

**NOWHERE TO TURN: MUST PARENTS RELINQUISH
CUSTODY IN ORDER TO SECURE MENTAL
HEALTH SERVICES FOR THEIR CHILDREN?**

HEARINGS

BEFORE THE

COMMITTEE ON
GOVERNMENTAL AFFAIRS
UNITED STATES SENATE
ONE HUNDRED EIGHTH CONGRESS

FIRST SESSION

—————
JULY 15 AND 17, 2003
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**NOWHERE TO TURN: MUST PARENTS RELIN-
QUISH CUSTODY IN ORDER TO SECURE
MENTAL HEALTH SERVICES FOR THEIR
CHILDREN? PART ONE: FAMILIES AND AD-
VOCATES**

TUESDAY, JULY 15, 2003

U.S. SENATE,
COMMITTEE ON GOVERNMENTAL AFFAIRS,
Washington, DC.

The Committee met, pursuant to notice, at 9:35 a.m., in room SD-342, Dirksen Senate Office Building, Hon. Susan M. Collins, Chairman of the Committee, presiding.

Present: Senators Collins, Pryor, and Durbin.

OPENING STATEMENT OF CHAIRMAN COLLINS

Chairman COLLINS. The Committee will come to order. Good morning. This week, the Committee on Governmental Affairs is holding hearings to examine the difficult challenges faced by families of children with mental illnesses.

Serious mental illness afflicts millions of children and adolescents. It is estimated that as many as 20 percent of American children under the age of 17 suffer from a serious mental, emotional, or behavioral illness. Of these, nearly half have a condition that produces a severe disability that impairs the child's ability to function in day-to-day activities. What is even more disturbing is the fact that two-thirds of our 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 that it can to help a son or daughter with a serious mental illness to be just like every other kid, to develop friendships, to do well in school, and to get along with their siblings and 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. As a consequence, the mental health and support services that these children and their families receive are often uncoordinated, inconsistent, intermittent, insufficient, and for some, almost completely non-existent.

Recent news reports in more than 30 States have highlighted the difficulties that parents of children with serious mental illness have in getting the coordinated mental health services that their

children need. My interest in this issue was sparked by a compelling series by Barbara Walsh of the Portland Press Herald last summer. She detailed the many obstacles that Maine families had faced in getting care for their children.

I have learned that 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 the juvenile justice system.

When a child has a serious health problem like diabetes or a heart condition, the family turns to their doctor. But when the family includes a child with a serious mental health problem, it is often forced to go to a child welfare agency or to court to secure treatment. 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 and to prevent such acts from occurring. 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.

In some extreme cases, families are actually forced to file charges against their own child or to declare that they have abused or neglected them in order to get the care that they need. As one family advocate observed, "Beat them up, lock them up, or give them up," characterizes the choices that some families face in their efforts to get the help that their children need.

While no one knows the exact number, child advocates estimate that one in five families with mentally ill children in the United States has surrendered custody in order to receive care for a child with bipolar disorder, schizophrenia, depression, or another serious disorder. Moreover, many child welfare systems make no distinction between children who have been given up in order to qualify for mental health care and those who have been removed from their homes because of abuse or neglect.

These children come from all walks of life and from every income level. In fact, we found that children from middle-income families are likely to be particularly vulnerable because their parents make too much money to be eligible for Medicaid and yet they simply do not have the funds necessary to pay for care once their private insurance coverage runs out. One outpatient therapy session can cost more than \$100, and residential treatment facilities can cost \$250,000 a year or even more. Since many private health plans have coverage that is more restrictive for mental illness than it is for physical illness, these families must pay for most of these costs out-of-pocket. That clearly is far more than all but the very wealthiest families can afford.

While some States have passed laws to limit or prohibit custody relinquishment, simply banning the practice is not the answer. That could leave mentally ill children and their families without any services or care at all. Custody relinquishment is merely a symptom of a much larger problem, which is the lack of available,

affordable, and appropriate mental health services and support systems for these children and their families.

The hearings that the Committee is holding this week will provide an overview of the problem and examine the barriers that prevent families from accessing mental health services. The Committee will also hear about innovative programs in some States, such as Kansas, that may help to improve access to services for these families and reduce the need for child welfare and juvenile justice placements.

Today, we are honored to first hear from Representatives Fortney “Pete” Stark and Patrick Kennedy, who joined me in requesting a General Accounting Office study of this issue.

We will also hear from those who are living with this challenge day in and day out, the families who have faced these tough choices as they have struggled to get the mental health care that their children need, and I am particularly appreciative of the testimony that we will hear today from three mothers who will tell us of their personal experience.

Finally, we will hear from advocates for these families who will give us an overview of the problem and make recommendations for improving the current system.

On Thursday, we will continue these hearings with testimony from the General Accounting Office. We will also examine the roles of various Federal agencies and programs that have responsibilities for children with mental health needs, and we will examine the extent to which these agencies work together to meet the needs of these children.

My hope is that these 2 days of hearings will pave the way for legislative and administrative reforms at both the Federal and State level to reduce the barriers to care for children who suffer from mental illness.

I am very pleased today that we are joined by two distinguished members of the House of Representatives who have been leaders in dealing with this very serious problem. We are hopeful that by working together in a bipartisan, bicameral manner, that we will be able to come up with solutions that make a real difference in the lives of mentally ill children and their families.

First, I would like to welcome Congressman Stark of California. As the Ranking Member of the Ways and Means Subcommittee on Health, Congressman Stark has been working to improve access to mental health services for children for a number of years.

Next, we will be privileged to hear from Congressman Patrick Kennedy of Rhode Island, a fellow New Englander whom I am very pleased to welcome. We always like to think that New England leads the way on issues that affect our Nation’s families. Congressman Kennedy serves on the House Appropriations Committee, where he has continued to advocate for more resources to be devoted to mental health care.

I mentioned that I was pleased to join the two representatives in commissioning a GAO study, which has been very illuminating in shining a spotlight and giving us some data on the extent of this problem.

Congressman Stark, we will begin with you, and thank you both for being here with us.

Mr. STARK. Madam Chair, if you would please, I would like to yield to Congressman Kennedy, who has a markup scheduled ahead, if that would suit you, and let him proceed.

Chairman COLLINS. My staff just passed me a note after the fact— [Laughter.]

Telling me that I should have called on Congressman Kennedy first, and you are very gracious to allow him to proceed.

TESTIMONY OF HON. PATRICK J. KENNEDY,¹ A REPRESENTATIVE IN CONGRESS FROM THE STATE OF RHODE ISLAND

Mr. KENNEDY. Thank you, Madam Chairwoman. I just want to thank my colleague, Congressman Pete Stark, who has been such a champion over the years for health care reform and ensuring that our health care system actually becomes a health care system and not a sick care system, which it currently is, and where we, unfortunately, spend too much of our resources on the back end rather than on the front end where we could more effectively address many of our health care needs of our people in this country, and also more efficiently on a cost side, effectively treat our people. I want to thank him for his leadership on this.

Madam Chair, you said it all in your statement. I really can't do much better than what you articulated in your opening statement. I know, as you said, the panelists who are going to be speaking can more eloquently address this issue because they can address it from personal experience, being a parent of a child that is caught up in this bureaucratic system that sorely needs change.

We have a callous system in this country when it comes to children and mental health services. Mental health is physical health. I often get concerned when I have to talk about it as if it is something separate from overall physical health. We have been so accustomed to delineating a change that is not there. It is irrelevant. The brain is part of the body, in case anyone didn't notice. We have got to worry about a check-up from the neck up, as I like to say, as much as anything else, because all we do on our health care side is neglect really an organ of the body that affects every other organ of the body.

And why, as a Nation, we spend, for example, at NIH, only \$5 of every \$100 we appropriate to the NIH on mental illness—that includes all neurological disorders, including alcoholism and substance and chemical abuse—unbelievable to me, unbelievable. And why, as a Nation, we don't step up and address this problem is beyond me.

I applaud you, Madam Chairwoman, for your interest in this issue and your leadership in this issue because I think it is long past due and we need to address this. And children and families are suffering. As a Nation, we do a lot, as you know, Madam Chairwoman, standing up here and saying how we are for children and we wear these ties with children on our ties and we all talk about how we are for families and family-friendly policies, and yet, when it comes to our actions, we are missing in action. This Congress and this administration is missing in action.

¹The prepared statement of Mr. Kennedy appears in the Appendix on page 75.

The administration's own commission, the New Freedom Commission, says our mental health system is in shambles, is in shambles. I think the most effective way for us to address this is to pass legislation that will include parity for mental health care in our overall insurance system.

As you said, Madam Chairwoman, we have a bifurcated system. In one, we have reimbursement for mental illness, which is far below reimbursement for every other physical illness, and it is just discriminatory. We wouldn't, as you know, say to asthmatics, well, we don't value your illness so we are not going to reimburse you for asthma, or if you have diabetes, forget about it. We don't value that. We are not going to reimburse it. This is just patently discriminatory.

The most effective way we can address this problem is pass parity, and I know, as you know, Madam Chairwoman, that Paul Wellstone dedicated his life to this in this chamber, made an enormous difference, and we would do well if we in the Congress passed the Paul Wellstone Mental Health Parity Act. That would bring a systematic approach to this. Where we are failing now is we are dealing with this in kind of picking up the threads instead of addressing it all together. We need a comprehensive approach, and the best way to address that is to get a comprehensive solution, and that is mental health parity.

Short of that, what can we do administratively? I know this is about getting things done, and we want to address this in whatever way we can. I believe there is money in the system. I think that we have a special education system, a juvenile justice system, a health care, HHS system, and, of course, all of the mental health that we have in our mental health systems in our States. We can address this. It is just that all of our funding streams, as you know, Madam Chairwoman, are isolated.

I can tell you, we have in our State \$248 million—it is a small State—\$248 million a year for DCYF, Department of Children, Youth, and Families. That is one of the biggest expenditures we have as a State. We are spending oodles of money on the back end. We are spending money in such ineffective, inefficient ways. When you consider the additional dollars, \$100,000 to keep a child in our children's correctional system, it is just foolish. We can spend our money so much more effectively.

What we need are systems of care. We need to make sure that the mental health folks and the Department of Health folks and the education folks and the judiciary folks can't say, this is my money. We have got to make sure that this is the child's money. This is the family's money. This doesn't belong to you and you don't say that this is, oh, this is just the juvenile side or this is just the special education side or this is just the education and this is just the health care side. This is a comprehensive pot of money that we need to insist upon. We can't have these stovepipe funding streams, as you know.

I will tell you, a lot of my folks who are involved in this area have said to me, "Congressman, you know what? There is too much turf war in this." There are too many organizations that are all trying to take their piece of the pie, and in the midst of that are the children who we are trying to spend the money on who are losing.

I just want to conclude by saying you are going to have a great panel, but Jane Adams has been someone who I have relied on for support on this issue from Kansas. As you pointed out, that is one of the models in this country. We need to listen to folks like her and the folks that you have on the panel because they can give us the best direction as to what to do on this issue.

I thank you for your interest and your leadership on this issue.

Chairman COLLINS. Thank you very much, Congressman. I am pleased to excuse you at this time so that you can get to your markup—

Mr. KENNEDY. Thank you.

Chairman COLLINS [continuing]. And thank you for taking the time to be with us.

Mr. KENNEDY. My pleasure. My pleasure.

Chairman COLLINS. Congressman Stark, it is an honor to have you here this morning.

TESTIMONY OF HON. FORTNEY “PETE” STARK,¹ A REPRESENTATIVE IN CONGRESS FROM THE STATE OF CALIFORNIA

Mr. STARK. Thank you, Senator. It is a particular joy to be here having just returned from a weekend at the Migis Lodge at Sebago Lake investigating welfare problems, and I can tell you that as far as I could tell, Maine has no problem in that particular location. [Laughter.]

But, if the State that I represent happens to have also two Senators who happen to be women, and if they were as well liked and as well known in California as you are in Maine, they would have no problem at all every 6 years. Let me say, it is a special honor to be here today and to say what a great State you represent, and also what a good job you are doing in focusing on this problem which gets, as my colleague, Congressman Kennedy indicated, kind of scattered to the wind.

Everybody wants a piece of it, and I think you are taking the lead in trying to depoliticize this and bring some calm and focused attention to what we can do here at the Federal level to help the States deal with it. Many States, Kansas, Vermont, have programs that are exemplary. What I suspect you are trying to do, and I would like to help, along with Congressman Kennedy and others in the Senate, is to bring some focus and direction.

I have been here long enough to remember that we had a problem years ago with what we then called AFDC, and we used to have fathers who used to have to leave home and abandon their children in order for them to qualify for public assistance, and they might have been poor or ineligible, and we suddenly woke up and said, that isn't right. The father just doesn't make enough to support the children well and we ought to deal with that. Eventually, we did, and we came into the 20th Century early on.

You know about the GAO report that we all requested and the number of children, and you are going to hear from witnesses, I know, who will tell you much more eloquently than I can what many of the problems are.

¹The prepared statement of Mr. Stark appears in the Appendix on page 78.

But some of the practical problems that the public may not realize and for our bean counters who always wonder how much money we are going to spend, I think it is interesting to note that about two-thirds of the children where custody has been relinquished are boys, and they tend to get big and strong and they tend to get around 15 or 16 and can be literally a physical threat to peers, to parents, to themselves, and get pushed, therefore, into what in California we would call the youth criminal justice system. That is not an answer. That just throws them in with people who are perhaps criminals, and that is not the kind of training they need.

It also seems that once children get into these systems, whether it is a combination of criminal justice or whether it is a youth system run by the States, they tend to stay there. Then, they are institutionalized for many, many years. The record shows that if a youngster is institutionalized before he or she is 20, the odds are they will spend half of the next 30 years of their lives in an institution. So if they go into a system into which they are mandated by the court and institutionalized, the odds are that from the age of 20 to 50, they will spend half of that time as a ward of the State or in jail or some other system. That costs us, in California, \$40,000 a year.

If you just want to look at the pure numbers, to the extent that we can stabilize young people and make them part of a family that is responsible for them and will love them and will maintain them, we are doing good work. How we best can achieve that is something that I know your staff has been working diligently, with others to craft some legislation that will help us move toward that.

Congressman Kennedy spoke eloquently about parity, and I would join in his support for that issue. But that deals only really with people who have health insurance. If it is adequate on the acute care side, parity will, indeed, help out with the mental health side, and that would take care of a segment of the population. But that is diminishing. The number of people with health insurance is diminishing. The value of their benefits is dropping as we have employment problems, and so we can't count on it. It will help.

Then we have to deal with Medicaid eligibility. That is another segment of the population, and that varies from State to state and what kind of benefits are available there. That is the very lowest of the low income. Then you have sort of people in between. You will hear from a witness today who, while being unable to work, I think failed to qualify for Medicaid because of the assets test.

All of these things are a hodgepodge of roadblocks, the unintended consequence of which is that children are institutionalized and parents are required to do that, to give up custody, both harming the child—the child feels abandoned in many cases—and I am sure the parents feel guilty. Both of those feelings can lead to a diminution of the parent-child relationship which I think, as a lay person, is invaluable to the stable, healthy maturation of a child into becoming an adult who fits into our adult society comfortably.

So that is what we are faced with. I know that in the bill that we are working on, we are talking about some money to the State, a reward. I don't think that we can intrude on the 50 States and say, you have got to run your welfare system this way or that way. I think the attitude that we are seeing is, yes, there is a carrot ap-

proach here and we are moving. To get some of this award to help you integrate your social services systems for children, one thing you have to do is stop, change your State law on custody relinquishment.

That seems to be the barrier that the States will have to hurdle. It should be easy. Every State that I know of is in great financial trouble and I think just dangling out what will be a small amount of money, but not insignificant, will go a long way toward getting the States to do, in whatever way they see fit, to proceed to deal with the custody relinquishment.

We also want to increase access and capacity, screening, services at schools, in public health departments, in welfare departments, and in the criminal justice system. All of these people are operating in little empires or little worlds, unaware of what is going on in the other's world. To coordinate that is to come into basically the 21st Century. Actually, it is the 20th Century. We have known that the Family Preservation Act, which is now, 10 or 15 years old, has encouraged welfare departments to move housing, food, child care, all of those things into one system to help a family survive economically.

We can create a system to deliver to eligible children a combination of home and community-based health systems, and all of that, it seems to me, will be through encouraging States to do that, and I know we have discussed giving States broad ability to use the funds to create State and local-level infrastructure and to expand public health insurance and deliver mental health care and wrap-around support, as we call it, to eligible children.

Also Outreach, letting people know that there is a problem and that some children aren't just always a behavior problem. Sometimes there really is an underlying health problem that should be addressed and studied and identified.

So that is the problem before us, and I think working together, with the help we get from the advocacy community and without threatening our colleagues that we are going to try and bust the budget, we don't need to do that. We need to focus attention. I think we do. I think that providing some enticement—I hate to call it a bribe, but some inducement to the States to coordinate will go a long way, and I am just so pleased that you are taking the lead on this.

We want to work with you. I hope we can rally as much support in the House and we wait for your introduction of a completed bill. It is not easy, I know, to get this all into legislative language, but we will continue to try and help you in every way we can and look forward to seeing some great accomplishments in this year.

Thank you again for the hearings. I want to thank the witnesses, who I know have poignant tales to bring here and it is not often easy to talk about problems in one's family. They are to be commended, as are you for these hearings. Thank you very much for letting me appear this morning.

Chairman COLLINS. Thank you very much, Congressman. You have been long a leader on health care issues and I am very grateful that you took the time to be here with us this morning. I look forward to continuing to work very closely with you. I really think the answer does lie in a bipartisan, bicameral effort supported by

what we learn through these hearings, the GAO report, and the advocate group. So we will continue our efforts, and thank you for taking the time to be here today.

Mr. STARK. Thank you.

Chairman COLLINS. I would now like to call forward our second panel, and I particularly want to thank the witnesses on our second panel for sharing their personal stories with the Governmental Affairs Committee today.

We have been joined by Senator Pryor, who has had a great interest in this issue. Senator Pryor, when you have a chance to get settled, I want to give you the opportunity, if you have any opening comments you want to make or if you would like to introduce Patricia Cooper, who is from your home State.

Senator PRYOR. Thank you. I don't have any opening statement, but when the Chair is ready, I would like to introduce Ms. Cooper.

Chairman COLLINS. Thank you very much.

I am particularly pleased to welcome Theresa Brown of Westbrook, Maine. Theresa was forced to relinquish custody of her daughter, Heather, on September 27, 1999, in order to obtain the care that her daughter so desperately needed. She tells her story very eloquently. I know it is a very painful story, and as she told me earlier today, that was the worst day of her life. I am very grateful for her taking the time to come from Maine and be with us this morning.

We are also very pleased to be joined by Cynthia Yonan of Glendale Heights, Illinois. She was also faced with the decision of whether or not to relinquish custody in order to find care for her twin boys, Sean and Ryan.

I would now ask Senator Pryor if he would introduce the witness from Arkansas.

Senator PRYOR. Thank you, Madam Chair. Again, let me thank you for your leadership on this issue. It is something I know that you have worked on for a long time and are very serious about and we appreciate your leadership. I speak on behalf of, I think, all the Committee members when we say that.

Here today, I would like to introduce Patricia Cooper. She is from a town in Arkansas called Fayetteville, Arkansas, which happens to be where I was born, and she is like so many American families who have to make terrible choices when they have children who are in need of mental health services.

Arkansas is one of those States, and I am sure there are a number of them, where we really don't have the mental health infrastructure that we need, and that is something that we need to work on on the State level and local level. But certainly, there are things that the Federal Government can do.

I am not going to try to steal your thunder this morning. I want you to tell your story because it is a very compelling story, but I just want to welcome you to Washington and welcome you to the Senate and thank you for being here.

Chairman COLLINS. Thank you, Senator, and Patricia, I join Senator Pryor in thanking you for coming to share your story this morning.

We are going to start with Theresa.

TESTIMONY OF THERESA BROWN,¹ WESTBROOK, MAINE

Ms. BROWN. Thank you, Chairman Collins. I am honored to be here and honored to tell you my story about my daughter.

Relinquishing custody of my daughter was not part of a birth dream, but soon became life's nightmare. My daughter is now 16.

When she was 6, my struggle to find appropriate and effective services were met with suggestions that I take a parenting class on "hard to manage" children and rely on school counselors, who are only available at school and responsible for hundreds of children. I now realize that it was not my child who was hard to manage, but a disorganized and undeveloped system that did not provide resources that could meet her needs in our community.

When the systems can't meet the needs of its children, it reflects its failures like in a mirror, on faces of the parents and families. Our skills are questioned. Our motives are questioned. We are blamed. In my eagerness to do everything I possibly could, we were also shamed.

By fifth grade, Heather had experienced countless visits to crisis units. Ineffective and missing services paved the way to police intervention. She assaulted her peers. I watched her life spinning out of control with terror and a broken heart. Feeling though we were drowning, I desperately grasped at each weak thread offered to us as though it were our lifeline. The police suggested that I send my daughter to live with her dad in Mississippi. Needless to say, her return trip followed soon because her symptoms continued to escalate.

Part of the problem for our children with mental health needs is that we don't teach them to live in our communities or provide them with the supports they need to do that. We teach them how to leave. When the behavior looks bad, we send them away. We send them to friends, relatives, programs, institutions. They are kicked out of schools, excluded from normal activities, and isolated from reality. We teach them that they are not acceptable or worthy of a loving environment. Systems break what bonds they have left and they are failed by systems. Systems make them believe they have failed, and so they sometimes do.

By age 12, my daughter's life was further complicated by the fact that she was sexually acting out, using alcohol and other drugs, and carving her body. Her pain and confusion and frustration came home to the person who loves her the most. She assaulted me. Police intervention led to hospitalization and more assessments. I knew she needed help, not punishment.

After 6 years of struggling to find appropriate services, I was told the only option for keeping her safe was residential treatment. This would come with a price tag of ultimate human sacrifice, custody relinquishment. In order to get her the service that she needed, I would have to refuse to take her home from the hospital, even though the Department of Human Services was notified 3 years prior and knew of her needs. They offered no other alternatives.

September 27, 1999, was the most devastating day of my life. I had to tell my fragile daughter that I would not take her home. I

¹The prepared statement of Ms. Brown appears in the Appendix on page 81.

had been told that no crisis bed was available, yet, though by magic, one appeared as soon as I complied.

What would you do? What price would you pay? What treatment or other medical condition in this great country comes with such a high prescription, relinquishment of custody?

Psychologists did not want to label my daughter with bipolar at age ten. Instead, they waited all those years and she got lots of other labels—delinquent, addict, promiscuous, violent, and run-away.

Within weeks, Heather was placed in an unsuccessful residential treatment program that refused to honor court orders to work towards reunification and allow visitations.

The following year, Heather entered another residential program and attended public school. The program ignored my request to include drug and alcohol treatment. Heather needed a special ed label in order to access specific therapies. She did not qualify due to past educational achievements, though her grades were failing. Behaviors at school and at her residential program and at home continued to spiral downward.

Fourteen months into the residential program, Heather assaulted a staff member, resulting in charges. The assault immediately resulted in a special ed label with an emotional and not academic basis. They were able to get what I had been asking for all along. Heather began giving up thinking that she would ever be able to return home and life.

When a staff member and facilities are unable to provide the promised mental health treatment, their backup becomes the police. Instead of increasing the capacity of the mental health service delivery, they often view emotional symptoms and behavioral issues and propel youth into the criminal justice system. Our children at this crucial, pivotal moment are no longer consumers of the mental health system. They are now viewed as delinquents of the juvenile justice system, often without treatment for their mental health disorders. I felt like we were going backwards. They were now doing what I needed to resort to.

In May of 2002, Heather was home on a visit and she ran away. She received an immediate discharge from the program, no transitional services, no school, nothing. CHS had no placement available for her at that time, so they sent her home to me, no supports, no nothing. I requested follow-up services, supports, counseling during the transition that would allow Heather to successfully live at home. DHS neglected to follow up with the services, saying they did not know if Heather would remain home.

In June 2002, I arranged some counseling for her myself. There was a month wait without any supports. Heather broke a window, acted out, used alcohol and other drugs. Criminal charges resulted. Heather ran away again, was picked up by the police and sent to the Maine Youth Center for 3 days and was released to DHS, who had done nothing to help find her. I had to file the report. They didn't even send me any supports to go through this horror.

June 2002, they still didn't have a placement for her, so they sent her home one more time.

In July 2002, she stole my car and was charged with possession of a Schedule Y drug and was again released to me. Within 30 min-

utes, she ran away again. She was sent to the Maine Youth Center again.

Heather's hearing for the pending assault charges on staff resulted in both assault and drug charges being dropped. She took a plea bargain of guilty on criminal mischief charge and was placed on 1 year's probation.

August 2002, she was sent to a locked behavioral treatment center. For the first time, she began to receive treatment for both mental health issues and substance abuse issues. It took being charged with a Schedule Y drug in order to provide my daughter with the appropriate services.

I have jumped through the hoops. I have continued to ask DHS what I can do to get my daughter back. The last treatment plan made was almost 2 years ago. It has been three-and-a-half years, treatment in exchange for custody. Heather is now in a locked facility and is on probation. Where are the outcomes? Is this the direction you want to see treatment take?

The new DHS goal for Heather is independent living, not reunification. Is this what you would want for your daughter? A DHS worker told Heather during a treatment meeting that she could get an apartment soon, and "if you stay with us, we will send you to college." Do you know many 16-year-olds who don't want that offer? Do you know many families who could compete with such financial inducement?

DHS defines jeopardy in this case as my inability to pay for service. Recent documents indicate that jeopardy has been reduced or eliminated. A January 2002 legal summary States the role primarily is there for special needs.

I have not been able to see my daughter since her 16th birthday. Have any of you seen her in the last 140 days? Have any of you talked to her or communicated with her? I haven't. She has been my life, and she did not deserve being treated the way she was. Thank you.

Chairman COLLINS. Thank you very much, Theresa. I just can't imagine any parent going through the agony of making the decisions that you have had to make in order to get the treatment that your daughter so desperately needed. It is my hope that by hearing from you and the other witnesses today that Congress will realize that we need to help the States solve this problem and come up with a system that ensures access to care for severely ill children without their parents having to either get them arrested or give them up altogether. Those are choices that no parent should have to make.

Cynthia, I would love to hear your statement now, too. Thank you.

**TESTIMONY OF CYNTHIA YONAN,¹ GLENDALE HEIGHTS,
ILLINOIS**

Ms. YONAN. Thank you. Madam Chairman and Members of the Committee, I want to thank you all for providing me the opportunity to testify at this hearing about a subject that is very near

¹The prepared statement of Ms. Yonan appears in the Appendix on page 87.

and dear to my heart, the struggle that my family has endured in attempting to access mental health services for my twin sons.

My name is Cynthia Yonan and I appear here before you today as a parent deeply concerned from Glendale Heights, Illinois. I am appearing today on behalf of NAMI, the National Alliance for the Mentally Ill, and NAMI will be submitting a written statement for the record.¹

In 1984, I was truly blessed with the birth of my identical twin sons, Ryan and Sean. Despite our blissful beginnings, both the boys showed early warning signs of mental health-related concerns. My husband and I were divorced early in their lives, and soon after his visitation was established, I discovered that he had physically, emotionally, and sexually abused my boys for one-and-a-half years.

The abuse had a devastating impact on Sean and Ryan. They both required hospitalization. Sean required it for suicidal tendencies and Ryan for homicidal tendencies. Both boys were hospitalized. Sean attempted suicide three times and was extremely unstable. He left the house in the middle of the night. He stole food, he stole money, clothing, and other items, and Ryan exhibited the same difficult behaviors and also could not control his anger. He was removed from school after making violent threats.

Because of the seriousness of their illnesses, both boys spent 3 months in a locked hospital. This quickly exhausted my private health insurance benefits. It had restrictive caps on the mental health coverage, and those caps caused my sons to be released back to me from the hospital, at which point I turned to the County Mental Health Department and they directed me to turn over my children to the State to secure the treatment that they needed.

Both of my sons were diagnosed early with bipolar disorder, attention deficit, hyperactivity, post-traumatic stress disorder, oppositional deviant disorder, and they were born with Klinefelter's syndrome. That is an illness that results from having an extra "Y" chromosome and makes them naturally overly aggressive and they have a lack of impulse control.

Our struggles grew after the boys returned from the hospital in January of that year. At that time, I also had three daughters at home, 16, six, and five. Sean and Ryan didn't return back to school like the other kids and I spent from January through May attempting to find them an educational placement. The school district failed to provide me with any assistance.

Tragically, during this time, and despite my attempts to keep a 24-hour watch on my sons, they threatened and assaulted two of my daughters. As you can imagine, this was devastating to my family. I was physically exhausted, at my wit's end and a nervous wreck every minute of the day. It was quite clear that the boys needed intensive mental health treatment services.

Through this incredibly trying experience, I was forced to quit my job to stay home to keep the boys and my daughters safe. Despite the loss of my job and income, Medicaid wasn't an option for mental health services because I owned my house and I didn't qualify under the strict minimum assets requirement. I could have

¹The prepared statement from NAMI—National Alliance for the Mentally Ill appears in the Appendix on page 214.

been living in the streets. That was the only way I could have gotten Medicaid at that time. I simply didn't know where to turn to secure the mental health services for my sons.

Extremely exhausted and frustrated, I searched for help from the Department of Mental Health and the Department of Children and Family Services. Both agencies informed me that I would have to turn my sons over to the State to secure mental health services. Frankly, I was shocked when faced with this decision. I couldn't fathom how State agencies could ask a family to abandon their ill child to secure mental health services. At the time, I wondered if families with children that had anything other than brain illnesses, like cancer, were ever asked to turn their child over to the State for treatment.

I love my sons, despite all that we have been through. They are ill, not bad. I was determined that I would not abandon them in their hour of greatest need. Giving up my sons was not an option and it would serve only to make them feel unwanted and unloved, not to mention further trauma that it would cause in their lives.

I spent 2 years calling and searching for mental health services for my sons. In 1998, I was directed to the Community Residential Services Authority. It is a well-kept secret and one that was offered to me only after years of struggle and pain and when it became clear that I was not going away. The State agency was created for kids that do not fit within the criteria of services established under DCFS, the Department of Mental Health, the Department of Corrections, or the Illinois Care Grant. With guidance and help of the CRSA, my sons were placed in a residential treatment facility in July of 1999. I am pleased to report that the treatment they have received has made a significant difference and given us hope for a brighter future.

No family should be forced to go through what I did, or anybody else at this table. Families with children that have serious mental illnesses want and deserve laws that provide funding for mental health treatment so no family is told they must give up custody of the child to secure mental health treatments and services.

I am so pleased that Senator Collins has proposed the introduction of legislation to address this crisis. Her leadership is greatly appreciated, and you have no idea what you are doing for us parents and our children, ma'am.

Again, I thank you for the opportunity to speak with you this morning and I am happy to respond to any questions that anybody has. Thank you.

Chairman COLLINS. Thank you very much, Cynthia, for your very eloquent statement. I think your experience shows what can happen when a family does not know where to turn for assistance, is denied coverage under Medicaid because of the asset test, and can't afford the treatment themselves. It is also interesting that it took you 2 years to even find some source of help, which is another part of the problem. It is another example of the flaws in the system.

Ms. YONAN. Can I say something?

Chairman COLLINS. Yes, please do.

Ms. YONAN. If I didn't have to go through that 2-year process, my two younger daughters would never have been hurt. My boys would have been picked up immediately from the hospitalization stay and

placed in a facility. Right now, my boys are turning 19 and they are moving into their own independent living program. One, Ryan, is going to be living on his own in an apartment in Chicago shortly and his brother will be there 3 months after him.

But what it did to the rest of my family, and I am not just talking the immediate family, my mother, my brothers and sisters, this affects every life that you are connected to, and these children had a right to have that care. I just want to know why that if I turned my child over, these agencies would fund them. It was the same money. It didn't matter whether they had custody or I had custody. The money was there anyway.

And what I don't understand, ma'am, and maybe you can figure this out at the Federal level, is why these agencies don't work together. We need an interstate agency agreement, whether it is on a Federal level or a State level, because one agency doesn't know what the other agency is doing. They don't know what funding they can do for this and what they—the money is out there. We do need—everybody needs more money, but the money is there and we need some kind of legislation passed to change this.

I am hoping that what you are proposing is going to go through, and if there is anything I can do personally, I will be more than happy to help you, and I can get as many parents as you need to come to Washington.

Chairman COLLINS. Thank you so much. The questions you raised are exactly the right questions. This really isn't a question of money because if you are willing to give up custody of your children, the money is there. Something is just terribly wrong with a system that withholds treatment that is desperately needed by these children until they get into "the system."

Ms. YONAN. If they had leukemia, they would be treated.

Chairman COLLINS. That is right.

Ms. YONAN. But like Representative Kennedy said, your brain is part of your body.

Chairman COLLINS. Right.

Ms. YONAN. They are sick. They are not bad, they are sick. If you have leukemia, you get the treatment. But if you have a mental illness, you don't, and that, to me, is inhuman.

Chairman COLLINS. Thank you.

I would now like to call on Patricia for her statement.

**TESTIMONY OF PATRICIA COOPER,¹ FAYETTEVILLE,
ARKANSAS**

Ms. COOPER. Madam Chairman and Members of the Committee, thank you for providing me this opportunity to testify at this hearing about the long struggle that my family has endured in attempting to secure appropriate mental health services for my son.

My name is Patricia Cooper. My son's name is Dakota. We live in Fayetteville, Arkansas. I am also appearing today on behalf of NAMI, the National Alliance for the Mentally Ill, and NAMI will be submitting a written statement for the record. Despite appearing on behalf of NAMI, this is my personal story about what my family has gone through.

¹The prepared statement of Ms. Cooper appears in the Appendix on page 90.

Our son, Dakota—this is him—came to live with me and my husband, his biological father, in 1997. John has full custody of Dakota. He is a wonderful boy with big bright blue eyes. They will get your heart. And he has blond hair. He loves sunsets and he always insists that we stop to enjoy them. He also loves everyone around him. Friday is Dakota's birthday and he will be 12 years old.

Dakota suffers from multiple mental illnesses, including attention deficit-hyperactivity disorder, reactive attachment disorder, left hemisphere processing deficits, oppositional defiant disorder, and post-traumatic stress disorder. The symptoms of these illnesses cause Dakota to act out in extreme ways, including attempts to start fires, using knives in dangerous and sometimes threatening ways, running out of school into busy intersections, and sometimes hurting the dog. But, of course, this dog is his best friend, his only sibling, and he loves her, as well. He is a really great kid. He cannot be left unsupervised at any time or anywhere.

Despite these challenges, John and I love our son. We know his actions are the result of his struggles with his mental illnesses. It is not because he is a bad kid. He is the best kid you could ever have. He picks you flowers. He loves sunsets. He loves colors. He is a very visual person. He wants to take care of you when you are sick, very attentive to your needs.

Our journey began in 1997 when the school noticed that Dakota was really struggling. The principal informed us that Dakota needed immediate help, and, of course, we were not surprised because of Dakota's behavioral struggles at home. Although we wanted to keep him in our home, it was clear to us that he could not continue to safely reside there without the appropriate support and services to address his mental health needs.

Unfortunately, our private insurance did not cover home and community-based mental health services that we needed for Dakota. Our policy included caps and restrictions on mental health coverage and fell far short of the intensive services that Dakota needed. Our income level does not qualify our family for Medicaid because both John and I work.

At this time, we decided that our only option was to place Dakota in a residential treatment facility. He did OK with the placement, and this first placement happened not long after he came to live with us. So we were extremely excited and full of hope and ready for him to return home and start anew.

But, of course, things did not go well at home with Dakota. The truth is, our family was falling apart. We were talking about divorce. We were working different shifts. I was trying to finish my degree at the University of Arkansas. My husband was working 80 hours trying to pay the bills. It was very hard.

We called the Department of Human Services and they informed us that there were no services for Dakota and our family. Of course, they would refer us to the mental health institutions, but if you don't have money, what are they going to do for you? Over time, they suggested that, given the seriousness of Dakota's mental illnesses, we consider giving up custody of him to the State to secure the level of services he needed. Over the past few years, we have heard this many times. I have been told this so much. We

refuse—I refuse to consider this option. He is worth loving and he is worth helping and I will not give up on him.

In late 1999, a school-based therapist told us about a TEFRA Medicaid option, and this is also known as the Katie Beckett option, that could help fund intensive home and community-based services that Dakota needed. Dakota also spent time in multiple residential treatment facilities. Unfortunately, not all of these placements went well. Actually, after one stay, we were told that we would need to take him home with virtually no appropriate home and community-based services. We expressed great concern that without the appropriate treatments and supports, Dakota would suffer serious setbacks and his illnesses would worsen.

This has happened almost after every release from a treatment facility because we don't have the support in our community. We need respite. We need someone to be with him when we can't be with him because he is a 24-hour, seven-day kid. But he needs to be in the community. He needs to know how to socialize from us. He needs to be a part of our family.

It was then that we were told that Dakota would be placed in a therapeutic foster care through a voluntary placement agreement. He was placed with a family that lived 4 hours for home and for 11 months. The State used an abuse and neglect proceeding to place Dakota in foster care. John and I were treated by the foster care system as parents who had abused and neglected our son. It was very painful and humiliating and I am never going to go through that again. They were very helpful and nice, but as soon as we said, "I do," the tone changed and we began to fight to get him back. It was not about help. That is my impression.

During the past year, Dakota has resided in residential treatment facilities in three States, Oklahoma, Colorado, and Arkansas. We only wish that the appropriate home and community-based mental health services existed for Dakota and our family and were adequately funded. That is a big part. We want Dakota home with us, the people that love him most, the family that loves him the most, the place where he can do the best. I just know it. We also wish that our families did not have to endure the long battle that we did, that we had to go through to secure the mental health services, and the toll it has taken on our family.

I want to thank you, Senator Collins, for your leadership in addressing the tragedy that far too many families in our Nation face in struggling to secure mental health services for their children. Thank you again for this opportunity to speak with you this morning and I am happy to respond to any questions you may have. Thank you.

Chairman COLLINS. Thank you very much, Patricia, for sharing Dakota's story and your story with us.

I couldn't help but think as I have listened to all three of you how difficult it is for a family to cope with the challenge of raising a child who is suffering from a mental illness. That is hard enough. But then for all of you to face obstacle after obstacle to getting the care that your children need is just placing an extraordinary burden on you at a time when you already have your hands full with a considerable challenge. That affects the entire family, as each of you have said.

Each of you has said that you realized that your children were suffering from a mental illness, or that something was desperately wrong and that they needed help. Yet in listening to your personal experiences, I noted that in each case, it took a long time for you to get the treatment that your children so desperately needed.

I would like each of you to comment, and Cynthia, you did a little bit, but I would like each of you to talk about how you think life might have been different for your child and for your family had you been able to get the help that they needed early, when you first realized that they were suffering. When you realized that it was beyond your ability to cope and that your children needed professional mental health services. How would that have changed life for you, Theresa, and for Heather?

Ms. BROWN. I think with Heather's diagnoses, if they would have given her residential treatment when they knew she needed residential treatment, then I don't believe she would be suffering so bad from post-traumatic stress disorder. She would not have this sexual addiction that she has. She would have been able—she wouldn't have had to turn to drugs and alcohol to cover her feelings. Us, as a family, I would be able to enjoy what a lot of families enjoy with a 16-year-old girl, being able to go with her to the store to buy a dress for prom, getting her license, I mean, just having her friends over at the house.

If they would have just diagnosed her. They wouldn't do it. And there were only two options out in Maine for her, and she didn't qualify for either one of them. And the two options were DHS, which they weren't involved, so they wouldn't help, or the school. And because she was a straight-A student, they would not sign off for her to get treatment.

Chairman COLLINS. Did people at Heather's school identify behavioral or other problems and come to you about them?

Ms. BROWN. Every report card, comments on behavior, and when it is brought to their attention, I was told that they would rather deal with her behavior, that they could deal with it and it was a parenting problem.

Chairman COLLINS. Cynthia, you started to talk about this in when you said that had your sons received the help that they needed, that you would not have had the devastating assault on your daughters. Could you talk more about the delays in getting treatment for your sons and what that meant to their progress and also your family?

Ms. YONAN. If my sons had gotten the proper funding, if there was some source after my medical care, health care ran out, my sons wouldn't have lost 3 years of their lives in residential facilities. They probably would have spent 1 year in a residential facility.

Our family was torn apart, my younger daughters, my older daughter, and my sons. I wouldn't have had to stop working. I wouldn't have had to go to food pantries to feed my family. I wouldn't have had to move out of my house into my niece's house just to get public aid and then do as much as I could to maintain a family on nothing and no money and nowhere to live. I wouldn't have probably suffered two heart attacks and have a disease that is going to kill me because the stress set off the heart attacks.

My whole life has changed. My sons' lives have changed. We lost—we lost years together, the things that mothers and sons do, baseball games and all the things that you do with your family, vacations and all the wonderful fun-loving things people take advantage of didn't exist in my family.

And had my sons gotten that funding and it would have taken them 1 year at a good facility like the one they are at now in Onarga, Illinois, I believe that they could have come back and lived in my house and we could have resumed our family life, because we are doing it now. But because there was nothing out there, and that 2 years I spent calling everybody in the State of Illinois, I wrote to legislators, senators, and governors and they had no answers because they didn't know how to tell me what to do except give up my kids. How could—I cannot fathom that.

I know what these women have gone through, and millions, and I am talking millions more across the world and in the United States of America, and I will tell you this much. I wish to God everybody had a CRSA. It is a State agency that was proposed by legislation in our State that helps families like ours. If I would have found out about that, I wouldn't have lost all those years of my life and my sons' life.

Chairman COLLINS. But it was 2 years before you found out.

Ms. YONAN. Yes, because it was the best-kept secret in the State. Nobody knew about it.

Chairman COLLINS. Thank you.

Ms. YONAN. Thank you.

Chairman COLLINS. Patricia, can you tell us the difference it would have made to your family and to the treatment of Dakota had you been able to find the help that you needed sooner and without relinquishing custody?

Ms. COOPER. I believe that Dakota would be a lot further along than he is now. Of course, we are reaching age 12. He is reaching age 12, which puts him in the really risky category, and we have been trying to do everything we can to try to beat that. Of course, if we would have started earlier, he could have possibly been further along in school. I mean, he is reading on a first grade level. His math is second. He socializes at a 5-year-old's level. We just wasted time and there was nothing I could do.

