sources of power. Once the process of transformation begins, a profoundly different organization emerges, including changes in structure, culture, policy, and program.

> *Transformation was meant to identify, to leverage, and to even create new underlying principles for the way things are done.*

If we accept that transformation means profound changes in the form and function of our national mental health care system, then how do we effectively manage what amounts to major change at all levels of health care service? David Nadler, one of our nation's leading experts on organization change, wrote, "The truth is that change is inherently messy. It is always complicated. It invariably involves a massive array of sharply conflicting demands, and despite the best-laid plans, things never happen in exactly the right order. And, in fact, few things turn out exactly right the first time around." Most importantly, the reality of change in the organizational trenches defies rigid academic models as well as superficial management fads. Why? Because change in real organizations is intensely personal and enormously political.

This is a realistic overview of systems transformation. It will help us navigate the rough water ahead if we can accept that change will take time, we will have false starts, and it will require massive amounts of collaboration and occasional relinquishment of traditional philosophies and turf.

This brings me back to my original question about how can we effectively manage transformation. I think we should approach it in the same way we approach other advances in health care – by looking to research, by examining what practice has proven effective.

There are several examples of effective transformations within large systems that can help guide us at the federal, state, and local levels through the necessary changes ahead. I am going to focus on one particular example: David Lawrence, former CEO of the Kaiser Permanente Healthcare System, recently led Kaiser Permanente through systems transformation that is relevant to our challenge. Kaiser Permanente is a loosely governed collection of autonomous, local health care programs allied with local medical groups. Its mission is to deliver high-quality, affordable health care to its members and communities through innovative delivery systems. It also is heavily involved in research, particularly in studying the outcomes of treatment among different populations. It traditionally has had a highly politicized management culture with decision-making

rooted in consensus rather than control. This is all very similar to the framework of our national mental health care system.

In the early 1990s, Kaiser Permanente was forced by external economic forces to undergo system transformation as a condition of survival, and this transformation is still ongoing. Lawrence looked back on the years of change management to compile 10 lessons from the battlefront. I am going to discuss these observations in terms of what the states, the federal government, local authorities, and all the constituency groups can do to change and manage the change within their mental health care systems.

Lesson one: *Do not expect people to embrace easily the need for change.* We all acknowledge that a very serious impediment to change is that people will resist doing things differently until they personally come to accept that radical change is needed. Lawrence was not able to build this sense of readiness until after he came up with the data that forced the people involved to recognize, accept, and own the problems and solutions. The lesson he learned was that readiness comes through a process of education and personal insight.

I think some of the research we have seen at this symposium has helped build that insight. For states, this means coming up with hard and fast facts about consumer needs, about service provider capabilities and capacities, and the gaps between the two. States can use this information to energize the public as well as the health care community and to argue for the additional resources needed to support the most pressing prevention or treatment needs.

Lesson two: *Sometimes it is better to experiment than to plan.* Traditionally, Kaiser Permanente had been a risk-averse organization. We can say the same thing about the federal and state governments, which are extremely reluctant to invoke public criticism. Lawrence came to the realization that systems transformation demands that organizations become more willing to take risks, to fail, and to learn from their mistakes. States, as well as the federal government, need to take risks in developing new delivery systems and then in forming new collaborations with the tools at hand.

One way that SAMHSA intends to encourage a culture of innovation at the state level is by restructuring its mental health block grants into performance partnership grants. Under this proposed structure, states will have greater flexibility in administering our block grant programs. In return, however, we will be asking for greater accountability in the progress being made by states in serving the mental health consumers. States will respond annually to a common set of mental health performance measures already agreed to by SAMHSA and states. The new commission advocated this approach under goal two when it called for providing incentives to the states by granting increased flexibility in exchange for greater accountability and improved outcomes.

Lesson three: *Pay close attention to the timing of change.* In retrospect, Kaiser Permanente admits that its leadership frequently mistimed the pace of change because it was dealing with very difficult issues both internally and externally. "The unavoidable fact," said Lawrence, "is that in health care, it takes a long time to figure out what to do and how to do it well." Change requires very careful pacing, which he defined as "moving simultaneously in a variety of areas and keeping each area progressing so that the combined cadence does not tear the organization apart."

Pacing mental health care transformation will require states to establish priorities for service changes. They will need to do so in careful collaboration with all of the stakeholders involved so there is broad-based acceptance and support for which issues need to be addressed first.

Lesson four: *When the need to remove people becomes clear, do not put off the inevitable.* Lawrence notes that not all people adapt well to change. Some are not going to mesh well with the new structures, processes, or cultures. States may need to replace people in senior decision-making positions with those less wedded to traditional methods, services, and practices. It may be necessary for states to abandon alliances that impede progress and forge different partnerships to support the change process itself.

Lesson five: *You cannot succeed without a senior team that thinks and acts like a team.* Within the Substance Abuse and Mental Health Services

Administration, we have a strong leader in administrator Charles Curie. He sets our direction and gives us a framework for action through the SAMHSA priority matrix. He has pulled together an executive team that unites all three centers within SAMHSA as a single responsive organization. In addition, I chair an action agenda work group. This team, along with other important partners, is going to make recommendations about ensuring that the federal government implements the goals and recommendations of the New Freedom Commission. We also are looking at public-private partnerships that can help shape the new paradigm of organization and services support for consumers in need of mental heath services. The goal of these partnerships will be to ensure that consumers will be able to access the care they need through any door in any system.

States need to create their own action teams to guide systems transformation. Like the SAMHSA team, it needs to contain representatives from different areas that have a key stake in mental health care outcomes, including children's services and a variety of other areas. Individuals with serious mental illnesses need more than treatment. They need employment, education, and housing. In other words, they need support systems that often are not recognized as part of the mental health treatment system. Although there is currently some relationship between the mental health system and these agencies, the New Freedom Commission report is emphasizing the need for us to intensify those relationships so everyone works more closely together. Engaging all key stakeholders and planning a change process will help ensure that they recognize, accept, and own the problems and devise the solutions together.

