

TRANSFORMING MENTAL HEALTH  
FOR CHILDREN AND FAMILIES  
IN LIGHT OF THE  
PRESIDENT'S  
NEW FREEDOM COMMISSION



The Twentieth Annual Rosalynn Carter  
Symposium on Mental Health Policy

NOVEMBER 9 AND 10, 2004

THE  
CARTER CENTER



*Waging Peace. Fighting Disease. Building Hope.*

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# OPENING REMARKS

*Rosalynn Carter*

Chair, The Carter Center Mental Health Task Force

In last year's symposium we focused on the final report of the President's New Freedom Commission on Mental Health, which asserted that the mental health system is so broken it cannot be repaired. Rather, it needs to be transformed. The entire mental health community was energized, and we wanted to mobilize everyone in support of the commission's recommendations. If we do not work together, nothing will improve, let alone achieving the complete transformation of the mental health system. No one thinks this is going to be easy.

This year we have chosen to focus specifically on transforming the mental health of children and their families. We all knew, even before the New Freedom Commission's report, that the mental health system in our country is in a shambles – and the system for children and families is no exception.

In our Mental Health Program here at The Carter Center, children's issues have always been important to us. Five of our symposia have focused on children, as have projects of some of our mental health journalism fellows.

Giving children a good start in life has long been one of my main interests. I have worked on immunization for years, when Jimmy was governor and again when he was president. In recent years Betty Bumpers, wife of former U.S. Senator Dale Bumpers, and I founded Every Child by Two, a program promoting childhood immunizations by age 2. Registering children for school by age 2 would ensure that they get this immunization on time, since school registration requires up-to-date immunizations.

This is a troubling time for all of us in the mental health field. Now, when we know more than we ever have about what to do to help people with mental illnesses, services are being cut in states and communities across the country, and everybody is competing for what few resources are available from federal, state, and local governments. We are at serious risk of losing the gains we have already made. But, thanks to the President's New Freedom Commission, we have an opportunity now to come together and determine how we can best leverage the recommendations of the commission's report to improve the mental health of children and their families.

## KEYNOTE ADDRESS

*Pamela Hyde, J.D.*

Secretary, New Mexico Human Services Department

I want to start by talking about going beyond the religion of recovery and resilience. What do I mean by that? I have been guilty of having a religion about whatever it is we were preaching in behavioral health at the time. Recovery and resilience are what we are preaching at the moment. I am an advocate for recovery and resiliency and have been for a long time, even before we had words to put to these concepts. But the fact is, while we have common commitment to these lofty goals and values, we really do not have a common agreement about what these terms mean operationally. We have a philosophy about recovery and resilience, but we need to get to the practicality of whose funds are going to be spent on what services and activities, with what outcomes, and how that translates into the goals of recovery and resilience.

We have values, but sometimes we have not really identified and helped others see what “child-centered” means, what “family-directed” means, and what “community-based” means in practical terms. For example, how do we measure these values? How do we evaluate whether they make a difference? Until we can show that these values translate into meaningful impact on our communities, they are just religious sayings. In other words, the values are something we can believe in, but they are not going to make a difference unless we can really make them operational.

Evidence-based practice is another religion that we have started to preach, but we have to ask hard questions about whose evidence, whose practices, and whose outcomes. Evidence-based practice matters only if we are clear about the outcomes we are trying to achieve. We have



outcomes that support mental health system goals. For example, we have outcomes defined around community-based care, symptom control, child and family functioning, wraparound services, reduced substance abuse, family engagement, or satisfaction. These are the types of things we tend to talk about in mental health.

But we have not done much about connecting the evidence-based practices that we preach to the needs of other systems. There are other systems that address children and family issues that have other system goals. For example, schools have outcomes such as school attendance and graduation and “adequate yearly progress,” which are the latest words for schools in terms of the No Child Left Behind laws. The juvenile justice system looks at reduced recidivism. Family reunification, reduction of kids in foster care – we do not talk a lot about those outcomes in mental health. There are other outcomes that support a better life for kids in communities, such as jobs with health care benefits for families; a decrease in teen pregnancy and youth suicide; an increase in the number of families able to support their children practically, emotionally, and financially; and an increase in the number of communities able and willing to accept and support persons with multiple disorders or disabilities. Those are all things that matter to communities, and we do not frame what we do in the children’s mental health system in terms they can hear.

We have to look at outcomes that sell politically. The behavioral health system typically does not look at the kinds of things that politicians look at, such as a reduction in dependence on publicly funded systems of care, a reduction in DWI violations, or a reduction in jail or prison time. Oil companies, farmers, and children and families all rely on government benefits. Why are ours not OK? Sometimes that is how we are viewed, and the fact is, politically sellable outcomes include a reduction in dependence on those publicly funded systems of care. Politically sellable ideas have to do with tax revenue rather than tax expenditures, that is, increased numbers of persons using publicly funded services being gainfully employed and paying taxes. These ideas have to do with reduction in unemployment or incarcerated adults and increased numbers of children meeting No Child Left Behind standards or being ready

for work upon completion of school. Those are the kinds of things that are more politically sellable than reduction in symptoms, decreased substance use, numbers of children served, or numbers of service units provided. We do not talk about what we are trying to accomplish in those politically sellable terms. So we have a mismatch in how people who are making decisions and policies think of outcomes and the way we talk about them for children’s mental health.

We have to think about evidence-based practices in context. I heard Marlene Wong, head of mental health issues in Los Angeles County, say that evidence-based practices have to be relevant in one minute, between classes, in the girls’ bathroom, when I find a girl who has just miscarried. That is where the need for evidence-based practice arises. That child is never going to come into a clinical setting. There needs to be an intervention that works in the context of these crises.

For example, in my state, if the police find a Native American youth drunk just outside the reservation, some of them drive the child around until he is no longer intoxicated and can be driven home. This is not a good evidence-based practice, but, rather than take the youth to jail, it is better to detox the child in the back of the car. What if those officers had a quality practice to use in that situation instead? Another example is in the methamphetamine lab just after a bust that sends a child’s parents to jail. There are so many substance abuse and mental health issues in that setting; yet we have no evidence-based practice to intervene at that place and time. How about on the streets, just after a young person turns his first trick for food? That is where we need a contextual evidence-based practice in order for children’s mental health to be real.

What outcomes are we seeking from these encounters? We have to be clear about that in order to transform children’s mental health. We have to think far beyond the fences and the boundaries that we are used to using.

What are we reforming in children’s mental health? We are not reforming just the specialty mental health system. We are not trying just to

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***We have not done much about connecting the evidence-based practices that we preach to the needs of other systems.***

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transform the children's service system. There are multiple systems that children and their families need in order to succeed, and the role of each of them is changing. Transformation of children's mental health calls for multiple systems that affect children's lives. Each of these systems is developed in different ways with different results and outcomes expected.

We have to get beyond multiple assessments of the same child; for example, one in a juvenile

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***Transformation of children's mental health calls for multiple systems that affect children's lives.***

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assessment facility, another in a school, another in a clinician's office, and another when there is home-based

care. We have to figure out how, as a collection of systems, we can interact with that child and family in a consistent way. And we need to get beyond the adult assessment process that happens in a court, in a jail, in an emergency room, in a doctor's office, in a case management team, and in a Temporary Assistance for Needy Families (TANF) office without consideration of the children who are affected by that adult situation. Rarely do those kinds of assessments of adults take into account the needs of the child impacted by that adult. We have to get beyond outcomes that are defined only by the mental health system.

As much as good clinical interventions are essential, children with mental health issues need a lot of things. They need good schools; stable families that include income support, jobs, and parenting skills; a decent place to live, with housing and community development. They need food: food stamps, school lunches, and breakfasts. They need quality health care and recreational opportunities. They need all of these things, and we really cannot have good positive mental health outcomes unless we are clear about the outcomes in these other systems.

As critical as mental health policy is, I would suggest to you that federal and state policy on such things as jobs and the economy, education, the No Child Left Behind legislation, health care reform, marriage initiatives, housing, Medicaid, and Medicare have as much or more to do with children's mental health and the outcomes we are seeking than anything we might do in the context of just something called children's

mental health. We cannot look only at the state mental health authority or the juvenile justice authority or the child welfare authority and think that we are going to impact children's mental health in a collective way. Just as important are adult behavioral health and correctional system policies and budgets. They impact the physical and behavioral health of children. Another issue is transportation policies: The single biggest issue about access to care beyond work force issues is transportation policies. None of us pays much attention to what is happening with transportation policies, either in transportation itself or within health care transportation.

Federal and state governments continue to struggle with the escalating costs of Medicaid. There are two bills in Congress right now, introduced before the election: Senate bill 2671 and House bill 4961. Both are state fiscal relief acts for state Medicaid programs. In my state, those congressional policies will have more to do with children's mental health and access to mental health care than probably anything else we could do, because they will determine whether states will have to constrain their Medicaid programs further to keep within the costs they are facing. There are a number of policies that conspire to keep families down, to keep them dependent, and to keep them incapable in order to get benefits and help. I cannot tell you the number of stories I have heard in New Mexico and in other states about people getting divorced or staying separated or refusing a raise at their work place in order to keep their child eligible for benefits. The whole issue of relinquishment of custody in order to secure medical and behavioral health services is a policy that conspires against families.

The marriage initiatives, the fatherhood initiatives, and the whole defense of marriage issue are not just about somebody's religious view of what marriage is or not. All these policies have to do with individual families and children having access to services, health care, and income. Minimum or living wage laws, Fair Housing, and HUD housing regulations and policies that will not allow mentally ill people into senior housing and will not allow people who have drug histories in HUD housing all impact kids.

All these interfacing systems call for a new style of leadership. Our sights really have to go beyond the system in which we work. Just because somebody else gets something does not mean you have lost something. In fact, it may mean you have gained. We need to work as hard to make these other systems successful as we do on our own.

We are required to coordinate a lot. Coordination may help us avoid mistakes, but it alone will not win the game. We need a common game plan. We need to make sure we are all on the same field and all trying to do the same thing. In a common game plan we have to put aside our batting average, our own ERA, our own home run or hit, and we have to have a clear goal for winning the game and for winning the series. That common game plan takes execution and sacrifice.

There is a call in the New Freedom Commission report for comprehensive state planning. I am 100 percent committed to that in our state, and I think it is a great goal. But I am telling you, one more comprehensive plan that only affects the mental health system, that sits on somebody's shelf so that the federal government can say, "Good state, you can now have your block grant monies," is not going to mean anything.

Change and transformation is personal. I have been in systems change all my life. We need behavioral health administrators and advocates to lead in corrections, child welfare, schools, housing, health care, work force development, aging, and, yes, politics. We cannot sit in our mental health systems anymore and expect to get this accomplished. It has been a challenge to me, and I particularly chose in my own life to take responsibility for some systems I was not normally used to. I am now responsible for Medicaid, TANF, child support, food

stamps. I do not always agree with the things that I have to do, such as Medicaid cost containment and TANF marriage initiatives. Sometimes these decisions are hard. But as someone once said to me, Medicaid is a wave to be ridden, not a bronco to be tamed. I think that is the way all of these systems are at this point.

We are in a field now where resources are shrinking. Sometimes it is in an era of shrinking resources that we can make the most changes toward what we are trying to accomplish. We need to understand the pressures, distractions, differing agendas, drivers, and parameters that other systems understand. I understand this more, now, while never losing my commitment to behavioral health. I understand more about what it means to be too distracted in Medicaid to pay attention to behavioral health. I understand a little bit more now about what it is like to be so distracted in schools that you cannot possibly attend to the child in your classroom with mental health problems, and, frankly, you just want him out of there. In the past, we have thought of these other systems as the enemy and said we needed to understand the enemy. But this is actually about understanding our colleagues.

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***All these interfacing systems call for a new style of leadership.***

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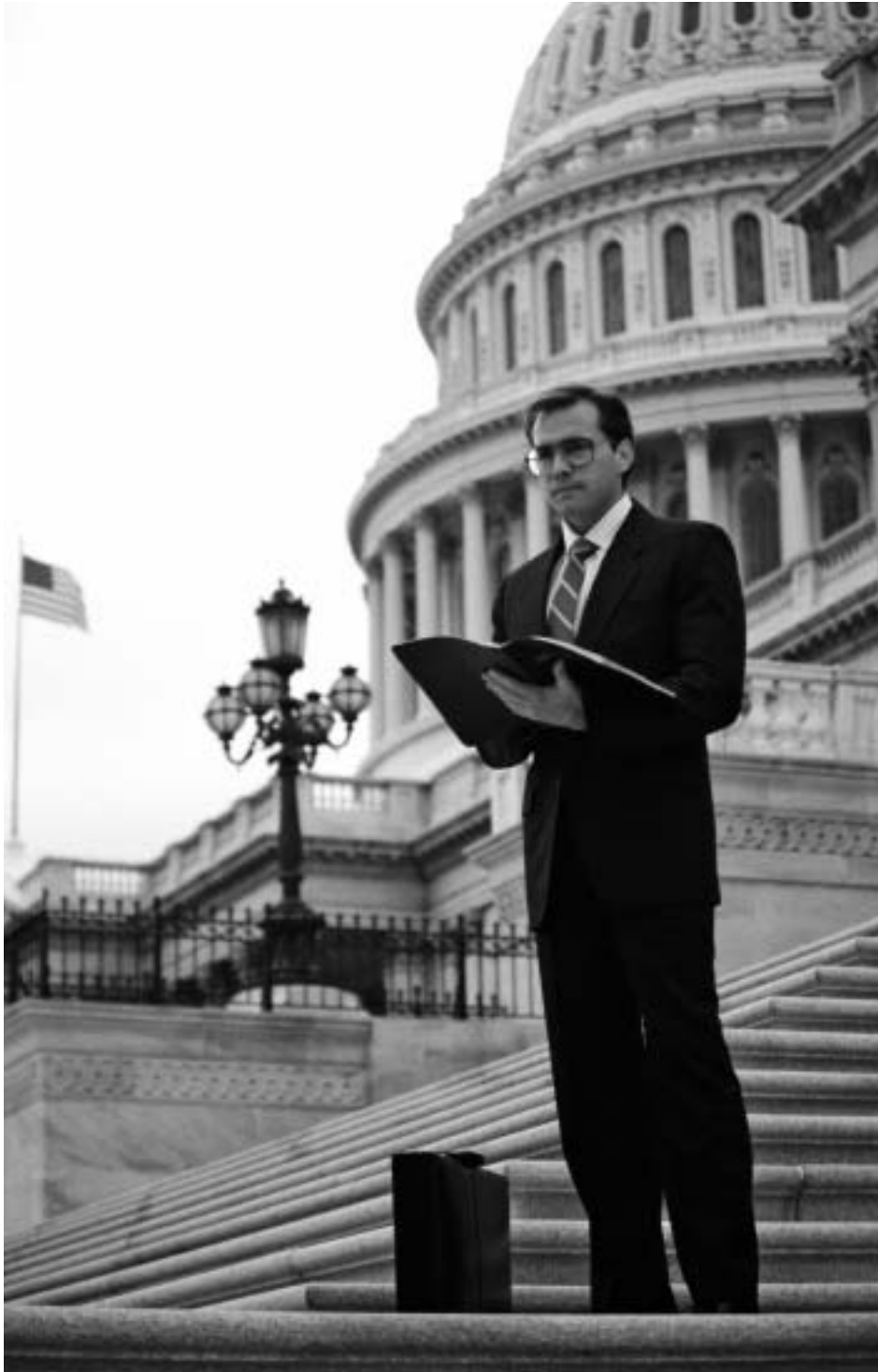
I am a big believer in the issue of attacking fragmentation. It was wonderful to have the New Freedom Commission report as a framework to talk about how we can reduce system fragmentation. But I also understand now that no matter how systems are organized, there is always going to be someone or something or some services that must or should be coordinated. So I ask myself whether or not fragmentation is a red herring.

Do we need to be careful about saying this is the silver bullet problem? While fragmentation is an incredible problem, it has always been here, and it is always going to be here. The New Freedom Commission report allows us to bring that issue to the forefront and do something about it, but, in fact, we need to think about what we need and should be doing about it, not in the present, but for the future.

I think the biggest problems are probably in the interface of all the systems touching children's lives. There is a discussion now surrounding exceptionalism versus mainstreaming, meaning we have to decide if we are going to continue to be a mental health system that is exceptional, or outside health care and other systems, or if we going to be a part of health care, juvenile justice, schools – all these other systems. Working with many different systems involves collaboration. It is hard work. It is a huge cost in time and lost opportunities to do otherwise.

We are doing a great deal of work in New Mexico about collaboration. The first thing the legislature asked us was, "How much money are you going to save?" My answer was that we are not going to save anything; we are going to use existing dollars better. Everybody wants collaboration, and no one wants to pay for it; therefore, nobody would hear about the required resources, time, and staff to collaborate.

There are huge chasms between these systems. What are these chasms and what causes them? Differences. We have different authorizing environments, so we have different people or different structures telling us what to do – governors, legislators, judges, county commissions, city councils, school districts, prosecutors, and sheriffs. Different systems are



authorized to do different things. We also have different structures and scopes of authority. We have different missions. Sometimes we have a safety mission, a treatment mission, an education mission, and we have forgotten to look at the mission commonality among these systems. We have different philosophies – sometimes community versus facilities, sometimes the three Rs versus critical thinking, sometimes mandates versus family engagement, sometimes abstinence versus the availability of condoms. We have different regulations and different regulating authorities. We have different financing mechanisms. We have different data systems and data management.