I want to believe that he would be further along than he is now and he very possibly would not be gone from me for this whole year. It has been a year since he has been home, in a residential treatment facility. Of course, if we had the step-down method of easing him back into our home, and then plus having more than just wrap-around with family therapy and individual therapy, if we actually had someone who could be a support to us and to him, it would have made a world of difference, I could bet my life on it, because if they could do what I can do in the home, if we could just make everything work together, he could do so much better.

Chairman COLLINS. Each of you have told a story that is just heartbreaking, and I know all of you want nothing more than to have your children living with you and with the support systems and the treatment that they need available to them right at home. You have given us a lot to think about.

I am going to call on Senator Pryor for his questions.

Senator PRYOR. Thank you, Madam Chair.

I would like to start, if I could, with Ms. Cooper. One of the things you mentioned in your statement is private insurance. In Arkansas, we have been having this ongoing fight down at the State legislature about mental health parity and trying to make sure that insurance covers mental health issues on an equal basis, and you know that fight. There have been some victories and some losses there.

Let me ask about your insurance. I believe you said it was inadequate to cover what you have.

Ms. COOPER. Right. Actually, at the time that Dakota came to live with us, the insurance my husband had put a two—I have just lost the word—we couldn't use the insurance—preexisting conditions for 2 years—

Senator PRYOR. Oh, OK.

Ms. COOPER [continuing]. So we weren't allowed to use it for anything with his mental illness except medication.

Senator PRYOR. So there is a preexisting clause in your insurance, so it doesn't help at all.

Ms. COOPER. Right, because we told them of his problems. Then they wouldn't allow us to use it.

Senator PRYOR. All right. Let me ask the other two witnesses about private insurance and your experience there.

Ms. YONAN. When my sons were hospitalized for the first time, they were in an inpatient setting and it is very costly to do that. My mental health—the capacity, the range, because there were caps on how much was expendable, was—it was just run dry. I had two sons in there.

Senator PRYOR. Sure.

Ms. YONAN. It wasn't on a yearly basis that this was—because I restarted in November and they went through to January, so they considered it split into two different years and it sucked up all of the expenditures that were available and there was nothing left. There was no way I could get separate insurance for these boys because they had preexisting conditions.

Senator PRYOR. Right.

Ms. YONAN. Nobody would touch them with a ten-foot pole.

Senator PRYOR. OK.

Ms. BROWN. I didn't have insurance at the time, but when I was able, when I was working and I did get insurance, it also had preexisting conditions that wouldn't enable any treatment. She was on Medicaid through the State at the time.

Senator PRYOR. And your struggle with what your families are going through on an ongoing basis, are you aware of anyone that has adequate private insurance to cover the needs of their families, their children for mental illness? Have you all talked to anyone who has?

Ms. YONAN. No.

Senator PRYOR. That is my impression, too. Go ahead.

Ms. YONAN. Well, like Representative Kennedy said, they don't consider it like a sickness. They give you a certain amount of dollars that you can spend, and when those dollars are spent, oh, well. I mean, your mental illness isn't going to go away like that. But

like I said previously, if it was leukemia, they would pay for it your entire life.

Senator PRYOR. Right.

Ms. YONAN. I don't know anybody who has personal insurance that would do that on a mental health basis.

Senator PRYOR. There may be a few out there, but my impression is just the vast majority are not going to be adequate to cover what your needs are.

What are you all hearing, and again, I will start with Ms. Cooper, what do you all understand to be, I mean, what are you told is the rationale for requiring you all to relinquish custody of your children? What is the rationale for that that has been given to you?

Ms. COOPER. Well, basically, because we don't have the supports in our community to keep him and he is continually having to leave to go back into a residential treatment facility, because he is getting older—with such short stays between each residential treatment, 6 to 9 months is not long enough to adequately treat anything, in my opinion, when it comes to mental illness. So, of course, we haven't really been able to find a way to help him, and given his age and he is very violent—potentially, he can be very violent, and bringing him home without support, he could run away, he could get involved with the juvenile court system, do things, and it may come to a point where at 15, when I need to watch him 24/7 and I can't find that help, I am going to be forced into that option of asking the State to help.

Senator PRYOR. What were you told about why you have to give up the custody of your children?

Ms. YONAN. They told me that they couldn't bend the rules to fund my child—children—because they didn't fit the specific criteria. They didn't have enough mental illnesses for one department. They didn't have the right mental illnesses for the other department. And, of course, DOC, the Department of Corrections, they didn't have a criminal record. So when they didn't fit, they couldn't go outside the box of their specific criteria in the State. On the local level, there was nothing that was intense enough to take care of my children because of the multiple diagnoses and the abuse and I didn't have any money to pay for it anyway because I had to quit and stay home and watch my kids.

Senator PRYOR. Has that been your experience, as well, that a lot of children don't fit in the right box for certain agencies?

Ms. COOPER. Right.

Senator PRYOR. Now, is that a State or Federal issue or both?

Ms. YONAN. That is State.

Ms. BROWN. State.

Senator PRYOR. State mostly? State?

Ms. YONAN. Each State has their own individual criteria on what they will accept. I believe, like in mental illness, they have, as far as the disease and the psychoses diagnosed, they have to combine—they go by the same criteria. But each State with their own funding manipulates it as they see necessary according to each department.

Senator PRYOR. And Ms. Brown, what was your answer on the rationale you have been given on why you have to give up custody?

Ms. BROWN. Because Medicaid did not pay for residential treatment of my daughter for mental illness and for long-term treatment, that would be residential, and so I had no other option, because if I put her in State custody, then they would be able to receive Federal funds which would help pay for her treatment.

Senator PRYOR. Thank you, Madam Chair.

Chairman COLLINS. Thank you.

Senator Durbin.

OPENING STATEMENT OF SENATOR DURBIN

Senator DURBIN. Thank you, Madam Chairman, and I want to especially thank you for this hearing. I am afraid there aren't enough of us on Capitol Hill talking about these problems.

I find it interesting when I go back to my State, or anywhere, for that matter, if I mention the issue of mental illness, after I have given my little talk, invariably, someone will come up to me and say, "I need to talk to you. I have had a problem in my family. We have had a problem with our neighbors, our friends." This is a real American family problem that we don't talk about. I don't know why.

I think it goes back to perhaps what Ms. Yonan said earlier. We just don't view this as an illness. It is something else. I think we view it as a 19th Century curse and we don't know if we want to be around the people who have been cursed, and that is just plain wrong. That isn't fair to the victims. It isn't fair to their families. And you see it evidenced so often.

Thank you, Ms. Yonan, for being here from Illinois—

Ms. YONAN. Thank you.

Senator DURBIN [continuing]. And telling your story, along with Ms. Cooper and Ms. Brown. But you really put your finger on it here. Who would ever consider telling a parent with a child just diagnosed with cancer that the only way your child can be treated is to be removed from your home, taken off somewhere and treated as if they have been incarcerated, or they are being punished? This is just totally upside down.

The current health care system in America is not rising to the challenge at all. We have talked about private health insurance here. We have 64 cosponsors of the Wellstone-Domenici bill on parity for mental illness and health insurance. Of all the important things we are doing in the U.S. Senate, for goodness sakes, in the name of Paul Wellstone and for our good friend Pete Domenici, why isn't this bill on the calendar today, next week, so that people are not discriminated against, so that they have an opportunity to have mental health services covered with their health insurance.

I have a bill on discrimination. I have people that I have talked to who are afraid to talk to a doctor about depression, which is a common illness in America and a treatable illness in America. They are scared to death to put it in their medical record for fear that from that point forward, there will be an exclusion on their health insurance policy so they can't be covered for it. Now, this makes no sense at all. People are unhappy, unproductive when they could be treated and treated successfully.

I am glad, Ms. Yonan, that you told the story about finding at least an answer to your prayers for your sons in Illinois, but thank

goodness you found it, because people weren't giving it to you as a first option at the outset. I understand some 5,000 people have been served by this in our State, in residential treatment facilities, that at least give you the peace of mind that professionals are helping your boys.

How did you discover this? I mean, the Department of Children and Family Services and others never brought this up?

Ms. YONAN. No. I started out being involved with the Department of Mental Health and they assigned an SAS worker to my case, and basically I asked, well, they need long-term health. Is there anything I can do? No, we don't know anything, la, la, la. A DCFS worker was assigned to my case. She didn't know anything. Without the kids being turned over, there was nothing out there.

I wrote to Senator Pate Phillips. I wrote to Kathy Wojcik and said, is there anything out there? I need help. I need help. And the caseworker in DCFS, who is an angel of God, found out about the CRSA and Senator Phillips, when he wrote to the governor about my case, found out about the CRSA and they gave me the phone number and my whole life changed.

Senator DURBIN. It took you 2 years, as I understand?

Ms. YONAN. Two years, 2 years of searching.

Senator DURBIN. Before you discovered this. And you were caught in the middle, not poor enough for Medicaid, not wealthy enough to pay out of your pocket—

Ms. YONAN. Exactly.

Senator DURBIN [continuing]. So you were stuck. Health insurance wasn't going to cover it, and but for this program stepping in, there was no place to turn.

Ms. YONAN. Absolutely none. My sons—I truly believe one would have been dead and one would have been in jail. I had nothing.

Senator DURBIN. Madam Chair, as if you don't have enough to do, my friend and former colleague Paul Simon has just done a program on the incidence of mental illness among those incarcerated. I call tell you, the Illinois Department of Corrections, probably the Federal Department of Corrections and so many others, totally unequipped to deal with this problem, prisons being filled with people with mental illness and no treatment. It is the worst memory of the snake pit that we recall from our youth, this terrible idea that you would be trapped in a prison with a mental illness and no place to turn, and that is what is happening.

Your sons were diverted into something where they can get some treatment. Had that not occurred and terrible things happened and they would have been arrested and put into the system, who knows. They could be sitting in Pontiac or Joliet or you name it, whatever prison, with no treatment whatsoever.

Ms. YONAN. And they would never get out.

Senator DURBIN. In the darkness and depths of their mental illness, and that is a fact and that is a cruel reality that this great Nation has to face up to, as well.

Madam Chair, thanks for your leadership on this and thank you all for joining us.

Chairman COLLINS. Thank you, Senator Durbin.

Theresa, I just have one more question for you that I want to bring out. When you very reluctantly relinquished custody of your

daughter, did you also then lose control of having any voice in her treatment? Were those decisions also taken from you, or are you able to be involved in deciding what happens to your daughter?

Ms. BROWN. In the beginning, they would ask me what I felt. But at this point, I have absolutely no say whatsoever, none.

Chairman COLLINS. So that must be extraordinarily difficult for you, also.

Ms. BROWN. It is, because I, on top of not having contact with her, I don't get to help make health decisions for her. She had to have a tooth pulled and they tell me after the fact. I mean, I don't get notified of anything anymore. I mean, it is just—I don't understand, and when I try to find out, nobody will tell me. And that—it makes it so difficult, because I haven't done anything wrong, and neither has my daughter.

Chairman COLLINS. And Patricia, I think that this is a point you were making, too, when your son was placed in a foster home, a voluntary placement, but essentially one that categorized you and your husband in the same category of people who had abused or neglected their children. Is that correct?

Ms. COOPER. Yes.

Chairman COLLINS. So that must be extremely painful for you, also.

Ms. COOPER. Yes. I did not like it—it wasn't a control issue, it was a mom and dad issue, that we had always done what we needed to do for him, and to get him services we were required to give him up and have that removed from us, it was very painful. He was 4 hours away. You miss holidays and the tooth fairy coming. If he is sick, you are not there. Of course, the communication, because we were over different counties, no one communicated. It was very hard to get people to communicate. If I knew something, it was because I probed. I didn't know anything much about his school grades. I didn't know who his teacher was. So, yes, I don't want to go through that again. I like being a part of the decisions that are made for him.

Chairman COLLINS. Cynthia, I want to inject a positive note and tell you that is why I think all of us are cosponsors of a bill called the Family Opportunity Act that would allow families who make too much to qualify for Medicaid but still can't afford the health care that their children need to buy into the Medicaid program on a sliding premium level. My hope, along with the mental health parity bill, the Family Opportunity Act, and the legislation that I am working on with the two Congressmen, I am hoping we can really put together a package of bills that will make a difference.

I want to thank each and every one of you for coming forward today. We read the statistics about the number of children suffering with mental illness. We have talked about the survey done by the NAMI that tells us that far too many families are forced to relinquish custody. But your personal stories remind us of what it is like for families, and I really appreciate your willingness to come forward. I know you have been through extremely painful experiences and hard times, but my hope is that your stories will enable us to work together to make a difference, so that other families don't have to endure the heartbreak that you each have endured. So thank you so much for being here today. Thank you.

Ms. BROWN. Senator Collins, can I say one more thing?

Chairman COLLINS. Yes, Theresa.

Ms. BROWN. I want you to know that, as of now, in the court's eyes, I am being selfish and inconsiderate of my daughter's needs because I want custody of my daughter, and so I just wanted you to be aware. I don't understand, when did not having a mother—I am her only blood relative in the State of Maine and I can't—she had a friend get in a car accident very recently who is in critical condition and I can't even be there to comfort her. It is just—I don't understand.

Chairman COLLINS. Well, it is devastating and there is something horribly wrong when you have a system that isn't a system—but rather just a series of coverage gaps.

Our next panel also has a great deal of experience, and again, I want to thank you so much for sharing your stories with us today.

Chairman COLLINS. I would now like to call our third panel forward. We will hear from representatives of organizations directly involved with families facing the challenge of finding appropriate mental health services for their children.

I would first like to welcome Trina Osher, who I had the pleasure of meeting earlier today and who will be testifying on behalf of the Federation of Families for Children's Mental Health. The Federation is a family-run organization, and I think that makes its views particularly important. It is really a grassroots organization. It focuses exclusively on children with mental health needs and their families, with 150 affiliates in communities throughout the country. Ms. Osher has a very strong personal as well as a policy perspective that she is bringing to this hearing because she, too, was forced to relinquish custody of her own child 17 years ago.

I would also like to welcome Tammy Seltzer, who will testify on behalf of the Judge David L. Bazelon Center for Mental Health Law. The Center is the leading national advocacy organization for adults and children with mental disabilities. Ms. Seltzer will help the Committee understand the challenges facing parents who must rely on public services to ensure that they have equal access to mental health care.

And finally, we are very pleased to have here today Dr. Jane Adams, the Executive Director of Keys for Networking in Topeka, Kansas. Dr. Adams will share with us the success of a home and community-based services Medicaid waiver program in Kansas, and when we talked with people in preparation for this hearing, over and over again, Dr. Adams came up and the State of Kansas came up as a model that we could look to in trying to encourage other States to improve their services.

So we are very pleased to have all three of you here today, and Ms. Osher, we will start with you.

**TESTIMONY OF TRINA W. OSHER,¹ COORDINATOR OF POLICY
AND RESEARCH, FEDERATION OF FAMILIES FOR CHILDREN'S
MENTAL HEALTH, ALEXANDRIA, VIRGINIA**

Ms. OSHER. Good morning, and thank you so much, Senator, for the opportunity to speak here today. As you said, I am speaking on behalf of the Federation of Families for Children's Mental Health and thousands and thousands of families who have faced the agony of relinquishing custody so their child could get mental health services.

As you said, it is 17 years since my husband and I, desperate, desperate, desperate for help and with no other options, relinquished custody of our own middle child so he could go to a therapeutic residential school. It was a devastating experience with life-long repercussions for everyone in our family and we are greatly encouraged by the attention this cruel social policy is now getting thanks to your efforts and we hope the Congressional action will soon put an end to it forever.

From a parent's point of view, what is the problem? Parents in general, parents around this country have limited mental health coverage in private and public insurance plans. This causes families to exhaust benefits before the mental health needs of their children are fully addressed, as some of you were asking about. This is especially true if a child's condition is chronic and intensive intervention is periodically required. We are either urged or required to relinquish custody to access funds that will pay for the mental health services so desperately needed.

A recent study of 176 Maryland families, and I am from Maryland, showed that almost two-thirds of families whose children had had lots of hospital visits were told to relinquish custody. How many other parents would do such a thing? How many of us would even be asked to do such a thing if our children didn't have a mental illness?

Children who are relinquished in order to get mental health service are deprived of their right to be connected to their family. A family should be a lifelong source of emotional support. Parents who relinquish custody are deprived of the right to make everyday decisions about their child, like what they will wear and what they will eat, who they will play with, where they will go to school, or if they will be taking medicine for their mental health problems. How would any of you feel if you could only see or talk with your child with the permission of a judge or under the watchful eye of a social worker?

Safety concerns often lead to custody relinquishment. A number of the stories we heard from in the previous panel illustrate that, and let me give you another example from Oregon. A family was seeking help for a child who is 16 years old, who was running away from home, who was not cooperating in school and refusing to take medication and living on the streets. Children's Services recommended residential treatment. They took custody of the child and placed him in a foster home, from which he continued to run. Would you feel good about this outcome if it was your child?

¹The prepared statement of Ms. Osher appears in the Appendix on page 94.

What is needed, as you said in your introduction a couple of hours ago now, I think, Mrs. Collins, is a combined approach that bans the practice but also increases access to effective mental health treatments and services for our children.

In inviting me here today, you asked me to identify some of the barriers we face in trying to get help for our children. No matter how hard we try, we can't seem to get what we need, when we need it, and how we need it. Continually being denied access exhausts us and eventually defeats even the most resourceful and stable of families.

Like all children, ours need outlets for physical activity and social interaction, but they can't participate in after-school activities or community recreation programs without some kind of supervision or support, like a mentor or someone to help them with the social interactions and help them control their behaviors. There is no insurance program that will pay for such assistance. It is not considered medically necessary.

We need a break from time to time. Unlike most parents, who get a babysitter so they can go out to dinner and a movie, there is almost no one who is willing to take care of our children because of their challenging behaviors, and if we do find someone, it is much more expensive than regular babysitting. It seems rather unfair to us that families who have a child with developmental disabilities easily get respite care and we can't.

Schools are not able to help most of our children, either. According to the Department of Education, about 50 percent of students identified as having emotional behavior disorders drop out of school. Once they leave schools, these students lack the social skills and other skills necessary to be successfully employed and eventually feed into some of the adult systems we have heard other people talk about already.

Many parents have to give up good jobs to care for a child who is repeatedly ejected or rejected from schools and other programs. One parent recently told me he has not been working for over a year just because his son needs adult supervision at all times, and this child is not in school because the school system says they can't serve him.

When we bring our children home from hospitals or residential treatment programs, we need intensive and flexible after-care services and transition services. Yet, most of our children return home without any follow-up. Typically, severe problems recur because they were not stabilized in the first place, mostly because the hospitalizations were too short because that is all the insurance would pay for, and then after-care arrangements with schools and community-based mental health treatment services and home-based family supports were never made.

Our children and families need more options besides a hospital bed and a typical 50-minute therapy hour. A few examples. Our children need special help to develop social skills and self-control in the real world where they are having their troubles, but mental health professionals don't work in these settings. They just work in their offices.

We often need special support to do normal family tasks, like getting ready for school or supervising homework. Many of us can't

even get to mental health services without getting help with transportation or care for other children. And ironically, as much as we may need and want the benefits of a support group, sometimes we are just too exhausted to go.

We are often caught between conflicting requirements of several different child-serving systems. I recall vividly one meeting on my own child where case managers from four different systems—four different systems, education, mental health, juvenile justice, and social services—could not agree on what the problems were or how to address them. Lack of common definitions, lack of terminology, lack of common mandates, and confusion about eligibility criteria across these systems and the providers within them contribute significantly to the problem.

You also asked me to identify what Federal and State Governments might do to help. Here are some suggestions for you. State and Federal policies really must make it possible for us to keep our children safe in the neighborhood, make it possible for them to make good progress in school and to live with us, the family that will love and care for them as no one else will.

I am going to digress for a second from my remarks. I was so struck by the previous panel, that every single one of them, their children weren't in school. Now, if parents of typically developing children didn't send their kids to school, what would we be doing? Charging them with abuse and neglect for failure to send your child to school. But because you have a mental health problem or a behavior problem, somehow or other, you don't get to go to school.

Congress must prohibit, and I really mean must prohibit States from requiring parents to voluntarily transfer legal custody of their child just to obtain mental health treatment, whether these are out-of-home placements, Medicaid eligibility, in-home supports, community supports, or access to any other Federal source of funding.

There is a huge lack of services in general in our communities and Congress should really consider increasing the State mental health block grant program substantially, maybe up to as much as 20 percent, and designating all of that money specifically for children and their families.

Congress also needs to think about establishing a long-term program and funding it so that there is a larger pool of people who are qualified to serve our children and our families in a manner that is respectful of family-driven practice and the values of systems of care. We don't have enough people who know how to help our kids in our communities.

And State agencies should be required to develop realistic and working interagency agreements that really can coordinate services and braid the funding streams. Such agreements should require that families have a voice and choice in decision making. They should allow the use of existing Federal funds to pay for home and community-based services, to help pay for family supports, and to enable families to stay together so our kids can graduate from school, so they can enjoy friendship like their peers, participate in community life, in other words, to be just like any other American kid. Thank you.

Chairman COLLINS. Thank you very much. Ms. Seltzer.

TESTIMONY OF TAMMY SELTZER,¹ STAFF ATTORNEY, BAZELON CENTER FOR MENTAL HEALTH LAW, WASHINGTON, DC

Ms. SELTZER. Good morning, Madam Chairman. I am a staff attorney for the Bazelon Center for Mental Health Law and I want to thank you very much for the opportunity to come here and share what we know about the custody relinquishment problem. I applaud you for holding today's hearing and for your role in requesting the GAO study on custody relinquishment with Representatives Kennedy and Stark. I was particularly moved by the panel before us, to allow the mothers to put a human face on this devastating problem. That is not done often enough.

Custody relinquishment has been a longstanding concern of the Bazelon Center. We have provided technical assistance to stakeholders, including States, and we have produced two reports on the issue. Every Committee member should have an executive summary of our "Relinquishing Custody" report, and if you don't have a copy of our newest publication, "Avoiding Cruel Choices" that talks more in detail about Medicaid, we would be happy to get you copies of those.

These reports highlight the two main culprits in this custody relinquishment problem. First, access to appropriate and timely mental health services and supports, both in the public and the private sectors. And the related second issue is a lack of oversight for existing programs that can and should be providing these services and supports.

Custody relinquishment is all the more tragic because it is preventable. It does not and should not have to happen to a single more child. During my testimony, I will describe how the Senate can address the access issue by passing the Family Opportunity Act, by enacting insurance reform, and preserving and strengthening the Individuals with Disabilities Education Act, or IDEA. I will also underscore the importance of improving Federal oversight of another aspect of the Medicaid program, the TEFRA or Katie Beckett option.

Today's hearing will describe our Nation's failure to meet the needs of families with children who have emotional and behavioral disorders, a failure, as we have heard, that is tearing apart families and putting children at risk. It is our hope that these proceedings will encourage you and your fellow lawmakers to support specific legislative fixes to end this unnecessary tragedy.

I believe there has already been quite a bit of overview of the custody problem. The GAO study documented over 12,000 cases in the year 2000 alone of children who ended up in the child welfare and juvenile justice systems just because they needed mental health services. We know that the GAO findings are just the tip of the iceberg.

Custody relinquishment has been documented in at least half the States. A survey found that 23 percent of parents who have children with serious emotional and mental problems were told that they needed to give up custody of their children to get services, and one in five families actually did.

¹The prepared statement of Ms. Seltzer appears in the Appendix on page 100.

At the Bazelon Center, we consistently hear from families that when they seek help for their children, they are offered none. Like the mothers who appeared before you, they are encouraged to call the police to document the problem or they are pushed to give up custody to the foster care system. Ultimately, children who need the most emotional support and stability are being ripped from their homes to live with complete strangers. This appalling practice must end.

A variety of barriers prevent parents from accessing appropriate mental health treatment. Custody relinquishment is largely the failure of all child-serving agencies, but two in particular, mental health and the education systems. They have a primary responsibility of addressing children's problems before they reach a crisis level. And the single most important obstacle that pushes families into giving up custody is a lack of access to appropriate and timely mental health services and supports.

It is clear that mental health is not a public health priority, as I believe Congressman Kennedy mentioned. Parents have to jump through myriad hoops to get the most basic services for their children. Based on the President's Commission and the Surgeon General's report, there is no doubt that the public mental health system is underfunded and crisis, rather than prevention, driven. In many cases, the lack of appropriate mental health care leads to a high use of expensive and unnecessary hospital and institutional use, money that could be used to help children stay at home with their families.

Parents of children with mental or emotional disorders often struggle financially to pay for services and supports their children need. Some parents lack insurance, either public or private. A growing number of children in this country are underinsured, with minimal coverage for mental health services.

Over 90 percent of private insurance plans carry limitations and restrictions on mental health care, such as limiting the number of outpatient sessions or limiting the number of inpatient days that are covered, limitations that do not appear in physical health care benefits. Moreover, private insurance plans do not cover the full array of intensive community-based rehabilitative services that children with the most severe mental or emotional disorders need, services that can be offered under Medicaid.

Students with emotional and behavioral disorders have been recognized among the most under-identified and under-served students with disabilities. Data suggests that schools may be failing to correctly identify four-fifths of children with mental or emotional disorders serious enough to adversely affect their educational performance. And even when students with emotional and behavioral problems are identified as needing services, schools often fail to deliver the positive behavioral supports required by the 1997 IDEA Amendments, interventions that have been proven to reduce behavior problems and improve students' chances to succeed in school.

Every parent that we heard from today and every parent that the Bazelon Center has ever come into contact with who has been faced with the decision to relinquish custody describes a deteriorating school situation as a significant factor in their decision.

So the situation is bleak, but the good news is that custody relinquishment doesn't have to happen. Public policy alternatives exist that could rescue families from the awful choice of giving up custody to the State or seeing children go without needed care.

Congress has bipartisan legislation before it right now, which, Madam Chairman, you mentioned, would take two giant steps toward preventing custody relinquishment. The Family Opportunity Act would, number one, help expand Medicaid coverage to children whose families would otherwise not be eligible, and number two, it would give States greater flexibility to use the home and community-based waiver to serve mental illness with serious emotional and behavioral disorders.

The Family Opportunity Act has maintained high bipartisan support for more than 3 years, but it has not yet become law. It would remove the barriers that today keep thousands of families from being able to meet their children's serious mental health needs. Last Congress, the Senate Finance Committee favorably reported the bill out of Committee. It is time for Congress to finally enact this important legislation.

The home and community-based services waiver is a critical tool that many States have failed to take advantage of because of obstacles that Congress has the power to eliminate. The three states that have taken advantage of this waiver, Vermont, Kansas, and New York, have found that they have been able to serve children in their homes at about half the costs that they were spending for institutional care.

Unfortunately, Federal law has not kept pace with the change in practice. When the waiver statute was first written, most children with emotional and behavioral disorders were served in psychiatric hospitals and that is the kind of care that the statute covers. Now, most children are being served in residential treatment centers and that is not what the statute explicitly talks about and that is a fix that would be handled by the Family Opportunity Act.

Insurance reform is another area where Congressional action is necessary. For parents who have insurance, Congress should ensure that insurance companies cover the range of mental health services that would prevent custody relinquishment and cover them without arbitrary limits. Enacting mental health parity legislation, like the Wellstone Act, is an important first step, but it is clearly not all that needs to be done in the area of insurance.

IDEA is currently in the process of reauthorization. Research demonstrates that the use of positive behavioral interventions and supports can significantly reduce discipline problems and ultimately result in school success for children who, right now, are dropping out of school and failing in school. We support Senate Bill 1248 with one exception. The Senate bill, unlike the House legislation, requires a behavioral assessment, but it requires only a general assessment rather than the functional behavioral assessment that is currently required and we would ask that the term "functional" be restored.

And finally, TEFRA oversight. The TEFRA option is an important option that allows States to cover home and community-based services for children who are at risk of hospitalization. It is the most underutilized facet of Medicaid that I can imagine, with serv-

ices being offered to children with emotional and mental disorders in only ten States out of 50 plus the District of Columbia. I mean, it is shocking that children with the most serious needs, who face the greatest risk of custody relinquishment, are not being served, not even having the opportunity to be served in 40 States.

In conclusion, many States are struggling to address the custody relinquishment tragedy, but they cannot do it on their own. They need the help of the Federal Government to remove the obstacles that are in their way to address this problem.

I want to thank you for holding this important and timely hearing. The Committee's oversight jurisdiction on Federal agencies that serve children is critical to fostering needed collaboration at the Federal, State, and local levels.

Far too often, in order to get essential mental health services for their children, caring parents have to choose between poverty and giving up the children that they love. Too many children with mental or emotional disorders and their families have suffered too long for the system's failures.

I end by stressing that custody relinquishment is not a rational choice for society and it is no choice at all for families. I urge you to take the necessary legislative action to ensure greater access to mental health services and supports and greater oversight to ensure that existing programs are used to their fullest potential to help families at risk of custody relinquishment.

I thank you, and I am available to answer any questions you have.

Chairman COLLINS. Thank you very much for your excellent testimony. Dr. Adams.

**TESTIMONY OF JANE ADAMS,¹ EXECUTIVE DIRECTOR, KEYS
FOR NETWORKING, TOPEKA, KANSAS**

Ms. ADAMS. Thank you for allowing me the opportunity to speak to you today. I am going to title my testimony, "No Place Like Home," and in Kansas, we take those words very seriously. [Laughter.]

I represent hundreds of people from Kansas who have been working since 1984 on developing an infrastructure to allow parents choice and opportunity to raise their own children. I am also the Vice President of the Federation of Families for Children's Mental Health.

My invitation to speak to you asked that I talk to you regarding the implementation of the Kansas home and community-based services waiver. Before I talk about Kansas, I want to share with you briefly my perspective from being a member of President Bush's New Freedom Commission on Mental Health.

Last year, President Bush directed the Freedom Commission to make recommendations which put in place and extend the protections of Olmstead so that people with disabilities have the right to live, work, learn, and participate in their homes and communities. For the last year, as part of the Commission work, we heard testimony from families and youth across the country about their per-

¹The prepared statement of Ms. Adams with attachments appears in the Appendix on page 115.

sonal experiences trying to penetrate the disarray of what we call the mental health system. They told us of their efforts to access opaque and complex non-systems, the difficulty to even understand service options, let alone secure access to grossly underfunded programs. Family members talked to us about discontented and overwhelmed providers, constantly changing and conflicting regulations, and they talked about losing their children to child welfare and State juvenile authorities.

Parents also talked about their fear that in working with agencies to get services for their children, they might lose their children. Parents told the Commission, and Kansas parents have told our legislature, that without financial resources to access mental health care, they are forced to turn to child welfare with the promise, implied or explicit, that mental health services will follow, or by default, families lose to the juvenile authorities when services are not available. Behaviors escalate to the point that law enforcement gets involved.

In Kansas, one problem with placing a child in foster care is that the child welfare system is not designed to provide mental health services. It is designed to provide a safe place, a home, usually. Child welfare providers in Kansas are not Medicaid mental health providers. In Kansas, a child welfare contractor who determines that a child in foster care has a diagnosis must then go back to a mental health center to confirm that diagnosis and assess eligibility for services in that system.

If the center agrees the child needs services, Medicaid funds the services. If not, the private contractor in Kansas must pay for services out of a capitated payment from the State for living allowance. I can tell you, this seems to deter advocacy for mental health services in the foster care arena.

In either case, when a child with mental health needs is placed in foster care, there is little or no involvement of the biological family in the child's mental health treatment. The child is frequently moved away, and it is likely to a different mental health center catchment area where different providers than he or she knows and who are too distant to the family are now going to try to work with the child. This is ten times worse in the juvenile justice system. Families are virtually locked out of participating.

The Freedom Commission has ended and the White House is anticipating a report which I hope may influence the development of services for the next decades. The Commission will recommend the development of full and comprehensive arrays of community services, developed in concert with the families and the youth who receive them.

Compelling testimony and a new awareness of the national perspective has left me an increased awareness of what the Kansas model can offer this Nation in the area of mental health. I am excited to explain the Kansas waiver to you, and I care that you know that the waiver is only one part of a full system which allows families to access services in Kansas. Today, though, I will talk about the waiver.

The waiver does two things in Kansas. One, it extends the service array, or the range of services, and it also expands or extends Medicaid eligibility to families. The expanded range of services in-

cludes, in addition to the usual Medicaid options, like attendant care and in-home-based therapy, it also adds wrap-around facilitation, parent support, respite care, and independent living supports.

Expanded eligibility means that in the waiver, only the child's income, not the parent income, is considered. This means that in Kansas, when a parent is faced with the imminent possibility of placing a child in a mental hospital, that parent may elect to keep the child at home and in school in the community where they live with Medicaid-funded supports.

With the waiver and the recognition of our legislature that children do better, are better, and demonstrate remarkably better outcomes in homes than any other setting, we are making progress. Since only two other States have adopted the home and community-based services waiver for children, New York and Vermont, I believe I must describe briefly how we secured the waiver, and one of the people is in this room who helped us with our legislature secure this waiver and that person is Mary Giliberti, formerly from the Bazelon Center.

We have had the waiver since 1998. It was evaluated by Medicaid in fiscal year 2000 and is now in place until fiscal year 2005. For Kansas, several agendas seemed to converge at the same time. We have long practiced the wrap-around philosophy and principles of planning and serving children with parents as partners in service delivery and evaluation.

SAMHSA awarded Keys for Networking, the State family organization, my organization, and Social and Rehabilitation Services, one of the first national grants in 1984 to develop a State infrastructure to begin to provide a health system of services for children. SAMHSA had also funded in Kansas two federally-funded demonstration grants. Those sites were in Wichita, which is an urban community, and in rural Southeast Kansas. What is important about that is with the demonstration sites, SAMHSA provided a means to develop, first of all, the array of community-based services, so we had services in place. And then SAMHSA also provided the means to collect data to profile service effectiveness.

By 1997 in Kansas, we knew what effective services should look like. We knew the cost per child in the community and we knew the cost per kind of service to maintain a child in the community. This is important, because one of Medicaid's requirements for the waiver is that it cost no more to serve a child in the community than in the hospital. We had the data to show what Medicaid calls "cost neutrality." We had to demonstrate that we could serve children in the community at no greater cost than it cost to serve them in the hospital. We had the services, and we had just made a decision to close a mental hospital so we had dollars we could divert to the community.

With a full alliance of mental health providers, Social and Rehabilitation Services, and Keys for Networking, we moved the legislature to fund the waiver and a family-centered system of care. I mention this alliance because it is not often in Kansas that we all agree on exactly what we want. We showed the legislature cost figures. We showed them charts of outcomes, and we provided testimonies from families.

I want to move for you to page four of my testimony, which delineates in a nice little table the cost of services, and as I move down the chart, I want you to notice that the farther you go away from home, the more expensive the treatment, comparing children served on our HCBS waiver at \$35 a day to foster care, juvenile detention, and State mental hospitals, which go as high as \$165,000 a year. This information is important. Every time we serve a child in the home in Kansas, we save the State money and we save families.

And we have outcomes to demonstrate what happens with these children on the waiver. Table 2 outlines for you and compares non-waiver children who are served in the community with children who are on the waiver, and I want to point out, as you look at those numbers, it is important to know that the waiver children are the most seriously mentally ill children who are living in our community, and the data shows that the outcomes, in fact, exceed those of other children, both in their permanent home placements, 97 percent compared to 95 percent. They are slightly lower on law enforcement, without law enforcement contacts. They are doing significantly better on a test, an instrument called the Child and Behavior Checklist. Their grades are better, and their attendance at school is better. The waiver does work.

Finally, I want to say, does the waiver stop custody relinquishment? We think so. We believe effective community-based services stops the relinquishment of custody.

What I am here, though, to ask you is since there is apparently difficulty in that other States are not accessing this same waiver, why does there need to be a waiver? Why don't we just make this possible across this country?

Thank you very much for the opportunity to share this program and to speak with you today.

Chairman COLLINS. Thank you very much, Dr. Adams.

Your testimony is certainly compelling. We know from our previous witnesses and from Ms. Osher that parents want, if possible, to be able to care for their children at home. Parents want to retain custody of their children. They love their children. They want to be with their children.

The information from Kansas shows that the care of children in a community-based setting leads to better outcomes. Your information also shows that it is significantly less expensive to care for children in community-based settings. So why do you think that so few States have taken advantage of the waiver? You have made a very good point that why should there even have to be a waiver process, but putting that aside for a moment, Kansas, New York, and Vermont are the three states that are known for having good systems using the waiver. Why do you think States are reluctant when it leads to lower costs and better outcomes?

Ms. ADAMS. I am not a Medicaid expert, and maybe that is precisely the problem. Many people who I talk to fear Medicaid rules and fear the complexity of joining this effort. I also understand that the cost neutrality issue is a huge issue and—

Chairman COLLINS. The fact that it has to be neutral under Medicaid for the waiver to be granted?

Ms. ADAMS. Yes, and that you can't just say it is neutral. You have to prove that it is neutral, and in my opinion, States who have had benefit of the SAMHSA demonstration sites and system of care dollars have then access to not only create community based services, but also demonstrate with real numbers and real figures what it does cost.

Chairman COLLINS. Ms. Seltzer, I want to ask you the same question. Given the very positive results of the states that have used this waiver for a community-based system, why don't you think more States are taking advantage of it?

Ms. SELTZER. I think there are at least two significant reasons. One of them, I would characterize as stigma. I think just about every State uses the same waiver for children who have developmental disabilities, but they don't use it for children who have emotional and behavioral disorders, and part of that is because of what earlier witnesses talked about. These children are being viewed as bad children as compared to children who have mental health needs, just like any other health care needs.

The other reason is the reason that I talked about, a problem that the Family Opportunity Act can solve, and that is the cost neutrality issue. The States have to be able to show that they are saving money. Well, if they have very few children in hospitals, which is the only way they are able to show that, then it is going to be very difficult for them. If they can use the figures from residential treatment centers, they would have a much easier time showing cost neutrality, and that is why it is so important that the Family Opportunity Act be passed.

Chairman COLLINS. With the Katie Beckett option, also, is there the issue that states elect this option far more often for children with physical disabilities or physical illnesses as opposed to emotional or behavioral illnesses?

Ms. SELTZER. You make a very good point. Let me add to my previous comments that Maryland applied for the home and community-based waiver recently and was turned around, so that is just another illustration of the obstacles that States face even when they want to address the issue.

With the Katie Beckett option, you are absolutely correct. Of the 20 states that offer the Katie Beckett option, only ten are serving children whose primary need is emotional and behavioral. And one of the biggest problems is that the States, when they are defining the children who are covered, often don't even mention children with emotional and behavioral disorders, even though the statute does not limit the option to children who have physical problems.

So parents who are looking for resources, like one of the parents who was up here earlier, aren't even going to know about the Katie Beckett option and that it is available to them because most of the information that is made available to parents doesn't even mention emotional and behavioral disorders. So this is an area, too—the Bazelon Center has done a survey and found that the States are desperate for information about the option and how to use it and how to make it more available to children with emotional and behavioral disorders.

Chairman COLLINS. Ms. Osher, do you have any insights that you could share with us on why States aren't taking advantage of the available waivers?

Ms. OSHER. I can give you a parent's perspective on that. I haven't done the research that the Bazelon Center has and I don't have all of that research experience behind it, but I think what the families are saying supports the research experience and also the positive experience they had in Kansas.

The issue is that—there are two parts of it. One is families are not being given information about any of these services being available, and we heard that a lot. The second is that the communities don't have the services in place in order to provide the home and community-based services, even if they had provisions for the waiver in terms of their policies and their funding streams.

So the advantage is—that made it possible for Kansas to get to a home and community-based waiver had to do with the fact that there were special extra resources available to them to develop—it was like seed money and an opportunity to try to build services in communities where there weren't any services, combined with methodologies to evaluate the cost of those services and demonstrate their effectiveness for kids so that they could create the data and the argument in order to have it. If we don't have services in so many of our communities, States may not want to go after a waiver without any money to bring the services up.

Chairman COLLINS. I am going to yield to Senator Pryor. I do have just a few more questions, so I am going to come back. But Senator Pryor?

Senator PRYOR. Thank you, Madam Chair. I have a couple of questions and then some comments, and the questions would be, I assume from what I am hearing today is that even though most parents want their children living at home, I assume there are circumstances in which everyone agrees the child should live in some sort of institution. Is that correct?

Ms. SELTZER. Well, from our experience, most parents, most would definitely want their children to be at home if they can. One of the biggest problems we see with custody relinquishment is the systems fail for so long—I mean, you heard parents talking about 3 years, 5 years—that by the time they get to the point where they are desperate enough to even consider custody relinquishment, residential treatment may be the only alternative. But—

Senator PRYOR. But they could still have legal—

Ms. SELTZER [continuing]. But if prevention services had been provided by the mental health and the education systems, we probably wouldn't be talking about those institutional services. They would not be needed.

Senator PRYOR. The way I look at it, as well, releasing custody is a separate issue because you could still have legal custody of someone and them be in an institution, I assume, but I will explore that on my own.

Give me those statistics again on TEFRA. How many States are utilizing TEFRA?

Ms. SELTZER. Twenty States right now are utilizing TEFRA, and only ten of those States have children who are accessing the pro-

gram whose primary need is for emotional and behavioral health care.

Senator PRYOR. Do you have an explanation for that, why only 20 States and why only ten States?

Ms. SELTZER. The reason that we were given by States when we took a survey of the states that don't have the option, that haven't selected it, is because they don't know very much about it and they would like more information about it. The states that have the option that are not serving children with emotional and behavioral needs, I think stigma is a huge part of it, ignorance on behalf of parents because the States are not informing them that children with emotional and behavioral disorders can and should be served under this program is a huge problem. How can you advocate for something that you don't even know you are entitled to get?

Senator PRYOR. Let me sort of sum up some of my observations today and just see if you all agree with these. I wrote down about six observations based on what you all have said and what the mothers said a few moments ago.

First is that most parents want their children to live at home or in a facility in the community, with the strong preference on living at home.

Second, there is just not enough money in the system.

Third, private insurance is inadequate.

Fourth, the existing agencies that are out there supposedly providing these services are not communicating with each other and oftentimes not with the parents and the public about what is available.

Fifth, mental illness in children, and adults, as well, but mental illness in children is very stressful on families, and the icing on the cake seems to be when parents have to give up their rights to their children.

