AUTHENTICATED
U.S. GOVERNMENT
INFORMATION
GPO

S. HRG. 108–682

MENTAL HEALTH IN CHILDREN AND YOUTH: ISSUES THROUGHOUT THE DEVELOPMENTAL PROCESS

HEARING

BEFORE THE

SUBCOMMITTEE ON SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES

OF THE

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

ONE HUNDRED EIGHTH CONGRESS

SECOND SESSION

ON

EXAMINING MENTAL HEALTH IN CHILDREN AND YOUTH, FOCUSING ON ISSUES THROUGHOUT THE DEVELOPMENTAL PROCESS, AND S. 1704, TO AMEND THE PUBLIC HEALTH SERVICE ACT TO ESTABLISH A STATE FAMILY SUPPORT GRANT PROGRAM TO END THE PRACTICE OF PARENTS GIVING LEGAL CUSTODY OF THEIR SERIOUSLY EMOTIONALLY DISTURBED CHILDREN TO STATE AGENCIES FOR THE PURPOSE OF OBTAINING MENTAL HEALTH SERVICES FOR THOSE CHILDREN

APRIL 28, 2004

Printed for the use of the Committee on Health, Education, Labor, and Pensions

U.S. GOVERNMENT PRINTING OFFICE

93–524 PDF WASHINGTON : 2004

For sale by the Superintendent of Documents, U.S. Government Printing Office
Internet: bookstore.gpo.gov Phone: toll free (866) 512–1800; DC area (202) 512–1800
Fax: (202) 512–2250 Mail: Stop SSOP, Washington, DC 20402–0001

COMMITTEE ON HEALTH, EDUCATION, LABOR, AND PENSIONS

JUDD GREGG, New Hampshire, *Chairman*

BILL FRIST, Tennessee
MICHAEL B. ENZI, Wyoming
LAMAR ALEXANDER, Tennessee
CHRISTOPHER S. BOND, Missouri
MIKE DEWINE, Ohio
PAT ROBERTS, Kansas
JEFF SESSIONS, Alabama
JOHN ENSIGN, Nevada
LINDSEY O. GRAHAM, South Carolina
JOHN W. WARNER, Virginia

EDWARD M. KENNEDY, Massachusetts
CHRISTOPHER J. DODD, Connecticut
TOM HARKIN, Iowa
BARBARA A. MIKULSKI, Maryland
JAMES M. JEFFORDS (I), Vermont
JEFF BINGAMAN, New Mexico
PATTY MURRAY, Washington
JACK REED, Rhode Island
JOHN EDWARDS, North Carolina
HILLARY RODHAM CLINTON, New York

SHARON R. SODERSTROM, *Staff Director*
J. MICHAEL MYERS, *Minority Staff Director and Chief Counsel*

SUBCOMMITTEE ON SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES

MIKE DEWINE, Ohio, *Chairman*

MICHAEL B. ENZI, Wyoming
JEFF SESSIONS, Alabama
JOHN ENSIGN, Nevada

EDWARD M. KENNEDY, Massachusetts
JEFF BINGAMAN, New Mexico
JACK REED, Rhode Island

KARLA CARPENTER, *Staff Director*
DAVID NEXON, *Minority Staff Director*

C O N T E N T S

STATEMENTS

WEDNESDAY, APRIL 28, 2004

	Page
DeWine, Hon. Mike, a U.S. Senator from the State of Ohio, opening statement	1
Reed, Hon. Jack, a U.S. Senator from the State of Rhode Island, opening statement	2
Dodd, Hon. Christopher J., a U.S. Senator from the State of Connecticut, opening statement	4
Kennedy, Hon. Edward M., a U.S. Senator from the State of Massachusetts, prepared statement	7
Collins, Hon. Susan M., a U.S. Senator from the State of Maine, prepared statement	8
Osofsky, Joy D., Professor of Pediatrics, Psychiatry, and Public Health, Louisiana State University Health Sciences Center, and President, Board of Directors, Zero to Three; Marleen Wong, Director, Crisis Counseling and Intervention Services, Los Angeles Unified School District, Los Angeles, CA, and Director, School Crisis and Intervention Unit, National Center for Child Traumatic Stress, UCLA and Duke University; Louise A. Douce, Director, Counseling and Consultation Services, the Ohio State University; Maryann Davis, Assistant Professor, Center for Mental Health Services Research, Department of Psychiatry, University of Massachusetts Medical School, Worcester, MA; Linda Champion, Child Advocate, National Alliance for the Mentally Ill, and Vice President, Alabama Family Ties, Montgomery, AL, and Barbara Altenburger, Family Advocate, Parents Involved Network, Mental Health Association of Southeastern Pennsylvania, Philadelphia, PA	12
Prepared statements of:	
Joy D. Osofsky	14
Marleen Wong, LCSW	23
Louise A. Douce, Ph.D.	34
Maryann Davis, Ph.D.	38
Sessions, Hon. Jeff, a U.S. Senator from the State of Alabama, opening statement	44
Altenburger, Barbara, prepared statement	51

ADDITIONAL MATERIAL

Statements, articles, publications, letters, etc.:	
Response to questions of Senator Reed from Joy Osofsky	20
Response to questions of Senator Bingaman from Marleen Wong	28
Response to questions of Senator Bingaman from Maryann Davis	40
Response to questions of Senator Reed from Maryann Davis	42
Response to questions of Senator Bingaman from Linda M. Champion	46
The Keeping Families Together Act (S.1704)	66
American Academy of Child and Adolescent Psychiatry	67
Michael Faenza, National Mental Health Association	72
Susan Mikolic, Parent and Advocate	74
The National Child Traumatic Stress Network (NCTSN)	82

MENTAL HEALTH IN CHILDREN AND YOUTH: ISSUES THROUGHOUT THE DEVELOPMENTAL PROCESS

WEDNESDAY, APRIL 28, 2004

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

The subcommittee met, pursuant to notice, at 10:05 a.m., in room SD–430, Dirksen Senate Office Building, Hon. Mike DeWine (chairman of the subcommittee) presiding.

Present: Senators DeWine, Sessions, and Reed.

OPENING STATEMENT OF SENATOR DEWINE

Senator DEWINE. Good morning. Let me thank all of you for being here today, and let me also welcome Senator Reed, with whom I have worked on so many issues in the past concerning children.

Today, we are meeting to talk about mental health issues concerning children and youth throughout their developmental process. The simple fact is that children and youth with emotional and behavioral needs face tremendous challenges in receiving care in our Nation today. Mental health care is dispersed across many systems for children, including schools, the juvenile justice system, the child welfare system, the substance abuse treatment system, through their primary care providers, and within their own families.

I have seen in my own home State of Ohio serious failures in the child mental health system. Just a few weeks ago, a series of disturbing stories ran in the Cincinnati Enquirer regarding the children's mental health system in Ohio. These articles focused on children who are mistreated at treatment centers, are in families unable to afford necessary care, and children whose parents give them up to child protection services in order to receive treatment. The many shortcomings of the current system resulted in mental health needs of children not being met and actual harm being done to children who were in the care of those paid to protect and help them.

Now, obviously, passing Senator Pete Domenici's mental health parity legislation—officially called the Senator Paul Wellstone Mental Health Equitable Treatment Act—would be the best solution for many of the children in these articles, as well as many chil-

dren facing similar problems in other States. We know that these children are many in number.

Each year, approximately 5 to 9 percent of children suffer from serious mental illness or serious emotional disturbances. However, fewer than one in five of these children will receive needed treatment.

Early childhood is a critical time period to prevent the onset of emotional and behavioral impairments. If these children do not receive appropriate treatment or if their illness is too severe, these children are more likely to continue on paths which lead to expulsion from school and child-care facilities for disruptive behavior, separation from their family, visits to juvenile justice facilities, and dropping out of high school.

Some of the issues concerning children and youth in the mental health system were discussed at a hearing that we held to examine the Final Report of the President's New Freedom Commission on Mental Health. The report found that fragmentation of the mental health system and gaps in care for children were serious problems.

The report also stated that the multiple programs created to finance and support children and youth with mental illness help foster an approach that is complex, fragmented, and inconsistent in its coverage, which makes the entire process very difficult for parents or caretakers.

Mental health is absolutely fundamental to a person's overall physical health and well-being and is critical to leading a productive and balanced life. Our children and young people deserve access to services that are appropriately and effectively provided. That is why I have worked with Senator Dodd and Senator Smith from Oregon to introduce the Youth Suicide Early Intervention and Prevention Expansion Act—a bill that would provide funding for the creation and expansion of statewide youth suicide early intervention and prevention strategies. Tragically, suicide is the third leading cause of death of children and youth ages 10 to 24.

I have also been working with my friend, Senator Reed, on a bill we have introduced called the Campus Care and Counseling Act that would provide needed funds to mental and behavioral health centers on our Nation's college and university campuses. We know that rates of university-age students seeking care while away at school are rising, and counseling centers are struggling to keep up with these rising numbers.

I look forward to discussing all these issues today and hearing the testimony from our witnesses. I believe that this testimony will serve to educate us on issues concerning the children and youth mental health system, and I am confident that these recommendations will serve as a real starting point for change and improvement.

Let me now turn to Senator Reed for his comments.

OPENING STATEMENT OF SENATOR REED

Senator REED. Thank you very much, Mr. Chairman. Thank you for calling today's hearing and also for your devoted and consistent attempts to help children of the United States in so many ways through the health care system. Thank you, Mr. Chairman.

As we all know, today we are facing a crisis in the mental health care system throughout the United States, particularly when it comes to the needs of our children and young adults. I would like to express my appreciation to the witnesses who are here today. Each of today's panelists offer a unique perspective on the critically important issue of children's mental health. Thank you all very much.

The recent rash of suicides on college campuses throughout this country has illustrated the dire consequences of failing to address the mental health needs of our young people. Just last week, the Washington Post reported the fifth suicide at the George Washington University since December 2003.

A recent study of counseling center directors found that 81 percent were concerned about increasing numbers of students with severe psychological problems, 67 percent reported a need for more psychiatric services, and 63 percent reported problems with the growing demand for services without an appropriate increase in resources.

I would like to share with you a sampling of the type of cases seen by just one counselor at the University of Rhode Island: one student with depression and a recent suicide attempt, one student with schizophrenia, two students with self-cutting behaviors, three with drug and alcohol problems, one victim of rape, two students with eating disorders, two with difficulty adjusting to college life, and one with panic attacks. And that is not even the entire caseload of this one counselor.

Along with Senator DeWine, we introduced the Campus Care and Counseling Act to increase access and enhance mental and behavioral health services for our college students. This bill authorizes grants to colleges and universities for a range of activities, including prevention, screening, early intervention, assessment, education, treatment, and ongoing case management of mental and behavioral health problems.

College mental health is just one piece, though, in the complicated puzzle of children's mental health. For young children in particular, access to care is a critical problem. In Rhode Island, as in most communities in this country, we are suffering from a severe shortage of child psychiatrists. The lack of competent providers, combined with limited outpatient mental health services, few substance abuse treatment programs, and virtually nonexistent residential treatment facilities, has left families literally with no place to turn.

With few options at hand to access treatment, some parents are even forced to give up custody of their children just to qualify for public mental health programs.

According to Dr. Greg Fritz, chairman of child psychiatry at Brown University School of Medicine, emergency room visits have tripled in the past 3 years. Outpatient clinics have waiting lists of 2 months or more. Patients being discharged from the hospital wind up being readmitted 6 weeks later because they decompensate before their number comes up on the waiting list for outpatient treatment.

We as a nation have failed children with mental illnesses on many levels. They are often not diagnosed in a timely fashion, they

are treated by providers with minimal mental health training, they are forced to bounce around between various systems of care—if they are able to access mental health services at all. Then when they finally figure out how the system works and provided that they do not end up as one of the many incarcerated mentally ill, they age out of the adolescent system and have to start all over in their transition into the adult mental health system, a system with even less to offer them.

Last, I would note and echo the comments of the chairman that tomorrow marks the 2-year anniversary of President Bush's call on Congress to pass mental health parity legislation. I am disappointed that, despite having broad support, Congress has refused to act upon legislation that would aid millions of Americans in obtaining needed mental health treatment and renounce the current system that allows private mental health insurance plans to discriminate with impunity when it comes to mental health coverage.

I extend to my colleagues the hope that this hearing will provide the impetus for us to take action on the Paul Wellstone mental health parity act. It would be a fitting tribute to literally a giant—well, not literally because we are the same size, but a giant in the U.S. Senate.

[Laughter.]

Mr. Chairman, I also have a statement from Senator Dodd. As you know, he is deeply interested in children's mental health, particularly with youth suicide and the use of antidepressant medication in children. He unfortunately is unable to attend today's hearing but asked that his statement be included in the record.

Senator DEWINE. It will be made a part of the record.

[The prepared statement of Senator Dodd follows:]

STATEMENT OF SENATOR DODD

Good Morning. I would like to begin by thanking Chairman DeWine and Senator Reed, two of the Senate's strongest advocates for children's mental health reform, for holding this important hearing today. While I am not a member of this Subcommittee, both Chairman DeWine and Senator Reed are aware that the issue before this Subcommittee today is one that holds great meaning to me. Unfortunately, while other Senate business prevents me from attending today's hearing, I appreciate the Chairman making my statement part of the hearing record.

I would also like to thank all of the witnesses who are testifying today and all of those in attendance. It is very encouraging for me to see that, collectively, you represent many different specialty areas within the issue of children's mental health—from initiatives designed to meet the needs of infants to those designed to meet the needs of young adults, from services and awareness campaigns designed to improve the mental health of our children in primary and secondary schools to those designed to improve the mental health of our young people in college. I commend all of your hard work, and I applaud your professional and personal commitment to this issue. If we are to start making a meaningful difference today, then we need the continued dedication and support of each and every one of you.

I am heartened to see all of you here this morning; yet, in a way, I am also disheartened. The fact that the United States Senate needs to hear testimony from professionals and advocates who come from across the children's mental health spectrum clearly reflects the alarming fact that the problems we face as a society in this issue also come from across the spectrum.

Ensuring that all of our children and young adults have access to comprehensive mental health care that adequately and fully addresses their individualized needs is one of the most acute crises facing our society today. We all know the alarming facts. According to most inter-agency studies done by the Department of Health and Human Services, approximately 20 percent of children in our country suffer from a diagnosable mental, emotional, or behavioral disorder, while up to 10 percent suffer from a serious disturbance or multiple disorders. Yet, well over half of these children are unable to access the appropriate community-based care they require. Children and their families across this country, regardless of their age, race, ethnicity, socioeconomic status, or location, all too often find themselves facing a seriously fragmented mental health delivery system—a system that all too often fails to assess and diagnose disorders and their possible causes accurately, cannot offer complete comprehensive community-based care in the child's natural setting, employs medical and health professionals who are well intentioned but improperly trained, and cannot provide adequate financial and emotional support, information, and hope. Clearly, these widespread problems, compounded by the relative paucity of research on the risk factors and causes of children mental health disorders, speak to the urgent need for greater Federal involvement in this area.

In my capacity as a Senator from Connecticut, I have recently addressed two areas within the issue of children's mental health: youth suicide prevention and the use of antidepressant medications in children and young adults.

We all know that youth suicide is a grave crisis in the United States. According to the Centers for Disease Control and Prevention (CDC), more than 3,000 young people take their lives each year, making suicide the third overall cause of death between the ages of 10 and 24. We also know that youth suicide is intricately linked to mental health—specifically to disorders like depression and substance abuse. More than 90 percent of young people who attempt suicide are found to suffer from a mental, emotional, and behavioral disturbance.

I am pleased that we have already taken several positive steps toward better understanding the tragedy of youth suicide and its emotional and behavioral risk factors—both on the Federal and local levels. Today, hundreds of community-based programs and statewide collaborative strategies across the country offer a variety of early intervention and prevention services to thousands of children and young adults—services that include comprehensive screening, assessment, and individualized counseling. However, we still face significant challenges in this area. As we all know too well, a large number of States and localities are finding themselves with unprecedented budget deficits—making the establishment of

new services and the retention of existing services increasingly more difficult.

I have introduced bipartisan legislation with Chairman DeWine along with Senators Gordon Smith and Harry Reid. This legislation, the Youth Suicide Early Intervention and Prevention Expansion Act of 2004, seeks to support further the good work being done on the community level, the State level, and the Federal level with regards to youth suicide. Through the establishment of a new grant initiative, this legislation supports the further development and expansion of statewide youth suicide early intervention and prevention strategies and the community-based services they seek to coordinate. It also encourages greater Federal support in the planning, implementation, and evaluation of these strategies and services and creates a new inter-agency collaboration that promises to focus on research, policy development, and the dissemination of data specifically pertaining to youth suicide. Along with Chairman DeWine, I am fully committed in working to pass the legislation this year.

Although today's hearing is not focused on prescription drug treatment for depression in adolescents and children, I would like to touch on the issue briefly. Last Friday, the Washington Post reported on the results of a study published in the Lancet, a British medical journal, showing an increase in the risk of suicidal behavior among children taking four popular antidepressants. The study also showed no measurable benefit to children. This disturbing report added to the growing questions surrounding the use of antidepressants, and specifically the class of drugs known as selective serotonin reuptake inhibitors (SSRIs), in children.

SSRIs are prescribed to millions of American children each year, and that number continues to increase. Families and physicians caring for children suffering from depression are desperate for answers about the appropriate use of antidepressants. While many experts insist that antidepressants can be a critical component of care, parents cannot help but take reports of ineffectiveness and increased risk seriously.

It is imperative that questions surrounding SSRIs are answered as quickly as possible. If these drugs do indeed pose a risk to children, physicians and the public must be made aware of that risk immediately. On the other hand, it is equally important to discover the truth in the case that SSRIs do not pose a threat to children's well-being, so that doctors can continue to prescribe these life-saving medicines without fear. In the current environment of uncertainty, there is a legitimate concern that children who now benefit, or who may benefit, from SSRIs will be inappropriately denied access to these drugs.

Yesterday, I sent a letter to Acting FDA Commissioner Lester Crawford urging the agency to bring some clarity to this issue as soon as possible. This letter was a follow-up to a letter that I sent on March 1 to then-Commissioner Mark McClellan, along with nine of my Senate colleagues. In that earlier letter, we asked the FDA to consider invoking its authority to require additional testing of SSRIs to determine once and for all whether or not these drugs benefit our children. With the recent report in the Lancet, our request has taken on even greater urgency.

I have asked Acting Commissioner Crawford to share with me the FDA's plans to address this issue. I have also offered to help in whatever way I can, so that families can be confident that their children are receiving the best possible care. We must get to the bottom of this issue as soon as possible.

Lastly, Mr. Chairman, no discussion of mental health would be complete without mentioning the critical absence of parity between our mental and physical healthcare systems. Two years ago this week President Bush endorsed the notion that there is need for equity between these two disparate systems. Sadly, however, legislation ensuring parity, originally championed by our dear friend Senator Paul Wellstone, has yet still failed to pass, despite the co-sponsorship of close to 70 members of the Senate, including both the Chair and Ranking Member of this Subcommittee. Mental health parity is critically essential not only if we are to address the mental healthcare needs of our children but also the needs of all Americans.

We have a societal obligation to break through the stigma that is still unfortunately attached to children's mental health—a stigma that still keeps these issues largely off our television airwaves and the front pages of our newspapers. We have an obligation to reach out to our young people—to help them understand that whatever difficulties or illnesses they might be experiencing are only temporary and treatable in a comfortable setting. And, most important, we have an obligation to instill in our young people a sense of value, self-worth, and resilience. Therefore, I am fully committed to working with each of you—doctors, psychiatrists, psychologists, counselors, nurses, teachers, advocates, and affected families—so that we can better understand the causes of mental health disorders and develop effective mental health initiatives and services that reach every child and young adult in this country—compassionate initiatives that give them encouragement, hope, and above all, life.

Senator REED. I thank the chairman again for holding today's hearing, and I look forward to working with him on these critical issues and listening to these outstanding witnesses.

Thank you, Mr. Chairman.

Senator DEWINE. Senator Reed, thank you very much.

At this time I would like to submit a prepared statement from Senators Kennedy and Collins to be included in the record.

[The prepared statement of Senator Kennedy follows:]

PREPARED STATEMENT OF SENATOR EDWARD M. KENNEDY

Thank you, Senator DeWine, for convening this important hearing and for your strong commitment to the well-being of the nation's children.

As the report of the President's New Freedom Commission stated, our mental health care system is in crisis. The quality of care isn't good enough, access, isn't broad enough, and the whole system isn't consumer-oriented enough.

No group in our population bears a greater burden of this failure than the young. One in five children and adolescents have mental health disorders, but three-quarters of them never receive the care

they need. The large racial disparities in access to care and quality of care are serious problems as well.

The results of this failure are higher school drop-out rates, more frequent family conflicts, higher rates of drug abuse and violence and higher rates of anxiety disorders, depression, and even suicide.

It is clear that we can do much more to prevent, treat, and cure mental illness in children. The panelists here today demonstrate that it is a problem we must meet at all stages of development.

The recommendations of the New Freedom Commission offer us a unique opportunity to act effectively. One of the key recommendations is to improve mental health care services in schools.

Schools have become the de facto providers of mental health care for children. In fact, 80 percent of the children who receive mental health care services receive them in schools. But the care in schools is plagued by the same factors that plague other systems of care—not enough funds, not enough personnel, poor quality of care, little involvement of parents, and few prevention efforts.

In addition, the lack of research and dissemination of evidence-based practices has meant few advances in intervention and treatment.

Complex and costly care has led to families doing the unthinkable—giving up custody of their child to the child welfare system or juvenile justice system in order to obtain services, even though such systems are ill-prepared to meet their needs. A lack of parity in financing for mental health care for children has contributed greatly to this disturbing defect.

It's clear we can't afford to wait any longer to make urgently needed improvements, and I look forward to working with Senator DeWine, Senator Reed and other Members of the Subcommittee on the recommendations made by today's panelists.

[The prepared statement of Senator Collins follows:]

PREPARED STATEMENT OF SENATOR SUSAN M. COLLINS

I want to commend the Subcommittee Chairman for holding this hearing to examine mental health issues in children and youth throughout the developmental process. Unfortunately, I am chairing a Governmental Affairs Committee hearing this morning, so I am unable to deliver my testimony in person, but I appreciate the Chairman's kind offer to make certain that it is included as a part of the hearing record.

Serious mental illness afflicts millions of our nation's children and adolescents. It is estimated that as many as 20 percent of American children under the age of 17 suffer from a mental, emotional or behavioral illness. What I find most disturbing, however, is the fact that two-thirds of all young people who need mental health treatment are not getting it.

Behind each of these statistics is a family that is struggling to do the best it can to help a son or daughter with serious mental health needs to be just like every kid—to develop friendships, to do well in school, and to get along with their siblings and other family members. These children are almost always involved with more than one social service agency, including the mental health, special education, child welfare and juvenile justice systems. Yet no one

agency, at either the State or the Federal level, is clearly responsible or accountable for helping these children and their families.

My interest in this issue was triggered by a compelling series of stories by Barbara Walsh in the *Portland Press Herald* which detailed the obstacles that many Maine families have faced in getting desperately needed mental health services for their children.

Too many families in Maine and elsewhere have been forced to make wrenching decisions when they have been advised that the only way to get the care that their children so desperately need is to relinquish custody and place them in either the child welfare or juvenile justice system.

Yet neither system is intended to serve children with serious mental illness. Child welfare systems are designed to protect children who have been abused or neglected. Juvenile justice systems are designed to rehabilitate children who have committed criminal or delinquent acts. While neither of these systems is equipped to care for a child with a serious mental illness, in far too many cases, there is nowhere else for the family to turn.

Last year, I commissioned a GAO report with Representatives Pete Stark and Patrick Kennedy that found that, in 2001, parents placed more than 12,700 children into the child welfare or juvenile justice systems so that these children could receive mental health services.

Moreover, I believe that this is just the tip of the iceberg, since 32 States—including the five States with the largest populations of children—did not provide the GAO with any data.

There have been other studies indicating that the custody relinquishment problem is even more pervasive. A 1999 survey by the National Alliance for the Mentally Ill found that 23 percent—or one in four parents surveyed—had been told by public officials that they needed to relinquish custody of their children to get care, and that one in five of these families had done so.

While some States have passed laws to limit or prohibit custody relinquishment, simply banning the practice is not a solution, since it can leave mentally ill children and their families without services and care. Custody relinquishment is merely a symptom of the much larger problem, which is the lack of available, affordable, and appropriate mental health services and support systems for children with serious mental health needs and their families.

I chaired a series of hearings in the Governmental Affairs Committee last summer to examine this issue further. We heard compelling testimony from mothers who told us that they were advised that the only way to get the intensive care and services that their children needed was to relinquish custody and place them in the child welfare system. This is a wrenching decision that no family should be forced to make. No parent should have to give up custody of his or her child just to get the services that the child needs.

The mothers also described the barriers they faced in getting care for their children. They told us about the limitations in both public and private insurance coverage. They also talked about the lack of coordination and communication among the various agencies and programs that serve children with mental health needs. One parent, desperate for help for her twin boys, searched for 2

years until she finally located a program—which she characterized as "the best kept secret in Illinois"—that was able to help.

Parents should not be bounced from agency to agency, knocking on every door they come to, in the hope that they will happen upon someone who has an answer. It simply should not be such a struggle for parents to get services and treatment for their children.

The Keeping Families Together Act, which I have introduced with a bipartisan group of my colleagues, would help to reduce the barriers to care for children with serious mental health needs and would assist States in eliminating the practice of parents relinquishing custody of their children solely for the purpose of securing mental health services.

The legislation authorizes $55 million for competitive grants to States to create an infrastructure to support and sustain statewide systems of care to serve children who are in custody or at risk of entering custody of the State for the purpose of receiving mental health services. States already dedicate significant dollars to serve children in State custody. These Family Support Grants would help states serve children more effectively and efficiently, while keeping them at home with their families.

The legislation would also remove a current statutory barrier that prevents more States from using the Medicaid home and community-based services waiver to serve children with serious mental health needs. This waiver provides a promising way for States to address the underlying lack of mental health services for children that often leads to custody relinquishment. While a number of States have requested these waivers to serve children with developmental disabilities, very few have done so for children with serious mental health conditions. Our legislation would provide parity to children with mental illness by making it easier for States to offer them home- and community-based services under this waiver as an alternative to institutional care.

The Keeping Families Together Act takes a critical step forward to meeting the needs of children with mental or emotional disorders and their families. Attached to my testimony is a more detailed summary of the Keeping Families Together Act, and I urge all of the Members of the Subcommittee to work with me so that we can get this legislation passed and signed into law before the end of the year.

Again, Mr. Chairman, thank you for allowing me to submit my testimony, and I look forward to working with you to ensure that appropriate and affordable mental health services and support systems are available for all children and young people with mental health needs and their families.

Let me introduce the panel. I will introduce all the members of the panel. We will keep your statements to 5 minutes. We are going to be fairly tight on that because that will give us an opportunity to ask some questions and hear your comments.

On our panel this morning, I would first like to introduce Dr. Joy Osofsky. She is currently professor of Pediatrics, Psychiatry, and Public Health at Louisiana State University Health Sciences Center in New Orleans and is the head of the Division of Pediatric Mental Health. She serves as director of the Violence Intervention Program for Children and Families and the Harris Center for In-

fant Mental Health. The doctor has published and edited numerous articles on the effects of violence in young children, and in June of this year, she will publish an edited book titled "Young Children and Trauma." She is president of Zero to Three: National Center for Infants, Toddlers, and Families, and in 2002, she was awarded the Nicholas Hobbs Award for contributions to public policy by Division 37 of the American Psychological Association.

Next, let me introduce Marleen Li Chen Wong. She is the director of Mental Health, District Crisis Intervention Teams, and Suicide Intervention Programs for the Los Angeles Unified School District, the second largest school district in the United States. She has administrative responsibility for four outpatient child clinics, a staff of 186 clinical social workers and clinical psychologists, child psychiatrists, and community workers; and 350 district crisis team members. She is also responsible for administering the mental health consultation program in over 100 children's day care centers in Los Angeles Unified School District schools. She is currently serving as director of the School Crisis and Disaster Recovery Program at the National Center for Child Traumatic Stress at UCLA and Duke University.

Next, let me introduce Dr. Louise Douse. She is the director of the Counseling and Consultation Service at the Ohio State University, which serves the full range of counseling and mental health needs of the Ohio State University student body. She is a specialist in college student mental health and has been counseling college students for the past 25 years. She is the immediate past president of the Society of Counseling Psychology, Division 17 of the American Psychological Association, and in the year 2003, the Association of University and College Counseling Center Directors presented her with the Lifetime Achievement Award.

Next, I would like to introduce Dr. Davis. Dr. Davis is currently an assistant professor in the Department of Psychiatry at the University of Massachusetts and a faculty member of the Center for Mental Health Services Research. Her current efforts focus on the mental health needs of children transitioning into adulthood. Dr. Davis has designed and implemented a transition support project, Project Nexus, to assist children with mental health needs during this difficult transitional period. Dr. Davis also serves as a consultant to the Center for Mental Health Services of the Substance Abuse and Mental Health Services Administration on their evaluation program of the Partnership for Youth Transition grant program.

Let me also introduce Linda Champion. Since 2002, Mrs. Champion has served as a data analyst for the Alabama Department of Mental Health and Mental Retardation. She is the vice president of Alabama Family Ties, an advocacy group which advocates for children and adolescents with mental illness. Mrs. Champion is also the Children's Issues Advisor to the National Alliance for the Mentally Ill in Alabama and serves on numerous planning committees working with the State of Alabama Department of Mental Health and Mental Retardation.

Finally, let me introduce Barbara Altenburger. As the parent of an adolescent with serious emotional and behavioral disorders, she has had to navigate the children's mental health system herself

and, therefore, can offer great insight to us. We commend her commitment to helping us all better understand this important and complex issue. She serves as a family advocate at Parents Involved Network of Philadelphia, a program of the Mental Health Association of Southeastern Pennsylvania. In addition to her work with the Parents Involved Network, she has shared her experiences at local workshops and conferences and is a long-time advocate for improved mental health and related services for children, adolescents, and their families.

We thank all of you very much for joining us, and we appreciate it. We look forward to all of your testimony. We will start on my right with Dr. Osofsky. Doctor, thank you very much.

STATEMENTS OF JOY D. OSOFSKY, PROFESSOR OF PEDIATRICS, PSYCHIATRY, AND PUBLIC HEALTH, LOUISIANA STATE UNIVERSITY HEALTH SCIENCES CENTER, AND PRESIDENT, BOARD OF DIRECTORS, ZERO TO THREE; MARLEEN WONG, DIRECTOR, CRISIS COUNSELING AND INTERVENTION SERVICES, LOS ANGELES UNIFIED SCHOOL DISTRICT, LOS ANGELES, CA, AND DIRECTOR, SCHOOL CRISIS AND INTERVENTION UNIT, NATIONAL CENTER FOR CHILD TRAUMATIC STRESS, UCLA AND DUKE UNIVERSITY; LOUISE A. DOUCE, DIRECTOR, COUNSELING AND CONSULTATION SERVICES, THE OHIO STATE UNIVERSITY; MARYANN DAVIS, ASSISTANT PROFESSOR, CENTER FOR MENTAL HEALTH SERVICES RESEARCH, DEPARTMENT OF PSYCHIATRY, UNIVERSITY OF MASSACHUSETTS MEDICAL SCHOOL, WORCESTER, MA; LINDA CHAMPION, CHILD ADVOCATE, NATIONAL ALLIANCE FOR THE MENTALLY ILL, AND VICE PRESIDENT, ALABAMA FAMILY TIES, MONTGOMERY, AL; AND BARBARA ALTENBURGER, FAMILY ADVOCATE, PARENTS INVOLVED NETWORK, MENTAL HEALTH ASSOCIATION OF SOUTHEASTERN PENNSYLVANIA, PHILADELPHIA, PA

Ms. OSOFSKY. Mr. Chairman and Members of the Committee, I am delighted to have the opportunity to appear before you today on behalf of Zero to Three. As you introduced me, I am Joy Osofsky, a professor of pediatrics, psychiatry, and public health at Louisiana State University Health Sciences Center, and president of the board of directors of Zero to Three. Zero to Three is a national, nonprofit organization that has worked to advance the healthy development of America's babies and toddlers for over 25 years. I would like to start by thanking the committee for their interest in addressing the mental health needs of infants, toddlers, and families, and I would particularly like to thank you, Mr. Chairman, for your leadership in helping to address the mental health needs of our most vulnerable infants and toddlers, those involved in the child welfare system through your support of the Court Teams for Change Project, an effort that I will describe in a few minutes.