Lesson six: *Enlist your board of directors as active partners in change.* Lawrence discovered an ally in systems transformation in Kaiser Permanente's board of directors. He exposed the board to major issues and to developments and trends within the health care field. He shifted their focus from operational details to strategic issues. In so doing, he created a knowledgeable and aggressive partner for change.

The board of directors for the federal government is the Congress, just as the board of directors for the states is the state legislature.

Engaging the legislature is critical to the change process and must be at the forefront of planned efforts. In addition, legislation authorizing community mental health block grants mandates that states establish a mental health planning council that will review and make recommendations concerning state mental health plans. In many respects, this planning council can act as a board of directors for the state's behavioral health care authority. Its members represent your shareholders. You can plan a critical role in identifying and promoting action within priority health areas. Expanding and involving your council at the state level as a sounding board and a crucial source of information and support on very difficult decisions is most appropriate.

Lesson seven: *Give coherence to the change process by clearly articulating a central mission and a consistent set of themes.* David Lawrence used to think that "vision" was just an empty term. Experience taught him very differently. In the health care system, each locality and each constituency had traditionally set its own agenda, pursued its own set of interests, and developed its own themes. States need to eliminate this fragmentation of purpose by creating a comprehensive state transformation agenda built around goals and objectives tied to a common mission with the consumers at the heart. The mission should epitomize the ultimate goal, leading to broad-based discussions on how to achieve it.

One case history about system transformation describes a rather vivid statement projected by the CEO of a different health care system. She wanted to drive her organization toward a focus on wellness, prevention, and delivery of patient care and away from institutional settings. Her vision statement was: "We will be successful when I can walk down the halls of the hospital and there are no patients."

We will be successful when we have a system grounded in recovery, one that reflects a belief in recovery, demonstrates a commitment to providing recovery-based services, and, through its actions, inspires in consumers and their families the hopefulness of recovery.

Lesson eight: *Even though the content of change may be radical, the building process must be methodical.* Lawrence admits that one of his organization's initial mistakes was to set out to do everything at once and to do it well. It did not

work. The primary reason it did not work was because he had failed to assess his organization's capacities. Most theories of change do not sufficiently emphasize an initial analysis of an organization's capacity. Where is the organization in relation to where it has to go? Which capacities must be added or enhanced before the organization can get there? How should each building block be put into place and in what sequence?

The answers to those questions about how you can, in fact, make an assessment of your organization's capacities should be the foundation of a comprehensive state plan called for in the New Freedom Commission report. In addition, those plans should reflect accountability through performance measures. Kaiser Permanente is a nonprofit organization, so it could not use profit as a performance measure. However, Kaiser eventually was able to create a plan that instituted performance measures tied to specific outcomes. It linked detailed objectives to growth, cost, quality, and customer satisfaction. Neither the federal government nor the states differ from Kaiser in the need to incorporate each and every one of these factors in their comprehensive mental health transformation.

SAMHSA is looking at ways it can help the states develop more comprehensive plans. We are in the process of developing mental health state infrastructure grants, or SIGs, to support states in this effort. As proposed, SIG resources would become available, hopefully, in fiscal year 2004.

Lesson nine: *Think of change as a fluid and dynamic campaign that must be waged simultaneously on a variety of fronts.* It is vitally important to see change in terms of a campaign. It is not only the content and planning that are important. It also is how a corporation goes about winning people over. As Lawrence noted, an organization has to use a range of tactics, all aimed at winning very broad support for a common vision. It is important to embrace the concepts of branding, social marketing, and public relations as it relates to this campaign.

States need to build their own mental health coalitions within their local and neighborhood communities. They need to engage participation and support among all key stakeholders, including those who may not be considered to have an equal stake in achieving a mental health vision. These stakeholders, of course, will include

criminal justice, education, faith-based organizations, businesses, and community leaders. Systems transformation cannot be achieved at any level without recruiting a lot more foot soldiers to fight at the front lines.

Lesson 10: *This race may not have a finish line, so keep looking for a reason to stop and celebrate along the way.* I do not think changing a mental health care system has a finish line. It must continue to evolve as we learn from the research, as we move science to service, and as we respond to the changing needs of the consumers we serve. However, we still need to find reasons to celebrate progress along the way. I think this is an important item not just for mental health providers and for mental health consumers who might get discouraged by the pace of change, but it is important for others as well. The more often we can trumpet success in treating mental illnesses, the more apparent it will become to legislatures and to the general public that mental illnesses are just that: illnesses that can be cured, treated successfully, or at least mitigated. Most importantly, this lesson reinforces the hopefulness in recovery that people currently living with mental illnesses and their families need to hear. It helps create more positive messages that in themselves will build greater momentum.

> *We need to embrace the idea that problems are opportunities dressed up in work clothes.*

The mental health care system is not a single, isolated corporation. It does not have a profit-making bottom line. It does have, however, customers who count their cost in terms of human misery, and it does take real resources to deliver quality care. Changing the current mental health care system will lower their cost, and then we as a collective nation will profit from increased human joy, less suffering and sorrow, and general improvements in social well-being.

We need to embrace the idea that problems are opportunities dressed up in work clothes. Many of the problems that the New Freedom Commission identified exist because the solutions are either not evident or they are not easy to accomplish. Some, such as the stigma that prevents persons from seeking the mental health treatment they need, are rooted in age-old ignorance and fueled by myths and fears. Others, such as the fragmentation of services among federal and state agencies, stem from the gradual and well-meaning evolution of services that followed upon new advances in science and new financing mechanisms.

Our search for solutions to these problems offers us incredible opportunities for innovation, collaboration, and success in improving mental health care across the nation. I am very privileged and very excited to be a part of this great crusade to alter forever and continuously our mental health care system so that it reflects the key promise of recovery for each and every American.