And sixth, mental health needs are more often than not treated as second-rate conditions.

So I think when I hear all those things and those observations, I think the bottom line I would like to apply to this is the system we have now just isn't working very well at all. Do you all have any comments, or do you disagree with any of those statements? Do you want to add anything?

Ms. OSHER. Right on.

Senator PRYOR. Do you want to add anything to that?

Ms. ADAMS. I would like to add that the waiver for us is so magic because it does not take anything away from families. It allows families full choice. At the point where, if my child were ready and I might be thinking about placing them, her, in a hospital, the waiver kicks in and I am to be given a choice of whether or not I want to proceed with that or I want to choose to keep her in my home community and have Medicaid pay for services.

Ms. SELTZER. Senator Pryor, I want to echo what Trina Osher said in terms of "right on." I think your observations are quite accurate. I do want to add the positive note that this problem is fixable. We are spending money right now very poorly. We are—if this was a private investment for your retirement, you would probably want someone arrested because this is not a good use of taxpayer dollars and it certainly is a great disservice to the children and

their families. So I think that we would encourage you to do what you can to fix this problem as soon as you can because it really is a mystery to me why this tragedy has not been resolved or addressed any sooner than it has been.

Senator PRYOR. I am glad you added that last little part that it is fixable. Madam Chair, I look forward to working with you on trying to fix it and make it better, and thank you for having this hearing.

Chairman COLLINS. Thank you very much, Senator Pryor, for your participation, and I look forward to continuing our efforts in this regard.

Ms. Seltzer, I want to bring up one more issue before I let you all go. You have been an extraordinary source of information about this problem.

I know the Bazelon Center has done at least two studies showing that custody relinquishment is a serious problem. We now have the GAO report that demonstrates that almost 13,000 children in some, I think it is 19 States where there was, say, a voluntary custody relinquishment in order to obtain services. We have heard the first-hand testimony of the mothers today. So we know that this is a serious problem.

Yet, it is my understanding that Federal law does not require custody relinquishment to obtain mental health services and that it even has specific language allowing voluntary placements. In fact, my staff did some research that showed that the Department of Health and Human Services sent out guidance to the States on this issue—many years ago, I might add, back in the 1980s. Why do you think there is so much misunderstanding among the State agencies about whether or not custody relinquishment is necessary in order to tap into these services?

Ms. SELTZER. I am glad that you brought that up. It is astounding that States still think that they have to require parents to give up custody in order to access what are called 4(e) dollars to provide mental health treatment to children. I think more and more States are becoming educated about that and they are engaging in the practice of voluntary placements. I do want to point out that that is not necessarily the answer—

Chairman COLLINS. It is not ideal, either, I realize.

Ms. SELTZER. It is wonderful that parents aren't forced to give up custody, but a voluntary arrangement doesn't necessarily create more services in the community that helps you keep your kids at home. It also still forces you to go through a system, the child welfare system, which is not an appropriate system for you to be in. You haven't abused or neglected your child. You just need mental health services. We wouldn't require a child with diabetes to go through a court or to go through any other sort of hoop like that in order to get basic health care needs met, and that should not happen for children with emotional and behavioral disorders, either.

Chairman COLLINS. I agree with your comments. I am, however, astounded at the lack of coordination and communication among the various systems, agencies, programs, and one of the recommendations the GAO made was to have an interagency task

force so that we can start ensuring that there is coordination and communication.

I am struck so much by the testimony that we heard earlier of parents' desperate search for help, and Cynthia telling us that after 2 years, she finally located the program that has been enormously helpful to her twin sons. But it shouldn't be a struggle for families to tap into the programs that they need.

So clearly, there is an outreach, education, and communication component of this problem in addition to the lack of community-based services and other issues. Would you agree with that? Is there a problem in terms of communicating with parents?

Ms. SELTZER. Absolutely. I think Trina Osher mentioned that, as well. We are dealing with bureaucracies here and it is very challenging to get any bureaucracy to change something that they have been doing for years and years and years. I think it is important for us to try to change. It would be wonderful if parents had one phone number, one place they could go to get all of the information they needed about what services were available for their children.

Chairman COLLINS. All three of the mothers are nodding in agreement to that.

Ms. OSHER. Can I comment on that for a second, too, please?

Chairman COLLINS. Certainly, Trina.

Ms. OSHER. Tammy mentioned particularly the educational system and the mental health system as being places where our children need to get services and where they can get services and there are mechanisms in place to help them. Just those two systems have different definitions of who is eligible for services. They have different mechanisms for paying for those services. They have different criteria about what needs to be provided. They have different mechanisms for making decisions about what will be provided and accounting for the outcomes and so forth. They don't speak the same language.

It is not just miscommunication. They are in two different vocabularies entirely, so anything that can be done to review existing Federal laws in any child-serving system to develop across the systems a common definition of who our children are and a common goal about what we want to accomplish for our children and a common respect for participation of families in the decision making about what those services will be for their children without families having to figure it out.

I mean, I do a lot of training for families and I think it is appalling in some ways that I have got to read them all these different Federal definitions and explain what they are. That is not the job of a parent, to know all those definitions. We are not supposed to be lawyers, with all due respect to Ms. Seltzer— [Laughter.]

And anybody else who is in that honorable profession. It is our job to love and care for our kids, to make them oatmeal in the morning and to read them bedtime stories and to make sure their homework is done and give them kisses and take them on vacations. And I think I will end right there.

Chairman COLLINS. Thank you. I want to thank all of you for being here with us today. The testimony has been extremely valuable, and I hope the three of you as well as the parents from whom

we heard earlier will help us make a difference to the families with children with mental illness.

A lot of the elements are out there, the waivers, the experience of States, in particular States, particularly Kansas, the Family Opportunity Act, insurance reform, wider use of waivers by States. The State of Maine, for example, has not applied for the waiver that Kansas has used so effectively, so we need to encourage States. I think we need a program that provides some grant money and technical assistance to States to provide a seamless approach to mental health services for children.

There is so much that needs to be done, but one thing is certain. No parent should have to give up custody of a child in order to obtain the services that a child needs. I think that that is the goal that we should be working toward, and by putting these elements in place, I am convinced that we can make a real difference.

So I hope that the three of you will continue to work with us as we seek to put together a legislative package that will include the Family Opportunity Act and broader use of waiver programs and wrap-around services, whatever is needed, because I think this is a problem that we can make tremendous progress on without enormous infusions of dollars. As one of our witnesses said earlier, the money is there in many cases. We just make it too difficult to tap into. Or, by using home-based and community-based programs, we can serve more people at a lower cost and keep them where they want to be, keep these children at home.

So I think, Dr. Adams, you said it best when you said, "There's no place like home," and that should be our goal for children for whom that is the appropriate response. For other children, a residential care facility is going to be the answer. We need to have a flexible system that meets the needs of these children.

So thank you so much for your assistance to us. We will continue to call upon you.

I want to thank all of our witnesses today for their assistance, particularly the three mothers who shared their unique perspectives on the challenges faced by families of children with mental illness. Theresa, Cynthia, and Patricia were so moving in their testimony, and you helped us gain a far better understanding of the challenges and struggles that families face. You are a real inspiration to those of us who are committed to making a difference in this area.

On Thursday, the Committee will hold a second hearing. We want to hear from the General Accounting Office and we want to hear from the Federal agencies that have responsibilities in this area, as well. So if any of you have any questions you would like us to pose, please do not hesitate to send them along.

I also want to thank my staff, which has worked very hard on this set of hearings, particularly Priscilla Hanley, who is my Senior Health Care Policy Advisor.

The record for this hearing will be held open for the submission of additional materials, but the hearing is now adjourned. Thank you.

[Whereupon, at 12:02 p.m., the Committee was adjourned.]

**NOWHERE TO TURN: MUST PARENTS RELIN-
QUISH CUSTODY IN ORDER TO SECURE
MENTAL HEALTH SERVICES FOR THEIR
CHILDREN? PART TWO: GOVERNMENT RE-
SPONSE**

THURSDAY, JULY 17, 2003

U.S. SENATE,
COMMITTEE ON GOVERNMENTAL AFFAIRS,
Washington, DC.

The Committee met, pursuant to notice, at 9:31 a.m., in room SD-342, Dirksen Senate Office Building, Hon. Susan M. Collins, Chairman of the Committee, presiding.

Present: Senator Collins.

OPENING STATEMENT OF CHAIRMAN COLLINS

Chairman COLLINS. The Committee will come to order.

Good morning. This is the second of two hearings that the Committee on Governmental Affairs is holding this week to examine the difficult challenges faced by families of children with mental illness. On Tuesday, we heard compelling testimony from three such families who told the Committee about their personal struggles to get mental health services for their severely ill children. The mothers who testified 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 have to make. No parent should have to give up custody of his or her child just to get the services that that child needs. The testimony that we heard earlier this week made it clear that custody relinquishment is merely a symptom of a much larger problem, which is the lack of available, affordable and appropriate mental health services and support systems for these families.

The mothers described barrier after barrier that they faced in getting care for their children. They told us about limitations in both public and private health insurance coverage for mental illness. While two of the mothers made too much money to qualify for Medicaid, their private health plans had coverage that was more restrictive for mental illness than it was for physical illness. As a consequence, their health care benefits were quickly exhausted and they were faced with the prospect of paying for the cost of their children's care, cost that amounted to hundreds of

thousands of dollars. This is more than all but the very wealthiest families could afford.

They also talked about the lack of coordination and communication among the various agencies and programs that serve children with mental health needs. One mother, 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 her sons. 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 finally has an answer for them. It simply should not be such a struggle for parents to get services and treatment for their children.

Today, we will first hear from the General Accounting Office which recently completed a report that I requested with Representatives Pete Stark and Patrick Kennedy, entitled "Child Welfare and Juvenile Justice, Federal Agencies Could Play a Stronger Role In Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services."

The GAO surveyed child welfare directors in all States and the District of Columbia as well as juvenile justice officials in 33 counties with the largest number of young people in their juvenile justice systems. According to the GAO survey, in the year 2001 alone parents placed more than 12,700 children into the child welfare or juvenile justice systems so that these children could receive mental health care. Moreover, the GAO estimates that this is likely just the tip of the iceberg since 32 States, including five States with the largest populations of children, did not provide the GAO with any data.

There have been other studies indicating that custody relinquishment problems are pervasive. In 1999, for example, the National Alliance for the Mentally Ill released a survey which found that 23 percent, or more than one in four of the parents surveyed, had been told by public officials that they needed to relinquish custody of their children to get care. Moreover, one in five of these families had done so.

We will also hear today from Federal agencies that have the responsibility for helping with children with mental health needs. We will have the opportunity to hear how these agencies work to respond to the needs of children with serious mental or emotional disorders and the needs of their families. Finally, we hope to identify ways that these programs and agencies can better work together to develop a more coordinated system of care for these children at both the Federal and State level. We want to ensure that parents such as the ones that we heard from on Tuesday will know where to turn for help, the help that their children so desperately need, without having to sever the ties that bind families together.

I am very pleased to welcome today our first witness, Cornelia Ashby, who is the Director of Education, Workforce, and Income Security Issues at the General Accounting Office. I mentioned the GAO report that the two congressmen and I commissioned. It has provided us with a very important overview of the current barriers that prevent families from accessing the mental health services that their children need. I am very pleased that the director, Ms. Ashby is able to be with us today to present the findings of the re-

port in more detail. I would ask, Ms. Ashby, that you proceed. Thank you for being with us.

TESTIMONY OF CORNELIA M. ASHBY,¹ DIRECTOR, EDUCATION, WORKFORCE, AND INCOME SECURITY ISSUES, U.S. GENERAL ACCOUNTING OFFICE

Ms. ASHBY. Thank you, Madam Chairman. Thank you also for inviting me here today to discuss our April 2003 report on children being placed inappropriately in the child welfare and juvenile justice systems in order to obtain mental health services. My testimony today will focus on three issues: the numbers and characteristics of children voluntarily placed in the child welfare and juvenile justice systems to receive mental health services; factors that influence such placements; and State and local practices that may reduce the need for some child welfare or juvenile justice placements.

I use the term placed to refer to instances in which parents, in order for their children to receive mental health services, have voluntarily taken or declined to take some action that has resulted in their children being placed in the child welfare system or arrested for behaviors related to their mental illnesses. Because information is not available, we could not determine whether parents subsequently released custody of their children to obtain the services.

My comments are based on our findings for the April report. As you explained, Madam Chairman, in conducting that study we analyzed responses to our survey of State child welfare directors in all States and the District of Columbia, and our survey of juvenile justice officials in 33 counties in the 17 States with the largest populations of children under age 18.

In addition, we interviewed officials of child-serving agencies, caseworkers, and parents in six States—Arkansas, California, Kansas, Maryland, Minnesota, and New Jersey—and judges in each State we visited except Minnesota. We also observed programs that State officials identified as model programs in those six States, interviewed key Federal officials and national experts, and researched State laws and regulations regarding voluntary placement and relinquishment of parental rights.

State child welfare and juvenile justice officials who responded to our survey estimated that in fiscal year 2001 parents in their jurisdictions voluntarily placed over 12,700 children in child welfare or juvenile justice systems so that the children could receive mental health services. Nationwide, this number is likely higher because officials in 32 States, including the five States with the largest populations of children, did not provide us with estimates. Officials in 10 of those States indicated that although they did not have an estimate to provide, such placements occurred in their State.

Also, we surveyed juvenile justice officials in only 33 counties, and officials in three did not provide estimates but also indicated that such placements occurred. Only estimates were available because no Federal or State agency kept formal, comprehensive records on children placed to obtain mental health services. Although no Federal or State agency tracks these children or main-

¹The prepared statement of Ms. Ashby appears in the Appendix on page 136.

tains data on their characteristics, State survey respondents indicated that placed children were mostly adolescent males. Officials from State and county child-serving agencies and parents we interviewed in the six States we visited said that children who were placed had severe mental illnesses, sometimes in combination with other disorders, and their parents believed they required intensive treatment that could not be provided in their homes.

Many of these children were violent and had tried to hurt themselves or others, and the seriousness of their illness strained the family's ability to function. Children who are placed or at risk of placement come from families that span a variety of economic levels. However, officials from State and child-serving agencies in all six States we visited said children from middle class families are more likely to be placed because they are not eligible for Medicaid and their families do not have the funds to pay for treatments not covered by insurance.

Multiple factors influence parents' decisions to place their children in the juvenile justice or child welfare systems to obtain mental health services. Private health insurance plans often have gaps and limitations in the mental health coverage they provide, and not all children covered by Medicaid receive needed services. Even when parents could afford mental health services, some could not access services at times when they needed those services because supplies of such services were inadequate. In other instances, mental health agencies and schools have had limited resources to provide mental health services.

Also, they are required to serve children with a mental illness in the least restrictive environment possible, which can limit the alternatives available to parents who believe their children need residential placements. In other instances, parents have had difficulty obtaining all needed services for their children in their communities because eligibility requirements for services provided by various agencies differ.

Furthermore, some State and local officials and service providers have misunderstood the role of their own and other agencies and therefore have given parents inaccurate or incomplete information about available services, thereby compounding service gaps and delays.

Although few strategies were developed specifically to prevent mental health related child welfare or juvenile justice placements, State and local officials we interviewed identified a range of practices in their States that they believe may prevent such placements by addressing key issues that limit access to child mental health services in their State. State and local practices focused on three main areas: finding new ways to reduce costs or to fund services; consolidating services in a single location such as a school or community center; and expanding community mental health services to include a continuum of services ranging from early intervention to crisis intervention and supporting families and encouraging parental involvement in their child's care.

One cost reduction practice was to ensure that children with lower level needs were served with lower level and less expensive services, reserving the more expensive services for children with more severe mental illness. Another involved substituting expen-

sive traditional mental health providers with non-traditional and less expensive providers.

New ways of funding services included the blending of funds from multiple sources, thus overcoming agencies' limitations on the types of mental health services and placement settings each can fund, and the use of flexible funds that have few restrictions to pay for non-traditional services that are not generally allowable under State guidelines.

Although States and counties are implementing practices that may reduce the need for parents to place their children with child welfare or juvenile justice agencies, many of the practices are new, have been implemented on a small scale, and only serve children in specific locations. Furthermore, their effectiveness in achieving their multiple goals, such as reducing the cost of mental health services, supporting families, and helping children overcome their mental illnesses has not been fully evaluated.

In our April 2003 report, we made several recommendations to Federal agencies to reduce the inappropriate placement of children in the child welfare or juvenile justice systems to obtain mental health services. To determine the extent of such placements, we recommended that the Secretary of Health and Human Services and the Attorney General investigate the feasibility of tracking these children to identify the extent and outcomes of these placements.

To help reduce at State and local levels misunderstandings of the roles and requirements of the multiple agencies with responsibility for these children, we also recommended that the Secretaries of HHS and Education and the Attorney General develop an inter-agency working group to identify the causes of the misunderstandings and to create an action plan to address those causes. We further recommended that these agencies continue to encourage States to evaluate their mental health programs and that the Secretaries of HHS and Education and the Attorney General determine the most effective means of disseminating the results of these and other relevant studies to State and local entities.

Madam Chairman, this concludes my statement. I will be happy to answer any questions you may have.

Chairman COLLINS. Thank you very much, Ms. Ashby. I want to thank GAO for conducting this study. I think it has been very valuable in giving us a picture, an overview of what is going on in several States. I also know from talking with the families who have gone through the agonizing decision of relinquishing custody, as well as talking to advocacy groups, that they have taken comfort in the fact that GAO has found this practice to occur in so many other States. Now they do not take comfort in the fact that it is a good thing. It obviously is a bad thing. But they hope that it will help build the case for reforming the system.

So many of these parents have felt all alone as they have gone through this struggle, and when they found out that nearly 13,000 children had been identified in the GAO study as being placed in either the child welfare or the juvenile justice system they realized that they are not alone. This is a problem that cries out for attention at the State and Federal level, and I thank you for that work.

I am convinced from what we have heard from experts at the Bazelon Center and what you have said today that actually we are greatly underestimating the number of children who have been placed. Do you agree with that, given that only 19 States responded?

Ms. ASHBY. I do agree. As I explained and as is explained further in our longer statement for the record, we did a survey of the States and adding up the numbers for all those States that responded—we only heard from 19 States and from 30 of the 33 counties that we had surveyed on the juvenile justice side. We were told by some of the States who did respond but who did not provide us with information that they knew such placements occurred in their State, they just did not feel comfortable with making any kind of estimate of how many.

Chairman COLLINS. That suggests that States are not tracking these children. Is that correct?

Ms. ASHBY. That is correct, they do not have a tracking system at all for these children, although they track other information about children that are in the child welfare system and the juvenile justice system. They do not keep separate records on children placed because of mental illnesses only.

Chairman COLLINS. I was interested, in reading your testimony last night, in the chart on page 11, and there is one on page 13 as well, that shows the variation from State to State in the number of placements. For example, the estimates varied widely. Kansas showed only 14 placements in the child welfare system versus Minnesota which had 1,071; Indiana reported none. You see the same kind of variations in the chart on page 13 looking at the juvenile justice system.

We heard from an expert on Tuesday from the State of Kansas, which is one of three States that is using a Medicaid waiver to develop community-based and home-based systems that may well explain the low number of placement in Kansas. So that they are having what appears to be a fair amount of success using this waiver to prevent parents from having to make this awful choice.

But I have also heard that Minnesota has a number of progressive programs in this area. So do you think that the variation in numbers reflects both differences in how good a job States are doing as well as whether or not they are tracking? What is your analysis of the variations?

Ms. ASHBY. First of all, none of the States are tracking this particular population so the numbers are based on the experiences of the respondent or the resources the respondent had to perhaps get ideas from other people in the particular agency. I am sure it does reflect both.

However, because it is based on, as I said, the personal knowledge of the respondent, or the respondent and perhaps the respondent's staff, I really do not think we can draw any conclusions about the relative degree to which it happens in various States, nor can we project nationally based on these numbers.

Chairman COLLINS. One of the witnesses at Tuesday's hearing indicated that a big part of the problem is that the various Federal and State agencies with responsibilities for meeting the needs of children with mental illness, her phrase was, they do not even

speak the same language. She said that there are different definitions and terminology, there are differing eligibility requirements, which you referred to in your testimony, and they do not always understand what programs are available in other agencies.

The mother from Illinois very eloquently testified about searching for help for her twin sons and she finally, just through sheer persistence, stumbled upon a State program, the Community Residential Services Authority, that was tailor-made to meet her sons' needs. But she found this program on her own. She did not find it as a result of someone directing her to it. Probably because it was funded through the State education department, the officials in Illinois Department of Child and Family Services, as well as officials in the Department of Mental Health with whom she had been dealing, were not aware of the program.

How common do you think that problem is? Did the GAO also identify lack of coordination and knowledge as well as misunderstandings among State and Federal officials as major problems?

Ms. ASHBY. It is definitely one of the issues we addressed, problems we discovered at the State and local level. Now I will say that at the Federal level, the Departments of Education, HHS, and Justice have various means of coordinating with one another and sharing information. They have issued guidance, each department and agency, and the State and local agencies under its purview have issued guidance. But in spite of that, at the State and local level there seems to be a lot of misinformation, a lot of confusion, a lot of just lack of knowledge about the total scope of services that are available to this population.

Chairman COLLINS. We found that there were State agencies that were unaware that you could tap into certain Federal programs without custody relinquishment.

Ms. ASHBY. That is correct. There is no Federal requirement that custody be relinquished. We definitely talked to some people at the State and local level who thought there was such a requirement.

Chairman COLLINS. It is so troubling to me that we hear case after case where State officials have advised parents to give up custody of their children truly believing that this is necessary in order to tap into the help that the child needs, when, in fact, it is my understanding that the Department of Health and Human Services has twice issued guidance telling States that that is not the case.

Ms. ASHBY. Yes. One of our recommendations, of course, was, at the Federal level, that the major agencies involved try to figure out a way to just disseminate more information, different types of information, perhaps use different media for disseminating the information to State and local officials so that they understand not only their own programs but the other programs available to parents and how different programs together can perhaps provide the full range of services that a particular family needs.

Chairman COLLINS. One of the family members who testified also recommended the kind of interagency task force that you have proposed. What was the reaction of the Federal agencies to your recommendation for an interagency task force?

Ms. ASHBY. In commenting on our report, the reaction we generally got was, that is not going to solve the problem, or in one case, I believe it was the Department of Justice and later you will

hear from someone from that agency if I have gotten it wrong, but I believe it was the Department of Justice that thought it was a good idea. They would participate in such an endeavor—in fact they all agree they would participate in such an endeavor, but the Department of Justice thought HHS should take the lead. And Education and I believe HHS had the idea or thought that there are surely are problems here but there are more fundamental problems than disseminating information, and we are already doing that, and they believe the recommendation does not get at some of the other problems.

We will agree that there is a multitude of issues here and that is why we had four different recommendations, to try to get at it from various aspects.

Chairman COLLINS. I think in some ways that that response typifies the problem that we are seeing. There is no one agency that is accountable and responsible for these children. As a consequence, each agency says someone else ought to be the lead, or someone else ought to take care of that. The result is that the children are falling through the gaps, and the parents do not know where to turn.

I noticed that one of your comments was the need for consolidating services. Based on the work GAO did, do you think it would be helpful if there were a single source for assistance that parents could turn to?

Ms. ASHBY. That definitely would be helpful. It would not solve the cost issues, but it certainly would help provide information to parents. It would be more convenient, having to go to one location, one location in the community, perhaps a school or a community center, to get the information. And then make informed choices about what course of action to take.

Chairman COLLINS. I know for a fact that families living in rural communities have a particularly difficult time getting help for their children. There are obviously fewer government doors to knock on in rural America, but there is also a real shortage of qualified mental health providers to give the kinds of services that these severely ill children need.

Did you visit or talk with program officials serving rural areas or remote locations? If so, can you give us an idea of the kinds of barriers that families living in rural America face? Is there a shortage of providers that exacerbates the problem of delivery of services?

Ms. ASHBY. We did visit rural areas and, yes, you are absolutely correct there is a shortage of providers. In some communities there are no providers at all. There are providers, in some cases, that do not have the full range of knowledge and resources that would take care of the problems of a particular child. In some cases, a parent, a family would have to go long distances or a child would have to be placed in another community because of lack of services, which does not facilitate any kind of re-establishment of connections and relationships within the family that could be part of the cure, as well as transitioning the child back into his or her home.

So, yes, you are absolutely right, the problem is perhaps exacerbated in rural areas just because of the remote locations and distances involved.

Chairman COLLINS. I was struck by the testimony of the mother from Arkansas who appeared before us on Tuesday who talked about her little boy being placed in a residential home for treatment that was far away from where the family lived, so the estrangement and the ability of these parents to be involved in the decisions involving his care was really diminished. That seems to me to argue for our trying to figure out a way to develop better community- and home-based programs.

All of the mothers who testified before us wanted so much for their children to be home with them, but they did not have the support and the services that could bring that about. It was just so tragic to hear that. That is a problem that you seem to have identified as well.

Ms. ASHBY. Absolutely. I was not here on Tuesday for that hearing but I did have staff here and they told me about some of the testimonies. This problem is devastating to families. It influences, in some cases, parents' ability to work, their ability to take care of other children in the home. Anything that can provide services that is more convenient and can allow the parents perhaps to visit the children or the children to perhaps visit their home on weekends or at some point as part of their program certainly would help the situation.

Chairman COLLINS. We heard over and over again of the devastating effect on the entire family. In one case, the ill child assaulted one of the step-sisters. In another case, the strain on the marriage was just terrible. These problems do affect the entire family.

One problem that we also heard is when custody relinquishment occurs, then the parent is cut out of any say in what happens to the child or treatment decisions. In the programs you reviewed during your field work, how important did program officials say it was to provide services that supported families and encouraged parental involvement or the opposite of custody relinquishment? Does that make a difference as far as the treatment of the child with the illness?

Ms. ASHBY. It does, and one of the things we did was look for promising practices in States and localities, things that they were doing that seemed to be helping to resolve the problem and reduce the need for these voluntary placements. And we did find one group of activities or group of programs that seemed to be working, although, as I have said, there have been no formal evaluations of these programs, and all of them are very limited. They are either operating in one State or a few counties in a State, so more needs to be done there. And one of our recommendations is that the Federal agencies try to encourage evaluation and disseminate information about the results.

But one group of programs definitely tries to help the family, and this is done in various ways. One thing that has occurred is that in some localities, funds from various programs have been combined to provide the total continuum of services that a family needs. And a family might need various things; perhaps economic support, if a parent cannot work or is reduced in the number of hours he or she can work, tutoring for the child, mentoring, perhaps some type of parent support group just because of the situa-

tion that the family is in, certainly mental health services, all kinds of things and things that various Federal agencies alone cannot take care of by themselves.

And in some cases even private nonprofit organizations have been brought into the mix and have, together, provided funding that has helped support families.

Chairman COLLINS. Senator Pryor and I were talking last night about the legislation that we want to introduce to help in this area. In addition, it seems to me we need to move on mental health parity for insurance coverage and also on the Family Opportunity Act, which would be very helpful to a lot of these families, but there are still other gaps.

My final question to you. Do you have any other recommendations for us on what you think would really make a difference in providing better coordination of care or any other recommendations as well?

Ms. ASHBY. Well, I guess I'll just reiterate what we have in our statement and what I said earlier in my summary of that statement. There are various things that need to be done. Money is an issue. Mental health services are very costly, even for middle class families, and there are very few families that can really afford the mental health services needed for a severely mentally ill child, even with private insurance in the current state of affairs because there are gaps, there are limitations on the extent of services, the length of time that the child can receive the services and so forth.

And, in fact, we found that in some cases Medicaid for the lower-income families provides better coverage for mental health than some private employer-provided plans. So money is an issue. So ways of providing the services either at less cost or subsidizing the parents, and families, and paying the costs.

Lack of information we have talked about extensively. Parents need to know the various options available to them. The children need to be screened properly, and that is another area we have not really talked about this morning, but there are instances where families, if they knew, could have available to them screening and diagnostic programs that could help them understand the nature of the mental illness and what type of treatment would be necessary.

And then the parent, knowing that, in combination with knowing what is available in the neighborhood or the community, could make informed, intelligent decisions about what to do, and that is lacking in a lot of neighborhoods. And part of that of course is to train the local caseworkers and providers in terms of what is available so that they will know not only what their agency can provide, but what other agencies can provide, and then just cooperation among the agencies to share in the cost, perhaps, for a particular family or a particular child because no one agency can necessarily provide all of what is needed.

Chairman COLLINS. I want to thank you very much for your testimony and for your hard work on this issue. Your testimony and the GAO report have been extremely helpful to the Committee.

We want to work closely with GAO, perhaps doing some follow-up work in this area, but also to get your input as we draft the legislation.

Ms. ASHBY. All right.

Chairman COLLINS. So we look forward to working with you, and thank you so much for being here today.

Ms. ASHBY. Thank you.

Chairman COLLINS. We are now going to call the next panel. We will hear from the officials testifying on behalf of agencies that have responsibilities for children with mental health needs.

I would like to welcome Charles Curie, the Administrator of the Substance Abuse and Mental Health Services Administration at the Department of Health and Human Services. Mr. Curie has more than 20 years of professional experience in the mental health arena, including service as the deputy secretary for Mental Health and Substance Abuse Services for the Commonwealth of Pennsylvania.

The Committee would also like to welcome Dr. Susan Orr, Commissioner of the Children's Bureau in the Administration on Children Youth and Families at HHS, who is accompanying Mr. Curie today. Dr. Orr, it is my understanding that you are not going to be presenting formal testimony, but you will be available to answer questions.

Next, I would like to introduce Mr. J. Robert Flores, the Administrator of the Office of Juvenile Justice Delinquency Programs at the Department of Justice. Prior to his appointment, Mr. Flores served as the vice president for the National Law Center for Children and Families.

I look forward to hearing your testimony today, and, Mr Curie, we would like to begin with you.

TESTIMONY OF CHARLES G. CURIE,¹ ADMINISTRATOR, SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, ACCOMPANIED BY SUSAN ORR, PH.D., ASSOCIATE COMMISSIONER, CHILDREN'S BUREAU IN THE ADMINISTRATION ON CHILDREN, YOUTH AND FAMILIES, ADMINISTRATION FOR CHILDREN AND FAMILIES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Mr. CURIE. Thank you, Madam Chairman, and good morning. I am Charles Curie, the Administrator of the Substance Abuse and Mental Health Services Administration at the U.S. Department of Health and Human Services. I ask that my written statement be entered into the record as well.

Chairman COLLINS. Without objection.

Mr. CURIE. Thank you.

I offer the apologies of the deputy secretary, whom you actually invited. His schedule did not permit him to testify this morning, but, again, we are pleased to be here, and I want to thank you, Senator, for your leadership on this critical issue, which those of us in the field have seen emerge over time and know absolutely has to be addressed.

I am here on behalf of the Department to discuss the plight of millions of families struggling to meet the needs of their children who have serious emotional disturbances. In particular, I am speaking about the parents of all socioeconomic backgrounds who

¹The prepared statement of Mr. Curie appears in the Appendix on page 170.

relinquish custody of their children to State welfare or juvenile justice systems solely to enable those children to get the mental health care they need.

The Department knows the situation is a significant and unacceptable one. We know this because we have been grappling with the larger constellation of issues that can lead parents to this difficult decision, issues such as gaps in health care coverage, inadequate coordination of community-based services and stress that can arise with a serious chronic family illness.

We know the significant scope and range of the problem, since as many as 5 to 9 percent of children and youth in America experience serious emotional disturbances, illness of a magnitude that can compromise their ability to learn, to work, to engage in family life and the life of their community. These are the very kinds of illnesses that can, and do, lead to placements in the child welfare or juvenile justice system.

Frankly, it does not matter whether the tragedy of patently relinquishment affects millions of families or one family alone. Even one is significant and an unacceptable situation for the family, the community and for this Nation.

Consistent with the President's New Freedom Initiative, promoting lives in the community and the Supreme Court's *Olmstead* decision, the Department of Health and Human Services has been working to seek solutions. Testimony that you have heard on Tuesday described how just a few of those programs are making a difference in different parts of this Nation.

The General Accounting Office report that you requested is very important, but it tells only part of the story. While useful to know where the problems are, as the GAO study and report details, it is even more useful to build a collaborative, integrated system, beginning at the community, with leadership at the State and Federal levels with the capacity to meet the needs of children with serious emotional disturbances and their families.

As requested, let me describe a few of the Department's activities and how we are coordinating them. In many cases, these are not simply promising practices that need evaluation. Rather, they are practices and programs with robust and still-growing evidence of success that can be modeled and adapted in States and communities across the country. The question is how we bring those practices to scale so that they make a difference nationally.

Let me begin with the Administration for Children and Families (ACF). The Federal Foster Care Maintenance Payments Program, which is title IV-E, provides upward of \$5 billion annually to States to assist with foster care maintenance for eligible children, thereby promoting State provision of proper care for children who need placement outside their homes, in a foster family home or institution.

First, in 1982, and again just last month, ACF has been clear with States that Federal law does not require that a family give up custody of their child to secure Federal funds for that child's placement in foster care. Yet some States continue to limit voluntary placements into foster care to situations in which a parent specifically relinquishes custody.

Even when a child is in foster care, however, there is no guarantee that his or her mental health needs will be met. State child welfare agencies often face the same challenges obtaining services that lead parents to place their children in foster care in the first place.

Children and families involved in child welfare face long waiting lists for mental health services. Distance to service providers also poses another difficulty. ACF is working to solve that problem and is engaging in other program efforts as well. A new ACF funding announcement is building on the experience of SAMHSA's Children Program to encourage the creation of community-based systems of care for children with serious emotional disturbances.

Promoting Safe and Stable Families Program funds can be used for mental health and other supportive services for children with serious emotional disturbances so foster care does not need to be an option for families in the first place. Other innovative welfare-related changes are proposed in the President's Fiscal Year 2004 budget, such as enabling States to use ACF funds in new ways that lets them help provide mental health services to families earlier, without ever removing children from the family or the community.

Let me turn now to SAMSHA, the Substance Abuse and Mental Health Services Administration.

Some of the strongest programs that SAMSHA administers promotes stable families, improve outcomes for children with serious emotional disturbances and reduce placements of children outside their homes and communities. Consistent with the President's New Freedom Initiative, the programs emphasize community-based systems of care over institutional care or other forms of child outplacement.

SAMSHA's comprehensive Community Mental Health Services Program for children and their families helps reduce the need for parents to reduce custody of their children in order to receive mental health services. Under the program, communities develop systems of care that are child-centered, family focused, community based and culturally competent. Perhaps as important, services are coordinated among the major child-serving systems, including child welfare, juvenile justice and education.

The goal is to create a positive, integrated and seamless experience in service delivery for the child and the family. The value of systems of care cannot be overstated. Evaluations of our program indicate that families feel supported by the services, and critically that children improve their functioning at home, in school, and in the community. The program has now served over 60,000 children in 46 States, 10 American Indian and Alaskan Native Tribes, the District of Columbia, and the territories of Guam and Puerto Rico.

Moreover, with an increasing State match over the tenure of each grant, virtually all of the graduated grant programs have remained in operation beyond their Federal funding lives.

SAMSHA has also provided grants in almost every State and the District of Columbia to statewide family network organizations. These organizations enable families of children with serious emotional disturbance the participate in the development of policies that result in effective services of children with serious emotional disturbance.

Families in these networks also support each other so children can be cared for in their homes and not have to be placed in more restrictive settings—like the Center for Medicaid and Medicare Services (CMS).

While services are available through many pathways for Medicaid-eligible children with serious emotional disturbances, I want to focus, in particular, on how children with serious emotional disturbances, whose family incomes or assets preclude them from eligibility for Medicaid actually can get Medicaid services.

States may use the TEFRA optional eligibility category to provide Medicaid coverage to chronically disabled children, including those with serious emotional disturbances who require an institutional level of care. Under this option, parent income and assets are not taken into account when determining eligibility. The option enables States to cover children who could be served in the community. Unfortunately, fewer than 20 States, 19 exactly, use this particular option.

Further, many children with serious emotional disturbances do not meet the criteria for an institutional level of care. So that also contributes to that option not necessarily always being operational.

Under this option, another option is the Home and Community-Based waiver. Under this option, States also can disregard income and resource rules enabling them to provide Medicaid to children with serious emotional disturbances and others who otherwise would be eligible only in an institutional setting. Three States—Kansas, New York and Vermont—have received HCBS waivers specifically for children with serious emotional disturbances, who otherwise would be hospitalized.

Children and their families in these States can get specific treatment and supportive services, and among them include respite care, case management, crisis intervention and family support services. These special waivers require States to demonstrate that community-based care is no more expensive than hospital care would be. The cost neutrality requirement does make the waiver difficult to obtain because, traditionally and currently, it refers to institutions such as hospitals, nursing homes and ICFMR for those individuals with mental retardation and developmental disabilities.

For that reason, President Bush included a demonstration proposal in his FY 2004 budget to provide home and community-based services for children currently residing in psychiatric residential treatment facilities, including them in that equation, along with the other three types of institutional settings.

Finally, the early periodic screening, diagnostic and treatment services is also available or EPSDT for Medicaid-eligible children. Under it, a child with a serious emotional disturbance may receive any and all necessary mental health service and may be even determined to have a mental health through EPSDT mandatory benefit within the Medicaid program.

We have learned one more thing, that it is critical, if we are to end the need to make children wards of the State to get mental health care, and it is the need for prevention and early intervention. We must engage early. We know that prevention and early intervention can save lives. We also know that it can save dollars, families, jobs and education.

In conclusion, I have tried to focus these remarks on what the Department is doing, and will continue to do, to help end the need for parents to relinquish custody of their children to State juvenile justice and child welfare systems in the hope of getting treatment for their children's serious emotional disturbances.

However, as in any public health effort, the Federal Government cannot act alone. We must work with States to help them organize themselves and respond in a similarly coordinated fashion. Local communities, families, mental health professionals, supportive services and other key groups are part of the solution and I know are willing to work on this issue.

Finally, parents of children with juvenile diabetes, cerebral palsy, with cystic fibrosis or other long-term chronic illnesses do not have to seek placement for their children in State child welfare and juvenile justice programs to ensure that their children get care and treatment. It is time to treat mental illness with the same urgency as other illnesses. Consistent with the President's New Freedom Initiative, it is time to provide children and adolescents, with serious emotional disturbances, the same dignity and the same opportunity for lives lived as members of both their families and their communities.

Thank you for the opportunity to address this critical and important issue. I request that you make the full text of my remarks part of the hearing record and would be pleased to respond to any questions you may have.

Chairman COLLINS. Thank you very much, Mr. Curie. I wanted to cheer at the end of your statement when you contrasted the treatment for children with mental illness and treatment of children with juvenile diabetes or other serious diseases, but who are suffering from physical ailments. These families know where to go to get help, and their parents certainly do not have to give up custody for them to get help. So I appreciate your making that very important point

Mr. CURIE. Thank you.

Chairman COLLINS. Mr. Flores, I would like to call on you next.

TESTIMONY OF J. ROBERT FLORES,¹ ADMINISTRATOR, OFFICE OF JUVENILE JUSTICE DELINQUENCY PROGRAMS, U.S. DEPARTMENT OF JUSTICE

Mr. FLORES. Good morning, Madam Chairman.

Chairman COLLINS. Good morning.

Mr. FLORES. I want to introduce myself. I am Bob Flores, the Administrator for the Office of Juvenile Justice and Delinquency Prevention, within the Justice Department's Office of Justice Programs. And on behalf of the Department of Justice, I am pleased to have the opportunity to testify here this morning about a very important issue that faces, unfortunately, too many parents; the voluntary custody relinquishment of their children in order for them to get necessary mental health services.

I would ask that my written statement be included entirely in the record.

Chairman COLLINS. Without objection.

¹The prepared statement of Mr. Flores appears in the Appendix on page 178.

Mr. FLORES. Thank you. Let me begin by emphasizing that it is our sincere belief that no child should have to enter the juvenile justice system in order to obtain mental health services. That just simply should not happen. And no parent should be confronted with the agonizing choice between relinquishing custody or allowing their child to suffer as that child's condition deteriorates for lack of mental health treatment.

Certainly, no one can hear or read the testimony of the parents who appeared before this Committee on Tuesday without being moved by their stories. And being even more convinced that we need to move quickly to help other parents who find themselves in similar heartbreaking circumstances.

Now, that this Committee and the GAO have outlined the problem and brought it to the forefront, these parents have every right to ask what the Federal Government can, and will do, to help them.

The Department of Justice solidly supports the overall goal of reducing and eliminating the inappropriate placement of children not only into the juvenile justice system, but into the child welfare system as well in order to obtain mental health services. We believe that improving the effectiveness, availability, and affordability of mental health services for at-risk youth as well and those already involved in the juvenile justice system will automatically reduce the need for parents to relinquish custody of children with serious emotional and behavioral disturbances.

My office, the Office of Juvenile Justice and Delinquency Prevention, has funded and will continue to fund a number of mental health initiatives. We are seeking to broaden our understanding of the mental health needs of at-risk youth and juvenile offenders so that we can both improve the quality of the services they receive and prevent these young people from any future involvement in the juvenile justice system.

An example is the Safe Start Program, which seeks to reduce the impact of family and community violence on children from birth to age six. Another project, the Mental Health and Juvenile Justice Initiative, is designed to develop a model for delivering a broad array of mental health services to youth within the juvenile justice system.

In its recent report, "Child Welfare and Juvenile Justice," the GAO stated the problem very clearly. GAO also went beyond a simple identification of the problem and provided a useful description of practices that may help to reduce the incidence of inappropriate child welfare and juvenile justice placements.

I am pleased to note that OJJDP already supports a number of programs that exemplify such practices. We concur with the recommendations in the recent GAO report and agree that this issue is a serious problem that needs to be addressed. We see the report as a useful starting point for resolving not only the issue of child custody relinquishment, but broader issue of making juvenile mental health services more accessible and affordable.

The GAO made four recommendations that apply specifically to the responsibilities that the Attorney General would share with the Secretaries of Health and Human Services and Education. I would like to address each of these recommendations in turn.