Despite what we know from science and research, discussions on children's mental health have consistently excluded babies and toddlers, focusing instead on school-age children and adolescents. Although they cannot talk to us about what they are feeling like older children can, sometimes referred to as "silent victims," babies

and toddlers have many ways of communicating, and we have many ways to assess their social and emotional needs.

Unfortunately, some infants and toddlers experience mental health problems. Their early social and emotional development is vulnerable to such factors as repeated exposure to violence, persistent fear and stress, abuse and neglect, severe chronic maternal depression, or biological factors such as prematurity and low birthweight and conditions associated with substance abuse.

Babies do not exist in isolation. The parent's mental health can also affect the young child. Conditions such as maternal depression and anxiety disorders can disrupt parenting. For example, infants of mothers who have chronic, untreated depression often withdrawn, ultimately affecting their language skills, as well as their physical and cognitive development.

The message I want to convey today, however, is not a pessimistic one. When we do identify these children and their parents, we know how to provide effective infant mental health interventions for the baby and for the significant adults in the baby's life. These interventions can prevent or ameliorate the effects of negative early experiences. What we are missing is the widespread awareness of the problem, the systems to identify children who are affected, and readily accessible services to meet their needs.

So why should we care about infant mental health? First, learning to regulate emotions and developing secure attachments form the very foundation of a child's ability to learn, and infants cannot wait. The early years are a period of extremely rapid brain growth, wiring and pruning of neuronal connections. The pathways that are laid down in these early years are the ones that will guide the child's reactions and emotions for the rest of her life.

Second, science supports our concern. The National Academy of Sciences report "From Neurons to Neighborhoods" concluded that the elements of early childhood programs that enhance social and emotional aspects of development are just as important as those supporting cognitive and linguistic competence. The goal of ensuring that all children are ready for school has become a national priority. Young children who do not achieve early social and emotional milestones perform poorly in the early school years and are at higher risk for school problems and juvenile delinquency later in life.

Infants and toddlers in foster care represent a group of children that are extremely vulnerable. Juvenile and family court judges are uniquely positioned to improve the well-being of infants and toddlers in the child welfare system to ensure that they are receiving the resources and supports they need to address their social and emotional needs.

I have been involved in developing an approach to working with these young children in Miami-Dade Juvenile Court. Three years of data show substantial gains in improving social and emotional development of infants, toddlers, and their families. Of the families selected to receive the intervention, 58 percent of the children improved in their developmental functioning, 100 percent of the infants were reunified with their families, and substantiated reports of abuse and neglect were reduced from 97 percent to zero.

The Federal Government is in a unique position to support the documented and growing needs of mental health services for infants, toddlers, and families. While some child-related services such as early Head Start and Part C early intervention address infant mental health, only a small number of children meet the eligibility requirements of these programs. Zero to Three recommends that the mental health needs of infants, toddlers, and families be recognized and addressed in bills currently up for reauthorization, including Head Start, Individuals with Disabilities Education Act, Child Care Development Fund, and Substance Abuse and Mental Health Services Administration.

These recommendations are supported by findings in President Bush's New Freedom Commission on Mental Health, as well as the National Research Council Institute of Medicine report "From Neurons to Neighborhoods: The Science of Early Childhood Development."

Our recommendations are as follows:

One, strengthen infant and early childhood mental health services and integrate such services into all child-related services and systems.

Two, assure earlier identification and intervention of mental health problems and disorders in infants, toddlers, and their parents.

Three, develop system capacity through professional development/training of service providers.

Four, assure comprehensive mental health services for infants and toddlers in foster care.

Five, provide infant/toddler child-care programs with access to mental health consultation and support.

Six, support and advance evidence-based practices in infant and early childhood mental health through the establishment of a national infant mental health resource center.

In conclusion, Mr. Chairman, existing Federal, State, and community programs for young children should be used as foundations to expand and improve infant mental health services. Although research is clear in demonstrating the importance of healthy social and emotional development at the earliest stages of life in assuring school readiness and developing healthy relationships later in life, we have not translated this knowledge into what we do for babies and toddlers. If we truly desire children to be ready to learn, much less to grow up as healthy adults, we need to make a concerted effort to address the critical mental health needs of our youngest children and families.

Thank you very much.

Senator DEWINE. Doctor, thank you.

[The prepared statement of Ms. Osofsky follows:]

PREPARED STATEMENT OF JOY D. OSOFSKY

Mr. Chairman and Members of the Committee, I am delighted to have the opportunity to appear before you today on behalf of ZERO TO THREE. I am Joy Osofsky, a psychologist and Professor of Pediatrics, Psychiatry, & Public Health at Louisiana State University Health Sciences Center and President of the Board of Directors of ZERO TO THREE. ZERO TO THREE is a national non-profit organization that has worked to advance the healthy development of America's babies and toddlers for over 25 years. I would like to start by thanking the committee for their interest in addressing the mental health needs of infants, toddlers, and their families. I would

also like to particularly thank Senator DeWine for his leadership in helping to address the mental health needs of our most vulnerable infants and toddlers, those involved in the child welfare system through his support of the Court Teams for Change Project, an effort that I will describe in just a few minutes.

WHAT IS INFANT MENTAL HEALTH?

Despite what we know from science and research, discussions on children's mental health have consistently excluded babies and toddlers, focusing instead on school-age children and adolescents. Although they cannot talk to us about what they are feeling like older children can, babies and toddlers have many ways of communicating, and we have many ways to assess their social and emotional needs.

Most babies experience healthy social and emotional development. They smile and coo, cry and recover, and become social beings. Babies and toddlers with typical mental health have the capacity to experience, regulate and express emotions; form close and secure interpersonal relationships; and explore the environment and learn. The healthy mental development of babies and toddlers is dependent upon their ability to manage their feelings, develop trust with others, and learn about the world in which they live.

This all happens as infants and toddlers work to make sense of their environment. It is then that they first find their efforts encouraged—or not; first attempt to concentrate and find that possible—or not; first conclude that the world seems organized and reasonably predictable—or not; first learn that others are basically supportive—or not. It is in the first years of life that the foundations for empathy, trust, curiosity, and competence are laid down.

Attachment is one of the most critical developmental tasks of infancy. We know from the science of early childhood development that early relationships and attachments to a primary caregiver are the most consistent and enduring influence on social and emotional development for young children.[1] Infants and toddlers who are able to develop secure attachments are observed to be more mature and positive in their interactions with adults and peers than children who lack secure attachments.[2] They may also have a better self-concept, more advanced memory processes, and a better understanding of emotions.[3] Those who do not have an opportunity to form a secure attachment with a trusted adult (for example, infants and toddlers who experience multiple foster homes) suffer grave consequences. Their development can deteriorate, resulting in delays in cognition and learning, relationship dysfunction, difficulty expressing emotions, and future mental health disorders.

Unfortunately, some infants and toddlers experience mental health problems. The early social and emotional development of babies and toddlers is vulnerable to such factors as repeated exposure to violence, persistent fear and stress, abuse and neglect, severe chronic maternal depression, biological factors such as prematurity and low birth weight, and conditions associated with prenatal substance abuse. Without intervention, these risk factors can result in mental health disorders. In babies and toddlers, the effects of these factors may look like excessive and inconsolable crying; a heightened sensitivity to touch and cuddling; excessive biting, kicking and hitting; inability to focus on activities, flat affect (no expression, no emotions) and depression. Infant mental health intervention for the baby, and for the significant adults in the baby's life, can prevent or ameliorate the effects of negative early experiences.

Unlike adults, babies and toddlers have fairly limited ways of responding to stress and trauma. They may respond through inconsolable crying, withdrawal from daily activities, sleeplessness or lack of appetite due to depression, anxiety, and traumatic stress reactions, poor weight gain, or aggressive behavior in older toddlers. If the underlying causes of the stress are not addressed, they can develop into serious mental health disorders, including depression, attachment disorders, and traumatic stress disorders. Infants can experience withdrawal and depression as early as 4 months of age.[4] Unfortunately, despite the severe consequences, these disorders are not being identified. Neither parents nor most providers know enough about how to identify the early warning signs to make effective referrals.

Babies do not exist in isolation. The parent's mental health can also affect the young child. Conditions such as maternal depression and anxiety disorders can disrupt parenting. For example, infants of mothers who have severe chronic, untreated depression often withdraw, ultimately affecting their language skills, as well as

[1] Shonkoff, J., & Phillips, D. (Eds.). (2000). *From neurons to neighborhoods: The science of early childhood development*. Washington, DC: National Academy Press.

[2] Ibid.

[3] Ibid.

[4] Luby, J. (2000). Depression. In C. Zeanah (Ed). Handbook of Infant Mental Health (pp. 296–382).

physical and cognitive development. Older children of depressed mothers show poor self-control, aggression, poor peer relationships, and difficulty in school.[5]

Ultimately, for the very young child, mental health disorders will have a significant effect on later school performance and life successes. In fact, more and more young children are being expelled from child care and preschool for behavior problems, and supports are not available for these children, their parents, or their caregivers. Without early identification, assessment and effective intervention these problems will escalate.

Given the importance of social and emotional development in the first 3 years of life, the scarcity of data on the mental health of babies and toddlers is disappointing, but not surprising, considering the lack of attention to social and emotional development in infants and toddlers. Although no data are available for children under age 3, it is estimated that between 2 percent and 8 percent of all children under the age of 18 are reported to have a mental/emotional problem or functional limitation.[6,7] If these same estimates are applied to the birth to 3-age population, between 228,000 to 913,000 infants and toddlers are at risk of mental health disorders.

WHY SHOULD WE CARE ABOUT INFANT MENTAL HEALTH?

Learning to regulate emotions and developing secure attachments are not simple, pleasant milestones in a baby's development that take a backseat to the growth of cognitive skills as a child prepares to enter school. Rather, they are the very foundation of the child's ability to learn. A child who has not developed consistent, positive relationships with adults, cannot regulate his own emotions, cannot consider the emotions of his peers, does not trust adults, has difficulty in being motivated to learn, or cannot calm himself to tune into teaching will not benefit from early educational experiences.

There are many good reasons to care about early social and emotional development. First, infants can't wait. The early years are a period of extremely rapid brain growth, wiring and pruning of neuronal connections. The pathways that are laid down in these early years are the ones that will guide the child's reactions and emotions for the rest of her life. Second, science supports our concern. The National Academy of Sciences report *From Neurons to Neighborhoods*[8] concluded that the elements of early childhood programs that enhance social and emotional aspects of development are just as important as the component that support cognitive and linguistic competence.

The goal of ensuring that all children are "ready for school" has become a national priority. As a result, programs that support children's school readiness are becoming more and more important to policy-makers, parents, and the general public. It is becoming very clear that efforts to improve school success cannot begin at preschool, nor focus exclusively on academics. In fact, studies suggest that emotional, social, and behavioral competence is a strong predictor of academic performance in elementary school. Young children who do not achieve early social and emotional milestones perform poorly in the early school years, and are at higher risk for school problems and juvenile delinquency later in life.[9]

Finally, we should all care about early social and emotional development because barriers exist for families and providers, and our inaction is making the problem of accessing infant mental health services worse. Barriers include the scarcity of infant mental health providers and supervisors; the lack of awareness by the general public, policy-makers, parents, teachers, health care providers and others about the importance of early social and emotional development; limited funding for infant mental health services; lack of capacity to provide mental health services to parents

---

[5] Embry, L. and Dawson, G. (2002). Disruptions in parenting behavior related to maternal depression: Influences on children's behavioral and psychobiological development. In J. Borkowski, S., Ramey, C. & Bristol-Powers, M. (Eds). *Parenting and the young child's world*. (pp. 203–214) Mahwah, NJ: Erlbaum.

[6] Colpe, L. (2000). Estimates of mental and emotional problems, functional impairments, and associated disability outcomes for the U.S. child population in households. Retrieved April 24, 2003, from www.mentalhealth.org/publications.

[7] Halfon, N. & Newacheck, P. (1999). Prevalence and impact of parent-reported disabling mental conditions among U.S. children. *Journal of the American Academy of Child and Adolescent Psychiatry, 38*(5), 600–609.

[8] Shonkoff, J. & Phillips, D. (Eds.) (2000). *From neurons to neighborhoods: The science of early childhood development*. Washington, DC: National Academy Press.

[9] Raver, C. (2002). Emotions matter: Making the case for the role of young children's emotional development for early school readiness. *Social Policy Report of the Society for Research in Child Development, 16*(1) 3–23.

along with their children; reluctance by families to use mental health services; and the overall lack of application of scientific knowledge to practice.

FEDERAL RECOMMENDATIONS

The Federal Government is in a unique position to support the documented and growing needs of mental health services for infants, toddlers, and families. While some child related services, such as Early Head Start and Part C Early Intervention address infant mental health, only a small number of children meet the eligibility requirements of these programs. ZERO TO THREE recommends that the mental health needs of infants, toddlers, and families be recognized and addressed in bills currently up for reauthorization including Head Start, Individuals with Disabilities Education Act (IDEA), Child Care Development Fund (CCDF), and Substance Abuse and Mental Health Services Administration (SAMHSA). These recommendations are supported by findings in President Bush's New Freedom Commission on Mental Health (2003) as well as in the National Research Council Institute of Medicine report *From Neurons to Neighborhoods: The Science of Early Childhood Development* (2000).[10,11] Our recommendations are as follows:

1. Strengthen infant and early childhood mental health services and integrate such services into all child-related services and systems.

Infant mental health services are scarce. Where they do exist, they are fragmented and disconnected from the settings and services most frequently used by young children and families. Infant and early childhood mental health services across the continuum of promotion, prevention, and treatment must be created, expanded, and improved. Services must be comprehensive: they should promote healthy social and emotional development for all young children, provide prevention services for families of young children experiencing or at risk of experiencing situations that jeopardize healthy social and emotional development, and provide individualized treatment services for children who have mental health disorders.

Illinois has utilized this comprehensive approach in addressing infant mental health. Evaluation of an integrated mental health approach in Illinois documented the effectiveness of including Social Emotional Specialists in Part C Early Intervention programs. These specialists provide training, technical assistance, as well as mental health consultation to the managers, coordinators, and providers of the Part C program. Evaluation findings revealed positive improvements in practice that are helping programs to address all components of Part C, easier access to mental health services, and earlier identification of mental health disorders.

Social and emotional development is not an isolated issue. It spills over into all areas of early childhood development. Infant mental health services must be integrated into all services that touch the lives of infants, toddlers, and their families. These may include child care, Early Head Start, pediatric and family health care, public health, community mental health, child welfare/social services, home-visiting, and Part C Early Intervention.

2. Assure earlier identification and intervention of mental health problems and disorders in infants, toddlers and their parents.

Early identification of risk factors is critical in preventing and treating mental health disorders in young children. All professionals who have contact with infants and toddlers, and families should be aware of early risk factors, how to screen and where to refer for assessment and intervention. Developmentally appropriate screening and assessment tools for infants, toddlers, and parents are critical for the early identification of, planning and delivery of effective interventions. Screening and assessment of parental mental health, stress and support systems are equally important in enabling providers to document the needs of parents. The well-child visit is an important opportunity for early identification of developmental, emotional, and behavioral problems. Physicians, time-pressured to provide both medical care and anticipatory guidance, would be best supported if they had ready access to screening tools, (including those that could be completed by parents), practical information about referral information, and financing strategies.

To encourage developmental and behavioral screening and assessment for all infants and toddlers, barriers to reimbursement must be eliminated. Strategies to improve financing include encouraging the use of appropriate diagnostic procedures and billing codes; expansion of billing options in Medicaid to allow for treatment of parents and infants together; maximizing use of Early and Periodic Screening, Diag-

[10] New Freedom Commission on Mental Health (2003). *Achieving the promise: Transforming mental health care in America. Executive Summary*. DHHS Publication No. SMA–03–3831. Rockville, MD: U.S. Department of Health and Human Services.

[11] Shonkoff, J. & Phillips, D. (Eds.) (2000). *From neurons to neighborhoods: The science of early childhood development*. Washington, DC: National Academy Press.

nosis, and Treatment Program (EPSDT) and State Children's Health Insurance Program (SCHIP), and recognizing infant, toddler, and parent mental health concerns as legitimate treatment issues.

3. Develop system capacity through professional development/ training of service providers.

Neurons to Neighborhoods informs us that, "Given the substantial short- and long-term risks that accompany early mental health impairments, the incapacity of early childhood programs to address these concerns and the severe shortage of early childhood professionals with mental health expertise are urgent problems."[12] If we hope to make a positive difference in the lives of children who are already affected by mental health disorders, violence, and trauma and promote healthy social and emotional development we must invest in building a strong infant mental health workforce.

The quality of a service system depends on the individuals that deliver the services. "Substantial new investments should be made to address the nation's seriously inadequate capacity for addressing young children's mental health needs. Expanded opportunities for professional training, as recently called for by the Surgeon General, and incentives for individuals with pertinent expertise to work in settings with young children are first steps toward more effective screening, early detection, treatment, and ultimate prevention of serious childhood mental health problems."[13]

Greater investments must be made in infant mental health. Both the community at large as well as parents and the early care and education providers need to be aware of the importance of early social and emotional development. In addition, there should be increased support for training, continuing education, recruitment, and retention of professionals with special training in infant and early childhood mental health services.

There are no national data to document shortages in infant mental health personnel. Anecdotally, based on calls and requests that ZERO TO THREE receives from States and communities, the need for specialized training as well as general awareness of social and emotional development is overwhelming. In a recent survey of unmet needs in the Illinois early care and education system, 62 percent of programs reported inadequate mental health resources. Investing in mental health training yields promising outcomes. In 24 Early Head Start programs that participated in the "Pathways to Preventions" training model, three critical objectives were achieved: staff knowledge and skills were extended into programs beyond Early Head Start, program supports were strengthened, availability of mental health providers were increased, and staff retention improved.

4. Assure comprehensive mental health services for infants and toddlers in foster care.

Infants and toddlers in foster care represent a group of children that are extremely vulnerable. Most have been seriously maltreated; they exhibit behavior problems such as failure to thrive, tantrums, self-endangering, aggression, and inability to be consoled. Nearly 80 percent are prenatally exposed to substance abuse, 40 percent are born prematurely and/or low birth weight, and all of them experience repeated and often traumatic separation from caregivers, placing them at risk for future mental health disorders. Infants are the fastest growing and single largest cohort in foster care. Babies placed in foster care before 4 months of age remain in foster care longer than other children.[14] Over 39,000 infants enter foster care each year. Infants and toddlers who have suffered physical or sexual abuse, neglect, and separation from their parents will also suffer emotional and developmental consequences unless they, and their parents, foster parents and other primary caregivers, are provided with supportive mental health interventions.

Juvenile and Family Court Judges are responsible for the well-being of the children in their courts and can be powerful agents of change. They are uniquely positioned to improve the well-being of infants and toddlers in the child welfare system and to ensure that they are receiving the resources and supports they need to address social and emotional needs. In fact, judges have an opportunity, perhaps the last one for these most vulnerable infants and toddlers, to focus on healing in the process of adjudicating the case.[15]

---

[12] Shonkoff, J. & Phillips, D. (Eds.) (2000). National Research Council and Institute of Medicine. *From neurons to neighborhoods: The science of early childhood development*. Washington, DC: National Academy Press.

[13] Ibid.

[14] Wulczyn, F., Harden, B. and Hislop, K. (2002). The placement of infants in foster care. *Infant Mental Health Journal*, 23(5), 454–475.

[15] Osofsky, J.D. & Lederman, C.S. (in press). Healing the child in juvenile court. In J.D. Osofsky (Ed). Young Children and Trauma: Intervention and Treatment. New York: Guilford, 2004.

I have been involved in developing an approach to working with these young children in the Miami-Dade Juvenile Court. Three years of data show substantial gains in improving social and emotional development of infants, toddlers, and their families. In this court, all infants, toddlers and their mothers receive screening and assessment services. Babies are screened for developmental delays and referred for services. A parent-infant psychotherapy intervention is available to a select number of mothers. An Early Head Start program connected to the court is the first designed specifically to meet the needs of maltreated children. Children showed significant improvements in enthusiasm, persistence, positive affect and a reduction of depression, anger, withdrawal and irritability.[16] Of the families selected to receive the intervention: 58 percent of children improved in their developmental functioning;[17] 100 percent of infants were reunified with their families;[18] and reports of abuse/neglect were reduced from 97 percent to 0.[19]

5. Provide infant/toddler child care programs with access to mental health consultation and support.

Increasingly, young children are being expelled from child care and preschool for behavior problems, including biting, tantrums, hitting, throwing objects, or inconsolable crying.[20,21] A survey of child care providers in New Hampshire found that 53 percent of respondents had expelled at least one child, age birth through six. Young children with behavior problems are difficult to teach, and if disliked by teachers and peers because of behavior, quickly lose motivation for learning, withdraw from peers, or face social rejection.[22]

An estimated 7 million babies and toddlers (nearly 65 percent of all children under age 3) spend time in non-parental care each day.[23] Good child care can be an excellent early learning environment where healthy social and emotional development can be promoted for all children. With mental health consultation and training, staff can support and promote social and emotional development, prevent behavioral problems, and identify early warning signs of mental health disorders.

A Kentucky study demonstrated success of mental health consultation in child care. Of the approximately 400 children served through June 2003, 88 were identified as being at-risk for such discharge. Of these, only 8 lost their placement due to behavior problems, while 80 had been successfully maintained in these programs.

6. Support and advance evidence-based practices in infant and early childhood mental health through the establishment of a national infant mental health resource center.

Parents and professionals are hungry for information about social emotional development. There is new research available and some promising models for addressing infant mental health, but providers are largely unaware of this information. One way to improve the mental health outcomes for young children is by creating a national resource center for infant mental health. Such a center would:

- Provide information, technical assistance, training and other resources about social-emotional development in infants and toddlers with disabilities to early intervention personnel and parents.
- Identify and disseminate infant mental health models.
- Translate current research about effective infant mental health intervention and treatment approaches for parents and early intervention professionals.
- Develop materials screening and assessment tools, how to integrate mental health goals into Part C Individualized Family Service Plans, and infusing relationship-based approaches into Part C practice.
- Coordinate with other mental health initiatives such as those through the Early Head Start National Resource Center to assure a systematic approach across birth to three programs.

---

[16] Lederman, C. (2003). Mental health trends in 2003: Miami's infant and young children's mental health program: A place where the healing begins. The National Center for State Courts.

[17] Adams, S., Osofsky, J., Hammer, J., & Graham, M. (2003). Program Evaluation Florida Infant & Young Child Mental Health Pilot Project, Year 3, Final Report, Tallahassee, FL: Florida State University Center for Prevention & Early Intervention Policy.

[18] Lederman, C. (2003). Mental health trends in 2003: Miami's infant and young children's mental health program: A place where the healing begins. The National Center for State Courts.

[19] Ibid.

[20] Wheatley, E. (2001). *Child care expulsion survey*. Bow, NH: New Hampshire Association for Infant Mental Health.

[21] Cutler, A. & Gilkerson, L. (2002). *Unmet needs project: A research, coalition building and policy initiative on the unmet needs of infants, toddlers and families*. Chicago, IL: University of Illinois at Chicago and Erikson Institute.

[22] McEvoy, A. & Welker, R. (2000). Antisocial behavior, academic failure and school climate: A critical review. *Journal of Emotional and Behavioral Disorders*, 8(3), 130–140.

[23] Oser, C. & Cohen, J. (2002). *America's Babies: The ZERO TO THREE Policy Center Data Book*. Washington, DC: Zero to Three Press.

Many States are in the process of developing strategic plans for early childhood mental health services, developing financing strategies, etc. This is an opportune time to identify and disseminate promising evidence-based practices, and translate what is known from the science of early childhood education into what we do for infants, toddlers and families.

In conclusion, Mr. Chairman, existing Federal, State, and community programs for young children should be used as foundations to expand and improve infant mental health services. Although research is clear in demonstrating the importance of healthy social and emotional development at the earliest stages in life in assuring school readiness and developing healthy relationships later in life, we have not translated this knowledge into what we do for babies and toddlers. If we truly desire children to be ready to learn, much less to grow up to be healthy adults, we need to make a concerted effort to address the critical mental health needs of our youngest children and their families.

RESPONSE TO QUESTIONS OF SENATOR REED FROM JOY OSOFSKY

Question 1. Is there evidence of improved outcomes, better compliance, and cost savings through providing combined services? For example, properly treating an alcoholic's bipolar illness to avoid relapsing on alcohol.

Answer 1. Unfortunately, many juvenile facilities have inadequate mental health services and limited programs to help change behaviors and provide rehabilitation for incarcerated juveniles. Incidences of recidivism are high. Most show antisocial behaviors entering the prison and many more show antisocial traits and mental health symptoms while in prison related to the harsh treatment and experiences while they are in the facility. Most juvenile facilities are understaffed with mental health professionals and do not have good individual and group services to meet the mental health needs of the youth. To address this issue, it can be helpful for correctional facilities to link with universities, medical schools, community programs, and other settings that may be able to provide services and help to develop more positive programs for the youth.

Question 2. Are different Federal funding streams a barrier to quality mental health care?

Answer 2. Barriers when they transition out of juvenile facilities include: (1) Traditional case management services that are often inadequate to help youth with the transition; and (2) few good community programs to help develop skills and support them when they return to their home communities.

What judges can do to help this situation:

(1) Judges can help to develop collaborations where youth and their families can participate in prevention and intervention programs in their communities to prevent their being incarcerated.

(2) Judges can work together with mental health professionals and school systems to try to develop diversionary programs for first time offenders who have not committed violent crimes in order to provide intervention and, hopefully, prevention in their communities.

(3) Judges can play an active role in monitoring the treatment of juveniles in facilities by periodic review.

(4) Judges can play a key role with youth being returned to the community in establishing and monitoring community programs to prevent recidivism.

(5) Judges need more education about mental health issues in juveniles and effective programs and interventions.

Senator DEWINE. Ms. Wong?

Ms. WONG. Good morning, Mr. Chairman and Members of the Subcommittee. I am Marleen Wong, and for the past 30 years, I have worked in School Mental Health Services, District Crisis Teams, and the Suicide Prevention Unit of the Los Angeles Unified School District. For 8 of those years, I was the director.

I have been asked today to comment on the state of school mental health services and the priorities that our country might establish in response to the recommendations of the President's New Freedom Commission on Mental Health, particularly the recommendation that school-based mental health services be expanded and enhanced. I temper my "Director of School Mental Health" remarks with my personal experience as a mother of two children, a

school social worker, a former school board member, a past member of the local teachers union, a current member of the local administrators union, the director of the school unit for the National Center for Child Traumatic Stress, a current member of the Institute of Medicine Board of Neuroscience and Behavioral Health, and a consumer of mental health services.

What is the scope of the problem for our school children who need mental health services? The 1999 Surgeon General's Report on Mental Health reported that in any given year about 20 percent of children have a mental disorder requiring the attention of a mental health professional. And yet a recent Rand study notes that only 8 percent of children who need mental health care actually receive services. This leaves 92 percent of our children who need are without any services. Of the 8 percent who do receive services, 85 percent of the children receive them in school mental health programs, making schools the de facto primary source of mental health services for children K–12 in this country.

Currently in the United States, there are about 15,000 school districts and approximately 100,000 schools. During a regular school week, 70 percent of the total population of children kindergarten through 12th grade in public and private schools are in attendance.

If we are to transform our mental health care system, we must establish a true system of care for all children, not just those with persistent and chronic mental illness. We must include children at every age and stage, those at risk for serious disorders, children caught in family or community crises, and disabled children. All aspects of children's lives are in a fluid state of development. early intervention and disability prevention means a shift in thinking to a "well child" mental health system, one that is adequately resourced for each of the components of early identification, early intervention, prevention, and effective treatments. One aspect of care should not be sacrificed for another because of funding disparities. One child should not be left behind because of another's needs.

School mental health services must be supported with adequately quality assurance and accountability measures. Most importantly, in measuring our success, mental health professionals must find a way to integrate the mission of mental health with the mission of education. Outcomes must not only include a decrease of symptoms but evidence of improved academic functioning—support for better grades, improved classroom behavior, fewer absences, and increased attendance, less dropout. These criteria are generally not within the realm of traditional treatment outcome. However, they are solid indices of health, rehabilitation, and recovery for children.

I would also like to speak about the Individuals with Disabilities Education Improvement Act, a critically important piece of legislation that helps to support children who are disabled. I would especially like to thank the committee for recognizing the disabling effects that trauma exposure can have for young children and for the inclusion of language in the bill that can help children who struggle in school as a result of trauma and the effects of traumatic events.

Fragmentation of funding, programs, and personnel is a growing problem for school mental health. They suffer from service and

funding fragmentation. I am proud to say that the Los Angeles Unified School District has supported mental health services for the past 71 years. However, in the 30 years that I have worked in the school district, we have had to fight to maintain those services during annual budget deliberations when categorical, special education, Title I, and general fund dollars wax and wane.

Finally, I would like to share a personal story, one that shows how far we have come. My involvement in this work goes to an earlier generation. From the time that I was 6 years old, my grandmother told me stories about her early life in San Francisco. That beautiful city was part of the Wild West in the early 1900s. For Chinese immigrants, it was a vibrant and dangerous place.

My grandmother, Ruth, was 5 years old when she was sold by her impoverished mother to a Chinese family emigrating to America. As a child, she remembered the day her mother pushed her toward a woman she had never seen and said, "This woman will be like your mother now." As a young child, she crossed an ocean with strangers to confront violence in the new world of San Francisco Chinatown.

Once she saw a group of men refuse to pay the bill for their dinner and many bottles of liquor. And when the owner of the restaurant insisted upon payment, they drew guns and destroyed the place. My grandmother, Ruth, hid in a corner, unharmed but traumatized. And in the following weeks, she refused to leave her home. She feared that she would be killed and that the violence would happen again.

Not long after that incident, the violence did happen again. And the head of her new family was shot and killed as an innocent victim during a gang shooting. My grandmother never completed elementary school.

In 1905, there was no counseling available in schools, nor was there any recognition of the paralyzing effects of violence on children. The year my grandmother died, in 1999, I began my association with Rand and UCLA to test our trauma intervention for its effectiveness with children in schools. And the results can be read in the Journal of the American Medical Association in the August 2003 issue.

We have come a long way in our country in recognizing the need for such services to children, and yet we have so much more to do.

The mission of schools is to educate. The mission of mental health services is to heal. And our responsibility is to the child who will benefit from both. The reality is that the mission of one cannot proceed without the success of the other.

So I thank you, Mr. Chairman and Senator Reed and Mr. Kennedy and members of the committee, for the opportunity to be here, to present this information, and to express the gratitude of those who work in schools. Your work is vitally important to the creation of a children's mental health system that truly cares for children.

Thank you.

Senator DEWINE. Ms. Wong, that is a very compelling story. Thank you very much.

[The prepared statement of Ms. Wong follows:]

PREPARED STATEMENT OF MARLEEN WONG, LCSW

Good morning Mr. Chairman and Members of the Subcommittee. I am Marleen Wong, Director of Crisis Counseling and Intervention Services for the Los Angeles Unified School District, and Director of the School Crisis and Intervention Unit for the National Center for Child Traumatic Stress (NCCTS) at UCLA and Duke University. For the past 30 years, I have worked in School Mental Health Services, District Crisis Teams and the Suicide Prevention Unit of the Los Angeles Unified School District. For 8 years, I was the Director of those services.