Building Coalitions for Better Outcomes in Mental Health

Mark L. Rosenberg, M.D., M.P.P
Margaret McIntyre, M.B.A

Task Force for Child Survival and Development

There are many challenges to implementing the report of the New Freedom Commission on Mental Health. The first challenge is the gap between known science and practice – between what we know and what we actually do. Mental health care delivery must change, not only to close that gap, but also to close the gaps between what we used to do and what we are doing now and between what we are doing now and what we should be doing in the future.

Because mental health deals with challenges that are very complex, it cannot be addressed in isolation. Overcoming the challenges requires

that we work very closely not only with the professionals who deliver this care but also with the consumers, the purchasers, and the other providers. All these stakeholders have to be at the table. Many different talents must come together from many different areas – from investment banking to psychiatry to nursing, from the scientists to the practitioners. We have to work together if we're going to be successful.

One important lesson we have learned in public health is that an independent task force that can take on the role of a neutral convener can play an important role in bringing about effective collaboration. Good collaboration does not happen by itself. It is a team process bringing together people from different disciplines to share their perspectives and to provide the creativity needed to overcome the many challenges that inevitably arise. This requires leadership and strong facilitation. When a coalition works, what can be achieved can far exceed anyone's expectations.

Bringing together the right people also enhances learning. Because we are working in a world that is consistently changing, successful

coalitions require continuous learning. We must be diligent to find ways to improve mental health practices.

The first coalition that the Task Force for Child Survival and Development created involved former President Jimmy Carter. When he left the presidency, he and Bill Foege, the first executive director of The Carter Center, started looking at the gap in childhood immunizations between the developed and developing world. Eighty percent of children in the developed world were immunized against the common childhood diseases. But in developing countries, the rate was less than 20 percent. If this gap could be closed, the lives of 3,000 children could be saved every single day. So, the visionaries who saw the possibilities went to the organizations that were involved – UNICEF and the World Health Organization – and asked how to begin work on closing the gap.

Initially, they were met with resistance. The people at UNICEF and WHO said they raised $35 million a year for immunizations and that was as good as it could get. Bill Foege looked at this and realized that these organizations were

not collaborating; they were competing. Instead, Bill asked, what if we all worked together to raise more funds and close that gap? The organizations agreed to come together, and with leadership

Successful coalitions require continuous learning.

support from the very top of these organizations, they built a coalition that included UNICEF, WHO, the World Bank, the Rockefeller Foundation, and the United Nations Development Programme, forming the Task Force for Child Survival. In the first year, they raised $100 million. The second year, they raised $200 million. By the sixth year, they had raised more than a billion dollars, and the immunization levels of children around the world were at 80 percent. We learned that a clear vision and commitment from top leadership are critical to be able to shift potential partners from a competitive position to collaboration and cooperation.

The task force also launched the Mectizan® Donation Program, another program in which The Carter Center played a very important role. Merck developed a drug to prevent heartworm in pets but found that this drug also could get rid of a blight in Africa, a parasitic disease called river blindness. This disease infects people through the bite of a black fly that lives on rapidly flowing rivers. If a person is infected, the parasite multiplies in the blood and over years creates an intense inflammatory reaction in the eye that leads to blindness. In many parts of Western Africa, all the old men were blind from river blindness, and the young boys could not go to school because they had to lead the old men around. Old, in this case, meant over 40.

Merck came to the task force and asked for help in distributing this drug. A lot of people said not to get involved because joining forces with a pharmaceutical company would be like working with one's opposition. But the coalition said "yes," and last year the Mectizan Donation Program celebrated the 15th anniversary of this coalition. It now has treated more than 250 million people in Africa. The young boys are going to school, and the old men are able to farm. We learned from this project that a trusted neutral convener can bridge the gap between suspicious partners, especially when you have different perspectives like those of pharmaceutical manufacturers and public health organizations.

We have had a number of other coalitions that have been very effective and have provided us with valuable lessons. In suicide prevention, for example, we learned that a coalition is an effective way to develop and implement a national strategy. In fact, the President's New Freedom Commission on Mental Health recommends forming a national-level private-public partnership to advance the goals and objectives of the national strategy for suicide prevention. And this private-public partnership would emphasize building voluntary coalitions to address suicide prevention in communities and would include local leaders, businesses, school personnel,

and representatives of the faith community. The main purpose of collaboration is to do something together that is not possible when we work independently.

Coalition building is not easy. Collaboration is fundamentally about the quality of relationships, and we think of a coalition like a marriage – it is easy to get into a marriage, but it is difficult to make it work. Coalitions are much the same, especially when bringing people together from different sectors with different needs, desires, outcomes, and organizations. Building successful coalitions takes energy. It needs more management attention than our individual organizations. But so frequently, we give coalitions even less management attention than we give our individual organizations.

There are four areas a coalition leader should focus on to build successful partnerships:

Strategy. Setting strategy builds a clear value proposition for the coalition as well as for each member. The strategy also should define specific, agreed-upon objectives so that the members understand their common purpose. A coalition must stay focused in scope so that the task is manageable.

Social Capital. This is the glue that holds a coalition together: the social connections and relationships among the members. Developing the ability to resolve the conflicts that will inevitably arise within the coalition is often overlooked in starting a coalition. It is important to foster trust and open communication and effectively manage conflicts and disputes.

Structure. It is important to establish the coalition's structure and how it will be managed so that the roles of each organization are clear. It also is important to have a plan addressing how the coalition itself will be funded. Without these two components in place, it is difficult to sustain the coalition for any length of time. It also is critical to pick the right number and mix of coalition members to maximize the coalition's effectiveness. If there are just a few people in the coalition, it is fairly easy to make decisions and coordinate. But if the number is too few, we risk excluding key constituencies that can obstruct what we want to do and create a barrier.

Management. The coalition must have accountable leadership and effective resource management. It also must have a clear operating plan and measurement of outcomes.

In addition to the four areas just mentioned, another important way to think about a coalition is its life cycle. Activities vary depending on the stage of development of the coalition. The phases and core activities in each include

- **Preformation.** An initial scoping of the issues and needs must occur. Activities include establishing what the coalition will address and identifying the critical players who should come together.