First, GAO recommends that the Secretary of HHS and the Attorney General investigate the feasibility of tracking children placed inappropriately in the child welfare and juvenile justice systems to identify the extent and outcomes of these placements. As I stated at the outset, the critical goal for our agency is to eliminate any need for parents to place their children into juvenile justice or child welfare systems to obtain those needed mental health services. It is not clear, however, how tracking the long-term placement outcomes would contribute to the goal of eliminating such placements entirely.

In addition, it seems premature to institute a long-term tracking program in the absence of even barely minimal reliable data regarding the true scope of the problem. As the GAO noted, after conducting site visits and surveys in numerous States, no agency tracks these children or maintains data on their characteristics.

We do agree that it is vital to collect data to determine the scope of the problem, and we believe that the Department of Justice has an important role to play in this effort. It is part of our responsibility. We see a particular need for the Department of Justice to support HHS as the likely lead agency in this type of inquiry by helping HHS understand the complexities of data collection within the juvenile justice setting, providing contact information for relevant juvenile justice facilities and engaging in other activities supportive of that inquiry.

Second, GAO recommends that the Secretaries of HHS and Education and the Attorney General develop an interagency working group to identify the causes of misunderstandings at the State and local level and create an action plan to address those causes. We concur with the need for an interagency effort to both clarify the causes of the problem and to identify policy and programmatic changes that would address those causes.

We are willing to participate in an existing interagency forum, and we offer the Coordinating Council on Juvenile Justice and Delinquency Prevention as a means to immediately implement that recommendation. The Coordinating Council, which is meeting this afternoon and tomorrow, includes the Department of Health and Human Services, the Department of Education, and five other Federal agencies, Cabinet-level departments, along with other agencies, as partners with us in coordinating Federal programs on delinquency prevention.

As the Council's Vice Chair, I have placed the issue of voluntary custody relinquishment by parents seeking mental health services on today's and tomorrow's agenda. I plan to recommend to the Council that we explore how the agencies represented on the Council can work together to ensure that parents are no longer forced to choose between giving up their children or obtaining needed services for them.

As an interagency body, the Council is well positioned to examine the multiple factors contributing to this tragic situation and to work towards developing strategies at the Federal level to address the needs of these children and families.

It was also made clear at Tuesday's hearing that there is a great need for State and local officials to receive clear direction regarding Federal regulations and requirements. It is important to clear up

the widespread misconception that Federal rules require parents to relinquish custody in order for their children to receive services under Medicaid.

Although DOJ has no direct role in Medicaid administration, we intend to work with HHS to ensure that juvenile justice agencies and professionals understand that issue because the Medicaid office may be one of the places parents turn first for information.

In summary, we accept the recommendation for an interagency working group to address the issue of inappropriate placement of mentally ill youth and propose to use an existing interagency forum for that purpose. This will allow us to rapidly move forward without having to build from scratch. As we do that, we would emphasize the need to address the more urgent problems of these young people which are again related to a lack of affordable mental health services.

Third, GAO recommends that these agencies continue to encourage States to evaluate the child mental health programs that they do fund or initiate. OJJDP and other Federal agencies already support numerous evaluation efforts involving State and mental health programs, and these efforts will no doubt continue for the foreseeable future.

However, a general evaluation alone does not appear to address the specific issues raised by the GAO report or address the acute situations described by some of the parents at Tuesday's hearing. The urgent problems described in Tuesday's testimony appear to result, at least in part, from a lack of appropriate mental health services at State and local levels, as well as from the unavailability or inadequacy of mental health insurance coverage.

Therefore, we recommend that States evaluate their entire systems of care for children in order to determine the following information. How many children with serious mental illness are in need of care but unable to obtain it? How do State and local child-serving agencies, such as Education, Child Welfare, Mental Health and Juvenile Justice, address the needs of these children and how effective are these systemic efforts in actually meeting the mental health needs of these youth and their families.

We also need to set some priorities in evaluating programs for children within the juvenile justice system who have severe and chronic mental illness, as these are the youth whose families may be very likely to be forced into giving up legal custody.

Further, from both a public safety and a mental health standpoint, any effort at systemic improvement requires us to address the problems related to teenagers who, as a result of their severe mental illness, endanger their families, their peers or themselves.

As reported in Tuesday's testimony, many of these youths are involved in setting fires, threatening or assaulting their siblings, harming family pets, engaging in self-mutilation, and threatening suicide. Law enforcement may, in fact, properly need to intervene in these cases to protect family members or peers.

This population, described in the Portland Press Herald as having one foot in the juvenile justice system and one foot in the mental health system, requires special services that will allow us to maintain public safety, while rehabilitating these youth and preparing their families so they can return home to lead safe, happy

and productive lives. We must make this group of youth a priority for accessible, affordable, and effective intervention.

Finally, the GAO recommends that the Secretaries of Health and Human Services and Education and the Attorney General determine the most effective means of disseminating the results of these and other available studies to State and local authorities. We agree that effective information dissemination is critical, and we will explore how to improve our existing methods of outreach, both within OJJDP and in concert with other Federal agencies.

Federal agencies already possess many effective avenues for disseminating the results of their work, but we could clearly do more. While it is important to reach State and local policymakers and officials, I believe it is even more vital that we reach parents who are searching, at times desperately, for the means to help their children.

We will explore how best to reach these parents and assist them in navigating the mental health, juvenile justice systems and child welfare systems in their States. In addition, we will look for better ways to help parents become effective advocates for their troubled children. As I said, we have heard directly from parents about barriers they face in trying to help their children with mental illness. It is now up to us to find ways to overcome those barriers.

This concludes my statement. I welcome the opportunity to answer any questions that you may have.

Chairman COLLINS. Thank you very much for your testimony. I have been trying to figure out why so many State officials, child welfare workers and families are under the mistaken impression that they have to relinquish custody in order to qualify for their children to receive an out-of-home placement in a residential setting. So I decided to look at the guidance that the Department of Health and Human Services has given on this issue. And, Dr. Orr, I am going to ask you to respond to this.

And I have to tell you that I understand why they are confused. It is not unambiguous. There is nothing that says that a parent can retain custody. I looked at the 1982 guidance that not only says nothing to suggest that a parent can retain custody and still qualify for Title IV-E dollars, but indeed the 1982 guidance, which I have right here from the website from the Administration for Children and Families says, and I quote, "Custody may be retained by the court or given to a private nonprofit agency." It says nothing at all about custody being retained by parents.

Now, just within the last week or so—I think it was on July 11th—the Department put out some new guidance on this, and there is a question in the manual that says, "Does responsibility for placement and care of the child, as used in Section 472(a)(2) of Title IV-E of the Social Security Act equate with custody?" And the answer says, "Not necessarily." That is not exactly crystal clear on this point.

I would also note that the new guidance is difficult to locate and is not included in your on-line policy manual. It is slightly less ambiguous than the 1982 guidance, but it still does not state unequivocally, clearly, that parents need not relinquish custody of their children to receive the needed assistance. What is the problem here? Why cannot HHS clearly say, in the on-line policy man-

ual and in all other guidance given to the States, that parents need not relinquish custody? I mean, why not say that clearly, Dr. Orr?

Ms. ORR. The guidance that you are looking at is in response to not simply questions of mental health. I grant that I am sure that we could be more clear in the future, and we will look to making it more clear, but that voluntary relinquishment is the question, and we have to define what placement and care responsibility requirements are. There are many paths for voluntary relinquishment. Some parents actually come to the Agency because they do not feel like they are adequate parents and ask for a voluntary placement. Others come for the reason that we are here today. The guidance is intended to address all kinds of scenarios.

Chairman COLLINS. But why not issue clear guidance on this point? If there is such widespread misunderstanding, which we know there is. You have all testified that there is, we heard testimony on Tuesday that there is, and the GAO found that there is. We clearly have a profound misunderstanding in this area that is affecting the lives of families struggling with mental illness.

Mr. Curie, would you like to—

Mr. CURIE. Yes. Again, I think the point we are at currently, and we have had discussions around what type of clear, not only in terms of making sure the language is clear, but what type of technical assistance can we provide in a more formalized, systemic way to State child welfare agencies, to juvenile justice authorities, translating that down to the county level.

And part of our process in addressing this will be bringing clarity and going beyond just the language, but also looking at ways we can provide active technical assistance. And my colleague, Mr. Flores also addressed the issue of technical assistance, and for it to be effective, it will have to be an interagency, not only within HHS, but also across the Departments of Justice and Education as well.

I think part of the solution and part of the way of addressing this at this stage is to have a systemic technical assistance approach bringing this issue to light.

Also, there are going to be a variety of forums where we are going to be able to address this issue. The timing of these hearings and the GAO study, along with the President's New Freedom Commission on Mental Health, which will be delivered to the White House, anticipated now before the end of this month, this issue is specifically addressed in the findings of the Mental Health Commission. And with an action plan that we anticipate being developed from the informed opinions of that commission, this will define the priority area in terms of streamlining and defining a clear children's mental health system.

I think one thing we are in agreement on right now, is that we cannot necessarily say we have a children's mental health system.

Chairman COLLINS. I was going to say "system" is a misnomer.

Mr. CURIE. So that is why we need to look at transforming what we do. Many of those efforts, when it comes to a cross-agency mental health agenda, have been underway this past year. Along with the council Mr. Flores mentioned, which we will be participating in actively, through SAMHSA as the lead agency within HHS on mental health services delivery, we brought aboard this past year an individual, Dr. Sybil Goldman. I refer to her as our children's czar.

Her major point, and what she is doing, is assuring that we have across agencies a children's mental health and substance treatment agenda. And ACF has been working very closely with Dr. Goldman, as well as CMS, within HHS. And we are also working with the Departments of Education and Justice, she is engaging them for the first time and as part of the action plan we are looking to define a Federal children's mental health agenda.

I think this is a symptom that we are dealing with, a tragic symptom, that we are dealing with because of that lack of a system. A part of the plan will be engaging States and looking for States to develop a comprehensive mental health plan across agencies. And, if we only collaborate at the Federal level about translating that, how that will happen at the State level, giving technical assistance and support, we are not going to see it translated at the community level.

Chairman COLLINS. I agree with your comments, and we do need to have an integrated system of care. The President's initiative is a terrific one that I think is going to make a real difference, but on a practical level, I have to ask all three of you to work together to come up with clear guidance to the States so that this misunderstanding will no longer exist. What is out there now is not clear guidance. It really is not.

And, Dr. Orr, I understand that the current guidance deals with a whole host of issues, but that does not preclude you from issuing guidance on this issue, and I would ask that you do that and provide the Committee with a copy.

Ms. ORR. We will make that commitment.

Chairman COLLINS. Thank you. I appreciate that.

Mr. Curie, you talked about two programs that are waivers under the Medicare program that can be particularly helpful to the States in this area, and one you refer to as the TEFRA waiver. I think most of us call it the Katie Beckett waiver.

Mr. CURIE. Right.

Chairman COLLINS. Is that the same thing, just for clarity?

Mr. CURIE. It is the same thing, correct.

Chairman COLLINS. And the other is the home- and community-based services waiver. And you have pointed out that only three States—it is Kansas, Vermont and New York—

Mr. CURIE. Correct.

Chairman COLLINS [continuing]. Have taken advantage of the home- and community-based services waivers. We have heard very promising results from Kansas in its use of this waiver, and I know from a series that the Portland Press Herald did in my State that Vermont is having a lot of success with this waiver as well.

Why are more States not availing themselves of this waiver? You brought up the cost neutrality issue, but Kansas has found that it is actually saving money to develop community and home-based systems that are an alternative to institutional care or residential care.

Mr. CURIE. I think, up until now, with only three States having taken advantage of that, other States are looking to the track record established in those States to determine both cost-effectiveness, and again we are receiving data on that, and I think it is the

dilemma and the challenge many States face around their Medicaid programs.

For example, there is an offset that you assume many times when you begin to move any waiver ahead; that you are going to do things differently, in a better way, to assure that the appropriate services are accessed, and if you had accessed the appropriate services in the first place, you do not spend money in a needless way, and also people are served better. Though, historically, if you take a look at many of those options that States have pursued, and I am not talking specifically about this one, but in general, many times the offset has not occurred, and States end up spending money the old way and a new way. And with the State budget crunches States are facing right now, I think they have wanted to move from a cost perspective in a conservative fashion.

And as what I mentioned earlier, they were only able to gauge cost neutrality based upon nursing home, hospital and ICFMR placement, and we have moved away, and this is somewhat good news, we moved away from institutional care being a mainstay to trying to develop community-based systems of care, and psychiatric residential treatment facilities have never been included in that equation.

So, in order to move it forward and put States in a position to take advantage of that, we believe including that institutional setting will give greater opportunities for States to prove cost neutrality and be able to move forward.

In the FY 2004 budget, we have proposed demonstration projects to be able to address that issue to inform the States. And I think the timing of both that, along with recommendations coming out of the commission, and of course the GAO study and this issue now being on the front burner, we will be in a position, as we never have been before, to be able to craft technical assistance and help States understand how they can move ahead with those waivers.

I think we have a responsibility to help States find the offsets that can occur. Because when you think about it, we are spending money on treatment for these children anyway.

Chairman COLLINS. Exactly.

Mr. CURIE. So we should be able to find the offset, and I think States need to have the confidence, if they are moving in this direction, that they will realize the offsets because many times when they have moved in certain directions, the offsets have not been realized. So the demonstration projects will also help us realize that.

Chairman COLLINS. I want to follow up on that point. I am delighted that the administration has proposed the demonstration project because it is my understanding that the current law requires that the current level of care the child must meet to be served by the waiver does include, as you say, hospital, ICFMR or a nursing home. And that obviously is not the norm nowadays.

Mr. CURIE. Correct. Absolutely.

Chairman COLLINS. It is psychiatric residential treatment center that is more the norm. Now, does CMS or does the Department believe that we need to change the law in that regard? I know you have done a demonstration project, but would it be helpful to have the law changed? I know there is a provision in the Family Opportunity Act, which I have cosponsored, which would expand the stat-

ute to include residential treatment centers. Do you think that statutory fix is needed?

Mr. CURIE. Yes. At this point, the Department has not reached the conclusion that a statutory fix is needed, and that is why they are looking at administrative remedies at this point. But we are committed to having ongoing dialogue with you in the process of legislation you are considering to determine if a legal or legislative remedy is necessary. But at this point, we have not taken a position that that is necessary.

Chairman COLLINS. So you may have the authority, and you obviously believe you have the authority to do the demonstration project.

Mr. CURIE. Yes.

Chairman COLLINS. I think it would be helpful to clarify the law, and that way it removes the doubt in the minds of the States, and it might lead to greater use of it. It seems to me, even if you may be able to do it administratively, why not clarify the law?

Mr. CURIE. And, conceptually, with the law that you are examining and considering at this point in time, I think it is a matter of pragmatically what is needed, and we look forward to the continued dialogue.

Chairman COLLINS. Another concern about the Katie Beckett option is that, according to the Bazelon Center survey, in many States that have elected the Katie Beckett option, children with mental and emotional disorders have been excluded. The States have focused on children with severe physical problems, and I do not believe, at least based on our analysis, that the rules for the Katie Beckett option exclude children with serious emotional disturbances, thus I think we have got another communication problem here about whether the materials prepared for the States leave most parents of children with emotional and mental disorders uninformed about their eligibility for the program. Could you comment on that as well?

Mr. CURIE. That is consistent with our knowledge as well, in terms of States where they do have the TEFRA option, children with serious emotional disturbances are not necessarily recognized or realized in that process or prioritized, and we do believe this must be part of, when we talk about providing technical assistance and clarity, working with those States that already have TEFRA to assure that we can bring clarity to that situation.

I think this is, unfortunately, as we discussed earlier, not uncommon; that when there are many options adopted to address the health needs of children, many times mental health or serious emotional disturbance is not necessarily given the clarity that the physical disorders or disabilities may have.

So it is an issue we need to address, and that is consistent with our findings as well.

Chairman COLLINS. Mr. Flores, what kind of assessments are typically made of children entering the juvenile justice system to determine whether or not they have a mental disorder? The reason I ask this question is I have seen several reports that suggest that a large number of people who are incarcerated are suffering from mental illnesses, which is obviously very disturbing, in terms of whether or not they are receiving the treatment. But is there a

screening when a child comes into the juvenile justice system, generally?

Mr. FLORES. I would like to be able to tell you that there is such a thing as a typical screening tool or a typical process that is engaged, but there simply is not. Situations vary widely from State-to-State and facility-to-facility, and things occur at different times in the system. One of the things that the Office of Juvenile Justice and Delinquency Prevention has been doing is really trying to work with key stakeholders in this issue to do two things:

One is to explain to people that mental health is a critical issue for us in the juvenile justice system because I think some would like to think it is only an issue for the mental health or the Health and Human Services system on the State or Federal level. And so we have done a great deal in working with some of our key stakeholders, such as the judges, and corrections officers, and we have spent a considerable amount of time, energy and resources, provided to us by Congress to develop good assessment tools and research. In fact, we now have a resource guide on assessment tools that is in final draft form that we expect to release fairly shortly.

Another responsibility of our office is to work primarily through the State juvenile justice coordinators, their specialists, and through different professionals, as opposed to directly providing services to individuals (although we do that too). We do have some work that is going on now with a number of Native American communities, through our Tribal Youth Program. We are providing funds directly to the Tribes so that they can initiate mental health programs in their communities.

But to go back to your question, there is no screening system, and I think we are still a little bit away from that, in terms of a true adoption of the understanding of how critical it is to address mental health needs. For example, as my colleague Charlie said, one of the keys here is the enormous benefit to restoring these children because that is what we are talking about.

For example, you take a girl who has been sexually abused over a period of time and somehow, because of just God's grace, she really is resilient, and she is able to go to school for a couple of years and do well, but there is a lot of anger there, and it does not get resolved, and so she is involved in a very nasty assault.

It is critical for people to understand that for her to work through that, and for us to have a child who once they leave the facility, is in a position to succeed and not come back into this facility, triggers all of those resource costs that States now, because of the budget concerns, really want to solve. For us to succeed there, to really restore that girl, we have to have the ability to do an assessment that really identifies that at an early point.

It does not have to wait either for when they are admitted to the correctional institution or the detention facility. It can be done when the case first goes to juvenile court. It can be done as an early referral, as part of the police process, or the arrest process.

So there are a number of opportunities which we are really trying to push because we would like to push that back as far as possible.

I would also like to say that one of the conversations we are beginning to have with Health and Human Services is to talk about

the use of early intervention moments. Whether it is a Head Start program, whether it is participation in Big Brothers, Big Sisters, membership in a Boys and Girls Club, it is an opportunity to really start to identify those children who are at risk very early, work with their parents, get them that information because we can not only save money, which is a concern, but we can save lives because we make the investment on the front end.

So we are very concerned that there is not widespread unanimity about what makes a good assessment tool. We are working very hard on this.

The other thing I want to give you as a point of encouragement is that we have people outside of government; the pediatricians are working hard to try to figure out what they can use as a screening tool to identify at-risk issues, of which mental health challenges are among the most significant that we have and that we know about.

So we have done the research, we understand mental health is key, and we are working very hard actually to really try to, almost like missionaries, going out and really talking to the different States and really getting them to see how they can help themselves by doing a very good, strong assessment on the front end with kids coming into the system. Because part of the mission that Congress has given JJ is to make sure that we do not have inappropriate placements, period, in the juvenile justice system.

So one of the areas that we have a way for us to work with States constructively is through the process of our Formula Grant Program which we provide to States. And one of the things that they have to succeed at is making sure that placements of children are appropriate, and they are not appropriate if it is a status offense, and it should not be appropriate if it is simply an admission to try to get mental health. Because, as Mr. Curie has said, there is no guarantee that once they get into that system, it is going to happen lickety split.

The other part of it is that I also think that when it is used to kind of cut to the front of the line, we really run a danger of pitting one group of parents against another, and I think that would be really destructive. So I think we have just an opportunity here to take some major strides, but we are looking very hard at the assessment issue, and it is fortunate for us that we do have judges who are involved in these cases.

And one of the things that we will be doing—in fact, I am heading to San Antonio this weekend to speak to the Board of Directors of the National Council of Juvenile and Family Court Judges, and to speak to one of their significant committees to talk to them about a number of issues. I will put this before them because I think that is one of the ways that we can disseminate information to a decisionmaker in the system who perhaps, if no one else points these things out, is in a position not only to do so, but to make sure that it gets the attention it deserves.

Chairman COLLINS. You mentioned in your testimony some of the efforts that you have underway to coordinate funding and programs with other agencies, and I think one was the Safe Schools Healthy Students Initiative. Are there other initiatives on which your agencies have joined forces or combined funding streams to

provide services? Because one of the lessons that I have learned from these hearings is how fragmented the system, well, there is not a system, but how fragmented the programs are as far as working together.

Mr. FLORES. The Office of Justice programs, of which we are part, prior to my arrival, initiated a reentry project. I think they did that also largely through the auspices of using the Coordinating Council. And one of the great things about it is that it brought together funding streams from the Labor Department, from HHS, from Education, from HUD, as well as the Justice Department funding to really try to build the capacity in States to address the question of how do we get kids to, when they leave the system, as well as adults—we happen to be responsible for the juvenile aspect—how do we get them to succeed when they come back out because we do not want them constantly riding the juvenile justice train or the adult train. It is destructive.

One of the opportunities there is for States to look at, with that money, and each of them received somewhere in the vicinity of around \$2 million to build this capacity, and we are working with them continually, providing technical assistance and training to them, is to look at mental health as a major issue. Because if the mental health needs are part of what brought that child into the system, and they are not addressed, then one should not ask for a different result if the ingredients were the same to get that child back in that system, whether or not their custody was relinquished by their parent.

So, for us, the mental health issue again is extremely important. So that is another example of where we have taken, and I think the budget figure is well over \$100 million of joint funding to do this project, and I think every State in the United States is currently participating in it.

Chairman COLLINS. That is good to hear because I do think, as GAO found, that the more interagency coordination, the more effective we will be in delivering these services.

Officials in the States and the GAO have said that supporting families is extremely important and that involving parents represented a change in philosophy for several of these programs. Previously, I have been told, the focus has been on providing services to the children, and the parents have not necessarily been included in decisions about their child's care.

Now, we are seeing a trend that I think is a promising one where the focus is on providing services to parents to help them keep their children in the home and to help them make an informed decision about their child's care.

Could you comment on those developments from the juvenile justice perspective?

Mr. FLORES. I would love to. Thank you, Senator.

I think if you went out to develop the most expensive and questionable system, in terms of providing mental health, it would involve sending children into the juvenile justice system to get it. The reason for that is, on top of whatever the costs might be of the mental health services, you have now added the cost of confinement to that. And if it is not necessary, then we are, in essence,

really minimizing the effectiveness of the money that Congress does provide for us to deal with this issue.

One of the challenges here and the opportunities here is that as we look at involving parents, we need to think about what the alternative would be, and that is that you take perhaps the most critical player and put them on the sidelines. This is if you took the star quarterback and said, "We are going to sit this one out, and we will just see what happens. We will have the halfback throw the passes."

In those cases where it is inappropriate to have the parent continue because they are perhaps the abuser or there is some other issue, where legitimately you do not want that parent, at least at the present time being involved, you need to find out. We need to find places where we can really engage the parents because they are capable of providing things and benefits to the system that we simply cannot pay for and cannot get any other way.

Let me give you the best example I have is through our Missing Children Program. We have a Missing Children Program because of parents. Parents came forward many years ago and said, "We know more about stolen cars than we know about missing children, and that cannot stand."

And so we came up with a process. Now, our office puts out not only materials by the foremost experts in law enforcement and in technology and missing children, and child pornography, and child exploitation, but we have materials that are put out by parents for parents; how to deal with this, how to access, how to advocate for their children.

We currently fund an advocacy organization which is made up of advocacy organizations that are primarily the parents of many of these children who have gone missing and who have not yet been recovered.

So I think it is a very encouraging trend, and what we would like to see at the Office of Juvenile Justice, as I believe was mentioned, and I know that Health and Human Services and the entire administration wants to see, is more ways that we can build and strengthen families and make sure that they are a prime player. Because, at the end of the day, we want them to go home and we want them to succeed. And so we have to make sure that if there is any way possible that we can work with those families, work with those moms and dads, work with those siblings.

I would add too that, as one of the parents I believe testified, and certainly it was covered in the news coverage that was done in your State, that special report about the tragic incident of walking in on one of the kids threatening the life of another one of the siblings. We cannot forget about those siblings.

I mean, there is the parent, there is that particular child who is troubled, but we also have to recognize the needs of the other children in the family. It is not likely that those children will ever see the juvenile justice system, with respect to that particular case. I mean, we are going to treat that young lady as a victim. We are not going to treat her, and she is not going to go into a kind of juvenile justice setting, but we cannot ignore the fact of what has happened—the trauma that has taken place.

And so how that need is going to be met, and what needs that child has, must be determined. If we are going to be successful, we have to work, as most good prosecutor's offices do, with victims' services. How do we provide for those other people in the family unit or in the community who have been impacted?

So I want to say that I think that there is a need to have a number of voices. And I want to also let you know that with respect to some of our programs, we are now making sure that children who have mental health issues in their lives are addressed and that parents are part of advisory boards or are part of the consultative process that we are engaging in so that we do not come out with a product or urge a best practice that really does not have someone who has lived through this providing information to us directly.

Chairman COLLINS. Mr. Curie, could you add to that also?

Mr. CURIE. Sure. Before I do, I do want to clarify something we discussed earlier for the record. That is, when it comes to the specific HCBS demo program, and including psychiatric residential facilities, and it is discussed in the President's budget, it does need legislative authority. So we will need to discuss that aspect with you.

Chairman COLLINS. Thank you for that clarification.

Mr. CURIE. Absolutely. There are two things I would like to discuss. One, we absolutely need to come up with ways to assure that the parent is always included, and that the family is always included. I mentioned in my testimony the systems of care approach that we are funding at SAMHSA. This very much is based on a principle, that there needs to be family and parental involvement at every step of the way. I think as we look at points of intervention being earlier, as much as possible, we are able to realize that. I think the question is what we have learned.

Right now we are funding systems of care at about \$97 million on an annual basis. We are proposing in the FY 2004 budget to add an additional \$10 million to that, because it has been also assessed as effective by the PART review that OMB has conducted as a way of assuring not only all entities that deal with children are at the table or around an individualized plan, but that parents very much are central to that process. I think it is in collaboration with, whether we are talking the child going into the juvenile justice system potentially, trying to divert them, or the child welfare system, we clearly have models that work.

The question you asked earlier too in terms of integration of funding, I think the critical thing is clear, where does the point of integration need to be clearest? That point of integration needs to be most clear at the level of the individual family. So they do not have to bend themselves to deal with a system that has desperate funding streams and different funding streams to navigate. There are models there, and there have been models that have been demonstrated through a variety of waivers through CMS. Some are managed care oriented. Some are oriented toward consolidation and integration of using, for example, the county, or using the local level of government as a point of integration and that the Federal agencies or the State agencies allow that integration to take place.

I think we need to examine those models and how they are working and see again what we can bring to scale.

Chairman COLLINS. Thank you. I have just one more question that I want to ask each of you, and that is, the GAO report that I commissioned along with the congressmen has now been out for, I guess, 3 months. It came out in April. I would like you to give me an update on where you stand on implementing the recommendations GAO had for the interagency task force, tracking, etc. Dr. Orr, I do not know whether you have any comments on that or whether it should be Mr. Curie.

Ms. ORR. You asked how we track data, and the automated foster care and adoption reporting system gives us some information. We are currently in the process of updating that system for the first time to see where we need to make modifications where appropriate, and we will certainly look at that.

We do know there was voluntary relinquishment. We just do not know whether it was because of a mental health issue on the part of the child or whether it was a voluntary relinquishment for some other reason. We are looking at ways in which we can improve our data collection efforts at this point. The public comment period just closed so it will be forthcoming.

Chairman COLLINS. Mr. Curie.

Mr. CURIE. Along with what ACF is looking at in terms of their data tracking, and again it is a collaborative effort within HHS to make sure elements are in there and determine how best those elements can be addressed. Again with the notion of the urgency of this issue, one thing we have been clearly focused on is the data tracking, because I do not think any of us in this room needs to be convinced it is a problem. I think it is a problem of relatively large scope. I think we all agree because of the GAO study and the response, the 12,000 to 13,000 figure is larger than that, that we need to be moving urgently.

When I mentioned earlier about setting a cross-systems mental health agenda, this issue is going to be central to that because I think it is a major symptom of the dysfunction of the current delivery structures throughout the Nation. So there has been an ongoing process in place.

We plan to continue to elevate this issue further as part of an area around problem-solving in terms of how systems can address this in such a way that once we achieve earlier intervention, make sure that there is screening available at the school system level, where children basically appear, primary care, as Mr. Flores mentioned earlier, the strong linkage of primary care to mental health because even though a child may not go to a community mental health specialty provider, which is rare, they are at least seen by a primary care physician typically twice a year, even if it is for 15 minutes each visit, which tends to be the average, there are ways of implementing an initial mental health type of screening.

These other types of things we are looking to, again—I do not want to use the word institutionalize, but institutionalize in our way of doing business to assure that there is a seamless children's mental health system that is transparent to the parent, and also that there is a clear single point of entry for a parent, or a pathway regardless of what door the parent enters, primary care, juvenile

justice, child welfare, school system. That there are pathways that lead to the same appropriate mental health assessment and treatment. If we attain that, we are going to address this particular problem. That is why we need to be looking at the overall systems approach, and keep this on the front burner as an area of concern.

What I do not want us to do is to develop just a special long-term work group to look at only this problem. I think we need to look at the greater children's mental health service delivery system, with this problem one of the primary examples for us as to why we need to move ahead.

Chairman COLLINS. Thank you. Mr. Flores.

Mr. FLORES. Senator, I think that if you were to ask law enforcement professionals, prosecutors, and judges generally where this problem ranks in their view, many would be unaware of it. So for us, our challenge is a little bit different than those of our colleagues over at HHS because we need to bring this to people's attention in perhaps a different way than has been done before.

We are having those conversations already. As I testified earlier, I have put the issue on the agenda for the coordinating council, so it will be a matter of discussion and then further work by the Subcommittee, I expect, on family health.

We are going to talk with the judges and then—I did not get a chance to develop it, but with respect to our State advisory groups and the juvenile justice specialists, one of the things that we have available that is administered by our office are block grants and formula grants. Those monies can be used to assist States to take a look at this problem and then to address it.

We have been working for quite some time on mental health issues in terms of assessment tools, in terms of its importance to the system, and the fact that without addressing them we are not going to see the kinds of progress and prevention that we would like to see. So that conversation has already begun and it has been going on for some time. But I am not sure that really our colleagues out in the JJ community really have focused on this as an issue. I think it is important for them to be aware of that, so we are going to bring that to their attention in a very clear way almost immediately.

But I would say I agree with Mr. Curie that one of the things that we want to do is make sure that we fix some of the underlying things that need to be addressed because I think one of the challenges that I am going to find as soon as I start talking to people is that they are going to ask me, how do you define that? How do you define some of the issues that you are talking about?

I will tell you, personally I was surprised as we started to get into the truancy issue, which is important and sometimes has a mental health causation—that is why children stop going to school—that there is not even a national definition for truancy. So that when I go and have conversations with people, even at the Department of Education, while we have a general understanding of what we want to say to each other and what we are talking about, we also have to be very careful. So I am looking forward to a very close collaboration with HHS and with folks at Education.

I would also say, and I would encourage you to also think about the other departments. For example, if we are going to see the

progress that we would like to see in communities, we need to make sure that we do not leave the Department of Agriculture out of this picture, because I know from my time as a former prosecutor that if children are having major problems with their blood sugar and it is going up and down because their diet is absolutely terrible, regardless of the medication that we give them it may not have the intended effect, it may not do the kinds of things we want them to do and we may end up with a situation where a child does engage in a crime as a young adult, or as an adult engages in really horrific conduct, and then we have got really a very difficult situation to address.

So I think that there is room here at the table and certainly it is, in some sense, a luxury we have with the coordinating council because we have such a broad membership that we will bring this to everyone's attention and the question will be: What is your mental health program and how are you going to contribute to the success of this, and how are we going to help. Again, our partners, which I think really will remain in the lead on this are at HHS. How are we going to really make it possible for them to succeed in a way that will be meaningful to the parents that came and who listened with rapt attention, whether it was on the Internet or however they get this testimony.

This speaks to me especially as a parent. I have three children. I cannot imagine the pain that some of those parents must feel. So I guess my response is that we are going to be moving very quickly to make sure that at least on our side of the table something is brought to the attention of people who may not recognize it at this time as an issue.

Chairman COLLINS. Thank you for your response. Thank all of you for your testimony today. This concludes the 2 days of hearings on this issue. It has been heart-rending to hear the agonizing decisions that too many parents who have children with severe mental or emotional illnesses have had to make. My hope is that we have not only put a spotlight on the problems that these parents face, but that we have paved the way for both administrative and legislative solutions. We really have to tackle this issue. It just should not be happening that children are not getting services unless their parents give up custody of them.

I think, as we have all said, the custody relinquishment is merely a symptom of a lack of a system to meet the needs of these children. So it is a complex issue, but it is one that demands all of our commitment and attention.

I am going to be working with several of my colleagues on legislative reforms. We welcome and need your help and your input. I look forward to receiving information on what you are undertaking administratively through the task force, and through clarifying the guidance and the President's commission. Working together I think we can make a real difference for these children and their families, and I know that is a goal that we all embrace.

So I want to thank you very much for being here today, and I want to thank the GAO for its excellent work. Most of all, I want to thank the families who were willing to come forward and talk about their personal struggles. It is very difficult, as we all can appreciate, to have a child who is suffering from a mental or behav-

ioral or emotional disorder. But then for the family to have to battle a system as well, or to have to encounter obstacle after obstacle to get care for those children is something that we just cannot allow to stand. The families who were brave enough to come forward and tell their personal tales really enriched these hearings and helped us gain a better understanding. So I want to thank all who participated.

I intend to introduce bipartisan legislation in September to help facilitate the provision of care to these children and assistance to families who truly have nowhere to turn.

The record of this hearing will be kept open for 15 days for the submission of any additional materials. Again, my thanks to our witnesses. This hearing is now adjourned. Thank you.

[Whereupon, at 11:18 a.m., the Committee was adjourned.]

A P P E N D I X

**Testimony of Congressman Patrick J. Kennedy
Senate Committee on Government Reform
342 Dirksen Senate Office Building
July 15, 2003**

Thank you, Madame Chairman and Senator Lieberman, for the opportunity to address the committee today and for holding this hearing to shed light on one of the unsung tragedies that afflicts our nation's families. I also must acknowledge my colleague, Pete Stark, who has shown unflinching leadership on this issue for many years. He has set his sights on this injustice, which makes me confident we will eventually eradicate it.

This hearing is about betrayal. We profess to be a nation that values families, but there are families we drive apart. We claim to care about children – how often are children invoked in our political rhetoric? – but we snatch away hope and opportunity from kids with certain health care needs. The gap between our words and our actions is measured in children, children whose parents are forced to relinquish custody to the state in order to save them.

You are going to hear from parents who can paint a much more poignant and tragic picture than I can of the suffering they and their children endure. Instead, I want to speak briefly about how these families wind up in this situation and what we can do about it.

Every day in every one of our communities, babies are born who are the center of universes. Their parents revolve around these new lives, eager to give every opportunity to their children. Sometimes, though, fate is cruel, and the babies grow up and develop health problems. Maybe a heart problem. Maybe leukemia. Or maybe a serious mental illness.

Those parents will do anything they can to help their babies, even if those “babies” are now toddlers, or school age, or teenagers. If the center of their universe needs help, those parents will move heaven and earth to get them the treatment they need.

For kids with physical health problems, our system can be far from perfect, but in moments of crisis, care is available. Not so for children or adolescents with mental illnesses. The kids with mental illness are also people's babies. They are also the center of their parents' universes. But when their lives are in jeopardy, we betray them.

We betray them by pervasive discrimination in health insurance. The growing body of science on the biochemical underpinnings of mental illness notwithstanding, nearly all health plans require much more extensive cost sharing for mental health care than for physical health care. Nearly all health plans put strict limits on the amount of treatment they will cover for mental illnesses. Imagine refusing to cover the twenty-first visit to the cardiologist or the thirty-first day in the hospital for cancer treatment.

Thousands upon thousands of parents live in terror of the day their child's insurance runs out.

And rightly so. Mary Ellen Clausen of Syracuse faced \$30,000 monthly bills to pay for care for her two anorexic daughters. How many families can afford that cost? Parents pay their hard-earned money for health insurance so that it will be there when their family is in need, but too often they are horribly disappointed.

We further betray these families by failing to provide a safety net. When parents are failed by the private health care system, either by being excluded altogether or by exhausting their benefits, they should expect that at a moment of desperation, a public system will help their children. Even the uninsured, after all, have access to emergency room care and we surely would not allow a child with a diagnosed, potentially fatal disease to go without treatment.

But in fact, our public mental health care system is, in the words of the President's New Freedom Commission on Mental Health, "in shambles." While mental illnesses are the second leading cause of disability in the United States, our funding for community-based services has actually fallen in real dollars in recent years. Nationally, we spend less than eight percent of our health care dollars on mental health care.

The underfunding of our system necessarily translates into lack of access for families in crisis. The access problem is compounded by abysmal reimbursement rates for providers of mental health care. In Rhode Island, I hear many stories of mental health professionals who simply cannot make ends meet while contracting with the public systems or taking insurance, and I understand that this phenomenon is common. And so in communities across the country, especially rural and inner-city urban areas, shortages of child psychiatrists, psychologists, and other professionals mean months-long waiting lists, even for children in crisis.

These access problems are made worse by bureaucratic obstacles and federal mandates which prevent states from implementing the systems of care approaches that have proven to be most effective – and most cost-efficient. Moreover, Medicaid, a large payer for mental health care, is statutorily unable to keep up with the shift from institutional to community-based services for children with mental illnesses. Medicaid is therefore not an option for most middle-class families in this situation, even when they face insurmountable mental health costs.

The result of these betrayals is that many parents simply have no way to get their children the care they so desperately need.

The horrible position this puts parents in is hard to fathom. Their child may be suicidal, may be posing a risk to other children. They watch the broad horizon of possibility they have dreamed of for their child shrinking, becoming ever narrower as his disease impairs his ability to learn in school. Relationships suffer and families are stretched to the breaking point.

And so these parents are forced to do the hardest thing imaginable: give their babies over to strangers. No good, loving parent should ever be in that position. It is barbaric that we break up families like this.

There must be a better way than telling parents that we will only give their children the care they need if they sacrifice custody to the state.

We clearly need to devote more resources to mental health care, both public and private, and I have fought and continue to fight to improve mental health funding on the House Appropriations Committee. But large increases in mental health funding are not necessary to solve at least the narrow problem of custody relinquishment.

There have been major advances in understanding how to best treat these kids with serious mental illness. There are great models around the country of collaborative efforts across agencies, working closely with families to help them give their children the necessary care. For the amount of money we spend on these kids – through child welfare, juvenile justice, special education, Medicaid, and so on – we can accomplish much more than we do. We need to give states the incentive and the flexibility to use their dollars to ensure that kids get the treatment they need without snatching them out of their homes and families.

Madame Chairman, it has been a pleasure to work with you and my good friend Mr. Stark to craft a solution along these lines. I hope that we can continue to work together in a bipartisan, bicameral fashion to put in place policies that will strengthen rather than pull apart America's families.

Thank you.

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Statement of Congressman Pete Stark to the
Senate Committee on Government Affairs
July 15, 2003

Thank you, Chairwoman Collins and the other members of the Senate Committee on Government Affairs for organizing this hearing and inviting me to speak today about this very serious problem. Parents should never be forced to relinquish custody of their children in order for their children to receive needed mental health services, but it is happening all too often today.

This is not an isolated problem. It is found throughout the country and in families at all income levels. A recent General Accounting Office (GAO) report surveying 19 states and 30 counties found that in fiscal year 2001, parents placed over 12,700 children into the child welfare system or juvenile justice system so these children could receive mental health services. The number of these children nationally is obviously much higher. Similarly, a recent survey conducted by the National Alliance for the Mentally Ill (NAMI) found that 25% of parents of children with serious emotional disturbance reported being advised to give up custody of their child to access needed mental health services.

We have known about this problem for many years. In fact, I first introduced legislation in 1995 attempting to address this issue. Since then I have been working with my colleagues to educate the public and other members of Congress about this issue and to find bipartisan means to solving it.

Often, I describe the lack of adequate mental health coverage as the disease that has caused the problem of parents being forced to relinquish custody of their children to get them mental health treatment and related services.

The act of giving up children to the custody of the juvenile justice and child welfare system is the horrible symptom of the disease. Both these systems are ill equipped to meet the needs of these children. Furthermore, the psychological bond between parent and child is unnecessarily disrupted by this act of relinquishing custody. These children feel abandoned and their parents feel guilty over relinquishing decision-making authority and control to the state agency.

The juvenile justice and child welfare systems have become the mental health providers of last resort. In desperation, families who have exhausted all available resources go to juvenile court and file neglect charges or declare their child in need of supervision. Or, they approach the local child welfare system and request relief and assistance due to their inability to handle their child's emotional problems.

A Bazelon Center report highlighted the situations that cause parents and guardians to give up their seriously emotionally disturbed children to state agencies to obtain needed in-home, community based or residential mental health services. These included:

- The family has either exhausted their private health insurance benefits or their benefits do not cover required mental health services (e.g. Residential Treatment Program).
- The family lives in a state or jurisdiction in which Medicaid services do not adequately address mental health needs and agency placement provides access or priority status for entry into needed care...
- The family lives in a state or jurisdiction in which children are deprived of federally mandated mental health services through the Individuals with Disabilities Act (IDEA) as a result of an exceedingly restrictive definition of serious emotional illness. That is, these schools often label these children as solely "discipline problems."
- The family lives in a state or jurisdiction in which the local child welfare system erroneously interprets federal law (Title IV-E of the Foster Care and Adoption Assistance Program) as requiring relinquish of custody even for temporary out-of-home placements.

What these children need is quality mental health treatment without being ripped out of the arms of their families.