As I have said, there are different expected outcomes, from school success to family functioning to symptom control to change in behaviors. And different systems have different leaders. Whether they like or dislike each other has a lot to do with some of these chasms.

So why is it so hard to overcome some of these differences and cross these chasms? If I have heard it once, I have heard it a million times: If we would just do early intervention and prevention, we could save money; if we would just serve these high-impact, high-cost kids early, we would save money; if we would just add chiropractic to Medicaid, we would save money. The fact is, savings in one system does not equate to savings in another. I can tell you that when I am in front of the legislature nobody asks me, “How much money did you save your sister agency last year?” And, in fact, if I said, “But I saved the Department of Health \$5 million last year,” they would look at me as if to say, “Huh?”

Savings on one child and family does not equate to savings within a system’s budget. So I can save money on a particular child, a particular family, but if there are 20 million more children and families waiting in the wings, then my budget is going to grow and I do not get any credit for that. Savings in the future does not equal savings today. I do not care how much we tell them, the truth is that the legislative process is a one-year or, at best, a two-year process. It is very, very hard for legislators to see that savings in the future will help out politically today.

We have to stop seeing mental health as the center with other systems around us that we have to reach out to and get back to seeing the child

as the center with all of those systems, trying to come up with common ideas, thoughts, and outcomes for that child and family. We have to look at each system as an equal partner rather than the center of the universe. It is not a Medicaid client, a student, a juvenile delinquent, a state custody child – it is our Medicaid money, our corrections money, our child welfare money, our public health offices, our school-based health centers, our families and children. Our systems need common goals, outcomes, definitions of success, service definitions, data elements, and ways to make midcourse corrections without distractions by other agendas. While this is easy to say, it is not easy to do.

In New Mexico, we are trying an experiment. We put into law an interagency behavioral health purchasing collaborative as of May 2004. It requires all state agencies to join in one single collaborative to purchase behavioral health services together. We have a single behavioral health advisory structure for children and adults that covers all funding sources and all programs. It involves funds such as Medicaid; mental health and substance abuse block grants; state general funds for children, adolescents, and families; state general funds for adults and seniors; juvenile justice; child welfare; homeless; and TANF. By putting everything we can in this procurement, we are trying to solve many problems that the New Freedom Commission talked about.

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***We have to stop seeing mental health as the center and get back to seeing the child as the center with all of those systems.***

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What have we done so far in this collaborative? We see this as a multiyear effort. We now have common values and philosophy, and that is no small thing. We have common service definitions consistent with the Health Insurance Portability and Accountability Act (HIPAA). That is a huge thing to accomplish across multiple agencies. We have a common request for proposal for one statewide entity, and we have common proposed outcomes. We intend to have, through our single statewide entity, common billing practices and common credentialing, and we now have a single advisory structure.

But even with all that, we still have pieces to coordinate. As much as we tried to wrap our hands and arms around every single factor that

touches children's mental health, we still have DWI treatment and prevention, which is a huge portion of services in our state; mental health and drug courts; and in-facility mental health and behavioral health services for adult prisoners. And we are still less than elegant at crossing the policy chasms.

So how do we, as a field, go about this work of reforming systems and crossing the policy chasms that we find? First, we have to take systems as we find them. We would never talk to clients and families about their failures. What we would talk

to them about is their strengths, and we would build on their strengths, not on their weaknesses. We would recognize that systems are dynamic and

have strengths that vary on any given day. We would understand that no one system can do it all.

These are problems to be managed, not to be solved. We cannot limit our vision, but we must focus on what we are trying to do together for children and families. And we cannot give up, not when children's lives and our future are at stake.

We have to be opportunistic and look for an opening to burst out of the pack. We have to not take it personally when we get benched for awhile, and there are some of us who feel a little benched at the moment. Whether we like it or not, human services and the idea of having commitments to families and children just because they are the right thing to do are not winning the day. Financial considerations are driving policies in many areas that are guiding our futures at the moment.

Mental health is focused on policies and programs rather than politics and economics. We are going to have to put our issues in those terms. We may have lost, or maybe never even found, our relevance. In the words of a great statesperson – I am going to paraphrase again – ask not what it costs and how much we get but how much we can contribute in jobs, taxes, and economic development to the community, state, and nation. I am spending a lot of time these days trying to understand and help legislators

understand how their investment in children and families and in health care and other areas will have an economic return.

Ask not who votes for or against our issues but who is pursuing issues that we can hook up with or trade with or have common goals with or support in exchange for something that we want. Ask not how much the behavioral health system gets but how much is available for the programs upon which families depend for food, jobs, health care, housing, and social support. We have to pay attention to the material conditions of people's lives, or mental health treatment may have little effect. Ask not who will help us but who has an idea that will impact children with mental health issues and adolescents and families that we need to help to be successful. And ask not what behavioral health outcomes we want but what life outcomes we will demand of our collective systems and how we get there.

To transform children's mental health, we must send a message of hope for systems as well as for children and families. If we provide a service the community wants, we will be funded. But we have to help the community – local, state, and national – understand what they should want: why a child with behavioral health needs who graduates, is employable, and has a future is a good outcome for the child, the community, and the country – not just why their behavioral health needs should be met. Communities, legislators, and governors will not always understand why systems of care, evidence-based practices, recovery or resiliency, or children's self-esteem are good things. It just does not speak to them. They will understand why children who are not incarcerated, who do not drive drunk, who graduate, and who have higher incomes as adults are a good thing.

The challenge is to bring together people in other fields that need us and whom we need. We need to find out what they want and how we can help them. We need to affect the philosophy of their efforts toward recovery and resilience in their most practical senses. We have to spread out and exercise broadened leadership. We have to use the New Freedom Commission report to focus on children's lives in their communities, not lives in our systems.

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***We cannot give up, not when children's lives and our future are at stake.***

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# Questions & Answers

**Q** I did not hear any reference to the private sector. What is your thought about incorporating the private sector in your plans?

**A** Dr. Hyde: For time considerations, I focused on the public system alone. But we could have the same conversation

about the differences in philosophy, missions, structures, and authorizing environments in private sectors as well. Whether it is health insurance or companies that have issues around how they impact their employees and how families are impacted by company employment policies, I think those are huge issues we have to talk about.



## PANEL I: IMPLICATIONS OF SCIENCE FOR CHILDREN'S MENTAL HEALTH

**W. Rodney Hammond, Ph. D., Moderator**

Director, Division of Violence Prevention, Centers for Disease Control and Prevention  
Member, The Carter Center Mental Health Task Force

Our theme will answer the question of what science has to say about the future of children's mental health. One of our key missions at the Centers for Disease Control and Prevention is to make a health impact in the nation. We already know that we cannot do that unless we focus the nation on early childhood intervention, including mental health. We already know from the best available science that

mental health has an impact on broader health issues. One of the things we have done at CDC is to integrate mental health professionals and scientists into the work of public health in general and CDC in particular. I think that that is one of the ways that we can, as an agency, cross some traditional boundaries, and I look forward to a great future in the integration of public health and mental health.

**David Mrazek, M.D.**

Professor and Chair of Psychiatry and Psychology  
Mayo Clinic College of Medicine

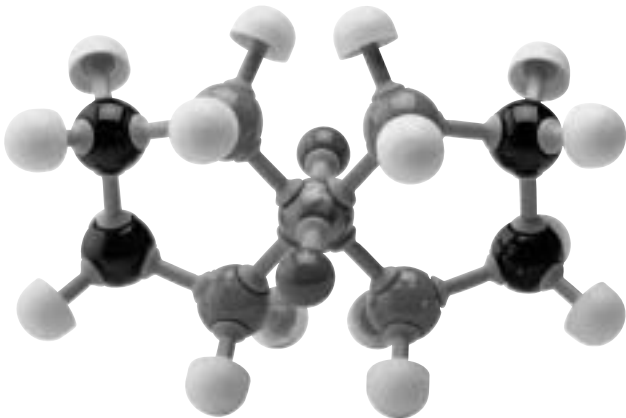
I am a child and adolescent psychiatrist. As I was listening to the first presentation, I realized that not only am I going to be sharing with you a tiny peek into the window of how science will be influencing practice, but also I will be sharing with you from the perspective of someone who is still seeing patients every day. I think that may provide an interesting contrast to the important work of trying to organize complicated service systems.

My goal is to try to provide a comprehensible perspective on how new research is currently impacting and how it will continue to impact the delivery of psychiatric care to children and adolescents. My premise is

that the psychiatric research going on right now will lead us inevitably to a new way of understanding psychiatric illnesses. That change will be the result of two new technologies that did not exist 10 years ago. The first technology is the ability to use genotyping to understand both the response to treatment and the nature of illness. A second new technology is the ability to look at the brain to see how it functions.

I have some wild predictions for the future. My view is that in a decade, almost all psychiatric illnesses for children will be diagnosed in a different manner and that 20 years from now, we will be describing illnesses in terms of variability in the genes that children have, and we will be able to see how their brains are working. We will have a different way of conceptualizing treatment.

What does this mean? When we look at a child with terrible obsessions and compulsions today, we obtain a history and then observe and count symptoms. When enough symptoms of enough severity are present we say, yes, this child has obsessive-compulsive disorder. I believe in the future we will take a very tiny sample of blood and look at a panel of genes. We then will look at the functioning of the brain and can state that



the strange symptoms are the result of receptor or transporter problems and the area that is affected is in the globus pallidus. That will be a different way of understanding illnesses.

What will happen if this view of the future evolves? We will have better treatments. For example, we will have specific treatments for individual children. I believe we will decrease the prevalence of psychiatric disorders. We also will be able to do effective selective preventions early in children's lives.

How is clinical genotyping currently improving the psychiatric care of children? The most immediate new development has been the ability to use genotyping to select and dose psychotropic medications for children who need them. This very new approach to providing care is referred to as pharmacogenomic management. Pharmacogenomics is actually not that new; there have been media stories about it for some time. Data reported in *Nature Genetics* pointed out that variability in genes explained variability in medication response. The first basic concept was that there are different forms of important genes that produce varying amounts of critical enzymes. These enzymes metabolize medicine.

We can measure the structure of genes with tools such as a microarray chip. By understanding the structure of these genes and the enzymes they produce, we can address two problems. First, if the gene is making too much enzyme, the medication cannot reach a level in the child's blood to have a positive impact. The second, more common, problem is that some children have genes that cannot produce enough enzymes, causing medication levels to go sky high in their bloodstream. They develop toxic reactions and severe side effects.

Let's take one gene, 2D6, as an example and look at how it interacts with codeine. Codeine is a drug that needs to be transformed into an active drug. 2D6 produces an enzyme that transforms codeine into morphine, a powerful analgesic. But if someone does not have enough of the 2D6 enzyme, they will not be able to transform codeine into morphine and there will be no pain relief. The enzyme 2D6 tackles about 80 different drugs. For example, it also metabolizes Prozac and Paxil. Dextromethorphan, the ingredient in cough syrups that suppresses coughing, is also

metabolized almost exclusively by 2D6. Abuse of these cough suppressants can lead to profound changes in mental status, possibly even development of a psychosis.

Poor metabolizers accumulate this medication at very fast rates.

To illustrate the impact of these proteins and their ability to metabolize these medications, I will describe a patient I met for the first time several weeks ago. This 13-year-old boy, Jeffrey, came into the clinical system because he took an overdose of ibuprofen. When he was evaluated, he did not really fit any easy Diagnostic and Statistical Manual of Mental Disorders (DSM) criteria. But while he did not meet the criteria for depression, he just overdosed and left a very strange suicide note. There was no ambiguity that he was intending to harm himself. As a result, the psychiatrist decided that he would treat what might be a masked depression and prescribed Prozac.

Jeffrey had already been tested for the 2D6 gene, and so Jeffrey's parents already knew that Prozac was metabolized by 2D6 and that Jeffrey was a poor metabolizer. While they agreed to start him at a very low dose of five milligrams, they also decided to get a second opinion. Since I have an interest in this gene, they brought Jeffrey to see me. I spent two hours with the family: some time with the parents, with Jeffrey, and with everybody all together. It was clear to me that Jeffrey did not show many signs of depression. As I listened carefully and reviewed the medical records, I noted that he had a normal development and was doing well in school.

While I was trying to put the pieces of this funny puzzle together, his mother told me that Jeffrey had a strange reaction to a hefty dose of Nyquil. He had become so dizzy he could not walk up the stairs. I suddenly realized that there was a high probability that Nyquil had dextromethorphan, and, in fact, a healthy dose would be about 40 milligrams of the drug. The

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***Psychiatric research going on right now will lead us inevitably to a new way of understanding psychiatric illnesses.***

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***The most immediate new development has been the ability to use genotyping to select and dose psychotropic medications for children.***

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pharmacokinetics in poor metabolizers in a 13-year-old child with that much dextromethorphan might have caused his blood levels to be 100-200 times normal levels, which was more than enough to make Jeffrey confused and change his mental status. After some time, however, even a poor metabolizer like Jeffrey could clear this dextromethorphan from his system and return to normal. I thought that was the most likely

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***The other technology that will change the face of psychiatric care is functional neuroimaging.***

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explanation for this out-of-context self-destructive behavior, and, therefore, suggested he

discontinue the Prozac and focus his treatment on better understanding some of the family issues that were being uncovered as a consequence of these two psychiatric evaluations.

In thinking about genotyping, there are, of course, ethical considerations, as there are with any aspect of the practice of medicine. Any laboratory value or EKG finding can have implications for a person's insurability and employment. Therefore, just as it is important to have privacy related to lab tests such as cholesterol levels, it is important to have privacy related to genetic information. The five rules that I try to keep in focus are:

1. Genotyping should be voluntary.
2. There must be appropriate consent so that the person understands what the test is and what it means to them.
3. Confidentiality is critical.
4. Results must be accurate.
5. Patients must be counseled so they fully understand the meaning of the test result.

The other technology that will change the face of psychiatric care is functional neuroimaging. While we have had structural neuroimaging for some time, it has been disappointing in terms of

guiding practice. Structural neuroimaging has been good at finding tumors and finding inflated ventricles but not so good at looking at variability in treatment response. It is functional neuroimaging that will provide that assistance.

What does neuroimaging mean? Neuroimaging is an elaborate picture of the brain. While previously there were pictures of the structure of the brain, today we are beginning to look at the brain in new ways. For example, we have the PET scan, which has certain areas that can light up and give you clues about what is happening within the brain, and a Spec Scan, which looks at blood flow. But for the new frontier of using neuroimaging to guide treatment, it is technology such as the magnetic resonant imaging spectroscopy that will help us. We are doing a number of studies trying to predict whether children with bipolar disorder will do better with one mood stabilizer or another based on the pattern of neurochemicals that we can show. The idea is to be able to spot early dysfunction using these elegant technological methodologies so we can know better how to treat our patients.

It is my contention that the diagnostics of the future will incorporate both genomic profiles of relevant target genes, including receptors and transporters, and the measurement of localized brain function. This makes it even more important to understand how environmental influences affect the expression of illness when we have these anchors of clear pathology. So it will be much more important than it is now to know which environments cause genes to turn on and which environments cause genes to turn off. We need to understand the developmental context. How those genes turn on and turn off is a very different thing when a child is 2 or when they are 18. Trying to understand the developmental context will give us clues about how to intervene early.

***Jane Costello, Ph.D.***

Professor of Medical Psychology, Department of Psychiatry and Behavioral Sciences  
Duke University Medical Center

**G**oing through the supplement of the President's New Freedom Commission – the report to the Subcommittee on Children and Families – I isolated several issues that epidemiology tries to help with. One issue is

recognizing the need: How many are there? Epidemiologists always get tired of being asked that question because we think it is boring, but actually it is very important. How big is the need? How many children need services? And



moving on from there, how many get services, what is the extent of the unmet need, and is the care going to the right children? Those are the sorts of questions that epidemiologists can help with.

Then there is another whole set of questions in the report that has to do with evaluating prevention, which is where epidemiologists sometimes are able to help. However, I am not going to talk about that because I do not have very long and there are many other expert people here who will be talking about prevention. I will talk about how epidemiology can help in informing the vision, both for clinical care and for state and national policy. The clinical care part is worth spending a moment on. People tend to think that epidemiologists are not interested in people as individuals. That is absolutely not true; they are just as interested in them as clinicians are, but in a slightly different context. The clinician asks, “What is wrong with this person?” and “What can I do to help?” The epidemiologist also asks, “What is wrong with this person?” but the next set of questions epidemiology asks is, “Why this person and not this person’s brother or sister or aunt or the guy

who lives next door? What is it about this person in context that can help me learn more about the disease and help me learn more about treatment and prevention?” We are all interested in the individual, but from different points of view.

We first need to understand the need – how many children need mental health care. The bad news is that we do not know. There have been no national surveys in the United States on rates of psychiatric disorder in children and adolescents. We have no way of tracking increases and decreases in occurrence, which are extremely important because they tell us how our social policies affect rates of disorder. We have no way of accurately calculating the need for or the likely cost of services at the national or state level. Child mental health has not yet become a central concern of the Centers for Disease Control and Prevention. They are putting their foot in the water here and there, but it is not a major surveillance issue for CDC.

What can we say about the need for mental health care for children and adolescents? Let’s first look at the issue of burden. The World Health Organization, together with the Harvard



School of Public Health, reviewed the major causes of disability for functional impairment around the world, and in industrialized countries

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***Age at first onset for major depression is in the late teens and early 20s.***

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in the 15-44 age group, which is the nearest I could get to children, nine out of 10 of the leading causes of disability are either psychiatric disorders or directly related to psychiatric disorders. So this means we are dealing with a huge public burden.