- **Formation.** Once the partners have been selected, the coalition will formalize a project plan, rules, roles, and procedures.

- **Implementation.** In this phase, the coalition begins taking action based on priorities and implements the project plan.

- **Maintenance.** During this time, the coalition reflects on the health of the coalition.

- **Completion phase.** At the completion of the project, the coalition can reflect on lessons learned and evaluate the results of project efforts.

Effective collaboration is like the art of psychotherapy. They both depend on skills in analyzing and developing relationships. These skills cannot be transferred in a brief lecture, through a book, or by reading a handout. They must be built over time and integrated into a practice. In addition, to build these skills, we need other people to help us overcome our own blind spots, so it often is useful to have an adviser – like a supervisor in psychotherapy – to help with the process.

In conclusion, the mental health community stands at a great spot today, a spot where it has the chance to use this commission report as a platform for important improvements in mental health care. And to implement that platform, effective partnerships and coalitions will be critical elements for making progress.

Questions & Answers

Q I am troubled by the absence of the concept of cultural sensitivity in the talks. How are we going to deal with people who are likely to fall through the cracks because of cultural differences and gaps?

A Dr. Knight-Richardson: I was chairman of the Cultural Competence subcommittee. We made recommendations and considerations to the other subcommittees to consider the aspects of culture and ethnicity. We understand that we have not done enough in this country. We understand that people of color and minority ethnic groups truly are not serviced as well as they might be. We have made recommendations in order to come to some solutions in that regard.

I think the solution, however, will not be just the recommendations of the committee. We have a problem with racism in this country, not just in mental health. So this issue needs to be embraced in our hospitals, teaching institutions, and social organizations across this country. Until we address the problem of racism, we will not effectively address the problem within mental health.

A Kathryn Power: We are looking at how to get a mental health work force that is not only interested and engaged in mental health care but that reflects the consumers that we serve. CMHS just hosted an African-American summit in Washington, which was the first time that we had African-Americans come in as a group to talk about specialized needs and the approaches we need to consider. I think we need to do this across all ethnic groups. We need to concentrate on what the cultures are and how we adapt that in our mental health care systems. Furthermore, we need to try to develop the work force of the future.

Charge to the Work Groups

Five themes appear throughout the final report of the President's New Freedom Commission on Mental Health: recovery, integration of mental health and physical health, fragmentation, science to services, and stigma. Identify action items to address the challenges and opportunities for all five themes.

Postscript

Thomas Bornemann, Ed.D.
Lei Ellingson, M.P.P.
The Carter Center Mental Health Program

The President's New Freedom Commission on Mental Health was chartered to address the problems in the current mental health service delivery system. It comes 25 years after The Carter Commission on Mental Health. Both were formed to assess the condition of the public mental health system and to address the needs of people who have mental illnesses. This comprehensive review brought to light many problems facing our nation, including the availability and quality of services for people with mental illnesses, as well as the lack of funding for mental health services. The findings were troubling, but a thorough appraisal was much needed. The report's findings and recommendations are useful for guiding the future of the public mental health system.

The Carter Center Mental Health Program was pleased to focus on the report for the Nineteenth Annual Rosalynn Carter Symposium on Mental Health Policy. It is extremely important that the entire mental health community take action on these findings. Speakers and panelists reviewed the advances that have been made in research, described ways of translating this knowledge into practice, and discussed possible policy changes to facilitate system reform. After hearing from the experts in their respective fields, the participants of the symposium broke into work groups to identify and address the challenges and opportunities that lay ahead. The symposium concluded with participants offering ideas for building the necessary elements to promote action. The President's New Freedom Commission on Mental Health and its report offer a platform, but the biggest challenges lie ahead. The hard work is just beginning, as we start to examine the ways in which we can act upon these identified problem areas.

Five themes run throughout the final report of the President's New Freedom Commission on Mental Health: *recovery, integration of mental health and physical health, fragmentation, translating science to services, and stigma.* By focusing on these central areas, it is more manageable to tackle the challenge of finally providing people with mental illnesses the treatment services they deserve.

The concept of **recovery** has been one of the most promising developments in mental health. As Rosalynn Carter observed during a meeting with the commissioners in February 2003, "We have made enormous strides in the science and research of the brain, as well as of treatment services that promote recovery." All of this was unimaginable years ago. But we still have room for further successes, and recovery could benefit from the following action steps suggested by the working groups:

- **Define recovery**: A clear definition of recovery is needed to communicate and act on the vision of recovery or set an action plan for systemic change. Defining recovery as the ability for a person to function in their interpersonal relationships and on the job and enjoy their life, instead of debating whether or not the illness is completely eradicated, is essential and may require new research or the better use of existing research and data to establish standards and to integrate these standards into indicators.

- **Redefine the funding system to support recovery**: Currently, recovery and billing systems are mismatched. Recovery measures must be established and linked to financing to provide an incentive for people to make recovery and resilience part of the system. This can be achieved by working with purchasers to develop more flexibility for preapproval processes that will support the continuum of care required for recovery or by showcasing the cost-effectiveness of aligning funding with an emphasis on recovery.

- **Empower the consumer and family movement and peer support**: Peer support is a model recovery strategy for consumers that can help reduce the cost of recovery care. Recovered members can be an alternative, empowering, and less expensive source of employment in the mental health system.

- **Increase public awareness:** The notion of recovery is still not well-known or understood within the mental health system and throughout the community. In order to change decision-making, policies, and build coalitions based on common vision and a common theme, a shift must occur in how our culture views these problems. The change should begin by featuring faces of recovery. In addition, to increase

understanding and support of mental health, education can be directed at communities by: reaching out to community leaders, developing a speaker's bureau to move out into the communities, forming coalitions to campaign for mental health issues, and involving the state mental health authority for support. To help raise public awareness, useful action steps would be to better use electronic communications, create a national recovery symbol such as the AIDS red ribbon, and make sure we do not forget about minorities and ethnic groups when addressing audiences.