The Los Angeles Unified School District, (LAUSD) is the second largest school district in the United States with a population of 738,000 students K–12 and over 80,000 employees, over half of them teachers. The School Mental Health Service was established in LAUSD in 1933 to assist special education students with social and emotional consequences of serious health conditions or physically handicapping challenges. During my tenure as Director, from 1993 to 2001, school mental health services grew from 25 to 200 staff members of child psychiatrists, clinical psychologists and social workers in outpatient clinics and schools.

In 2001, I was appointed the Director of Crisis Counseling and Intervention Services in LAUSD. My responsibility is to train and oversee district level crisis teams comprised of 250 school counselors, nurses, social workers, school psychologists, school police, and attendance counselors. Crisis teams are required at every school site. Eleven district crisis teams support and enhance site teams during incidents that overwhelm the resources of a school.

As a school social worker, I have worked with children representing every community of our diverse district and responded to hundreds of crisis events involving the injury or death of students or staff. Twenty years ago, at the 49th Street Elementary School, a man who lived in the second floor apartment across the street from the school, opened fire with multiple weapons as our students were dismissed for the day. He held the school under sniper fire for an hour and a half, killing a 9-year-old girl and wounding several other students and staff. That tragedy prompted the development of the first formal policies and procedures in LAUSD, initiating our current system of crisis response, i.e., the formation of a crisis intervention team at every school and a district level team to support the school response.

Two large scale disasters in Los Angeles, the Los Angeles riots and fires and the Northridge earthquake, required a larger crisis response and recovery programs. Our district worked closely with the Los Angeles County Department of Mental Health, receiving several FEMA Crisis Counseling Grants to reach out to our students and encourage their return to school. After the riots, human relationships had to be mended. After the earthquake and the hundreds of powerful aftershocks, parents sought out school mental health services for their children. Many of our children were afraid to return to school, suffering from traumatic stress and depression due to the complex interactions of fear, ruined homes, multiple residential relocations, and family conflict.

In 2001, I was asked to join the National Center for Child Traumatic Stress (NCCTS), a national program initiated by Congress and funded by the Substance Abuse and Mental Health Services Administration (SAMHSA). The NCCTS oversees the National Child Traumatic Stress Network (NCTSN), a mental health network of 54 university, hospital, and community programs dedicated to raising the standard of care and improving access to services for traumatized children, their families and communities across the United States. My work as the Director of School Crisis and Intervention for the National Center, builds on my focused view of local needs and the problems of organizing and sustaining a school mental health program within a local education agency. It enables me to have a broader national perspective of the range of the needs and challenges confronted by community agencies and school districts who wish to establish school mental health services in rural, suburban and urban environments.

I have been asked today to comment on the state of school mental health services and the priorities that our country might establish in response to the recommendations of the President's New Freedom Commission on Mental Health, particularly the recommendation that school-based mental health services be expanded and enhanced. I temper my "Director of School Mental Health" remarks with my personal experience as a mother of two children, a school social worker, a former school board member, a past member of the local teachers' union, a current member of the local administrators' union, a current member of the Institute of Medicine (IOM) Board of Neuroscience and Behavioral Health, and a consumer of mental health services.

Demographic Information About Children, Schools and School Mental Health Services

What is the scope of the problem for our school children who need mental health services?

The 1999 Surgeon General's Report on Mental Health reported that in any given year, about 20 percent of children have a mental disorder requiring the attention of a mental health professional. In 2002, SAMHSA's National Survey on Drug Use and Health reported that an estimated 5 to 9 percent of children and youth have a serious emotional disturbance in any 1 year.

And yet, a 1995 RAND study notes that only 8 percent of children who need mental health care actually receive services—this leaves 92 percent of our children who need care without any services. Of the 8 percent who do receive services, 85 percent of the children receive them in school mental health programs. Community agencies, pediatricians, public mental health services agencies, even correctional facilities, have a role to play in providing care, but the reality is that schools have become the de facto primary source of mental health services for children.

The Goals and Recommendations of the President's New Freedom Commission on Mental Health

I would like to discuss school mental health services within the context of the goals and the recommendations of the President's New Freedom Commission on Mental Health.

The Commission has recommended that we:

• **Place consumers and their families at the center of service decisions.**

Currently in the United States, there are about 15,000 School Districts and approximately 100,000 Schools. During a regular school week, 70 percent of the total population of children Kindergarten through 12th grade are in attendance at one of these schools. If we add to this large number, the parents, siblings and families of the students, and the families of teachers, administrators and other school personnel, over 50 percent of the total United States population is connected during the work week to a school somewhere in this country. Schools are natural sites of service for children and families.

The Commission has recommended that we:

• **Reduce disparities and the burden of unmet needs and lack of access to services among minority groups.**

and

• **Develop a model that emphasizes early intervention and disability prevention.**

If we are to transform our mental health care system, we must establish a true system of care for all children, not just those with persistent and chronic mental illness. We must include children at every age and stage, those at risk for serious disorders, children caught in family or community crises, and disabled children. All aspects of children's lives are in a fluid state of development. Early intervention and disability prevention means a shift in thinking to a "well child" mental health system, one that is adequately resourced for each of the components of early identification, early intervention, prevention, and effective treatments. One aspect of care should not be sacrificed for another because of funding disparities. One child should not be left behind because of another's needs.

School personnel are intimately aware of the social, psychological, and academic toll that mental health disorders, traumatic experiences, and mental illness can take on our children and adolescents. Early identification and intervention can make a difference at any grade. Children may not do well in preschool because their experience of domestic violence has interfered with their brain development, capacity to learn, and behavior. Elementary school children exposed to trauma and violence can lead to poor sleep and poor learning, compromising their acquisition of basic educational skills. A child who has done well in elementary school may be bullied in middle school or exposed to violence in the community, and go on to develop symptoms of posttraumatic stress that disturb academic performance, classroom behavior, and school attendance. A student in high school may suffer a traumatic loss because of the death of a close friend through a traffic accident, catastrophic school violence, or suicide, and become seriously depressed.

Middle school and high school students often respond to experiences of trauma and loss by abusing alcohol or drugs or by engaging in reckless or high-risk sexual behaviors. They may also struggle with thoughts of suicide.

Schools are the place where the loss of motivation for learning of such students can be noted as a symptom of depression or trauma, and can best be addressed through school mental health programs.

In our crisis intervention work in the Los Angeles Unified School District and in many other parts of the country, we have worked with children in a post-crisis school setting. Often, while working with their trauma, we discovered children with other mental health problems that had never been addressed. Unfortunately, schools are limited by the lack of personnel to adequately provide intermediate and long term mental health and case management services that children need.

Our crisis intervention work showed that most students suffer silently from trauma or depression, spending their school days "hidden in plain sight". Schools routinely screen for vision and for hearing, two conditions which we would all agree are crucial to learning. Just as crucial may be school screening for trauma and depression, where fear, disturbing thoughts, feelings and images become barriers to school attendance and classroom participation.

The Commission has recommended that we:

• **Establish "evidence-based practices" as the bedrock of service delivery.**

We can do this by supporting ongoing practical research that is embedded in schools and communities, and by providing training linked to scientific findings and clinical experience. This is one of the central goals of the National Child Traumatic Stress Network.

The Commission has recommended that we:

• **Improve quality and accountability:**

Establishing school based mental health services is not a panacea. Services must be supported with adequate quality assurance and accountability measures. An example of such requisite oversight is that 44 percent of the students who seek help at school-based health clinics present with mental health disorders or problems. Of the students who seek help for depression, few receive evidence-based treatments. The average number of three to four visits suggests that few ever receive the full "dose" of recommended treatment, and follow up is rarely done.

Some disorders, such as psychological trauma and depression, are very amenable to identification and treatment within a school setting. These are also the disorders that are being identified as leading causes of disability among the general population of children in the United States. Our work in LAUSD with RAND and UCLA Health Sciences Research Center, documented disrupted academic performance, negative classroom behavior and less school attendance among students traumatized by their exposure to community violence. In fact, scientific studies are showing that childhood trauma further affects the onset and course of many other child and adolescent health and mental health conditions, from attention deficit and bipolar disorder to substance abuse and conduct disorder.

Most importantly, in measuring our success, mental health professionals must find a way to integrate the mission of mental health and the mission of education. From an organizational perspective, mental health services in schools cannot operate outside the structure and organization of the educational environment. In order to succeed within the educational environment and to gain acceptance from educators, the integrity of the academic day must be preserved. Outcomes must include not only a decrease of symptoms but also evidence of improved academic functioning—better grades, improved classroom behavior, fewer absences, and increased attendance. These criteria are generally not within the realm of traditional treatment outcomes. However, they are solid indices of health, rehabilitation, and recovery for children.

IDEA

I would also like to speak about the Individuals with Disabilities Education Improvement Act, a critically important piece of legislation that helps to support services for children who are disabled. Although IDEA has not yet been enacted, I would like to commend the committee for the progress it has made in the Senate. I want to affirm that school children with disabilities need the help that can be provided through this bill, and they need it now. I would especially like to thank the committee for recognizing the disabling effects that trauma exposure can have for young children, and for the inclusion of language in the bill that will help children who struggle in school as a result of trauma and the effects of traumatic events.

A report on developmental disabilities and trauma was developed by the NCTSN, and has been submitted for the record. That report includes information from population studies showing that the national prevalence rate for developmental disabilities in the United States is 1.8 percent. This translates into many children in our school systems needing the specialized education provided through IDEA. Additional studies have shown that individuals with developmental disabilities are at increased risk for abuse as compared to the general population. For example, 64 percent of maltreated children have a disability, such as behavioral disorders; speech, language, or learning disabilities; or mental retardation. Children with mental retarda-

tion were the most severely abused. When we identify a child with special needs, it is essential to determine the full context of the child's life and history so that the most appropriate services can be provided.

It is therefore a major step forward for the Senate to recognize that the development of vulnerable young children can be thrown off course because of traumatic experiences, and that, with timely intervention, a child's life can be supported back onto a normal developmental path.

Obstacles to Mental Health Services Access

In establishing the New Freedom Commission on Mental Health, President Bush noted three key obstacles that keep people with mental illnesses from getting the services they need:

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

Lack of Parity

In our society, and in our health care system, children with mental disorders face the same stigma and discrimination as adults. It is unfair that an illness that can affect the brain, emotions, intellectual development and capacity, and relationships, and can so tragically affect the development of a child, is treated as less than serious, less than real. Schools can only do so much. When children are referred for mental health care, even those whose families have private insurance often cannot get medically necessary care because of the lack of parity in mental health coverage. This situation is worse than unfair . . . it can be lethal. Efforts to enact Federal mental health parity legislation have been close to success many times, and even now, parity has the widespread support of the Senate, the House, the President, and over 360 national organizations. Yet, American families are still waiting. It is the hope of all of us who work with children and their families that a full and fair mental health parity bill will be finally enacted in this Congress.

Overcoming Stigma Through School Mental Health Programs

In Los Angeles, we have completed 4 years of trauma work with students who have been exposed to community violence. Through concerted effort, our program of mental health services has overcome much of the stigma that often surrounds such programs. Perhaps the greater acceptance of our mental health services is that we approach problems as developmental challenges and tasks, providing education, case management and support to parents; making consultation available to teachers; and providing treatment to children so that they can succeed in school. In the initial cohort of 20 LAUSD schools receiving special trauma intervention, only 3 percent to 5 percent of parents declined mental health services for their children.

Our intervention was tested in randomized clinical trials and the results were published as an "original contribution" in the August 2003 Journal of the American Medical Association. A screening of thousands of children in LAUSD over the past 4 years found that 90 percent of students in some neighborhoods had been exposed to multiple incidents of violence, as witnesses and victims and that 27 percent of them had clinical levels of PTSD and 16 percent of them had clinical levels of depression. After 10 sessions of CBITS, the majority of children significantly decreased their symptoms of PTSD and Depression to the extent that they could no longer be diagnosed as traumatized or depressed. In the evaluation of an early group of students, there was a significant increase in grade point average as compared not only to students who had not yet received the intervention, but also as compared to students who had tested negative for either of the disorders.

More importantly, after students completed the Cognitive Behavioral Intervention for Trauma in Schools (CBITS), over 92 percent of the parents understood that exposure to community violence had created serious psychological and academic problems in their children's lives. Eighty-five percent of the parents were pleased with the outcomes of treatment and 76 percent wanted to refer another family member or friend to receive services.

Fragmentation of Funding, Programs, and Personnel

Like public mental health systems, school mental health programs also suffer from service and funding fragmentation. I am proud to say that the Los Angeles Unified School District has supported mental health services for the past 71 years. However, in the 30 years that I have worked in LAUSD, we have had to fight to maintain those services during annual budget deliberations when categorical, special education, Title I and general fund dollars wax and wane. This year, many mental health professionals, such as school counselors and social workers, will lose their jobs because of severe budget cuts necessitated by the downturn in the economy.

In 1992, I worked with our Los Angeles County Department of Mental Health Services to negotiate the first Medi-Cal (Medic-Aid) contract between a school district and a county mental health service. We are currently able to draw down "rehabilitation" reimbursements for services to Medi-Cal eligible students and their families.

This funding stream, however, does not provide any financial support for the work we do with indigent, uninsured children and families. Over 73 percent of LAUSD students and their families live below the poverty level and receive free and reduced lunch. The budget crisis in California has been so severe that there is no longer public mental health funding available for indigent, uninsured children, the largest socioeconomic group of students within our school district.

Further hampering the foundation of economic support, reimbursement dollars for school mental health services are often absorbed by the larger district budget to offset losses in other areas. Locally, reimbursements "earned" through these programs and others, such as designated instructional counseling mandated by the Individual Education Plan (IEP) for special education students, or Local Education Agency (LEA) Medic-Aid, are not necessarily returned to support the programs that provided the services.

What is needed are multiple sources of funding earmarked for school mental health services that is protected within State, Federal and local education budgets to establish and sustain programs that serve children's needs.

The NCTSN: The National Child Traumatic Stress Network and the National Center for Child Traumatic Stress (NCCTS)

In my work with the National Center for Child Traumatic Stress, and the 54 affiliated sites that form the larger National Child Traumatic Stress Network, we are enacting one of the basic principles in delivery of services to children—to make services available to the children where they are, in schools and other community settings where they live their lives. This is why our network is helping to bring trauma-informed services to children in schools, residential treatment centers, child welfare systems, correctional facilities, rural clinics, domestic violence shelters, community-based programs, refugee services, and many more. Our goal is to raise the standard of care for traumatized children by developing and delivering evidence-based treatment and services in a timely and effective way.

In my role as Director of the School Crisis and Intervention Unit of the National Child Traumatic Stress Network, I can attest to the increasing acceptance of school-based mental health services by families and school communities. These services are critical to meeting our nation's mission of promoting academic excellence, good citizenship and the well-being of our children.

Children and adolescents in our schools feel comfortable asking for these services, courageously commit to the hard work involved in treatment, and even refer their friends. Parents and guardians have told us that they are very pleased that the services are being offered. Teachers have seen the results in their classrooms, and have enthusiastically expressed their support. Integrating mental health services in schools can be successful with sufficient support.

Historical Roots: The Story of Ruth

My involvement in this work goes back many generations. From the time I was 6 years old, my grandmother told me stories about her early life in San Francisco. That beautiful city was part of the Wild West in the early 1900's. For Chinese immigrants it was a vibrant and dangerous place. The residents of Chinatown were vulnerable to violence from Chinese gangs who victimized businesses, from Tong warfare (kinship and clan organizations fighting for economic, social and political dominance), and from white Americans who viewed the Chinese as less than human.

The process of immigration from Macao, the island of my grandmother's birth, to San Francisco was no less dangerous. Pirates and thieves preyed on children and adults who boarded boats to escape the effects of the Boxer Rebellion in South China. They fled to find their way to "Gold Mountain", the name given to California and the promises it held for a better life.

My grandmother, Ruth, was 5 years old when she was sold by her impoverished mother to a wealthy Chinese family emigrating to America. As a child, she remembered the day her mother pushed her toward a woman she had never seen before and said, "This woman will be like your mother now." As a young child, she crossed an ocean with strangers to confront violence in the new world of San Francisco Chinatown.

Once she saw a group of men refuse to pay the bill for their dinner and many bottles of liquor. When the owner of the Chinese restaurant insisted upon payment, they drew guns and shot bullets into the walls, ceiling and floors, smashing the fur-

niture and laughing as they left. Ruth hid in a corner, unharmed but traumatized. In the following weeks, she refused to leave her home. She feared that she would be killed and that the violence would happen again.

Not long after that incident, the violence did happen again. The head of her new family was shot and killed as an innocent bystander during a gang shooting. My grandmother never completed elementary school.

In 1905, there was no counseling available in schools, nor was there recognition of the paralyzing effects of violence on children. The year my grandmother died, in 1999, I began my association with RAND and UCLA Research to test our intervention for its effectiveness in schools.

The scars of violence can last a lifetime, but with early identification and early intervention in schools, the distress, anxiety, depression and trauma can be lifted and healed and children can be helped to resume productive and successful social, emotional and academic lives.

We have come a long way in our country in recognizing the need for such services to children, and yet we do have so much more to do. The children are waiting.

In Closing

The mission of schools is to educate. The mission of mental health services is to heal. Our responsibility is to the child who will benefit from both. The reality is that the mission of one cannot proceed without the success of the other.

I thank you, Mr. Chairman, Mr. Kennedy, and Members of the Subcommittee, for the opportunity to be here, to present this information to the subcommittee, and to express the gratitude of those of who work in the schools. Your work is vitally important to the creation of a children's mental health system that truly cares for children.

RESPONSE TO QUESTIONS OF SENATOR BINGAMAN FROM MARLEEN WONG

Question 1. Every year, an estimated 9 percent to 13 percent of children and adolescents in the United States experience a clinically significant mental disorder that warrants treatment. Yet, according to the Surgeon General's Report on Mental Health, two-thirds of these vulnerable young people do not receive any mental health treatment at all. What can we do to improve access to treatment?

Answer 1. In establishing the New Freedom Commission on Mental Health, President Bush noted three key obstacles that keep people with mental illnesses from getting the services they need: 1. The stigma that still surrounds these illnesses; 2. The fragmented mental health care service system; and 3. Existing treatment and dollar limits for mental health care.

If we are to transform our mental health care system, we must establish a true system of care for all children, not just those with persistent and chronic mental illness. We must include children at every age and stage, those at risk for serious disorders, children caught in family or community crises, and disabled children. All aspects of children's lives are in a fluid state of development. Early intervention and disability prevention means a shift in thinking to a "well child" mental health system, one that is adequately resourced for each of the components of early identification, early intervention, prevention, and effective treatments. One aspect of care should not be sacrificed for another because of funding disparities. One child should not be left behind because of another's needs.

Lack of access to treatment is the result of many failures in the health care system. One way that access to mental health treatment would be improved is through the funding of preventive programs and early intervention mental health services in schools. The Early Periodic Screening, Diagnosis and Treatment (EPSDT) programs were meant to serve this purpose but have never been instituted or sufficiently funded to operate effectively in schools. Unlike community mental health clinics, hospitals or doctor's offices, schools are natural settings for children and parents. School mental health programs have demonstrated that children and families accept such services with less stigma and are more likely to complete the course of treatment.

Community agencies, pediatricians, public mental health services agencies, even correctional facilities, have a role to play in providing care, but the reality is that schools have become the de facto primary source of mental health services for children. A 1995 RAND study noted that only 8 percent of children who need mental health care actually received services—this leaves 92 percent of our children who need care without any services. Of the 8 percent who did receive services, 85 percent of the children received them in school mental health programs.

In our crisis intervention work in the Los Angeles Unified School District and in many other parts of the country, we have worked with children in a post-crisis

school setting. Often, while working with their trauma, we discovered children with other mental health problems that had never been addressed. Unfortunately, schools are limited by the lack of personnel to adequately provide intermediate and long term mental health and case management services that children need.

To improve access, we need to address the barriers to treatment on several fronts. One approach is greater detection through improved education of professionals who work with children such as teachers, pediatricians, DCFS workers, and probation counselors, a principle supported in proposed S. 1223. Community leaders, including school superintendents, principals, union officials and faith leaders must also be included in an educational campaign to ensure that their decisions about children's programs are informed by scientific knowledge. Developing cultural competency in addition to high quality, and effective services, also noted in S. 1223, are crucial to this goal. National education and media campaigns about children's mental health should address this problem in multiple communities. One of the issues pertinent to access and disparity are the racial and ethnic differences among groups which include stereotypes that prevent appropriate treatment from being provided, language and cultural barriers, and lack of resources in disadvantaged communities. The work of Drs. Sheryl Kataoka and Ken Wells, UCLA Health Services Research Center, has elucidated these issues in details.

Making mental health screening in schools routine for easily treatable problems, such as traumatic stress and depression will identify unmet needs and improve access to care. Our crisis intervention work showed that most students suffer silently from trauma or depression, spending their school days "hidden in plain sight". Schools routinely screen for vision and for hearing, two conditions which we would all agree are crucial to learning. Just as crucial may be school screening for trauma and depression, where fear, disturbing thoughts, feelings and images become barriers to school attendance and classroom participation. Schools are the place where the loss of motivation for learning of such students can be noted as a symptom of depression or trauma, and can best be addressed through school mental health programs.

In our society, and in our health care system, children with mental disorders face the same stigma and discrimination as adults. It is unfair that an illness that can affect the brain, emotions, intellectual development and capacity, and relationships, and can so tragically affect the development of a child, is treated as less than serious, less than real. Schools can only do so much. When children are referred for mental health care, even those whose families have private insurance often cannot get medically necessary care because of the lack of parity in mental health coverage. This situation is worse than unfair . . . it can be lethal. Efforts to enact Federal mental health parity legislation have been close to success many times, and even now, parity has the widespread support of the Senate, the House, the President, and over 360 national organizations. Yet, American families are still waiting. It is the hope of all of us who work with children and their families that a full and fair mental health parity bill will be finally enacted in this Congress.

Question 2. Evidence-based treatments are now available for the full range of child and adolescent mental disorders. Yet these effective treatments fail to reach a majority of those who can benefit from them. How can we close the gap between research and real-world practice to ensure that evidence-based treatments are available in community service settings?

Answer 2. Closing the gap between research and practice begins in graduate training programs. S. 1223 supports the concept that teaching evidence based treatments begins in graduate programs of psychiatry, psychology, school psychology, psychiatric nursing, social work, school social work, marriage and family therapy, school counseling, and professional counseling. Support for continuing education through loan repayments, scholarships, and grants that increase the number of mental health providers expert in child and adolescent mental disorders will facilitate the infusion of sufficient numbers of providers in all child settings and enhance the quality of evidence-based services for children.

In my work with the National Center for Child Traumatic Stress, and the 54 affiliated sites that form the larger National Child Traumatic Stress Network, we are enacting one of the basic principles in delivery of services to children—to make services available to the children where they are, in schools and other community settings where they live their lives. This is why our network is helping to bring trauma-informed services to children in schools, residential treatment centers, child welfare systems, correctional facilities, rural clinics, domestic violence shelters, community-based programs, refugee services, and many more. Our goal is to raise the standard of care for traumatized children by developing and delivering evidence-based treatment and services in a timely and effective way. And we are doing this

by directly linking the researchers and the providers in ongoing collaborations to improve care based on research and clinical practice.

The New Freedom Commission stated that "evidence-based practices" are the bedrock of service delivery and that we improve quality and accountability. We can support this effort by supporting ongoing practical research that is embedded in schools and communities, and by providing training linked to scientific findings and clinical experience. This is one of the central goals of the National Child Traumatic Stress Network.

Establishing school based mental health services is not a panacea. Services must be supported with adequate quality assurance and accountability measures. An example of such requisite oversight is that 44 percent of the students who seek help at school-based health clinics present with mental health disorders or problems. Of the students who seek help for depression, few receive evidence-based treatments. The average number of 3 to 4 visits suggests that few ever receive the full "dose" of recommended treatment, and follow up is rarely done.

Some disorders, such as psychological trauma and depression, are very amenable to identification and treatment within a school setting. These are also the disorders that are being identified as leading causes of disability among the general population of children in the United States. Our work in LAUSD with RAND and UCLA Health Sciences Research Center, documented disrupted academic performance, negative classroom behavior and less school attendance among students traumatized by their exposure to community violence. In fact, scientific studies are showing that childhood trauma further affects the onset and course of many other child and adolescent health and mental health conditions, from attention deficit and bipolar disorder to substance abuse and conduct disorder.

Most importantly, in measuring our success, mental health professionals must find a way to integrate the mission of mental health and the mission of education. From an organizational perspective, mental health services in schools cannot operate outside the structure and organization of the educational environment. In order to succeed within the educational environment and to gain acceptance from educators, the integrity of the academic day must be preserved. Outcomes must include not only a decrease of symptoms but also evidence of improved academic functioning—better grades, improved classroom behavior, fewer absences, and increased attendance. These criteria are generally not within the realm of traditional treatment outcomes. However, they are solid indices of health, rehabilitation, and recovery for children.

Question 3. Children with serious emotional disturbance often have multiple problems and require services from several systems, including the mental health, educational, child welfare, and juvenile justice systems. How can we enhance the coordination and collaboration of various child-serving systems?

Answer 3. What is needed are multiple sources of funding earmarked for mental health services that are protected within State, Federal and local education budgets to establish and sustain programs that serve children's needs. Coordination and collaboration of various child servicing systems can be enhanced by placing those services at one location within an area or geographic region. In addition, a multi-disciplinary collaborative team approach to serving each child would enhance and promote "wrap-around" services, tailoring the services to the changing needs of the child.

Many public mental health systems suffer from service and funding fragmentation. I am proud to say that the Los Angeles Unified School District has supported mental health services for the past 71 years. However, in the 30 years that I have worked in LAUSD, we have had to fight to maintain those services during annual budget deliberations when categorical, special education, Title I and general fund dollars wax and wane. This year, many mental health professionals, such as school counselors and social workers, will lose their jobs because of severe budget cuts necessitated by the downturn in the economy.

In 1992, I worked with our Los Angeles County Department of Mental Health Services to negotiate the first Medi-Cal (Medic-Aid) contract between a school district and a county mental health service. We are currently able to draw down "rehabilitation" reimbursements for services to Medi-Cal eligible students and their families.

This funding stream, however, does not provide any financial support for the work we do with indigent, uninsured children and families. Over 73 percent of LAUSD students and their families live below the poverty level and receive free and reduced lunch. The budget crisis in California has been so severe that there is no longer public mental health funding available for indigent, uninsured children, the largest socioeconomic group of students within our school district.

Further hampering the foundation of economic support, reimbursement dollars for school mental health services are often absorbed by the larger district budget to offset losses in other areas. Locally, reimbursements "earned" through these programs and others, such as designated instructional counseling mandated by the Individual Education Plan (IEP) for special education students, or Local Education Agency (LEA) Medic-Aid, are not necessarily returned to support the programs that provided the services.

In my work with the National Center for Child Traumatic Stress, and the 54 affiliated sites that form the larger National Child Traumatic Stress Network, we are enacting one of the basic principles in delivery of services to children—to make services available to the children where they are, in schools and other community settings where they live their lives. This is why our network is helping to bring trauma-informed services to children in schools, residential treatment centers, child welfare systems, correctional facilities, rural clinics, domestic violence shelters, community-based programs, refugee services, and many more. Our goal is to raise the standard of care for traumatized children by developing and delivering evidence-based treatment and services in a timely and effective way.

I would also like to speak about the Individuals with Disabilities Education Improvement Act, a critically important piece of legislation that helps to support services for children who are disabled. I would especially like to thank the committee for recognizing the disabling effects that trauma exposure can have for young children, and for the inclusion of language in the bill that will help children who struggle in school as a result of trauma and the effects of traumatic events.

A report on developmental disabilities and trauma was developed by the NCTSN, and has been submitted for the record. That report includes information from population studies showing that the national prevalence rate for developmental disabilities in the U.S. is 1.8 percent. This translates into many children in our school systems needing the specialized education provided through IDEA. Additional studies have shown that individuals with developmental disabilities are at increased risk for abuse as compared to the general population. For example, 64 percent of maltreated children have a disability, such as behavioral disorders; speech, language, or learning disabilities; or mental retardation. Children with mental retardation were the most severely abused. When we identify a child with special needs, it is essential to determine the full context of the child's life and history so that the most appropriate services can be provided.

It is therefore a major step forward for the Senate to recognize that the development of vulnerable young children can be thrown off course because of traumatic experiences, and that, with timely intervention, a child's life can be supported back onto a normal developmental path.

Question 4. The New Freedom Commission on Mental Health and the Surgeon General's report both identified a national shortage of mental health professionals trained to treat mental illness in children and adolescents. I have introduced S. 1223, The Child Health Care Crisis Relief Act, which creates incentives to help train, recruit, and retain child mental health professionals through loan repayments, scholarships, and grants. Do you feel passage of this legislation would be helpful in reducing the shortage of qualified professionals?

Answer 4. The passage of S. 1223 would significantly reduce the shortage of qualified professionals in several ways. First, it provides graduate students and working professionals with much needed financial support to further their studies with competitive grants. The proposed bill also addresses all the major issues and recommendations of the President's New Freedom Commission Report, especially the need to:

Reduce disparities and the burden of unmet needs and lack of access to services among minority groups.

Establish "evidence-based practices" as the bedrock of service delivery.

Improve quality and accountability.

Through my work with the National Center for Child Traumatic Stress, and the 54 affiliated sites that form the larger National Child Traumatic Stress Network, I am very aware of the difficulties of insufficient numbers of trained health care providers who are expert in child mental health or child trauma. In our network, we are directly linking providers with training programs so that we can enact one of the basic principles in delivery of services to children—to make services available to the children where they are, in schools and other community settings where they live their lives. This is why our network is helping to bring trauma-informed services to children in schools, residential treatment centers, child welfare systems, correctional facilities, rural clinics, domestic violence shelters, community-based programs, refugee services, and many more. Our goal is to raise the standard of care

for traumatized children by developing and delivering evidence-based treatment and services in a timely and effective way. But without sufficient numbers of providers, and without a decent and fair health care reimbursement system, even the best training programs may not lead to successful integration of more providers throughout the system of child health care. This is why school-based mental health programs, IDEA improvements, and mental health parity legislation must be pursued at the same time that we enhance training programs for child health care providers.

Senator DEWINE. Dr. Douce, thank you.

Ms. DOUCE. Good morning, Chairman DeWine and Senator Reed. Thank you very much for inviting me here today. As a member of the American Psychological Association and as director of the Counseling and Consultation Services at the Ohio State University, I oversee the provision of a broad range of mental and behavioral health services to nearly 50,000 students a year. I appreciate this opportunity to speak with you today about the growing mental and behavioral health needs of college students as you consider the College Care and Counseling Act.

Let me start with an example. Consider a senior in the business school who is struggling with a broken relationship. He cannot sleep, he cannot concentrate, he does not go to class, and he finds himself sitting outside his ex-girlfriend's apartment at night waiting to see whom she is dating. He imagines beating that man to a pulp. He is a first-generation college student. He works 25 to 30 hours a week in addition to going to school, and he is qualified for significant financial aid to put himself through college. If he cannot address his emotions and his behavior, he is at risk of not graduating and, frankly, at risk for stalking. It is hard for him to seek help, but seeing his whole future disintegrating has convinced him to try counseling.

In my written testimony, I offer an example of a young woman with a severe eating disorder and a young man that is at high risk for suicide.

Situations like those I have just shared are common to college and university campuses throughout our country. During the period from 1975 to 1995, college and university counseling centers saw a dramatic increase in both the numbers and the severity of the mental health concerns.

In fact, many of the students that colleges and universities want to retain leave school for personal rather than academic difficulties. A number of studies have shown a positive relationship between counseling services and actually staying in school and graduating. It is a lose-lose situation when a student who has taken out loans, received Federal grant aid, does not complete his or her degree. The loans do not go away. The student is not better off. And neither is our government investment in them.