The second thing that epidemiology can tell us is that most of these disorders begin in childhood and adolescence. Data from the Epidemiological Catchment Area studies done in the 1980s showed the age at first onset of psychiatric disorders. Age at first onset for major depression is in the late teens and early 20s. Peak onset for phobias is even younger, in the teens. Alcohol and drug abuse both show peak onset in the late teens and early 20s.

We have just completed a study at Duke University looking at 2- to 5-year-olds where we are finding rates of DSM-IV psychiatric disorders equivalent to those seen in children before puberty and similar to rates we see postpuberty. One of the things that epidemiology is going to be telling us in the next decade is that we are grossly overestimating the age at onset of most of the major psychiatric disorders.

Serious emotional disturbance, which is the federal definition for children who are eligible for various kinds of federal funding, occurs

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***We are seeing between 5 and 10 percent of children being affected by a serious psychiatric disorder by the time they are 16.***

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consistently in the 10-15 percent range over time. And when we look at cumulative percentage of disorders over period of time, even rare disorders over time affect a surprisingly large number of children. We are seeing between 5 and 10 percent of children being affected by a serious psychiatric disorder by the time they are 16. So the answer to the first question, "How many children need mental health care?" is "a lot." For most of them, the need for care does not go away.

The second question that epidemiology can help with is how many children get care. We gathered some data from a reasonably well-served

area in rural North Carolina. Two out of three children with serious emotional disturbances had received some service in the past three months. The largest number of children receiving any kind of care for mental health problems was in the education system.

Next, look at the proportion of children with no psychiatric diagnosis who received services in the past three months. Fewer than 10 percent of children with no impairing symptoms or diagnosis were receiving services. On the whole, the services are going to the children who need them. Based on these studies, we have very little evidence of children without problems seeking services or getting them. However, because normal children are the majority, they will be using quite a large proportion of services in some sectors. This may be entirely appropriate for some services, like schools and pediatrics, but there is evidence that the triage process is not working very well in specialty mental health care settings. I think that is something that we need to work on.

The fourth question is unmet need: How many children with service needs are not receiving any services? Seventy percent of children with serious emotional disturbance were not receiving any services except maybe some in the schools. What is the impact of insurance on this issue of unmet need? This is a question epidemiology cannot address; however, the bottom line is that if a child does not have public insurance of some sort, they do not receive the services they need. The level of services going to children with needs was as low among those with private insurance as among those with no insurance. These results are for an area in North Carolina and may not reflect the reality in other geographic areas, but I rather suspect it does.

In conclusion, we are talking about a very large need and very disabling disorders. We are talking about chronic, serious conditions – analogous to diabetes and asthma – most of which are untreated and most of which are not being helped by the private insurance system.

The second set of questions that epidemiology can help with is informing the vision for clinical care and state and national policy. In the first place, I just want to make the point again that we are talking about chronic diseases that need a treatment system designed to manage chronic

disease. The treatment system is currently designed to treat acute conditions. That is the wrong model. The odds ratios for children with a past case of a disorder are very high compared with a child with no episodes of disorders. A child seen with ADHD is 15 times more likely to come back with ADHD than a child who never had ADHD. The odds ratios for conduct disorder and depression are eightfold; for oppositional disorder and anxiety disorders they are three- to fourfold.

Now, what about national policy and local policy? I will end with a story here. In 1996, a casino was opened on an Indian reservation in North Carolina, and as a result of the deal that the tribe cut with the casino company, everybody on the reservation was given a percentage of the take. It came to around \$6,000 a year. Because

we had been studying these children, we realized we had a natural experiment: We could look at the impact of this additional funding on children's mental health. There was a dramatic decrease in psychiatric symptoms in the children of the families who were moved out of poverty by this income supplement.

My final conclusions are that:

- We need a child mental health surveillance system like those in place for physical health and drug abuse, run by an agency with the skills and the resources to do it, such as the CDC.
- We need to treat child mental illnesses as chronic, needing lifelong management.
- We need to pay far more attention to early intervention.

### ***Mina Dulcan, M.D.***

Head, Child and Adolescent Psychiatry, Margaret C. Osterman Professor of Child and Adolescent Psychiatry, Children's Memorial Hospital Professor, Psychiatry and Behavioral Sciences and Pediatrics, Feinberg School of Medicine, Northwestern University  
Editor, Journal of the American Academy of Child and Adolescent Psychiatry

I have been asked to speak about the evidence base for treatment in child and adolescent psychiatry. The topic is much too long for this talk, but I will give some highlights.

First, where do we get empirically supported treatments? They come from randomized controlled trials where we select and assess subjects for age and diagnosis, determine exclusion criteria, measure their baseline condition, and randomly assign subjects to two or more treatment conditions. We then systematically evaluate the outcome, blind to treatment condition, by looking for improvement in symptoms and/or adverse effects. This is the only way to demonstrate cause and effect. Without these trials, we end up with confusion surrounding coincidental results, such as whether the results can be attributed to treatment or the natural course of disorders, the fact that people often come to treatment just when their symptoms are the worst, and the placebo effect. The placebo effect is a complex mechanism probably composed of expectancy, hope, and feeling understood and supported.

Treatments in research may not be analogous to the treatments received in the community. For example, treatment is usually free in research studies, plus there are research assistants ensuring that people come to treatment, stay in treatment, and follow the treatment protocols. It is important to remember the placebo effect in this context. The placebo effect is not just a sugar pill. You cannot walk up to someone on the street, put something in their mouth, tell them it will work, and get the effects. The placebo effect is the entire constellation of the therapeutic effects of the research study procedures minus the active treatment. Another way that treatments in research are not like those in the community is that the samples are selected and the subjects are willing and able to participate. The comorbidity is limited, and the treatment duration is controlled and standardized. In general, the treatment is less individualized in studies. We do not know whether this lack of individualization is better or worse for outcomes.

The treatments in research studies are carefully managed clinically. For medication, we do not simply write a prescription and say, "See me in



six months.” There is a careful assessment prior to treatment, systematic titration of dose, frequent and careful monitoring, and psychoeducation and support. Psychotherapeutic interventions are clearly defined, performed by highly trained clinicians with constant monitoring for fidelity to treatment.

Look at the recent fuss over pediatric psychopharmacology. Why is there such media attention? There are greatly increased rates of prescribing of psychotropic medications for children, which perhaps is necessary. However, there are not enough child and adolescent psychiatrists for appropriate evaluation, treatment, and monitoring of these youth. We do not know whether prescribing is appropriate. Is it the right diagnosis? The right medications? The right dose? Some people are afraid that managed care is forcing us to use medications we would not otherwise use to save money. Some people oppose any medication use for psychiatric problems in youth.

There are some disorders for which there is evidence to guide practice, and I will talk a little bit about attention deficit hyperactivity disorder (ADHD), obsessive-compulsive disorder (OCD), and major depressive disorders. There are a lot of myths about ADHD; some believe that ADHD is not a real disorder. We know from studies of impairment, of genetics, and of brain imaging that, in fact, ADHD is a real disorder. Some believe that ADHD is overdiagnosed and overtreated. I can hardly go to a restaurant without overhearing somebody saying there is too much Ritalin being prescribed. We know from studies and clinical experience that frequently a diagnosis is not made, or it is delayed, and that treatment is often inadequate or nonexistent for ADHD. Others say that stimulant medications are dangerous. We have no evidence for that.

What are the evidence-supported treatments for ADHD? We have medication. We know the most about stimulants such as the methylphenidate and amphetamine preparations. We also now know a fair amount about atomoxetine, or Strattera. Through hundreds of studies, we know that behavior modification works in the short term when and where it is applied, if it is done correctively and consistently. In controlled settings, behavior modification can add to medication or even replace it.

We have learned probably the most about the treatment of ADHD from the National Institute of Mental Health (NIMH) Multimodal Treatment Study for Attention-Deficit Hyperactivity Disorder (MTA) study. This is a very complex study, and I will try to give you the highlights. The study followed 7- to 9-year-olds with ADHD with intensive evaluation and 14 months of treatment. In all the treatment conditions, the core ADHD symptoms improved. Carefully titrated and monitored stimulant medication, which we call MTA medication, was the most effective for core ADHD symptoms, with or without additional intensive psychosocial treatment. The MTA medication treatment was better than community treatment, typically stimulant medication that was not very well-administered. The very intensive psychosocial treatment alone was equal to medication that was not very well-done but not as good as MTA

medication. Intensive psychosocial treatment, with or without medication, was helpful for comorbid conditions.

Switching to OCD, there are three FDA-approved medications for youth with OCD – fluoxetine, sertraline, and fluvoxamine. We also have research to support efficacy of clomipramine in the treatment of youth OCD as well as research to support the use of cognitive behavioral therapy (CBT). Recently, the NIMH Pediatric OCD Treatment Study (POTS) of OCD was published, which included extensive assessment and 12 weeks of treatment. All the youth received clinical management. This is a complicated study, and depending on how you measure the results, the picture looks a little bit different. If you look at global symptom reduction, CBT alone, sertraline alone, and the combination of the two – medicine and therapy – all were better than placebo. The combined treatment was better than either CBT or sertraline alone. CBT alone was about the same as sertraline alone.

However, if you look at the rates of clinical remission – in other words, how many children met criteria for being significantly better – it is slightly different. Fifty-four percent who received sertraline and CBT met these criteria. This was not statistically different from CBT alone. Almost 40 percent who received CBT, which was 14 sessions in 12 weeks, met the criteria for remission. About a fifth who received sertraline alone met the criteria for remission, but that was not statistically better than placebo. Only 4 percent on placebo met the criteria for remission.

Moving on to discuss treatments for depression, the medication fluoxetine was studied in the Emsley studies and the NIMH Treatment for Adolescents with Depression Study (TADS). Fluoxetine does have an FDA-approved indication for youth depression. We have data on sertraline, while we do not have conclusive data for paroxetine and citalopram. For psychotherapy for adolescents, we have data to support the efficacy of CBT and interpersonal therapy (IPT).

In TADS, all of the subjects received extensive assessment and 12 weeks of treatment, and everyone received clinical management. Looking at the rates of global positive response, 71 percent who received both fluoxetine and CBT were considered to be responders; 61 percent who

received medication alone and 43 percent who received therapy alone were responders, but this was not statistically better than placebo. About a third improved on placebo. Given the current controversy, it is important to note that suicidal ideation decreased in all four groups.

Currently, there is a lot of fuss about anti-depressants in the FDA. Why? The older drugs – tricyclics and MAO inhibitors – were less effective, more dangerous, and more difficult to use than SSRIs. But now that we have the SSRIs, which are actually very safe and very easy to use by primary care physicians, we have seen a dramatic increase in prescriptions as a result.

Why is there so much controversy surrounding psychotropic drugs? First, the results of the studies are not clear-cut. Studying depression is more like studying hormone replacement therapy than it is like studying pneumonia. With pneumonia, if you don't get a medicine, you will likely die, and if you do get the right medicine, you are cured. Depression is not so clear. The results are different according to the measure used, and many studies are underpowered with too small sample sizes. The placebo response, this nonspecific positive response, can be as high as 30 to 60 percent. The nonspecific effects of being in a study are quite powerful, and so it is difficult to demonstrate separation of active treatment from a response this large. Treatment in the community is poorly monitored. Also, there is the possibility for unfortunate events: Suicide is a consequence of untreated depression. I was taught as a resident, and it has not changed, that the risk of suicide initially increases as depression improves.

What is the current data? There is currently a reanalysis of pooled data from 24 short-term placebo-controlled antidepressant trials of well over 4,000 subjects with a variety of disorders. What comes out in studies is that looking at depressed subjects, the risk of suicidal thinking or behavior is about 2 percent of those on placebo and about 4 percent of those on active drug. There is no evaluation of the risk in untreated youth who are not getting all of the things that go along with a research study, and there is no evaluation over the longer term. It is



important to remember that not a single one of these 4,000-plus subjects in any of the studies completed suicide.

On the other hand, of all of these studies, only fluoxetine was statistically superior to placebo for the treatment of major depressive disorder. An interesting epidemiologic point for which we cannot demonstrate causality is that in geographical locations where prescriptions of SSRIs have increased, the youth suicide rate has, in fact, decreased.

In conclusion, we know a lot more than we did 10 years ago about effective treatments. But we need far more research, and we especially need to know which treatment is best for which child and which family. And we need the resources to implement the results of the research we have – the specialized manpower and the funding of services.

# Questions & Answers

**Q** I would like each of you to comment on the difficulty in transferring from the laboratory to the clinic, particularly in psychiatry or behavioral health.

**A** Dr. Mrazek: The translation process is interminably slow at times. I am personally aware of that in genetic testing, where the background knowledge to comfortably understand the results is not universally available to some practitioners. I think that it is education and communication. But I do not have the answer.

**A** Dr. Dulcan: I think it is an issue of resources. It is difficult in large communities where there are diverse means of funding and diverse clinicians to enforce any kind of standards. I think we are all here together to work on these issues and challenges.

**A** Dr. Costello: I would add that the problem is not so much the introduction of new treatments but the introduction of new evidence-based treatments. If you look

at, for instance, Julie Zito's papers on the increase in the use of psychotropic medications, particularly in children under 5, people have not been slow to do it. What has been slow is the research to demonstrate whether or not it is the right thing to be doing.

**Q** I am struck by the contrast between the opening presentation by Pam Hyde and the research presentations. The opening presentation highlighted the complex public systems that impinge on the lives of kids. The science approach was more focused on single-dimensional, single-diagnosis conditions, rather than the co-occurring issues or complex interventions. I would be interested in any thoughts on those issues.

**A** Dr. Mrazek: Ideally, the science will evolve, and there could be a greater integration between the highly focused evolution of new knowledge and the application within a complex system. I think the fact that we are putting them in juxtaposition and are talking about them may give us some ideas about how to do better integration.



# YOUTH PANEL

**Carl C. Bell, M.D., Moderator**

President and CEO, Community Mental Health Council

Director of Public and Community Psychiatry and Public Health, University of Illinois

Member, The Carter Center Mental Health Task Force

**T**his panel is going to talk about some of the challenges its members have had, some of the difficulties in their lives, some of the things that they have experienced, and – this is the critical piece – what has given them hope, resiliency, and what I refer to as “cocurro,” which is indomitable fighting will.

**Sinead:** I am 13 years old, and I was born in Atlanta, Ga. I had two parents who were on drugs, and I was poor with love for myself. I started doing bad things that I do not do anymore. Before I came to CHAMPS, a program children go through before they go to Inner Harbour and stay, I was inspired to do good things. I joined the orchestra at school: I play the cello. I also joined the Freddy Hendrix Youth Ensemble of Atlanta, a theater program. I just turned my life around and started doing the good things instead of the bad things. I am proud of myself as a person, and my heart is filled with love for myself right now.

**Jeremy:** I am 15, and I am currently residing at Inner Harbour’s group home. They have a boy’s group home that houses eight teenagers. I had a dotted childhood. My dad was in the Navy, and he was gone three months at a time. I did not see him at all. And when he was home, he was working. He got out of the Navy when I was 7, and after that he worked. He would get up real early, come home late, and sleep. I really did not have a dad.

When I was younger, I went through a crash course in death. My grandmother died when I was 6, then my dog, and then my grandfather shortly after that. My mom was always busy cleaning, and I have a brother and sister she was looking after. I would try to help out around the house.

I got sad because my girlfriend dumped me, and my parents thought I was depressed. They took me to a psychiatrist who thought it would be

helpful to send me to Ridgeview. Ridgeview sent me home, my parents sent me back to the psychiatrist, and the psychiatrist sent me back to Ridgeview. That kept happening over and over, and I got very angry. My brother had anger problems, and he would attack me all the time. I got very angry, and I did some very stupid things, self-mutilation, suicide ideations — you name it, I have done it. The only thing I have not done is drugs, and I am very glad for that.

What inspired me to turn myself around and get my act together is my natural gift from God: my intelligence. When I started landing in these places, I saw my schooling slip out from under my feet. It is hard to get a scholarship to a college if you are struggling in high school, and I need a scholarship because I do not have a family to pay for college. I figured out that when I get angry, the only person it is hurting is myself. I fixed that, and I started handling my anger a lot better and not doing any of the stupid things. I started getting my mind right. In the group home we are allowed to go to public school, so I am in public school and I am making straight As. I have turned myself around using my schooling to help me.

**Billy:** I am 17 years old, and I have been in treatment since I was 9 or 10 years old. When I was a little guy, I watched my dad be very abusive to my mom. I would get really angry, and I would feel like I could not do anything except hope and pray that he would quit. I do not really remember much of that stuff anymore because I have tried to forget about the things that hurt me.

At one point when I was young, I also was abused by people I trusted. That pain made me feel as though I needed to hurt others, and so I abused people I cared about. Before I knew it, my family fell apart, and I blamed myself. My family did not know what to do with me, so I ended up going to several treatment centers – too many for me to remember. In the past few months, after





working very hard, with the help of my mother, my therapist, and all the staff at Inner Harbour, I have begun to realize that my teenage years are almost gone. It just clicked in my head that I needed to be back with my family and restart my life.

**Angela:** I am currently in medical school, and I work at Georgia Parents Support Network where I am a peer mentor and also on the peer staff.