- **Reach out to professionals, facilities, and institutions outside the traditional mental health system**: Without understanding that recovery is an option, underserved populations may not present themselves to the mental health system. Therefore, it is important to not only involve the primary health care system but also reach out to the general public, such as community organizations and schools, with the message of recovery.

- **Transform education and training for mental health professionals**: Current training and academic education has not kept up to date with the notion of recovery

and resilience. To ameliorate this situation, we must develop curricula based around recovery in academic settings and include recovery processes in the standards of accreditation as well as implement continuing education requirements. Successful education and training programs can be used as models. To support these additional programs, funding sources must be developed.

- **Build the science supporting recovery**: Especially important in the achievement of support and funding is the availability of real evidence that recovery works and is possible. We must become aware of existing research and use it to drive standards and processes for recovery. The addiction field can be used as a successful model.

- **View this as a cultural transformation**: Learn from other cultural transformations like the feminist movement that the vision of recovery involves a profound change in the language we use. We must abandon the language of the permanency of mental illnesses while developing a new language that is more pro-recovery.

- **Garner community involvement for effective recovery**: Recovery goes beyond the mental health system to deliver opportunities required for people who want to recover, such as employment and housing. Relationships must be garnered in the business community to supply initial jobs for newly recovered consumers.

The **integration of mental health and physical health** is a crucial next step in the fight to overcome the obstacles that people with mental illnesses encounter every day. To ensure adequate mental health care, the following action steps are recommended:

- **Integration must be tied to funding**: Integrative health care must be tied to an ongoing system of funding to be sustainable. Without that, progress beyond model programs and research projects will not be achieved. Another possibility for receiving necessary funding is to work with Medicaid and other payers to support the creation of teams, both mental and physical health care and social services, around patients. Strategies for people who are uninsured

should also be taken into consideration. Further, primary care physicians will not attend to mental health issues if they are not fairly reimbursed for their effort.

- **CDC survey should include mental health**: Mental illnesses should be tracked and treated like other illnesses by the CDC so that the mental health field can benefit from their epidemiological expertise.

- **Educate all stakeholders that mental illnesses are real, how they can recognize and address mental health problems, and what services are available**: Generalists such as family physicians, primary care physicians, and nurse practitioners must be educated on how to recognize mental illnesses in their settings. These professionals are most often the first contact for people with mental illnesses, and they must be accurately aware of mental health problems and provided with tools for effective treatments. In the same manner, outreach to nonmedical settings, such as schools, the justice system, faith-based organizations, and community organizations, with awareness campaigns is needed.

- **Develop coalitions for common co-occurring illnesses**: Coalitions and alliances between the mental health system and organizations that deal with other illnesses that have a high co-occurrence with mental illnesses, such as Alzheimer's, diabetes, and epilepsy, can help drive greater integration of physical and mental health.

- **Provide education and training:** In addition to training our primary care practitioners, especially pediatricians, to identify mental health disorders and make appropriate referrals, we must encourage medical school curricula to include more cross-disciplinary training. Partnering with medical associations could aid in educating and disseminating critical mental health information.

- **Learn from other health care models**: Models already have been implemented that showcase effective delivery of multidisciplinary care. A helpful example would be chronic disease, social work, and hospice work models that place the patient or

consumer at the center of treatment and ensure that resources are mobilized to address the full needs of the patient.

- **Bridge the differences between the mental and physical health communities**: The cultures of mental and physical health communities differ, which contributes to the difficulty of integration. However, by addressing the differences in the language use (such as "patient" with HIV as opposed to a "consumer" with depression) and the variation in practice models (40-minute sessions as opposed to six-minute office visits), a necessary common ground can be built between the two fields.

Fragmentation has long been an enormous barrier to progress in the mental health field. Integration is not only necessary within the mental health community itself but also with the physical and public health fields. To facilitate this process, the following actions are suggested:

- **Develop state strategic plans to reduce fragmentation**: A first step should be involving the National Governors' Association or similar representative organizations to coordinate all the various stakeholders so that care can be centered around individuals instead of in fragmented silos. The push must be made from the bottom up as well as the top down. Another possible plan is to have statewide conferences and summit meetings that include the governor, legislators, health professionals, community organizers, and consumers focusing on reducing fragmentation.

- **Develop better funding streams that cross agencies**: Because funding issues are driving competition and acting as one of the key barriers to eliminating fragmentation, we must join a unified vision that includes a transformational approach (as opposed to an incremental approach) and a financial model that showcases the costs of fragmentation vs. the costs of collaborative care as a basis for advocacy.

- **Identify areas of fragmentation**: Areas of focus include fragmentation that occurs in prevention, across the life span (from child through old age), across mental disorders, and in hospitals (where different departments

work independently of each other instead of coordinating care for the patient). Fragmentation is especially evident among the federal, state, and local levels of agencies and includes restrictive legislative language that exacerbates fragmentation.

- **Learn best practices**: Sharing information, including the best practices on successful programs, can be achieved by using communications technology (such as the Internet) and learning from outside the mental health community.

- **Drive information out to the local level:** Providers in the field must understand changes in funding as well as the opportunities and flexibility of services accessible to the community, such as possible Medicaid waivers that may be available.

- **Create a federal advisory team**: Developing a diverse team responsible for advising and aiding states in the development of their strategic plans is important. This group could serve to brainstorm creative ways to use state and federal funding across barriers and fragmentation to develop a more cohesive solution. Similarly, a model state Medicaid plan could be initiated by creating collaborations between Medicaid and mental health directors to brainstorm a plan that states can use to develop their own strategic plans.

The idea of **translating science to service** is another important theme that needs improvement. Currently, the gap between the level of scientific knowledge and implementation is 15 to 20 years. This gap must be shortened in order for policy practices to match the knowledge gained from research. To help mental health services reach their potential, the following action steps are recommended:

- **Translate science into service**: It is crucial to have people with the skills to work with front-line organizations translating scientific research into something they can put into practice. It is important to integrate research from multiple areas to address community and individual needs as well as to explore and report the social relevance of research findings instead of just the research results. Encouraging federal efforts, such as collaborations between SAMHSA and NIMH and

their respective initiatives of "Center for Mental Health Services Moving Science to Services" and "Bridging Science and Service," represents concrete progress and needs full funding and support.