Thankfully, States have started to take action. So far, 13 states have passed laws to prevent custody relinquishment as a requirement for accessing needed mental health services. This form of legislation is needed throughout the nation. Also, a number of states are attempting to address the problem by increasing accessibility to mental health services for these children through the use of "voluntary placement agreements", Medicaid "Katie Beckett" and 1915 (c) Home and Community Based Services Waivers, and various statutory modifications. Finally, a number of states and local communities have taken advantage of grants through the Comprehensive Community Mental Health Services for Children and Their Families Program. This matching grant program, administered through the Center of Mental Health Services, has demonstrated that systems of care can increase access to needed mental health services and increase the amount of effective in-home and community-based interventions. We need to build upon this model and encourage all states to develop the infrastructure to provide state-wide systems of care so that these children have access to a full array of in-patient, community-based and residential mental health services and can receive the most appropriate treatment in the least restrictive setting.

I am pleased to report that Chairwoman Collins, Representative Kennedy and I are working together to develop a bill to help the states in this regard. Of course we all know that the biggest barrier facing states these days is adequate funding. Recognizing that fact, our legislation will create a new federal grant program to provide funds to states that choose to develop systems of care to eliminate the practice of parents being forced to relinquish custody of their children in order to secure needed mental health care. Priority would be given to those states that have a history of developing local and statewide systems of care and have already taken steps to broaden access to community-based services for children with serious emotional disturbance.

Our bill also calls for the Secretary of Health and Human Services to provide technical assistance to the states, establish a means of measuring the success of each state's intervention and report these results back to Congress. We are working with advocates, states, and other interested parties to finalize our legislation. We hope to introduce it before Congress leaves for the August recess. Our bill isn't the final solution, but it moves us forward in partnership with the states to find solutions to this barbaric practice.

Chairwoman Collins, I thank you for holding this important hearing. I am hopeful that it will help publicize this terrible plight of far too many families throughout the nation and help generate interest in finding solutions to this unnecessary and harmful situation.

Testimony Before the Senate Committee on Governmental Affairs

Theresa Brown
Westbrook, Maine

July 15, 2003

Introduction & Background

Chairman Collins, Senator Lieberman, esteemed members of this committee – I am honored by the opportunity to speak with you today regarding the tragic situation that has been created for my family merely because of our desperate search for mental health services for my daughter. I am nervous and I am talking with you about the most important and emotional thing in my life – please be patient with me if there are moments when I must breathe. My name is Theresa Brown – without my daughter, I exist in Westbrook, Maine.

Relinquishing custody of my daughter was not part of a birth dream, but soon became life's nightmare. My daughter is now 16.

When she was 6, my struggle to find appropriate and effective services were met with suggestions that I take a parenting class on "hard to manage children" and rely on school counselors (who are only available at school and responsible for hundreds of children). I now realize that it was NOT my child who was "hard to manage", but a disorganized and undeveloped system that did not provide resources that could meet her needs in our community.

When the system can't meet the needs of its children, it reflects its failures like a mirror on the faces of their parents and families. Our skills are questioned; our motives are questioned; we are blamed. In my eagerness to do everything I possibly could, we were also shamed.

By 5th grade Heather had experienced countless visits to crisis units. Ineffective and missing services paved the way to police intervention – she assaulted her peers. I watched her life spinning out of control with terror and a broken heart. Feeling as though we were drowning, I desperately grasped at each weak thread offered to us as though it was our lifeline. The police (who are not mental health treatment providers) suggested that I

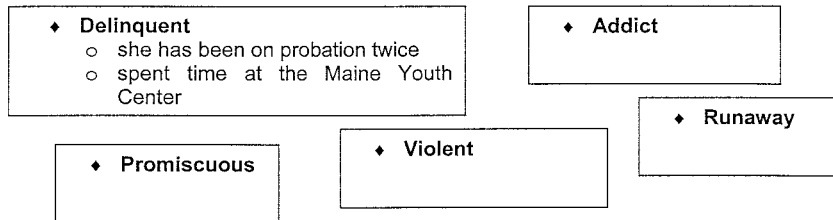
send my daughter to live with her Dad in Mississippi. Needless to say, her return trip followed soon because her symptoms continued to escalate.

Part of the problem for our children with mental health needs is that we don't teach them to LIVE in our communities or provide them the supports they need to do that – we teach them how to LEAVE. When their "behavior" looks bad, we send them away. We send them to friends - to relatives - to programs – to institutions. They are kicked out of schools – excluded from normal activities – and isolated from reality. We teach them that they are not acceptable or worthy of a loving environment. Systems break what bonds they have left. When they are failed by systems, systems make them believe they failed! And so they sometimes do -

By age 12, my daughter's life was further complicated by the fact that she was sexually acting out, using alcohol and other drugs and carving her body. Her pain, confusion and frustration came home to the person who loved her the most – she assaulted me. Police intervention led to hospitalization and more assessments. I knew she needed help, not punishment. After 6 years of struggling to find and access appropriate services I was told that the only option for keeping her safe was residential treatment. This would come with a price tag of ultimate human sacrifice – custody relinquishment. In order to get her the service that she needed, I would have to refuse to take her home from the hospital. I had to tell my daughter that I would not take her home! September 27, 1999 was the most devastating day of my life. I had been told that no crisis bed was available – yet ,as though by magic, one appeared as soon as I complied.

What would you do? What price would you pay? What treatment for other medical conditions in this great country comes with such a prescription?

Psychologists did not want to label my daughter with **bi-polar** at age 9. Instead they waited all those years and she got lots of other labels:



Consequences

Within weeks, Heather was placed in an unsuccessful residential program that REFUSED to honor a court order to

- ♦ work toward reunification
- ♦ allow visitation with me

The following year, Heather entered another residential program and attended public school

- ♦ The program ignored my requests to include drug and alcohol treatment
- ♦ Heather needed a Special Ed label in order to access specific therapies – she did NOT qualify due to past educational achievement, though her grades were FAILING at the time!
- ♦ Behaviors at school, residential program and home continued to spiral downward

14 months into the residential program

- ♦ Heather assaulted a staff member, resulting in assault charges
- ♦ The assault immediately resulted in a Special Ed label with an emotional (not academic) basis!
- ♦ Heather began to 'give up' thinking that she would ever be able to return home to live

When staff in treatment facilities are unable to provide the promised mental health treatment, their back up becomes the police. Instead of increasing the capacity of their mental health service delivery they often view emotional symptoms as behavioral issues and propel youth into the criminal justice system. Our children at this crucial pivotal moment are no longer consumers of the mental health system, they are now viewed as delinquents in the juvenile justice system – often without treatment for their mental health disorders. I felt like we were going backwards – they were now doing what I had needed to resort to!

In May of 2002- Heather ran away (she was visiting home and due to return to residential treatment when she ran)

- ♦ She received an immediate discharge from the program with NO transition services – including school!
- ♦ DHS had no placement available & sent her home without supports or treatment
- ♦ I requested follow-up in home services, supports and counseling during the transition that would allow Heather to successfully live at home

DHS did not follow up with services saying they didn't know if Heather would remain at home

In June 2002 – I arranged for counseling for her myself - there was a 1 month wait - without any supports

- ♦ Heather broke a window, acted out, used alcohol and other drugs
- ♦ Criminal charges resulted
- ♦ Heather ran away, was picked up by police and sent to the Maine Youth Center for 3 days and was released to DHS – who had done NOTHING to help find her when she was missing.

June 2002 - DHS has no placement available, charges were dropped, Heather was sent home to me

- ♦ NO services and NO supports accompanied her

In July 2002 – She stole my car, was charged with possession of a schedule Y drug and was again released to me! Within 30 minutes she ran away again – She was sent to the Maine Youth Center again.

Heather went to a hearing for the pending assault charges on staff. Hearing resulted in assault & drug charges dropped. She took a plea bargain of guilty on criminal mischief charges & was placed on 1 year's probation.

August 2002 – she was sent to a locked behavioral treatment facility

For the first time she began to receive treatment for both mental health and substance abuse issues.

I have “jumped through the hoops” and I continue to ask DHS what else I can do to get my daughter back --- with no clear plan and to no avail. Heather is now in a locked facility and is on probation 3 ½ years after ‘treatment in exchange for custody’ – where are their outcomes? The new DHS goal for Heather is independent living – NOT reunification. Is that what you would want for your daughter? A DHS worker told Heather during a treatment meeting that she can get an apartment soon and “if you stay with us we will send you to college”. Do we know many 16 year olds who don't want that offer?

DHS defines jeopardy in this case as my inability to pay for services. Recent documents indicate that jeopardy been reduced or eliminated. A **January 2002** legal summary states “the role of the Department at this time is primarily as a funding source and an advocate for (name) to continue to receive services for her special needs.” 1 ½ years after this statement, I still do not have custody of my daughter!

What Are the Issues Related to Custody Relinquishment

1. Worst of all, I am no longer her "parent" and am not treated like I am. I have been guaranteed inclusion, but been excluded.
2. Broken promises to me resulted in broken promises to my daughter
3. My relationship with my daughter has been damaged because court mandated rights to visit and be involved have been arbitrarily ignored by case workers and members of my daughter's treatment team
4. Custody causes emotional trauma for youth and their families
5. My daughter has been cut off from her natural supports and isolated from her family
6. Heather does not have a quality of life that includes human touch, a range of emotions, special relationships, family celebrations, family supports and love, lasting friendships or simply participating fully in life as a 16 year old girl!
7. Heather is deemed to be jeopardy because I can't afford her services, yet DHS has now ordered me to pay child support!
8. Custody relinquishment devalues and undermines the importance of the family unit & the role it plays in society
9. I have become the "place of last resort" when placements aren't successful or law enforcement is involved - sending her home with no supports allows her to fail at home and allows me to be blamed
10. When I express any concerns regarding her treatment I am viewed as having aggressive behavior
11. Funds used for ongoing court processes, DHS services, Case workers, foster care, permanency placement, etc. could be better used to simply fund the services we need, when and where we need them
12. Once custody has been relinquished, it appears impossible to get your child back home, no matter what you do.

I have yearned for the opportunity to see her jump rope with her friends; to take her shopping to go to the prom; to complain because her hair was pink or that she left the cap off the toothpaste; to be kept up all night by giggling girls at a pajama party; to know that my favorite sweater might be residing

in her closet or to find my much loved CD missing. Unlike most parents, I have missed the stories of her school day, her date, or her summer job. I cannot console her when her day has been difficult or celebrate with her when it has been great.

In the past few months YOU have seen as much of my daughter as I have!

I appreciate your dedication to this important issue and applaud your efforts. I implore you to change what is happening for children and youth with mental health issues and their families. The human cost is far too great to continue. The financial incentives seem to be just reversed – families should have the resources and services early on. It just seems wrong that there is a federal draw down for states for permanency placement when families want to be permanent – We must stop putting a dollar sign or price tag on the heads of our kids. Let's not fool ourselves; OUR KIDS ARE PAYING WITH THEIR LIVES. I wish you the strength and wisdom to continue this effort, because I cannot do it alone.

**Testimony of Cynthia Yonan
Senate Committee on Governmental Affairs**

Hearing Tuesday, July 15, 2003

**Nowhere to Turn: Must Parents Relinquish Custody in Order to
Secure Mental Health Service for Their Children? Part 1:
Families and Advocates**

Madam Chairman and Members of the Committee

Thank you for providing me with this opportunity to testify at this hearing about a subject that is near and dear to my heart – the struggles that my family has endured in attempting to access mental health services for my twin sons. My name is Cynthia Yonan, and I appear before you today as a parent and a deeply concerned citizen from Glendale Heights, Illinois.

I am appearing today on behalf of NAMI – the National Alliance for the Mentally Ill – and NAMI will be submitting a written statement for the record.

In 1984, I was truly blessed with the birth of my identical twin sons – Ryan and Sean. Despite our blissful beginning, both boys showed early warning signs of mental health related concerns. My husband and I divorced early in their lives and soon after his visitation was established, I discovered that he had physically, emotionally and sexually abused the boys for one and a half years.

The abuse had a devastating impact on Sean and Ryan. They both required hospitalization. Sean required it for suicidal tendencies and Ryan for homicidal tendencies. Before the boys were hospitalized – Sean attempted suicide 3 times and was extremely unstable – leaving the house in the middle of the night, stealing money, food, clothing and other items.

Ryan exhibited the same difficult behaviors and also could not control his anger. He was removed from school after making violent threats. Because of the seriousness of their illnesses, both boys spent 3 months in the hospital. This quickly exhausted our private health insurance benefits, which included restrictive caps on mental health coverage. Those caps caused my sons to be released from the hospital, at which point I turned to the County Mental Health Department and they directed me to turn my children over to the state to secure the treatment that they needed.

Both of my sons were diagnosed early on with bipolar disorder, attention deficit and hyperactivity disorder, post traumatic stress disorder, oppositional deviant disorder, and Klinefelters Syndrome – an illness that results from an extra “Y” chromosome and that makes the boys aggressive and lack impulse control.

Our struggles really grew after the boys returned from the hospital in January of that year. At that time, I also had 3 daughters, ages 16, 6, and 5. Sean and Ryan did not return to school and I spent from January through May attempting to find them an alternative educational placement. The school district failed to provide me with any assistance. Tragically during this time – and despite my attempts to keep a 24-hour watch on my sons – they threatened and assaulted 2 of my daughters. As you can well imagine, this was devastating to my family. I was physically exhausted, at wits end and a nervous wreck. It was quite clear that the boys needed intensive mental health treatment and services.

Through this incredibly trying experience, I was forced to quit my job to stay home to keep the boys and my daughters safe. Despite the loss of my job and income, Medicaid was not an option for mental health services because I owned my house and did not qualify under the

strict minimum asset requirements. I simply did not know where to turn to secure mental health services for my sons.

Exhausted and frustrated, I searched for help from the Department of Mental Health and the Department of Child and Family Services (DCFS). Both agencies informed me that I would have to turn custody of my sons over to the state to secure mental health services. Frankly, I was shocked when faced with this agonizing prospect. I could not fathom how state agencies could ask families to abandon their ill child to secure mental health services. At the time, I wondered if families with children with other brain illnesses – like cancer -- were ever asked to turn their child over to the state for treatment. I love my sons – despite all that we have been through. They are ill not bad. I was determined that I would not abandon them in their hour of greatest need. Giving up my sons was not an option and would serve only to make them feel unwanted and unloved – not to mention the further trauma that it would cause in their lives.

I spent 2 years calling and searching for mental health services for my sons. In 1998, I was directed to the Community Residential Services Authority (CRSA) – a well kept secret and one that was offered to me only after years of struggle and when it became clear that I was not going away. The state agency was created for kids that do not fit within the criteria for services established under DCFS, the Department of Mental Health, the Department of Corrections or the Illinois Care Grant. With the guidance and help of CRSA, my sons were placed in a residential treatment facility in July of 1999. I am pleased to report that the treatment they have received has made a significant difference and given us hope for a brighter future.

No family should be forced to go through what I did. Families with children with serious mental illnesses want and deserve laws that provide funding for mental health treatment so that no family is told that they must give up custody of their child to secure mental health treatment and services. I am so pleased that Senator Collins has proposed the introduction of legislation to address this crisis. Her leadership is greatly appreciated.

Again, thank you for this opportunity to speak with you this morning. I am happy to respond to any questions that you may have.

**Testimony of Patricia Cooper
Senate Committee on Governmental Affairs**

Hearing Tuesday, July 15, 2003

**Nowhere to Turn: Must Parents Relinquish Custody in Order to
Secure Mental Health Service for Their Children? Part 1:
Families and Advocates**

Madam Chairman and Members of the Committee

Thank you for providing me with this opportunity to testify at this hearing about the long struggle that my family has endured in attempting to secure appropriate mental health services for my son. My name is Patricia Cooper – my step son’s name is Dakota. We live in Fayetteville, Arkansas.

I am also appearing today on behalf of NAMI – the National Alliance for the Mentally Ill – and NAMI will be submitting a written statement for the record. Despite appearing on behalf of NAMI – this is my personal story about what my family has gone through.

Our son, Dakota, came to live with me and my husband John – his biological father -- in 1997. John has full custody of Dakota. He is a wonderful boy with big bright blue eyes and blonde hair. Dakota loves sunsets and always insists that we

stop to enjoy them. He also loves everyone around him. Friday is Dakota's birthday -- he will be 12 years old.

Dakota suffers from multiple mental illnesses -- including attention deficit—hyperactivity disorder, reactive attachment disorder, left hemisphere processing deficits, oppositional defiant disorder, and post traumatic stress disorder. The symptoms of these illnesses cause Dakota to act out in extreme ways -- including attempts to start fires, using knives in a dangerous and sometimes threatening way, running out of school into busy intersections and sometimes hurting the dog. He cannot be left unsupervised -- anywhere or at any time. Despite these challenges, John and I love our son and we know that his actions are the result of his struggles with his mental illnesses. It is not because Dakota is a "bad kid."

Our journey began in 1997, when the school noticed that Dakota was really struggling. The principal informed us that he thought that Dakota needed immediate help. We were not surprised because of Dakota's behavioral struggles at home. Although we wanted to keep him in our home, it was clear to us that he could not continue to safely reside there without appropriate support and services to address his mental health needs. Unfortunately, our private insurance did not cover the home and community based mental health services that we needed for Dakota. Our policy included caps and restrictions on mental health coverage and

fell far short of the intensive services that Dakota needed. Our income level does not qualify us for Medicaid because both John and I work.

At that time, we decided that our only option was to place Dakota in a residential treatment center. He did ok with the placement – which renewed our hope and he returned home.

Things did not go well with Dakota at home – the truth is that our family was falling apart. We needed help. We called the Department of Human Services and they informed us that there were no services for Dakota and our family. Over time, they suggested that, given the seriousness of Dakota’s mental illnesses, we consider giving up custody of him to the state to secure the level of services that he needs. Over the past few years, we have heard that many times. We refused to consider that option. We love Dakota and we are not about to give up on him.

In late 1999, a school-based therapist told us about a TEFRA Medicaid option (also known as the Katie Beckett option) that could help fund the intensive home and community based services that Dakota needed. Dakota also spent time in multiple residential treatment centers. Unfortunately, not all of those placements went well – and after one stay, we were told that we would need to take Dakota home, with virtually no appropriate home and community based mental health services. We expressed grave concerns that without the appropriate treatment and supports – Dakota would suffer serious setbacks and his illnesses

would worsen. It was then that we were told that Dakota would be placed in therapeutic foster care through a voluntary placement agreement. He was placed with a family that lived 4 hours from our home for 11 months. The state used an abuse and neglect proceeding to place Dakota in foster care. John and I were treated by the foster care system as parents who had abused and neglected our son. It was painful and humiliating.

During the past year, Dakota has resided in residential treatment facilities in 3 states -- Oklahoma, Colorado and Arkansas. We only wish that appropriate home and community based mental health services existed for Dakota and our family and were adequately funded. We want Dakota home with us – the people who love him most. We also wish that other families did not have to endure the long battle that we did to secure mental health services and the toll that it has taken on our family.

I want to thank Senator Collins for her leadership in addressing the tragedy that far too many families in our nation face in struggling to secure mental health services for their children. Thank you again for this opportunity to speak with you this morning. I am happy to respond to any questions that you may have.



**Testimony Before the Senate Committee on
Governmental Affairs**

Trina W. Osher, Coordinator of Policy & Research

July 15, 2003

Introduction

My name is Trina Osher. I am speaking on behalf of the Federation of Families for Children's Mental Health, the nation's only family-run organization focused exclusively on children with mental health needs and their families. Our 150 affiliates reach into communities as different from each other as Dover-Croft in Maine, San Diego in California, Warwick in Rhode Island, Topeka in Kansas, or the Pine Ridge Reservation. Our mission includes providing and sustaining leadership for family-run organizations and harnessing the passion of our members as a potent force for change so that our children and families can have a decent quality of life. On behalf of thousands of families I thank you for the opportunity to present testimony today.

It is seventeen years since my husband and I, desperate for help and with no other options, relinquished custody of our middle child - an adopted son who was only 10 years old - so he could go to a therapeutic, residential school in Connecticut. At the time, we faced the shame and blame alone. It was a devastating experience with life-long repercussions for every one in our family. It is appalling that families are still being asked to relinquish custody as we meet and here today. I am greatly encouraged by the attention this cruel social policy is now getting and hope that Congressional action will soon put and end to it.

General overview of the problem

The insufficient mental health coverage in private and public insurance plans (or not having any insurance) causes families to exhaust benefits before the mental health needs of their child are fully addressed. This is especially true when the child's condition is chronic and intensive intervention is periodically required.

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Families in such situations are then either urged or required to relinquish custody of their child to access funding that will pay for the essential mental health services so desperately needed. A recent study of 176 Maryland families showed that 62.5% of families whose children had 7-15 hospital visits in the two years prior to the study were told to relinquish custody.¹ How many of you would do this?

Children who are relinquished in order to get mental health services are deprived of their right to be connected to their family although their parents, siblings, and extended family should be a consistent and unconditional, lifelong source of emotional support. How would you feel if you could see or talk with your child with the permission of a judge and under the watchful supervision of a social worker?

Concern for a child's or other's safety at home, at school, or in the community is a critical factor contributing to custody relinquishment. A family in Oregon, for example, sought help from Children's Services for their 16 year old son who was running away, not cooperating with his special education program, refusing to take medication, and living on the streets. Children's Services recommended residential treatment, went to court, obtained custody of the child, and placed him in a foster home from which he continued to run away.²

The practice of requiring parents, who have exhausted all other resources, to relinquish custody in order to obtain essential mental health services for their children must cease. But simply banning the practice is not sufficient to solve the problem. What is needed is a "combined approach that bans the practice while providing increased access to mental health treatment for children."³

¹Karen Friedman and Jane Walker. *Relinquishing Custody: An Act of Desperation*, Maryland Coalition of Families for Children's Mental Health, Columbia, MD, 2002, (p. 33).

² Stephanie Limoncelli. *Custody Relinquishment Case Studies*. Oregon Family Support Network and the Research and Training Center on Family Support and Children's Mental Health. Portland, OR, 2003, (Case 1).

³ Barbara Friesen, Mary Giliberti, Judith Katz-Leavy, Trina Osher, Michael Pullmann. Research in the Service of Policy Change: The "Custody Problem" in *Journal of Emotional and Behavioral Disorders*, Spring 2003, Vol. 11, No. 1, (p. 46).

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Barriers FFCMH families face in trying to access needed mental health services and supports for our children.

Families of all kinds, are doing their very, very best to care for and get treatment for children whose mental health problems require intensive interventions and constant supervision or attention. But they can't get the help they need, when they need it, and how they need it. Continually being denied access to needed services exhausts and eventually defeats even the most resourceful and stable of families.

Our children with mental health problems need to have outlets for physical activity and social interaction with peers but they typically can't participate in after school activities or community recreational programs without some kind of support (like a mentor or coach to help them with social skills and behavioral control). There is no insurance program that will pay for such assistance. It is not considered a "medically necessary" service.

Our families who are raising children with mental health problems need a break from time to time. Unlike most parents who get a relative or babysitter to care for their children while they go out for dinner and a movie, there is no one who is willing to take care of our children who have challenging behavior. Few communities have a pool of respite care providers with training to serve this population - and it is more expensive than conventional care. It seems unfair that families who have a child with development disabilities or mental retardation have ready access to respite care that is subsidized with public funds and families whose child has mental health needs don't.

Schools are not effective for most children with mental health needs. Our children experience higher rates of suspension and drop out from school than typical children or children with other disabilities. According to the U. S. Department of Education, "About 50 percent of students identified under IDEA as having emotional and behavioral disorder drop out of school. Once they leave school, these students lack the social skills necessary to be successfully employed; they consequently suffer from low employment levels and poor work histories."⁴

⁴ U. S. Department of Education. *Twenty-third Annual Report to Congress on the Implementation of the Individuals with Disabilities Education Act*, Washington, DC. 2001, (pp. xx-xi).

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Many of our families have to give up working to care for a child who is repeatedly suspended from school, expelled from day care, or denied admission to after school programs. A Maryland parent has, "not been working for over a year since by son's diagnosis because he needs adult supervision at all times."⁵

Families bringing children home from hospitals or residential treatment programs need intensive and flexible transition services in their homes and in natural community settings for their children. Yet, most children return home without any follow-up simply because they have reached the maximum number of days for which insurance will pay. Typically, these children have a recurrence of acute problems because they were not stabilized in the first place and linkages with, schools, community-based mental health treatment services and home-based family supports were not made on discharge.

Children with mental health needs and their families need more options besides the typical 50 minute therapy hour - which is often scheduled at a time and place that is inconvenient or impossible to get to. Our children must have special help help to develop skills for social interaction or self-control that transfer into the natural school and community settings in which they are having trouble. But, mental health professionals don't work in these settings. We often need extra help and specialized strategies for managing to do normal family tasks like getting ready for school, fixing lunch, doing laundry, supervising homework, visiting relatives, shopping for groceries, or having a peaceful family supper together. Mostly we learn about these from our peers - if we are lucky enough to be connected with a Federation chapter or other family support group. Many parents cannot take advantage of these services when they exist with out getting help with transportation. And all of us need to find someone willing and able to care for our children in order to go to support groups. Ironically, as much as we may need and want the benefits of a support group, sometimes we are just too tired to go.

Deep budget cuts are making it even more difficult to get appropriate services. In Clackamas County, OR for example, since January 2003, the community mental health center has had to cut its children's staff from 19 to 4.

⁵ Karen Friedman and Jane Walker. *Relinquishing Custody: An Act of Desperation*, Maryland Coalition of Families for Children's Mental Health, Columbia, MD, 2002, (p. 38).

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The only children's service available now is group therapy,⁶ which is clinically insufficient to address the wide range of children they are serving.

Our families often find themselves between a rock and a hard place trying to balance the conflicting mandates, requirements, and demands of several different services or systems. I recall one county-based meeting on my own child where we were confronted with case managers from four different systems who could not agree on what the problem was, which programs our son was eligible for, where we should go for help, or which agency was responsible for providing services. We asked to leave the room while they continued to debate amongst themselves and told we would get a letter from them in two weeks with their decision. Lack of common definitions, terminology, and eligibility criteria across systems and providers and the paucity of incentives for states and communities to develop effective community-based systems of care contribute significantly to the problem.

What federal and State governments can do to develop better "systems of care" to provide community-based mental health services and supports for children and their families.

Families need an array of service options, good information for deciding which services to choose, and a significant voice in determining where these will be provided. State and federal policies must make it possible for us to keep our children in their neighborhood and living with us - the family that will love and care for them as no one else ever will. This means being able to realistically choose a temporary out-of-home placement when needed to stabilize or resolve a crisis and to have ongoing access to a wide range of assistance, including at a minimum: home-based services and supports, culturally relevant spiritual healing, traditional clinical mental health treatments; and appropriate special education services necessary.

Congress should prohibit states from requiring parents to transfer legal custody of a child with a mental health problem for the sole purpose of obtaining necessary treatment, services, supports, or out-of-home placements or to enable the child to become eligible for Medicaid or access funding from any other federal source.

⁶ Personal communication by phone with Theresa Rea July 8, 2003.

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Congress should increase the appropriation for the state mental health block grants by 20% and designate all of these funds specifically for the development of family-driven support services and the expansion of effective community-based treatment services for children with mental health needs and their families.

Congress should establish and fund a long term higher education program to expand the pool of qualified professionals to serve children with mental health needs and their families in a manner that is consistent with family-driven practice and the values and principles of systems of care.

State agencies should be required to develop effective working interagency agreements that create the infrastructure necessary to insure coordination of services and braiding of funding streams from all child serving agencies so that children with mental health problems and their families have affordable and convenient access to a comprehensive array of family-driven supports and services and effective, culturally competent, community-based mental health treatment services. Such agreements should:

- ✓ encourage and allow the use of existing federal funds from all child serving agencies to pay for home-based supports and community-based services for children with mental health needs and their families to prevent or forestall temporary out-of-home placement when appropriate;
- ✓ require the use of existing federal funds from all child serving agencies to develop home-based supports and community-based treatment services to help families stay together and enable their children to graduate from school, enjoy the friendship of peers, and participate in community life; and
- ✓ require that families have voice and choice in decision making.

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“KEEPING FAMILIES TOGETHER:
REMOVING BARRIERS THAT FORCE PARENTS TO RELINQUISH CUSTODY OF
THEIR CHILDREN TO SECURE MENTAL HEALTH SERVICES”

TESTIMONY

OF

TAMMY SELTZER
STAFF ATTORNEY, BAZELON CENTER FOR MENTAL HEALTH LAW

BEFORE THE

COMMITTEE ON GOVERNMENTAL AFFAIRS
UNITED STATES SENATE

JULY 15, 2003

Good morning Madame Chairman, Senator Lieberman and members of the Committee. My name is Tammy Seltzer. I am a staff attorney for the Judge David L. Bazelon Center for Mental Health Law. The Bazelon Center is the leading national nonprofit, legal-advocacy organization representing people with mental disabilities. The center works to define and uphold the rights of adults and children with mental disabilities who rely on public services and to ensure them equal access to health and mental health care, education, housing and employment.

Thank you for the opportunity to share with you our knowledge about the custody relinquishment problem, including the scope of the problem, why the practice continues to occur, and practical suggestions for what you can do to end this national tragedy. I applaud you for holding today's hearing on the heels of the release of the recent General Accounting report (*Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services, GAO-03-397, April 2003*) you requested, along with Representatives Pete Stark and Patrick Kennedy. The bicameral commitment you share to further study and address this devastating practice is commended.

The issue we are here today to discuss has been a long standing concern to the Bazelon Center. We have provided technical assistance to stakeholders, including states, worked with the media, including *Time*, *Newsweek*, *ABC PrimeTime* and others and have published two reports (*Relinquishing Custody: The Tragic Result of Failure to Meet Children's Mental Health Needs* and *Avoiding Cruel Choices: A Guide for Policymakers and Family Organizations on Medicaid's Role in Preventing Custody Relinquishment*) directly related to this issue. These

reports document the two main culprits for custody relinquishment: a lack of access to appropriate and timely mental health services and supports for children in both the public and private sectors and a lack of oversight for existing programs that should be providing these services and supports. Custody relinquishment is all the more tragic because it does not and should not have to happen to one more child.

During my testimony, I will describe how the Senate can address the access issue by passing the Family Opportunities Act, improving flexibility to the states through the Medicaid Home- and Community-Based Waiver, enacting insurance reform, and preserving and strengthening the Individuals with Disabilities Education Act (IDEA). I will also underscore the importance of improving federal oversight of another aspect of the Medicaid program, the TEFRA or Katie Beckett option.

Today's hearing will describe our nation's failure to meet the needs of families with children who have emotional and behavioral disorders— a failure that is tearing apart families and putting children at risk. It is our hope that these proceedings will encourage you and your fellow lawmakers to support specific legislation to end this unnecessary tragedy.

BACKGROUND

First, let me provide the committee with an overview of the custody relinquishment problem. Neither the juvenile justice nor the child welfare system is designed to address children's mental health needs. Yet increasing numbers of children with mental or emotional disorders are unnecessarily and inappropriately dumped into both systems. The US General Accounting Office (GAO) documented at least 12,700 cases in fiscal year 2001 of children placed in child

welfare and juvenile justice systems so they could access needed mental health services. Approximately 3,700 children were placed in child welfare systems; another 9,000 were “placed” in the juvenile justice system by police who had detained children—sometimes at parents’ request—for delinquent behaviors that stemmed from or were related to their mental or emotional disorders.

We believe the GAO findings are just the tip of the iceberg. The tragic and inhumane practice of custody relinquishment has been documented in at least half the states in the country. A survey by the National Alliance for the Mentally Ill found that 23 percent of parents with behavioral disorders had been told that they needed to relinquish custody to get intensive mental health services for their children and that 20 percent had actually done so (*Families on the Brink: the Impact of Ignoring Children with Serious Mental Illness, 1999*). At the Bazelon Center, we consistently hear from families that when they seek help for their children, they are offered none. Instead, they are encouraged to call the police to “document” the problem or pushed to give up custody to the foster care system. This appalling practice must end.

FACTORS THAT CONTRIBUTE TO CUSTODY RELINQUISHMENT

A variety of barriers prevent parents from accessing appropriate treatment, perpetuating the tragic practice of custody relinquishment. Custody relinquishment is largely the result of the failure of all child serving agencies, but particularly mental health and education agencies, which have the primary responsibility of addressing children’s needs before they reach a crisis. The failure of mental health and school systems to provide access to care drives families to the brink of custody relinquishment--families who would prefer to care for their children at home but cannot do so

without effective services and proper support.

The single most important obstacle that pushes families into giving up custody is a lack of access to appropriate and timely mental health services and supports for children in both the public and private sectors. It is clear that mental health is not a public health priority—parents have to jump through hoops to get the most basic services for their children. Imagine a child with diabetes being torn from his family in order to get basic health care—I can't, but for children with mental health needs, it happens every day in communities across the country. There is no doubt the public mental health system is underfunded and crisis-, rather than prevention-driven. As a result, many children are placed in the custody of child welfare or juvenile justice systems because that is the only way their parents can gain access to care that should have already been available to them through a comprehensive healthcare delivery system. In many cases, the lack of appropriate community mental health care leads to high use of emergency and hospital care or unnecessary costs to other systems, like welfare and juvenile justice. Many describe the lack of child services as worse than the crisis we know exists for adults.

Recently, the interim report of the President's Commission on Mental Health declared that the public mental health system is in "shambles." Additionally, the Surgeon General's National Action Agenda detailed a public crisis in children's mental health with many "falling through the cracks." As the Surgeon General points out, "children and families are suffering because of missed opportunities for prevention and early identification, fragmented treatment services and low priorities for resources." Only one in five children with mental health needs

receives services. In our report entitled, *“Disintegrating Systems, The State of States’ Public Mental Health Systems,”* we note that states’ own documents’ describe the extent of system failure. Connecticut, for example, reported that children are languishing in detention cells and more than 350 children are placed in out-of-state facilities. In Arizona, children and adolescents have a less than 50% chance of being adequately served by the system. And in Ohio, access to mental health services for children is “substandard.” Where children and youth need services and supports, they are not provided early enough or in sufficient supply.

Across the country, children who need intensive mental health treatment are not getting it early enough to prevent a host of adverse outcomes, such as custody relinquishment. Parents of children with mental or emotional disorders often struggle financially to pay for services and supports that are medically necessary for their children. Some parents are caught in a gray area where they lack any insurance—public or private. These families typically deplete their financial resources paying for intensive services. The Kaiser Commission on Medicaid and the Uninsured estimated the uninsured rate at 15.6% in 1998. With the slow down in the economy, this rate has likely risen since the Kaiser study. A growing number of children in this country are either uninsured or under-insured, with minimal coverage for mental health care. Private insurance is often inadequate because it carries limitations and restrictions on mental health care, such as number of outpatient sessions or inpatient days covered-- limitations that do not apply to their physical health care benefits. Data show that 94% of health maintenance plans and 96% of other plans have such restrictions. In these cases, families that face health insurance restrictions or exhaust their benefits are left without options. Moreover, private insurance plans do not cover

the full array of intensive, community-based rehabilitative services that children with the most severe mental or emotional disorders need—services that can be covered under Medicaid.

When families are uninsured or have exhausted their private insurance benefits, both mental health providers and public child welfare agency staff often advise parents that relinquishing custody of their child to the state is the only way to obtain services. Custody relinquishment carries with it a host of negative outcomes, including making children feel abandoned by their family. It also leads to children being placed in more expensive and less supportive residential placements. Residential treatment centers, according to the 1999 Surgeon General's Report on Mental Health, are the second most restrictive form of care for children with severe mental disorders (next to inpatient hospitalization) with only weak evidence for their effectiveness. Additionally, parents have no say in their day-to-day activities—what they eat, what they wear, who their friends are. They may not even know where their children are. Ultimately, children who need the most emotional support and stability are being ripped from their homes to live with complete strangers.

Students with emotional and behavioral disorders (termed emotionally disturbed under the IDEA) have been recognized as among the most under-identified and under-served students with disabilities. Something is obviously wrong when the U.S. Surgeon General estimates that nationwide five percent of all school-aged children have mental disorders and “extreme functional impairment” and 11 percent have mental disorders with “significant functional impairment” while, for more than two decades, the national rate of students identified with emotional disturbance under IDEA hovered just under one percent. By 2001, the rate of

identification under IDEA had fallen to 0.74 percent. Data suggest that schools may be failing to correctly identify four fifths of children with mental or emotional disorders serious enough to adversely affect their educational performance. The federal definition—due to its vague language, undefined terms and inappropriate criteria—leads to significant under-identification of children with emotional disturbance. The exclusion of children on the basis of “social maladjustment”—an ambiguous distinction with no basis in research—contributes to the fact that many children who need special education services are failing to qualify for them under IDEA.

Even when students with emotional and behavioral problems are identified as needing special education services, schools often fail to deliver the positive behavioral supports required by the 1997 amendments—interventions that have been proven to reduce behavior problems and improve students’ chances to succeed in school. Instead, without the necessary interventions, students’ problems worsen, escalating to a point where parents lose their jobs because they must stay home with children who are repeatedly suspended or expelled or the juvenile authorities are called to arrest the child. Every parent we’ve come into contact with who has been faced with the decision to relinquish custody describes a deteriorating school situation as a significant factor.

REMOVING THE BARRIERS

The situation is bleak, but I have good news—custody relinquishment need not happen. Public policy alternatives exist that could rescue families from the awful choice of giving up custody to the state or seeing their child go without needed care. Families of children with mental or emotional disorders requiring intensive services and supports to avoid out-of-home placement

must have access to a full range of community-based services and supports.

Family Opportunity Act/Medicaid Home and Community Based Services Waiver

Congress has bipartisan legislation before it right now that would take two giant steps toward preventing custody relinquishment. The Family Opportunity Act would 1) help expand Medicaid coverage to children whose families would otherwise not be eligible and 2) give states greater flexibility to use the Home- and Community-Based Services Waiver to serve children with serious emotional and behavioral disorders. The Family Opportunity Act (S. 622, sponsored by Senators Charles Grassley and Edward Kennedy) has maintained high bipartisan support for more than three years but has not yet become law. It would remove the barriers that today keep thousands of families from being able to meet their child's serious health and mental health needs. Last Congress, the Senate Finance Committee favorably reported the bill out of Committee. It is time for Congress to finally enact this important legislation.

The Home- and Community-Based Services Waiver is a critically important tool that most states have failed to take advantage of because of obstacles Congress has the power to eliminate. The three states (Vermont, New York and Kansas) that have taken advantage of this waiver to provide more flexible services to children with mental or emotional problems have found that the costs of serving these children in the community is about half of what would be spent on institutional care. For example:

1. Kansas: Average annual per child costs are \$12,900, compared with institutional costs of

\$25,600

2. Vermont- Average annual per child costs (2001) were \$23,344, compared with inpatient costs of \$52,988
3. New York- Approximate annual per child costs (2001) were \$40,000, compared with institutional costs of \$77,429

The Kansas home and community based waiver for children with serious emotional disturbance has reduced custody relinquishment and led to positive outcomes in schools. The benefits of a home and community based waiver in this regard is that states have considerable flexibility. They can limit the number of slots, apply to certain geographic region and can be initiated with a relatively small state investment. Furthermore, the costs of the wavier services are offset by institutional savings.

The Surgeon General Report on Mental Health discusses the strong record of effectiveness for home-based services—which provide intensive services within the homes of children and youth with SED. Most important, under the Home- and Community-Based Services waiver, families remain intact.

Unfortunately, States have requested this waiver for children with SED and have been turned down (e.g. Maryland). Federal law has not kept up with changes in practice. The current “level of care” a child must meet under the statute to be able to be served by the waiver includes a hospital, ICF/MR or nursing home. Children are now rarely in psychiatric hospitals for extended periods of time, but are instead in psychiatric residential treatment centers (RTCs)—an

institutional level of care not explicitly covered by the statute.

Congressional support is needed to modify the Medicaid's Home and Community-Based Services Waiver statute to allow children receiving or at risk of receiving inpatient psychiatric services in a RTC to be able to receive services in the community. Removing this barrier will go a long way toward helping to eliminate custody relinquishment. The Family Opportunity Act contains a legislative provision to eliminate this barrier so states can provide services to these children.

Insurance Reform

Insurance reform is another area where Congressional action is necessary. For parents who have insurance, Congress should ensure that insurance companies cover the range of mental health services that would prevent custody relinquishment and cover them without arbitrary limits. Enacting mental health parity legislation (currently sponsored by Senators Pete Domenici and Edward Kennedy, S. 486, "The Senator Paul Wellstone Mental Health Equitable Treatment Act") would be an essential first step. Parity legislation would help by prohibiting private insurers from denying access to needed services because of stigma and discrimination through current limitations and restrictions on mental health care that are not placed on physical health care. But parity alone will not solve the problem.

IDEA Reauthorization

IDEA is currently in the process of reauthorization. Research demonstrates that the use of positive behavioral interventions and supports can significantly reduce discipline problems

(see the recent Bazelon Center publication *Suspending Disbelief*). The current IDEA supports this approach, and S. 1248 would continue the requirement that schools adopt a proactive approach to manage students' problem behavior by providing positive behavioral interventions and supports. The Senate bill would provide funds for schools to expand the use of behavioral supports and school-wide behavioral interventions—funding absent in the House-passed version of the bill.

Although the Senate bill, unlike the House legislation, requires a behavioral assessment, it requires only a general assessment, rather than the more specific “functional behavioral assessment” currently mandated by the IDEA. If the word “functional” is omitted, schools could rely heavily on teachers' notes or subjective observations, rather than using a science-based approach to determine the impetus behind the child's behavior. Educators argue that functional behavioral assessments are essential to designing effective behavioral intervention plans to reduce or eliminate troubling behaviors. We urge you to support S. 1248 with the restoration of the term “functional behavioral assessment.”

In addition, the federal government, at a minimum, should drop the “social maladjustment” exclusion in the federal IDEA definition of emotional disturbance. It should also develop programs and materials to assist states in making more accurate assessments so as to correctly identify students with emotional disturbance in order to provide appropriate services and to encourage earlier identification, including identification of preschoolers and very young children. Students with mental and emotional disorders exhibit behaviors that are hard to manage, especially if they do not receive the services they need. But if appropriate services were

furnished earlier, the outcomes could be very different.

TEFRA Oversight

The TEFRA option is another important tool for expanding access to Medicaid. TEFRA, or the Katie Beckett option as it is sometimes called, allows states to cover home- and community-based services for children with disabilities who would otherwise need the kind of skilled care provided in a medical institution. Eligibility is based on the child's disability and care needs, not on family income.