My life in foster care began when I was 6 years old. My mom did not want me. For years I said that it was because she was very young. Before then, when I was still at home, it was like I played the mother role to my siblings. When I left my mom to live in a foster home, I was very, very upset because nobody told me why I left. They could not tell me anything. I was 6, so if they had said anything, I would not have understood it. I have been in different foster homes and group homes. I have been in mental institutions.

I was the fighter. I fought for everything. I was ready to fight anybody who got in my way. I did not trust anybody. It was really hard growing up, having to fight in different group homes and foster homes. One of the things that used to bother me the most was one of the girls always got to go home on holidays, and I wished I had a family that I could go home to. That used to eat me up inside so much.

I am so happy now. I like my life. Right now I really hope my story can inspire other young women or young men, so they can know that even though you had a bad life and it was hard growing up, it can always turn out good later on in life.

**Dr. Bell:** What turned you around?

**Angela:** When I was younger, I got into a fight at church. I did not care what anybody said. I thought they were all gossips, and I thought they were fake, that they came to church on Sunday to praise the Lord, hallelujah, and everything,

but on Monday, Tuesday, Wednesday, Thursday, they are cursing and drinking. That was how I felt.

So one day when I got into a fight at the church, I left the church, and I said I would never go back there. I went on to another religion for a couple of years. Then one day I got hit in the head real hard. It was as if me and God had a little fight. After that I think I got beat down. That made me change. I really feel like the Lord beat me down and showed me some things, showed me the path that I was going down, and that it was not the right one. So that is pretty much what changed me.

**Dr. Bell:** Sinead, what changed you around? You are playing the cello and you want to be a pediatrician.

**Sinead:** Basically, the people who changed me were my mom and my auntie. I was still mad when I moved to Atlanta because of my situation, and I was terribly disrespectful. I just did not want to be that way anymore – I do not want to be that way anymore – because it is not nice being that way. It is kind of hard, because that takes friends away from you, and I have been hurt because of that. I am glad that I changed, because if I would not have, I would have been in jail somewhere. Or maybe dead.

**Dr. Bell:** Was there a lot of stress, growing up?

**Sinead:** I was not really stressed, I was just a person who would run away. I would be mad, but I would just run away from everything.

**Dr. Bell:** So when you were under stress you would escape?

**Sinead:** Yes.

**Dr. Bell:** And Jeremy?

**Jeremy:** What would I do with the stress? I would escape, but in a different manner. I would escape mentally. I would just not be there. I would get on my computer, and I would be in

fantasyland – goodbye, world, I was not there. I was in my own little world, and it was just a better place for me to be able to cope. I played role-playing games where I could be who I wanted to be, and it did not matter if my dad was not there. I did not have to do dishes; I did not have to make up for extra work that was around the house that my dad could not do since he was not there. Or I would read books. I read incessantly.

**Dr. Bell:** And so now your plans are?

**Jeremy:** I plan to become a computer programmer and program various Windows software. I am going to go to a technical college once I get out of high school, and then I am going to become a programmer. I am going to use my brain to get ahead.

**Dr. Bell:** So here is a perfect example of somebody turning lemons into lemonade. He retreats into his own world on the computer as a reaction to stress, and now he is turning that into a positive. Sinead, you did that with the cello. How did you take your negatives and turn them into positives?

**Sinead:** I replaced the negatives with the positives when I found something that I really like to do, and I do not have to go outside and get in trouble or something. I can just practice a lot for a show, which I have to do when I get home. And I can just practice my notes, look in my book, and I rarely go outside because it is dark when I get home, and that kind of keeps me out of trouble, too.

**Dr. Bell:** So did your experiences in life help you do better with your stage and theater activities?

**Sinead:** Yes, because I go every Saturday. When I was not in theater, I just used to go outside and play, or I would go downtown.

**Dr. Bell:** And shop.



**Sinead:** No, just walk around like everybody else. And I just really turned my life around because I really have something to do with my life every day – go to school, go to CHAMPS, then go to practice every Wednesday, then practice my cello, then on Saturdays I go to rehearsal for theater.

**Dr. Bell:** So you have structured, clear things you are supposed to do. Did that help you stay out of trouble?

**Sinead:** Yes, because I am usually busy during the week. I do not get home until 6:00, and there isn't anything to do when it gets dark except go to sleep.

**Dr. Bell:** Billy, how do you cope with stress? One of the issues which I think is particularly healing for people is when they take their stress and they do something to keep themselves from feeling victimized and helpless, and they take that feeling of helplessness and do something. And that turns it into a positive. Any examples?

**Billy:** Yes, sir. I have come up with a lot of ways to cope with my stress. I like reading books, and sometimes if I try to evade my issues and I go and read my books, it is like one of the only things that comforts me. Also, I talk to two people, my mom and Ms. Martini. They have taught me a lot about anger and stress and how to cope with it.

**Dr. Bell:** So you have had people in your life who have been there for you, whom you trust. I have always said I would not mind being an Indian if I could find a chief I could trust. And they are out there – they are just hard to find. You have people you trust, and there are people that are there for you. So there is a certain safety zone.

**Billy:** Yes, sir.

**Dr. Bell:** Well, Jeremy, you are shaking your head no. You do not have a safety zone?

**Jeremy:** I write. That is my safety zone. I write poetry, and I have one children's book written already that I want to get published. I am also working on a novel.

**Dr. Bell:** No people?

**Jeremy:** Not really.

**Dr. Bell:** We have to get some. It is not that hard to do.

**Jeremy:** I have switched schools every two years of my life, never had much time for friends, and my family is just my family here lately.

**Dr. Bell:** I know. But just because it was that way does not mean it has to be.

**Jeremy:** I have one person that I trust back at the group home I can talk to.

**Dr. Bell:** Angela, your turn. Stress, coping skills – what do you do?

**Angela:** When I am stressed out, usually I will go walking. I can walk for miles. That is just how I cope when I am stressed. Even when I am angry, I walk.

There was one bad experience that I had. I went to my mom's around Christmas. My sisters get real excited to see my mom, but I am not really so excited about it because sometimes it does not go right. This particular day, my mom was angry, and she started to take it out on us. We got into an argument, and I was looking at my sister and she was crying. So I told my mom, "Let's chill this time, just for her; let's not argue." Our fighting was upsetting and stressing out my little sister. That was one time when I actually said something positive to my mom.

**Dr. Bell:** So how did that feel, to take the high road?

**Angela:** It felt good. I felt real good that day. And after that, our visit went really, really well.

**Dr. Bell:** Do you believe that your experiences will help you be a good peer counselor?

**Angela:** I really do feel that. I have been through so much. There is a girl now – I sit down with her and I talk to her, and when she is talking, I see myself. I have been there; I did the same thing, and I am still coping with it. And I look at her and think, "That was where I was at that age." And to hear her tell me that I am a very good person to talk to really makes me feel good. It makes me feel like I am doing something.

**Dr. Bell:** Jeremy, what does Spiderman say?

**Jeremy:** "With great power comes great responsibility."

**Dr. Bell:** Right. And when we talked about the four of you cultivating and obtaining power, Billy, do you remember what you said?

**Billy:** Yes, sir. I said I do not want power over anybody except myself. I have a future planned, and I have power over my future and that is all I need to have power over: my future, me, and my life.

**Dr. Bell:** And your plans are?

**Billy:** I want to become a draftsman. I want to go to Northwestern Technical College. I also want to go into the Air Force when I turn 18. I am 17, a senior in high school, so when I go home next year, I want to try to go into the Air Force. After the Air Force, I figure that I will go to college and that is when I will become a draftsman and I will work with my dad.

**Dr. Bell:** Terrific. And where did you get the idea that you could make plans and they could happen?

**Billy:** From myself. I have thought about being a draftsman since I was little. I have always drawn pictures, which I have shown my mom, saying, "Mom, I want to invent this someday." And they were always farfetched ideas. My mom and a lot of other people I showed them to thought that they were farfetched. But I say just because you cannot do it does not mean I cannot.



they are resilient, strong, capable, competent, and have self-respect. Some of them know they are intelligent; others probably think – and they would be correct – that they are quite gifted. And they are OK. They have a future. There were barriers and there were struggles. There were things in life that knocked them down. And early on, they probably got mad at those

**Dr. Bell:** Anybody have anything else they want to say? Next we are going to take questions.

**Sinead:** The other negativity that I turned into a positive was when I got angry I was ready to fight. But now I just walk away. I just changed so much. I don't even recognize myself. I am really, really proud of myself. I want to be a pediatrician or become a singer or a cellist, whichever one comes first, and I hope singing comes first.

**Dr. Bell:** You can do all three.

**Sinead:** I hope the singing comes first so that I could just do my singing and quit when I'm 38 and then go to medical school, because I will already have a house, and I will not have to worry about having to pay bills. And when I do that, my mother is the first person I will spend my money on.

**Dr. Bell:** I think what you are seeing here are four exemplary examples of youth who have caught a fair amount of hell, and yet, you can see

things that knocked them down, but they went an extra step and they got back up. They got back up because there was social fabric around them that valued their future and cared for them. They got back up because there were services available.

Now, sometimes those services were “off the wall,” and sometimes those services were on target. We are here to fix the “off the wall” part and make it a little more on target. They did better because they were connected to people whom they could trust and believe in who believed in them. They learned skills. They have developed a sense of power. They have developed a sense of connectedness. They have developed a map and a sense of their uniqueness. They are addressing their issues of stress and trauma. I would expect that in the next few years we are going to see them in this room as decision-makers.

# Questions & Answers

**Q** Jeremy, what is your book about?

**A** Jeremy: My children's book is about a leprechaun in a forest. It is basically a life lesson about greed and wanting too much.

**Q** Could each of you tell us if there was a special person who helped you when you were down?

**A** Sinead: My sister helps me when I am down and when I just don't feel right. And my little niece, Cameron, is the only one I can cuddle up with when I'm sad. She's my comforter. I love her very much.

**A** Jeremy: My friend and fellow writer who is currently at the group home helps me. He has been through a lot, too, similar to me. He has done a lot of the stuff I have done in the past, and he understands where I am coming from. So I can trust him. When he is not upset, he sees things from a logical standpoint, and when I am not upset, I will see it from a logical standpoint, so we can help each other out. When we are both upset, we are in trouble.

**A** Billy: There is not just one person who helps me; there are a whole bunch of people.

**A** Angela: For me, it was my former foster mother, because she reminded me so much of me. I still call her to this day to get advice from her. And there is someone who stayed with me even though I got into so much stuff. Her name is Beverly.

**Q** Dr. Bell: I have a question. I am a psychiatrist and I sometimes see foster kids, and I sometimes see foster parents and biological parents bumping heads. Once I had a foster parent come in who was very good,

and I asked her why. She said, "Well, I always try to make friends with the biological parents, because a lot of times people catch stuff and it is not really their fault – they get caught up into some mess and it drags them down and they are not bad people. If I am friends with the biological parents and I am working with the foster kid and we are all trying to create a team, it works out better than if I get into an argument with the biological parents." What do you think about that as a plan? How do you think that should go?

**A** Sinead: Well, I agree with her because it is easier to get into the child's head when the child knows that the foster parent is closer to their parents, and it is easier for the child to trust the foster parent.

**A** Jeremy: I think it would be better not to get into arguments with the biological family. Right now I have a grandmother, and we have never gotten along too well. When I was little, she said "Let's go shopping," and when we were about to leave, she asked me who I wanted to ride with, my mom or her. I said, "Mom." And my grandmother said, "If you don't ride with me, I won't buy you anything." When she talks bad about my parents, it gets me upset. I cannot imagine living with a foster family who is getting into arguments with my parents, because even though they may not act like they care for me, I still love them, and I always will. And it hurts me for someone to be talking bad about them.

**Q** You talked about in about five years they are going to come back and be decision-makers. What can they tell us right now? What can they tell us today that will make things better? What can we do to make things better? What do they want to change?

**A** Jeremy: The most major thing I can think of is funding and stuff like that, because right now I'm funded by Georgia's MATCH program and they're threatening to stop paying for me because I don't get in trouble and I supposedly don't need to be in the group

# Questions & Answers

home. But I have nowhere else to go. They put pressure on my family, and then my family takes it out on me. And it causes more stress on me, and I don't need all that stress because someone wants money. They need to chill out with the money.

**A** Sinead: I would just talk to the children and tell them what I went through, and hopefully that will make them open their mind up to me because I've been in their situation. And I would try to help them and be their friend. I wouldn't just be a comforter, I would be a friend.

**A** Jeremy: I'd say listen more than speak. I've been to a few places where all they do is preach. Sometimes all a person needs when they are going through trouble is a shoulder to cry on and someone to talk to. There is this poem that's called "Listen," and it's beautiful. Basically the gist of it is that if I ask you to listen and you start giving me advice, you are not doing what I asked. Sometimes all people need is someone to listen to them so that they can talk. And not have to worry about getting in trouble because they say they are feeling depressed or worry about getting put on 20 different medications because they are saying they are a little upset over things that are happening in their family. My brother was in the hospital, his blood sugar was 597, and he had just developed diabetes. I was really worried about

him, and I said to my therapist that if he slips into a coma or something, I am going to see him. And she said that she didn't know if she could make that feasible. And I said I am going to go see him if he slips into a coma, because I really love my brother and I am not going to let him die without me seeing him. Then I got in trouble and had to sleep on the loft unit under close staff supervision for saying that if my brother slipped into a worse condition, I would want to go see him.

**A** Billy: I wrote a poem called "Please." It was about how I don't like it when people judge other people. A lot of people nowadays judge people for what they see on the outside, and they don't wait to get to know somebody. There's that saying, "Don't judge a book by its cover." I take that to heart, and it sort of hurts my feelings when somebody does that.

**A** Sinead: That's what happened to me. I had just come to middle school, and there were two girls – I hadn't even been there a week – and they were always trying to fight with me. Speaking of poems, I wrote a poem called "Earth," and I keep it in my agenda so when I get mad at school over something, I open up my agenda and read it, and it calms me down.



## PANEL 2: MOVING SCIENCE TO SERVICES

### **Larke Nahme Huang, Ph.D., Moderator**

Director, American Institutes of Research

Member, The Carter Center Mental Health Task Force

This panel is focusing on moving science to services. The New Freedom Commission report draws from the Institute of Medicine report, *Crossing the Quality Chasm: A New Health System for the 21st Century*, which stated that the lag time between discovery of

effective forms of treatment and incorporating them into routine care and practice takes 15 years on average. If you think of that in terms of the lifetime of a child, that means we are losing a whole generation of children.

### **William Beardslee, M.D.**

Psychiatrist-in-Chief, Children's Hospital

Gardner Monks Professor of Child Psychiatry, Department of Psychiatry, Harvard Medical School

Member, The Carter Center Mental Health Task Force

The subject of this panel, moving science to services, is the central challenge that we will face over the next 15 years. If we were meeting 15 years ago, we would have said we did not have very good evidence about what treatments or preventions work for kids. We now have a pretty good evidence base for both preventions and treatments, but we have virtually no experience in taking them successfully to scale. That is going to be crucial in improving the mental health of families and children. The Corcoran Collaboration, which is a group focused on when discoveries in medicine are implemented, estimates that it takes 15 years to move medical science to services.

It is important to acknowledge that the reason the children's mental health system needs transformation is that it is very badly broken. We must set an agenda for child mental health. Four recent reports have looked at the transformation project: the Institute of Medicine (IOM) report on prevention, an NIMH report bridging science to services, a Blueprint for Change report on research of children and adolescents, and recently the World Health Organization (WHO) report about prevention. They all emphasize the importance of the translation from science to services.

There are principles that run across all these reports: evidence-based practice, staff and family change, systems change, and integrative preventive interventions. It is clear that an intervention is far more effective if you can do several things within an intervention. We all believe strongly in the empowerment of staff, and we believe that we should be doing interventions that eventually become self-sustaining.

That said, it is extremely difficult to do this and very difficult to bring about long-term change, so we must be mindful of that as we embark on this endeavor. Some of the difficulties are the extensive time and effort involved in doing science-to-services work. We lack a tradition in child mental health of using evidence-based practice at all, let alone implementing new evidence-based practice. We certainly lack cultural competence in many different areas in terms of the way treatments are devised. In asking people to adopt a new strategy, you also are asking them to think in a new paradigm. We are trying to get caregivers to think about taking care of families, not taking care of individuals. That is a new paradigm, and using evidence-based practice is a new paradigm as well. Finally, whether we are talking to families, practitioners, or those of you in leadership positions in mental health, everyone



says the child mental health system is overwhelmed. There is a far greater demand than we can meet. Those are some of the difficulties.

I thought I would tell you a little bit about our own work. We did a major long-term efficacy trial on a preventive intervention for families facing depression. That forms the science base, and then we have done four replications of that in four different communities using different strategies. Our own work started out with one

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***Depression constantly shows up as the explanatory construct in why people do not do well.***

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of the first studies of children of parents with depression and then an examination of their resilience. We then did a pilot study and have done 10 years of enrollment and follow-up, with most of the hundred families we worked with being followed for at least eight years. After we had some pretty good evidence that the interventions worked, we went back and tried to figure out what actually happened to the families through a process of narrative reconstruction, going over everything they had said to us, and in many instances, going back to them and saying, "Did we get it right?" Then from the year 2000 on, we have been involved in the efficacy-to-effectiveness paradigm.