Now, let me just speak to some of the most serious issues. The most serious issue to me is suicide. Suicide is the second leading cause of death among college students. A 2000 survey by the American College Health Association found that within the previous year 22 percent felt they were so depressed that they could barely function, 9 percent had seriously considered suicide, and 1.5 percent had made attempts. In our own center, last year, 273 students admitted to suicidal ideation at intake, 11 had plans and means. None of those students died, yet tragically three other OSU students did end their lives by suicide.

Suicide is preventable with knowledgeable and skilled intervention. Depression and anxiety are often at the root, and these are curable diseases. increased awareness, early detection, effective referral, and skilled intervention are the keys, and I would like to commend you, Mr. Chairman, for your leadership on the issue of suicide prevention.

A second major issue is alcohol and substance abuse. Approximately 1,400 college students between the ages of 18 and 24 die each year from alcohol-related injuries; 500,000 students are injured while under the influence of alcohol; 600,000 students are assaulted by another student who has been drinking; and 70,000 students are victims of alcohol-related sexual assault and date rape. These numbers are astounding.

We know that facing the consequences of addictive behavior is one of the first steps to change. College and university counseling centers can play a major role in participating in wellness and prevention programs, counseling students in trouble, providing court-mandated therapy for students in the legal system for alcohol-related behavior. Our services assist students in facing their consequences, examining their choices, and learning to choose more appropriate alternatives.

I would like to take my last few minutes to acknowledge the leadership of Senators Reed and DeWine in meeting the mental and behavioral health needs of college students with their introduction of the College Care and Counseling Act. Along with the support and involvement of Senators Smith and Clinton, you have introduced significant legislation that can really make a difference in the lives and successes of our Nation's students enrolled in post-secondary education.

Funds would be made available for use for activities such as prevention, screening, early intervention, assessment, treatment, management, and education of mental and behavioral health needs of students on campus.

This year, the Federal Government expects to spend $70 billion in student financial assistance. This investment often makes the difference in a student's decision to pursue their dream of a college education. While undoubtedly significant, it is an investment that may not always yield the results we anticipate.

Mental and behavioral health concerns and how they are addressed can make this difference. I sincerely believe it is one of the best returns on investment you can make. I hope that as the Senate Health, Education, Labor, and Pensions Committee moves forward with its reauthorization of the Higher Education Act that this legislation will be a priority for inclusion in the final bill. It is too important not to.

Finally, I would again like to thank you, Senator DeWine, for having me testify in this important hearing today and for cosponsoring this bill.

I will be glad to respond to any questions.

Senator DEWINE. Thank you very much.

[The prepared statement of Ms. Douce follows:]

PREPARED STATEMENT OF LOUISE A. DOUCE, PH.D.

Good morning Chairman DeWine and Members of the Subcommittee. Thank you for inviting me here today. As an active member of the American Psychological Association and as Director of Counseling and Consultation Services at the Ohio State University, I oversee the provision of a broad range of mental and behavioral health services to nearly 50,000 students each year. I appreciate this opportunity to speak with you today about the growing mental and behavioral health needs of college students as you consider the College Care and Counseling Act (S. 2215).

Let me outline why these mental and behavioral health services on college campuses are so important:

- *Maximize student success*
- *Increase rates of retention and graduation*
- *Provide crisis management and services*
- *Provide mental health consultation to faculty and staff*
- *Develop prevention strategies and contribute to a wellness culture*
- *Advance multicultural competency in a global community*
- *Ensure appropriate continuum of care*

I would like to begin by sharing some real life stories of college students that have sought help at our counseling center at Ohio State.

Consider a senior in the business school who is struggling with a broken relationship. He can't sleep, he can't concentrate and he finds himself sitting outside his ex-girlfriend's apartment at night waiting to see whom she is dating. He imagines beating that man to a pulp. He is a first generation college student, works 25 hours a week and has qualified for significant financial aid to put himself through college. If he cannot address his emotions and his behavior, he is at risk of not graduating and, frankly, at risk for stalking. It is hard for him to seek help, but seeing his whole future disintegrating has convinced him to try counseling.

Now consider a young woman who is a freshman in the Honors program. She is very bright, has very high SAT scores and feels pressure from everyone's expectations for her success. She has also had an eating disorder since junior high school. She worries constantly, is obsessed with her weight and limits food. Since starting school her anxiety has been very problematic, she rarely eats and her weight has gone below 100 pounds. She realizes she needs help and seeks counseling.

Finally consider a graduate student who is struggling with depression. He cannot get to sleep at night until 3 or 4 a.m. and then oversleeps his 9 a.m. class. He has trouble getting out of bed some days, does not enjoy anything he used to, pushes friends away, knows he is failing and blames himself. About the only way he can think to escape his despair is suicide. His mother, who lives 1,500 miles away, convinces him to find the counseling center.

Increased Need

Situations like those I have just shared are common on college and university campuses throughout our country. During the period from 1975 and 1995 colleges and university counseling centers saw a dramatic increase in both the numbers and severity of mental health concerns. A national survey of counseling center directors confirmed that this trend of increased demand continued throughout the 1990s.

More specifically, a research consortium of 36 counseling centers found increases in anxiety, fear and worries and dysfunctional behavior including eating disorders, alcohol and substance abuse and anger/hostility. They also reported increases in the impact of violence, family dynamics, depression and bipolar disorder.

This study outlines the major issues in college student mental health:

- *Depression, anxiety and anger (also referred to as Affective Disorders)*
- *Eating Disorders and body image distortion*
- *Traumatic Stress Reactions following exposure to*
    - *Violence in community and war (returning veterans & internationals)*
    - *Date rape, harassment and stalking*
    - *Family discord, dysfunction and abuse*
    - *Natural disasters around the world*
- *Alcohol and substance abuse*
- *Future, career and crisis of hope*

In the years ahead, I would expect to see the trend of an increasing number of students seeking mental and behavioral health services to continue—if not grow at a more significant pace. Current research suggests that more students are entering college with prior treatment histories of severe mental illness now controlled with medication, a great thing. However, they may have more difficulty with adjustment to change and are at increased risk of relapse or reoccurrence without appropriate mental health support. In addition, the Institute for Higher Education Policy re-

cently reported that between 2000 and 2015, the college-age population will increase by 16 percent or 2.6 million students, 80 percent of whom will be ethnic minorities, and nearly half Hispanic. The report noted that students from ethnic minority communities historically suffer most from financial, academic, and cultural barriers. This may be especially salient for first generation college students. Providing culturally competent therapy and prevention programming is a vital element in graduating a fully diverse class. A better-educated population is in turn necessary for the United States to remain competitive in a global economy. We, as a Nation are counting on them to be successful.

Students Who Receive Mental and Behavioral Health Services Have Higher Retention Rates

In fact, many of the students that colleges and universities want to retain leave school for personal rather than academic difficulties. Recent research has demonstrated that students who receive counseling for their mental and behavioral health needs reported increases in "personal well being, academic success and retention." Further, a number of studies have discovered a positive relationship between counseling services and retention rates. It's a lose-lose situation when a student, who has taken out loans and received Federal grant aid, doesn't complete his or her degree. The loans don't go away. The student is not better off—and neither is our government investment in them. On the other hand, both the student and the government win when a student who received financial assistance from the Federal Government graduates and goes on to future success. That student is better off—and so is our Nation. Sometimes all that it takes to turn a potentially tragic situation into a success story is an interest and commitment to a student's mental health needs.

Suicide Prevention

Let me speak to one of the most serious issues in this population, suicide. Suicide is the second leading cause of death among college students. A 2000 survey by the American College Health Association found that within the last year 33 percent of college students reported feeling hopeless, 22 percent said they felt so depressed they could barely function, 9 percent seriously considered suicide; and, 1.5 percent had actually attempted suicide. Last year in our center, 273 students admitted to suicidal ideation at intake, 11 had plans and means. None of those students died yet, sadly, three other OSU students did end their lives by suicide.

The Ohio State University participated in a decade long study of suicide at Big 10 Universities in the 1980's. The researcher, Dr. Mort Silverman, visited with coroners and traced all student deaths to verify all deaths by suicide and determine patterns. The overall number of such deaths was less than the rate for the general population aged 15 to 24. Dr. Silverman attributed this to the relatively greater access to mental health care through the Big 10 university counseling centers. What were especially helpful from this study were patterns specific to each university. At Ohio State we had a significant number of deaths by cyanide and a higher rate among international graduate students than the other schools. We immediately addressed access to cyanide in chemistry labs and developed greater prevention efforts with the international population including orientation workshops on family stress, dating "American style" and stress management. Since then we have had no cyanide deaths and reduced our suicide rate by 40 percent from 4.5 persons to 2.7 persons over the last 5 years. That is 2.7 too many, but lower than one would predict for 50,000 students. Suicide is often preventable with knowledgeable and skilled intervention. Depression and anxiety are often at the root and those are curable diseases. Increased awareness, early detection, effective referral and skilled intervention are the keys. I would like to commend you Mr. Chairman for your leadership on this issue of suicide prevention.

Alcohol and Substance Abuse

Approximately 1,400 college students between the ages of 18 and 24 die each year from alcohol-related unintentional injuries, including motor vehicle crashes. Five hundred thousand students are injured while under the influence of alcohol and 600,000 students are assaulted by another student who has been drinking. Seventy thousand students are victims of alcohol-related sexual assault or date rape. These numbers are astounding. The related damage in drunk driving, vandalism, property damage and police involvement is incredible. In 2001, approximately two in five (44.5 percent) college students reported high risk or binge drinking. Our own data at Ohio State University indicates that this rate continued to climb in 2002 to 52.8 percent (from 44.2 percent in 2000). We also saw a 10 percent increase for women, students of color, students of legal drinking age and seniors. We did see a decline in use by first year students, which we attribute to a multifaceted education cam-

paign. We have known for years that college students engage in high risk drinking. We also know that many of these students stop this behavior sometime during their college career. Many do not. We also know that facing consequences of addictive behavior is one of the first steps to change. College and university counseling centers can play a major role in participating in wellness and prevention programs, counseling students in trouble and providing court mandated therapy for students in the legal system for alcohol related behavior. Our services assist students in facing their consequences, examining their choices and learning to choose more appropriate alternatives.

Counseling and Mental Health Service Reductions

As you probably know, college tuition continues to rise dramatically. State subsidies for higher education continue to be cut across the Nation and college administrators are caught in the squeeze. They look to cut costs internally wherever possible and mental health services have been severely impacted. In the last 10 years colleges and universities have had to set session limits (39 percent 1992; 44 percent in 2002), impose fees (7.4 percent in 1992, 15 percent in 2000) and reduce staff. At a time when the mental and behavioral health care needs of students are increasing, the means to meet those needs are being reduced. Employing usage fees affects students on financial aid disproportionately. These students have fewer resources to start with and may be at higher risk for leaving school because of personal problems—problems that could be resolved with appropriate and accessible care.

Campus Care Act

I would like to take my last few minutes to acknowledge the leadership of Senators Reed and DeWine in meeting the mental and behavioral health needs of college students with their introduction of the College Care and Counseling Act—S. 2215. Along with the support and involvement of Senators Smith and Clinton, you have introduced significant legislation that can really make a difference in the lives and successes of our Nation's students enrolled in postsecondary study. This bill will help thousands of students get the help they need, when they need it and better insure the return in our Nation's investment in them.

S. 2215 authorizes $10 million in competitive grant funds to college counseling centers, mental health clinics, and psychology service centers within institutions of higher education to create or expand the mental and behavioral health services to students. Funds made available can be used for activities such as prevention, screening, early intervention, assessment, treatment, management and education of the mental and behavioral health needs of students on campus. Resources may also be used to better educate families about the psychological health of their children. These are critical areas identified by counseling centers on campus that need attention. Over the past 5 years, counseling center directors reported substantial increases in the percentage of students they see with severe psychological problems, sexual assault concerns, alcohol problems, illicit drug use, and eating disorders with little to no increase in resources to support their work.

Why Support College and University Counseling and Mental Health Services? Why the Federal Government?

This year, the Federal Government expects to spend nearly $70 billion in student financial assistance. This investment often makes the fundamental difference in a student's decision to pursue the dream of a college education. It is the most significant contribution the Federal Government makes to our Nation's postsecondary students. And while undoubtedly significant, it is an investment that may not always yield the results we anticipate—for a variety of reasons, but often due to undiscovered, unaddressed or unmet needs related to mental and behavioral health problems.

Mental and behavioral health concerns and how they are addressed—can make the difference between a student that finishes in 4 years versus 7; a student that graduates and one who drops out; and a student who takes his or her own life and one that goes on to live a healthy life. The Campus Care and Counseling Act calls for a small contribution of resources but it offers a sound, targeted, intervention, based on research, that can yield big contributions in areas including academic success, retention, graduation rates and life and death.

I sincerely believe it is one of the best returns on investment you can make. I hope that as the Senate Health, Education, Labor, and Pensions Committee moves forward with its reauthorization of the Higher Education Act that this legislation will be a priority for inclusion in the final bill. It is too important not to. Finally, I would again like to thank you, Senator DeWine for having me testify at this important hearing today and for cosponsoring S. 2215.

I will be glad to respond to any questions.

Senator DEWINE. Dr. Davis?

Ms. DAVIS. Mr. Chairman and members of the subcommittee, I am grateful for this opportunity to talk with you today about a developmental stage that is ignored and a group of young people that we cannot afford to lose. I study the transition into adulthood of youth with the most serious mental health conditions and the public systems with which they are involved. I hope my testimony, which is based on my and my colleagues' research, convinces you that we need to change our service systems to help these young people become contributing members of society rather than what our service systems do now, which is to abandon them and their families in the middle of this critical developmental stage.

The transition period covers ages 14 to 25. Of those who are 14 to 25, 2 to 3.5 million of them have the most serious mental health conditions. The typical transition to adulthood that most of us experience is based on the steady accumulation of cognitive, emotional, and social maturity and increased skills and knowledge so that by age 25 society reasonably expects us to have finished school, to be working, and to move out of the family home.

For adolescents with serious mental health conditions, particularly those in public systems like special education, child welfare, or child mental health, their odds of becoming successful young adults are bleak. Disability and circumstance slow their steady accumulation of maturity skills and knowledge. By young adulthood, about 30 percent have experienced homelessness. The rate of school dropout, unemployment, drug or alcohol problems, and pregnancy covers around 50 percent. And by age 25, up to 65 percent have been arrested. In essence, they are failing in every domain of adult functioning.

But the real failure is our inadequate service systems. While their need for services does not go away, our service systems do, right in the middle of this critical developmental stage.

This mid-transition service loss is caused by unintentional barriers that are produced by the separateness of our child and adult funding streams, entitlements, and service systems. Not only do individuals lose services, but the services that do exist rarely address the particular needs of youth with serious mental health conditions.

Let me illustrate some of these barriers through real life stories. Matt, who had been involved with special education, child welfare, and the State child mental health system since age 5, could not access the State's adult mental health system when he turned 19. Matt lived in a State, like many other States, in which child and adult mental health systems restrict access to their services to those who have one of a list of qualifying psychiatric diagnoses. In 62 percent of States, the list of diagnoses for adult services is more restrictive than they are for child services. Matt did not have one of those qualifying adult diagnoses, and he was denied any further access to the State's mental health system.

Hannah, who developed a major depressive disorder when she was 16, had been on an adolescent psychiatric hospital unit for 6 months when she turned 18. With little notice, she was transferred to the adult unit. There she was the only patient under age 30. The sudden shift of unit that broke off her relations with those on the

adolescent unit and put her with older adults that she found frightening led to despair and suicide attempts. When she eventually left the hospital, like most young adults in the adult mental health system, she found few programs that had any younger adults in them and no recognition of her transition support needs.

We have learned that the causes of this service inadequacy and the mid-transition service loss are complex. For example, State mental health systems are greatly dependent on Medicaid funding. Child eligibility for Medicaid is different from adult eligibility. And as a result, each day some young people with serious mental health conditions lose the payer of their needed services because of the passage of a birthday that marks entry into adulthood.

While the solution to these problems is complex, the goal is clear. Give these young people a chance for successful adulthood by providing supportive services throughout the transition age, until adult functioning has been attained. No States have come close to this goal, although most are making efforts.

To achieve this goal, we need to motivate our systems to be creative in solving the system problems, to embrace this developmental stage, and to embrace these young people. We also need to develop more knowledge to guide these efforts.

I thank you for providing a forum from which greater progress may evolve. I would especially like to thank you, Chairman DeWine, and Representative Stark for your focused effort in the transition issue.

Senator DEWINE. Doctor, thank you very much.

[The prepared statement of Ms. Davis follows:]

PREPARED STATEMENT OF MARYANN DAVIS, PH.D.

Mr. Chairman and Members of the Subcommittee, I am Maryann Davis, Ph.D., a psychologist on the faculty of the Center for Mental Health Services Research, in the Department of Psychiatry at the University of Massachusetts Medical School. Over the past 10 years I have conducted research on the developmental needs of youth with serious mental health conditions during the transition to adulthood and the public systems with which these young people are involved. I am very grateful for the opportunity to talk with you today about a developmental stage that is ignored, in a group of young people we can't afford to lose. I hope my testimony convinces you that we need to change our service systems to help these young people become contributing members of our society, rather than what our systems do now, which is to abandon them, and their families, in the middle of this developmental stage.

The transition period covers ages 14 through 25. At any given time, there are 2–3.5 million individuals in the transition age who have the most serious mental health conditions. The typical transition to adulthood that most adolescents experience involves the steady accumulation of cognitive, emotional, and social maturity, that under most conditions, results in increased skills and knowledge so that by age 25 we reasonably expect young people to finish school, be working, move out of the family home, develop adult friendships and loving relationships, and begin to contribute to our society. For adolescents with serious mental health conditions involved with public systems, like special education, child welfare, or child mental health services, their odds of becoming successful young adults is bleak. During adolescence their psychosocial development is delayed in every area. By young adulthood about 30 percent have experienced homelessness, almost half have a developed drug or alcohol abuse or dependence, half have dropped out of high school, about half are unemployed, up to half of these young women have become pregnant, and, by age 25, up to 65 percent have been arrested. In essence, as a group, they largely fail in every domain of adult functioning.

But the real failure is our inadequate support system. While their psychiatric disability does not go away, our support system for them does. In the midst of this important developmental stage there is an abrupt loss of services that has no cor-

relation with an improvement in their state of mental health. Rather it is the result of myriad system barriers erected by the separateness of our child and adult services, agencies, funding streams, and entitlements. Adolescent services that address the particular transition needs of those with serious mental health conditions are too rare. Few of these adolescents gain access to the adult mental health system, which contains vocational, supported education, housing, and substance abuse services in addition to mental health treatment. However, the few who are given access to adult services encounter find that adult systems typically have no developmental framework in their policy or practice. There is little recognition that a 22-year-old needs different types of services than a 40-year-old. Thus the adult system, that frequently denies them any entry, also typically offers few services that are appropriate or appealing to this young adult population. Currently, there is no State that has been able to overcome these system problems.

I'd like to relate one young person's story to demonstrate this point. Matt became involved with special education, child welfare, and the child mental health system since age 5. By age 17 he had a social worker from each of these systems who were responsible for finding services for him. He had a single mother and younger siblings. His residential treatment ended at age 17. He was sullen, depressed, and had angry outbursts. He was on numerous psychotropic medications. He yearned for acceptance, but put up a gruff unfriendly exterior to ward off the expected rejection.

His special education program couldn't find a school program for him for months. Things got worse at home. He joined a gang, fathered a son, and turned 18 in the ensuing months. Like so many youth with serious mental health conditions he dropped out of school. His transition plan, mandated by the Individuals with Disabilities Education Act became moot upon his dropping out. The school made an application for him to access adult mental health services which could start serving him when he turned 19. But, in his State, like many States, the child and adult mental health system restricts their services to those who have one of a narrow list of qualifying psychiatric diagnoses. In 62 percent of States the list of diagnoses is more narrow in the adult than child mental health system. Matt didn't have one of the adult diagnoses, and was denied any further access to the State's mental health system after age 19.

Upon his 18th birthday his child welfare case was closed. The John Chaffee Foster Care Independent Living Act allows many youths to continue voluntarily in child welfare services after age 18, receive independent living supports, and extends their Medicaid coverage to the age of 21. But, like many young people in his position Matt was not interested in any further involvement with this Agency.

By age 19 he was a legal adult, with little guidance, who had lost all his child services. He didn't know how to apply for disability. He was uninsured. He had no diploma. No steady source of reliable income. And no hope. He was soon hospitalized for a suicide attempt, and was never able to provide financially or emotionally for his son.

Matt's situation is unfortunately common among the young people with serious mental health conditions in our public systems. While special education and child welfare systems have developed many programs and approaches to aide the transition to adulthood, those approaches are targeted at nor well suited for youth with serious mental health conditions. Transition supports in the State child mental health system are sparsely distributed across the country, and adult mental health system has not begun to address the needs of the younger adult population. We miss a critical window of development. We have an opportunity to help these youths become productive adults in our society, to work, have homes, have friends, and start families. But we squander that opportunity, to the detriment of us all.

The solution to these system problems is complex, but the goal is clear. We need to provide appropriate transition supports continuously into adulthood until the services are no longer needed. If we are to achieve this goal we need to encourage innovation and creative solutions to the current system barriers. We need to create the motivation to change these systems and we need to develop more knowledge to guide us as we solve this complex problem.

There are solutions to be had at every level. At the Federal level, changes such as extending eligibility for Medicaid coverage for youth with disabilities to age 25, would facilitate the provision of continuous services throughout the transition stage. State mental health authorities can work to make their eligibility criteria the same for adult and child services. At the local level, young people can be invited into the change process, to help guide the changes so that they are appealing to them. We also need more research to develop and demonstrate treatments or services that are effective with this age group. Achieving our goal will prevent crime, homelessness, lost productivity, and lost members of society.

Thank you, Mr. Chairman and Members of the Subcommittee, for providing a forum from which greater progress may evolve. I would especially like to thank Senator DeWine and Representative Stark for their focused interest in the transition issues.

RESPONSE TO QUESTIONS OF SENATOR BINGAMAN FROM MARYANN DAVIS

Question 1. Every year, an estimated 9 percent to 13 percent of children and adolescents in the United States experience a clinically significant mental disorder that warrants treatment. Yet, according to the Surgeon General's Report on Mental Health, two-thirds of these vulnerable young people do not receive any mental health treatment at all. What can we do to improve access to treatment?

Question 2. Evidence-based treatments are now available for the full range of child and adolescent mental disorders. Yet these effective treatments fail to reach a majority of those who can benefit from them. How can we close the gap between research and real-world practice to ensure that evidence-based treatments are available in community service settings?

Question 3. Children with serious emotional disturbance often have multiple problems and require services from several systems, including the mental health, educational, child welfare, and juvenile justice systems. How can we enhance the coordination and collaboration of various child-serving systems?

Question 4. The New Freedom Commission on Mental Health and the Surgeon General's report both identified a national shortage of mental health professionals trained to treat mental illness in children and adolescents. I have introduced S. 1223, The Child Health Care Crisis Relief Act, which creates incentives to help train, recruit, and retain child mental health professionals through loan repayments, scholarships, and grants. Do you feel passage of this legislation would be helpful in reducing the shortage of qualified professionals?

The first three questions are covered very thoroughly in the New Freedom report for children and adolescents. What is not covered very well in that report are the specific needs of youth during the transition into adulthood. I will focus my answers on that age group.

(1) INCREASING ACCESS. Your question is particularly important for youth with mental health conditions during the transition to adulthood. All studies converge on the fact that there is a critical loss of services between ages 16–23. Thus, that figure of 67 percent not receiving needed services increases dramatically during these ages. I will address some of the factors that contribute to the loss of services and to not accessing service in the first place.

(A) Stigma. Teens and younger adults want to fit in with their peers, they do not want to be labeled as mentally ill. In this age group it is the young people themselves who need to be encouraged to identify their mental health need and to access services that can help them. The social stigma of mental illness is the worst of any disability group. Thus, more young people can be identified and treated if access is destigmatized. Reducing the stigma of screening or treatment can be achieved in various ways. The first principal is to go to where they are; the internet, schools, the mall, public transit, etc. For example, USE THE INTERNET. Having an internet screening device with some link to services is an anonymous way that any teen or young adult, who is struggling in their functioning can get some sense of whether they have a mental health condition that could benefit from treatment. The second principal is to imbed the screening and treatment into issues that youth care about. For example, youth might not want to take a mental health screening test, but they may be very interested in finding out why they're struggling to work, finish school, earn money, or move out on their own. Imbedding screening for mental health, and other conditions, into tools that they can readily access to help them figure out how to do these things better is a friendly way to help them find out that not only do they have a mental health condition, but that its getting in the way of things that they want to achieve, and there's help to be had. The third principle is ensure that the development of screening and treatment mechanisms is guided by young person input (young people with mental health conditions). They are the only ones who can really indicate what approaches will attract or repel young people. Making these kinds of innovative approaches work, and making them ethical could be the focus of Federal programs, like SAMHSA, NIMH, OSERS, NIDRR, NIDAA. Encouraging these agencies to work collaboratively increases the likelihood that the issues that young people care most about will help overcome the issue of stigma.

(B) Disappearing Payors. Many young people who have mental health conditions, and are receiving treatment for them, lose access to treatment upon the passage of an "adult" birthday. Essentially the payor of their "child" treatments no longer covers them at this age, and the payors of "adult" treatments will not fund them. This

occurs across numerous payors. Each suggestion below focuses on the kind of action that would increase access to mental health services because of the continued presence of a payor for those services. Parents' insurance can cover a young adult child as long as they remain in school. However, for young people with serious mental health conditions, this offers little help because fewer than half finish high school and only a small fraction go on to post secondary school. Encouraging insurance companies to allow parents of youth with disabilities to maintain their coverage until age 25, regardless of school status, would help maintain the continuity of services. It might also be a motivator for screening—since they would have to document disability. Medicaid eligibility is much broader for children than for adults. The changes take place somewhere between age 18 and 21. Extending eligibility for Medicaid automatically for anyone with a disability up to age 25 would go a very long way toward providing access to needed services. Changing the definition of disability, as used for Medicaid or social security, so that those between the ages of 18 and 25 could qualify as disabled under EITHER the child or adult definition of mental health disability would also ensure that those who were considered disabled as a 17.99 year old, would still be considered disabled throughout the period of transition. Extend the eligibility for independent living supports provided through the John Chaffee Foster Care Independent Living program to the age of 25 for those with disabilities. Provide an extra pot of money in the Federal mental health block grants administered through SAMHSA for States to access to increase the numbers of youth who receive State mental health care during ages 16–25.

(C) Embrace the developmental stage of emerging adulthood. In "normative" or "typical" development there is a new stage of development that has been recognized and described; emerging adulthood, which starts around age 18 and ends around age 25. There is all kinds of legislation around entitlements and programs that defines childhood as ending at 18, or 21. For youth with disabilities, their development is delayed, and society's expectation that they function as adults at 18 or 21 is misplaced. Supports for youth with disabilities need to uniformly be extended to at least age 25. If "typical" development means full adult functioning at 25, then, really, supports, entitlements, programs, etc., should be extended to age 28 for youth with disabilities. This is a guiding principal that should be applied to many legislative efforts that affect the population of adolescents and young adults with mental health conditions.

(2) Evidence-based practices do not exist for youth in transition. Like so many other realms, we have focused our evidence-based approaches on either child/adolescent or adult populations. The efficacy Multi-Systemic Treatment that is so impressive for reducing delinquency is unknown for youth aged 18–25. The efficacy of the Assertive Community Treatment Program is unknown for 14–21 year olds. The first step for youth in transition to adulthood is to develop evidence-based practices; perhaps emphasizing the need to test and perhaps modify existing models for this age group. NIMH should be encouraged to offer funding in this area. The various other recommendations from the New Freedom report for extending the evidence base to real world setting holds for this age group as well.

(3) Youth in transition have needs that extend from the child to the adult system. Thus, not only do the various child-serving agencies need to be involved, but the various adult-serving agencies as well; adult mental health, housing, vocational rehabilitation, substance abuse services, supported education, corrections, etc. The recommendations in the New Freedom Commission Report for reducing fragmentation are excellent. I would encourage one particular aspect for youth in transition; the embracing of outcomes across domains of functioning to guide funding. Many of the "costs" of not treating youth during the transition to adulthood aren't mental health costs but they are broader societal costs; homelessness, unemployment, crime, substance use, youthful pregnancy. We need to bring together the Federal, State and local agencies that are involved in these domains of functioning so that their accountability cannot be shifted off to the other. If we use young adult outcomes as our guides we will definitely improve services for this age group, and improve our society.

(4). Child Health Care Crisis Relief Act. Looks good to me, except that it does not include professionals specializing in young adults, I'd VERY MUCH like to see that age group included. Again, if we can conceptualize the developmental process leading to adulthood as including the "emerging adult" stage rather than ending at that stage we will be more closely aligned with the real development of these individuals, and with the supports that they need to be launched into a successful adulthood.

RESPONSE TO QUESTIONS OF SENATOR REED FROM MARYANN DAVIS

A significant number of mentally ill patients also suffer from substance abuse problems, known as "co-morbid conditions". As you well know, there are different funding sources for each. Likewise, these individuals access services in a variety of settings, such as residential facilities and the juvenile justice system. Many of you spoke to the fragmentation of mental health care and the difficulty of accessing services.

Question 1. Is there evidence of improved outcomes, better compliance, and cost-savings through providing combined services? For example, properly treating an alcoholic's bipolar illness to avoid relapsing on alcohol.

Answer 1. The simple answer is yes.

Comorbid mental health conditions and substance abuse. Let me say that I am not an expert on the dual diagnosis/comorbidity literature. So I have examined the literature to provide an answer to you for this specific population. Two current critical analyses of the existing research on the subject indicate that, there are still many holes in our knowledge, the most common finding is that **treatment of both disorders (combined services) is more successful in terms of improved functioning, symptomatology, or drug/alcohol use, than either alone.** For those with comorbid mental illness and substance abuse disorders, there is evidence of improved outcomes when both conditions are treated.

This said, both reviews were quite clear that the evidence at this point is thin. There have not been many or many well-designed studies to draw from, and the specifics of the question are vast. Just as specific disorders of mental illness differ, so do the specific disorders of substance abuse, and we don't have a complete picture about combined treatments for all of the different combinations. One specific study even found that subjects with social anxiety disorder and alcohol dependence who were treated for both conditions simultaneously actually fared worse in their subsequent alcohol use, than those who were treated only for their social anxiety disorder. However even this finding argues for the coordination of substance abuse and mental health treatment; if for some conditions it is advantageous to hold off on treatment of one condition that needs to be coordinated. **Thus, all evidence points to the need for well-coordinated services.**

Overall, the specifics of good, evidence-based treatments for individuals with dual diagnoses are just beginning to emerge. Even less is known about combined treatments for adolescents, for youth in transition to adulthood, or for different cultural groups. I saw no literature on cost savings or specific findings on combined services improving treatment compliance. Cost improvements are implied by some of the findings that combined services reduce emergency room/detox visits, but cost analyses have not been conducted. These questions have simply not been addressed through research. **Many more studies are needed.**

My own research indicates that **for transition-aged youth with dual mental health/substance abuse conditions, the combined condition is exponentially worse in terms of high school dropout, not living with family, and trouble with the law.** Again, the little bit of evidence from the research literature is supportive of coordinating treatment for both conditions. One study found that youths with SED, whose substance use disorder went undiagnosed by clinicians during adolescence, fared much worse than either youth with identified dual conditions, or youth with mental health conditions alone. One interpretation of the findings is that those who were *identified* as comorbid received some treatment for both conditions, while those whose substance use disorders were unrecognized deteriorated from lack of treatment for the substance use disorder. Similarly, a study of adolescents with ADHD (Attention Deficit/Hyperactivity Disorder) found that adult substance use disorders were much higher in adolescents who had not received pharmacological treatment for their ADHD. Taken together these studies suggest that either untreated substance use or mental health conditions can both lead to increased substance abuse in young adulthood.

Combined services in other areas of multiple needs. There is no direct evidence about better outcomes, engagement, or cost effectiveness of combined services in the transitioning population. The circumstantial evidence is strong.