Only 20 states have selected the TEFRA option for children with disabilities. In the states that have the TEFRA option, half have no children who qualified as a result of a mental or emotional disorder even though there is nothing in the program requirements that would exclude children with mental or emotional disorders. It's shocking that children with the most serious needs—children who face the greatest risk of being given up in order to receive necessary mental health services—would be virtually shut out of a program in 40 states plus the District of Columbia.

States that do not currently select the TEFRA option have clearly stated that they need more information about the program, as documented by a Bazelon Center survey (*see Avoiding Cruel Choices*). In states that have TEFRA, the state TEFRA rules are written in such a way as to exclude children with mental and emotional disorders, primarily by their failure to mention how these children can qualify. State-prepared materials for parents leave most parents of children with mental and emotional disorders uninformed about their eligibility for the program.

Congress can and should provide greater oversight of the TEFRA program to ensure that states can make informed decisions to take advantage of the option and that when they do, children with mental and emotional disorders are fully included with other children who have serious disabilities.

CONCLUSION

Many states are struggling to address the custody relinquishment tragedy, but they cannot solve the problem without Congressional assistance. Currently, thirteen states (Colorado, Connecticut, Idaho, Indiana, Iowa, Maine, Massachusetts, Minnesota, North Dakota, Oregon, Rhode Island, Vermont and Wisconsin) have statutes that prohibit child welfare from requiring custody relinquishment in order for parents to obtain mental health services for their children. These statutes purport to stop the practice at its current point of origin, but these outright bans have a limited effect if families are still unable to access the mental health services and supports they need without going through a judge or signing “voluntary” custody agreements with child welfare agencies. Prohibitions on custody relinquishment must be coupled with efforts to address the underlying cause—the lack of mental health services. A ban alone will not reduce the number of children placed in the child welfare system solely for mental health purposes.

States and the federal government need to work together to ensure that more and better mental health services are available for more kids. A coordinated effort between states and the federal government aimed at removing barriers to needed mental healthcare for children is paramount to ending custody relinquishment.

In conclusion, I again want to thank you for holding this important and timely hearing. The Committee's oversight jurisdiction on federal agencies that serve such children is critical to fostering needed collaboration at the federal, state and local level. Far too often, in order to get essential health and mental health services for their child, caring parents must choose between living in poverty in order to keep custody or giving their child up to the state so the child can qualify for needed care. Too many children with mental or emotional disorders and their families have suffered too long for the system's failures. I end by stressing that custody relinquishment is not a rational choice for society—and it is no choice at all for families. In all cases, the societal costs of custody relinquishment greatly exceed the cost of adequate and preventative health and mental health treatment. I urge you to take the necessary legislative action to ensure greater access to mental health services and supports and greater oversight to ensure that existing programs are used to their fullest potential to help families at risk of custody relinquishment.

I would be happy to answer any questions you might have.

Testimony Before the Senate Committee on Government Affairs

**Jane Adams, Ph.D., Executive Director
July 15, 2003**

Thank you for allowing me the opportunity to speak to you today. My invitation to speak before you asks that I speak regarding the implementation of the Kansas Home and Community Based Services (HCBS) Waiver for children with Serious Emotional Disturbance. Before I talk about Kansas, I want to share with you for a moment my perspective from being a member of President Bush's New Freedom Commission. Last year President Bush directed the New Freedom Commission on Mental Health to make recommendations which put in place and extend the protections of Olmstead so that people with disabilities have the right to live, work, learn, and participate in their homes and communities. For the last year, as part of our Commission work, we heard testimony from families and youth across the country about their personal experiences trying to penetrate the disarray of what we call the mental health system; they told us of their efforts to access opaque and complex non systems, the difficulty to even understand service options, let alone secure access to grossly under-funded programs. Family members talked to us about discontented and overwhelmed providers, constantly changing and conflicting regulations; and they talked about losing their children to child welfare and state juvenile authorities. Parents talked about their fear, that in working to secure services they expose their family to intense community scrutiny and risk losing their child.

Parents told the Commission and Kansas parents have told our legislature that without financial resources to access mental health care; they are forced to turn to child welfare with the promise, implied or explicit that mental health services will follow. Or by default, families lose to the juvenile justice authorities when services are not available and behaviors escalate to the point that law enforcement gets involved. In Kansas, one problem with placing a child in foster care is that our child welfare system is designed to provide the child with a safe place to live, a home, usually. Child welfare providers in

Kansas are not Medicaid mental health providers. In Kansas, the child welfare contractor who determines that a child in foster care has a diagnosis, must access a mental health center for Medicaid funded services. If the center agrees that the child needs services, Medicaid funds the services. If not, the private contractor must pay for services out of the capitated payment from the state for living allowance. I can tell you this seems to deter strong advocacy for mental health services in the foster care arena. In either case when a child with mental health needs is placed in foster care, there is little involvement of the biological family in the child's mental health treatment. The child is frequently moved away and it is likely to a different mental health center catchment area, with different providers than he/she knows and who are too distant for the family, already fractured, to access; and too distant for providers to include.

The Freedom Commission has ended and the White House prepares to issue a report which may influence the development of services for the next decades. The Commission will recommend the development of full and comprehensive arrays of community services developed in concert with the families and youth who receive them. Compelling testimony and a new awareness of the national perspective has left me with an increased awareness of what the Kansas' model offers the nation in the area of children's mental health. I am excited to explain the Kansas system of services to you. I will talk about our Medicaid funded Home and Community Based (HCBS) waiver for children with Serious Emotional Disabilities (SED).

The Kansas waiver both expands the range of services offered to families of Medicaid eligible children and it expands Medicaid eligibility to those families whose incomes exceed standard Medicaid eligibility requirements in our state. The expanded range of services includes the addition of four Medicaid services: wraparound facilitation, parent support, respite care and independent living supports. Expanded eligibility means that for the waiver, only the child's income is considered, not the parents. This means that in Kansas, when a parent is faced with the imminent possibility of placing a child in a mental hospital, that parent may elect to keep the child at home in school and in the

community with Medicaid funded supports and services including the four new services and the usual cocktail of in-home therapy, case management, attendant care, etc.

With the waiver and the recognition of our legislature that children do better, are better, demonstrate remarkably better outcomes in homes than in any other setting, we are making progress. Since only two other states have adapted the HCBS waiver for children with SED (New York and Vermont) I believe I must describe, briefly how Kansas secured the waiver and is developing community based services for children.

Background: We have had the HCBS waiver since 1998. It was evaluated in FY 2000 and is now in place until FY 2005. For Kansas several agendas seemed to converge at the same time. We have long practiced the Wraparound philosophy and principles of planning and serving children with parents as partners in service delivery and evaluation. SAMHSA awarded Keys for Networking, the state family organization, and Social and Rehabilitation Services one of the first national grants in 1994 to develop a state infrastructure to provide children's services with family members influencing the decisions. SAMHSA had also funded two System of Care demonstration sites in Kansas, one in Wichita (an urban community) and one in rural southeast Kansas. With the demonstration sites, SAMHSA provided the means to develop children's community based services and the means to collect the data to profile service effectiveness. By 1997, we knew what effective services should look like; we knew the cost per child, per kind of service to maintain children with SED in the community. This is important because one of Medicaid's requirements for the waiver is that it cost no more to serve a child in the community than in the hospital. We had the data to show cost neutrality, which is another requirement of Medicaid. We had to demonstrate that we could serve children in the community at no greater cost than to serve them in hospital placements. We had the services and we had made the decision to close a state mental hospital.

With the alliance of mental health providers, Social and Rehabilitation Services and families, organized by Keys for Networking, we moved the legislature to fund not only

the waiver in 1998 but in 2000 a statewide family centered system of care with \$5 million dollars to allow centers to support children's services in the community. I mention this alliance because it is not often that we are all able to agree exactly on what we want from the legislature. WE showed the legislature cost figures, we showed them charts of outcomes and we shared testimonies from families whose children had benefited from community based services.

Impact: With minimal changes and in only a few months turn around, Medicaid approved the 1998 waiver. SRS had not asked for a large appropriation. We started with \$1 million. As of March 2002, the waiver is funded at \$2.5 million in state funds (approx \$6.5 million from all funds). In 2002, Kansas is spending an average of \$12,900 for mental health service per child per year on the waiver. Hospital costs are exponentially higher. Let me share with you the following grid which delineates our service costs. Please notice that costs rise the farther the child is from his/her home and community.

Table 1
Comparison of costs in state care for children

	Per Child/per day	Per child/per year
Home and Community Based Services Waiver	\$35	\$12,900
Foster Care: Adoption	\$39+	\$13,908
Foster Care: Return to biological families	\$83+ Average across regions	\$29,928
Juvenile Detention Residential	\$150*	\$54,750
Larned Mental Hospital	\$398#	\$145,270
Rainbow Mental Hospital	\$454#	\$165,710

+Information obtained via telephone 2/10/03 from Sue McKenna, SRS

*Information obtained via telephone 2/12/03 from Ed Gray, Youth Authority

#Information obtained via fax 2/12/03 from Cornelia Jeffery, SRS

This information is important. Every time we serve a child in his/her home thru our wavier we save the state money and we save families. And we have outcomes to demonstrate the effectiveness of serving children in the community, raised by their own parents.

Table 2
Outcomes for Children with SED as reported in the Kansas Consumer Status Reports

		STATE AVERAGES					
		Caseload Size	Permanent Home %	Without Law Enforcement	Clinically Significant CBCL %	A, B, or C Grades %	Regular Attendance in School
FY 2002, Q3	Non-Waiver	3660	95.9%	91.4%	85%	76.7%	86.0%
	SED	1132	97.1%	90.8%	92%	78.3%	87.5%^
	Waiver						

Table 2 shows that children on the wavier, children with the most severe mental health needs, are doing as well, often better than other children in community based settings. Both sets of children are benefiting enormously from wraparound designed arrays of individualized service plans. Kansas providers do well with children who get the services. The Freedom Commission finds that nationally, of all children who need mental health services, only 50% percent ever receive the services.

According to national prevalence estimates from the Surgeon General's report and previous National Institute of Mental Health profiles which look at 5--9% of the population having mental illness. In Kansas, 5% of 600,000 children (Census, 2000 data) suggests that 30,000 children need mental health services. Last year, the Kansas public mental health system served, 10,860 children with 4,074 of them receiving case management and other intensive services. Only 1154 receive services under the waiver. The graphs, the data shows how well we do with children we reach with community based services, all community based services. The waiver is only one way to access services. The problem is we are not reaching enough of them. Even in

Kansas our juvenile jails and our foster care providers are still serving children with enormous mental health needs.

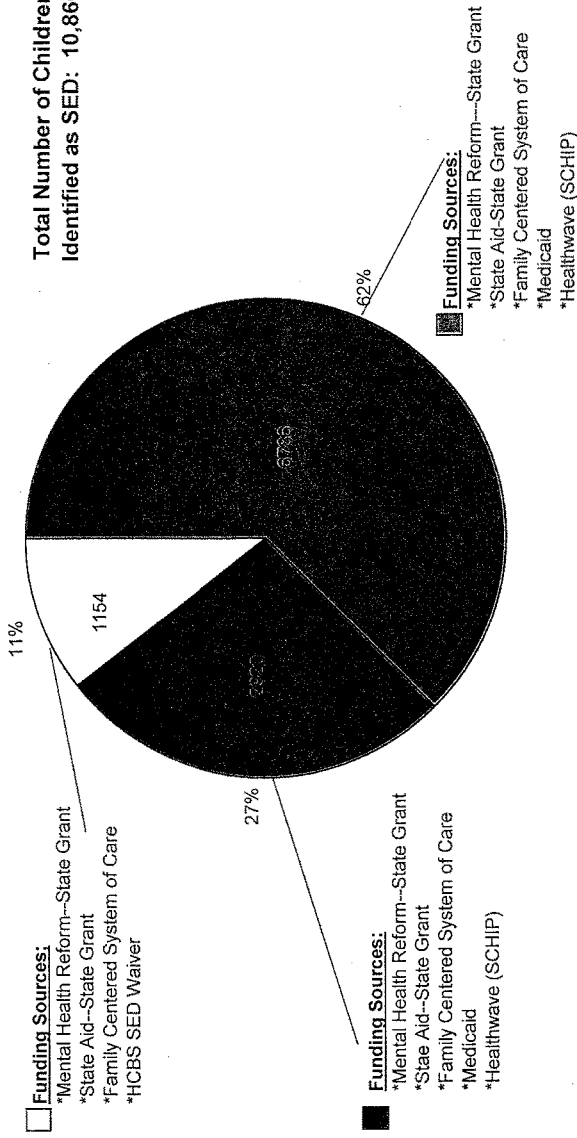
Does the waiver specifically stop the relinquishment of custody? We believe so. We believe effective community based care stops the relinquishment of custody. What I ask you to consider, though, is the apparent difficulty of other states to pursue the waiver or why there are waivers when accessing appropriate care with the financial supports to do so, should be the norm, should be the promise of this Committee.

Thank you for allowing me the opportunity to explain our program.

**STATE OF KANSAS
FUNDING SOURCES FOR CHILDREN IDENTIFIED AS SERIOUSLY EMOTIONALLY
DISTURBED (SED)**

Data Source: State Of Kansas Health Care Policy-MH-AAPS Children's Mental Health Team (785)296-3471 7/03

**Total Number of Children
Identified as SED: 10,860**

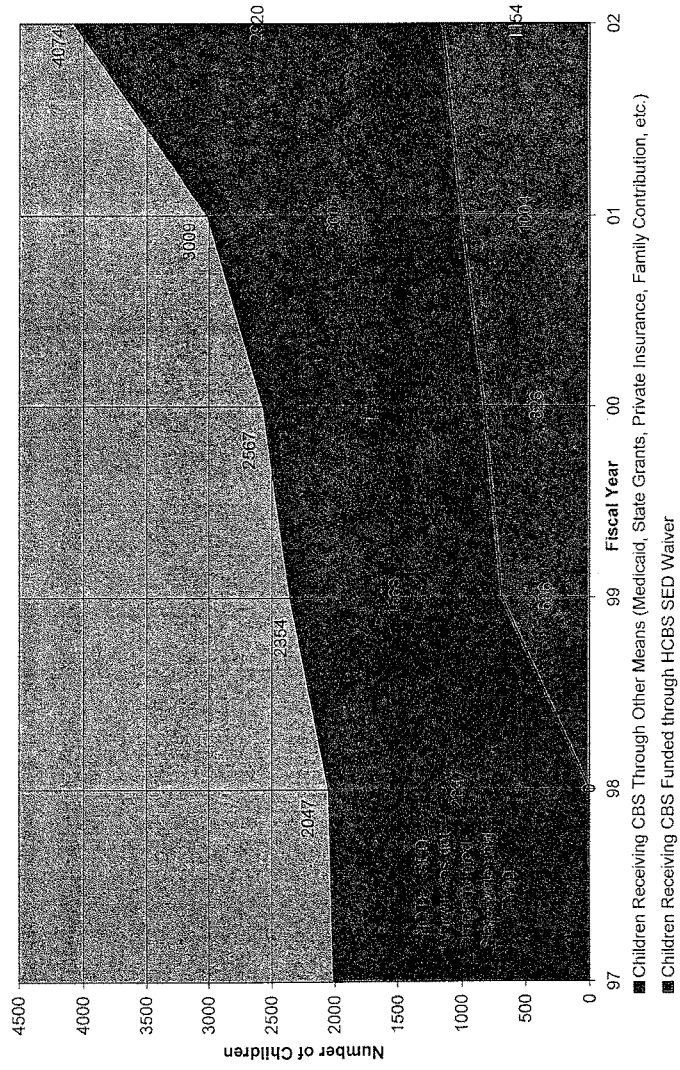


*Note: Other funding sources not specific to SED Children may be utilized within the Community Mental Health Center to support programs and services. These include: Federal Social Services Block Grant, Federal Mental Health Block Grant, Private Insurance and County Funds

- Children Identified SED but not in need of Community Based Services (CBS)
- Children Receiving CBS Mental Health Services funded through other means
- Children Receiving CBS and Funded through the HCBS SED Waiver

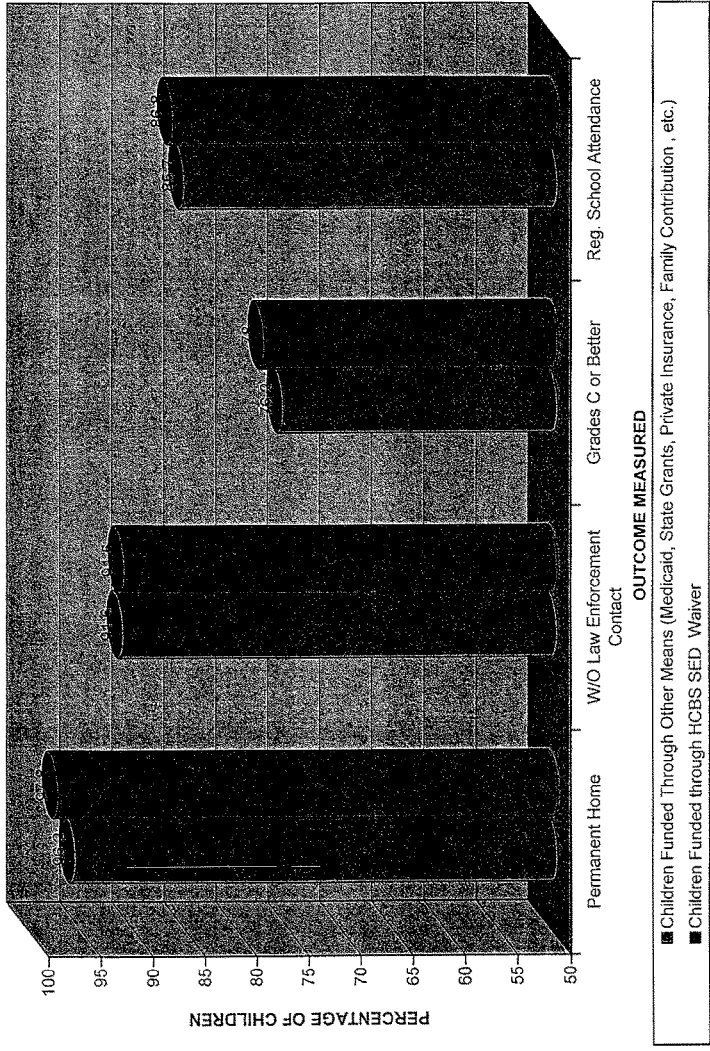
**STATE OF KANSAS
CHILDREN FUNDED THROUGH THE HCBS SED WAIVER AS COMPARED TO ALL CHILDREN
IN HOME AND COMMUNITY BASED MENTAL HEALTH SERVICES**

Data Source: State of Kansas Health Care Policy MFAAPS Children's Mental Health Team (785)296-3471 7/6/03



**STATE OF KANSAS
OUTCOMES FOR CHILDREN IN HOME AND COMMUNITY BASED SERVICES**

Data Source: State of Kansas Health Care Policy-MHAAAPS Children's Mental Health Team (785)296-3471 7/03



Legend:
 ■ Children Funded Through Other Means (Medicaid, State Grants, Private Insurance, Family Contribution, etc.)
 ■ Children Funded through HCBS SEID Waiver

Custody testimony

History: hospital closure

MH reform did not address children

WA grant in 94 introduced WA to Kansas and Keys for Networking

Kan Focus/Sedgwick County SOC grant

Children's Initiative

Development of the waiver

Consultant and task force, list members

Legislative work: Keys, Assn, SRS coordination—all wanted same thing

Reasons for the waiver

Very poor, very wealthy, access to care—public and private

Eligibility determination: Clinical and child income (not family income)

Show Kansas statistics, cost for hcbs, foster care, jo and residential hospital, maybe also

level 6—have jill get fy 03 figures tomorrow

Problems implementing

Happened very fast to get approval, so fast we were not ready to implement in 99

7/11/03

2000 legislative hearing to take away monies because they were not used by centers, lost
\$\$\$\$--need to know how much

increase Medicaid rate to centers do not have to pay anything—cite Bazelon report, need
to site Kansas something

cannot attribute the numbers saved from custody directly to waiver because no data is
kept—problem, farm form shows parent as overwhelmed or unwilling—need to check
this and check with Steve Solomon

benefit to state of waiver: alternatives and expansion of hcbs offerings

jo: all state funds, FC: state and Medicaid, Residential hospital: Medicaid; hcbs:
Medicaid, state, county

The waiver, which must be approved by the federal centers on Medicare and Medicaid
services can both expand the range of services for Medicaid eligible children and families
and can also be used—at the state's option—to expand Medicaid eligibility to those
whose incomes exceed standard Medicaid eligibility requirements in the state. To be
eligible, children must have disorders so severe that they would otherwise need hospital
level care.

At home and community based care waiver of Medicaid rules can also address the issue
of families who lack private insurance or whose insurance fails to cover needed services.

7/11/03

Although children in these families may not normally qualify for Medicaid due to their family's income, the waiver can be used to expand eligibility so children can access services available through Medicaid. Without adequate insurance or the waiver, families sometimes turn to the child welfare system, relinquishing custody of their children to access needed mental health services.

However some states have been reluctant to implement the waiver. Bazelon Center staff surveyed officials from 17 states that are not currently utilizing a home and community based waiver for children with SED and asked them to identify the barriers to applying for such a waiver. We then conducted an extensive interview with state level officials from New York, Vermont, and Kansas, the three states that are currently implementing a waiver for this population, to discover how they overcame these barriers.

In Kansas the tobacco settlement provided an opportunity for state match dollars for the waiver. Kansas received a large settlement and there was a general commitment to use the money for children. In addition the Commissioner of Mental Health Mental retardation at the time was very supportive of the waiver. He had a background in DD and believed that the waiver for that population had been very successful, and it should also be used for children with mental or Emotional disorders. KS was in the process of closing its state hospital and needed a plan for alternative ways to serve children. Accordingly the agency and the advocates were able to argue that the waiver met an emerging need. One official described it as "the right people in the right place."

The KS agency also didn't ask for a large appropriation and started with \$1 million. They believed it was important to start small and demonstrate success by measuring outcomes. As of March 2002 the program was funded at \$2.5 million in state funds (approx \$6.5 million from all funds). Advocates have been helpful at the state legislature in arguing for additional match money for the program and have highlighted the stories of the families who have been helped. The waiver now pays 30-40% of the dollars spent on intensive community based mental health services for children in Kansas's public mental health system.

KS also used data from its state psychiatric hospital prior to closing the beds, so it did not have to confront the issue directly. However, it does not currently have nearly as many beds available as waiver slots because the state estimates the number of children meeting the level of care, not those actually residing in the hospital. In addition, children who currently live in residential treatment facility who also meet the level of care criterion could be candidates for the waiver when they return to an appropriate community setting. Like VT the state's mental health system rarely places children in residential treatment. The place of residency is important for remaining eligible for the waiver once implemented (basically, youth must be in a community setting to be on the waiver, but this is less important in determining initial eligibility than whether the child's behaviors and symptoms meets a hospital level of care). KS officials note that they want to avoid residential and hospital care so children are still given access to waiver services in the community whenever possible. Most youth are at home when they become eligible for the waiver and 90% are able to continue living at home.

The three states currently operating a waiver reported no problem with cost neutrality because of lower average costs for community-based services compared to the high cost of institutional care. Each state found that it had an adequate level of funding and that average costs in their waiver program were lower than their institutional costs.

Kansas currently spends \$12,00 for mental health service per child per year on the waiver, hospital costs are much higher.

KS had an existing MIS system that had supported five other state waivers and could be used to gather data for the children's waiver.

All of the states viewed the waiver as part of the state's larger strategy for increasing access to effective mental health services for children with SED. The waiver provided helpful financing and incentives for working very closely with the provider community to better the overall system of care for these children. As a KS official stated, "the waiver was a crucial step that has led to more steps to building a community based system."

KS faced initial reluctance by some providers and a need to improve infrastructure. State officials addressed the reluctance by changing the reimbursement structure for waiver services so the mental health centers would not have to contribute any of the state match that is normally required for non-waiver services. KS also include start up funds for some of the MHC and provided training on Wraparound services. KS built on the

experience with some demonstration projects that had successfully implemented wraparound services for children with a high level of need.

In KS although the waiver did provide for additional services reimbursed by Medicaid, it was not regarded as a major expansion. It was instead considered a step to help implement effective community based alternatives for children already receiving hospital services or those at risk of hospitalization. Because the state was closing its hospital, the waiver was viewed in the larger picture as part of a strategy of redirection of funds. The state also hoped that the waiver would reduce the state's incidence of families' turning to child welfare and relinquishing custody of their child in order to access mental health services. Family groups and the state report that the practice was reduced by the waiver, finally the tobacco settlement funds were very helpful in allowing the mental health agency to secure the funding for the waiver.

In KS, a task force was formed that included families, advocates, providers, state policy makers, and others to work on a series of issues. At first the task force worked on the waiver application, defining what services would be included in the waiver. It continued to operate and give input after implementation. The benefit of forming a task force is that it provides a forum for identifying a meaningful package of services, gaining consensus and building widespread support for the waiver.

KS added wraparound facilitation, parent support and training, respite care, and independent living services.

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State officials in KS, VT, and NY illustrate the adage, “where there’s a will, there’s a way.” The reality is that, in most other states, children with mental health needs continue to experience the effects of uncertain political will. All of the barriers identified by these 3 states were overcome. For example, when NY did not have adequate data on the cost of community service under the new waiver, the state surveyed its providers to get that information. When the community mental health centers in KS were hesitant about the waiver, the state agency did not require them to contribute any funds to the state match, carving out an exception to the usual Medicaid arrangement and creating an incentive to participate. The states made use of opportunities, such as tobacco settlement money, closing of state hospital beds, and other fortuitous events. Working closely with state legislatures and family advocates was also helpful.

I am testifying today on behalf of Kansas families who have children with serious emotional disabilities. Before I talk about Kansas, I want to share with you for a moment the national perspective of President Bush’s New Freedom Commission. I am a member. President Bush has directed the New Freedom Commission on Mental Health to make recommendations directly to him which put in place and to extend the protections of Olmstead--people with disabilities have the right to live, work, learn, and participate in their homes and communities. Prisons, forced hospitalizations for children or adults with mental illness are no longer appropriate or acceptable in this country. Nationally, we have learned that the state of mental health is in terrible disarray. Let me share with you the attached documents, which you may read later. I have included a copy of the Interim

7/11/03

Report from the Commission. The final report will be available in April. From reviewing the state of affairs nationally, I want you to know how proud I am to be from Kansas, to represent the accomplishments in mental health services for children. Kansans--this legislature, the 29 Kansas Mental Health Centers, SRS, and advocates, of course have developed the premier children's mental health program in the United States. Components include--our statewide family centered system of care•the Home and Community Based Services waiver•the statewide consumer satisfaction surveys--- conducted outside of agencies that deliver the services• the documented outcomes of those services•a proven five year track record of accomplishments keeping children in school, helping adolescents avoid illegal activity and incarceration•improving their grades. We have our own evidenced-based programs for children.

I am proud to have been a part of these accomplishments. In Kansas, we are leaders in what can be accomplished nationally. The needs are enormous. According to national prevalence estimates from President Bush's Freedom Commission, 20% of children in this country have major mental health needs. This is a significant increase from the Surgeon General's report and previous National Institute of Mental Health profiles which look at 7—13% of the population. In Kansas, 20% of 600,000 (Census, 2000 data) would mean as many as 120,000 children need mental health services. The Commission's finding is that nationally, of all children who need mental health services, only 50% percent ever receive the services. In Kansas this is probably about accurate. Last year the public mental health system served approximately 14,000 children. We do not know how many were seen by private mental health providers.

7/11/03

Because the need is so great and because you have long supported mental health services for children, I am here asking for your continued support to restore waiver funding and state aid to the centers. Kansas children truly need the services. Community –based mental health services prevent out of home placements and save the state money. Available and accessible mental health services maintain family unity. I ask you to compare the costs of community and home based mental health care with all other Kansas placements: state hospital, foster care and juvenile corrections.

Table 1
Comparison of costs in state care for children

	Per Child/per day	Per child/per year
Home and Community Based Services Waiver	\$24	\$8,600
Foster Care: Adoption	\$39+	\$13,908
Foster Care: Return to biological families	\$83+ Average across regions	\$29,928
Juvenile Detention Residential	\$150*	\$54,750
Larned Mental	\$398#	\$145,270

Hospital		
Rainbow Mental Hospital	\$454#	\$165,710

+Information obtained via telephone 2/10/03 from Sue McKenna, SRS

*Information obtained via telephone 2/12/03 from Ed Gray, Youth
Authority

#Information obtained via fax 2/12/03 from Cornelia Jeffery, SRS

Please note the rising costs of every service location away from the family. The farther away, the more expensive the treatment. Though state mental hospital treatment is the most expensive service in the state, Keys for Networking considers acute care hospitalization critical as an option for children who have mental health needs. We believe that hospitalization for mental health is very much like hospitalization for physical health. The hospital must be close and immediately available. The hospital is part of one service continuum, which offers appropriate effective services, and choices, close-to-where-people live. In the past reform efforts focused on improving hospitals, then they focused on emptying them and today we focus, as the President makes clear in his Executive Order to the New Freedom Commission, to helping people attain community membership. Let us not focus on how to provide safe havens and safety nets, but instead focus on the supports needed to help people address their needs in the community.

7/11/03

We ask you to maintain all services and all funds for Home and Community Based Care. I can tell you from my experience on the Freedom Commission, the entire country looks to Kansas for the leadership of this legislature, our mental health centers, and the Secretary of SRS in the mental health arena for children. Our Kansas waiver for children with serious emotional disabilities is considered the number one program in this country. It is seen nationally, as the premier support families need to avoid custody and out of home placement. I ask you, specifically, to restore the \$1.5 million in state aid, the \$1.4 million in MediKan rates to CMHCs. I ask you to support the funding recommendations of the Children's Cabinet for Therapeutic Preschool (\$1 million), Family Centered System of Care (\$5million), the SED waiver (1.8 million), and School Violence Prevention (\$228,000).

Finally, I ask you to order a legislature directed planning of mental health, juvenile justice, education and foster care providers with the families and youth who use mental health services. I believe this planning should occur outside of any specific agency. We must have a long-range plan and an open planning process with public hearings to guide the decisions we make for Kansas children who need mental health services. I believe that the 9/11 aftermath, the impact of the Challenger fall, and in the eminent threat of war, it will be the Kansas mental health community who will serve our families and our children..

7/11/03

Press Release

For Immediate Release

Dr. Jane Adams is the Executive Director of Keys for Networking, Inc., the Kansas state organization of the Federation of Families for Children's Mental. President George W. Bush appointed Dr. Jane Adams of Topeka, Kansas, to the President's New Freedom Commission on Mental Health on May 31, 2002, which was asked to advise the President on methods of improving services to enable adults with serious mental illness and children with serious emotional disturbances to live, work, learn, and participate fully in their communities.

Dr. Adams also serves as Vice President of the Federation of Families for Children's Mental Health. She is a member of the Kansas Social Rehabilitation Services 2002 Task Force to explore the role of state mental hospitals in community-based services for children and she serves on the executive committee of the Kansas Mental Health Coalition. She has served as an appointee to the Governor's Mental Health Planning Council, the 1997 Topeka State Hospital Closure Committee, and the 2001 Legislative Hospital Review Commission.

As director of Keys since 1994, Dr. Adams has been instrumental in securing the Medicaid Home- and Community-based Services waiver for Kansas children with severe emotional disability. (Kansas is one of only three states to offer Medicaid-funded choices to allow parents of children to raise children with severe emotional disabilities at home.) In addition, she has provided the leadership to mobilize families statewide to connect to their legislators to secure mental health parity, Healthwave coverage at 200% of poverty level, and funding for a statewide mental health system of care for children and their families. With her leadership, Keys for Networking has grown from operating on a yearly budget of \$40,000 with a staff of three to a \$2 million per year grassroots-mobile-parent voice.

Dr. Adams has authored and co-authored such products as the Keys CD-ROM and online WrapAround Training modules; STAR, A Parent's Guide to Proactive Discipline; "Blamed and Ashamed", a youth-directed research study of co-occurring treatments; "Best Practices in Facilitating Meaningful Family Involvement in Educational Decision Making" for school psychologists; "Moving Forward Together: Parent Professional Partnership;" *Children Time Forgot, A Study of Children Who Died While Incarcerated in the 1800s*; and others.

Dr. Adams served as an Associate Professor of Special Education in Learning Disabilities and Behavior Disorders at Washburn University in Topeka, KS. She received her Bachelor's degree in 1969 from Marymount in Salina, KS, and her Master's and Ph.D. from Kansas State University, Manhattan, KS. Dr. Adams has two grown children: James Adams served in the U.S. Marine Corps and a 2002 graduate of Southeast Missouri State University. Sarah Adams served Kansas in 2001 by offering testimony to the Legislature on behalf of mental health parity and the failure of insurance to meet the mental health needs of working citizens. Sarah holds a Computer Information Systems degree from Friends University and directs the Keys' technology infrastructure and web page (www.keys.org).

Keys for Networking, Inc.

June, 2002

United States General Accounting Office

GAO

Testimony
Before the Committee on Governmental
Affairs, U.S. Senate

For Release on Delivery
Expected at 9:30 a.m. EDT
Thursday, July 17, 2003

CHILD WELFARE AND JUVENILE JUSTICE

Several Factors Influence the Placement of Children Solely to Obtain Mental Health Services

Statement of Cornelia M. Ashby, Director
Education, Workforce, and Income Security Issues



July 2003

CHILD WELFARE AND JUVENILE JUSTICE

Several Factors Influence the Placement of Children Solely to Obtain Mental Health Services



Highlights of GAO-03-865T, a testimony for the Committee on Governmental Affairs, United States Senate

Why GAO Did This Study

Recent news articles in over 30 states and prominent mental health advocacy organizations have described the difficulty many parents have in accessing mental health services for their children. As these reports documented, some parents choose to place their children in the child welfare or juvenile justice systems in order to obtain the mental health services that their children need. Senators Susan Collins and Joseph Lieberman of the Senate Committee on Governmental Affairs asked GAO to testify on: (1) the number and characteristics of children voluntarily placed in the child welfare and juvenile justice systems to receive mental health services, (2) the factors that influence such placements, and (3) promising state and local practices that may reduce the need for child welfare and juvenile justice placements. This testimony is based on our April 2003 report on the results of a study addressing these same objectives. For that report, we surveyed state child welfare directors in all states and the District of Columbia and juvenile justice officials in 33 counties in the 17 states with the largest populations of children under age 18. We surveyed juvenile justice officials at the county level because of the decentralized nature of the juvenile justice system. We also researched laws and regulations and conducted site visits to 6 states.

www.gao.gov/cgi-bin/getrpt?GAO-03-865T.

To view the full product, including the scope and methodology, click on the link above. For more information, contact Cornelia Ashby at (202) 512-8403 or ashbyc@gao.gov.

What GAO Found

Child welfare directors in 19 states and juvenile justice officials in 30 counties estimated that in fiscal year 2001 parents placed over 12,700 children into the child welfare or juvenile justice systems so that these children could receive mental health services. Nationwide, this number is likely higher because many state child welfare directors did not provide data and we had limited coverage of county juvenile justice officials. Although no agency tracks these children or maintains data on their characteristics, officials said most are male, adolescent, often have multiple problems, and many exhibit behaviors that threaten the safety of themselves and others.

Neither the child welfare nor the juvenile justice system was designed to serve children who have not been abused or neglected, or who have not committed a delinquent act. According to officials in the 6 states we visited, limitations of both public and private health insurance, inadequate supplies of some mental health services, difficulties accessing services through mental health agencies and schools, and difficulties meeting eligibility rules for services influence such placements. Despite guidance issued by the various federal agencies with responsibilities for serving children with mental illness, misunderstandings among state and local officials regarding the roles of the various agencies that provide such services pose additional challenges to parents seeking such services for their children.

Officials in the states we visited identified practices that they believe may reduce the need for some child welfare or juvenile justice placements. These included finding new ways to reduce the cost of or fund mental health services, bringing services into a single location to improve access, and expanding the array of available services. Few of these practices have been rigorously evaluated.

In a related report, we recommended that (1) the Secretary of Health and Human Services (HHS) and the Attorney General investigate the feasibility of tracking these children to identify the extent and outcomes of these placements, (2) the Secretaries of HHS and Education and the Attorney General develop an interagency working group to identify the causes of the misunderstandings and create an action plan to address those causes, and (3) the agencies continue to encourage states to evaluate the child mental health programs that states fund or initiate and that they determine the most effective means of disseminating the results of these and other available studies to state and local entities. In commenting on a draft of that report, Education, HHS, and the Department of Justice generally agreed with our findings but did not fully concur with the recommendations, particularly related to tracking the children. All three agencies said they would participate in any interagency working group that might be established based on our recommendation.

Madam Chairman and Members of the Committee:

Thank you for inviting me here today to discuss how federal agencies could do more to help states reduce the number of children placed in child welfare and juvenile justice systems solely to obtain mental health services. As recent news articles in over 30 states and prominent mental health advocacy organizations have reported, many parents have difficulty accessing mental health services for their children with severe mental illnesses.¹ In some cases, parents must choose to remove their children from their homes and seek alternative living arrangements by inappropriately placing them in the child welfare or juvenile justice system to obtain mental health services—two systems not designed to care for children solely because of their mental health needs.² Various federal laws require that state and local agencies provide services to mentally ill children in the most integrated setting appropriate to their needs; that is, children have a right to receive services in their communities unless their needs can only be met by the state in residential or institutional placements.

My testimony today will focus on three key issues: (1) the numbers and characteristics of children voluntarily placed in the child welfare and juvenile justice systems in order to receive mental health services, (2) the

¹Federal agencies and states have varying definitions for children with serious emotional disturbances (SED). For example, the Department of Health and Human Services' (HHS) Substance Abuse and Mental Health Services Administration (SAMHSA) defines SED as a diagnosable mental disorder found in persons from birth to 18 years of age that is so severe and long lasting that it seriously interferes with functioning in family, school, community, or other major life activities. Because of these differences, we use the term "children with severe mental illness" to describe such children throughout this statement.

²Child welfare systems are designed to protect children who have been abused or neglected by, for example, placing children in foster care or providing family preservation services; and juvenile justice systems are designed to rehabilitate children who have committed criminal or delinquent acts or status offenses—that is, according to the Department of Justice (DOJ), behaviors that are law violations only if committed by juveniles—and to prevent such acts from occurring. Consequently, the goals of these systems and the background and training of their staff reflect these purposes. In addition, parents cannot voluntarily place their children in the juvenile justice system. Children are detained in this system as a result of their delinquent acts or status offenses. However, parents sometimes request that police arrest their children for behaviors that are related to or stem from their mental illness when they cannot obtain services through other means. In this statement, we use the term "placed" to refer both to children who have been voluntarily placed in the child welfare system and children who enter the juvenile justice system to receive mental health services. Because information was not available, we were not able to report on whether parents relinquished custody of their children to obtain the services.

factors that influence such placements, and (3) state and local practices that may reduce the need for some child welfare and juvenile justice placements. My comments are based on the findings from our April 2003 report, *Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services* (GAO-03-397, April 21, 2003). In conducting that study, we analyzed responses to our survey of state child welfare directors in all states and the District of Columbia and our survey of juvenile justice officials in 33 counties in the 17 states with the largest populations of children under age 18. We surveyed juvenile justice officials at the county level, rather than at the state level, because of the decentralized nature of the juvenile justice system. In addition, we interviewed officials of child-serving agencies,³ caseworkers, and parents in 6 states (Arkansas, California, Kansas, Maryland, Minnesota, and New Jersey) and judges in each state we visited except Minnesota.⁴ We also observed programs that state officials identified as model programs in those 6 states; interviewed key federal officials and national experts; and researched state laws and regulations regarding voluntary placement and relinquishment of parental rights.

In summary, state child welfare officials in 19 states and county juvenile justice officials in 30 counties estimated that in fiscal year 2001 parents in their jurisdictions placed over 12,700 children—mostly adolescent males—into the child welfare or juvenile justice systems so that these children could receive mental health services. Nationwide, this number is likely higher because 32 state child welfare officials, including officials of 5 states with the largest populations of children, did not provide us with data. However, officials in 11 of those states indicated that although they did not have an estimate to provide, such placements occurred in their state. Also, we surveyed juvenile justice officials in only 33 counties; 30 of which responded with an estimate. Although no federal or state agency tracks these children or maintains data on their characteristics, officials said most are male, adolescent, and often have multiple problems. Many exhibited behavior that threatened their safety and the safety of others. In addition, these officials said children who were placed came from families of all financial levels and that the seriousness of the child's illness strained the family's ability to function.

³Child-serving agencies include mental health, Medicaid and State Children's Health Insurance Program (SCHIP), juvenile justice, education, and child welfare.

⁴We did not interview judges in Minnesota primarily due to scheduling conflicts.

A variety of factors influenced whether parents placed their children in the child welfare and juvenile justice systems to receive mental health services for them; these included limitations in health insurance coverage, shortages of mental health services in some localities, difficulties in accessing services through mental health or education agencies, eligibility requirements for services provided by different agencies and programs, and misunderstandings among state and local officials and service providers regarding the responsibilities of various agencies to meet children's mental health needs. For example, despite guidance issued by various federal agencies with responsibilities for serving children, state and local officials' views of the roles of their own agency and other agencies, such as mental health, child welfare, education, and juvenile justice, showed that they misunderstood those roles and, therefore, could not effectively give parents complete and accurate information about available services their agency and other agencies could provide.

The state officials that we interviewed identified a range of practices in their states that they believe may help to prevent some child welfare and juvenile justice placements. These included finding new ways to reduce the cost of or to fund mental health services, bringing mental health services into a single location to improve access, and expanding the array of available services. However, the effectiveness of these practices is generally unknown because many were new, few were rigorously evaluated, and many served a small number of children or only children in specific locations.