Depression is many different things. It is a diagnosis in DSM-IV. It often is the result of social injustice, as potent risk factors for depression are poverty, economic insecurity, exposure to violence, and lack of access. Depression is largely a chronic illness, a chronic recurrent condition. We need to think about how to manage that condition over the long term. It certainly is a rearrangement of neurotransmitter function. The key point about these different definitions is that the science base is going to keep changing all the time. We are going to have new treatments and new preventions, and so we must engage in understanding and implementing the changing science base.

We were most interested in what depression did to families. We think depression paralyzes the ability for families to have meaningful conversations together. It shuts down talking because depression is misunderstood, it is often stigmatizing, and because people who are depressed withdraw and try to protect themselves by not engaging. So our intervention is focused on getting families to have meaningful

conversations together about depression, and hopefully, through that, to have meaningful conversations about many other things as well.

Why should we be concerned about depression? It is the fourth leading cause of morbidity and mortality in the world today. But we should be concerned about it for a very different reason, which is that it constantly shows up as the explanatory construct in why people do not do well. For example, one paper reports that maternal depression has a great deal to do with why families are unable to implement care for asthma. Therefore, we must think about taking care of maternal depression if we are interested in asthma. Other studies have shown that if you are interested in simple things like health status, hunger, loss of financial support, and food stamps, you need to look at maternal depression because moms who are losing those supports are depressed. Early Head Start investigators estimate that 50 percent of the mothers in Early Head Start are depressed. Functionally, depression shows up throughout our health care and public services system. This is a problem we really need to take on in a big way.

We believe in a strength-based and resiliency-based approach. We did years of work looking at resiliency in various populations and in the children of depressed parents. The three characteristics that came through in the children of depressed parents were their intense involvement in age-appropriate developmental tasks, their deep commitment to relationships, and their self-reflective capacity, which involves both understanding the situation and also allows them to enter into religious faith or other kinds of membership in larger organizations. We believe that parents can be very effective parents despite depression.

Our aims were to increase positive family interaction, to help families have effective conversations about how to overcome depression, and to enable families to talk over the long term. All of the literature on depression in families shows that it is the interactions between parents and kids through which risk- or strength-based capacities are transmitted. That is why we were trying to influence family interactions. We also tried to do a public health intervention that could be used by everyone and was not dependent on a lot of extensive training.

The criteria were that the work had to be compatible with a lot of different theoretical orientations, have a strong teaching component, and involve the family as a whole.

We transmitted this information through talented young preventionists who did six-session family interventions by talking to the parents, to the kids, and then working with the parents until they felt ready to have a conversation with their kids. We then sat in and helped them have those conversations. In the classic public health sense, we contrasted that intervention with having a boring, aging, white male – me – give lectures about depression. Those were our two strategies because they are the two strategies most widely used in public health with families.

We have a tremendous set of findings. We have found that families reported eight to 10 behavior and attitude changes that were sustained over years. The parents who reported the most change had kids who increased the most in understanding. So this study did foster positive interactions and provide us with the data required to give us a science base. Then we went

back and asked the families about the behavior and attitude changes that they had attributed in earlier interviews to the intervention, and they said, “We are doing this because it is a good thing; it doesn’t have anything to do with intervention.” That is what we think intervention should do. The ownership should be given to the families.

As we looked at families over time, these two constructs really organized what was going on. Healers emerged from within families. They would help the person who was depressed get treatment. They would help the kids along, and they really took care of themselves. Another key point about depression is that the explanation for it cannot be static; it must be dynamic as the children age and ask more penetrating questions. As children develop, they ask different questions, and so the depression has to be understood anew.

We have done four different replications. Because this work originally was done largely with middle-class families, it was important to see whether it worked with inner-city families who are in poverty. We did a randomized trial in



Dorchester that showed the same effects as the middle-class sample. We also developed a program for Latino families, and we are working on a large-scale implementation strategy in Finland as well as working with Head Start.

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***One of the key components of our work was to join with other caregivers.***

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In Dorchester, we felt that we had to engage first with the community, then with caregivers, and then with families, in that order. We worked with a community organization, Dorchester Care, as we formed a specific group to do research. That way, the research group was part of the community. People have a lot of resentment toward outsiders coming in, so for nine months we engaged with the community, working in food pantries, conducting public education about depression, and working on a variety of community projects. It is absolutely crucial to go slow and build trust.

One of the key components of our work was to join with other caregivers. If somebody else was working with the family on depression, we called them and reinforced the work. In that way, we were able to integrate our work into the care system.

Finally, we worked directly with the families. In the middle-class setting, it was very helpful to view depression in a medicalized context, as a medical illness. In Dorchester, however, the families universally said, "We are depressed because we are oppressed, because we are confronted with violence, with lack of access, with racism. And it has led us to be beaten down." We absolutely agreed with that. Another issue in working with the poor was that we had to become very engaged in the immediate needs of the family, such as getting the lights turned back on, getting food stamps, and getting basic life necessities. By viewing depression within the social context and helping families with their



basic requirements, we were able to have very powerful family conversations and to show the same kind of effects that we showed in the earlier work with middle-class families. When a replication is done well, it transforms the intervention. We learned so much from the folks in Dorchester.

As we moved then to the Latino community, we put together a bicultural, bilingual team to work on adapting the intervention. We wrote a conceptual review and saw some families in a pilot. We rewrote the manual, and we are now underway on an open trial. There were several adaptations that had to be taken into consideration. First, Latinos were more interested in the family as a whole. They had an allocentric orientation, which is an orientation to positive group work as opposed to individual work. Also, many families were in immigrant situations where part of the family was in the country of origin and family members here in this country all were in very different stages of acculturation. Some kids were very fluent in the dominant culture while the parents were not.

We had a wonderful opportunity in Finland because we were asked to think about implementing the intervention countrywide. We got support from the health ministry and from the Finnish Academy of Sciences. We then ran two public health campaigns, one for Finland's administrators to interest them in a program for depressed parents and one for general public health. Those campaigns really provided a lot of groundswell for the work. We chose to use a three-phase strategy: first, public awareness; then training the trainers; then implementation. We have done two open trials of the intervention. We have a randomized trial underway, and it is now in use in about a quarter of the 20 health districts. What we learned in Finland was that it is wonderful to work in a country with national health insurance because there are tremendous incentives for prevention and there are also incentives to be very conscious about cost. Finland is a wonderful, young social democracy with a lot of optimism and idealism. They really do believe that there is a public responsibility to care for families.

Finally, the Head Start program in Boston approached me because they had seen the book I had written about families. The challenge in

Head Start is how to take a program that is doing very well and celebrate and support the people on the front lines while we add a new element. This happened to be an Early Head Start that we started with, so we had a new issue of how to work with infants to 3-year-old children. We were able to think about the same principles of positive family interaction and reaching out and cast it in a center-based way. We incorporated a series of training programs for staff and for families, asking them what they wanted. We then coupled that with classroom support for teachers, the evidence base about what works in early development, and with a specific knowledge of depression. We recast depression to be families facing adversity and how they could talk to their kids.

The most striking information we learned in Head Start was that as we began to do these workshops with staff, we found that they themselves were wrestling with depression in many different ways – with the families of the children in their care as well as with their own lives. It was very important to support front-line staff in their own journey to make sense of depression.

I could say much more, but recognizing that time is short, will sum this up in a couple of recommendations for doing replications:

- Each replication was like doing it anew. We wrote a new manual and engaged local community and staff to be the lead authors of it.
- Building in support for one another is crucial. In each of these replications, the teams met once a week, often for years.
- Administrators must create for their staff time and space for reflection.
- Seek partnerships with other caregivers.

Here we are in Atlanta, the place where Martin Luther King was most active. As we are working on the front lines, it is important to remember Dr. King's words, "Of all the forms of inequality, injustice in health care is the most shocking and inhumane." We need to come back to the fact that it is simply wrong not to take care of all children and all parents.

**Carl C. Bell, M.D.**

President and CEO, Community Mental Health Council

Director of Public and Community Psychiatry and Public Health, University of Illinois

Member, The Carter Center Mental Health Task Force

**W**e keep having this difficulty of efficacy. We do the research; it goes on the shelf and so what? We have been doing work for years at the Community Mental Health Council in partnership with the University of Illinois to try to do the kinds of things that we need to do to put children in a good position. Despite all the talk about genetics, it is the environmental context that causes those genes to pop out or not to pop out.

I have been doing public health for 30 years, and what causes people to change their behaviors can be summed up in seven field principles, which you heard from the children last night:

- Rebuild the village
- Create access to evidence-based health
- Be connected
- Develop social skills
- Gain self-esteem and self-respect
- Re-establish an adult protective shield
- Minimize trauma

Today we are working at cross purposes. Everybody is working hard to save children, but we are going in different directions, with different languages, resource silos, and goals. We need to develop a model of synchronicity, evidence-based common languages, outcomes, and maximized resources. In other words, we need to have all these different organizations

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***If you are connected, it makes you feel stronger.*** working together. To do that, you have one player who brings all the other players to the table, and they construct a shared common vision

about how this should work. And, of course, it helps if all the money is going in the same direction toward the same purpose as well.

At the Community Mental Health Council, we have several evidence-based interventions. We are doing research on consumer satisfaction. We have multisystemic therapy, which reduces delinquency from 70 percent to 40 percent. We are doing a lot with juvenile justice, trying to do assertive community treatment. It is clear that as

academicians and as clinicians we have the ideas, but we do not put them into play. So a big piece of what we do is develop the leadership and the management style that will put ideas into action.

There is no reason why a Chicago-based service would have a research grant to do research in South Africa on HIV prevention, but we do because I have two businesspeople who take my ideas, which are hopefully directionally correct, and put them into practice. I am connected with the University of Illinois Institute for Juvenile Research, which has been doing evidence-based manualized interventions with delinquents. The work is good, evidence-based interventions. Together, we decided to take this approach out into the real world and begin to break the paradigm of taking 15 or 20 years to get this type of work out into the community. So the Community Mental Health Council collaborated with academia to develop a model and spread it around to many other community-based organizations.

We are currently doing an HIV prevention program in South Africa. This is an intervention that we developed on the west side of Chicago, which we brought to New York, Trinidad, and now to Durban, South Africa. It is a family-based model. The academicians and the service providers partner with the community facilitators, and it is the community family members who deliver our intervention. I do not speak Zulu and have no intention of learning. I do not need to. I have partners in South Africa who are going to do the work for me.

The principle of rebuilding the village is that if you are by yourself and you are raising a child, your child is in danger. You need social fabric. You need people around you who are going to help you. It is our notion that if we could get families to pool resources, they would actually be stronger, and so we had games that we would play, connectiveness games. What makes children resilient is connectiveness. If you are connected, it makes you feel stronger.

We also try to give kids social skills. For example, teaching children the skills to refuse drugs in a way that is acceptable to their peers and how to get support from parents and other adults. We also teach parents how to monitor their kids. Sinead last night talked about playing the cello and working in the theater. Because she is in all these activities, she is being monitored. That is what is keeping her safe and out of harm's way. We also addressed the issue of parents' social skills in terms of parenting.

It is hard to have federal conversations about this, because they say, "Why are we giving you taxpayer money to go to South Africa and help them?" Well, the reason is, as Satcher said, "Hey, germs do not need a passport." So if we do not take care of the health of the world, we are in trouble in America. Secondly, in my experience, it is a lot easier to do an efficacy, effectiveness, and possibly a dissemination effort in another

country because there are not 12 people outside the school or outside the community coming in to say, "Hi, I have an intervention I want to test." So if we

can show efficacy and then re-import it to

the United States, I think we will have gotten a lot farther. Through this work in South Africa, we are getting good, hard scientific results in regard to the issue of AIDS.

We have another intervention to try to look at ways to reduce rape in South Africa by working with kids 10 to 13 years old. Then we are going to import that back into the Department of Children and Family Services in the state of Illinois.

Let me shift gears and talk quickly about another intervention around bonding and

attachment. We developed a "cradles to classroom" intervention in Chicago. For the life of me, I do not understand why this cannot be everywhere. The Chicago Public School System identified every pregnant teenager throughout the school system. Instead of kicking those kids out of society and out of life, we gave them this program, in which they got support and connection with others. Before we started the program, half of these 2,000 girls dropped out of school. After the program, all stayed in school, and 78 percent went on to college.

If you hear nothing else that I have said, the key message is that we have to stop being academicians, policy-makers, and service providers, and we have to partner with some businesspeople. Those of us who are bright and intellectual and doing all this good work think we can hold hands, sing "Kumbaya," and something is supposed to happen. That is not how it works. We must have a plan. We must have a way to make our plans operational.



**Trina Osher, M.S.**

Program Director, Family Leadership Initiative, Federation for Families for Children's Mental Health

Goal two of the New Freedom Commission report is about mental health care being consumer- and family-driven. There was a set of recommendations under that goal. I am going to focus on the second recommendation: seeks to involve consumers and families fully in orienting the system toward recovery.

The question I have is, "Why should we shift gears? Why bother to change what we are doing now?" The first reason is to get better results because families and youth are the engine for system change.

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***We will not give up, as individuals seeking help for our children or in our collective voices seeking systems change for our nation.***

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We know what works for us. I have a tremendous appreciation for research, but frankly, I do not need a researcher to tell me if my life is getting better or worse. But I do need a researcher to define, describe, manualize, and educate others about what works for me and for my friends and the other families I work with. Because together our collective experience is what research is about.

We also know what our limitations are. We know whether or not we can participate in what you are offering us and asking us to do. Sometimes, because we are so desperate for service, we say "yes" to anything that comes along, even though it is not something we are prepared to participate in or can participate in. We can keep track of services and change better than anybody because we see it day to day. Those of you who are clinicians have to wait a week or sometimes a month until you have an opportunity see any change. We see it on a regular basis. We can make shifts. We can see the necessity of adjusting treatment on a more frequent basis.

Another reason to shift gears is because we really need family involvement to change systems. Beyond our individual interventions, beyond the wellness and health of our own families, we must have a mission for change in our country. Our experience as individual

families collectively becomes holistic for our nation. We face challenges every day. And you know your children never grow up. My children, who have brought me into this life, this work, this system as an advocate for families and kids are now young adults with their own children.

This is a multigenerational issue. That is why we are talking about families. What happens to children affects other children in the family. It affects adults. Adults respond to what is going on in their children, the same way children respond to what is going on with their adults. This is a constant in our lives. We can never get away from it. We are passionate, and we will not give up, as individuals seeking help for our children or in our collective voices seeking systems change for our nation.

Let us find a definition for "family-driven" because if we are going to have family-driven, we need to have a common understanding about what it is about. With support from the Substance Abuse and Mental Health Services Administration (SAMHSA); the Center for Mental Health Services; and the Child, Adolescent, and Family Branch, the federation has been working in collaboration with many people on developing a definition. What have the steps been in the process? First we organized an expert panel. It was a professional, family-balanced panel. It was culturally diverse, geographically distributed, and included a variety of perspectives. We also interviewed recognized leaders in the family movement and recognized leaders in children's mental health in general. We held open forum discussions. A literature review was conducted. We solicited feedback and have continued to solicit feedback from communities in the system of care and from family-run organizations across the country. We have been getting reactions from people like you at presentations like this. We are now at the fifth version of the definition.

"Family-driven" means families have a decision-making role in the care of their own children as well the policies and procedures governing the care for all children in the community, state, or nation. This includes:

- Choosing the support services and providers that are involved
- Setting the goals for individuals and systems
- Designing and implementing the programs
- Monitoring the outcome and determining the effectiveness of efforts to promote the health of all children
- Promoting the mental health of all children, not just treating the illnesses

When we first started doing this work, developing this definition, one of the first questions that came up was, “OK, so it is great we have families; what about the youth?” Now, you heard youth last night. They spoke very well for themselves. Youth has a voice. Even though we do not give it to them, they take it. So we may as well start listening and thinking about the directions youth want to go in their care as well. Just as the federal agencies are working with families to develop a family-driven definition, they have begun to work with a group of young people to develop an understanding of what the role of youth is in directing their care. I want to pay attention to that and look for it at future meetings.

While we thought it was great to have a definition, we also needed more than that. We also need to know how to find it and how to get it. We needed more meat on the bones. So we have developed a set of guiding principles. The first is that families and youth have accurate, understandable, and complete information. A lot of the information presented is not understandable or usable. Right now, every time I want to write something, I must go through special efforts to find extra funding to translate it into Spanish. Yet half the families I deal with are Spanish-speaking. This is

not fair. This is not a family-driven system. Families need information if they are going to make choices.

Families and youth need to embrace the concept of sharing decision-making responsibilities with providers, researchers, policy-makers, and others. We have to share responsibility for the decisions and the results. The same thing is true for folks on the other side of the table. Providers and policy-makers have to shift their thinking and embrace the concept of sharing the authority they have for decision-making. The authority they already have comes with their expertise, training, position, and the budget that they control. That should be shared with families and youth.

Providers have to take initiative to change practice. Each of us has to take personal responsibility for our own change. Providers have to make a personal commitment to change, and administrators can support that by allocating resources, allocating staff training and all the support that go into running an agency in ways that support this shift.

Speakers before me talked about the importance of connectiveness. Peer-to-peer support is the one thing that reduces the isolation that families experience more than anything. The first time I ever spoke with somebody who had an experience like mine, I cried, because it was the first time I felt I was not so weird or so out of the mainstream. It was the





first time I felt it was not all my fault, that I was not crazy. I learned that I was dealing with an incredibly difficult situation and somebody else had survived it. It gave me a vision of a future that I never got and never could get from a professional.