(1) They clearly are involved across multiple systems; mental health, education, child welfare, juvenile justice, substance abuse, homeless-runaway youth, etc.

(2) Their functional impairments span different agencies' expertises; jobs/career, education, housing, adequate parenting.

(3) Their "conditions" are often multiple, mental health combined with substance abuse, learning disabilities, developmental disabilities, and chronic health conditions are common, and treatment for these other conditions are most commonly offered through non-mental health agencies.

(4) Services that address multiple needs have been shown to be associated with better outcomes in various domains of functioning, which can be translated into cost savings.

The general literature on well-coordinated services across different service domains is supportive of the notion that coordination alone is insufficient. That is, coordinating average care may not be any more effective than not coordinating it, though families are more satisfied when even insufficient care is coordinated. What is really needed is the coordination of high quality care. Several clinical trials are now showing things like combined pharmacotherapy with highly specified cognitive behavioral therapy is more effective than either alone. Although these particular services wouldn't necessarily come through different funding streams, it does highlight that combined and high quality services are more effective than ill-informed uncoordinated services.

Question 2. In your experience, are different Federal funding streams a barrier to quality mental health care?

Answer 2. Yes.

Quality mental health care, particularly during the transition stage, depends on being able to fluidly address functional needs as they arise. A young person is not going to focus on their mental health treatment needs if they are imminently homeless, if they can't get a job and they need to support themselves, or if their lives are miserable at school. Similarly, not attending to their mental health care will interfere with their abilities to address these problems.

Funding streams are service-based, not people-based. They help foster the silos of agencies at the State level. Those silos are not well coordinated at the individual or State level. As a result of that, families and youth experience gaps and redundancies in services and treatments, and providers are frustrated with an inability to access needed services. More subtly, the silos foster silo-think. That is those working with these young people tend to think about only the services that their systems offer in addressing their needs, and know less, have less access to, and less often consider services offered through other systems.

My research has also shown that one of the barriers to accessing transition support services for adolescents in State mental health systems was that other agencies held the purse strings for many of the needed services, and were not motivated to address the unique needs of the youth in their systems that had mental health conditions. For example, many administrators described that there were foster care independent living dollars (Chaffee funds) that were available to youth in foster care. However, those funds were invested preferentially in youth who were succeeding (i.e. expected to complete high school), or were used for generic independent living supports that didn't address the needs of youth with mental health conditions.

Administrators also described that the differing eligibilities for different Federal programs, such as Medicaid, EPSDT, etc., added to the complexity of how long they could provide services to youth. Some youth were eligible for Federal programs until they were 18, while others were eligible until age 21, so the child system "covered" to age 21, but only if an individual had health care coverage to that age.

Finally, an analysis of "transition support" programs for youth with serious mental health conditions revealed that service providers attempting to serve this population must currently expend tremendous effort cobbling together fragments of funding that are generally time-limited, service-limited, age-limited, disability-limited, or income-limited. In a study of 18 providers serving the transitioning population, researchers found that these 18 providers used 40 different fund sources, most of which were not shared by more than 2–3 providers. The most common category of funding was private (i.e. private foundations), rather than public sources. Without a stable, comprehensive funding base, the system of care for youth in transition will develop at a snail's pace.

Similar issues of silos exist within children's services. An excellent publication analyzing the impact of separate Federal funding streams in children's systems is **Help or Hindrance?: The Federal Government and Interagency Systems of Care for Children with Serious Mental Disorders.**

Fragmentation of services and conflicting program rules have long impeded children's and families' access to needed care. This issue brief examines the Federal Government's role from the perspective of State officials responsible for children's mental health programming. (February 2003), which can be found at http://store.bazelon.org/children.html.

Senator DEWINE. Senator Sessions has joined us. Jeff, do you have any opening comments?

OPENING STATEMENT OF SENATOR SESSIONS

Senator SESSIONS. I am delighted to have Linda Champion here. She is a champion for the mentally ill and has been a friend of mine for a number of years, has always been exceedingly helpful in helping me understand these issues, and is a leader in Alabama in it.

I thank you for inviting her to testify. Good to see her husband, Graham, back there. They are really fine Alabama citizens and leaders in particular on this issue.

Senator DEWINE. Very good.

Mrs. Champion, with that introduction, you are next.

Mrs. Champion. Thank you so much, Chairman DeWine, Senator Sessions, Senator Reed, and Members of the Committee. Thank you so much for holding this critically important hearing today. I am truly honored to be part of this panel and to speak on children's mental health issues.

I am Linda Champion of Montgomery, AL. Since 2000, I have been a member of NAMI Alabama working as a child advocate. I am also vice president of Alabama Family Ties, an advocacy group that collaborates with NAMI Alabama to provide support and education to parents of children and adolescents with mental illness. I am first and foremost the mother of a 17-year-old son who has been struggling with mental illness since the age of 7. It is from the perspective of both a mother and a child advocate that I am honored to come before you today and provide this testimony on the current state of the children's mental health system.

NAMI is the Nation's largest grassroots advocacy organization, with 220,000 members representing children and adults with mental illness and their families.

So often I have listened to families pour out their heartfelt stories of failed attempts to access mental health services for their child in a system that is fragmented, overly bureaucratic, and not at all family-friendly. The system fails to offer support, adequate information, and resources to parents and caregivers of children with mental illness. The opening statement of Surgeon General Satcher's Report on Children's Mental Health really says it all: "the burden of suffering experienced by children with mental health needs and their families has created a health crisis in this country." For families of children with mental illness, this is, quite frankly, an understatement. Our family's experience is right in line with the finding of the President's New Freedom Commission that our Nation's mental health system is in shambles, with no defined or coherent system at all. At various times, we are accused of being ambivalent and uncaring. It is also suggested to us that the sins of the father are visited on sons, a direct reference that Lee, who is my adopted son, was being punished for the sins of his father. Parents and caregivers of children with mental illness in my State and communities across this country are forced to navigate a fragmented, overly bureaucratic, and family-unfriendly system.

You have my family's personal story in the written testimony submitted for the record. I would like to highlight some of our struggles in attempting to access mental health services for Lee. I will do so in referencing numbers: three, the number of acute-care

placements Lee has had in his short life thus far; five represents the number of residential treatment facilities Lee has lived in before he was finally stabilized so that he could function in a less restrictive environment; six is the number of different psychiatrists he has seen in his short life because of changes in residential treatment places; seven represents the number of changes that have occurred in medication combinations; 10,000-plus is the number of miles each year that we have traveled to visit Lee and stay involved in his treatment in the various residential treatment facilities he has been placed in; two is the number of custody changes that have occurred in Lee's life with our family. We gained custody through adoption, lost custody to obtain mental health treatment, and fought for custody of Lee, and he is now with us.

But one represents the life of a child who has missed out on far too many normal childhood things—scouting, dating, going to proms, the normal things that parents usually experience with their children.

As a parent who has lived through a difficult struggle in attempting to secure appropriate mental health services for Lee, I have the following suggestions of immediate actions that should be taken to help eliminate the burden that families are forced to endure and to improve services for children with mental health illnesses:

End the discriminatory cap on private insurance coverage for mental health services. Our family was forced to give up custody because we quickly exhausted our lifetime private health benefits to provide the treatment for Lee. Please support the mental health parity legislation, S. 486.

End the practice of forcing families to give up custody of their child to access mental health services. There is no greater injustice than forcing a parent to choose between maintaining custody of their child or seeking services for him. No parent should ever face this choice, yet it happens every day in this country, and families like ours are forced to give up custody and live with the consequences. Please support the Keeping Families Together Act to help end this practice, S. 1704.

Encourage States to develop effective interagency collaboration and partnerships between all child-serving agencies and with families. We were forced to act as case manager for Lee over and over again to work with the multiple agencies that failed to communicate.

Train and educate all child-serving professionals about the early warning signs of mental illnesses in children. All child-serving professionals, especially school professionals and those working in child welfare and juvenile justice, should be trained to recognize the early warning signs of mental health-related concerns in children and know what to do when they exist.

Build an effective children's mental health treatment system. Alabama and every other State must invest in building an effective children's mental health treatment system that provide a full array of services for children and families.

Parents need to be provided with appropriate information about their child's diagnosis and treatment. We were often left in the

dark about Lee's diagnosis and treatment options that were available to us. Much of what we learned we had to learn on our own.

The good news is that the scientific community has made great strides in understanding childhood mental illnesses and treatment works for many children, if you can get it. Of course, we deeply regret that it took so long to access services for Lee and what we have missed along the way.

Mr. Chairman, my dream is that the U.S. Senate and the House of Representatives will realize the precious treasure we have in our Nation's children. We can only help them reach their full potential if we can ensure that children who suffer from mental illnesses receive appropriate treatment and services. The health care needs of our children should be a national priority just like it is for juvenile diabetes, obesity, cancer, and other childhood illnesses.

You and your colleagues are in a unique position to truly impact the quality of the lives of our children. We ask that you do so by doing the right thing today for our children and their families.

I want to thank you for the opportunity to present one parent's story. I hope and trust that in some small way I have raised questions in your mind about what we can do to help our children.

Thank you so much. I will be glad to answer any questions.

Senator DEWINE. Mrs. Champion, thank you very much.

RESPONSE TO QUESTIONS OF SENATOR BINGAMAN FROM LINDA M. CHAMPION

Question 1. Every year, an estimated 9 percent to 13 percent of children and adolescents in the United States experience a clinically significant mental disorder that warrants treatment. Yet, according to the Surgeon General's Report on Mental Health, two-thirds of these vulnerable young people do not receive any mental health treatment at all. What can we do to improve access to treatment?

Answer 1. Improve Access to Treatment—Early Identification and Intervention

The majority of children and adolescents suffering from a mental illness largely go undiagnosed due to a number of reasons: parents are uninformed of normal childhood development, schools label their erratic behavior as delinquent thus forcing them into a juvenile justice system that we already know from private and governmental studies are ill equipped to handle mental illness within their systems, and the appalling gaps in our child and adolescent mental health system force families to seek treatment far from their communities or none at all, and the lack of coordination within child serving agencies who serve some of these children in different capacities or not at all. Our child serving systems must be given opportunities and challenges to work together in identifying and treating children and adolescents with mental illnesses. From a parent's perspective, child-serving agencies do not work together and will point to their sister agencies for treatment services—forcing parents to become case managers for their child's treatment. My recommendations would be as follows:

Train and educate all children-serving professionals about the early warning signs of mental illnesses in children. All child-serving professionals: day care providers, teachers, pediatricians, child welfare, juvenile justice professionals must be trained to recognize the early warning signs of mental health concerns.

Build an effective children's mental health system. Federal, State Government, and commercial insurers should be encouraged to realign funding policies related to children's mental health needs and develop a comprehensive array of services to meet their needs. Alabama and every other State must invest in building an effective children's mental health treatment system that provides the full array of services for children and families. This includes home and community-based services, school-based services, respite services and more. We learned first hand about the critical shortage of qualified children's mental health providers and the lack of appropriate services. Our nation needs to address the critical shortage of children's mental health professionals and the lack of appropriate services, especially in rural communities.

Question 2. Evidence-based treatments are now available for the full range of child and adolescent mental disorders. Yet these effective treatments fail to reach

a majority of those who can benefit from them. How can we close the gap between research and real-world practice to ensure that evidence-based treatments are available in community service settings?

Answer 2. Close the gap between research and real-world practice to ensure that evidence-based treatments are available in community service settings.

We know there is a large, reliable, and evidence-based body of knowledge in the research community to know what works for our children, yet there is a definite delay in the transference of this knowledge to the very people who would benefit from it. From my perspective, professionals often do not have sufficient knowledge to make both accurate diagnosis and effective pharmacological interventions. Parents must then do the research themselves and advocate for their children. Not all parents are able to do this and our children languish in ineffective mental health systems. A collaborative public/private oversight organization comprised of both Federal representatives and private professionals from the child and adolescent psychiatric community should be established to review; approve and certify; publicize, their findings; and lastly educate all mental health care professionals on these findings. Federal grant programs should follow their recommendations. Accurate information on evidence-based practices must be disseminated to States, training initiatives on these practices should be established, and policy changes in Federal funding to States willing to effect change should be made. And lastly, families should be involved in the process to ensure fidelity to the process.

Question 3. Children with serious emotional disturbance often have multiple problems and require services from several systems, including the mental health, educational, child welfare, and juvenile justice systems. How can we enhance the coordination and collaboration of various child-serving systems?

Answer 3. Enhance the coordination and collaboration of various child-serving agencies.

Encourage States to develop effective interagency collaborations and partnerships between all child-serving agencies and with families. Encourage all Federal child serving agencies to establish performance based indicators for collaboration programs—reward those States that are willing to work together by blending and braiding Federal and State dollars. Provide Federal seed money to States so that data systems can be created to provide both monitoring of collaborative programs, but accountability for agencies back to their respective Federal grantor. On the flip side, penalize those States that are not willing to set up true collaborative efforts.

Question 4. The New Freedom Commission on Mental Health and the Surgeon General's report both identified a national shortage of mental health professionals trained to treat mental illness in children and adolescents. I have introduced S. 1223, The Child Health Care Crisis Relief Act, which creates incentives to help train, recruit, and retain child mental health professionals through loan repayments, scholarships, and grants. Do you feel passage of this legislation would be helpful in reducing the shortage of qualified professionals?

Answer 4. Passage of S. 1223, The Child Health Care Crisis Relief Act.

Absolutely, as we know the bill creates incentives to help recruit and retain child mental health professionals providing direct clinical care, and to improve, expand, or help create programs to train child mental health professionals. The passage of this legislative would create a richer infrastructure of child and adolescent professionals. The lack of qualified mental health providers is part of the reason for the unacceptably high number of youth with mental illnesses that fail to receive treatment and why families are often told that they must wait on long waiting lists for services for a seriously ill child.

The Surgeon General put it best in stating that there is a "dearth" of child psychiatrists, appropriately trained clinical child psychologists, and social workers in this country. Here are the facts:

The Federal Government has designated 3,543 urban, suburban, and rural localities as Mental Health Professional Shortage Areas due to their severe lack of psychiatrists, psychologists, social workers and other professionals to serve children with mental illnesses;

According to the U.S. Bureau of Health Professions, the demand for the services of child and adolescent psychiatrists is projected to increase by 100 percent by 2020, while the number of these professionals is expected to increase by only 30 percent resulting in a severe shortage of child and adolescent psychiatrists;

According to the American Academy of Child & Adolescent Psychiatry, there are currently approximately 6,300 child and adolescent psychiatrists in this country with a need at 32,000;

The National Center for Education Statistics within the U.S. Department of Education reports that the national average student-to-school counselor ratio in U.S. schools is 513:1, more than double the recommended ratio of 250:1.

The consequences of untreated mental illnesses in children are devastating. These youth are at higher risk for school failure and drop out, alcohol and drug use, suicide (the 3rd leading cause of death for 10–24 year old young people), and engaging in high risk and unlawful activity.

In Alabama, our families know on a very personal basis the effect of mental health professionals. Many times, parents will see three or four different therapists and/or psychiatrists per year in visiting mental health clinics, or need to travel great distances to seek services for their children.

Senator DEWINE. Ms. Altenburger?

Ms. ALTENBURGER. Mr. Chairman, Members of the Subcommittee, my name is Barbara Altenburger, and I am from Philadelphia, PA. I am the mother of Bruce Altenburger, who is a 15-year-old. I would like to thank you for the opportunity to speak about a serious problem I and many other parents across the country have encountered in trying to access services for our children through the public mental health system. We struggle to become our child's advocate—often learning how to make the system respond through a trial-and-error process. We become overwhelmed, frustrated, confused, and emotionally drained by the process. Many parents give up.

It is important for you to know that the range of needed mental health services is frequently unavailable, that there is very little coordination among the systems that are mandated to serve our children, and that there is usually no plan to determine which public agency should be responsible for serving a particular child. This evasion of responsibility results in long delays in providing children with desperately needed mental health and related services. Consequently, our children are unserved, underserved, and inadequately served.

The mental health needs and problems of children are diverse in nature and intensity. Some children have disorders that respond to intervention, diagnosis, treatment, and services. Others with more complex disorders and needs often find that their tragic plights are made more extreme by inadequate mental health services. Although every parent's story is unique, let me outline generally what my experience has been and how it is relevant to the experience of many other parents and children with severe emotional disturbances.

My story and that of my son Bruce is a story of the difficulty of diagnosing mental disorders in children and adolescents. It is about the difficulty of finding qualified specialists to care for a very troubled child, and the even greater difficulty of getting access to needed care because of health insurance barriers. It is about the pressures put on parents to give up custody of their children to get needed mental health services. Finally, for children who are eligible for publicly funded care, it is about what some call the "public mental health system." Parents across the country can tell you that there is no system. But it is worse than that. It is a maze.

My child and many other children have gotten services through a variety of different, uncoordinated programs. The school system has provided certain services. Behavioral issues have led to contact with the juvenile justice system and its services. We have gotten services through other publicly funded programs. But there has

never been any coordination between these agencies and no true system of care providing needed wraparound services.

As a result, parents must become their child's best advocate and case manager. I have no reason to think that mental health services in Philadelphia are markedly better or worse than those elsewhere. My experience is that rather than enlisting parents in their child's recovery, too many programs lack respect for parents. In the children's recovery too many programs lack—I am sorry. Parents are seldom given a role in planning or even decisionmaking concerning their child's care. My experience is that while public programs are intended to help our children, they too often fail them. Yet the philosophy too often is that the "child failed the program" rather than vice versa.

What is it like to have a child with bipolar disorder and learning disabilities? What is it like to be a mother perceived as incompetent? What is it like to be the parent of a child who, from an early age, always seemed to require more? A child who was noticed, but often for negative reasons. A child whose school, from nursery school on, continually suggested conferences. A child whose years in elementary schools were marked by frequent contact with principals, teachers, counselors. A child who seemed to be almost but never quite okay.

At different times my house has been a battleground. My son has been severely depressed, angry, out of control, hysterical, and manic. At times he would be full of remorse—[Pause.]—excuse me—and experience great bewilderment over his behaviors. I felt helpless and pained by his apparent distress.

My family had urged me to have my son evaluated by a child psychiatrist. It took over 90 days for our first appointment paid for by my personal insurance. As a result of the evaluation, my son was diagnosed as having severe emotional problems and possible bipolar. From that time on, Bruce has been seen by a variety of psychiatrists, and every one tried a different approach, different medication, and gave a different diagnosis. And during this period, Bruce was evaluated by the school psychologist because of a variety of behaviors, including running out of school, crying in the classroom, walking in the hallway while class was in session, and yelling that he wanted to go home. It was at this time that I could no longer afford private insurance because of the high out-of-pocket costs it required me to bear. I then turned to the county mental health system.

My first experience at a community mental health center was devastating as I was told that I was the cause of my son's problems—the cause of my son's problems and that I needed treatment, that he was perfectly okay. I was stunned that a professional could make this statement after meeting with me, not my son, for approximately 40 minutes and when the psychiatrist wanted to give me a prescription for Bruce which would calm him down and enable me to handle him. I went to another community mental health center and was put on a long waiting list.

And the process continues across our country of long waiting lists, inexperienced mental health workers, and a dramatic lack of public health system psychiatrists, and of parents being told that their child has failed the program.

What I thought would make a difference never made enough of a difference. My child does not stay on an even keel for longer than a month or two.

My child has attended many different special education programs for children with severe emotional disturbance provided by the school system. Through our public mental health system, he has been placed in residential treatment facilities for long-term treatment and has been hospitalized. During his hospital stays, he has been drugged to the point where he became incoherent. He has been labeled as "severely emotionally disturbed" as well as "conduct disordered" and "bipolar." I have been told that his future is bleak, and at other times that he could have a productive life. I have been criticized for being overly involved and for doing too much, as well as reproached for being underly involved and not trying hard enough. I have been blamed for the "failures" at our home, school, and community by some and praised for good parenting by others. I have been treated with respect, and ignored.

Parents across the country feel that they are their best resource for their children. They are the only consistent factor in their child's treatment and can provide information and insight that can come from no other source. They steel themselves against the subtle and not so subtle accusations of blame and failure. Parents go from agency to agency, all professing to help troubled children. We read books written by "experts." We receive counseling and attend seminars. We try to find a "cure" for our children's outbursts, inability to learn and socialize like apparent "normal" children, and a few of us do manage to find help from the mental health system. But for the unlucky majority, the feeling of hopelessness increases as they see little improvement despite their efforts to work cooperatively with professionals that work with their children. Many see a future full of heartache and little hope.

I have not given up on my son and continue to fight for his well-being and for the provision of needed services to help him overcome his problems. But I demand that our public mental health programs not give up on him either. There is much that must be done to improve public mental health service delivery. I agree that it must be transformed. But the one key element of that change, I believe, must be a change in the relationship between these programs and the parents of these children.

Regardless of whether a child is living at home or away from home, family members must be viewed as a primary resource for their children and must have a voice and a vote as an equal partner in the planning and decisionmaking concerning their child.

Mr. Chairman and Members of the Committee, children are not little adults. They must be treated by professionals that have been trained to work with children and adolescents. Parents in every State urge you to make children's mental health a real priority and to develop and fund effective Federal programs that serve our children's mental health needs. We know that there are pockets of expertise, but that is not on a scale that bears any relationship to the magnitude of the problems we encounter every day. Designing these needed programs may not be simple, but they must include a few elements. They must have child-centered services that are family-focused, community-based, multisystem, culturally com-

petent, and least restrictive. Such services must be available across the country, not just as pilots in a handful of communities. And given that our children represent the Nation's future, we must approach this with the seriousness, energy, and scope of the Manhattan Project.

Thank you.

[The prepared statement of Ms. Altenburger follows:]

PREPARED STATEMENT OF BARBARA ALTENBURGER

Mr. Chairman and Members of the Subcommittee: My name is Barbara Altenburger and I am the parent of Bruce Altenburger who is 15 years old. Thank you for the opportunity to speak to you about the serious problems I and other parents like me across the country have encountered in trying to access services for our children through the Public Mental Health System. We struggle to become our child's advocate—often learning how to make the system respond by a trial-and-error process. We become overwhelmed, frustrated, confused, and emotionally drained by the process. Many parents give up!

It is important for you to know that the range of needed mental health services is frequently unavailable; that there is very little coordination among the systems that are mandated to serve our children and there is usually no plan to determine which public agency should be responsible for serving a particular child. This evasion of responsibility results in long delays in providing children with desperately needed mental health and related services. Consequently, our children are unserved, underserved or served inappropriately.

The mental health needs and problems of children are diverse in nature and intensity. Some children have disorders that respond to intervention, diagnosis, treatment, and services. Others, with more complex disorders and needs, often find their tragic plight exacerbated by an inadequate public mental health system. Although every parent's story is unique, let me outline generally what my experience has been, and how it is relevant to the experience of many other parents and children with serious emotional disorders.

My story and that of my son Bruce is a story of the difficulty of diagnosing mental disorders in children and adolescents. It is about the difficulty of finding qualified specialists to care for a very troubled child, and the even greater difficulty of getting access to needed care because of health insurance barriers. It is about the pressures on parents to give up custody of their children to get needed mental health services, finally, for children who are eligible for publicly funded care it is about what some call the "public mental health system." Parents across the country can tell you there is no "system." But it is worse than that. It is a maze. My child, and many other children, has gotten services through a variety of different, uncoordinated programs. The school system has provided certain services. Behavioral issues have led to contact with the juvenile justice system and its services. We have also gotten services through other publicly funded programs. But there has never been any coordination between these different agencies and no true system of care providing needed wrap-around services. As a result, parents must become their child's most effective advocate and their case manager. I have no reason to think that mental health services in Philadelphia are markedly better or worse than they are elsewhere. But my experience is that rather than enlisting parents in the children's recovery, too many programs lack respect for parents. Parents are seldom given a role in planning or even decision-making concerning their children's care. My experience is that while public programs are intended to help our children, they too often fail them. Yet the philosophy too often is that the "child failed the program" rather than vice-versa.

What is it like to have a child with a Bipolar Disorder and learning disabilities? What is it like to be perceived as the incompetent mother? What is it like to be the parent of a child, who from an early age, always seemed to require more? A child who was noticed, but often for negative reasons. A child whose school, from nursery school on, continually suggested conferences. A child whose years in elementary schooled were marked by frequent contact with principals, teachers, and counselors. A child who seemed to be almost, but never quite, okay.

At different times my house has been a battleground. My son has been severely depressed, angry, out of control, hysterical, and manic. At other times he would be full of remorse and expressed great bewilderment at his behavior. I felt helpless and pained by his apparent distress.

My family urged me to have my son evaluated by a child psychiatrist. It took over 90 days for our first appointment paid for by my personal insurance. As a result

of the evaluation he was diagnosed as having serious emotional problems and possible Bipolar Disorder. From that time on Bruce was seen by various psychiatrists and each one tried a different approach, different medication and gave a different diagnosis. And during this period Bruce was evaluated by the school district psychologist because of his various behaviors including running out of the school, crying in the classroom, walking the hallways while classes were in session and yelling that he wanted to go home. It was at this time that I could no longer afford private insurance because of the high out-of-pocket cost it required me to bear and I then turned to the county mental health system.

My first experience at a community mental health center was devastating as I was told that I was the cause of my son's problems and that I needed to be in treatment and that he was perfectly okay! I was stunned that a professional could make this statement after meeting with me, not my son, for approximately 40 minutes. I was astonished when the psychiatrist wanted to give me a prescription for Bruce which would calm him down and enable me to then "handle him". I went to another community mental health center and was put on a long waiting list.

And the process continues across our country, of long waiting lists, inexperienced mental health workers, a tremendous lack of public mental health system child psychiatrists, and of parents being told that their child failed the program.

What I thought would make the difference never made enough of a difference; my child does not stay on an even keel for more than a month or two at a time.

My child has attended many different special education programs for children with serious emotional disturbance provided by our school system. Through our public mental health system he has also been placed in residential treatment facilities for long-term treatment and been hospitalized. During his hospital stays he has been so drugged, that he became incoherent. He has been labeled "severely emotionally disturbed" as well as "conduct disordered" and "Bipolar." I have been told his future is bleak and, at other times, that he can have a productive life. I have been criticized for being over-involved and doing too much, as well as reproached for being under-involved and not trying hard enough. I have been blamed for the "failures" at home, school, and community by some, and praised for good parenting by others. I have been treated with respect, as well as patronized and ignored.

Parents across the country feel they are the best resource for their children. They are the only constant factor in their children's treatment and can provide information, insight, and continuity that can come from no other source. They steel themselves against the subtle and not-so-subtle accusations of blame and failure. Parents go from agency to agency, all professing to help troubled children. We read books written by "experts." We receive counseling and attend seminars. We try to find a "cure" for our child's outbursts, inability to learn and socialize like other apparent "normal" children and a few of us do manage to find help from the mental health system. For the unlucky majority, the feeling of hopelessness increases as they see little improvement despite all their efforts to work collaboratively with the professionals that work with their children. Many see a future full of heartache and little hope!

I have not given up on my son, and continue to fight for his well-being and for the provision of needed services to help him overcome his problems. But I demand that our public mental health programs not give up on him either. There is much that must be done to improve public mental health service delivery. I agree that it must be "transformed." But the one key element of that change, I believe, must be a change in the relationship between these programs and the parents of these children.

Regardless of whether a child is living at home or away from home, family members must be viewed as a primary resource for the child and must have a voice and a vote as an equal partner in planning and decision-making concerning their child.

Mr. Chairman and Members of the Committee—children are not little adults and they must be treated by professionals that have been trained to work with children and adolescents. Parents in every State urge you to make children's mental health a real priority and to develop and fund effective Federal programs that serve our children's mental health needs. We know that there are pockets of excellence, but not on a scale that bears any relationship to the magnitude of the problems we encounter every day. Designing these needed programs may not be simple, but they must include a few key elements. We must have child-centered services that are family-focused, community-based, multi-system, culturally competent and least restrictive/least intrusive. Such services must be available across the country, not just as pilots in a handful of communities. And given that our children represent our Nation's future—we must approach this with the seriousness, energy, and scope of the Manhattan Project. Thank you.

Senator DEWINE. Thank you very much.

Senator Reed?

Senator REED. Thank you very much, Mr. Chairman, and thank you, ladies, for your eloquent and very effective testimony.

Senator Kennedy and Senator Dodd asked me to raise some questions on their behalf, so if I may, Ms. Wong, in our schools today children are so often subject to some traumatic events—snipers, CNN war stories, and contaminated mail. How can schools best help these students when they face these unusual traumatic circumstances? And what resources become paramount when responding to these types of situations?

Ms. WONG. In our work also with the Department of Justice with Cops in Schools as well as our National Center for Child Traumatic Stress, we found that children are exposed to violence at a far higher rate than in previous generations and if we exclude even the violence that they see on TV. The research would suggest, at least the little that we have, after the Oklahoma City bombing, show that especially younger children are quite traumatized by television viewing of this sort. But with older children, we are finding higher rates of exposure to community violence, to bullying in schools, to acts of violence in the community.

In Los Angeles, for instance, in certain of our communities, especially, I think this can be generalized in communities where there are large urban centers, communities where there are high rates of crime, gang activity, drug abuse, etc, we found up to 90 percent of our students in these selected communities had high rates of violence exposure, and 27 percent of them had posttraumatic stress disorder at clinical levels, 16 percent of them had depression at clinical levels. We suspect that among special education children as well that are integrated into the school district programs that there might be high rates of violence exposure.

I think what we have, we are very lucky in Los Angeles to have a school mental health program, but I think the testimony you heard today is very true. I think it is quite fragmented. I think schools try to piece it together as best they can and that there needs to be a system in place where across the country—it does not matter whether you live in a rural or urban or suburban area—that any parent can access these programs for their children, and particularly, as we said, programs that respond to trauma and depression and suicide.

I think these in particular are problems and disorders and challenges that can be very well addressed, addressed early, and really have a very good outcome, both for the mental health of children and success in education.

Senator REED. Another question, if I may, and I will address it to Ms. Wong and Ms. Osofsky. We screen children for vision. We screen children for hearing. We screen children routinely for many things. And there is some discussion, at least in the literature, about screening children for mental health issues. Is that something that you would advocate or could comment upon? Ms. Osofsky and then Ms. Wong perhaps.

Ms. OSOFSKY. The issue you raise, Senator Reed, is very important. The answer is yes, we do need to screen for mental health as

we screen for medical conditions, physical conditions, vision, hearing, those types of issues.

One of the problems and I think one of the very important areas that I would urge the subcommittee to consider as we are putting forth these bills is prevention and early intervention is very important, but we cannot accomplish prevention and early intervention unless we do screening. And there are ways to do screening ranging from better education for child-care providers, better education for child protection, certainly better education for primary care providers and pediatricians who see children as part of their well-baby checkups, including mental health screening as part of ESDP, the Medicaid screening that occurs routinely or is supposed to occur routinely for children when they are referred or an evaluation.

And I think we need to turn to experts in the mental health community to develop screenings that are feasible to use. It is not feasible during a well-baby checkup to have to spend half an hour inaddition to other kinds of things. But what we are really interested in are screenings that would alert primary care physicians or child-care providers or child protection or even parent advocates under certain circumstances, a whole variety of people, to what we call red flags. And when they recognize some of these red flags, which could be behavior that is out of control, aggressive behavior, which could be withdrawal on the part of the child, which could be other types of things, to then refer them for a more extensive evaluation. So we need a variety of levels there.

But if these things are picked up earlier, we are able to do much more in the way of prevention and early intervention.

Senator REED. Thank you very much, Dr. Osofsky.

Dr. Davis, you sketched out a very complex and troubling situation where people age out of the system. The story of the young woman who was transferred from a pediatric psychiatric setting to an adult one sounds like something out of Hollywood in the 1930s—horrific.

Part of the problem is trying to coordinate the system, not just the health care system but the housing system, the substance abuse system. Any thoughts you have on how we can better coordinate that?

Ms. DAVIS. You are right. It does all need to be coordinated. Quick thoughts are difficult.