- **Communicate between and among various stakeholders**: Information must be shared, not only from science to service but from service to science. Consumers, families, and other stakeholders must be involved. This process could be aided by having scientists, trainers/educators, and program designers/developers work in the same setting so there are opportunities for collaboration and closer interactions. Similarly, organizing dialogues among people who are doing research, providers, and consumers could assist in mutual learning from each other. Lastly, the Internet is a valuable tool for information, knowledge, and experience sharing.

- **Develop strategies to produce new knowledge**: All types of research, not only randomized clinical trials but also mixed methods that would include the life stories

and experiences of mental health consumers, need to be explored. Possible avenues toward achieving this task of driving science to services include: funding multiple ways of obtaining knowledge, which would speed up time to service and increase the social relevance of findings; advocating for multisystemic change in how research is funded through NIMH and SAMHSA grants, state agencies, and research centers; and broadening the scope of research to include sociological, psychosocial, social-environmental, and sociopolitical factors that can affect mental health (e.g., poverty and racism).

- **Build a research agenda:** Researchers and stakeholders much join together for discussion and the building of a research agenda that supports recovery. Possible actions to be taken could include implementing change management strategies and programs into scientific organizations to include the idea of recovery in research models.

- **Develop a clearinghouse for information**: Research information must be easily disseminated in a form and style accessible to front-line providers and organizations. Hence, it is important to simplify the ability for field personnel to gain research information and to present the information in a manner relevant to the field.

Reducing the stigma of mental illnesses has gained much attention in the past years, but unfortunately **stigma** remains a great barrier in the mental health field. Continued work is necessary to overcome this barrier. For that reason, the following actions are suggested:

- **Showcase positive portrayals of people with mental illnesses**: It would be advantageous to utilize the media and public programming in order to put positive portrayals of mentally ill people before the public.

- **Link to recovery**: Research from Australia indicates that permanency of mental illnesses increases stigma, while the optimism of recovery reduces it. Thus, we should advocate for the rights of people in recovery from mental illnesses to reduce prejudice and bias in insurance, housing, and occupational opportunities.

- **Understand the social aspects of stigmatizing mental health issues**: Basing our policy on European social policy, which is built around the concept of social inclusion of populations previously excluded, we could reduce the process of stigma. Developing outreach programs to marginalized populations also will help.

- **Normalize care for mental health**: The lack of parity in insurance promotes the idea that people with mental illnesses are less worthy of care than those with other illnesses. By normalizing the care we provide, we will normalize the attitudes and consequently reduce the stigma that follows mental illnesses.

- **Develop a social marketing strategy**: An effective strategy would guide widespread public education efforts by ensuring that anti-stigma campaigns are positively promoting recovery and not actually reinforcing the negative stereotypes they are trying to combat. Also important is championing the idea that mental illnesses are part of the human experience.

- **Combat ignorance**: In order to combat the stigma of mental illnesses, strong action and evidence must be supplied to the public and

policy-makers. This includes using science to dispel the myths of mental illnesses, insisting on using proper language and terms when discussing mental illnesses, and being proactive in correcting misinformation and misuses of terminology.

- **Learn best practices from examples of overcoming stigma**: Plans of action can be based on past examples of how other diseases, such as cancer and AIDS, overcame stigma.

Following the work groups, an open discussion was held, moderated by Bill Emmet, the project director for the National Association of State Mental Health Program Directors (NASMHPD). Emmet is the current campaign coordinator and a driving force behind the Campaign for Mental Health Reform, which has been organized as the mental health community's united voice on federal policy. It is a unique organization, with its unprecedented collaboration of national mental health organizations, in the fight for access, recovery, coherence, and quality in mental health services. The campaign's partners have been brought together by a common recognition that the current challenges and environment present an unavoidable need, as well as the best opportunity in a generation to make a well-functioning mental health system a national priority.

With the goal of the Campaign for Mental Health Reform in mind, members of the general discussion expanded on the action steps developed through collaboration in the work groups. The following ideas are a sampling of the suggestions made:

- Examine the social context of mental health care. For example, we know that unemployment is the major marker for demand for mental health services. It is important to talk about and recognize that the focus must be on efforts that will lower unemployment.

- Examine the major campaign currently being launched in Europe to address the problem of what is termed "social exclusion." This is a process by which community regeneration, health promotion, health services, and mental health services are packaged together in an effort to help people who are struggling with various illnesses or problems, as well as trying to prevent those circumstances.

- A significant part of this transformation process will be retraining providers early on with the idea that mental illnesses touch the lives of virtually everybody. This message has to be expressed and reinforced continuously, for as a society, there needs to be a firm and consistent voice for change.

The President's New Freedom Commission on Mental Health has focused the spotlight on significant problems within the public mental health system but also identified six goal areas as the foundation for transforming mental health care in America. The commission further offered specific recommendations for achieving these goals. We are aware of the condition in which we find our public mental health system, specifically regarding the five main themes of the report: *recovery, integration of mental health and physical health, fragmentation, translating science to services,* and *stigma*. The findings were troubling, but the work groups and open discussion from the symposium have offered ideas to change the outlook for the public mental health system. This is an exciting time, for it is now our turn for action. We must take these suggestions and execute them and keep going until significant changes are achieved in the mental health system.

Closing Remarks

Rosalynn Carter

Chair, The Carter Center Mental Health Task Force

It has been 25 years since the previous, and first, presidential commission on mental health, which was held during Jimmy's administration. While I am gratified to help roll out the final report for the President's New Freedom Commission, it would have been preferable if additional commissions had been formed during the last quarter century. Mental health is an issue affecting all Americans and certainly is worthy of national attention from the highest office in the land.