And overall, the big shift we have to make is in community attitude. If we remove the barriers created by stigma, we will be able to embrace the notion that children's mental health is important.

One criterion of a family-driven system is that administrators and staff actively demonstrate their partnership with families and youth by sharing power, resources, authority, and control. Administrators and staff need to share how they are going to operate and involve families in decision-making about all aspects of service delivery and about the design of the systems themselves. When the power balance is out of whack, when there are people in the room who

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***Know where you are going  
but consider alternative  
ways to get there.***

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have the authority to do things such as take your children from you, or kick them out of school, or deny them a service, or give them a service, you are cautious. This is not about being resistant; it is about being protective. We want to keep our children safe. We want to keep our families whole. We have to create an environment where even when there are those threats, we can ensure that speaking honestly does not create a negative consequence. We need to create an environment wherein when there are threats to family safety, we can be honest about those threats and talk about them candidly. We have to think about consequences in a very different way.

How do we get there? We can use the analogy of driving on a road trip. First, we must consider the alternative routes. Know where you are going but consider alternative ways to get there. There is more than one way to do it. Research the pros and cons of any choice before you make one. Use tips from other families who have made this journey before, from other professionals who have worked with families that have made this journey before, and consult with people who have a lot of knowledge about this kind of trip.

Once you know where you want to go, get the training and help you need to get there safely. Have companions with you who watch for landmarks, hazards, and detours. As a family member, I often tell a little story about a journey. The family is in the car, mom is driving, and in the back seat are all of these agency providers. They are the experts. They are the traveling companions who support me in my journey. But I am still driving. If they see a hazard coming up, they tell me about it so I can avoid it or pull off the road. If I have a flat tire, they can get out and help me fix it. But it is really important for everyone in the back seat to have a common vision along with me about where we are going and how we are going to get there. Because when the corrections authority, the school authority, the mental health authority, and the child welfare authority do not agree about what the course of action should be, I am not able to drive because if I make a left turn, someone is screaming at me, "You should have turned right." I cannot function that way. That adds to my stress and my depression. It makes the whole thing a disaster.

To be successful, you must take precautions. You have to know in advance where you can get emergency help. This is the crisis plan. You have to have a determination that if you are diverted from your goal, you will get back on that road as soon as possible. Do not let the little things take you off the main course.

When you are done, you have to share what you did, how you did it, and what helped you do it with other people so they can learn from what you did. That is where the family-to-family network really counts. We have to teach our youth how to drive, because someday every single one of them is going to be in the driver's seat. We want them to be good at driving. We want all their journeys to be safe.

This is about changing relationships. Everybody has a point of view, but everybody needs to take a moment to view the process from somebody else's point of view to better understand it. We have to interact in different ways, and we cannot unless we know a little bit more about how other people are responding to what we do. We have to believe that we can do this together.

# Questions & Answers

**Q** I have been trying to get a little synergy going in my county with some local organizations such as the NAACP. Also, I have been trying to move toward prevention, particularly in the area of juvenile justice. The question I have is whether there is one manual for all the different resources and work being done that would be a good starter kit that is action-oriented?

**A** Dr. Bell: My MBA folks and I have been developing actual steps on how to go into a community and make friends. You make sure you get trust. You involve the community in the design of what you are doing. The hard part is that models are like toothbrushes – everybody has one, but they want to use their own. So what you really have to do is get people in that room and do the work.

**Q** I am interested in the combining of knowledge from the heritage at the Salvation Army with good science. My problem is how I get good science so I can apply it in two sites in Atlanta in the next few months.

**A** Dr. Beardslee: You get the organization to a point of being willing to make change, being willing to implement two or three different strategies. You start by picking an area that is central, prominent, and important and one you are likely to have some success with. Think about the transformation process as a several-year effort at best.



## PANEL 3: STRATEGIC IMPLEMENTATION

**Mary Jane England, M.D., Moderator**

President, Regis College

Member, The Carter Center Mental Health Task Force

I just want to spend a minute to say thank you, California, for passing Proposition 63. Proposition 63 puts a 1 percent tax on people who make more than \$1 million to fund mental health services for children and families. It will fund the community health services that we want.

The juvenile justice system is really the *de facto* mental health system for most of this country. There has been a good report done by APP Associates looking at the numbers of kids who languish in child detention in need of community mental health services. It is something that I think all of us have to get really involved in because that is where the kids are ending up. And as you know, many of those kids attempt suicide. There are tremendous tragedies that occur in those detention centers. They are ill-equipped. There are some good models about how we can begin to address that, however.

We have an opportunity to look at modern quality improvement techniques that industry started in 1980 when the Japanese car companies

were beating the pants off the Detroiters. They realized they had to put in continuous quality improvement. As you know, the Institute of Medicine (IOM) came out with a report that jump-started the quality initiative in health care by reporting about how 95,000 people die each year from medical error. They then came out with an approach and a set of principles with the *Crossing the Quality Chasm* report.

We have a lot of kids with mental health and addiction problems in our colleges. We are beginning to come together to look at some of these issues, particularly those that directly relate to depression and suicide. We find that the kids who commit suicide are not necessarily kids that we would think of as depressed. Often they are doing well in school and active.

I have a national policy solution that addresses the issue of providing health care coverage for everyone in this country. In Massachusetts, we have a law that every student who enrolls in college or university must have health insurance. So the colleges and universities cover the

students, purchasing health insurance for them. We have our own student health services and health insurance for every single student in university and college in Massachusetts. New Jersey has an adaptation of that.

If we were to cover all college and university students who are uncovered today, we would get \$4 million toward that \$44 million. So this is an area that I challenge you all to look at. If you have any interest in data and how it is worked and what it costs, I have plenty of that information.



**Jane Knitzer, Ed.D.**

Director, National Center for Children in Poverty, Mailman School of Public Health, Columbia University

I have been asked to provide some context for the transformation of children’s mental health and then talk about some of the critical implementation issues. How do we create the enabling infrastructure to support the range of things that we need? I am going to start with the Joint Commission on Mental Health of Children Report in 1969 that said, “If you think of the nonsystem for children’s mental health, try to change it.” That was 1969. It can still be said today. So we need to get it right. Time is running out and knowledge is increasing.

I am going to start with what we learned. I did a report in 1982 when I was at the Children’s Defense Fund called *Unclaimed Children: The Failure of Public Responsibility to Children in Need of Mental Health Services*. The mistake in the title was that it did not say “Children and Families.” This report was based on interviews with families. I spent a lot of time talking to families and hearing their stories of how they knew something was wrong with their kids but the pediatrician said, “They will outgrow it.” These are stories all of you have heard. We did a 50-state survey of mental health agencies. And we did a survey with the National Mental Health Association. I want to talk about the findings because, in a time of often high rhetoric and less implementation capacity, I think it is important that we stay grounded in what is really going on out there. So, we can use 1982 as kind of a benchmark.

Too many children are underserved. It is conservatively estimated that two-thirds who need services get them. The nonmental health systems were responsible for most children in need of mental health services, such as juvenile justice, child welfare, and special education. In those days, we talked about exchangeable children and said that one of the policy solutions would be to have exchangeable administrators who moved from system to system, the way kids move from system to system.

Families struggle greatly, and these are the conversations that echo in my mind still today: little help in finding services and no respite. Parents desperately need respite care. I have

talked with parents who said they had not been to a movie in 10 years because they could not get anybody to take care of their child. It is very humbling, and we need to do better. At that time, families had to give up custody for respite. I am demoralized to have to say that we still have not solved the issue, which is primarily a fiscal problem.

There were few parent support groups and few intensive community-based services. Only 21 states had a dedicated children’s mental health person. We found that only seven states had taken any steps to create a “system of care including a full range of mental health services delivered in a coordinated fashion.” Now that has changed, but we do not know to what extent. Woefully few states targeted resources to infants, toddlers, and young children, and that is still true.

Taking stock in 2004, too many children are still unserved or underserved. There is still no respite care except for custody relinquishment, but many more families are having positive experiences. I have been in some meetings with parents of young children who tell me how supported they feel as the early intervention programs are beginning to understand that they have to deal with relationships and behavioral issues. We have not really done what we need to do with the health care system or with pediatricians, but there are some significant changes.

On the other hand, there are still the same kinds of horrors such as not being able to get a psychiatric assessment until you had a certain number of “visits,” no matter how severe the need. A mother reported she could not get any help for her 5-year-old until the child tried to smother another child. We need to take these stories very seriously, not only to create a family-driven system but also to listen to the pain families still experience and get them connected to family networks.

New issues are emerging. I did not talk about substance abuse and comorbid conditions in my report. I did emphasize that the children least likely to be served were poor children,



adolescents, children of color, and children whose parents were involved with the adult mental health system, and that has not changed. I think a major transformation could occur if we could get the adult system talking to the children's system and get both thinking about how to support family-centered care. I have spent the last eight years talking about early childhood mental health, and it is impacted by parents dealing with domestic violence, by maternal depression, and by substance abuse.

No one agency or system is clearly responsible or accountable. While there is significant funding, they are for demonstration projects and not for building capacity. I wonder whether the funding actually pays for the right services. And will the greater reliance on Medicaid and managed care mean a clash between a family-focused, developmental mental health paradigm and a medical-model paradigm? I think that is a major clash that we must figure out how to confront.

There are three powerful new drivers for change. First, we now have a stronger family voice through numerous family organizations. I do think that there are opportunities for bringing family voices together. There are parallel groups

in the health care system, family voices for children with chronic health disabilities. We have never had a conference that has brought all of those family groups together. I actually have pledged that the National Center for Children in Poverty would love to convene such a meeting because we are all out working in parallel structures on the same kind of framework, and I think there is a real potential for advocacy there that we have not tapped. Second, we clearly have a stronger knowledge base. Finally, we have both the New Freedom Commission Report and IOM report as the drivers.

Next, I would like to talk through three core policy challenges. First, I want to say "hats off" to the president's commission for calling for a shift away from a focus only on serious emotional disturbances and toward an approach that is developmental, paying attention to early childhood mental health, to school-based mental health, and to mental health issues for older kids. Developmentally, those are different kinds of challenges, and we need a workforce that is skilled and knowledgeable about development. We need resource allocations that vary, and we need partnerships that are different. Engaging

with the early childhood community is different from engaging with the juvenile justice community.

The second challenge is getting fiscal practices in sync with emerging knowledge and with the paradigm shift. This is the elephant in the room. Given the tough environment that we are in now, I would like to ask that The Carter Center take a leadership role in helping us figure out how to build the intellectual capital and a community vision on what funding for children's mental health really ought to look like.

The third core policy challenge is developing models and incentives for infrastructures to integrate ongoing emerging knowledge.

The bottom line is that public mental health for children, for better or for worse, is focused now on seriously emotionally disturbed kids. It was not always that way. In the 1970s we had a mandate through the community mental health centers that community mental health centers provide consultation and outreach to early childhood settings and to schools. We have lost that as a definition of an appropriately reimbursable mental health expense. That is dreadful.

What should the mental health system be? Should it be for all children? That is obviously not feasible. Should it be for high-risk children and seriously emotionally disturbed children? Should it be only for seriously emotionally disturbed children if we could move the other systems to pick up the high-risk children? Where should we be going? This has implications for state and federal legislation, and I do not think we have actually talked about how we get from here to there.

We do know a couple of things that we can do tomorrow. We can deliver services where the children and families are. We are still battling in some states with office-based therapy. That is ridiculous. In evaluating the national Early Head Start program, it was found that it made a series of modest but significant gains, all in the right direction, in both outcomes for the children in behavior and cognitive measures and for the parents in reducing harsh parenting and learning more about child development. However, in families with four or more risk factors, Early Head Start did not work as well. It did not harm kids,

but it really did not help them either. For those children, we need to nest more intensive mental health and trauma-informed initiatives into normal settings, such as Early Head Start and schools. That is why it is critical to get out of the office.

We have some other challenges on the paradigm shift. We do not really organize the level of our interventions around the intensity of risk factors, despite the fact that we know that the more risk factors children and families experience, the more likely mental health problems will emerge. The nested kind of thing I was talking about in Early Head Start is one model. We do not maximize the impact of existing prevention and early intervention funds. What if we asked states or counties to do strategic plans around all the prevention money that comes in? We have prevention money by single-risk factor, but that is not what makes the difference. The cumulative multiple risks make the difference, and we have to organize our funding that way.

For the fiscal challenges, we have to learn how to spend smarter. There are disconnects between the rhetoric and the reality. I am going to be fairly blunt: I do not think Medicaid is often part of the solution. We have a family-driven system that we aspire to, yet we still talk about indicated clients. Some states cannot pay for a team meeting through Medicaid if the child is not present. Some states cannot pay for parent/child therapy. Then we get into truly ridiculous situations where you have infant-toddlers and the community mental health center says they do not know whether it is the mother or the baby who is the indicated client. That does not make any sense.

And, as you heard last night, if kids get better, we may make them homeless. That is not consistent with the *Crossing the Quality Chasm* principles of continuous quality care and healing relationships. We have a lot of those Catch-22s.

We have a cumbersome change process around fiscal issues that is even worse than our other change processes. We change Medicaid service by service, state by state, region by region, without any guidance or help from the federal government. That is not a very cost-effective way to build in our knowledge. Many states have

figured out how to use Medicaid in good ways, but those best fiscal practices do not routinely transmit to other places.

For the infrastructure challenges, the question is, "How do we create state, community, and academic infrastructures to integrate emerging knowledge in an ongoing way?" As you heard yesterday, mental health diagnosis and treatment are going to look different in 10 years as we understand more about genes. How do we make sure that we have the capacity to build that in? Some of us in this room have spent more time than we care to remember trying to change academic training requirements so that we

actually train people who can go out into the field and do what they need to do. We need to move ahead on that.

The New Freedom Commission's vision creates hope, is developmentally responsive, and has the potential to create knowledge-informed, cost-effective systems. We need to follow the money and reallocate the money. We need to build partnerships. We need to think populations, public health, and mental health. We need to think common system. We need to explore new legislative frameworks, particularly around how we get targeted funding for those multiple-risk kids without a diagnosis, and we need to mobilize new kinds of advocacy.

**Sheila Pires, M.P.A.**

Partner, Human Service Collaborative

**W**e need to take a "strengths-based" approach to model for advocating reform. There are two opposing truths: There are strengths in the system and a body of knowledge to build on, while at the same time, things are a mess. We must not get lost in the mess and recognize the strengths.

As one of the co-authors of the issue brief for the President's New Freedom Commission and the Children's Subcommittee, I am going to talk a little bit about those recommendations. Maybe more importantly, I am going to talk about some of the strategies already being implemented around the country. Listening yesterday to Pam Hyde, I was struck that the purchasing collaborative that Pam talked about did not appear from nowhere. It is built on a body of knowledge around building more integrated delivery systems, more systems of care for children and their families, and on a body of knowledge about what works best in managed behavioral health care for children and their families. To its credit, New Mexico has taken advantage of that knowledge and built on it.

I want to begin with some context from a policy standpoint about who the children and families are that depend upon public systems for behavioral health services and support. This is an important question because I think we tend to

think in a very compartmentalized way about children and families and because the public system is so critical to the provision of services and support. We have not only children and families who are eligible for Medicaid and the state children's health insurance program but also poor and uninsured children in families who do not qualify for the eligibility cutoff in Medicaid. We also have families who are not poor uninsured but who have exhausted their commercial coverage, usually because they have a child with a serious disorder. Since our health care system is built on an acute care model, it has historically relied on the public system for more extended or long-term care. Then we have a population of families who are neither poor nor uninsured and they have not exhausted their commercial coverage, but they turn to the public system because they need a particular type of service that their commercial carrier will not provide, such as respite services, treatment in foster care, or behavioral management.

When we do something around one of these populations, it will affect the other populations. We have not done enough thoughtful thinking about that. For example, when states begin to Medicaid their systems – take general revenue dollars and move it into Medicaid match arrangements – it leaves fewer general revenue dollars available for families that do not qualify

for Medicaid. It then creates more tension in the system and more instances of families having to relinquish custody in order to gain access to services. I can remember when the state children's health insurance program was launched. Some states actually cut their children's mental health budgets on the premise that State Children's Health Insurance Programs (SCHIP) would now be covering children and providing mental health services. But the mental health benefit in SCHIP arrangements, unless it is modeled after Medicaid, is a very acute care benefit package. This is of limited utility if you are a family who has a child with a serious disorder.



What system can families, this total population of families, turn to? As we have heard repeatedly, there is no one system. The fact that we have no one system is driven primarily by the financing. In most places, it also is impossible to find a locus of accountability. There is no locus of accountability for prevention in children's mental health. The President's New Freedom Commission broadened the focus on children with serious disorders to include early intervention for children at risk and prevention for all children. We have many examples of categorical system reforms, efforts to try to reduce foster care placements and lengths of stay in child welfare, and efforts to provide alternatives to incarcerations in juvenile corrections. The President's New Freedom Commission report built on a system of care values and principles that begin with a population focus and then looked at the array of stakeholders and the resources that they control that need to be mobilized in order to make a difference.

Transformation requires change at multiple levels – policy level, management level, front-line practice level, and community level. It is sort of multitasking, which makes it so difficult.

People have a lot to do in their lives, and it is hard to undertake something as complex as systems transformation. On the other hand, we expend an extraordinary amount of energy complaining about the problems created because we do not expend the energy to collaborate and transform systems.

The subcommittee identified 10 interrelated challenges for transforming children's mental health. I am going to talk about some of them in turn, with some examples of strategies around the country. My feeling is, if something exists, it is possible. Therefore, it is possible to do it on a broader scale.