I think one of the things that we have learned in children's mental health systems, the system-of-care principle where we recognize that children have needs across many different agencies certainly holds through this developmental stage. And so one of the things that we might think about would be the various mechanisms that we have already used to try to encourage more system-of-care development where there is a recognition that needs go across many different domains of functioning and that there is expertise and resources that go across our various public agencies.

And so I think to the extent that we can extend that philosophy and those approaches—and basically there are various different mechanisms. There are Federal funding mechanisms. There are a variety of different mechanisms that have developed to try to enhance a wraparound or a system-of-care approach that would extend through age 25, I think we would benefit tremendously.

I think what we have learned in children's mental health would help us tremendously. There is a tremendous strength in thinking about individuals developmentally, about thinking about the critically important role of families, that when you get into the adult mental health system, and other adult systems, it does not exist. They tend to think monolithically about the adult and not think developmentally, and tend to even more so minimize family involvement. So I think that we can take that strength from the kid side.

On the adult side, there is a lot of expertise that the kid side does not have in terms of how do you help with vocational rehabilitation, the more current models on recovery. Those are very important—housing, co-morbid substance abuse.

Those are all issues that the adult system knows about. They just do not know how to apply it to this developmental stage. So I think that there is a lot to be done concretely.

I think at the Federal level there are many different things that we can examine and I cannot give you a short answer as to exactly what those should be, but clearly an examination of the funding mechanisms, as I mentioned, in Medicaid would be extremely important to look at in detail about what are some of the mechanisms there that are barriers? What are some mechanisms that could actually facilitate systems to solve this issue?

I will just tell you quickly, last summer I spoke with one member from every State who was in charge of, who was a lead administrator for adult mental health systems for every single State in the country. And one of the things that they said about this population is that this age group, they are just one of many populations that they have to worry about. In essence it had not received a priority enough for adult systems to turn around and handshake with child systems. I think that we have many different mechanisms for encouraging that kind of prioritization and that is really what needs to happen at this time.

Senator REED. Thank you.

Mr. Chairman, I am asking questions for both Senator Dodd and Senator Kennedy, so I will not ask for three times the time, but——

Senator DEWINE. I was going to say that would give you about half an hour.

[Laughter.]

Senator REED [continuing]. Half an hour, that is right, just the warm up time.

First, Dr. Douce, thank you for your kind words about the legislation that the Chairman and I are sponsoring. One of the aspects of getting health care is the community's support for the individual. However, there is a stigma attached to asking for help particularly for a college student asking for help, any kind of help. Do you find that as a problem on campus?

Ms. DOUCE. Yes, I do, although I think it is lessening, and we in fact have a stigma reduction committee as part of our counseling center prevention outreach. Next week is Suicide Prevention Week and our Stigma Reduction Group has designed a number of sort of informational pieces to reduce the stigma of accepting help and to demonstrate that it is actually a strength to seek help, and it is a strength to seek help earlier when the problem is just beginning

than to lose your whole term by sinking deeper and deeper into a depression of anxiety.

Senator REED. Thank you very much. Senator Dodd wanted me to pose this question, and I recognize that none of the panelists are MD's, but the recent controversy surrounding antidepressants, and specifically the class of drugs known as selective serotonin re-uptake inhibitors, SSRIs, raises real questions about the appropriate use of these medicines in children. Would anyone like to advance a view as to the use of these medicines from your perspective, not as physicians but as someone who closely looks at the children's mental health system throughout the country? Dr. Osofsky.

Ms. OSOFSKY. I work within a medical center and I consult frequently with child psychiatrists, and I am not an expert in psychopharmacology. However, we see a great deal of use of medications for children of all ages. We focus a great deal on very young children as well, even children 3-years-old, where we find their primary care physicians, often pediatricians, will put them on sometimes even more than one medication. Many of us are very, very concerned about the fact that instead of the issues that you are addressing in terms of screening, recognizing the problems, evaluation, early treatment, intervention, actually that speaks to the whole age range. People are very quick to put children on medication.

Part of it is I think the reimbursement system because some of the reimbursement system is for a very few number of sessions, sometimes even just a short consultation, and people are looking for quick fixes. They think that the medication will change the behavior, and I think it is really not only unfortunate, but it does need to be used in a much more cautious way.

What we would urge is to be able to do the things we have been talking about in terms of screenings, good evaluations, and then sometime medication is very helpful in conjunction with treatment, but that better evaluations will probably lead to much less medication as well as better reimbursement for services.

Senator REED. Thank you very much.

Thank you, Mr. Chairman, you have been most gracious. Thank you.

Senator DEWINE. Good questions. Thank you very much.

Senator Sessions?

Senator SESSIONS. Thank you, Mr. Chairman. You have been a leader on this issue for so many years, and I am glad I could be here. I am sorry I had to be at a conference on health care this morning that caused me to be late.

One of the things we talked about, Dr. Osofsky, at the hearing on how to contain health care costs, one of the suggestions that I made is, with regard to prescription drugs, that we are prescribing drugs that not only do not work, but sometimes are harmful. That article that Senator Dodd referred to and Senator Reed, indicates that is true on occasion. Do you feel like there is enough certainty of efficacy of certain drugs, and can we do a better job as a government helping to establish which ones are effective and which ones are not, therefore helping the psychiatrists and psychologists as they treat young people?

Ms. OSOFSKY. Training is a very important issue, and certainly in our medical schools and our medical centers we offer a great deal of training related to psychopharmacology. I would agree that if people were better informed about medications that may work under certain circumstances and how they might be used, that it would be helpful.

I think that, unfortunately, medications are being prescribed, medications that speak to issues of mental illness and mental disorders, and these kinds of issues, by people who have had less experience with how those medications might relate in various ways, but I also think, again, we are very quick to think that we can provide some kind of medication to a young person, as I say, even as young—we see them as young as 3-years-old and 4-years-old. Instead of evaluating the problem in the context of what is going on with them, what is going on with the problem, provide support to the family, a much more integrated approach, so that then we might choose medication after a period of time, and certainly it is very helpful with various disorders, certainly bipolar disorder, other types, depression, it can be very effective. But we do need to evaluate certainly children within the context of relationships and be very careful in terms of the types of treatment. And we do need more reimbursement for services.

Senator SESSIONS. Any brief comment on that subject?

Ms. Champion, you are indicating, as did Ms. Altenburger, that you did not feel like that some of the professionals or health care personnel respected you or understood the difficulties you were facing. At one point I think you indicated they thought you were indifferent. Why do you think that is? Is that a problem in the system?

Ms. CHAMPION. Yes, it definitely is a problem in the system. Parents go through this blame and shame cycle. There is something inherent that a parent is to be able to control a child, and if you cannot control a child, you are deemed a bad parent. So you are not only——

Senator SESSIONS. Is that at school too sometimes?

Ms. CHAMPION [continuing]. It is at school. I think it is throughout the entire community, in school settings, in social circles, church circles as well, and it is very difficult. Parents usually feel very alone, very alienated. And mental health professionals by and large, unless you really get in and establish a dialogue and a relationship with the mental health professional, it is very difficult to do so. You are essentially separated from your child, whether you are entering an acute care system or a residential system. Your child is taken into the system and you are immediately separated from that child, and not much interfacing with them. The systems usually are not very family friendly to do so.

That also bears witness to a lack of coordination among the child-serving agencies. There is a lot of finger pointing going on, and that of course, boils down to dollars and cents. If child-serving agencies can learn to braid and blend Federal and State dollars in a different way, I think that you will find a much better system overall for children, and a much fuller array and richer array of services for children.

Senator SESSIONS. You certainly had a number of situations in which your child was moved, and you had to make a lot of different

changes. Is that sort of symptomatic of what you were saying, that the system is fragmented and not well organized?

Ms. CHAMPION. Yes, sir. It certainly is. Mental health professionals usually are not aware of a higher level of care that is required for your child. They may certainly be able to recognize that an outpatient treatment is not suiting the needs of their child, that maybe residential treatment is required, but oftentimes they cannot point you to a residential treatment facility that would meet the needs of your particular child.

Senator SESSIONS. Thank you.

Ms. Altenburger, I thank you for sharing similar comments from your background. I think my time has expired.

Thank you, Mr. Chairman.

Senator DEWINE. Dr. Davis, I am not sure I understand fully the barriers you are talking about in regard to this transitional period of time. Can you spell that out for me so that we can, my staff and I, and Senator Reed and Senator Sessions maybe can do something about this?

Ms. DAVIS. I would be happy to. I think that the most concrete barrier that we see is that we have separate funding for child and adult services, and so what typically happens is those systems evolve to serve each of their mandated population as best they can. So we have various systems just preserving children. You have those who are in the child welfare system, special education. I do not have to tell you all the various systems that we have.

What surprises me the most is when you get to a system where there is no obvious reason why there should not be a continuity within the mental health system. We have children, adolescents, young adults, adults, older adults, all who have mental health needs. We have split our systems into separate child and adult systems, and what happens within those systems is that the priority populations get defined differently, so in the child system we have youth with serious emotional disturbance, and adults is typically adults with serious mental illness.

While in fact those disorders do not have to look very different, States tend to interpret those as being very different definitions. So in the adult system, they will typically have a more narrow definition because they feel like the adults that they are meant to serve are those with the most serious and chronic conditions, and they often then do not take into consideration what might be child—typically conditions that develop in childhood that could continue into adulthood. They say in their list, those are not diagnoses that get you entry into the adult system.

So you have a group of young people, particularly things that involve more behavioral kinds of components like conduct or disruptive behavior disorder. If a young person is identified as primarily suffering from that kind of diagnostic criteria, when they go to—somebody has to apply for them to get into the adult system even though they are in the State's child system. They then have to apply. And at that point the eligibility person typically says: this is not one of our qualifying diagnoses. You cannot enter. So that is one of the major things.

We just completed a study where we looked at, just in policy, the differences for eligibility for child and adult mental health systems

within a singular State mental health agency, and with the exception of one State, every single State has some difference and some meaningful difference in their eligibility requirements, and they require youth who have just been served because they are a child, to meet the new service eligibility for adulthood. That is a funnel. In essence there is a significant group of young people who do not make it through that funnel because of that eligibility difference.

What we tend to see as a result of that, the people who work with these young people know that they are not going to get them into the adult mental health system. They start screening them out, in essence.

There are several States that show a tremendous marked decrease in receiving services at age 16, and while not all of that can be attributed to the service system, per se, young people can decline services. There are a variety of reasons. But one of the major ones that we know forces a barrier is that if case managers know that they are not going to be entitled, they start essentially screening them out of the system at that point. So you end up with a very small number who actually applies for eligibility to the adult system. That is at the State level.

When we were doing that study we looked at Medicaid eligibility entitlements and definitions, and what you see over and over is that there are conditions and situations that will entitle a child to access Medicaid eligibility. Those definitions typically end at age 18. Sometimes States have the flexibility to end that at 18, 19, 20 or 21. None of those goes beyond age 21. What happens, in essence, is that you had a condition that could qualify for a child but now that you are now adult, you are no longer eligible for and you can lose those Medicaid entitlements at that point or that Medicaid service that you needed because you are not qualified any longer.

Those are some of the simple concrete things that get in the way of being able to provide continuous services. I think the thing that more broadly leads to that is that we haven't recognized this as a developmental stage, that we tend to as a society say there is some age at which you are an adult, and we have legally made that 18. For drinking purposes and those kinds of things it is 21. But we do not recognize—we do for ourselves and for those of us who have children who are college age, most of us would not boot them out the door at 18. We know that they continue to need services and we know that there is sort of a new developmental stage that is being defined within developmental psychology called "emerging adulthood," and that is defined as existing up to age 25. We as a society are not yet making our service systems accommodate the fact that we are not ready at 18 or 21 typically to function as adults, and yet these more vulnerable young people who have even fewer resources to draw from and forced out without any further recognition.

So I think part of it is that we have made this false dichotomy, you are either a child or an adult, and our systems follow that and our funding follows that and our entitlements follow that, but it is not in fact matching up at all with what naturally occurs with a young person's development which extends much more toward age 25.

Does that help clarify?

Senator DEWINE. Sure. I think it is difficult, I think you would agree it is difficult to translate that into legislation.

Ms. DAVIS. It is, although I think an examination of Medicaid and——

Senator DEWINE. I mean your point is very well taken and I understand what you are saying, and we have got these artificial barriers and they have been erected over the years, and the question is how do you begin to try to break that down and how do you begin to deal with the reality of the way people live their lives, and we do not do that for anybody else, but yet we have set this up for this group of people, and we have kind of set this artificial barrier, and boom, there it is.

Ms. DAVIS [continuing]. I think one of the things that I was impressed with when I looked at the Medicaid eligibility is that there are some things that will extend for children who have disabilities, certain entitlements from 18 to 21. That is the kind of mechanism that may not open up the door for everybody, but given that this is a partly vulnerable group who has a disability, that kind of thing is possible.

Senator DEWINE. Thank you very much.

Ms. DAVIS. You are welcome.

Senator DEWINE. Dr. Douce, let me ask you about—you have detailed, particularly in your written statement, what you have done at Ohio State. What is your feeling as far as the universe of colleges and universities across the country in how well they are doing, how well we are doing as a society in regard to providing mental health services to students today? How are we doing today versus in 1990, 1980, 1970? I mean what have been the trend lines here, particularly when we look at the suicide problem? Let us just focus on that.

Ms. DOUCE. I think services are uneven I think across all colleges and universities. Some have extensive, comprehensive services available. Some have very limited services available. Some have no services available. I think the issue of suicide continues to be an issue, and I think the issue of anxiety and drivenness feeds that suicidality, that it is actually a combination of depression and anxiety that causes someone to choose to end their lives, to end the despair.

The fact that it is uneven, the fact that college administrators struggle with the rising costs of college and trying to cut costs in any ways they can, some cut mental health services out all together. Some provide very limited mental health services.

Senator DEWINE. If you do not know the answer to this, just tell me, but is there a difference between campuses that are residential campuses and campuses that are less residential or more commuter campuses?

Ms. DOUCE. Absolutely. The reality is when you have students on campus and you have a high residential population, you have them 24 hours. So you have suicide attempts in the dorms. You have drug overdoses. You have assaults. You have things that you have to deal with. Those campuses tend to also put mental health services in play because they need them for the residential students.

For campuses that are primarily commuter, sometimes those campuses, especially if they are regional campuses or draw from a

variety of different counties, those students are really at risk to get the services they need because the local county may not choose to serve them if they are not a resident of that county. So the commuter services, the regional campuses, the campuses that actually are trying to attract more rural students, more first generation students, have some of the greatest need and some of the fewest services.

The Act, what I think is important about this Act is it applies grants. There will be competitive grants. There will be a strong evaluative component to those grants, so that services that are needed in unmet areas can be responded to.

Senator DEWINE. You use the term "availability of services." It is one thing to be available. It is another thing to be accessed. How do you deal with that?

Ms. DOUCE. I think there is a real important need to have prevention and outreach services to really try to establish a wellness culture on your campus. If we are out there doing programs at different clubs, in classrooms, in residence halls, in a number of places, you present yourself as someone for whom you might go seek help. That is how you fight stigma reduction.

Availability is also about waiting lists and——

Senator DEWINE. About what? I am sorry.

Ms. DOUCE [continuing]. Waiting lists, and the reality on college campuses, when you talk about a trend from 1975 to 1995, many, many, many more students are seeking services, and most university counseling centers have a hard time meeting those services at the time they need to be met. If you spend several weeks getting up the courage to go seek counseling, you finally go, you get an urgent important or an intake appointment, and then you wait another 3 or 4 weeks to get service, you have lost your term. That is a problem.

Senator DEWINE. Can you comment at all about the culture on a campus? Is there any relationship between, if you know, if you have read any studies on this or if there have been any studies on this, about the pressure on campus, the academic pressure or any other kind of social pressure connected with the suicide rate?

Ms. DOUCE. I am trying to think of studies in my head. Certainly the biggest increase that we have seen in the last 10 years is anxiety-related disorders, full-blown panic attacks, obsessive-compulsive disorders, anxiety disorders in general. That anxiety is related to the stress that many people feel about needing to be at a certain place, needing to achieve in a certain way, where we in our attempt to maximize student success, have created a younger generation that is quite driven, and driven with a sense of fear of not meeting certain expectations, and that fear drives self-destructive behavior, suicidal behavior, alcohol abuse behavior, cutting. We are seeing more cutting in college students than we ever have.

Senator DEWINE. Seeing more what?

Ms. DOUCE. Cutting, which is a self-injurious behavior, where you actually cut yourself in a ritualistic way. Twenty years ago when I started, if I saw a student who was cutting, I could assume that they had had childhood sexual abuse. Today that is not the case. It is actually a shared behavior, a very self-destructive shared behavior, to relieve the anxiety and stress that builds up. That

does then relate to suicide. It does then relate to serious mental health issues.

I would like to say that we have covered a whole gamut, and more of the students in your system are coming to my system. That is an advantage. One of the real advantages of medication is we have many, many more people who are able to go to college with serious mental disorders than they ever have before. We have many, many more people with a variety of disabilities going to college than we ever have before. They struggle with transition. They struggle with adjustment. They are at higher risk and need higher services, but it is to this Nation's advantage to have our country continue to be able to compete globally, that we graduate a much greater range of students, more diverse students, more culturally sensitive.

Senator DEWINE. Sure. I wonder if you could talk in more detail about the alcohol and drug abuse focused services that you provide. In particular, I am interested in students with these co-occurring disorders. I wonder if you find a large number of students with clinically diagnosed mental health and substance abuse disorders.

Ms. DOUCE. Yes, the dual diagnosis is a major issue. In my center we have expertise, a full range of expertise, but specific expertise in substance and alcohol abuse. We work with the Students Wellness Committee to try to do both alcohol education and substance abuse education. We have groups that focus on success, not excess, which is really not an abstinence-based program but a responsibility-based program. We accept court mandated DUIs. Part of my dream is actually to develop a college student DUI program, because I think when college students are sent to the community DUIs, they look at a number of people that are older, have more serious addictions and distance themselves. Yet, I think that first legal or judicial infraction is an absolute educational opportunity to require people to look at their own behavior.

Senator DEWINE. Dr. Osofsky, you talked about the need to have professionals better trained to identify people who have these problems. I wonder if you could talk, for example, about pediatricians. Are they getting the professional training today in medical schools?

Ms. OSOFSKY. Actually, that is one of the groups that we need to address very clearly related to training. The focus in pediatric training has been, or primary care training as well, primarily physical health. They may focus on vision and hearing and those types of things, but much more on taking care of those types of issues than mental health issues, and, yes, I would agree with you very strongly that we need to address, in medical school education as well as additional training for pediatricians, ways to identify, the red flags to identify mental health issues and refer for additional consultation.

One of the programs that I am involved with, Harris Center for Mental Health, where we provide training to mental health professionals, we also are actually just starting a program where we are going to be consulting with pediatricians and pediatric clinics as well to offer mental health consultation, but also education and training for pediatricians.

So many things are missed at that point that that issue is very important because often either at a well-baby check, or even an

emergency room check, that is the only time we are going to see some of these people with the kinds of problems that we are talking about, and I think that the issues that are being raised on the college level with older children are also very relevant for the younger children, the issue of availability of services, access to services, the stigma around services, and I think if we broadened our education related to mental health issues for primary care physicians and pediatricians, perhaps some of that stigma could be reduced and be part of a regular care that they generally achieve.

Senator DEWINE. Senator Sessions.

Senator SESSIONS. I do not know whether NIH is investing enough in that. To me, some more research in general might be helpful in how to diagnose and how to treat these illnesses but that is another issue I suppose.

Dr. Davis, you really raise an interesting point about children growing into adulthood. I visited a group home in Huntsville, AL. It was basically built by HUD. We provide housing for people who have difficulties anyway, and so they pooled that money with some other money from other agencies, and had a very nice group home for people with mental illness, and it helped them, many of whom were working independently. Do you think that would be something that might work for a number of these children? And what percentage do you think could benefit from something like that?

Ms. DAVIS. If I understand specifically what that represents, this is certainly a group of young people who need support around housing as they age out of the children's system. Many of them are leaving foster care and foster care settings, so they do not have——

Senator SESSIONS. A home to live in.

Ms. DAVIS. Any homes to go to, yes. So there is a large number. I cannot put a precise number, but there are various States that have looked at the child welfare population and estimated up to 60 and sometimes higher proportions, have a serious emotional disturbance, depending on where those studies have occurred. So there is a good number of young people who have those kinds of conditions exiting foster care with a disability. That would clearly be helpful.

I think that there are many things that are available within adult systems for adults with mental illness. I think the crux of the difficulty for this age is twofold. You have a group that is aging out of the children's system with a category that we consider serious emotional disturbance, that there is a group of them that will not meet the eligibility for adults with serious mental illness because we define that slightly differently. So because of that sort of arbitrary distinction, some of them will not get into that housing because somebody will say, oh, you do not have a mental health disability because you do not meet the criteria any longer.

For those who do meet that criteria, they may have developed their mental illness as a young adult, or they may have had it since they were younger. The difficulty that we have is that a lot of those programs that are currently funded that adults can access are largely holding adults that are 30- to 50-years-old, and so when we create a group situation in particular, it is not very feasible to just make any old adult program open to our younger adult population. First of all, they will not accept it, they will not stay. For

many of them if they do stay it can be quite traumatizing for them. For many of them essentially they just walk away. So it is a complicated issue. It certainly is helpful. I certainly would not want to say no, it would not be helpful, but I think we have to look at some of these other barriers that are contributing to that not being as helpful as it should be.

Senator SESSIONS. Thank you very much.

Ms. CHAMPION, I know you and I talked one time about the school and IDEA Individuals with Disabilities Education Act. Most schools are supposed to be able to provide appropriate care for children with any disability, and they heroically try really. But if you made a decision that there was a private center that your child would be particularly benefited by going to instead of going to school, and you decided you were prepared to fund that yourself, would you get any reimbursement from the system at all for that today, even though it would relieve a financial burden on the school system if you had sent the child to the school?

Ms. CHAMPION. I would probably need to work very aggressively with the school system in accessing services through an IEP, and quite frankly, would more than likely involve some litigation on the part of trying to do that. I think some come full circle in thinking that schools have been given quite a bad rap in trying to provide services for children that they consider seriously emotionally disturbed, and I think more often that advocacy groups and family networks need to reach out to school systems and provide a better relationship with them, to go in and actually assist them in providing a safe environment within the school system or an alternate environment that is going to the school system instead of parents going in and being very contentious in trying to access services for their children.

I would say that in our State, I think that is beginning to happen. Certainly with the school officials that we have had an opportunity to talk with recently, they know that they cannot handle this age, this population on their own and that it is not going away. By just putting them into alternative schools or boot camps, they are still coming back into the system with the same issues, and they need to look at alternative ways in approaching it.

NAMI has a very wonderful program called Parents and Teachers as Allies that certainly needs to be looked at in every school system, but I think that particularly in our State we are going to try to reach across that bridge to school officials and work more effectively with them, and quite frankly, it is going to take a culture change.

Senator SESSIONS. I know you have been a leader in that, and I thank you for it and the advice you have given me on it.

I think making it easier, Mr. Chairman, that a person could use just a small amount of the money the school system would have used for care for this child, plus their own. They may have an opportunity to make a decision that could provide really special care for a child, and it is pretty inflexible as it is today. I think we can do better on that.

Thank you very much, and thank you for your leadership.

Senator DEWINE. Thank you, Senator Sessions.

This has been a great panel. Thank you very much. We appreciate all of you being here, sharing your experiences with us. We intend to move forward. This subcommittee has two bills that we have introduced. Senator Reed and I have introduced one. Senator Dodd and I have introduced another bill. We hope to move forward on this legislation. We also have taken from you some very specific, several specific recommendations which we would hope in the future to be able to move forward on. So this has been a very productive meeting. Thank you very much.

[Additional material follows.]

ADDITIONAL MATERIAL

THE KEEPING FAMILIES TOGETHER ACT (S. 1704)

Each year, thousands of parents are forced to relinquish their custody rights to the State in order to obtain mental health care for their seriously ill children. Services to treat severe mental disorders in children can be extremely expensive and private insurance tends to run out after a few months, leaving even middle class parents unable to afford the cost. Yet affected children often remain ineligible for Medicaid because their parents' income and assets keep them from qualifying for assistance. With no other way to get their treatment for their children, parents are forced to choose between custody or care. The GAO reported in April that, in 2001, parents in 19 States placed 12,700 children in State welfare or juvenile justice agencies in order to obtain mental health services for them. Moreover, that estimate is considered low, because 31 States did not respond to the survey.

The Keeping Families Together Act seeks to keep these children with their families and includes three main components:

FAMILY SUPPORT GRANTS TO STATES

Authorizes $55 million in competitive grants to States that would be payable over 6 years to create an infrastructure to support and sustain statewide systems of care to serve children who are in custody or at risk of entering custody of the State for the purpose of receiving mental health services. These grants are intended to help States serve these children more effectively and efficiently, while keeping them at home with their families.

The Family Support Grants could be used to:

- Foster inter agency cooperation and cross-system financing among the various State agencies with responsibilities for serving children with mental health needs. This will help to eliminate fragmentation of services and will increase the capacity of agencies to share public resources. States already dedicate significant dollars to serving children in State custody, and this will enable them to use those resources more effectively, while still allowing children to remain with their families;
- Provide a comprehensive array of community-based mental health and family support services for eligible children and their families that will be sustainable after the grant has expired;
- Facilitate the design of a State plan through a collaborative process involving State child-serving agencies, parents, providers, and other stakeholders;
- Provide outreach and public education programs to increase awareness about the services that are available to eligible children and their families;
- Carry out administrative functions related to the programs and activities carried out under the grant, including the development and maintenance of data systems.

Requires States to provide matching funds over the 6-year period of the program, ultimately equaling not less than $2 for each $1 of Federal funds provided under the grant. States would also be required to report annually, beginning with the second fiscal year in which a State receives funding under a grant, on the progress and success of the programs and activities carried out by the State under the grant. Not later than 3 years after the date of enactment, and after the full 6 years of the grant, a report to Congress is required evaluating the success of States in using the grants to eliminate the problem of custody relinquishment.

FEDERAL INTERAGENCY TASK FORCE

Requires the Administrator of the Substance Abuse and Mental Health Services Administration, acting in conjunction with the Director of the Office of Juvenile Justice and Delinquency Prevention, the Administrator of the Administration for Children and Families, the Administrator of the Centers for Medicare&Medicaid Services, and the Assistant Secretary of Education for Special Education, to establish a Federal interagency task force to examine mental health issues in the child welfare and juvenile justice systems and the role of their agencies in promoting access by children and youth to needed mental health services. The task force would also be charged with monitoring the family support grants, making recommendations to Congress on how to improve mental health services, and fostering interagency cooperation and removing interagency barriers that contribute to the problem of custody relinquishment.

ALLOWS STATES TO USE THE MEDICAID HOME- AND COMMUNITY-BASED WAIVER TO TREAT CHILDREN WITH MENTAL ILLNESS IN LESS RESTRICTIVE SETTINGS

Modernizes a critical Medicaid State waiver program by making children and adolescents in residential treatment facilities, like those in hospitals, eligible for home- or community-based services under Medicaid, providing that the cost is no higher than that of institutional care.

PREPARED STATMENT OF THE AMERICAN ACADEMY OF CHILD AND ADOLESCENT PSYCHIATRY

Introduction

The American Academy of Child and Adolescent Psychiatry (AACAP) is a medical membership association established by child and adolescent psychiatrists in 1953. Now over 6,900 members strong, the AACAP is the leading national medical association dedicated to treating and improving the quality of life for the estimated 7–12 million American youth under 18 years of age who are affected by emotional, behavioral, developmental and mental disorders. AACAP supports research, continuing medical education and access to quality care. Child and adolescent psychiatrists are the only medical specialty fully trained in the treatment of mental illness in children and adolescence.

The AACAP thanks Substance and Mental Health Services Subcommittee chairman, Sen. Mike DeWine (R-OH) for holding this important hearing, and we applaud his continued commitment to increasing access to treatment for children and adolescents with mental illnesses.

The Surgeon General's 2000 report on children's mental health estimated that 20 percent of American children and adolescents have a diagnosable mental or emotional illness. Of this number, fewer than one in five receive treatment. Barriers to treatment include a lack of affordability, lack of availability of specialists, including child and adolescent psychiatrists, and stigma. Anxiety disorders, ADHD, and depression are the most common mental illnesses occurring in children and adolescents.

Early Intervention

The barriers to early identification and treatment are the critical areas of focus for children and adolescents with mental illnesses. Five studies funded by NIMH have consistently identified under-recognition of mental illnesses as a major problem. Missed opportunities, because of under-identification or no opportunity for identification, translates into losing the option of early intervention. For children and adolescents, an early diagnosis and adequate treatment may limit the severity of a life-time disorder or minimize a less severe disorder. After the option of early intervention is lost, the chain of life-time devastation from mental illness looms ahead: school failure, family crises, substance abuse, entrance into the juvenile justice system, more and more costly interventions, and on into adulthood. The President's New Freedom Commission on Mental Health listed the expansion of early intervention services for children and adolescents with mental illnesses as one of its main recommendations in its final report, Achieving the Promise: Transforming Mental Health Care in America. In the report, the Commission states, " If the system does not appropriately screen and treat them early, these childhood disorders may persist and lead to a downward spiral of school failure, poor employment opportunities, and poverty in adulthood. No other illnesses damage so many children so seriously." The increased availability and affordability of treatment will enable earlier identification and interventions for children and adolescents with mental illnesses.

Coverage

Today, approximately 85 percent of all privately insured families, and a growing number of those covered by Medicaid, are in a managed health care plan. Children are being enrolled in managed care plans at a higher rate than adults and represent a disproportionately larger number of managed care members. The current efforts to contain costs increase the risk of compromises in the quality of care for a population that is still growing.

One of the key barriers to treatment for children and adolescents with mental illness is a lack of parity in insurance coverage for mental illness. Discriminatory coverage, including limiting the number of inpatient and outpatient visits, and higher copays and deductibles for children and adolescents, is uniquely counterproductive. Reducing treatment options contributes to missed school days, involvement with the juvenile justice system or even suicide attempts. Too often, a misperception of the cost of mental health coverage prevents access to care, but the Congressional Budg-

et Office (CBO) estimates that managed nondiscriminatory mental health benefits will increase average premiums by less than 1 percent the cost of the average benefit. The cost offset of not treating a child with a mental illness will prove to be much more expensive in the future.

Due to the risk-adjustment strategies to protect the financial interests of managed care organizations, there is little incentive in a managed care system to offer parity for services for children with the most serious disorders. These children tend to be high service utilizers and are often involved in multiple agencies. They pose a challenge to managed care systems because they require services at various levels of intensity for extended periods of time. These children are then left underserved, resulting in shifting the responsibilities for care to other systems such as special education, child welfare or juvenile justice. Co-pays for children and adolescents should not only reflect parity but should be set so moderately that families seek early intervention, evaluation and treatment for mental and physical illnesses without the fear of financial disaster. With early intervention and treatment, children will live healthier, productive lives into adulthood. When managed care systems deny coverage to children and adolescents, an expedited appeals process should be in place to resolve denials.

Coverage that Meets Developmental Needs

Children and adolescents are too often treated according to adult standards. They are not little adults and need age-appropriate treatment coverage that respects developmental needs. Accurate comprehensive evaluations are more time consuming for children and adolescents. This is recognized in the *CPT* manuals for interactive psychotherapy. Health care plans should not limit the assessment of all levels of neurological and behavioral development. There are current pressures for child and adolescent psychiatrists to prescribe medication without a full evaluation, which is not good medicine or an efficient use of resources.

Most managed care systems for behavioral health have been designed without input from a child and adolescent psychiatrist or family members of children with serious emotional disorders. Most do not understand the importance of strong links among the treatment, home, and community environment. Services that support a system of care for a child's treatment plan should not be denied automatically if they fall outside the inpatient or outpatient benefit or be discriminated against because the benefit is for a mental illness. Children and adolescents with serious emotional disorders and their families need many kinds of services from a variety of sources, such as schools, community mental health centers, and social service organizations. Many managed care systems are not yet coordinating these services that children with serious emotional disorders and their families need, and, too often, when the services are implemented, the coverage for their use is denied and only partially covered.