The findings contained in the commission's final report illustrate how terrible the situation has become. The interim report declared the public mental health system is in shambles. The final report asserts that the system cannot be mended. Reforms around the edges are no longer enough to ensure that people with mental illnesses and their families get the treatment services they deserve. Instead, it says that the entire system must be transformed.

Unfortunately, presidential commissions do not carry with them the means for implementing their recommendations. It is overwhelmingly the responsibility of the larger community to ensure that the issues identified stay in the forefront of policy-makers' and the general public's minds. It is up to all of us in the mental health community to take the recommendations from the final report of the New Freedom Commission and make sure that they are not forgotten, but are acted on and integrated into our organizations' activities. Government at all levels will be charged with the mechanics of the transformation. Our responsibility is to help them where we can and to take the recommendations even further than they are able.

Today we have explored how we as individuals and as part of our organizations can contribute to this effort. Our challenge is for each organization represented here today to implement at least one of the recommendations from the New Freedom Commission's final report. The Carter Center Mental Health Program will follow up to track your progress.

The President's New Freedom Commission report on mental health presents us with a huge opportunity to reform a woefully inadequate system of care. As individual organizations, we can determine what works and what does not and positively impact our communities. Working together under the commission's sphere of influence, we can create broad reforms and improve the quality of care for all Americans with mental illnesses for generations to come.

Rosalynn Carter

Biographies

Rodolfo Arredondo Jr., Ed.D.

Dr. Arredondo is professor of neuropsychiatry at Texas Tech University Health Sciences with a secondary appointment to the Department of Health Organization Management. He is the director of the Southwest Institute for Addictive Diseases. Dr. Arredondo is a licensed professional counselor and a licensed marriage and family therapist. He served on the President's New Freedom Commission on Mental Health. Dr. Arredondo is an appointee of Secretary Tommy Thompson to the National Advisory Council for the National Institute on Drug Abuse. He is a gubernatorial appointee to the Texas Department of Mental Health and Mental Retardation where he currently serves as chairman of the board. Dr. Arredondo also serves as a consultant to the Texas Medical Association Committee on Physician Health and Rehabilitation and is appointed to the American Cancer Society, Texas Region, Tobacco Control and Governmental Affairs committees.

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

Tom Bryant, trained as both physician and attorney at Emory University, chairs the organizational management firm he founded, Non Profit Management Associates Inc., in addition to conducting a part-time, health-related law practice. He is also the chairman of the Aspirin Foundation of America Inc. Dr. Bryant began his career in Washington at the end of the Johnson administration when he directed the Emergency Food and Medical Services Program of the Office of Economic Opportunity and continued as the director of the Office of Health Affairs of the OEO, directing programs designed to improve the health of poor Americans. In 1977, he was named by President Carter as chairman and executive director of the President's Commission on Mental Health, where he began a long association with Rosalynn Carter, which continues to this day as a member of both The Carter Center Mental Health Task Force and the Rosalynn Carter Institute for Human Development at Georgia Southwestern College in Americus, Ga.

Barbara J. Burns, Ph.D.

Dr. Barbara Burns is professor of medical psychology and director of the Services Effectiveness Research Program in the department of psychiatry and behavioral sciences at the Duke University School of Medicine. She also holds academic appointments at the University of North Carolina at Chapel Hill, the University of Arkansas for Medical Sciences, and the Medical University of South Carolina. Dr. Burns is a nationally recognized mental health services researcher with more than 200 publications in this area. For nearly a decade at the National Institute of Mental Health, she pursued a range of topics directed toward improving mental health care for all age groups, but focused on community-based services. Dr. Burns prepared a review of effective treatment for mental disorders in children and adolescents for the U. S. Surgeon General's Report on Mental Health and is currently conducting research on the dissemination of effective clinical interventions for youth with severe emotional disorders.

Charles G. Curie, M.A., A.C.S.W.

President George W. Bush appointed Charles Curie in November 2001 as administrator of the U.S. Department of Health and Human Services' Substance Abuse and Mental Health Services Administration. Curie has more than 20 years of professional experience in the mental health and substance abuse arena. His core commitment to ensuring that people with addictive and mental disorders have the opportunity to realize the dream of equal access to full participation in American society has earned him national recognition. Before joining SAMHSA, Curie was appointed by former Governor Tom Ridge as deputy secretary for mental health and substance abuse services for the Department of Public Welfare of the state of Pennsylvania. Curie's passion and commitment for service started in his early childhood when he began to hold leadership positions at church, school, and community activities. Curie is a graduate of Huntington College, Ind., and holds a master's degree from the University of Chicago's School of Social Service Administration. He also is certified by the Academy of Certified Social Workers.
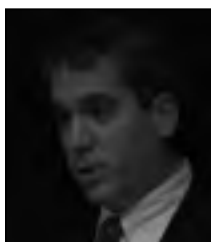
Benjamin Druss, M.D., M.P.H.

In January of this year, Dr. Druss joined the faculty at the Rollins School of Public Health and the department of psychiatry at Emory University. Prior to that time, he had been on faculty at Yale University since 1996. As the first Rosalynn Carter Chair in Mental Health at the Rollins School of Public Health, Dr. Druss is working collaboratively with The Carter Center to bridge gaps between research and mental health policy, between clinical and public health models of care, and between the health and mental health systems. Dr. Druss has published more than 50 peer-reviewed articles; his work has led to several national awards, including the 2003 Alice S. Hersh New Investigator Award for the top junior investigator in the field of health services research.

Larry Fricks

Larry Fricks currently serves as the director of the Office of Consumer Relations for the Georgia Division of Mental Health, Developmental Disabilities and Addictive Diseases. He is a founder of the Georgia Mental Health Consumer Network Inc., that now has some 3,000 members; a founder of the Georgia Consumer Council; a founder of Georgia's Peer Specialist Training and Certification; and a founder of the Georgia Peer Support Institute. He served on the planning board for the Surgeon General's Report on Mental Health and currently serves on the board of directors of the Depression and Bipolar Support Alliance and the board of directors of the National Mental Health Association. He is also on the National Advisory Council for the Center for Mental Health Services and the Advisory Board for the Rosalynn Carter Fellowships for Mental Health Journalism.