Let's talk a moment about *developing home- and community-based services and supports*, which are a problem in virtually every state and community. The rehabilitative services option in Medicaid is a major strategy moving away from a clinic option, and I see many states that go through the efforts of converting to a rehabilitation services option and then implement it like a clinic option. It makes absolutely no sense. They write service definitions for an adult population. Or they continue to ask providers to bill in 15-minute increments when we know that



evidence-based practices and home-based services, things like multisystemic therapy, all lend themselves to case and bundled rates.

We do not do enough in experimenting with different kinds of financing arrangements. There are exceptions to that, such as Ohio, which is developing a service definition for intensive home-based services and multisystemic therapy under Medicaid so that they can then build a case rate that Medicaid will buy, creating more flexibility around those services. This is redirecting funding from restrictive placements to home- and community-based services. It used to be that restrictive placements were primarily hospital care and residential. Now, as states have ratcheted down hospital care, restrictive placements tend to be residential placements, and in some states, they are out-of-school day treatment placements.

New Jersey has implemented a statewide systems change in which it is systematically creating a locus of accountability for children with serious disorders at a local level and a statewide locus of accountability for prevention

and early intervention. It is taking a total population focus. It is building systematic services that we know are effective, such as mobile response and stabilization. They are getting very good outcomes in reducing emergency room and hospital placements.

Milwaukee and Indianapolis counties are redirecting service dollars out of residential treatment for populations of kids involved in child welfare and juvenile corrections, building home-based services, respite, and behavioral support. They are getting very good outcomes in reducing recidivism in juvenile corrections and increasing school attendance, outcomes that are important to communities.

We also need to re-engineer residential treatment. We have very strong residential lobbies in the country, and I do not mean to speak against residential treatment. It is just the way we use residential treatment. We approach residential treatment with a placement mentality, so that the average length of stay ends up being 18 months to two years. There is nothing in the literature that would support that length of stay



in a residential facility. So what we see are innovative examples, such as Eastfield Ming Quong in Santa Clara County, Calif., which was a traditional residential provider with 300 beds. Over the last several years, it has re-engineered down to 50 beds. It has not changed the population it serves one bit. It is still serving all those kids, such as kids with fire-starting behaviors, kids that have sexual offenses, kids with co-occurring mental retardation, developmental disabilities, and emotional disorders. They are serving those children in the community. You have an example of that here in Atlanta with the CHAMPS program that is serving kids involved in juvenile corrections in the community through home- and community-based wraparound support.

Fortunately, we have a growing body of evidence-based practices that did not exist 10 years ago. Getting them into public systems is a challenge. The Kauffman Foundation recently issued a report on three evidence-based practices for children who were involved in child welfare and exposed to severe neglect and abuse. I work with child welfare systems around the country, and most of them have never heard of it.

*Developing family and youth partnerships* was another recommendation of the subcommittee. We need to develop organizations and partnerships with other family-run movements, such as Family Voices, that grew out of the world of children who have physical and developmental disabilities. For example, both Florida and Rhode Island have done that to maximize the impact of the family movement on state legislatures and administrations. This collaboration also helps these groups learn from one another because those other movements are about 15 years more mature than the movement of families who have children with emotional disorders.

We must *provide culturally competent and relevant care*. The literature on the racial and ethnic disparities in our health and behavioral health care systems is out there. I want to talk particularly about the strategy of using data in order to develop targeted strategies. Even as we are trying to change larger financing systems, there are targeted strategies we can do to change a systemic problem.

*Individualizing care* was another recommendation. We have a growing body of literature on what a good individualized wraparound approach should look like. We have examples from good systems of care that a broad provider network is really essential. Milwaukee has 240 providers in their network representing 80 different services and supports – everything from in-patient hospitalization to mentoring programs to natural supports in a community. For example, there is a grandmothers' group that is connected to a faith-based organization. That is the kind of flexibility that you need. It also allows for family and consumer choice. I think that the days of community mental health centers having a lock on the market in terms of providing the services and supports needed in our delivery systems for children and families are over. I think that the community mental health centers have to partner. We have to look for ways of getting child welfare providers, juvenile corrections providers, alternative youth service agencies, and natural supports into our provider networks in an organized way.

I see *implementing evidence-based practices* as a sort of dichotomy building between evidence-based practices and systems of care. Some believe we should do one or the other, which will not work. Obviously, you want to imbed and do what works within your systems of care, but you can not just do evidence-based practices because that will only help the relatively small number of families who are lucky enough to get into that program. What you want to do is link the incorporation of evidence-based practices to larger system goals, for example, reducing out-of-home placements. Multisystemic therapy is being used in that fashion to create alternatives to more expensive services that have little efficacy. To build evidence-based practices, you have to give people capacity-building. Looking at the financing, the 15-minute billing increments do not work for evidence-based practices. We have to come up with case rate and bundled rate arrangements. They exist. There are examples where managed care and managed care technologies are very supportive of trying to do more innovative things in children's mental health.

We have to *coordinate services, responsibility, and funding to reduce fragmentation*. Child welfare, juvenile corrections, mental health, and

education all need to be on the same page. Why are we not doing screening of those kids in schools and linking them to mental health services and supports early in the process? I do not understand it.

The notion of cofinancing of services must include shared governance, shared policy-making, and shared liability. As a former child welfare juvenile corrections deputy commissioner, if somebody had come to me and said, "We want to take your behavioral health dollars and put them in our mental health pot," if they were not willing to share liability with me, I would not give them my dollars. I know that the courts would turn to me and say, "You need to do X, Y, and Z," and I could not get what I needed out of that so-called blended funding arrangement. But with shared liability, everyone is accountable.

We talked about *early childhood intervention and prevention*. We need a public health approach for children's mental health. If we had continued to take a disease management approach toward HIV/AIDS in the early 1980s, we would be in a world of trouble today. I do not understand why we do not do that with children's mental health. And it is not just about surveillance and screening. It also has to do with building community awareness, reducing stigma,

educating people, and changing behaviors. We need much more understanding about who is using services and how much they are using. A lot of times the data is there and simply not analyzed.

We talked about locus of accountability and integration of related reform agendas. I find it heartening that many of the major federal children's systems – child welfare, substance abuse treatment, mental health, even Medicaid – have issued RFPs in the last year to build systems of care for children and families. Every state in the country has failed on the emotional well-being outcomes in child welfare. How are they going to meet those outcomes without the involvement of the mental health system? We have so many parallel behavioral health delivery systems for what is a limited pool of providers and practitioners.

I am going to leave you with a quote. This is from John Foster Dulles, President Eisenhower's secretary of state. He said, "The measure of success is not whether you have a tough problem to deal with but whether it is the same problem you had last year." I think we need to stop celebrating the problems of last year and go on to create some new problems while we resolve challenges such as fragmentation, lack of collaboration, and others.

### A. Kathryn Power, M.Ed.

Director, Center for Mental Health Services, Substance Abuse and Mental Health Services Administration

Let us now praise famous men. James Agee wrote, "In every child who is born, under no matter what circumstances and of no matter what parents, the potentiality of the human race is born again." We come together

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***The gathering momentum, evidenced at this meeting and elsewhere, for mental health transformation presents us with an unprecedented opportunity to move forward.***

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this morning at the 20th Annual Rosalynn Carter Symposium

on Mental Health Policy to plan how we can make that potentiality a reality. The President's New Freedom Commission on Mental Health released its final report 16 months ago. I know you are familiar with the report, and it has

inspired and energized many to begin or to continue transforming their mental health systems. It has motivated federal and state governments to rethink how they can collaborate more effectively to bring about needed change. Furthermore, the president has included funds for mental health transformation state incentive grants in his proposed fiscal year 2005 budget. You can be sure that services for children and their families will have a prominent place in the comprehensive mental health plan. Each grantee will develop, implement, evaluate, and sustain with these funds.

The gathering momentum, evidenced at this meeting and elsewhere, for mental health transformation presents us with an unprecedented opportunity to move forward. We must

seize the moment because the cost of not doing so is just too high. We all know that when childhood disorders are not prevented or not diagnosed and treated early, they often persist. For many children, this leads to a downward spiral of social isolation, school failure, poor employment opportunities, and poverty in adulthood. Indeed, untreated childhood disorders can close the door on a lifetime of opportunity.



The challenge to us at this conference is how to use the report as the foundation to improve policies affecting children and their families. We clearly have heard the message: We must rethink our traditional ways of creating systems and making decisions. Just as the report begins with a bold vision, so, too, must we be bold in envisioning what we want for children and their families.

When I envision what I want our mental health system to look like for children and their families, I imagine high-quality parent training, readily available – at the birth of a child, during the adolescent years – whenever the parent needs help. Raising a child is the most difficult task a person ever undertakes, and who among us has not needed a little help as we try to do so. The wisdom of such a program as the Nurse/Family Partnership is that the caregivers help the mother attend to her own life trajectory. As the mother finds new possibilities for herself, she also finds new ways to interact with her child, to the great benefit of them both. My dream of a transformed system includes the widespread and appropriate use of evidence-based programs. I imagine that all communities will use such programs to promote mental health and prevent mental and behavioral disorders for all children and adults and parents, especially those at risk.

For example, Harrisburg, Pa., is working with a program developer to implement the “Path” program, Promoting Alternative Thinking, in

every elementary school in that city. My children used to attend the schools in that city. This program has been shown in many controlled studies to increase children’s social development and emotional regulation and decrease their aggressive behavior. In the process of transformation, we must continue to see that “prevention” is the cornerstone for our new system, not an afterthought. I also imagine that when a child experiences difficulties, confident well-trained caregivers will identify the problems early and assess them accurately. I imagine that the family, and in some cases the child, will join providers in selecting appropriate individualized services. I imagine that the child and the family will receive excellent services, whether those services are delivered in a primary care office, a mental health clinic, a school, a juvenile justice setting, a child welfare agency, or a domestic violence shelter. In an ideal system, any door is the right door to appropriate care. And finally, I imagine that the same high-quality care will be readily available for all children, regardless of their color, their culture, their geographical area, or their socioeconomic status.

So how do I propose that we turn these grand visions into reality? We really have to rethink a lot of what we have been doing and how we have been making decisions. I know the report helps point the way. When you read the report with children in mind, you realize that every single goal and every single recommendation is relevant

for mental health care for children. The report recommends efforts to promote the mental health of children, to prevent mental disorders whenever possible, and to intervene early to prevent, reduce, or entirely eliminate the long-term consequences of childhood disorders.

I want to emphasize in particular one aspect of the report that is especially relevant to all of us gathered here. The New Freedom Commission report recommends that a public health approach in transforming the nation's mental health system be taken. This is clearly an important step and one that requires education. This means that instead of focusing solely on the diagnosis of individuals who already have a disorder, we must, in fact, take a population-based approach. We must consider how to improve the mental health of the entire population, whether the population in question is a nation, a state, a county, a community, a school, or a family. We do not ignore the individual in distress, and treatment certainly continues to play a key role, but the public health population-based approach requires that we develop a continuum of mental health services. This continuum must include promotion, prevention, early intervention, treatment, and recovery.

A good example of the public health approach in action is the Safe Schools/Healthy Students Project that SAMHSA is sponsoring in cooperation with the departments of Justice and Education. This program, begun in 1999, is also a good example of transformation in progress. Although we launched it four years before the release of the commission's report, it directly advances the commission's recommendations to improve and expand school mental health programs. It requires grantees to use interventions that prevent violence and promote positive academic, social, and emotional development. It insists that grantees provide effective treatment for youth who need it. It does not focus solely on individuals. Instead, it promotes "system-focused interventions" that build on strengths available within the school and the broader community. That increases the resilience of the youth and adults in the school, in the family, and throughout the community.

Similarly, our Systems of Care for Child and Adolescent Mental Health Grant Program takes the public health approach and focuses on systems. These grants help communities bring together the agencies. The needs of many children cut across a number of child-serving systems, and they can be met effectively only through those collaborative and coordinated efforts. Moreover, our systems of care grants attempt to get the adult-serving systems and the child-serving systems within the mental health system to work together. And, as you know, this is not an easy task.

These and other public health programs force us to rethink how we train mental health professionals. For those of us who were trained clinically, the public health approach requires a new body of knowledge and a whole new way of thinking. We must hold onto the best of our clinical training, for it helps us understand why people think and feel and behave as they do, and moreover, there will always be individuals and couples and families in need of clinical services. But we also must begin training new mental health professionals in how to implement evidence-based programs with fidelity. Our community needs to better understand how to link practices across agencies so that all child and family caregivers speak the same language and have a common ground for linking practice efforts. We must train administrators of different agencies on how to pool resources and provide cross-training for professionals from these very different sources.

Perhaps most importantly, we must think long and hard about how we prepare leaders to lead transformation. This issue is of utmost relevance to all of us, because by virtue of you being at this conference, you already see yourself as one of those leaders. This gives me enormous cause for hope. I know you to be as idealistic as I am, and I also know you to be pragmatic and action-oriented. We all may still be dreamers, but we have lived long enough and worked through enough challenges to know how to realize many of our dreams. I believe in the power of our collaboration and our leadership to ensure, as James Agee would wish, that the potentiality of every child and, thereby, the potentiality of the human race become the reality that we all dream it can be.

# Questions & Answers

Q What does this transformation truly mean for all of us in this room, for the organizations that we represent? I think we have to recognize that if we are talking about true transformation and not just another program or another initiative, we have to be prepared to rethink ourselves, what we are doing, and what our organizations are doing. Those things are going to be difficult, and I am just wondering if there has been any thought given to transitional assistance to the field and people in the field and organizations who need to figure out ways to transform and not just focus on their own survival.

A Ms. Power: Last year at this same forum, we started talking about how we defined transformation. So there is a lot of work that has been done in this past year to look at the questions of “What is transformation?” and “What are transformation strategies?” One of the things that we are looking at is to provide some development of transformational leadership. We are also taking a look at providing technical assistance for those states or entities that would like some support in transformational strategic thinking.

A Dr. England: I would ask that we not reinvent the wheel. Transformation is not unique to the mental health and addiction field. Transformation has been an industry, and we have had some examples, so this is a good time for us to reach out to other people who have done this transformation.

Q Is there a serious reason why a medical model could not be supportive and complimentary to a family model?



A Ms. Pires: I think it is clear they can. You heard from two child psychiatrists this morning doing powerful family-focused interventions. The problem is in some of what we agree to fund in the medical necessities standard in Medicaid. The problem is not with the thinking in the field or the interventions; it is in the lag between how we use our dollars that do not necessarily support the kinds of programs that you heard about this morning.

A Dr. England: We cannot continue with the either/or mentality. We really have to understand the importance of both. I think it is true in all of our lives, but particularly true in this area. We should not set up camps and must really look at ways of helping each area.

## CHARGE TO THE WORK GROUPS

**T**ransforming the U.S. mental health system to better serve children and their families requires the commitment of everyone. This is no longer just a mental health community. If we do not start reaching across lines and to the public itself, then we are not going to transform the mental health community. Panelists have reviewed the opportunities and challenges facing the country in transforming mental health for children and families in light of the President's New Freedom Commission report.

## GENERAL DISCUSSION

**Sybil K. Goldman, M.S.W., Moderator**  
**Senior Adviser on Children, Substance Abuse**  
**and Mental Health Services Administration**

At SAMHSA, we are actively working on implementing the goals and the 19 recommendations of the New Freedom Commission report. We are examining all of our activities to see how they either are aligned with these goals or moving them forward. We recognize that we cannot talk about mental health transformation on one hand and, on the other hand, keep doing things the same way.

We also are working with 19 federal agencies that have committed to this process. They have done an inventory of activities they are engaged in that address these goals and recommendations. The group meets monthly and reports on the progress they are making in each area. I think we have a lot to build on in that group, but transformation cannot occur only at the federal level. It needs to involve the federal, state, and local levels. It needs to involve multiple partners, public and private.

Transformation also means small steps, medium steps, and very large leaps that can change things. We are good at what I call "multitasking incrementalism" – working on multiple fronts in incremental kinds of ways. The challenge for us is how to make some of the big leaps. I hope we can discuss ideas about how to take these leaps forward.

There are four themes we can address:

How do we really, truly bring to scale many of the innovations and the good things that are happening in our states and communities?

How do we translate what we know works into policy? When we say "translate into policy," we are talking about interrelatedness. It is not mental health policy – it is health policy; it is human services policy. How do we generate the political will for doing that?

How do we achieve a public health approach?

How do we approach the fiscal issues in making this transformation?

**Dr. Carl Bell, M.D.**  
**Community Health Council and Foundation**

When Kathryn Power had a prevention symposium in the New England Governors' Conference on Prevention, William McFarland from Maine talked about how he had the schools in Maine identifying youth who were at risk for developing schizophrenia and identifying prodromal symptoms of schizophrenia. He had them on prophylactic medication. As a result, none of these students became clinically ill. I asked him whether he believed that science has progressed to the point that with early identification technology, it would be unethical not to identify these kids and give them prophylactic treatment. And he said, to my surprise, "Yes." Perhaps we need to shift some of these conversations to ethical conversations as opposed to economic and best practice conversations. I hope that CMHS will put out a grid or a guideline for us around prevention.

**Ms. Goldman**

Clearly, this whole area of prevention, early intervention, screening, and assessment is a major issue, not only for the Center for Mental Health Services but for many of the agencies we work with. We do have to provide some leadership in that area. We need to work with our colleagues. We have started a number of different projects around effective screening tools, how can they be used, what are training programs, and how we link with services once we identify. I think that is the key. Your comment is another way to frame these issues around the ethics, and that is important.