Coverage, with parity, should include a full continuum of treatment—including, but not limited to, preventive interventions, early identification, assessment and diagnosis, case management, outpatient treatment, partial hospitalization, home-based services, detoxification and inpatient treatment. Treatment for children and adolescents requires that services involve the child or adolescent and family as well as appropriate collaboration with other significant caregivers, teachers, physicians or providers of other needed services.

Access

The health system's denial of access to specialists, such as child and adolescent psychiatrists for mental illnesses is a major concern. Children and adolescents should have access to all providers in the plan, with direct access to specialists with training in treating the disorders of childhood and adolescence. Child and adolescent psychiatrists are physicians specifically trained to treat children and adolescents with mental illnesses. The denial of access to such specialists can result in inadequate diagnosis and treatment of the illness and delayed treatment.

Often children and adolescents are faced with discriminatory coverage combined with their physicians being eliminated from the provider networks. Continuity of care between a child and adolescent psychiatrist and his/her patient is crucial to the well being of the child. Trust between a doctor and patient is critical, and the relationship between a child or adolescent and his/her psychiatrist must not be compromised. When a child or adolescent is suddenly required to change therapists, the trust and confidence that child depends on is undermined, damaging the outcome of the treatment and of future treatments.

Systems of Care

Currently, most State mental health, education, juvenile justice, social service and child welfare agencies do not provide coordinated treatment for children and adoles-

cents with mental illnesses; although, a number of federal laws and programs, including Medicaid and the Individuals with Disabilities Education Act (IDEA) mandate comprehensive coverage for low-income children, children in the child welfare system and children with disabilities, including children with serious emotional disorders. Differing eligibility criteria for services and a lack of State mandates or funding streams contribute to fragmentation of State service systems. This lack of coordination across State service systems, coupled with the lack of parity in the insurance system, has forced many families to consider the unthinkable—giving up custody of their children to State child welfare or juvenile justice agencies in order to access treatment for their children.

No services should be denied that support a system of care for a child's treatment plan. Children and adolescents should have direct access to the services that support them and their families. A serious emotional disturbance touches every part of a child's life. Therefore, children and adolescents with serious emotional disturbances and their families need many kinds of services from a variety of sources, such as schools, community mental health centers, and social service organizations.

Studies suggest that effective systems of care:

- reduce the need for hospital and out-of-home residential treatment placements;
- improve how children behave and function emotionally;
- improve school performance;
- reduce juvenile involvement with the justice system; and
- provide services to more children and families who need them.

Model Systems of Care Program

The Substance Abuse and Mental Health Administration's (SAMHSA) Comprehensive Community Mental Health Services for Children and Their Families program is a model systems of care program for States. The program is a discretionary grant and contract program that supports the development of intensive community-based services for children and their families based on a multi-agency, multi-disciplinary approach involving the public and private sectors. Recent evaluation data found notable improvements for children after 1 year of services in the following areas: reduced law enforcement contact, improved school attendance and academic performance, and improved emotional and behavioral problems. The program currently funds 67 programs in 43 States and services a total of 46, 633 children and adolescents with serious emotional disorders. The AACAP recommends an increased appropriation for the SAMHSA's Children's Mental Health Services Program so that it may be expanded to serve all States.

Medicaid Access

The Medicaid program provides low-income families with comprehensive health care. Medicaid's Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) program mandates that all children eligible for Medicaid receive comprehensive mental health treatment. Despite this mandate, full implementation in all States has not occurred, leaving many eligible children without access to the comprehensive care they are entitled to by law. This is due to a lack of parity for mental illnesses in State Medicaid systems, differing State eligibility criteria and regulations, and a lack of coordination between service systems. Allowing middle-income families of children with mental illnesses to buy-in to the Medicaid program, for example through the Katie Becket waiver currently available in the States of Kansas, New York and Vermont, provides access to intensive treatment services such as residential treatment centers for these families that they would otherwise not be able to afford. Increased access to Medicaid coverage for middle-income families and low-income families who are ineligible for Medicaid because of family assets such as ownership of a home, would remove one of the barriers to treatment for these children and their families. The AACAP recommends passage of the Dylan Lee James Act, S. 622 and H.R. 1822, to allow families of children with serious emotional disorders to buy into the Medicaid program.

Shortage of Children's Mental Health Professionals

A final barrier to treatment for children and adolescents with mental illnesses is the lack of available specialists trained in the diagnosis and treatment of these disorders. In particular, there is a critical national shortage of child and adolescent psychiatrists. There are about 7,000 child and adolescent psychiatrists nationwide while the prevalence rate for children and adolescents with mental illnesses is between 10 and 15 million. Data on this professional shortage comes from several sources including the Surgeon General, the President's New Freedom Commission on Mental Health, the Council on Graduate Medical Education (COGME), a committee of the Department of Health and Human Services and the Bureau of Health Professions. The Abt Associates report for COGME concluded that by 1990, the Nation

should have over 33,000 child and adolescent psychiatrists. The Bureau of Health Professions projected that between 1995 and 2020, the use of child and adolescent psychiatrists will increase by 100 percent, with general psychiatry's increase at 19 percent. An increase in the numbers of all children's mental health professionals can help reduce one of the barriers to treatment for the families of children with mental illnesses. The AACAP recommends congressional action in this effort, including passage of the Child Healthcare Crisis Relief Act, S. 1223 and H.R. 1359, which would encourage individuals to enter all children's mental health professions through the creation of education incentives.

Conclusion

Children and adolescents in America, regardless of their family income level, should have access to psychiatric treatment, which should be provided on a non-discriminatory basis integrated with other necessary medical services. Services should include a full continuum of treatment—including, but not limited to, preventive interventions, early identification, assessment and diagnosis, case management, outpatient treatment, partial hospitalization, home-based services, detoxification and inpatient treatment. Treatment for children requires that services involve both the child or adolescent, and family as well as appropriate collaboration with other significant caregivers, teachers, physicians or providers of other needed services.

Summary of Legislative Recommendations:

• Enactment of the Paul Wellstone Mental Health Parity Act, S. 486 and H.R. 953, sponsored by Sen. Domenici (R-NM) and Kennedy (D-MA), and Reps. Kennedy (D-RI) and Ramstad (R-MN).

• An appropriation of $140 million for SAMHSA's Comprehensive Community Mental Health Services for Children and Their Families program.

• Enactment of the Keeping Families Together Act, H.R. 3309 and S. 1704.

• Enactment of the Dylan Lee James Act, S. 622 and H.R. 1822, sponsored by Sens. Grassley (R-IA) and Kennedy (D-MA), and Reps. Sessions (R-TX) and Waxman (D-CA).

• Enactment of the Child Healthcare Crisis Relief Act, S. 1223 and H.R. 1359, sponsored by Sens. Bingaman (D-NM) and Collins (R-ME) and Reps. Kennedy (D-RI) and Ros-Lehtinen (R-FL).

The AACAP appreciates this opportunity to submit a statement for the record on issues throughout the developmental process for children and adolescents with mental illnesses.

Attachment: Health Care System Leaves Mentally Ill Children Behind. Boston Globe, March 26, 2004.http://www.boston.com/news/globe/health_science/articles/2004/04/27/health_care_ststem_leaves_mentally_ill_children_behind/

boston.com

PEDIATRIC PERSPECTIVE

The Boston Globe

Health care system leaves mentally ill children behind

By Dr. Darshak Sanghavi | April 27, 2004

British and American regulators recently warned doctors about prescribing certain antidepressants to children. Though these actions earned headlines, the publicity was misplaced.

The extra probability that some antidepressants could drive kids to suicidal behavior – while concerning – is only about 1 percent. And the discussion ignores a bigger problem: Our medical system is profoundly biased against young people with mental illness.

A case in point: A teenager was admitted to a community hospital with sudden chest pain. After evaluation, including stress tests and cardiac ultrasounds, his doctors were baffled. Though the tests were normal, the teenager had crushing pain. Perhaps he had some coronary abnormality, his doctors wondered. They transferred him to my hospital's cardiac unit.

The testing was repeated, but was still normal. One day, he suddenly collapsed with chest pain. Luckily, a senior cardiologist was present and rushed to his aid. He astutely noticed that the teenager was hyperventilating, which suggested something other than a heart problem. It turned out, he was having anxiety attacks.

What happened next shows how psychiatric illness gets neglected. His hospitalization had already cost thousands of dollars. If he had a coronary problem, the additional surgery could cost his insurance company up to $50,000. No claims adjuster would call us to bicker about the diagnosis. After all, he would have a serious condition requiring specialized treatment.

Instead, because he lacked a "biologically-based" illness – more on this later – the teenager entered a parallel medical universe with its own laws.

Today, most insurers outsource, or "carve-out," mental health services, often to for-profit companies who strictly ration inpatient and outpatient care. In some cases, outsourcing can

provide much-needed expertise, when funded well and not driven solely by profit. In North Carolina, an independent, nonprofit carve-out of mental health centers dramatically improved youth mental health services; however, costs tripled. More often, HMOs and state Medicaid programs hire for-profit firms not to expand care, but to cut costs.

According to the Hay Group, an accounting firm, spending by large corporations on mental health care dropped by 55 percent from 1988 to 1998 largely due to cuts made by carve-outs, while the companies' other health-care spending dropped only 12 percent over the same period.

Carve-outs save money in part by making it harder for children to get psychiatric care. In recent studies in Tennessee and Arizona, for example, half of all children diagnosed with mental illness received no services from for-profit carve-outs.

When I called the teenager's family three months after his discharge, they still hadn't been able to see a psychiatrist even though he was unable to attend school regularly.

Mental health providers feel the pressure. Few claim reviewers interfere with the patient care in the cardiac intensive-care unit.

Yet doctors at my hospital's psychiatric ward often get calls questioning why their patients are still in the hospital. Once the child gets discharged, their outpatient therapists are buried in arcane paperwork.

When David DeMaso, a senior psychiatrist at my hospital, made a single change on a claim form -- a patient's "global assessment of function" went from 70 to 68 out of 100 -- therapy was suddenly approved. With personalized care rationed so arbitrarily, it's no wonder many kids just get prescribed drugs like Prozac.

As outpatient care worsens, children suffer. In Worcester, for example, pediatric visits for psychiatric emergencies increased 30 percent over the course of six months in 2001.

In a 2003 study at Children's Hospital, one-third of the children with psychiatric problems were initially admitted to the general medical ward because no psychiatric beds were available. In 2000, one child in our hospital waited 51 days for a psychiatric bed where he could get more focused care. Without adequate funding of mental health, there's little incentive to improve the supply of both outpatient and inpatient care.

Unfortunately, when state legislatures tried to soften the blow of cuts, they created more confusion. They created a misleading distinction between "biologically-based" mental conditions -- which get full coverage -- and other mental disorders, which are presumably all in a person's head and get limited coverage.

But this bogus difference between "real" and "unreal" mental problems now frames public policy disputes.

In 2000, Massachusetts passed the Mental Health Parity Law, which guarantees coverage (and continues to allow carve-outs) for roughly 10 "biologically-based" mental illnesses, including schizophrenia, major depression, and obsessive-compulsive disorder. This was good for many patients who lacked any guarantees of coverage. But it excluded eating disorders, drug addiction, and others conditions determined not to be "biologically-based."

This makes little sense. First, despite pseudoscientific terms like "chemical imbalance," nobody really knows what causes mental illness. There's no blood test or brain scan for major depression. No geneticist can diagnose schizophrenia.

Second, illness severity doesn't correlate with being "biologically-based." Shockingly, one in 10 anorexics dies from the disease, but anorexics still don't get equal treatment. Finally, if you try hard enough, you can find a "biological basis" for any behavior; for example, having a Y-chromosome predicts whether a teenager likes pro wrestling.

The more one tries to understand the distinction, the more it seems designed to exclude people in need. Still, advocates work within the bounds; Boston-based Health Law Advocates is campaigning now to get eating disorders on the "biologically-based" list.

Regardless of the vocabulary applied to them, children like the teenager I treated need care and not excuses. They have conditions every bit as disabling as coronary problems -- and they deserve not to be targets of cost-cutting.

Dr. Darshak Sanghavi is a clinical fellow at Harvard Medical School. His e-mail address is sanghavi@post.harvard.edu. ■

© Copyright 2004 The New York Times Company

PREPARED STATEMENT OF MICHAEL FAENZA

Mr. Chairman and Members of the Subcommittee: The National Mental Health Association (NMHA) is the country's oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. In partnership with our network of 340 State and local Mental Health Association affiliates nationwide, NMHA works to improve policies, understanding, and services for individuals with mental illness and substance abuse disorders, as well as for all Americans. Established in 1909 by a mental health consumer, NMHA's philosophy has consistently been that the needs of consumers and communities must be at the center of all policy and practice concerns in the mental health field.

We applaud the careful work this committee is undertaking in studying the many facets of mental health in this country. The subject of your hearing today is critically important because **children are falling through the cracks of our "mental health system," and those cracks are widening**. We welcome your focus.

As a society, we attach a high value to children's well-being. Yet our country is failing children and adolescents by not addressing or treating their mental and emotional health. We are failing because we are not addressing the issues that keep

children and adolescents from receiving appropriate care: these include the limited access to treatment and services; the fragmentation of services; the lack of investment in prevention; the shortage of providers with sufficient expertise; stigma of mental illness; and the failure to engage families and children in mental health and substance abuse prevention and treatment efforts. Sadly, even the limited research information we possess about children's mental health is not being translated into clinical practice. If we do not change this trajectory, we will continue to foster a cycle of emotional and behavioral problems for our children resulting in school failure, substance abuse, violence, imprisonment, and most tragically, wasted lives that could have been changed.

"Symptoms" Compromising Quality of Care

While there are many serious problems in the mental health system that cross the age span, a **unique set of "symptoms" too often compromise the quality of children's mental heath care.** They include:

• Requiring diagnosis prior to treatment. As noted by the U.S. Surgeon General, due to the ongoing physical, emotional, and cognitive development of children, it can be difficult to accurately diagnose mental disorders. Premature or inaccurate diagnosis can result in inappropriate treatment and labeling. In addition, a key aim of children's mental health should be to address mental health problems before they progress into conditions that meet the diagnostic criteria for a mental disorder. Unfortunately, both public and private financing mechanisms tend to require that a child be diagnosed prior to receiving treatment.

• Treating only "ED children." Many public systems require not only that a child have a diagnosis, but that the child meet the diagnostic, durational, and functional requirements set by the State/county for a "serious emotional disturbance." In other words, systems purposely avoid treating children until their condition reaches a point where functioning is severely impaired.

• Lack of child- and family-centered services. When children's mental health needs are addressed at all, the system for serving them is often treated as an extension of the adult system, and as a result truly child- and family-focused service planning and delivery is in short supply. In many cases, children with mental disorders are not served at all by the mental health system, but end up instead in other systems, such as juvenile justice.

• Shortage of practitioners specifically trained in children's mental health.

• Too many children inappropriately placed in the juvenile justice and child welfare systems due to lack of MH services for children and families. Some families are even forced to relinquish custody to these systems just to get MH services for their children. Increasing numbers of children with emotional or behavioral disorders are entering the juvenile justice system. Researchers estimate that between 50–75 percent of youth in the juvenile justice system have diagnosable mental health disorders; one in five has a serious emotional disorder (ED). Correctional systems are simply not designed to provide mental health services and are ill equipped to meet and often even recognize the mental health needs of children.

• Lack of prevention and early intervention.

This committee, in its oversight capacity and as an architect of SAMHSA reauthorization legislation, has an opportunity to address these problems, and make children's mental health and well-being the priority it must be. **We urge the Committee to make the needs of America's children and youth with, or at risk of, mental disorders a major focus of SAMHSA's authorizing legislation**. We recommend that you develop legislation that places major emphasis on high-quality community-based mental health treatment services and prevention (to include screening, preventive services and early intervention) of mental disorders in children and youth.

Core Principles:

We believe the following core principles should shape the development of that needed policy direction:

(1.) The promotion of good mental health, prevention and treatment for children and youth with mental disorders is the responsibility of every family, school, social service agency including child welfare, law enforcement, and juvenile justice system.

(2.) Effective mental health services for young people are based and administered in the communities where children and families live.

(3.) Parents, siblings and other caretakers are central to the treatment of children with mental disorders, and should be seen as critical partners and participants in every child or youth receiving treatment.

(4.) In addition to specific centers or agencies that need to be developed and funded to deliver community-based services for children and youth with mental health needs, organizations that serve children and families—including child welfare, juve-

nile justice and schools—need adequate resources to screen and identify children and youth at risk of increased mental health challenges.

(5.) Schools, child welfare agencies, and juvenile justice systems need to provide preventive mental health services, identify and provide basic services for children and youth who are screened and known to have mental disorders, and work collaboratively with other community organizations to ensure good outcomes for each child.

(6.) Many youth with mental disorders also have substance abuse problems, and substance abuse prevention and treatment should work in an integrated fashion with children and youth, not separately, for good outcomes for children.

(7.) Children and youth are often the most adversely affected individuals regarding the experience of living through any disaster, witnessing or being exposed to violence, loss of family members, living in poverty, having poorly met physical health care needs, and experiencing acute medical problems. Community organizations that address these issues need the resources to identify the mental health needs of children and youth and ensure that appropriate treatment is accessed.

Policy recommendations:

Building on those principles, we urge that a SAMHSA reauthorization bill, and this committee's oversight of SAMHSA, address the following:

(1.) SAMHSA leadership must address the reality that mental health services and preventive programs for children and adolescents are scarce in number and poor in quality; given the magnitude of the need, the situation could aptly be termed a national crisis.

(2.) Mental health services and prevention programs targeting the needs of vulnerable children and families should be near the top of SAMHSA's goals and investments in community.

(3.) Federal agencies including the Department of Education, Office of Juvenile Justice and Delinquency Prevention, Maternal and Child Health and other URSA programs, CDC, NIGH and Homeland Security should all be linked formally and with clear charges to SAMHSA. SAMHSA needs support and direction to move much more vigorously towards collaborative planning and pooled resources with other Federal agencies to meet the challenges to the mental health of children across the United States.

(4.) Prevention resources within CMHS need to be greatly expanded, and should be a public health cornerstone of the agency.

(5.) A fourth SAMHSA center that focuses on the promotion of mental health and the prevention of mental disorders in children and youth, as well as the risks and solutions for adults, is needed.

(6.) The Children's Mental Health Services Grant program (hereinafter the "Systems of Care" program) within the Center for Mental Health Services should have greater flexibility to meet the needs of youth. We urge that you revisit eligibility rules that limit program access to youth who meet the criterion of having a "serious emotional disturbance," and, as a result, too-frequently deny needed services until a youngster's condition deteriorates.

(7.) The needs of children in communities who are at risk because of traumatic events or disaster argue for a robust new Grant program within SAMHSA.

(8.) A new Grant program to support community-based planning would help move many more communities toward developing needed systems of care.

The National Mental Health Association looks forward to working with this Committee to make its vision for meeting the special needs of children a reality for tomorrow.

STATEMENT OF SUSAN MIKOLIC, PARENT & ADVOCATE

Chairman DeWine and members of the Committee, I am Susan Mikolic of Lake County, Ohio. I have two children with mental illness. My oldest son, now 16, has been ill since age 5. His challenges include Bipolar Disorder, Attention Deficit Disorder, Oppositional Defiance Disorder, Post-Traumatic Stress Disorder, multiple medical problems, and several learning disabilities. My youngest son, now 14, has been ill since age 6. His challenges include Bipolar Disorder, Attention Deficit Disorder, Anxiety Disorder, multiple medical problems, and several learning disabilities.

I am a registered nurse by education and experience. I have, however, out of necessity, devoted the last 6 years to mental health advocacy. Today I present to you as a very concerned parent and citizen. It wasn't long after my children were diagnosed and I attempted to access services that it became clear to me that a large portion of the services my children needed didn't exist, or if they did exist, were either of poor quality, ineffective, inaccessible, or cost prohibitive. I rolled up my sleeves and got involved in an attempt to make the system better for my children

and all others to walk in their footsteps. I served as President of National Alliance for the Mentally III (NAMI) Lake County, member of the NAMI Ohio Board of Directors, Co-chair of the NAMI Ohio Children's Committee, co-chair of the Ohio Department of Mental Health Children's Division Strategic School Success Committee, co-chair of the Professional Development work group of the "Mental Health, Schools, and Families Working Together Toward a Shared Agenda" Initiative, and countless other task forces, committees, work groups, panels, and advisory groups. Due to the extent of my involvement, visibility, and expertise I have become an established advocate for childhood mental health issues, assisting families around the entire State as they attempt to secure needed services for their children.

I mention all this to provide a framework for your interpretation of my testimony as I will not only relate my personal family experience, but will also reflect those of struggling families all around the State of Ohio. I will focus my comments primarily in the area of middle-income families as this is my area of expertise and experience.

I stated earlier that it became clear that the services my children needed were either non-existent, poor quality, ineffective, inaccessible, or cost prohibitive. I will expand.

1. High quality, effective, accessible, and affordable psychiatric care—My children, and all these children, need high quality, effective, accessible, and affordable psychiatric care for our children.

As you know, there is a critical shortage of Child Psychiatrists. I am blessed to live in Cleveland, a medical hub in the State of Ohio. We have a large number of Child Psychiatrists, yet waiting lists remain at 3 months for an initial appointment, with many practices closed to new patients. We are blessed. There are areas around the State and nation that have few, if any, Child Psychiatrists. I see the initiative to stem this gap with use of Pediatricians. This practice concerns me. As a healthcare professional, it is clear to me that in this information age one cannot know all there is to know in multiple specialties. Many pediatricians have a special interest in Attention Deficit (Hyperactivity) Disorder (ADD/ADHD), for example, and diagnose and treat the child for ADHD with stimulants. Because they rarely are well versed in the entire field of Child Psychiatry, they often miss comorbidities, as well as exacerbate other undiagnosed illness by medication management. Specifically, I refer to the use of stimulants and antidepressants, the use of which can unmask an underlying Bipolar Disorder. Children are given stimulants for ADHD, and antidepressants for Depression, Anxiety Disorder, and Obsessive-Compulsive Disorder, and often no one is watching for a potentially emerging mania. Both of my children were originally treated with antidepressants and mood stabilizers for depression, anxiety, and ADHD, and both were triggered into mania. Had they not been under the care of a Child Psychiatrist I believe the mania would have been identified as the "impulsiveness" of ADHD and they would not have been appropriately diagnosed and treated until some time later when untold health and social damage would have taken place.

I will relate a personal experience where such a thing happened even with the oversight of a Child Psychiatrist. My youngest son was diagnosed with Bipolar Disorder. His Psychiatrist eliminated pediatrics from her practice. It was too time-consuming. It was better for her economically to only treat adults who didn't need interaction with school systems, etc. We changed care to another local Child Psychiatrist. He did not concur with the Bipolar Diagnosis and promptly took my son off his mood stabilizer, remaining on antidepressants and a stimulant. My son went into a manic mood swing shortly thereafter. He was walking on the roof on one foot, was extremely activated, etc. When notified that my son was walking on the roof the Psychiatrist responded, "Is that dangerous?", saying my son was getting more impulsive and increased his stimulant dose. Eventually he ended up on triple the recommended dosage when I sought a 2nd opinion, where the Psychiatrist looked at his mood charts and promptly concurred that he indeed had Bipolar Disorder. If I did not know what mania looked like, from having experienced with my other child, the mania would have continued unchecked, indeed, exacerbated, by his medication management.

I hear stories like this all around the State. It is my personal opinion that these children's illnesses need to be managed by a psychiatric specialist.

Now, one decides their child needs to see a Child Psychiatrist. They must next determine if that Psychiatrist is a provider on their insurance panel. Most are not on all panels and now the family finds that the pool of Child Psychiatrists available shrinks by perhaps 50 percent or more. Then the family calls to make an appointment with the Psychiatrist only to BE scheduled 3 months out even though their child is in crisis. One is then guided in the meantime to go to the Emergency Room for any crisis situations. This is not a helpful option. The staff in most Emergency

Rooms are not adequately trained to assist with this population. If indeed the child is admitted to a psychiatric hospital based on the Emergency Room visit, which only occurs if the child is actively homicidal or suicidal, the child only stays 3–5 days and is discharged with poor follow-up care. Essentially hospitalizations are non-productive in terms of helping stabilize a child.

In this area of discussion I will relate two personal experiences to highlight some of today's realities.

We have a family history of 5 suicides. I took my son to the Emergency Room hoping to have him hospitalized for his safety. He was not admitted because he was not suicidal "enough" I ask you, if you had a significant family history of suicide, your child has a personal 10 year history of profound depression and suicidality, and is now actively suicidal, would you feel that suicidality is so measurable that one's suicide risk could be nonchalantly dismissed?

I now relate another example of how Emergency Room care may be used. My son's illness was increasingly unstable. At one point he refused an appointment with his Psychiatrist due to this instability and limited energy to make the trip to the physician's office. His illness continued to escalate. I called his attending Child Psychiatrist asking for an urgent appointment, a med change over the phone, or some guidance. His Psychiatrist told me to take him to the Emergency Room. I said that would do no good as he was not suicidal or homicidal. She said, "Yes, I know, but maybe if he waits in the Emergency Room for 4 or 6 hours he will think twice about canceling an appointment with me." My, what a cost-effective, compassionate, and humane approach to a cry for help. We changed Psychiatrists.

Now, in the area of changing Psychiatrists I would like to address an increasingly common complication. The parent who carries the family health insurance changes jobs or the employer changes carriers, and, the child's established Child Psychiatrist is not a provider on the new insurance panel. One must then choose if they will self-pay or put their child through the distress and care lag inherent in relaying history and trying treatments already attempted, once again. In addition, changing Psychiatrists is not equivalent to changing orthopedists or pulmonologists. One has to build a relationship with the Psychiatrist to trust them enough to share troubling symptoms. Changes in the treatment team create excessive and unnecessary distress as well as treatment delays as the new physician learns the patient.

2. Financial Burdens—Let's talk cost. If you stay with the child's current Psychiatrist on a self-pay basis, you will pay $65–$150/hour. Also, virtually all insurance plans limit the number of appointments per year that are covered for psychiatric care. If your child has a typical care schedule they will see the Psychiatrist once per month, and their therapist once per week. This totals 64 appointments per year, of which greater than 2/3 will be self-paid by the family. And if they self-pay for an out of network psychiatrist that cost increases. At one time our family paid $500/week out of pocket for psychiatric care. Historically, for the last 11 years, our family has spent $20,000–$25,000/year out of pocket on medical expenses. My husband and I are college educated, professional people, earning good wages, but a family cannot sustain bills like this on an ongoing basis. We took 3 home equity loans against our home and eventually could no longer afford all the loan payments. Last fall we sold our home.

If my child had leukemia, we would not have lost our home, we would not be broke. The lack of insurance parity creates an unconscionable, unnecessary burden on families. It is truly a present day discrimination as clear as lack of voting rights for women or the historical discriminatory practices against minority populations. I read somewhere a great analogy regarding this practice. I do not recall where I read it and therefore cannot credit the author, but the author noted that the illness of Parkinson's Disease is thought to be related to a deficit in the neurotransmitter Dopamine and that Schizophrenia is associated with abnormally high levels of dopamine. Yet Parkinson's Disease is well covered under insurance plans and Schizophrenia is not. The author suggests that this practice is as ludicrous as insuring the right leg but not the left. This practice is plain and simple, unadulterated discrimination and this country should be outraged at the discriminatory nature of this practice.

But they aren't . . . and why not? I believe insurance parity has not been achieved yet, in large part, due to misunderstandings and stigma about mental illness. In our old neighborhood the children were forbidden to play with my children because of their illness. This was a professional, educated community. But they were afraid, out of a lack of knowledge. They assumed mentally ill children were violent children. For 10 years my children had no friends. The families would not even acknowledge us if we said hello. We have to do better than this for our children. We recently moved when we had to sell our home. My son is trying to make friends in his new environment, which has truly been a blessing in this one sense.

He said to me last night, "Mom, I can't be myself. I want friends and if I act myself I won't make any friends. Do you have any idea what it was like to not have any friends for 10 years. I don't want that again . . . so I pretend to be someone else with them."

The need for friends and to fit and to be accepted is at it's strongest in the school environment. The children use what little coping energy they have to try to fit in and be accepted. This leaves little reserves to devote to education.

3. Educational Issues—School related issues are the number one reason families call me for assistance. They are in tears, desperate to find help. The biggest common denominator in this struggle has been the lack of knowledge about mental illness among the school staff interacting with our children as well as ingrained judgments about children with mental illness. We, as most all parents of mentally ill children, have been told that our child was just being lazy, refusing to do work. Yes, on the most surface level this would be the observation. But our children's struggles are much more complex than that superficial assessment. My children are coping with extreme emotion swings, concentration problems, attention problems, medication side effects, poor sleep, and the list goes on. We need to ask, "What are the child's behaviors telling us? What do they need?" and work to meet those needs so that our children can involve themselves in learning. One cannot learn when they are falling asleep from powerful medication, when their thoughts are racing in a mania, when they have entirely lost initiative from a depression. When children are in exacerbations of their mental illness, they cannot access the general education curriculum. Instead of providing accommodations to help our children, we are repeatedly told by school staff that we are enabling our children as they push our children beyond their limits and sacrifice their health. I have repeatedly heard this scenario over and over again in my advocacy work with families. And I have experienced it first-hand throughout my children's school careers.

We have had to pay a Psychiatrist to come to a school meeting to explain, in her words, "that we are dealing with a situation where my son is making a choice between 'should I kill myself today' and algebra." We had to bring the doctor because we, as parents, are not believed when we inform the school of our children's challenges. We have been offered a "choice" of home instruction Mon./Wed. and Tues./Thurs. at 2:45 or 3. What if a parent's work schedule necessitated them never being home from work prior to 5 p.m.? When I pointed out to the school that this hardly reflected true choice, I was told again, "You have a choice. You may CHOOSE between Tues./Thurs. and Mon./Wed. And you can choose either 2:45 or 3 p.m." That's hardly a variety of choices. My son at one point could only handle 1 hour of home instruction per day, but the district couldn't secure a tutor who would tutor 1 hour/day 5 days a week. So his services were reduced to 1/hour day twice a week.

As a more complete example of what our children are up against, I will briefly describe the challenges our family fought when my oldest son was in 7th grade. In the spring we met to plan his 7th grade Individual Education Plan (IEP) with services in an Serious Emotional Disturbance (SED) inclusion setting. Yes, plan for what 7th grade would bring. However, none of the 15+ school personnel at that meeting informed us how very different the structure of 7th grade would be, requiring him to change classes for every class, 11 different personalities to adjust to, 11 different sets of expectations, chaos in the halls, gym and hall lockers. These things may seem insignificant to a healthy adult, or even a healthy child, but for my child and most children with mental illness, these are huge barriers. Again, I imagine out of lack of knowledge, those at the IEP meeting felt these things weren't worthy of mention. They were, however, to prove to be the antecedent of my son's decompensation into suicidality and catatonia. Fall classes began and within 2 weeks my son was identifying how stressed and pressured he was feeling. I began to communicate with the school about the need to reduce his stress and the need to access the accommodations planned for in his IEP. At 1 month into school his Child Psychiatrist was alarmed at the decompensation that had occurred in just 1 month. She cautioned we must reduce his stress immediately. I sent letters, notes, made calls, and had meetings with school personnel as we tried to implement his IEP plan that allowed for him to return to his SED class if he was feeling stressed or having a bad day. I asked that the school use my son as his own barometer of what he could handle for the day. He knows best how he is feeling. This suggestion was met with disdain. I was "called to the principal's office" and told I was enabling my son. I was actually supporting my son's survival strategy. During exacerbations of his illness he cannot handle large groups of people, sometimes any people at all. He was feeling very volatile and was asking to accommodate his need for less chaos and stress. As I said in a recent letter to our Special Education Director, "If my child had leukemia and was asking to go to the nurses office because he was feeling nauseated, he would be escorted there—no questions asked—and, with much empathy." At a

minimum, my child should be able to state his needs and have them honored. Instead, they labeled him and pushed him relentlessly to go to inclusion classes. Eventually he became so unstable, depressed, and suicidal that we had to remove him from school. He was hospitalized twice that fall and was so severely depressed he was unable to dress, talk, or leave the house. He slowly emerged from the depression with the stress of school eliminated. He returned to school the following spring to a self-contained SED class, attending 3 periods of school a day. It took him 1/ 1/2/ years to return to a full school day. He lost nearly 2 years of education because the staff refused to believe that his disability was getting in the way of his education and reduce his stress. Had his stress been reduced via strategies agreed to in his legal IEP, it is likely this exacerbation and 2 year recovery would have been avoided.