To determine the extent to which children may be placed inappropriately in the child welfare and juvenile justice systems in order to obtain mental health services, we recommended in our April 2003 report that the Secretary of Health and Human Services (HHS) and the Attorney General investigate the feasibility of tracking these children to identify the extent and outcomes of these placements. To help reduce misunderstandings at the state and local level, we also recommended that the Secretaries of HHS and Education and the Attorney General develop an interagency working group to identify the causes of the misunderstandings and to create an action plan to address those causes. We further recommended that these agencies continue to encourage states to evaluate the child mental health programs that states fund or initiate and that the Secretaries of HHS and Education and the Attorney General determine the most effective means of disseminating the results of these and other available studies to state and local entities. In commenting on a draft of the report, the Department of Education, HHS, and DOJ generally agreed with our findings but did not fully concur with the recommendations. Education

said that it did not understand how tracking the children would increase the likelihood of progressive practices to provide children's mental health services and noted that no recommendations were made for increased grant spending to duplicate or disseminate the positive features of such practices. HHS said that asking the agencies to track this population of children in foster care does not address the larger point of the lack of mental health resources for families and communities and does not address the problems of the children or their parents. DOJ agreed that tracking should occur, but only in the short term, and said that HHS should take the lead in this activity. All three agencies said they would participate in any interagency working group that might be established based on our recommendation.

Background

As defined by the President's New Freedom Commission on Mental Health, the mental health system in the United States collectively refers to the full array of private and public programs for individuals with mental illness that deliver or pay for treatment and services. The federal government plays a major role in funding mental health services through public insurance—Medicaid and SCHIP—and grants to states and local agencies, and state and local governments play a major role in delivering services. Most families depend on private and public insurance to pay for mental health services because such services are expensive, although, as we discussed in a previous report, children may face certain limitations in coverage barriers depending on their type of coverage and where they live.⁶

At the federal level, several federal agencies—including HHS's SAMHSA, Centers for Medicare & Medicaid Services (CMS), and the Administration for Children and Families (ACF); DOJ's Office of Juvenile Justice and Delinquency Prevention (OJJDP); and Education's Office of Special Education and Rehabilitative Services (OSERS)—have a role in addressing the mental health needs of children. However, all have individual mandates, target different but often overlapping populations, and share responsibilities to varying degrees with state and county agencies. (See table 1.)

⁶U.S. General Accounting Office, *Mental Health Services: Effectiveness of Insurance Coverage and Federal Programs for Children Who Have Experienced Trauma Largely Unknown*, GAO-02-813 (Washington, D.C.: Aug. 22, 2002).

Table 1: Characteristics of Key Agencies with Responsibilities for Mentally Ill Children

Department and agency	Key activities related to children's mental health	Statute	Population targeted and definition of mental illness
HHS (CMS)	<p>Administers the Medicaid and SCHIP programs that provide health insurance coverage to certain low-income individuals and disabled children, including some children with severe mental illness.</p> <p>Awards research grants.</p> <p>Provides technical assistance to state agencies.</p>	Title XIX of the Social Security Act	<p>Certain low-income individuals and certain disabled individuals.</p> <p>Uses a clinical classification of diseases to identify children with a mental illness.</p>
HHS (ACF)	<p>Oversees the Adoption and Safe Families Act (ASFA) of 1997 that improves the safety of children and promotes adoption and permanent homes for children who need them and supports families.</p> <p>Administers Title IV-B of the Social Security Act that provides funds to states for services that protect the welfare of children. For example, these services address problems that may result in the abuse and neglect of children. The funds may also be used to provide services to families of children with a mental illness.</p> <p>Administers the Title IV-E Foster Care Funds Program that provides funds to states to partially cover the costs of room and board for eligible children from low-income families who are placed in approved out-of-home living arrangements.</p> <p>Maintains the Adoption and Foster Care Analysis and Reporting System (AFCARS), to which states report demographic data on children in foster care, including diagnoses of mental illness.</p> <p>Awards development, training, research, and demonstration grants.</p> <p>Disseminates research.</p> <p>Provides technical assistance.</p>	Title IV, Part B and Part E of the Social Security Act ASFA	<p>Children and families.</p> <p>Uses a clinical classification to identify children with a mental illness and accepts classifications used by individual states in identifying children with mental health needs.</p>
Education (OSERS)	<p>Monitors the implementation of the Individuals with Disabilities Education Act (IDEA). IDEA established the right of disabled children—including children with mental illness—to receive special education and related services, such as mental health services, designed to meet their unique needs and prepare them for employment and independent living when such services are needed for children to make adequate progress in school. IDEA requires schools to evaluate children who are referred for special education services and, if services are required, develop an individualized education program (IEP) that documents the type and intensity of services that will be provided.</p> <p>Funds formula and discretionary grants.</p> <p>Provides technical assistance.</p> <p>Disseminates research.</p>	IDEA	<p>Promotes improvement in educational results for infants, toddlers, and children with disabilities.</p> <p>Under IDEA, the term "child with a disability" means a child, who by reason of a physical or mental disability, needs special education and related services.</p>

Department and agency	Key activities related to children's mental health	Statute	Population targeted and definition of mental illness
HHS (SAMHSA)	Provides funds to states and local entities to help them administer, support, or establish programs that specifically target the mental health needs of children and block grant funding that enables states to maintain and enhance mental health services. Sponsors the Systems of Care Initiative to help children and adolescents with serious mental illnesses and their families receive a variety of services from schools, community mental health centers, and social services organizations and facilitate coordination among these service providers. Awards formula and discretionary development and demonstration grants. Disseminates research. Provides technical assistance.	Public Health Service Act	Individuals with substance abuse problems, mental illness, or at risk of substance abuse and mental illness. Children served meet the following criteria: <ul style="list-style-type: none"> • age 0 to 18 and • have a diagnosed mental, behavioral, or emotional disorder of sufficient duration to meet diagnostic criteria that results in impairment that substantially interferes with or limits the child's functioning in family, school, or community activities.
DOJ (OJJDP)	Helps oversee juvenile justice programs across the nation and supports states and local communities in their efforts to develop and implement effective and coordinated prevention and intervention programs. Helps improve the juvenile justice system's ability to protect public safety, hold offenders accountable, and provide mental health treatment and rehabilitative services. Funds formula and discretionary grants. Provides technical assistance. Disseminates research.	Juvenile Justice and Delinquency Prevention Act	Children who commit crimes or are delinquent and children at risk for delinquency. Accepts mental illness classifications used by states to identify children with mental health needs.

Source: GAO.

Note: Other agencies, such as HHS's Social Security Administration, DOJ's Division of Civil Rights, and HHS's and Education's Office for Civil Rights, also have responsibilities for children with disabilities, including children with a mental illness.

Federal law does not require parents to relinquish their parental rights to place their children with child welfare agencies. However, after children are in care for a specific period of time, the law requires that the court be involved to determine if termination of the parents' rights are in the best interest of the child. State laws addressing the ability of parents to place their children in child welfare systems vary across states. Nationwide, laws in 11 states allow parents to place children in child welfare systems on a voluntary basis in order to access mental health services for as long as necessary without relinquishing custody of the child to the state.⁶ Child

⁶The 11 states are: Alaska, Colorado, Connecticut, Iowa, Maine, Minnesota, North Dakota, Oregon, Rhode Island, Wisconsin, and Vermont.

welfare directors in 8 other states and the District of Columbia advised us that their states do not allow parents to place children voluntarily in child welfare agencies to access such services.⁷ Laws in the remaining states are generally silent regarding voluntary placements for mental health.

Federal agencies with responsibilities for children with mental illness support interagency collaboration at the federal and local level. For example, officials at SAMHSA are collaborating with officials at Education and OJJDP to improve mental health services for children with emotional and behavioral disorders who are at risk of violent behavior by developing and implementing a large grant program that targets these children. At the state and county level, a similar array of agencies provides or funds services for mentally ill children, and state and federal laws and policies often determine their roles and responsibilities. Importantly, federal agencies play a key role in funding research and evaluation studies and disseminating the findings of these efforts. For example, SAMSHA, OJJDP, and OSERS fund research and evaluation studies that target children with mental illness and disseminate the findings of these efforts, descriptions of promising practices, and other information through their clearinghouses, journals, and Web sites.

Despite their differences, programs run by agencies at all levels of government adhere to the principle of "least restrictive alternative." Under this principal, the state has the burden of demonstrating that state-funded out-of-home placements are necessary for the protection of the child or society. In 1999, the U.S. Supreme Court established this principle as a right for disabled children. In *Olmstead v L.C.*, the Court held that under Title II of the Americans with Disabilities Act, states may be required to serve people with disabilities in community settings when such placements can be reasonably accommodated.

Mental health treatment can be very expensive, and most families rely upon insurance to help cover the cost of these services. For example, one outpatient therapy session can cost more than \$100, and residential treatment facilities, which provides 24 hours of care, 7 days a week, can cost \$250,000 a year or more. Nationwide, about 87 percent of American children are covered by private or public health insurance plans. Private plans, such as employer-sponsored or individually purchased plans,

⁷The 8 states are: Florida, Georgia, Hawaii, Kansas, Missouri, Montana, New Hampshire, and Texas.

provide health insurance coverage to about 68 percent of American children, and public programs, such as Medicaid and SCHIP, provide health insurance coverage to about 19 percent.⁸

Most private health insurance plans offer different coverage for mental health services than for physical health services. To ensure more comparable coverage, the federal government passed the federal Mental Health Parity Act (MHPA) of 1996. MHPA prohibited certain employer-sponsored group plans from imposing annual or lifetime restrictions on mental health benefits that are lower than those imposed on other benefits. However, the act did not eliminate other restrictions and limitations on mental health coverage, such as limiting the number of treatments per year that are reimbursable. In addition, the law does not apply to plans sponsored by employers with 50 or fewer employees, group plans that experience an increase in plan claims costs of at least 1 percent because of compliance, and coverage sold in the individual market. According to the National Council of State Legislatures, as of November 2001, 46 states have passed mental health parity bills. Most of these laws meet or exceed the federal MHPA standard. However, the Employee Retirement Income Security Act of 1974 preempts states from directly regulating self-funded, employer-sponsored health plans; under such circumstances, states requirements usually do not apply.

For more than 30 years, Medicaid has provided comprehensive health insurance for children from low-income families. Although individual states determine many coverage, eligibility, and administrative details, the federal government sets certain requirements for state Medicaid programs. These requirements include coverage of screening and necessary treatment for children. Under Medicaid, states may apply for and receive approval from the federal government to waive certain provisions of the Medicaid statute in order to operate a specific program, change the benefits offered under Medicaid, or make comprehensive changes to their Medicaid or SCHIP programs. For example, states can use the Home and Community-Based Services (HCBS) (section 1915(c) of the Social Security Act) waiver to provide home and community-based long-term care services to targeted groups of individuals who would otherwise require care in a hospital, skilled nursing facility, or intermediate care facility. To receive the HCBS waiver, states must demonstrate that the cost of the

⁸U.S. General Accounting Office, *Health Insurance: States' Protections and Programs Benefit Some Unemployed Individuals*, GAO-03-191 (Washington, D.C.: Oct. 25, 2002).

services to be provided under the waiver is no more than the cost of institutionalized care plus any other Medicaid services provided to institutionalized individuals. Additional flexibility is available to states under the “Katie Beckett” option, which enables states to use federal Medicaid funds more flexibly to cover the costs of health care services in the home and community rather than just in institutional settings, regardless of the income and assets of the family.⁹ States choosing this option provide Medicaid coverage for children under age 19 who meet certain standards for disability, would be eligible for Medicaid if they were in an institution, and are receiving medical care at home that would be provided in an institution. Although family income and resources are not considered in determining eligibility for services under the Katie Beckett option, states can require families to contribute to the cost of the program. The Rehabilitation option allows states to provide optional Medicaid services such as psychiatric rehabilitation and other diagnostic, screening, and preventive services in nonmedical settings.

States are pursuing a variety of approaches for expanding public health insurance for uninsured children from low-income families by implementing SCHIP programs. States have three options in designing SCHIP programs. For example, 24 states implement SCHIP by expanding Medicaid programs to include children from low-income families with earnings too high to qualify for Medicaid. Fourteen have developed a separate or independent child health insurance program with benefits that differ from those offered under Medicaid. Others use a combination of Medicaid and non-Medicaid plans to serve children in families at different income levels.

States operating Medicaid programs—including SCHIP Medicaid—expansions—must offer the same benefit package to SCHIP beneficiaries as they do to Medicaid beneficiaries.¹⁰ These benefits include the Early and

⁹This waiver authority for seriously ill children was inspired by the case of a ventilator dependent child, Katie Beckett. Katie’s mother successfully argued that the nursing services her daughter required could be provided in her home and at a cost less than that of providing the same care in a hospital. What resulted was the so-called “Katie Beckett Waiver,” enacted as part of the Tax Equity and Fiscal Responsibility Act of 1982.

¹⁰A state that chooses a stand-alone or combination SCHIP program may introduce limited cost sharing and base its benefit package on one of several benchmarks specified in the statute, such as the Federal Employees Health Benefit program, or state coverage. See 42 U.S.C. §1397cc(a) and (b) and U.S. General Accounting Office, *Children’s Health Insurance Program: State Implementation Approaches are Evolving*, GAO/HEHS-99-65 (Washington, D.C.: May 14, 1999).

Periodic Screening, Diagnostic and Treatment (EPSDT) provision that requires states to provide children and adolescents under age 21 with access to comprehensive, periodic evaluations of physical and mental health and developmental and nutritional status, as well as vision, hearing, and dental needs. States must provide all services needed for conditions discovered through these routine pediatric screenings regardless of whether the service is covered by the state Medicaid plan for other beneficiaries. In 2000, more than 1 million children were enrolled in SCHIP Medicaid expansion programs and were, therefore, eligible for EPSDT screens.

While No Formal Tracking Occurs, Available Estimates Indicate That Many Children—Primarily Adolescent Males—Were Placed with the State to Access Mental Health Services

State child welfare and county juvenile justice officials estimated that parents in their jurisdictions placed over 12,700 children in fiscal year 2001, generally adolescent males, in child welfare and juvenile justice agencies so that the children could receive mental health services. Nationwide, this number is likely higher because officials in 32 states, including the 5 states with the largest populations of children, did not provide us with estimates. Moreover, we surveyed juvenile justice officials in only 33 counties and three did not provide estimates. Only estimates were available because no federal or state agency tracked children placed to obtain mental health services in a formal or comprehensive manner. Officials in the 6 states we visited reported that placed children came from families of all financial levels and said that the seriousness of the children's illnesses strained families' abilities to function.

Some Officials Estimate That Parents Placed Over 12,700 Children to Access Mental Health Services

State child welfare officials and county juvenile justice officials estimated that over 12,700 children entered the child welfare or juvenile justice systems in order to receive mental health services in fiscal year 2001. Of these children, about 3,700 entered the child welfare system. State child welfare officials reported estimates that ranged from 0 to 1,071 children, with a median of 71. Table 2 provides detailed information about the estimated number of children placed in the child welfare system. County juvenile justice officials reported estimates that totaled to approximately 9,000 children and ranged from 0 to 1,750, with a median of 140. Table 3 provides details on the estimated number of children placed in the juvenile justice system.

Table 2: States' Estimated Number of Children Placed in the Child Welfare System to Obtain Mental Health Services in Fiscal Year 2001

State	Number of children placed
Alaska	^a
Alabama	130
Arkansas	^b
Arizona	^b
California	^c
Colorado	^c
Connecticut	738
District of Columbia	^d
Delaware	0
Florida	^d
Georgia	^d
Hawaii	^d
Iowa	^b
Idaho	123
Illinois	^b
Indiana	0
Kansas	^d
Kentucky	14
Louisiana	^a
Massachusetts	^c
Maryland	54
Maine	^b
Michigan	^c
Minnesota	1,071
Missouri	^d
Mississippi	13
Montana	^{d,e}
North Carolina	440
North Dakota	^b
Nebraska	^c
New Hampshire	^d
New Jersey	^c
New Mexico	^c
Nevada	20
New York	^c
Ohio	^b
Oklahoma	3
Oregon	101
Pennsylvania	71
Rhode Island	279
South Carolina	^a

State	Number of children placed
South Dakota	^b
Tennessee	^b
Texas	^d
Utah	^b
Virginia	^b
Vermont	60
Washington	423
Wisconsin	^c
West Virginia	135
Wyoming	5
Total	3,680

Source: GAO survey.

^aState did not respond to our survey.

^bState did not provide the data requested, but indicated that voluntary placement happens.

^cState did not provide the data requested.

^dState officials said the practice of voluntary placement is not legal in the state.

Table 3: Estimated Number of Children Placed in the Juvenile Justice System in 33 Counties to Obtain Mental Health Services in Fiscal Year 2001

State	County	Number of children placed
Arizona	Maricopa	60
Arizona	Pima	1,750
California	Los Angeles	*
California	San Diego	200
Colorado	El Paso	40
Colorado	Jefferson	100
Florida	Broward	0
Florida	Miami-Dade	999
Georgia	Fulton	172
Georgia	Gwinnett	100
Illinois	Cook	0
Illinois	DuPage	35
Indiana	Lake	600
Indiana	Marion	100
Louisiana	Jefferson Parish	50
Michigan	Oakland	160
Michigan	Wayne	400
New Jersey	Bergen	*
New Jersey	Middlesex	999
New York	Brooklyn	74
New York	Queens	49
Ohio	Cuyahoga	*
Ohio	Franklin	363
Pennsylvania	Montgomery	20
Pennsylvania	Philadelphia	500
Texas	Dallas	200
Texas	Harris	200
Virginia	Fairfax	350
Virginia	Prince William	840
Washington	King	575
Washington	Pierce	0
Wisconsin	Dane	120
Wisconsin	Milwaukee	0
Total		9,056

Source: GAO survey.

* County did not provide an estimate of the number of children.

Nationwide, the number of children placed is likely to be higher. Eleven states reported that they could not provide us with an estimate of child welfare placements solely to obtain mental health services even though

they were aware that such placements occurred. Moreover, officials in 9 additional states that responded to our survey did not provide an estimate and did not mention whether or not parents turned to the child welfare system to access mental health services. However, child welfare workers we interviewed in 2 of these 9 states—California and New Jersey—told us that these placements did in fact occur. Although some of the state child welfare officials that we visited in California said children do not enter that system to obtain mental health services, county child welfare workers said that they knew of such placements and explained how the cases were coded in their system. Four states did not respond to the survey.¹¹ Information on the prevalence of children present in the juvenile justice system is also limited in this statement since we surveyed only 33 counties. In 3 of those counties, juvenile justice officials reported that while they did not have an estimate to provide, they knew that children were entering the system to obtain mental health services because they were not able to access such services in other ways.

Federal and state systems that track children in the juvenile justice and child welfare systems do not formally or comprehensively track children placed to receive mental health services. For example, ACF's AFCARS, which contains data reported by states about children in foster care or adopted out of foster care, does not have a data element that identifies this population. Similarly, every 2 years OJJDP conducts the Census of Juveniles in Residential Placement, which gathers information on children in juvenile residential facilities and their characteristics but no data base variable exists to isolate children whose parents sought the help of the juvenile justice system to meet children's mental health needs from other children in the juvenile justice system who may also have mental health problems. OSERS maintains extensive data about children who receive special education services, but data are aggregated at the state level and do not include information about who has custody of the child.

Officials Said Placed Children Were Mostly Adolescent Males with Severe Mental Health Problems

According to our survey of state child welfare directors, placed children are more likely to be boys than girls and are more likely to be adolescent. Child welfare directors in 19 states reported that, in fiscal year 2001, 65 percent of placed children were male and 67 percent were between the ages of 13 and 18. While juvenile justice officials did not provide information about the gender and ages of children placed in their system,

¹¹These four states were Alaska, Illinois, Louisiana, and South Carolina.

children in the juvenile justice population are mostly male and range in age from 13 to 18.¹²

The officials from state and county child-serving agencies and parents we interviewed in the 6 states that we visited said that children who were placed had severe mental illnesses, sometimes in combination with other disorders, and their parents believed they required intense treatment that could not be provided in their homes. Many of these children were violent and had tried to hurt themselves or others, and often prevented their parents from meeting the needs of the other children in the family. For example, in Maryland, officials told us about a teenage boy who was mentally ill, developmentally disabled, autistic,¹³ and hospitalized. Because the boy was both violent and sexually aggressive, the county told his mother that if she brought him home from a stay in the hospital, they would remove her other children from the house. Caring for children with severe mental illness can also prevent parents from obtaining full-time work or cause disruptions in their work lives. For example, an Arkansas parent now raising her grandchild does not work because of the time necessary to care for her mentally ill granddaughter. State and county officials from child-serving agencies in 5 of the 6 states that we visited told us that finding placements for children who were mentally ill and who also had other developmental disabilities was particularly difficult. Children who are placed or are at risk of placement come from families that span a variety of economic levels. However, officials from state and county child-serving agencies in all 6 states that we visited said children from middle class families are more likely to be placed because they are not eligible for Medicaid and their families do not have the funds to pay for treatments not covered by insurance.

Multiple Factors Influence Decisions to Place Children

Multiple factors influence parents' decisions to place their children in the child welfare and juvenile justice systems so that they can obtain mental health services. Private health insurance plans often have gaps and limitations in the mental health coverage they provide, and not all children

¹²In commenting on a draft of our April 2003 report, DOJ said that, in the absence of formal tracking and official data, describing with any certainty the characteristics of youth placed voluntarily by their parents in the juvenile justice system is impossible.

¹³Autism is a developmental disability typically affecting the processing, integrating, and organizing of information that significantly impacts communication, social interaction, functional skills, and educational performance.

covered by Medicaid received needed services. Even when parents could afford mental health services, some could not access services at times when they needed those services because supplies of such services were inadequate. In other instances, some mental health agencies and schools have limited resources to provide mental health services and are required to serve children with a mental illness in the least restrictive environment possible—which can limit the alternatives available to parents who believe their children need residential placements. In other instances, parents sometimes have difficulty obtaining all needed services for their children in their communities because eligibility requirements for services provided by various agencies differ. Furthermore, some officials and service providers have misunderstood the role of their own and other agencies and, therefore, gave parents inaccurate or incomplete information about available services for families. These misunderstandings created gaps in services for some children.

Limitations in Private and Public Insurance Often Restrict Access to Mental Health Care, and Some Services are Limited

Almost all state child welfare directors and county juvenile justice officials who responded to our surveys reported that private health insurance limitations were increasing the number of child welfare and juvenile justice placements to obtain mental health services, and well over half reported Medicaid rules also increased such placements. For example, according to parents and state and local officials in all 6 states that we visited, many private insurance plans and separate SCHIP plans offered limited coverage for traditional or clinical treatments, such as psychotherapy or psychiatric consultations,¹⁴ and did not cover residential treatment placements. In addition, state officials in 3 of the 6 states we visited said that Medicaid rules in some states that require the preauthorization of services could result in delays and denials of community-based services.

The legislatures in the 6 states that we visited passed health insurance parity laws to increase the coverage that was available for mental health services by requiring insurance companies to provide mental health coverage that was comparable to what they offered for physical health care. Although these laws met or exceeded the standard established by the federal MHPA, they did not require private plans to cover intensive, long term, and nontraditional services such as respite care and wrap-around

¹⁴These services are generally provided by licensed or certified psychiatrists, psychologists, or masters-level social workers.

services.¹⁵ Mental health officials and service providers in the states that we visited said these services were often necessary to help families maintain children with a severe mental illness in their homes. Furthermore, federal law preempts states from directly regulating self-funded, employer-sponsored health insurance plans and in doing so exempted many families from protection under state laws.

In the 6 states that we visited, state and local mental health officials agreed that Medicaid had far fewer restrictions and limitations than private health insurance plans. In addition, mental health officials in Arkansas, California, and Maryland told us that differences between private insurance and Medicaid programs had created two distinct systems of child mental health services. Under these systems, children covered by Medicaid had greater coverage for mental health services than children covered by private insurance.

All 6 of the states that we visited covered optional Medicaid and SCHIP services by expanding their programs for children with mental illness who were ineligible for Medicaid on the basis of their families' income. These included the HCBS waivers, Katie Beckett option, Rehabilitation option, and SCHIP programs.

For example, states used different approaches to expand Medicaid coverage. Medicaid officials in Kansas received permission from CMS to implement a HCBS waiver to expand coverage for community-based mental health services for a limited number of children who are chronically mentally ill. Although Medicaid officials in New Jersey financed its new child mental health system through a Medicaid Rehabilitation option, the option extends Medicaid coverage to only a limited number of children who have exhausted benefits under other insurance and who have chronic and severe mental illness. This option generally provides 60 days of community-based services and limited hospitalization.¹⁶ Arkansas, Maryland, and Minnesota used Medicaid's

¹⁵Respite care refers to the supervision of mentally ill or other disabled children by a trained caretaker for brief periods of time in order to provide parents relief from the strain of caring for a child with serious mental illness. Wrap-around services encompass a variety of community supports, including counseling, mentoring, tutoring, and economic services that are designed to meet the individual needs of children and their families.

¹⁶In commenting on a draft of our April 2003 report, a Kansas official said that the state had expanded the services the state provides under the Rehabilitation option and does not limit the services to 60 days, but bases services on the individual clinical and medical needs of the child.

Katie Beckett option to expand Medicaid coverage to physically or mentally disabled children who meet CMS's requirements for institutional care. Arkansas' program did not require parents to pay into the program to receive services, but Minnesota's program required parents to pay according to their ability as defined by a sliding scale.

Although Medicaid's EPSDT provision requires Medicaid coverage for all necessary physical and mental health services that are identified during routine periodic screening as long as the treatment is reimbursable under federal Medicaid guidelines, some state officials said many eligible children are unable to access necessary services through Medicaid because practitioners in the states implement EPSDT unevenly. For example, a Medicaid official in Maryland told us that the implementation of EPSDT varied from county to county. Medicaid officials in California said implementation varied from practitioner to practitioner although access to EPSDT services was increasing as a result of litigation. These officials explained that some practitioners are reluctant to recommend services if such services are not available, some do not have the time to question parents about their child's mental health, and others are not well informed about children's mental health issues. In a July 2001 report, we recommended that the Administrator of CMS work with states to develop criteria and timelines for consistently assessing and improving EPSDT reporting and provision of services.¹⁷ As we stated in that report, comprehensive national data on the implementation of EPSDT are needed to judge states' success in implementing EPSDT requirements.

Low Medicaid reimbursement rates may restrict the participation of some practitioners and thus further restrict services. In all 6 states, officials from a variety of agencies said Medicaid rates for some services are lower than the usual and customary rates in their areas and, in some areas, psychiatrists and psychotherapists will not accept Medicaid patients or expand the number that they are presently seeing because of low Medicaid reimbursements. For example, a psychologist in Minnesota told us that Medicaid reimbursement for a psychotherapy session is about half the customary rate, and a mental health official in New Jersey said that Medicaid reimburses only \$5 per visit for monitoring the use and effects of psychotherapeutic medication.

¹⁷U.S. General Accounting Office, *Medicaid: Stronger Efforts Needed to Ensure Children's Access to Health Screening Services*, GAO-01-749 (Washington, D.C.: July 13, 2001).

Even when insurance covered the costs of mental health services, some mental health officials and parents indicated all parents could not access services or placements in their community because the supplies of these services were limited. Fifteen of the 28 child welfare officials and 9 of the 23 juvenile justice officials who responded to our survey question on the relationship between community mental health services and voluntary placements indicated that the lack of such services increased voluntary placements. In every site we visited, officials of state and local child-serving agencies and parents reported inadequate supplies of mental health service providers and specialized mental health placements. Many of these officials said that shortages of child psychiatrists, child psychologists, respite care workers, and behavior therapists existed on statewide levels and were worse in rural areas. Also, specialized, out-of-home mental health placements, such as psychiatric in-patient services and residential treatment facilities, were often not available or had long waiting lists. For example, Arkansas officials said that the state has no state-run psychiatric hospital placements for children under age 12, and, in California, some children have to wait about 8 months for a residential placement. Officials in 3 states noted that relatively fewer residential placements are available for girls than are available for boys and that few placements would accept children with histories of arson and sexual aggression. Moreover, these officials noted children placed in the child welfare or juvenile justice systems received preference for services, particularly when the services were court-ordered.

Difficulties Accessing Services through Certain Agencies, Difficulties in Meeting Service Eligibility Requirements, and Misunderstandings among Officials and Service Providers Can Influence Placements

In the 6 states that we visited, limited resources in mental health agencies and public schools to fund mental health services and agency officials' attempts to minimize the use of residential services posed additional challenges for parents seeking services and placements for their children. In addition, some children who needed multiple supports experienced gaps in services because of differences in the eligibility requirements for obtaining such services. Moreover, some officials and service providers often misunderstood the responsibilities and resources of their own and other agencies and communicated the misunderstandings to parents, compounding service gaps and delays.

Difficulties Accessing Services through Mental Health or Education Agencies

According to some mental health and education officials, budgetary shortfalls in the 6 states that we visited contributed to agencies' attempts to cut or control costs, including the cost of mental health services. Mental health agencies used a variety of strategies to control costs, such as reducing spending, requiring that services covered by Medicaid be approved before they are provided, and limiting the number of children

served. In each state we visited, some parents believed the strategies affected the quality of the services their children received and created unnecessary delays in getting services. In Arkansas, private, nonprofit mental health providers that contract with the state to provide community mental health said that state officials cut their funding and, as a result, they had to reduce the length of treatment sessions and increase the length of waiting lists. In Arkansas, Maryland, and New Jersey, state officials said that they contracted with private, nonprofit agencies to authorize the medical necessity of mental health services covered by Medicaid. Arkansas required preauthorization of all Medicaid-financed mental health services, including those that were legally required, such as the screening of foster children for mental health services. A variety of officials in this state and a parent reported that the preauthorization agency often denied services for children because they had not benefited from similar services in the past. For example, this parent said the preauthorization agency refused her son's therapist's request to hospitalize him to treat his suicidal behavior because past hospitalizations for suicide attempts had not reduced the behavior. In New Jersey, state mental health officials reduced the number of counties that had been targeted to implement the state's new child mental health system and limited the number of children served by the system. For example, officials from a variety of county agencies reported that the new system of care limited the number of children receiving the highest level of care in their county to 180 a year, although juvenile justice officials said that at least 500 children in their system alone needed such services. Officials from child welfare, mental health, and juvenile justice agencies said eligible children who did not receive the highest level of care were placed on waiting lists and provided less intensive services.

Officials from a variety of county agencies and some parents also reported that public schools in their county—in order to control costs—were often reluctant to provide individualized mental health services for special education children beyond services that are routinely available. For example, child welfare officials in 3 locations we visited said schools fit children with a mental illness into preexisting programs, and school officials in two of these locations agreed, stating that children's IEPs could only contain services that were available in the schools. Almost all the parents that we interviewed said that school officials were reluctant to evaluate their children to determine eligibility for special education services or provide specialized services for them. For example, a parent of a child with a mental illness in Kansas said officials in her daughter's school refused to evaluate the child for a year and a half. After the evaluation, the school recommended that the child work with a learning

disability specialist for 30 minutes a week, even though the parent said this service was insufficient and did not address her daughter's destructive, violent, and aggressive behavior.

As a result of the difficulties encountered at both mental health agencies and schools, some parents could not access the community-based services they needed to care for their child at home nor place their child in a residential treatment facility. In 4 of the 6 states that we visited, some teachers and mental health service providers encouraged parents to refuse to bring their child home from a hospital or other supervised placement, such as a detention center, when they were informed their child was being discharged in order to obtain mental services from child welfare agencies. Although these parents realized they were abandoning their child and, as a result, could be arrested and lose custody, they believed that this was the only alternative that remained to obtain services. Some parents that we interviewed told child welfare workers they would physically abuse their child in their presence to force them to place the child in their system if they could not get help for their child any other way, and juvenile justice officials told us other parents asked the police to arrest their children. However, officials in 2 of the states that we visited said children often remain hospitalized for months without appropriate services because child welfare agencies did not have the resources to provide the needed level of services or specialized placement, could not obtain resources from other agencies, or could not access appropriate services or placements that had the capacity to treat another child. In addition, although federal law does not require custody relinquishment to obtain mental health services, state child welfare officials in two states that we visited said that their state required parents to relinquish custody of their child to the state after the voluntary placement period ends. In one state, these officials misconstrued federal requirements and believed that they required relinquishment and in the other state, officials said relinquishment enabled them to have more control over the child's care.

Difficulties Meeting Eligibility Requirements for Mental Health Services

Eligibility requirements for obtaining mental health services pose several challenges for parents. For example, state and local Medicaid officials in 3 states told us that some children lose their eligibility for Medicaid-funded services because their families' income increased beyond Medicaid's threshold or move in and out of eligibility as their families' income fluctuates. Also, some child welfare officials said some children receive Medicaid because they are in foster care and lose their eligibility when they return home if the family is not eligible. Alternatively, juvenile justice officials in 6 states said that children in juvenile justice correctional or

detention facilities lose Medicaid eligibility and have to reapply to resume coverage when they are released from the facility.

In addition, in all 6 of the school districts we visited, schools used different eligibility criteria for mental health services than mental health or other child-serving agencies in their area. For example, school officials in 4 districts told us that some mentally ill children are not eligible for mental health services through their special education programs because they were making adequate educational progress or because behavior problems—rather than mental illness—prevented them from making adequate progress. However, mental health officials who work with children attending some of these schools reported that schools often have a narrow definition of educational progress and do not recognize that inappropriate behavior might be a symptom of mental illness. For example, a parent of a child with attention deficit¹⁸ and bipolar¹⁹ disorders said her son's school refused to provide special education services for him because his lack of educational progress was due to his failure to pay attention and to get his work done, rather than his mental illness, and a parent of a bipolar, schizophrenic²⁰ son said school officials told her that she was responsible for her son's behavior and poor school performance.

Although a variety of officials said schools had more restrictive eligibility requirements for mental health than other child-serving agencies, school officials in a county in California said that their county mental health agency used a more restrictive definition than the schools. In California, state law required that county mental health agencies treat children covered by Medicaid and SCHIP who were diagnosed as SED or who were eligible for special education services.²¹ California also requires that children be evaluated by county mental health agencies and fit a statutory definition of SED. School officials said that these children get priority and their services consumed all available county child mental health resources. According to these officials, other children, including children

¹⁸Attention deficit disorder is a syndrome characterized by serious and persistent difficulties in attention span, impulse control, and, sometimes, hyperactivity.

¹⁹Bipolar disorder is characterized by the occurrence of one or more major depressive episodes accompanied by at least one manic episode over a brief time interval.

²⁰Schizophrenia is a cluster of disorders characterized by delusions, hallucinations, disordered thinking, and emotional unresponsiveness.

²¹The California legislature transferred the responsibility for providing mental health services to children in special education from schools to counties in the late 1980s.

Misunderstandings of Agencies' Responsibilities and Resources	<p>with dual diagnoses of mental illness and substance abuse, mental retardation, or autism-related disorders and children without the required diagnoses have to wait for county mental health services or might not receive services at all, although some may receive services through their school guidance counselors or social workers.</p> <p>Program officials' and service providers' misunderstandings of agencies' responsibilities and resources also affect service provision. For example, misunderstandings about Medicaid coverage created gaps and delays in services. In 3 states, some state and county officials did not know the Katie Beckett option could expand Medicaid coverage for children with a mental illness regardless of family status. In one of these states, a parent told us that county Medicaid officials incorrectly told her that her son was ineligible for coverage under this option because he had a two-parent family. In 2 other states, county mental health officials erroneously told us that this option applied only to children with very severe medical conditions. In another state, a Medicaid official did not know that children enrolled in SCHIP Medicaid expansion programs were eligible for EPSDT services. Furthermore, state child welfare officials in 2 states and mental health workers in a third did not know Medicaid's EPSDT provision includes mental health screenings, diagnosis, and treatment and thought the provision covered only physical health services.</p> <p>In all 6 states, some parents, a variety of state and local officials, mental health service providers, caseworkers, and judges misunderstood the role and responsibilities of schools in implementing IDEA. For example, some parents we interviewed in 5 of these states said that their children waited over a year to receive special education services because they and the mental health professionals they worked with did not understand the procedures IDEA required schools to follow. For example, some parents were told that referrals for special education had to be in writing. Also, some parents and professionals misunderstood that IDEA gives all eligible children, including children with a mental illness, the right to a free appropriate education and parents did not know that they could appeal a school's decision about providing special education services. For example, a parent in Kansas agreed to home-school her 10-year old, sexually aggressive, child with a mental illness because the school would not put the child in a setting that would ensure the safety of his classmates. Despite her long-term involvement with a community mental health agency, this parent believed home schooling was her child's only option.</p>
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States Have Developed a Range of Practices That May Reduce the Need for Some Mental Health-Related Child Welfare and Juvenile Justice Placements

Although few strategies were developed specifically to prevent mental health-related child welfare and juvenile justice placements, state and local officials identified a range of practices that they believe may prevent such placements by addressing key issues that have limited access to child mental health services in their state. State and local practices focused on three main areas: finding new ways to reduce costs or to fund services, consolidating services in a single location, and expanding community mental health services and supporting families. Although some programs were modeled on practices that had been evaluated in other settings, the effectiveness of the practices is unknown because many of them were implemented on a small scale in one location or with a small target group or were too new to be rigorously evaluated.

Finding New Ways to Reduce Costs or to Fund Services May Help Agencies Pay for Mental Health Treatment

According to officials in the 6 states that we visited, one way to reduce the cost of services is to better match children's needs to the appropriate level of service. One goal of some of the programs we reviewed was to ensure that children with lower-level needs were served with lower-level and less expensive services, reserving the more expensive services for children with more severe mental illnesses. Under New Jersey's Systems of Care Initiative, the state contracted with a private, nonprofit organization for a variety of services, such as mental health screenings and assessments to determine the level of care needed, authorization of service, insurance determination, billing, and care coordination across all agencies involved with the children. When the Initiative is fully implemented statewide, the contractor in each county will use standardized tools to assess children's mental health and uniform protocols to determine appropriate levels of care. Children requiring lower levels of care will be referred to community-based providers, while children requiring a higher level of care will be approved to receive services from local Care Management Organizations specifically created to serve them. Presently, the System of Care Initiative has been implemented in 5 of the state's 21 counties.

As another cost-saving method, some programs substituted expensive traditional mental health providers with nontraditional and less expensive providers. Many state and local officials we interviewed in 5 of the states we visited told us that the historic way to treat children with a mental illness included psychiatrists and residential placements. However, officials in New Jersey, Kansas, and Minnesota said their states had switched their focus to using less expensive providers such as using nurses to distribute medicines instead of psychiatrists or nontraditional bachelors-level workers for case management instead of masters-level social workers. For example, Uniting Networks for Youth—a private,

county-based provider in Minnesota—used two commercially available, highly structured programs that allowed them to substitute lower-credentialed bachelor-level staff under the supervision of a masters-level clinician as the primary service provider instead of using higher-level clinicians. County officials told us this structured program has many safeguards, including the collection of extensive data from providers, teachers, and families that allow masters-level clinicians to review the appropriateness and effectiveness of provided mental health services.

In addition to reducing the cost of services, state officials in all 6 states identified the blending of funds from multiple sources as another way to pay for services, thus working around agencies' limitations on the types of mental health services and placement settings each can fund. For example, in a county in Maryland, a local Coordinating Council blends funds from multiple agencies to provide community-based services to children with a mental illness involved with the judicial, child welfare, and mental health systems and with district special education programs. The Council, headed by a judge, leveraged funding by inviting key decision makers—those who could commit resources—from a variety of child-serving agencies and organizations, including the local departments of social services and juvenile justice, the public defenders office, prosecutors, attorneys, and Catholic Charities, to serve on the Council.

In addition to blending funds to pay for services, state officials in 4 of the 6 the states that we visited identified the use of flexible funds, with few restrictions, to pay for nontraditional services that are not generally allowable under state guidelines. For example, Arkansas's Together We Can Program used flexible funds from a federal Social Services Block Grant, state general revenue, and the Title IV-B program to provide a wide array of nontraditional supportive services, such as in-home counseling, community activities, respite care, mentoring, tutoring, clothing, and furniture that helped the family care for the child at home and supported the child in his community.

Bringing Mental Health Services into a Single Location May Improve Access

To improve access to mental health services and bring clarity to a confusing mental health system, 3 of the states that we visited developed a facility to be a single point of entry into the mental health system. Typically, several agencies are represented at the facility and children are assessed with a common instrument and eligible for the same services regardless of what agency had primary responsibility. Kansas's Shawnee County Child and Family Resource Center is a one-stop facility and, according to state mental health officials, a model for the rest of the state.

The center houses workers from 11 social services agencies, including mental health, child welfare, juvenile justice, and education. All children with mental health needs, regardless of which agency first encountered the child, are referred to the center. Case managers at the Center assess the child's psychological, educational, and functional needs, determine appropriate services and placements, make referrals, provide direct counseling services, and determine how to pay for services. The facility includes four bedrooms for children who need to be removed from their homes for short periods of time and a secure juvenile justice intake suite that is staffed 24 hours a day.

State officials in all 6 of the states that we visited also identified collocated services in public facilities such as schools and community centers as another way to improve access. In Harford County, Maryland, for example, mental health services are collocated at an elementary school specifically to improve access to care for students with a mental illness. Using county health and mental health funds, the school developed an in-house mental health clinic that provides mental health services through a bachelors-level social worker, a nurse practitioner, and consultative services from a physician and a psychiatrist. In addition, the school has a variety of internal support staff available to children with a mental illness, including a guidance counselor, a behavior specialist, a home visitor who supports families and assesses the home situation, and a pupil personnel worker who visits homes and helps with transportation issues. The school has several programs available to children with a mental illness, including an intensive, in-school program staffed with a full-time school psychologist; a mentoring program that is run by paid school staff, high school students, and volunteer community members; a program that provides counseling, tutoring, recreation, social skills groups, home visits, referrals, and some psychiatric rehabilitation services; a program to identify elementary school children with a mental illness and increase their access to services; and two collaborative programs with contracted mental health providers that provide community support and prevention services and intensive case management services.

**Expanding Community
Mental Health Services and
Supporting Families May
Improve Treatment for
Children with a Mental
Illness**

Officials from child-serving agencies in all 6 states we visited identified the expansion of the number and range of community-based services to provide an entire continuum of care as a way to improve treatment for children with a mental illness. Some programs we reviewed developed a complete range of community-based mental health services for children, including early intervention, diversion,²² transitional services, and crisis intervention. In addition, some programs supported families of children with a mental illness and encouraged parent involvement in their children's care. Examples of these programs follow.