**Cynthia Folcarelli  
National Mental Health Association**

There are a few things we need to be prepared for over the next few years if we really want to not just improve children's mental health but even protect what we already have. One of those things is that the administration has made it very clear that they would like to block-grant Medicaid. This is not a partisan statement. This administration has been quite clear that they

want to cut back these programs. Quite frankly, if Medicaid gets block-granted, then a lot of our discussion over the last two days has been largely academic. It would be absolutely disastrous to health services for a host of populations, including children, families, and adults with mental health service needs. I would like to encourage not only the advocacy groups in the room but everybody to commit themselves to really fighting to protect and expand Medicaid and the other funding sources for these programs over the next four years and beyond.

Another area where our community has to be more mindful is the Scientologists. They have an organized, sophisticated anti-child-mental-health campaign. They are using the media attention about anti-depressants, for example, to influence constituents who are not Scientologists, portraying the children's mental health system as scary stuff that no parent would want to allow their child into. We have heard from some congressional offices that when an issue around children and medication comes up, they get constituent mail 10 to one expressing the Scientology viewpoint. We have to make sure





that we are not just talking to each other but thinking about the viewpoints of the people out there who are going to determine what happens.

**Jack Gordon**  
Hospice Foundation of America  
Member, The Carter Center Mental Health Task Force

An interesting presentation for me was the study in western North Carolina showing that the incidence of mental health problems among the Cherokees dropped precipitously after they received an annual income supplement of \$6,000, raising some out of poverty. The implication of those results is that raising the minimum wage is a significant way to reduce the incidence of mental health problems. I do not say this to denigrate the work of the psychiatrists and psychologists and everybody else who is here, because they are certainly necessary. Today's minimum wage is less than the minimum wage in the Eisenhower administration, if you allow for inflation. We need a living wage because poverty puts a burden on, among other things, mental health and public health systems. I want to call your attention to the fact that in light of evidence that connects poverty to mental health issues, there often is something you can support locally or in your

state that, hopefully, will push a requirement to help improve the standard of living at the federal level.

**Frank Berry**  
KidsNet Policy Council

I am extremely concerned about the juvenile justice/mental health partnerships. I wanted to know if there are any initiatives or strategy at the national level for partnering either with the Office of Juvenile Justice or the Department of Justice. Are there collaborative thoughts? There is an overrepresentation of minority youth in group homes, residential care, and the juvenile justice system. Perhaps if better or earlier interventions were available, they might not enter the juvenile justice system.

**Dr. Bell**

In Illinois, we recognize this because a lot of the work on epidemiology of mentally ill youth in corrections came from Linda Teplin at Northwestern. NIMH came to Chicago, and we had a conference on youth where Linda Teplin reported her evidence about how many kids were ill in the system. The head judge for the juvenile detention center did not realize until then how



bad the situation had become. He then wrote an order for the county detention center to put a mental health infrastructure in place. Two years later, they had suicide prevention protocols in the detention center. The other thing that Illinois did was screen all the children in the detention center who got into trouble. Now kids are being referred to services and sometimes actually being extricated from the criminal justice system for services.

**Ms. Goldman**

I think the answer to your question is some things are happening but not enough. Policy Research Associates in New York has been leading an initiative on mental health and juvenile justice. I was recently in a meeting with Bob Flores, who heads the Office of Juvenile Justice and Delinquency Prevention, and we talked about his interest in wraparound approaches and working with us on that and also working on diverting kids from the juvenile justice system and serving them in their communities. So there are small things happening.

**Ellen Jeager**

**National Mental Health Association of Georgia**

I have to say that I am very frustrated with how little noise mental health makes. We need a real rally or a march on Washington. It is not about who the president of the United States or your governor is now. Mental health does not move the way other illnesses move. We are quiet; we are dignified. We are all of the things that sound good at a meeting but do not move us forward. When you go into the communities, people say, "It does not make a difference what I do." They have no sense of power, no sense of control, and they know their rights are being stepped on. Clearly, if the state can tell a parent, "You must give up your child to get services," what kind of society is that? So I would really like to know when there is going to be a real march on Washington? Mental health has its day at the Capitol, NAMI has its day at the Capitol – everybody has their day at the Capitol, but they are not the same day. This is not even about meeting with legislators – it is about having the entire area wall-to-wall with mental health folks demanding that mental health be taken more seriously.

## POSTSCRIPT

*Thomas Bornemann, Ed.D.*

*Lei Ellingson, M.P.P.*

The Carter Center Mental Health Program

This is the second symposium addressing the final report by the President's New Freedom Commission on Mental Health. Mrs. Carter and the Carter Center Mental Health Task Force chose this topic because the significance of such a commission warrants continued national attention. They also recognized that such an important report with its sweeping conclusion that the mental health system needs actually to be transformed necessitates that all sectors of the mental health community be engaged. This is beyond the capabilities of government, academia, or advocacy alone.

The symposium seeks to highlight how the recommendations of the President's New Freedom Commission could be applied specifically to

children and their families. We thought the mental health community would benefit from this opportunity to gather together, call attention to what is known about effective mental health treatments for children, discuss what needs to be learned, and strategize how to use the President's New Freedom Commission on Mental Health to urge for improvements in child- and family-serving policies.

To that end, we asked the working groups to specifically commit themselves or their organizations to work toward improving the mental health of children and their families. Discussion among the working groups was lively as always. Several themes evolved among them:

- *Put children and families at the center of care* as stated in goal two of the final report by the President's New Freedom Commission on Mental Health: "Mental health care is consumer- and family-driven."
  - *The importance of advocacy*, particularly lobbying and advocating consistently to dispel the myths that are still out there and the stigma around children's mental health. Several suggestions included how to market evidence-based treatment modalities using scientific data to counteract the negative impression in the marketplace.
  - *The need to screen*, particularly in multiple sites. There already are good examples of screening in primary care settings.
  - *Connecting with families*. Cultural competence must consistently be an issue.
  - *Developing customer service models* so that when people enter or look into mental health services they feel like it is a consumer-friendly approach.
  - *Develop appropriate partnerships*. Mental health and public health need to come together again, plus continue partnerships with known organizations, such as the National Alliance for the Mentally Ill (NAMI), the National Mental Health Association, and policy-makers. Also important are continued partnerships with academic institutions, community organizations, faith-based organizations, and, of course, families. Partnerships between grass-roots organizations and local, state, and federal agencies must be enhanced.
  - *Public health approach* with emphasis on prevention and early intervention. An infrastructure to support practice and system design changes must be developed. In order to accomplish this goal, there must be knowledgeable, effective, and coordinated advocacy efforts and the political will to confront the barriers to making change happen. This information must be disseminated in ways that make it useful to advocates and to change agents.
  - *Work force development*. There are a dearth of providers overall and an uneven distribution of current providers, leaving serious gaps in several areas, including rural mental health, ethnic and cultural minority groups, and treatment for children and the elderly.
  - *Engage business school expertise* to help with the transformation.
  - *Build trust* in our communities. We must draw in all of our partners and make mental health transformation a community initiative. One effective strategy is to hold regional summits to build relationships, partnerships, and the required trust. It also is important to engage in community activities with agencies or civic groups.
  - *Link political agendas with mental health goals*. This requires data and building a consensus platform as well as both long- and short-term goals.
  - *Build an action plan* with specific activities dedicated to specific time lines in order to implement strategic vision.
  - *Continued research* to build the base of evidence-based modalities. A broad base of research that includes not only medical research but also basic, applied, and psychosocial research must be translated and used as a basis for advocacy.
- Examples of commitments made by organizations include:
- Develop support groups for 16- to 18-year-olds and their families and implementing family support and education
  - Develop an alumni program for families and children who have graduated from a treatment facility, using the program both for support and outreach
  - Develop a depression-monitoring kit for parents
  - Produce a documentary film showing how kids and families can succeed in coordinated systems
  - Create a series of books for parents titled *Growing Healthy*
  - Think about how to promote careers in children's mental health through social marketing
  - Continue to engage churches, corporations, and other areas of the community in children's mental health issues

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- Provide leadership training and include youth in mental health planning and advisory councils
  - Encourage parents who have children with mental illnesses to complete family satisfaction surveys along with parents from other child-serving systems
  - Seek collaboration with Rotary International on adopting childhood depression as a priority area
  - Identify an issue for improved multisystem coordination and convene a national group to work on it
  - Support funding for the ad hoc CDC mental health working group that has developed
  - Commit to advocating for the Child Health Care Crisis Relief Act, HR 1359 and SB 1223, which addresses shortages in human services professionals through loan repayments

Examples of commitments made by individuals include:

- Engage the American Academy of Pediatrics in a dialogue about access to screening
- Develop a curriculum to include mental health/public health perspective in professional training
- Review what screening instruments state Medicaid agencies are required to use
- Design a developmental health screening tool that cuts across the juvenile justice, mental health, social services, and educational fields
- Commit to advocating for the Child Health Care Crisis Relief Act, HR 1359 and SB 1223, which addresses shortages in human services professionals through loan repayments



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## CLOSING REMARKS

*Rosalynn Carter*

Chair, The Carter Center Mental Health Task Force

This has been a wonderful learning experience. My thanks go to all of you leaders and experts in your fields for being here to add your knowledge and talent to this important issue. We all – professionals and advocates – have a huge role to play if the mental health system serving children and their families is going to be reformed.

We have heard a number of ideas about what we can do to create change in the communities of our country, but this information is only useful if we take advantage of it, if we go home and do something about it – personally, through our organizations, or both. So I look forward to hearing about all the good things that you are doing, the specific actions that you are taking, and sharing your success with others.

We are at a critical time in our nation. The financial strain on state and local budgets is enormous. But we cannot allow the gains of recent decades to be lost.

*Rosalynn Carter*

# Biographies



## **William Beardslee, M.D.**

Dr. Beardslee has received the Blanche F. Ittleson Award of the American Psychiatric Association for outstanding published research contributing to the mental health of children, has been a faculty Scholar of the William T. Grant Foundation, and in 1999, received the Irving Philips Award for Prevention and the Catcher in the Rye Award for Advocacy for Children from the American Academy of Child and Adolescent Psychiatry. In 2003, he received the Agnes Purcell McGavin Award for Prevention of Mental Disorders in Children from the American Psychiatric Association. Currently, he directs the Preventive Intervention Project, a NIMH-funded study. He is also the principal investigator of the Boston site of a new four-site, prevention-of-depression trial using a cognitive behavioral group approach for children at double risk because their parents are depressed and they themselves are already manifesting symptoms of depression. He also serves on the advisory board of the Center for Mental Health Services for SAMHSA.



## **Carl C. Bell, M.D., Moderator**

Dr. Bell is president and CEO, Community Mental Health Council and Foundation, Inc., a \$20-million, 400-employee, comprehensive community mental health center in Chicago. He is also the director of public and community psychiatry and a clinical professor of psychiatry and public health at the University of Illinois. He is principal investigator of an NIMH R-01 grant, "Using CHAMP to Prevent Youth HIV Risk in a South African Township." During 30 years, Dr. Bell has published more than 275 articles on mental health. He recently authored *The Sanity of Survival: Reflections on Community Mental Health and Wellness*. Television shows such as "Nightline," "CBS Sunday Morning," "The News Hour With Jim Lehrer," and the "Today Show" have utilized his expert opinion.



## **Jane Costello, Ph.D.**

As professor of medical psychology in the department of psychiatry and behavioral sciences at Duke University Medical Center, Dr. Costello helps run the Center for Developmental Epidemiology, which brings together researchers from different disciplines in order to advance our understanding of the origins, course, and prevention of mental illness across the life course. In her work as an epidemiologist, she is using the data sets to which she has access through the Center for Developmental Epidemiology to develop a model of child psychopathology that will help integrate findings about the cause of mental illness with a better understanding of risk factors and the options for prevention. She is currently directing the eighth annual wave of data collection from the Great Smoky Mountain Study, a longitudinal study of the development of psychiatric and substance abuse disorders and access to mental health care in a representative sample of 1,400 children and adolescents living in the southeastern United States.



### **Mina Dulcan, M.D.**

Dr. Dulcan is head, child and adolescent psychiatry, and Margaret C. Osterman professor of child and adolescent psychiatry at Children's Memorial Hospital. She also is professor, psychiatry and behavioral sciences and pediatrics, Feinberg School of Medicine, Northwestern University as well as editor-in-chief of the *Journal of the American Academy of Child and Adolescent Psychiatry* and co-author of the academy's practice parameters for stimulant medication. Dr. Dulcan received her undergraduate degree in chemistry with high distinction from Cornell University and her medical degree from Pennsylvania State University College of

Medicine. She trained in adult and child and adolescent psychiatry at the University of Pittsburgh. Dr. Dulcan is a fellow of the American Psychiatric Association, the American Academy of Child and Adolescent Psychiatry, and the American College of Psychiatrists.



### **Mary Jane England, M.D., Moderator**

Prior to her role at Regis College, Dr. England served as president of the Washington Business Group on Health (WBGH), a health policy research and education organization that represents Fortune 500 companies and large public employers in the national health system policy debate. Dr. England has served as program director for the Robert Wood Johnson Foundation's Mental Health Services Program for Youth, vice president of medical services for The Prudential Insurance Company of America, associate dean and director of the Lucius N. Littauer Master's in Public Administration at the John F. Kennedy School of Government at Harvard University,

commissioner of Massachusetts' first Department of Social Services, associate commissioner of the Massachusetts Department of Mental Health, and president of the American Psychiatric Association (1995-96) and the American Women's Medical Association (1986-87). Currently, she is chair of the IOM/National Research Council of the National Academies' Crossing the Quality Chasm Committee on Adaptation to Mental Health and Addictive Disorders as well as a member of the IOM board on children, youth and families.



### **Sybil K. Goldman, M.S.W., Moderator**

Ms. Goldman is the senior adviser for children, Office of the Administrator and Office of Policy, Planning, and Budget at the Substance Abuse and Mental Health Services Administration, an agency of the U.S. Department of Health and Human Services. Prior to serving in this position, Ms. Goldman was the director of the National Technical Assistance Center for Children's Mental Health at the Georgetown University Child Development Center, Georgetown University Medical Center Department of Pediatrics, where she is an assistant professor. Ms. Goldman has more than 30 years' experience in health, mental health, substance

abuse, and human services at the national, state, and local levels, involved in policy, administration, research, training, service delivery, and advocacy. She is the author of numerous publications on child health and mental health policy and service delivery.



### **W. Rodney Hammond, Ph.D.**

Dr. Hammond is director of the Division of Violence Prevention within the National Center for Injury Prevention and Control at the Centers for Disease Control and Prevention. His research and programmatic publications have focused on violence as a public health concern, especially youth violence. He developed Project PACT (Positive Adolescents Choices Training), distinguished by its violence prevention outcomes for at-risk youth. He is author and executive producer of the series "Dealing with Anger: A Violence Prevention Program for African-American Youth." He works closely with the World Health Organization and was the CDC

representative to the Health Working Group of the Gore-Mbecki Bilateral Commission to the Republic of South Africa. He has received the U.S. Department of Health and Human Service's Secretary's Award for Distinguished Service for his efforts in public health and mental health collaboration.





**Larke Nahme Huang, Ph.D.**

Dr. 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 at 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. Dr. Huang is a member of The Carter Center Mental Health Task Force and was a commissioner on the President's New Freedom Commission on Mental Health.



**Pamela Hyde**

Ms. Hyde was appointed in December 2002 as the secretary of New Mexico Human Services Department. A lawyer by training, Ms. Hyde has 25 years' experience in management and consulting for public sector systems of health care and human services. She has held several key public sector management positions, including those of a state mental health director, state human services director, and city housing and human services director as well as chief executive officer of a private, nonprofit behavioral health care organization that both managed care and provided direct services. Ms. Hyde is a member of or has served as a consultant to many national organizations, including the President's New Freedom Commission on Mental Health. She has received awards from the National Governors Association and a number of consumer and provider organizations for her leadership and creativity and for her commitment to the well-being of those who rely on publicly funded health and human services.



**Jane Knitzer, Ed.D.**

Dr. Knitzer is a psychologist whose career has been spent in policy research and analysis of issues affecting children and families, including mental health, child welfare, and early childhood. Her landmark work on children's mental health includes the groundbreaking policy reports, *Unclaimed Children: The Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services* and *At the Schoolhouse Door: An Examination of Programs and Policies for Children With Behavioral and Emotional Problems*.



**David Mrazek, M.D.**

Dr. Mrazek is the chair of the department of psychiatry and psychology at the Mayo Clinic in Rochester, Minn. He is a fellow of the American Psychiatric Association, the American Academy of Child and Adolescent Psychiatry, the American College of Psychiatrists, the American Psychological Society, the Royal College of Psychiatrists, and the Royal Society of Medicine. He also serves as a director of the American Board of Psychiatry and Neurology.

**Trina Osher, M.S.**

Ms. Osher provides information on national issues and trends as well as training and technical assistance to help family members take leadership in developing comprehensive, community-based systems of care for children with mental health needs and their families. She and her husband have raised three children, two with significant special needs. As a result, she has gained an intimate consumer's knowledge of all the child-serving systems. She speaks with a family voice to the mental health, education, child welfare, and juvenile justice communities and works to build collaborative alliances between families, policy-makers, and providers.

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