Another major challenge once there is agreement to provide services, is that the type of services our children need are, for the most part, unavailable. Our children need a therapeutic approach. Some also need a behavioral approach, but that's just a portion of the affected children. Most programs available to our children are behavior-oriented programs. They are missing the mark. Our children need therapy in their day. My son did transfer into a behavior-oriented SED class. We placed him there because he needed a small group setting. He does not need to be with SED kids all day, but that is the only way to get him into a small group setting with the present menu of program options. We do not design services for kids . . . we place kids into existing programs. We as parents must pick the "least of the evils" among the "programs" offered. My son might just make it in a self-contained SED class, but what he will achieve will not be "school success" he will survive school.

Not only are our children not learning, but the stressors place on the child by an uninformed educational system exacerbate their illnesses even further. As the stressors continue their health continues to decompensate . . . their illness becomes unstable. And with every exacerbation the possibility of them returning to their previous functioning level declines. So if they were operating at a 90 percent functioning level, then decompensated into another episode, they may only return to a functioning level of 86 percent next time, and so on the spiral goes, until 1 day we reach the current outcomes detailed in the National Longitudinal Transition Study of Special Education Students commissioned by Congress. The study was initiated in 1987 and completed in 1994. The study showed the following outcomes for students with Serious Emotional Disturbance (SED).

- 41.7 percent of students with SED graduate from high school
- They earn a grade point average between 1.7–2.1
- They earn an average of 2.1–3.0 credits per year.

In Ohio a child needs to earn 21.5 credits to graduate from high school. At this credit rate it would take a typical SED child 7–10 years to complete high school. And we wonder why they don't graduate from high school?

Post-graduation statistics showed that at 3–5 years post-graduation:

- Less than half were competitively employed (47.4 percent)
- A little less than half were already mothers (48.4 percent)
- More than half were already arrested (57.6 percent)
- Nearly half were living with their parents (45.4. percent)

4. Recommendations—Clearly, our nation needs to do better for this vulnerable population than this. I implore you to search your souls. Be afraid of mental illness if you need to. But do the right thing. I think a great deal of stigma is related to fear that these tragic illnesses might strike one's own family. And indeed they often do. One in 4 families are affected by mental illness. It will strike someone you know and love and all of this could happen to them. PLEASE stop this atrocity today. Search your souls and roll up your sleeves. Make changes to this horribly broken system that is as much a tragedy as the children's and families struggles themselves. Make a difference for future generations. In the "The Report of the Surgeon General's Conference on the Children's Mental Health: A National Action Agenda" released January 3, 2001 David Satcher states, quoting The World Health Organization, that "by the year 2020, childhood neuropsychiatric disorders will rise proportionately by over 50 percent to become one of the five most common causes of morbidity, mortality, and disability among children." The time is now. If we don't change this, who will?

So, what do we need to do? First and foremost, what is critically needed, yesterday, is a national educational media blitz. Every mental health board, mental health agency, advocacy group, etc. knows this needs to be done, but it is expensive. No groups budget can handle the cost of this initiative alone. It is done for AIDS. It is done for drug abuse. It is time to do this for mental illness. Once people understand that mental illness is like any other illness, other changes will fall into place naturally. Many of this countries citizens are wealthy. Every day they donate mil-

lions of dollars to museums, parks, and other assorted groups. The money is out there. It's just that mental illness is not yet identified as a worthy recipient for a variety of reasons. But information, education, splashed everywhere, will open eyes. We know that. It happens time and time again. If you do nothing else, help this country establish an anti-stigma campaign. A lot of the rest will fall into place then. Parity will occur because people will understand that is the only right and decent thing to do. College students will see the need and the rewards of pursing a career in Psychiatry. Teachers will approach children with compassion. The tasks to improve the system will all be easier.

Goal 1 of the President's New Freedom Commission Report clearly states this recommendation as follows: Recommendations 1.1: Advance and implement a national campaign to reduce the stigma of seeking care and national strategy for suicide prevention.

Recommendations 1.2: Address mental health with the same urgency as physical health.

Secondly, school issues for children with mental illness need to be addressed immediately. Changes will only be made through collaboration. These are complex inter-system issues. Collaborative projects need to be supported. In the Ohio "Mental Health, Schools, and Families Working Together Toward a Shared Agenda" initiative, the mental health, educational, and family/advocacy communities are uniting to make a difference. We can only make this very complex system effective if we unite. Education about childhood mental illness for all teachers, on an preservice and in-service basis, is essential. The education community cannot know how to help our children unless they are educated on how to do this. Mandatory education on how to support academic success for children with mental illness is crucial.

The President's New Freedom Commission was charged to "make recommendations that would enable adults with serious mental illnesses and children with serious emotional disturbance to live, work, learn, and participate fully in their communities."[1] Please help to assure that the recommendations in that report are enacted. Our children, your children, will thank you.

5. Conclusion—Chairman DeWine and Members of the Committee, I thank you for the opportunity to share my views on this important issue. And I stand ready to serve and work with you as you move forward on your work.

In closing I would also like to add that I have attached an addendum to this testimony. It is a newspaper article that appeared in the Cincinnati Enquirer on Sunday, March 21, 2004. The Enquirer ran a special report on Childhood Mental Illness. My family and it's story was one of the families highlighted in that report.

The cabinets in Sue Mikolic's home office are filled with medical research and documents about her family and mental illness issues.
(Michael E. Keating photos)

[1] Report of The President's New Freedom Commission on Mental Health, July 22, 2003

EVERYTHING SPENT, AND NO HELP

MOTHER FIGHTS TO SAVE HER BIPOLAR SONS

BY DEBRA JASPER AND SPENCER HUNT ENQUIRER COLUMBUS BUREAU

After 14-year-old Matthew Mikolic chased his younger brother with a knife, his mother asked Lake County officials to pay to send him to a psychiatric center. They refused.

"They said he wasn't violent enough, that he had only tried to kill his brother once," Susan Mikolic says.

Now, the Eastlake, Ohio, mom lives in fear that next time, Matthew, who is now a 220-pound, mentally ill 16-year-old, will succeed. She hides tools and poisonous household cleaners in a locked fishing tackle box in the garage. She started locking up kitchen knives after Matthew tried to stab Brian, then 12.

"Brian locked himself in the bathroom, called me and said, 'Get home, Matthew's got a knife and he's trying to kill me," Mikolic, 44, recalls.

"I called the police, and a whole SWAT team came. By the time I got there, Brian was crying in the driveway, and Matthew had his hands in the air."

Mikolic sought help from the county because she had no money left for more care. When her insurance ran out, she sold her $287,000 suburban home to cover treatment for both of her sons, who have bipolar disorders that cause them to swing from overly hyper to depressed or violent.

At first, the boys needed weekly counseling, but insurance only covered half the cost of 20 sessions with a psychiatrist a year at $125 each per child. Eventually, Mikolic and her husband were shelling out more than $20,000 a year for family therapy. They took out three home equity lines of credit to pay for treatments, including lightbox therapy, music therapy, and anti-psychotic drugs.

For Mikolic, the pressures finished off her marriage and forced the couple to sell their home to pay off their loans. In the end, she was left with just enough to put a small downpayment on a modest white house that needs a $3,000 roof.

She also developed diabetes and such deep depression that she could no longer work as a nurse.

"It was a process of letting go, selling the house, the furniture, everything," she says. "I've had relatives look at me and say, 'How could you lose your home, your husband, your job?' And I say, 'Where would you have stopped? What would you do to save your kids?' "

Mikolic says what happened to her shows just what families with mentally ill children are up against. She and other advocates are pushing Ohio lawmakers to pass a bill that would force insurance companies to cover a mental illness in the same way they cover a physical illness.

If her sons had leukemia, Mikolic reasons, she wouldn't have had to sell her home. "Why should it be different for us because they are bipolar?" she asks.

Roberta Barb, an administrator of child protection services in Lake County, says her agency opted not to send Matthew to a treatment center because, "As a group, we decided he was not in need of placement. We can't make everybody happy, and we're not placing a kid in treatment just because a parent believes he needs to go."

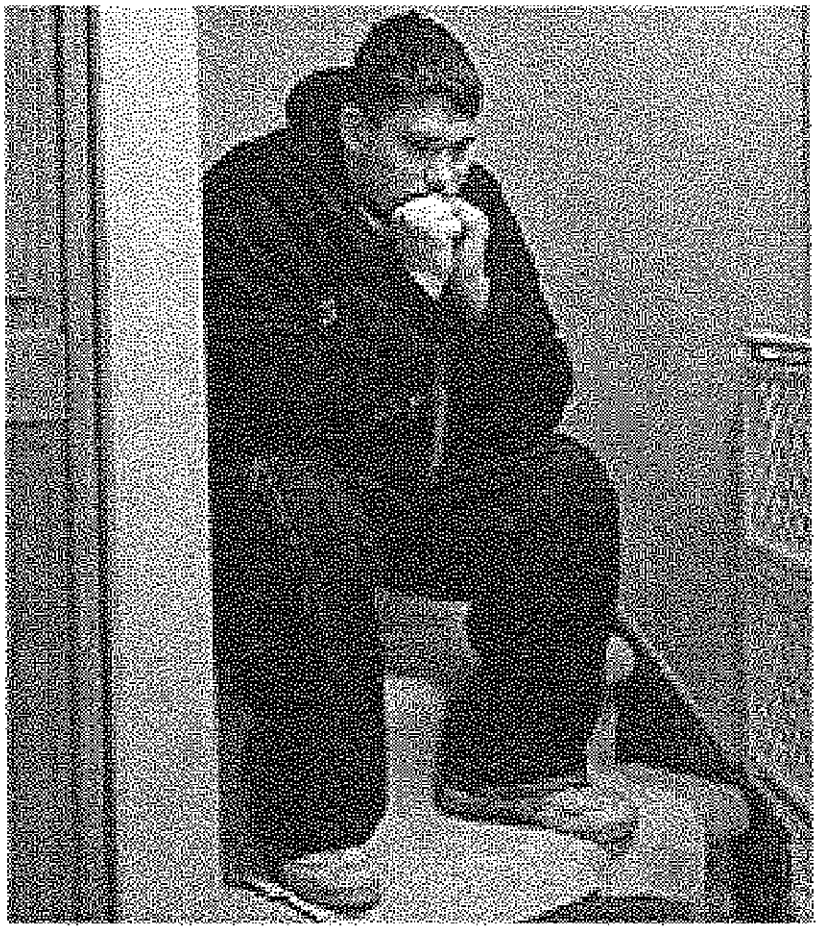
The teen has tried everything to get his emotions under control, even shock treatments that applied electric jolts to his brain. So far, nothing's worked. He refused more shock treatments after he was given two drugs during a procedure—one to paralyze him and one to put him to sleep. The drug to paralyze him took effect first.

"I could hear the machine start, but I couldn't tell them I was awake," Matthew says. "I kept thinking, I should put my hand up, but I couldn't. It was scary. Once they started the procedure, I didn't know if I'd feel it."

He's frustrated, but grateful for his mom for refusing to give up on him. "If it weren't for her, I'd be dead. If she didn't support me, I would have killed myself."

He pauses and lowers his voice.

"The illness puts that in your head," he says. "People say you can control it, but I don't think so. I know I can't control it."



Matthew Mikolic first tried to kill himself at age 5. Now 16, he struggles with emotions.

NCTSN The National Child Traumatic Stress Network

Facts on Traumatic Stress and Children with Developmental Disabilities

National Child Traumatic Stress Network
Adapted Trauma Treatment Standards Work Group

This project was funded in part by the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services

Facts on Traumatic Stress and Children with Developmental Disabilities

From the

National Child Traumatic Stress Network
Adapted Trauma Treatment Standards Work Group
Subgroup on Developmental Disability

Margaret Charlton, PhD,
Matthew Kliethermes, PhD, Brian Tallant, MS,
Anne Taverne, PhD, Amy Tishelman, PhD,

Dr. Charlton is from the Aurora Mental Health Center. Dr. Kliethermes is from the Greater St. Louis Child Traumatic Stress Program. Mr. Tallant is from the Aurora Mental Health Center. Dr. Taverne is from the Child Trauma Treatment Network—Intermountain West Dr. Tishelman is from Children's Hospital, Boston.

National Child Traumatic Stress Network
www.NCTSNnet.org

2004

The National Child Traumatic Stress Network is coordinated by the National Center for Child Traumatic Stress, Los Angeles, Calif., and Durham, N.C.

This project was funded in part by the
Substance Abuse and Mental Health Services Administration (SAMHSA),
U.S. Department of Health and Human Services (HHS). The views, policies, and opinions expressed are those of the authors and do not necessarily reflect those of SAMHSA or HHS.

Contents

Federal Definition of Developmental Disability	3
Incidence of Disability in the General Population	4
Statistical Information Regarding the Incidence of Trauma for this Population	4
Special Characteristics of the Population that May Influence the Incidence of Trauma	5
Possible Reasons for a Higher Incidence of Mental Illness for Clients with Developmental Disabilities Than the General Population	7
Suggestions for Modifying Evaluation and Therapy to Meet the Needs of this Population	7
Special Diagnostic Considerations with Clients Who Have Developmental Disabilities	8
Suggestions for Therapy	9
References	10
Adapted Trauma Treatment Standards Work Group Contacts	12

Facts on Trauma and Children with Developmental Disabilities

Federal Definition of Developmental Disability

General
The term *developmental disability* means a severe, chronic disability of an individual that

1. is attributable to a mental or physical impairment or combination of mental and physical impairments;

2. is manifested before the individual attains age 22;

3. is likely to continue indefinitely;

4. results in substantial functional limitations in three or more of the following areas of major life activity:

    a. self-care,
    b. receptive and expressive language,
    c. learning,
    d. mobility,
    e. self-direction,
    f. capacity for independent living,
    g. economic self-sufficiency; and

5. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Infants and Young Children
An individual from birth to age nine, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting three or more of the criteria described in clauses (a) through (g) of subparagraph (4) if the individual, without services and supports, has a high probability of meeting those criteria later in life.

Reference: *Developmental Disabilities Assistance and Bill of Rights Act of 2000*, Public Law 106-402.

Incidence of Disability in the General Population

- The national prevalence rate for developmental disabilities in the U.S. is 1.8 percent, based on an estimate conducted by Golay & Associates and used by the Federal Administration on Developmental Disabilities to extrapolate state level prevalence rates.

- About 3 percent of the population has an IQ of less than 70. The standard Wechsler IQ tests are based on a normal curve, so that 13 percent of the population has an IQ between 70 anc 85, 68 percent between 85 and 115, 13 percent between 115 and 130, and 3 percent above 130.

- The exact prevelance of autism is not known, but estimates range from 1-in-250 to 1-in-1,000 in the United States (National Institutes of Mental Health, 2003).

Statistical Information Regarding the Incidence of Trauma for this Population

The following statistics should be interpreted with caution. Most reports regarding the incidence of trauma for people with developmental disabilities indicate it is likely the statistics reported under-represent the prevalence of trauma. A variety of factors interfere with the ability to report, such as difficulty communicating that abuse has occurred, difficulty in being believed, and problems related to communication in general.

- Individuals with developmental disabilities are at increased risk for abuse as compared to the general population (Gil, 1970; Mahoney & Camilo, 1998; Ryan, 1994).

- Goldson, 2002 reports maltreatment among children with disabilities:

Incidents per 1,000

	Children without Disabilities	Children with Disabilities
Physical Abuse	4.5	9.4
Sexual Abuse	2.0	3.5
Emotional Abuse	2.9	3.5

- Individuals with disabilities are over four times as likely to be victims of crime as the non-disabled population (Sobsey, 1996).

- Sixty-four percent of the children who were maltreated had a disability. The most common disabilities were behavior disorders, speech/language, learning disability, and mental retardation. The most common type of maltreatment was neglect. Children with mental retardation were the most severely abused. Children with communication disorders were more likely to be physically and sexually abused (Sullivan & Knutson, 1998).

- Five million crimes are committed against individuals with disabilities each year in the United States (Petersillia, 1998).

- Individuals with disabilities are 2-to-10 times more likely to be sexually abused than those without disabilities (Westat Ind., 1993).

- Maltreatment of children with disabilities is 1.5-to-10 times higher than of children without disabilities (Baladerian, 1991; Sobsey & Doe 1991; Sobsey & Vamhagen, 1989; Sullivan & Knutson, 2000; Westat, 1991).

- One of 30 cases of sexual abuse or assault of persons with developmental disabilities is reported as opposed to one of five in the nondisabled population (James, 1988).

- Even when the abuse is reported, the charges are rarely investigated when the victim is disabled (Senn, 1988).

- Victims typically have difficulty accessing appropriate services (Sobsey & Doe, 1991).

- Risk of abuse increases by 78 percent due to exposure to the "disabilities service system" alone (Sobsey & Doe, 1991).

- Immediate family members perpetrate the majority of neglect, physical abuse, and emotional abuse. Extrafamilial perpetrators account for the majority of sexual abuse (Sullivan & Knutson, 2000).

- Sexual abuse incidents are almost four times as common in institutional settings as in the community (Blatt & Brown, 1986).

- Ninety-nine percent of those who commit abuse are well known to, and trusted by, both the child and the child's care providers (Baladerian, 1991).

Special Characteristics of the Population that May Influence the Incidence of Trauma

Abuse and neglect have profound influences on brain development. The more prolonged the abuse or neglect, the more likely it is that permanent brain damage will occur. Not only are people with developmental disabilities more likely to be exposed to trauma, but exposure to trauma makes developmental delays more likely.

- "The developing brain is exquisitely sensitive to stress." Persistent states of fear in children impair their capacity to benefit from cognitive, social, and emotional experiences (Perry, 2001).

- Exposure to trauma can modify the child's ability to access different levels of brain functioning, resulting in changes in their perception of time, cognitive style, affective tone, ability to develop solutions to problems, and ability to respond to and understand rules, regulations, and laws (Perry, 2001).

- Severe neglect can result in reduced brain size, density of neurons, and head circumference (Perry and Pollard, 1997).

People with developmental disabilities are

- trained to be compliant to authority figures;
- dependent on caregivers for a longer period of time for more types of assistance than a nondisabled child, and they are dependent on a larger number of caretakers;
- often unable to meet parental expectations;
- isolated from resources to whom a report of abuse could be made;
- sometimes impaired in their ability to communicate;
- sometimes impaired in their mobility;
- more likely than other children to be placed in residential care facilities;
- sometimes more credulous and less prone to critical thinking than others, which may result in it being easier for others to manipulate them;
- often not provided with general sex education, and caregivers may feel that people with developmental disabilities are asexual, although
    - for people with mild to moderate mental retardation sexual development and sexual interest occur at approximately the same age as the normal population (Tharinger, 1990), and
    - precocious puberty is 20 times more likely to occur in persons with developmental disabilities than in the normal population (Siddigi, 1999); and
- viewed negatively by society, which may label them as "bad" because they are different or may view them as less than human.

People with developmental disabilities may also experience

- cognitive and processing delays that interfere with understanding of what is happening in abusive situations, and
- feelings of isolation and withdrawal due to their differences, which may make them more vulnerable to manipulation because of their increased responsiveness to attention and affection.

In addition, the effect of trauma is increased for people with developmental disabilities due to

- a predisposition toward emotional problems and impaired resiliency before the abuse occurs (Burrows & Kochurka, 1995);

- reduced protective factors that could lessen the effects of sexual abuse (Mansell et al., 1998);
- a long-standing belief that people with developmental disabilities cannot benefit from traditional verbally oriented therapies (Mansell, et al., 1998); and
- a lack of trained professionals who are comfortable in working with people who have developmental disabilities to help them in processing traumatic incidents.

Possible Reasons for a Higher Incidence of Mental Illness for Clients with Developmental Disabilities Than the General Population
(Avrin, Charlton, Tallant, 1998)

- It is more difficult to cope with normal life stressors given the limited resources the client has available.
- There is increased vulnerability to abuse in the home, since these children are often very difficult to raise and place a high level of strain on the family.
- These children are more vulnerable to abuse in the community because of their poor judgment and lack of self-protective skills.
- An additional stressor for the higher functioning clients is awareness of their intellectual deficits. They have many grief and loss issues associated with their functioning problems.
- People with developmental disabilities experience greater difficulty in getting help for mental illness due to communication and processing problems.

Suggestions for Modifying Evaluation and Therapy to Meet the Needs of this Population

- Because of the high likelihood that the ability to communicate will be severely impaired, it is extremely important that a wide range of caregivers be involved in both the assessment and treatment process. These should include parents/guardians and school and daycare personnel.
- Since reporting of trauma by this population is unlikely, it is important that caregivers receive training on the type of behavioral changes that may be associated with trauma exposure so they may assist in reporting and obtaining services.
- All children with developmental disabilities tend to behave like much younger children, so when working with very young children with developmental disabilities, it is extremely important to slow down speech, use simple language, present one concept at a time, supplement therapy with drawing and play materials, and make related adaptations.

Special Diagnostic Considerations with Clients Who Have Developmental Disabilities
(Avrin, Charlton, Tallant, 1998)

1. Their thought process are usually very concrete. Responses to common mental status questions may sound very bizarre because of the client's concrete interpretations.

2. Their concrete thought processes make the use of projective assessment techniques such as the Rorschach and TAT ineffective in identifying pathology.

3. If the client has sufficiently high verbal skills, sometimes the MMPI-2 or A can be helpful, if interpreted conservatively. Use of audio tapes is recommended, even if the reading level seems sufficient, as the multisensory input often improves comprehension of the questions.

4. People with developmental disabilities often share the following thought processes:

    a. difficulty with fluidity and flexibility of thinking,
    b. a dislike of ambiguity (black and white thinkers),
    c. a tendency to concentrate on one aspect of a situation while neglecting other aspects,
    d. difficulty prioritizing and breaking down tasks into manageable projects,
    e. a tendency to have highly focused areas of expertise and interests, e.g., beets, weather, sports, statistics, phone numbers, dates, and so on,
    f. a tendency for poor generalization skills—a person belongs in one and only one environment—and utilization of a skill in one situation but not others.

5. People with developmental disabilities often share the following communication problems and social issues:

    a. idiosyncratic speech,
    b. inability to perceive social cues,
    c. difficulty utilizing or understanding nonverbal communication well,
    d. frequent miscommunications and misunderstandings,
    e. a tendency toward one-sided conversations,
    f. a tendency to ask many questions, especially when uncomfortable with a conversation,
    g. a tendency to return to familiar, rote questions, or subjects of personal interest when anxious,
    h. intrusive behavior,
    i. an ability to pretend to be normal,
    j. a poor understanding of the impact of behavior on others, and
    k. difficulty making and keeping friends.

6. People with developmental disabilities may also have the following miscellaneous issues:

    a. special talents, including memory for facts, artistic talents, and unique insights (Albert Einstein, Temple Grandin);
    b. difficulty with change, especially unexpected changes, including
        i. anticipatory anxiety and
        ii. continued use of a familiar plan even if it doesn't work;

c. significant anxiety in many situations, which may present as agitation, acting out, worry, perseveration, or obsessive-compulsive behaviors, often with the following characteristics:
    i. responses when anxious tend to be highly predictable,
    ii. even though the pattern is predictable, it may be hard to see when the anxiety is high, and
    iii. the acting out may be chaotic;
d. difficulty with impulse control, particularly when frustration, anxiety, or tension builds until behavioral acting out occurs.

Be aware that all types of psychiatric treatment are useful if properly selected and executed (Szymanski et al., 1994). Behavioral and cognitive behavioral strategies are particularly effective and easy to adapt for this population.

Suggestions for Therapy
(Avrin, Charlton, Tallant, 1998)

1. Slow down your speech.

2. Use visuals whenever possible to reinforce your verbal messages:
    a. draw pictures, and
    b. write down suggestions for change in brief, outline form.

3. Present information one item at a time.

4. Ask for feedback after each item to ensure clear comprehension.

5. Be specific in making suggestions for change.

6. Practice different ways of handling tough situations the client is likely to encounter.

7. Format your therapy session so that several repeats of key information occur. For example

    a. review information covered in the previous meeting,
    b. discuss how week has gone,
    c. work on specific ways of handling various troublesome events that occurred,
    d. review the key things you want the client to work on during the week, and
    e. write the homework assignment out and review it with the client to be sure it is clear.

8. Work on building coping skills rather than insight.

9. Remember that with these clients change will occur more slowly than with others. Be content to measure change with a micrometer rather than a yardstick.

10. Remmber that effective treatment for people with developmental disabilities must also include a variety of support and education services for families and caregivers.

References

Avrin, S., Charlton, M., & Tallant, B. (1998). Diagnosis and treatment of clients with developmental disabilities Unpublished manuscript, Aurora Mental Health Center.

Baladerian, N.J. (1991). Sexual abuse of people with developmental disabilities. Journal of Sexuality and Disability, 9 (4): 323-335.

Blatt, E. R. & Brown, S. W. (1986). Environmental influences on incidents of alleged child abuse and neglect i New York state psychiatric facilities: Toward an etiology of institutional child maltreatment. Child Abuse and Neglect, 10 (2): 171-180

Burrows, H. C. & Kochurka, K. A. (1995). The assessment of children with disabilities who report sexual abuse A special look at those most vulnerable. In Ney, T. (Ed.), True and False Allegations of Child Sexual Abuse: Assessment and Case Management. New York: Brunner/Mazel, 275-289.

Goldson, E. (2002, July). Maltreatment among children with disabilities. In 14th International Congress on Child Abuse and Neglect. Denver, Colorado.

Gil, D. G. (1970). Violence against children: Physical abuse in the United States. Cambridge: Harvard Universit Press.

James (1988). In Tharinger, D., Horton, C., & Milleas, S. (1990). Sexual abuse and exploitation of children and adults with mental retardation and other handicaps. Child Abuse and Neglect, 14: 301-312.

Mahoney, J. & Camilo, C. (1998). Meeting the needs of crime victims with disabilities. (Draft). Crime Victims Compensation Program Mental Health Treatment Guidelines Task Force.

Mansell, S., Sobsey, D., & Moskal, R. (1998). Clinical findings among sexually abused children with and withou developmental disabilities. Mental Retardation, 36 (1): 12-22.

National Institute of Mental Health (2003). Report to Congress on Autism. U.S. Department of Health and Human Services.

Perry, B. D. (2001). The neurodevelopmental impact of violence in childhood. Chapter 18: In Textbook of Child and Adolescent Forensic Psychiatry, (Eds., D. Schetky and E. P. Benedek) American Psychiatric Press, Inc., Washington, D.C., pp. 221-238.

Perry, B. D. and Pollard, D. (1997). Altered brain development following global neglect. Neuroscience: Proceedings from Annual Meeting, New Orleans.

Petersillia, J. (1998). Written presentation to the California State Senate Public Safety Committee, p.4.

Ryan, R. (1994). Posttraumatic stress disorder in persons with developmental disabilities. Community Mental Health Journal, 30 (1): 45-54.

Senn, C. Y. (1988). Chapter 1: Prevalence of child sexual abuse. In: Vulnerable: Sexual abuse and people with in intellectual handicap. G. Allan Roeher Institute, Ontario, Canada pp. 1-8.

Siddigi, S. U., Van Dyke, D. C., Donnohoue, P. & McBrien, D. M. (1999). Premature sexual development in individuals with neurodevelopmental disabilities. Developmental Medicine and Child Neurology, 41, 392-395.

Sobsey, D. (1996). Relative victimization risk rates: people with intellectual disabilities (unpublished manuscript).

Sobsey, D. & Doe, T. (1991). Patterns of sexual abuse and assault. Sexuality and Disability, 9 (3): 243-259.

Sobsey, D., & Varnhagen, C. (1989). Sexual abuse and exploitation of disabled individuals. In C. R. Bagley & R. J. Thomlison (Eds), Child Sexual Abuse: Critical Perspectives on Prevention, Intervention and Treatment (pp. 203-216). Toronto, Canada: Wall & Emerson, Inc.

Sullivan, P. M. & Knutson, J. F (1998). The association between child maltreatment and disabilities in a hospital-based epidemiologic study. Child Abuse Neglect, 22: 271.

Sullivan, P. & Knutson, J. (2000). Maltreatment and disabilities: A population-based epidemiological study Child Abuse & Neglect, 24 (10): 1257-1273.

Szymanski, L., King. B., Feinstein, C., Weisblatt, E., Stark, J., & Ryan, R. (1994). American Psychiatric Association Committee Draft Practice Guidelines for Mental Health Care for Persons with Developmental Disabilities.

Tharinger, D., Horton, C., & Milleas, S. (1990). Sexual abuse and exploitation of children and adults with mental retardation and other handicaps. Child Abuse and Neglect, 14: 301-312.

Westat, Inc. (1991). A Report on the Maltreatment of Children with Disabilities, U. S. Department of Health and Human Services. Washington, D. C.

Westat Inc. (1993). A Report on the Maltreatment of Children with Disabilities, U. S. Department of Health and Human Services. Washington, D. C.

Adapted Trauma Treatment Standards Work Group Members

Name	Role	Affiliation	Email Address
Margaret Charlton, PhD	Chairperson, Work Group and Subgroup on DD	Aurora Mental Health Center	dr_charlton@yahoo.com
Matt Kliethermes, PhD	Subgroup on DD	The Greater St. Louis Child Traumatic Stress Program	kliethermesm@msx.umsl.edu
Brian Tallant, MS, LPC	Subgroup on DD	Aurora Mental Health Center	briantallant@aumhc.org
Anne Taverne, PhD	Subgroup on DD	Child Trauma Treatment Network—Intermountain West, Primary Children's Medical Center, Salt Lake City	ataverne@yahoo.com
Amy Tishelman	Subgroup on DD	Children's Hospital in Boston	amy.tishelman@TCH.Harvard.edu
Amy Oxman, LCSW	Co-Chair Subgroup on Deaf/Hard of Hearing	Child Trauma Treatment Network—Intermountain West, Primary Children's Medical Center, Salt Lake City	pcaoxman@ihc.com
Ric Durity	Co-Chair Subgroup on Deaf/Hard of Hearing	Colorado Mental Health Association for Deaf and Hard of Hearing	rdurity@mhcd.com
Ami Garry	Subgroup on Deaf/Hard of Hearing	Colorado Mental Health Association for Deaf and Hard of Hearing	Agarry@mhcd.com
Karen Mallah	Subgroup on Deaf/Hard of Hearing	Colorado Mental Health Association for Deaf and Hard of Hearing	kmallah@mhcd.com
Joene Nicolaisen	Subgroup on Deaf/Hard of Hearing	Child Trauma Treatment Network—Intermountain West, Robert G. Sanderson Community Center for the Deaf and Hard of Hearing, Salt Lake City	Agarry@mhcd.com
Mary Sterrit	Subgroup on Deaf/Hard of Hearing	Colorado Mental Health Association for Deaf and Hard of Hearing	msterrit@mhcd.com
Annette Stewart, LCSW	Subgroup on Deaf/Hard of Hearing	Child Trauma Treatment Network—Intermountain West, Robert G. Sanderson Community Center for the Deaf and Hard of Hearing, Salt Lake City	Ajstewart@utah.gov
Barbara Boat	General Member		barbara.boat@uc.edu
Bill Harris	General Member		DdSheedy1@aol.com
Pamela Marshall	General Member		pam.marshall1@juno.com
Amy Shadoin	General Member		ashadoin@nationalcac.org
Greg Taliaferro	General Member		Gltlouky@aol.com

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

○