Michael Hogan, Ph.D.

Dr. Hogan has served as director of the Ohio Department of Mental Health since 1991. He has held leadership positions and led mental health reform in three states. He was appointed in April 2002 by President George W. Bush to chair the President's New Freedom Commission on Mental Health. He is also a member of the MacArthur Foundation Network on Mental Health Policy Research and served from 1994 to 1998 on the NIMH National Advisory Mental Health Council and from 1989 to 1999 as the president of the National Association of State Mental Health Program Directors Research Institute.

Larke N. Huang, Ph.D.

Dr. Larke Nahme Huang is a senior policy associate in the National Technical Assistance Center for Children's Mental Health and the director of research at the Center for Child and Human Development in the department of pediatrics, Georgetown University Medical Center. She has worked in the field of mental health for more than 25 years with a primary focus on mental health services for children and underserved culturally diverse populations, research and evaluation of mental health services, and policy development. Currently, she provides technical assistance to states and communities to build their capacity to plan, implement, and evaluate systems of care for children with mental health needs. She is a member of The Carter Center Mental Health Task Force and, most recently, was a commissioner on the President's New Freedom Commission on Mental Health.

Thomas Insel, M.D.

Dr. Thomas Insel is director of the National Institute of Mental Health. Dr. Insel sees as priorities for NIMH the discovery of susceptibility genes and diagnostic biomarkers for the major mental disorders; research that will lead to a reduction in suicide, which today is globally responsible for as many deaths as wars and homicides combined; enhanced behavioral strategies for reducing HIV/AIDS transmission; and elucidating causal risk processes that will enable prevention of mental disorders.

Ronald Kessler, Ph.D.

Dr. Ronald Kessler is a professor of health care policy at Harvard Medical School. He is the author of more than 300 publications and the recipient of numerous awards for his research. His research deals broadly with the psychosocial determinants of mental health and the comparative societal costs of illness. Dr. Kessler is the principal investigator of the U.S. National Comorbidity Survey, the first nationally representative survey of the prevalence and correlates of psychiatric disorders in the United States, as well as of a series of follow-up surveys based on the NCS. He is also the co-director of the WHO World Mental Health survey initiative, an international comparative epidemiological study of the prevalence of psychiatric disorders, patterns of help-seeking for these disorders, and barriers to treatment for these disorders in 28 countries around the world.

Norwood W. Knight-Richardson, M.D., M.B.A.

Dr. Norwood Knight-Richardson is chief executive officer of the Richardson Group, a privately held consulting company, and associate professor at Oregon Health and Sciences University in Portland, Ore. Tommy Thompson, the secretary of the Department of Health and Human Services, appointed him to serve on two national advisory councils. These are the National Advisory Mental Health Council for the National Institute of Mental Health, National Institutes of Health in January 2002 and the National Advisory Committee for Injury Prevention and Control for the Centers for Disease Control and Prevention in November 2001.

A. Kathryn Power, M.Ed.

A. Kathryn Power is the director of the Substance Abuse and Mental Health Services Administration's (SAMHSA) Center for Mental Health Services (CMHS). As director, Ms. Power leads the SAMHSA/CMHS staff in addressing both the challenges and opportunities presented to the nation's system of quality mental health care – from developing approaches to reduce disparities in access to services and negotiating the complexity of financing and funding concerns to building on presidential priorities such as the New Freedom Initiative, the President's New Freedom Mental Health Commission, and growing support for mental health parity. Prior to her appointment as SAMHSA's CMHS director, Ms. Power served for more than 10 years as director of the Rhode Island Department of Mental Health, Retardation and Hospitals, a Cabinet position reporting to the governor, which was responsible for four systems of care serving individuals with serious disabilities: mental illnesses, substance abuse and addiction, developmental disabilities, and long-term medical needs.

Mark L. Rosenberg, M.D., M.P.P.

Dr. Mark Rosenberg serves as executive director of the Task Force for Child Survival and Development, a nonprofit public health organization that combines public health expertise with skills in collaboration to promote global health and human development. Before assuming his current position, Dr. Rosenberg served 20 years with the Centers for Disease Control and Prevention, including early work in smallpox eradication, enteric diseases, and HIV/AIDS. He contributed his public health perspective to violence and unintentional injury prevention and was instrumental in establishing a national center at CDC to focus on injury surveillance, research, and prevention. Dr. Rosenberg was named acting associate director for public health practice when the National Center for Injury Prevention and Control was formed, became the first permanent director in 1994, and served as director until 1999.

David Satcher, M.D., Ph.D.

Dr. Satcher completed his four-year term as the 16th surgeon general of the United States in February 2002. He also served as assistant secretary for health from February 1998 to January 2001. From 1993 to 1998, Dr. Satcher served as director of the Centers for Disease Control and Prevention and administrator of the Agency for Toxic Substances and Disease Registry. In January 2002, Dr. Satcher was named the director of the new National Center for Primary Care at the Morehouse School of Medicine in Atlanta, Ga.

Glenn A. Stanton

Glenn Stanton is currently the acting director for the Disabled and Elderly Health Programs Group within the Center for Medicare and Medicaid Services. He has 20 years of service within the public health care sector at the county, state, and federal levels, much of that time devoted to assisting persons with disabilities. His experiences have included managing the direct provision of supports and services as well as policy development and oversight. In his current role within CMS, he provides leadership and organizational management for a highly skilled staff devoted to issues related to Medicaid state plan and waiver services directed to older adults and persons with disabilities. In particular, he has served as the alternate CMS commissioner on the President's New Freedom Commission on Mental Health, has provided leadership for the Health and Human Services' self-directed initiative Independence Plus, and has led several emerging initiatives regarding quality in home and community-based services. He accepted this position in January 2001.

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