Early Intervention: Working with local hospitals, workers from the Family Service and Guidance Center in Shawnee County, Kansas, screen newborns in local hospitals. If babies appear at-risk, social workers conduct home visits and refer families to health care professionals or others for support. The Center also developed a therapeutic preschool practice directed at 3-5 year old children, with or without a mental illness diagnosis, who were likely to need special education services when they entered kindergarten. The program serves 32-36 children and provides a half-day of services.

Diversion: Los Angeles' Juvenile Alternative Defense Effort (JADE) was designed to prevent or reduce the time of expensive juvenile justice placements for youths with mental illness, by arranging assessments, providing referrals to mental health providers and advocating for these youth to ensure they receive the treatment they need. Upon referral to JADE, a psychiatric social worker performs an extensive psychosocial evaluation, including a developmental history, family history, and educational history that includes failures and successes, delinquency behaviors, and a mental health status exam. Based on the evaluation, the social worker makes placement and service recommendations to the juvenile court judge. JADE officials said that the evaluations and recommendations give the judges the information they need to consider alternatives to incarceration.

Transitional Services: State and county juvenile justice and mental health officials in all 6 states we visited stressed the importance of including transitional services in a continuum of care. These services are typically provided to a child leaving a residential setting and returning to

²²Diversion programs attempt to prevent or reduce the time children spend in inappropriate placements.

his or her home or community. For example, Minnesota's Red Wing facility is a secure juvenile justice facility that provides in-house mental health services and places a strong focus on transitional services so youth can successfully reenter their own community. The transition program is designed with various levels that allow youth who exhibit good behavior to move to lower levels of supervision. For instance, at level 4, youth begin to transition back to the community by making periodic visits to their homes. At level 5, youth move to a transitional living unit at Red Wing that focuses on applying new skills to activities in their homes and communities. After youth leave Red Wing, a county juvenile justice worker monitors them for 90 days.

Crisis Intervention: Programs we reviewed in 4 states had a mobile crisis unit consisting of teams of staff that visit homes to stabilize crisis situations. Funding, staffing, and authority of these teams vary. Some of the crisis teams can provide direct mental health services; others conduct assessments and make emergency petitions to psychiatric hospitals on behalf of the family. One of the difficulties noted by program officials is determining how to pay for crisis services since these services may not be covered by insurance and families may not have the ability to pay. In Harford County, Maryland, the mobile crisis team is not a fee-for-service provider but is funded by a grant. The team—a psychiatrist, a psychologist, and a licensed social worker—provide direct mental health services and are authorized to make emergency petitions to get a child with a mental illness admitted to a hospital psychiatric unit.

A second way some states improve treatment for children with a mental illness is to provide services to support families and encourage parental involvement in their child's care. State and local officials in all 6 states pointed out that involving parents was a fundamental change in philosophy. Previously, services were provided solely to the children and parents were not included in the decisions about their child's care. Now, the focus is on providing the services parents need to maintain the child in the home and helping parents make informed decisions about their child's care. For example, The Sycamores, a residential mental health facility in Los Angeles County, California, works extensively with parents of children with severe mental illness at its facility and requires their participation. The Sycamores also provides a variety of supportive services, including household items and services such as transportation to and from the facility. In addition, as part of its transitional program, The Sycamores uses Therapeutic Behavioral Services (TBS), one-on-one services provided whenever needed 24 hours a day, 7 days a week to assist youth in

maintaining their current living situation and in developing the coping and problem-solving skills needed.

Concluding Observations

Some parents are placing their children, mostly adolescent boys with severe mental illness, in the child welfare and juvenile justice systems to access mental health services. Although these children may not have been abused or neglected, or may not have committed a criminal or delinquent act, parents are turning to these agencies because they see no alternatives for obtaining comprehensive services for them. Because federal, state, and local agencies do not systematically track these children, the extent and outcomes of these placements are not fully known. To determine the extent to which children may be placed inappropriately in the child welfare and juvenile justice systems in order to obtain mental health services, we recommended in our April 2003 report that the Secretary of HHS and the Attorney General investigate the feasibility of tracking these children to determine the extent and outcomes of these placements. In commenting on a draft of that report, DOJ agreed that tracking should take place, but only in the short term, and that HHS should take the lead in such an effort. HHS said that asking agencies to track this population does not address the lack of mental health resources for families and communities and does not address the problems of the children and their families. However, we believe that knowledge of the extent of this practice is a necessary first step to determine what corrective actions might be taken and may be useful in identifying which progressive practices will most benefit these children.

Experts, agency officials, and service providers agree that agencies must work together to meet the needs of children with severe mental illness because these children have complex problems and are likely to need services from multiple agencies if they are to remain in their communities or if they are to successfully transition from a residential facility back to their communities. However, in some cases, state and local officials' misunderstandings of each agency's service requirements, responsibilities, and resources prevent the provision of interagency services that have the potential to address the needs of these children and their families. In our April 2003 report, we recommended that the Secretaries of HHS and Education and the Attorney General develop an interagency working group (including representatives from CMS, SAMHSA, and ACF) to identify the causes of these misunderstandings and to create an action plan to address those causes. All three agencies said they would participate in any interagency working group that might be established based on our recommendation and DOJ recommended using the existing

Coordinating Council on Juvenile Justice and Delinquency Prevention for the purposes we stated. We believe several organizational entities may be appropriate and that the member agencies forming this group should determine the entity that is best suited.

Although states and counties are implementing practices that may reduce the need for parents to place their children with child welfare or juvenile justice agencies, many of the programs are new, small, and only serve children in specific localities. Furthermore, their effectiveness in achieving their multiple goals—such as reducing the cost of mental health services, supporting families, and helping children overcome their mental illnesses—has not yet been fully evaluated. Given that states and localities are developing new approaches to meeting the needs of children with mental illness, it is important that the federal government continue its role in supporting evaluations of these programs and disseminating the results. To further such efforts, we recommended in the report that the agencies continue to encourage states to evaluate the child mental health programs that the states fund or initiate. In commenting on a draft of our April 2003 report, Education said that no recommendations were made for increased grant spending to duplicate or disseminate the positive features of the practices we highlighted. As a result, we added a recommendation that the Secretaries of HHS and Education and the Attorney General determine the most effective means of disseminating the results of these and other available studies to state and local entities.

Madam Chairman, this concludes my prepared statement. I would be pleased to respond to any questions that you or other members of the Committee may have.

GAO Contact and Acknowledgments

For further contacts regarding this testimony, please call Cornelia M. Ashby at (202) 512-8403. Individuals making key contributions to this testimony include Diana Pietrowiak and Kathleen D. White.

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TESTIMONY OF

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BEFORE THE

SENATE COMMITTEE ON GOVERNMENT AFFAIRS
UNITED STATES SENATE

JULY 17, 2003

Good morning Chairman Collins and Members of the Committee. I am Charles G. Curie, M.A., A.C.S.W., Administrator of the Substance Abuse and Mental Health Services Administration (SAMHSA) at the U.S. Department of Health and Human Services.

On behalf of the Department, it is an honor to be here to provide the insights of the Department into the plight of millions of families across the country who are struggling to meet the needs of their children with serious emotional disturbances. I am speaking, in particular, about parents – of all socioeconomic backgrounds – who find that they must relinquish custody of their child to State welfare or juvenile justice systems solely to enable that child to get the mental health care he or she needs. This was the focus of the GAO Report “Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services”, a report we found comprehensive and valuable because it brought further attention to an unacceptable problem.

The DHHS – particularly SAMHSA, the Centers for Medicare and Medicaid Services (CMS), and the Administration for Children and Families (ACF) – knows this situation is a significant and unacceptable one in which too many American families find themselves. We know this because we are aware of and have been grappling with the larger constellation of issues that can lead parents to this difficult decision – issues such as gaps in health care coverage, inadequate coordination of community-based services, and stress that can arise with a serious, chronic family illness. We know the significant scope and range of the problem, since as many as five to nine percent of children and youth in America experience serious emotional disturbances – illnesses of a magnitude that can compromise their ability to learn, to work, to engage in family life and the life of their community. These are the very kinds of illnesses that can – and do – lead to placements in the child welfare or juvenile justice systems. Yet, wherever these children and youth find themselves, whether at home, in residential treatment, or in the child welfare or juvenile justice systems, well over half never get the treatments and services they need.

Through its words and deeds, and consistent with the imperatives of the President’s New Freedom Initiative promoting community-based services and community living choices for people with all types of disabilities, and the Supreme Court’s *Olmstead* decision, the Department of Health and Human Services has been working – including work in collaboration with the Departments of Justice and Education – to identify those issues and to seek solutions. Testimony that you heard on Tuesday described how just a few of those programs and activities are making a difference in States, communities and families across the Nation. As you requested, I would like to take a few moments to describe those initiatives and activities, and how we are coordinating across agencies and Departments. In many cases, these are not simply promising practices that need evaluation. Rather, they are practices and programs with robust and still-growing evidence of success that can be modeled and adapted in States and communities across the country.

THE AGENCIES

Administration for Children and Families

From the child welfare perspective, foster care is sometimes the vehicle through which parents of children with serious emotional disorders may have to relinquish the custody of their child for the purposes of seeking and receiving mental health services not otherwise available or accessible to the family. Often parents attempt to resolve their children's mental health concerns without resorting to the child welfare agency, but face no other alternative when their efforts fail. Let me highlight a few programs and initiatives ongoing at the ACF and in collaboration with SAMHSA and other HHS agencies.

The title IV-E Federal Foster Care Maintenance Payments Program provides upward of \$5 billion annually to States to assist with foster care maintenance for eligible children, thereby promoting State provision of proper care for children who need placement outside their homes, in a foster family home or an institution.

ACF has been clear with State child welfare agencies that Federal law does not *require* that a family give up custody of their child to secure Federal funds for that child's placement in foster care. ACF issued guidance in 1982 that clarified that States need only have "placement and care responsibility" for a child for the purposes of Federal foster care. Moreover, just last month, ACF issued additional guidance that "placement and care responsibility" does not necessarily mean that a parent has relinquished all custody. Despite these clarifications, some States have chosen to limit voluntary placements into foster care to situations in which a parent specifically relinquishes custody. As we know, all too often, that is done simply to help their child get the mental health treatment and services that he or she needs and cannot get at home.

Once a child is in foster care, however, there is no guarantee that his or her mental health needs will be met. Results from ACF's Child and Family Services Reviews that evaluate the strengths and gaps in State child welfare systems, confirm that children and families face obstacles to appropriate mental health care. In particular, many States need to improve their assessments of families, since caseworkers frequently do not identify the mental health needs of children when case plans are being developed and services are being provided. State child welfare agencies often face the same challenges obtaining mental health services that lead parents to place their children in foster care in the first place. Children and families involved in child welfare face long waiting lists for mental health services; distance to service providers poses another difficulty.

ACF has found a Systems of Care approach offers an effective way to better serve children and youth with high-end mental health needs. ACF has just released a funding announcement for a Systems of Care initiative designed to help build a strong infrastructure of multi-agency collaboration, individualized care practices, culturally competent services and supports, and, critically, child and family involvement in all aspects of the system – including assessing its

accountability and effectiveness. It is an approach that has been spearheaded by SAMHSA and one I will discuss in greater depth in a moment.

States also can use funds from the ACF Promoting Safe and Stable Families Program to fund mental health and other supportive services for children with serious mental disturbances, so foster care does not need to be an option for families in the first place. That program provides States with flexible funding for a number of services, including family preservation and support. Another innovative child welfare-related change is proposed in the President's FY 2004 budget. The President's proposal would allow States to use Federal foster care funds to develop innovative approaches to prevent foster care placements and to develop services that meet the needs of children and families in the State – enabling States to provide mental health services to families earlier, without ever removing children from the family or the community.

Let me turn now to SAMHSA.

Substance Abuse and Mental Health Services Administration

Some of the strongest child and family programs that SAMHSA currently administers promote stable families, improve outcomes for children with serious emotional disturbances, and reduce placements of children outside their homes and communities. The focus of these programs is consistent with the President's New Freedom Initiative by placing an emphasis on community-based systems of care in lieu of institutional care or other forms of child out-placement.

For the past ten years, SAMHSA has administered the most vigorous program in the Nation to address the needs of children with serious emotional disturbance and their families. The Comprehensive Community Mental Health Services Program for Children and Their Families has successfully reduced the need for parents to relinquish custody of their children in order to receive mental health services.

It has done so by requiring that funded communities develop systems of care that are child-centered, family-focused, community-based, and culturally competent. The program also requires that services be coordinated among the major child-serving systems including child welfare, juvenile justice and education. ACF has helped support the program and has worked with SAMHSA to that end. Further, both the Department of Education's Office of Special Education and Rehabilitative Services and the Justice Department's Office of Juvenile Justice and Delinquency Prevention have each provided a senior technical assistance advisor to program grantees. The goal is to create a positive, integrated, and seamless experience in service delivery for children with serious emotional disturbances and their families.

The need for this broad embrace of services is simple. Families are not the only people concerned about children with serious emotional disturbances. About 15 percent of children with serious emotional disturbances referred into systems of care come from family courts and

correctional facilities, another 13 percent come from child welfare agencies, and another 18 percent from schools.

The removal of American Indian and Alaska Native children and youth with serious emotional disturbance from their homes and their communities, and the placement of these children in juvenile justice and out-of-State residential facilities is a particularly acute problem, due in part to the lack of resources to develop tribal systems of care. The SAMHSA-sponsored Circles of Care program has now funded approximately 16 Tribes and tribal organizations that have developed and implemented culturally sensitive strategies to keep children in their homes and communities.

The value of the systems of care approach cannot be overstated. Outcomes from the national evaluation of this SAMHSA program indicate that families feel supported by the services and, critically, that children improve in their functioning at home, school and the community. The Children's Services Program has now served over 60,000 children in 46 States, 10 American Indian and Alaska Native tribes, the District of Columbia, and the territories of Guam and Puerto Rico. Moreover, with an increasing State match over the tenure of each grant, virtually all of the graduated grant programs have remained in operation beyond their Federal funding lives.

The system-of-care approach has another benefit as well. A large proportion of the program grants have been funded through State departments of mental health, enabling States to implement multiple models for statewide implementation of community-based systems of care such as regional models, rural and frontier models, county models and city models. Another mechanism promoted by the program that States have used to coordinate implementation of home and community-based policies is a children's cabinet, typically composed of the State commissioners of child welfare, juvenile justice, education, health and mental health. At the community level, program coordination is driven by a team created to implement the individualized care plan for each child served. The goal is to identify the best possible set of services, interventions and supports available in the community to help children recover from their mental health problems, many of which are co-occurring with substance abuse problems.

SAMHSA also has provided grants over the past six years to develop Statewide Family Network organizations across most of the 50 States and the District of Columbia. These organizations enable families of children with serious emotional disturbance to participate in the development of policies that result in effective services for children with serious emotional disturbance. Families in these Networks also support each other so that children can be cared for in their homes and not have to be placed in more restrictive settings. Statewide Family Networks have now been implemented in almost all of the 50 States and the District of Columbia.

The issue of custody relinquishment does not only affect families of children, it also affects the families of young adults with serious emotional disturbance who are transitioning into adulthood. SAMHSA's recently funded Partnerships for Youth in Transition program is now providing youth, ages 14 to 21, with individualized services and supports needed to make the transition to

jobs, educational opportunities, and successful community living which will reduce significantly the possibility that parents of the younger youth must relinquish custody.

SAMHSA also has taken the lead in cross-agency and cross-Department coordination of programs focused on children with serious emotional disturbances and their families. It annually convenes the Federal-National Partnership on Children's Mental Health, a group of Federal agencies and national organizations – including ACF and CMS – that plan innovative technical assistance activities for States and communities best accomplished through coordinated efforts. The Departments of Education and Justice also are well represented during the meetings of this partnership.

Let me turn, finally, to the HHS's Centers for Medicare and Medicaid Services

Centers for Medicare and Medicaid Services

The Centers for Medicare & Medicaid Services (CMS) oversees the Medicaid program – a jointly funded State-Federal entitlement program that serves more than 40 million low-income beneficiaries. Operating as a State-administered program that functions within Federal guidelines, Medicaid provides eligible children with serious emotional disturbances with both institutional and community-based services.

While there are many pathways for Medicaid eligibility for children, I will briefly describe how children with SED whose family incomes or assets make it difficult for them to meet the eligibility rules for Medicaid are able to get Medicaid services.

1. A State may use what is referred to as the TEFRA optional eligibility category to provide Medicaid coverage to chronically disabled children who require an institutional level of care. Under this option the parent's income and assets are not considered when determining eligibility under this group. While the TEFRA option is a useful tool, fewer than 20 States have elected this option. In addition, many children with serious emotional disturbances do not meet the criteria for an institutional level of care.
2. A State may not consider the parent's income and assets when determining Medicaid eligibility for a child residing in an institution. It is this part of the law that led years ago to the creation of the TEFRA option just described so that a child who either 1) becomes eligible for Medicaid may continue to remain eligible once he or she leaves an institution, or 2) a child who would require an institutional level of care, but had never been institutionalized to receive care in the community. AND
3. States may cover children needing home and community-based services if the child would otherwise need institutional care covered by Medicaid. With a Home and Community-Based Services (HCBS) waiver, States can waive certain income and resource rules to provide Medicaid to persons (such as children with SED) who would otherwise be eligible only in an institutional setting.

CMS has granted HCBS waivers specifically for children with serious emotional disturbances in three States: Kansas, New York and Vermont. Children and their families in these waiver States may receive specific treatment and supportive services, among them respite care, case management, crisis intervention, and family support services. The law only permits HCBS waiver programs as an alternative to care in a hospital, nursing facility or intermediate care facility for the mentally retarded and not as an alternative to care in a psychiatric residential treatment facility. In most States, long-term care is provided to children with SED in psychiatric residential treatment facilities that are not hospitals. However, to repeat, the law does not recognize psychiatric residential treatment facilities as an institution. For those States that do provide services to children with SED in hospitals, the stay is usually of very short duration. Thus, it is difficult for a State to demonstrate cost neutrality of long-term community-based services in the community compared to short-term hospital stays.

Because removing this barrier would help this vulnerable population of children remain in treatment in their communities and with their families, President Bush included a demonstration grant proposal in his FY 2004 budget to provide home and community-based services for children currently residing in psychiatric residential treatment facilities.

In addition, CMS is working to make States aware of their options to help children with serious emotional disturbances, allocating approximately \$525,000 to \$1.4 million of the Real Choice Systems Change Grants for Community Living funds, a significant New Freedom Initiative, for grants to help States develop a comprehensive community-based mental health service delivery system through Medicaid for children with SED who would otherwise require care in a residential treatment facility.

Finally, for children already eligible for Medicaid, or those who become eligible under one of the Medicaid options discussed previously, the EPSDT program, or Early Periodic Screening, Diagnostic and Treatment Services requires that a child receive any necessary health care and treatment listed at section 1905(a) of the Social Security Act to correct or improve physical and mental illness and conditions discovered by the mandatory screening service. This is true even if the services needed are not covered under the State's Medicaid program. Thus, a child with a serious emotional disturbance may receive any and all necessary mental health services and may even be determined to have a mental illness through the EPSDT mandatory benefit within the Medicaid program

CONCLUSION

While the GAO report has focused on what has not been done, I have tried to focus these remarks on what the Department already is doing and will continue to do to help end the need for parents to relinquish custody of their children to State juvenile justice and child welfare systems in hope of getting treatment for their children's serious emotional disturbances.

However, as in any public health effort, the Federal government does not – and cannot – act alone. States must develop better capacity to organize themselves and respond in a similarly coordinated manner, with designated leadership for the effort. Local communities, families, mental health professionals, supportive services providers, and other key groups must be part of the solution, as well.

What is clear to us all is that the solution involves real system change. As the President’s New Freedom Commission on Mental Health pointed out in its interim report that the mental health service delivery system is fragmented leaving serious gaps in care for those with serious mental illnesses especially children.

Today, the parents of children with juvenile diabetes, with cerebral palsy, with cystic fibrosis or other long-term chronic illnesses do not have to seek placement for their children in State child welfare or juvenile justice programs to ensure that their children get care and treatment. It is time to treat mental illness with the same urgency as other illnesses. Consistent with the President’s New Freedom Initiative, it is time to provide children and adolescents with serious emotional disturbances the same dignity, and the same opportunity for lives lived as members of both their families and their communities.

Thank you for the opportunity to address this important issue. I would be pleased to respond to any questions you may have.



Department of Justice

STATEMENT

OF

THE HONORABLE J. ROBERT FLORES
ADMINISTRATOR
OFFICE OF JUVENILE JUSTICE AND DELINQUENCY PREVENTION
OFFICE OF JUSTICE PROGRAMS
U.S. DEPARTMENT OF JUSTICE

BEFORE THE

GOVERNMENTAL AFFAIRS COMMITTEE
UNITED STATES SENATE

REGARDING

CHILDREN'S MENTAL HEALTH
SERVICES AND PARENTAL CUSTODY

ON

THURSDAY, JULY 17, 2003

Madam Chairman, Senator Lieberman, and Members of the Committee: I am J. Robert Flores, Administrator of the Office of Juvenile Justice and Delinquency within the Department of Justice's Office of Justice Programs. On behalf of the Department of Justice, I am pleased to have the opportunity to testify today regarding the voluntary custody relinquishment of children in need of mental health services. Let me begin by emphasizing that no child should have to enter the juvenile justice system in order to obtain mental health services. And no parent should be confronted with the agonizing choice between relinquishing custody or allowing their child to suffer as the child's condition deteriorates for lack of mental health treatment.

Since the early 1990's, the Office of Juvenile Justice and Delinquency Prevention (OJJDP) has recognized the critical role that mental health problems play in the lives of many youth who enter the juvenile justice system. Untreated mental illness can contribute to delinquent and criminal behavior, and can interfere with efforts to safely rehabilitate youth in correctional settings. In 1992, OJJDP began supporting state and local efforts to improve mental health services for juvenile offenders. In October of 1996, OJJDP convened a Mental Health/Juvenile Justice Working Group to advise the agency regarding the future direction of mental health programming.

Since that time, OJJDP has pursued a strategy that involves leveraging current funding, coordinating with other federal agencies, and linking the agency's programming to existing state and local initiatives. This strategy allows OJJDP to participate in collaborative efforts that address the needs of juveniles with mental health and co-occurring substance abuse disorders,

enhance the capacity of community-based services, and increase family involvement in the provision of mental health services to children and adolescents.

To date, mental health initiatives in OJJDP have not focused exclusively on the goal of reducing voluntary custody relinquishment, in part because of the lack of reliable and valid data on the nature and extent of this problem. As the General Accounting Office (GAO) noted in its Report, *Child Welfare and Juvenile Justice: Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services*, “No agency tracks these children or maintains data on their characteristics.” Although data have not been available, we have taken the approach that improving the effectiveness, availability, and affordability of mental health services for at-risk youth and those already involved with the juvenile justice system will automatically reduce the need for parents to relinquish custody of children with serious emotional and behavioral disturbances.

The overall goal of OJJDP’s mental health initiatives is to increase our understanding of the mental health needs of at-risk youth and juvenile offenders, in order to improve the quality of services and treatment they receive and prevent their future involvement in the juvenile justice system. Three objectives support the achievement of this goal:

- ◆ Identify and disseminate information regarding best practices in the following areas:
screening and assessment; treatment programs; service delivery models; and collaborative approaches involving juvenile justice and mental health agencies, schools, and other

child-serving institutions.

- ◆ Increase the quality and cost-effectiveness of organizational structures for providing mental health services both in the community and in the juvenile justice system. Promote the involvement of families in these structures.

- ◆ Develop and implement models of service delivery to underserved populations, including Native Americans and girls, with special emphasis on meeting the needs of youth in detention and secure corrections facilities, and on successfully reintegrating these youth into the community.

In order to clarify how working toward these objectives can reduce the incidence of voluntary custody relinquishment, I'd like to provide the Committee with an example of OJJDP's efforts in each of these areas.

"Mental Health and Juvenile Justice: Building a Model for Effective Service Delivery," is OJJDP's largest mental health initiative and typifies our efforts to identify best practices in the area of mental health service delivery. The project's goal is to create a model for the delivery of mental health services to youth at every point in the juvenile justice system, from arrest to aftercare. In order to ensure that the work is grounded in both current practice and cutting-edge research, project staff must complete these tasks before they can develop the model:

- a) a comprehensive review of relevant theoretical and empirical literature;

- b) a study of mental health needs and services in the juvenile justice system in three under-studied areas of the country (the West, Southwest, and rural Northwest); and
- c) site visits to nine selected promising mental health programs across the country.

Information obtained from this process will be used to create an initial draft model, which will be reviewed and refined by an expert panel. OJJDP has stipulated to the grantee that this panel must include at least one youth with mental health needs and one family member, both of whom have had direct experience with the juvenile justice system. If funding is available, OJJDP plans to use the model developed under this initiative in a demonstration and evaluation project that will replicate and evaluate the model at several sites around the country.

OJJDP strives to increase the quality and cost-effectiveness of organizational systems that provide community services, and to promote positive family involvement with these organizations. For example, the Office of Justice Programs' "Safe Start" initiative seeks to reduce the impact of family and community violence on young children from birth to age six. Communities selected for Safe Start awards are charged with creating or enhancing comprehensive service delivery systems that incorporate providers in the fields of early childhood education and development, primary health care, mental health, family support and strengthening, domestic violence, substance abuse prevention and treatment, crisis intervention, child welfare, and law enforcement. Exposure to violence in early childhood can result in the later appearance of serious mental health conditions such as Post-Traumatic Stress Disorder (PTSD). Providing appropriate services as close in time as possible to the traumatic event(s) can reduce the likelihood of later behavioral disturbance that might cause parents to relinquish

custody in order to obtain mental health treatment for their child.

OJJDP's third mental health objective involves the provision of appropriate and effective services to underserved populations. The agency allocates a significant portion of its Tribal Youth Program funding specifically for mental health and substance abuse services. American Indian and Alaskan Native tribal communities receive grants to provide diagnostic and treatment services in a variety of juvenile justice settings. OJJDP works with Tribal grantees to address the needs of their youth in a holistic manner, integrating evidence-based practices with tribal traditions and customs.

Rural youth with mental health disorders constitute another underserved population. Rural areas often lack professional mental health practitioners, and significant portions of rural communities consist of uninsured families and the working poor. As noted by the South Dakota Rural Youth-At-Risk Outreach Program, "In many rural and most frontier communities in South Dakota, the juvenile justice system is the only available form of intervention for these youth." Using OJJDP funding awarded in FY03, the South Dakota program plans to increase the number of youth with emotional and behavioral problems who receive effective, evidence-based services in their home communities, rather than in out-of-home or out-of-state placements.

The GAO Report contains a useful description of practices that may reduce the incidence of inappropriate child welfare and juvenile justice placements. As noted in the report, OJJDP already supports a number of programs that exemplify such practices. For example, the GAO

notes that, “According to officials in the 6 states that we visited, one way to reduce the cost of [mental health] services is to better match children’s needs to the appropriate level of service.” The first step in the matching process is to accurately identify the presence and severity of a child’s mental health needs. Accurate detection requires the use of valid and reliable screening and assessment instruments. Until now, the juvenile justice field has lacked a reliable guide to selecting and implementing these screening tools. In order to address this critical information gap, OJJDP initiated the project, “Screening and Assessment: Instruments and Models.” This project is intended to create a compendium of reliable and comprehensive information on screening and assessment instruments and protocols for their use with youth in the juvenile justice system. The resulting Resource Guide (now in final draft) will ultimately allow juvenile justice and mental health professionals to better match the needs of youth with the appropriate type and level of services.

Another promising practice identified by GAO is the co-location of mental health services in public facilities such as schools and community centers. In conjunction with the Department of Education and the Department of Health and Human Services (HHS), OJJDP supports the “Safe Schools/Healthy Students” (SS/HS) initiative. Applicants for SS/HS grants must demonstrate the existence of a partnership comprising the local educational agency, local public mental health authority, and local law enforcement agency. Mental health prevention and intervention programs are often located on school grounds, as are family strengthening programs, which are scheduled during the evening so that working parents can participate. Co-locating educational and mental health services makes mental health services more accessible and reduces

the stigma associated with seeking help.

The GAO Report also discusses the expansion of the number and range of community-based services to provide an entire continuum of care as a way to improve mental health treatment for children. The report recognizes the importance of including early intervention as a component of this continuum, and cites a Kansas program in which social workers conduct home visits with families whose infants are identified at birth as being at risk. OJJDP has provided support for David Olds' "Prenatal and Early Childhood Nurse Home Visitation" program, which provides similar services. Three randomized clinical trials have demonstrated that home-based interventions provided by nurses are effective in preventing adverse maternal behaviors such as prenatal drinking and drug use, and can also reduce the later incidence of child abuse and neglect.

Another important area we would like to address is how OJJDP coordinates its activities with programs at the Departments of Health and Human Services and Education, as well as with programs at the state, tribal, and local level. Several mechanisms promote and support the coordination of activities at the federal level. The Coordinating Council on Juvenile Justice and Delinquency Prevention, an independent body within the Executive Branch, coordinates federal programs related to delinquency prevention, missing and exploited children, and the care and custody of unaccompanied juveniles. The Attorney General chairs the Council, and the OJJDP Administrator serves as vice chair. The other statutorily-mandated members represent other federal agencies, including HHS and the Department of Education.

OJJDP also coordinates its activities at the federal level through staff involvement in a variety of inter-agency steering committees and working groups. OJJDP staff are active participants, for example, in the Federal Working Group on Children's Mental Health, the Interagency Coordinating Committee on Fetal Alcohol Syndrome, the Federal/National Partnership for Children's Mental Health, and the National GAINS Co-Occurring Disorders and Justice Center Federal Steering Committee.

OJJDP also engages in a variety of activities to ensure that its programs are coordinated with similar efforts at the state and local level. Approximately 90 percent of OJJDP's appropriated funds go directly to the states, primarily in the form of block and formula grants. Staff in the agency's State Relations and Assistance Division (SRAD) monitor the use of these funds, and ensure that states receiving grant funds comply with the four core protections contained in the recently reauthorized Juvenile Justice and Delinquency Prevention (JJDP) Act. It should be noted that these protections were designed, in part, to reduce the incidence of inappropriate placements within the juvenile justice system. One of the core protections, for example, requires that states make every effort to deinstitutionalize status offenders. (Status offenses are behaviors, such as truancy and underage drinking, that would not be considered criminal if committed by an adult.) SRAD staff conduct regular site visits, and maintain frequent phone and e-mail contact with the states they monitor. In addition, SRAD staff use information derived from other OJJDP programs to provide guidance to states seeking to enhance their provision of juvenile justice and mental health services.

The GAO Report contains an example of a California program supported by OJJDP block grant funds in the section titled, “Finding New Ways to Reduce Costs or Fund Services May Help Agencies Pay for Mental Health Treatment.” The Juvenile Alternative Defense Effort (JADE) is designed to reduce or eliminate the time youth spend in expensive juvenile justice placements. JADE arranges assessments, provides referrals to mental health providers, and advocates for youth to ensure that they receive the treatment they need. In many cases, psychosocial assessments conducted by JADE staff convince judges to consider less restrictive alternatives to incarceration.

OJJDP also coordinates its programs with those at the state and local level through the provision of training and technical assistance. The OJJDP National Training and Technical Assistance Center (NTTAC) was established in 1995 to promote best practices in training and technical assistance, and coordinate the activities of approximately 70 OJJDP grantees and contractors. States and localities looking for assistance on a wide variety of topics can consult NTTAC’s Resource Catalog, which provides descriptions and contact information for every training and technical assistance provider supported by OJJDP. In the area of mental health, for example, a local detention center might call upon the expertise of the Council of Juvenile Correctional Administrators (CJCA). This organization has developed a set of Performance-Based Standards for juvenile detention and correctional facilities, which include health and mental health guidelines. In addition to providing information regarding the Standards, CJCA can teach facilities to use standardized outcome measures and self-assessment tools to evaluate their own progress.

Response to the GAO Report:

The Department of Justice solidly supports the overall goal of reducing and eliminating the inappropriate placement of children into the juvenile justice and child welfare systems in order to obtain mental health services.

Though we concur with the general outline of their recommendations, as we advised the GAO in our response to its draft report, we do not feel that implementing these recommendations as written would effectively address the unfortunate circumstances faced by parents who must relinquish custody of their children to the juvenile justice and children's welfare systems in order to obtain needed mental health services.

The GAO provided four recommendations that apply specifically to responsibilities that the Attorney General would share with the Secretaries of Health and Human Services and Education. I will address each of these recommendations in turn. For convenience, the report recommendations are presented in bold, followed by our response.

- 1. To determine the extent to which children may be placed inappropriately in the children's welfare and juvenile justice systems in order to obtain mental health services, we recommend that the Secretary of HHS and the Attorney General investigate the feasibility of tracking these children to identify the extent and outcomes of these placements.**

As I stated at the outset, the ultimate goal for our agency is to eliminate any need for parents to place their children into the juvenile justice or child welfare systems to obtain needed mental health services. It is not clear, however, how tracking long-term placement outcomes would contribute to the goal of eliminating such placements entirely. In addition, institution of a long-term tracking program appears premature, as we currently have no valid or reliable data regarding the true scope of the problem.

We do agree that the collection of relevant data to determine the nature and extent of these placements is critical. Because the primary source of the problem appears to be a lack of available and affordable mental health care services, we would recommend that HHS take the lead in this investigation. DOJ could also play a role, especially where data are collected within the juvenile justice system, by assisting HHS in understanding the complexities of data collection in juvenile justice settings, providing contact information for relevant juvenile justice facilities, and engaging in other activities supportive of the investigation.

- 2. To help reduce misunderstandings at the state and local level, we also recommend that the Secretaries of HHS and Education and the Attorney General develop an interagency working group (including representatives from CMS, SAMHSA, and ACF) to identify the causes of these misunderstandings and create an action plan to address those causes.**

We concur with the need for an inter-agency effort to both clarify the causes of the problem, and to identify policy and programmatic changes that would address those causes. We are willing to participate in another existing interagency forum, such as HHS' Public-Private Partnership on Mental Health Services for Children and Youth. We also offer the Coordinating Council on Juvenile Justice and Delinquency Prevention as a means to implement this recommendation.

At the July 2003 meeting of the Coordinating Council, which is being held today, I will highlight the issue of inappropriate placement in a discussion with our federal partners, including the Departments of Education and HHS. The primary purpose of this discussion will be to initiate planning for a series of regional conferences. These conferences will include representatives from states whose efforts are highlighted in the GAO's report, as well as from states who are not currently engaged in relevant efforts, and states identified in the GAO's report as placing large numbers of children in the child welfare and juvenile justice systems for the sole purpose of obtaining mental health services. These regional conferences will facilitate the sharing of information among states and enable those states with greater knowledge and expertise in this area to assist those that have yet to develop strategies and programs for preventing the inappropriate placement of children in the juvenile justice and child welfare systems.

In addition, the term "misunderstandings" in this recommendation does not appear to reflect the more urgent problems identified in the GAO Report: the lack of appropriate mental health services at state and local levels, and the unavailability or inadequacy of mental health

insurance coverage. As noted by the Department of Education in its response to the draft report, it might be more productive to focus attention on the “multiplicity, fractionalization, and incongruity of legislation and funding” streams that govern services to youth with serious mental illness and their families.

Overall, we accept the recommendation for an inter-agency working group to address the issue of inappropriate placement of mentally ill youth, and propose to use an existing interagency forum for this purpose and shift the focus of the group from “misunderstandings” to the specific, concrete problems underlying this issue.

3. We recommend that these agencies continue to encourage states to evaluate the child mental health programs that they fund or initiate.

While we believe that evaluating mental health programs is a worthwhile goal in and of itself, it does not appear to address the specific issues raised by the GAO Report. First, the youth most likely to be inappropriately placed in the juvenile justice and child welfare systems are those with severe and chronic mental illness. Therefore, programs serving this population should be priority targets for evaluation. More importantly, however, the report does not identify the ineffectiveness of existing mental health programs as a source of inappropriate placement. Rather, the key issue is a lack of placement opportunities in existing mental health facilities.

We recommend instead that states evaluate their entire systems of care for children in order to determine: a) how many children with serious mental illness are in need of care but unable to obtain it; b) how state and local child-serving agencies (e.g., education, child welfare, mental health, juvenile justice) attempt to address the needs of these children; and c) how effective these systemic efforts are in actually meeting the mental health needs of these youth and their families.

4. **We recommend that the Secretaries of HHS and Education and the Attorney General determine the most effective means of disseminating the results of these and other available studies to state and local entities.**

We agree that effective information dissemination is critical, and will explore appropriate mechanisms for achieving this goal with the Departments of Education and HHS. Federal agencies already possess many effective avenues for disseminating the results of their work. At OJJDP, for example, all publications are announced via the JUVJUST listserv. The listserv reaches a national audience, and is available free of charge to anyone who wishes to subscribe. Individuals, as well as state and local entities, can download most publications from the OJJDP Web site, or contact the Juvenile Justice Clearinghouse by phone, e-mail or fax to request hard copies. It is likely that the three agencies mentioned in the recommendation have each developed their own successful strategies for information dissemination, and that each could benefit from discussion of this topic.

This concludes my statement to the Committee. I would welcome the opportunity to answer any questions that Committee members may have. The Department of Justice remains committed to learning more about the nature and prevalence of this problem, and to working with federal, state and local partners to devise creative, practical and cost-effective solutions.

**TESTIMONY OF LEX FRIEDEN, CHAIRPERSON
NATIONAL COUNCIL ON DISABILITY**

**submitted for the record
to the United States Senate
Committee on Governmental Affairs
“Castaway Children: Must Parents Relinquish
Custody in Order to Secure Mental Health
Services for Their Children”
Washington, DC**

The National Council on Disability (NCD) is an independent federal agency making recommendations to the President and Congress on issues affecting 54 million Americans with disabilities. It is composed of 15 members appointed by the President and confirmed by the U.S. Senate. NCD is charged by Congress with monitoring federal statutes and programs pertaining to people with disabilities, and assessing their effectiveness in meeting their needs. As part of its mission, NCD provides a voice in the Federal Government and to Congress for all people with disabilities in the development of policies and delivery of programs that affect their lives.

NCD provides leadership in the disability policy arena by building on its traditions of innovation, objectivity, independence, and by transcending disciplinary boundaries to meet the changing needs of society. Influencing the Federal Government's policy process is increasingly important to NCD in the works that it undertakes and the range of arenas in which it operates. Many NCD project and program activities reflect the expectation that the work it undertakes and supports will influence or have a positive impact on the policy process, and ultimately improve the quality of life and outcomes for Americans with disabilities.

NCD believes that parents should not have to relinquish custody of their sons or daughters in order for them to receive the necessary mental health services that they need. The fact that too many parents in America have to do so is a national tragedy, and one that requires active leadership to address.

Within the past ten months, the National Council on Disability (NCD) released two reports related to today's hearing on “Castaway Children: Must Parents Relinquish Custody in Order to Secure Mental Health Services for Their Children.” In September 2002, NCD released *The Well Being of our Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports*. In May 2003, NCD released *Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Status of Evidence-Based Research*.

The Well Being of Our Nation

On September 16, 2002, NCD released its report *The Well Being of our Nation: An Inter-Generational Vision of Effective Mental Health Services and Supports* (<http://www.ncd.gov/newsroom/publications/mentalhealth.html>), calling for fundamental reform in a mental health system in crisis. One of the most significant findings of this report is that *children and youth who experience dysfunction at the hands of mental health and educational systems are much more likely to become dependent on failing systems that are supposed to serve adults. What issues lie at the heart of our national crisis for children and youth with mental health needs?*

As is well document elsewhere,¹ children with severe emotional disturbance (SED) experience significant gaps between the systems of care designed to serve their needs to support them with their families and in the community. Due to the stresses of poverty, children and youth from low-income families are disproportionately represented among young people diagnosed with SED. While this labeling theoretically entitles children to a wide range of services and supports, these are often not delivered. In addition, the labeling itself may serve to reinforce a view of these children as dysfunctional, and relegate them to segregated settings. Public policy must seek to reduce this stigma while delivering supports and services (including naturalistic supports, such as mentoring, after-school programs and improved housing).

The Substance Abuse and Mental Health Services Administration (SAMHSA) estimates that 20 percent of all children from birth to 17 years of age suffer from a diagnosable mental, emotional or behavioral illness.² According to SAMHSA, approximately 7 million children had a diagnosable mental disorder in 1997. Among children and adolescents aged 9 to 17, SAMHSA estimates 2.1-4.1 million (five to 13 percent) have a mental or emotional disorder that seriously impairs their functioning in day-to-day activities.

America's youth is the human resource capital of America's future. The value of these human resources is incalculable. We cannot define or put a value on the loss incurred when today's children and youth with SED are damaged in their formative years by systems' failures to provide needed mental health care and/or special education services. For example, children who lack these services often cannot utilize the free and appropriate public education to which they are

¹ National Council on Disability, *From Privileges to Rights: People Labeled with Psychiatric Disabilities Speak for Themselves*, available at <http://www.ncd.gov/newsroom/publications/privileges.html#5>, at Chapter 5; Bryant, E. S., Rivard, J. C., Addy, C. L., Hinkle, K. T., Cowan, T. M., & Wright, G. (1995). Correlates of major and minor offending among youth with severe emotional disturbance. *Journal of Emotional and Behavioral Disorders*, 3 (2), 76-84.

² Mental Health Needs Of Many U.S. Children Going Unmet, available at <http://www.pslgroup.com/dg/4D1FA.htm>.

entitled under federal law. Children with unrecognized or untreated emotional disabilities cannot learn adequately at school or benefit readily from the kinds of healthy peer and family relationships that are essential to becoming healthy and productive adults.

Many young people with SED are already involved in the juvenile justice system.³ Rates of SED among youth in the juvenile justice system have been estimated at 60-70 percent. A significant percentage of the 100,000 youth detained in correctional facilities each year suffers from serious mental disorders and a commensurately large percentage suffer from addictive disorders. Seventy-five percent of the youth in the juvenile system have conduct disorders and more than half have co-occurring disorders.

According to a 1999 report by SAMHSA, when compared with adolescents having fewer or less serious behavioral problems, adolescents with behavioral problems such as stealing, physical aggression, or running away from home were seven times more likely to be dependent on alcohol or illicit drugs.

While major mental illness, such as schizophrenia is often evident only when the individual reaches the late teens or early twenties, there is little doubt that many other disorders found among the adult prison population surfaced at much younger age — and went untreated.

The failure to identify (and treat) children and youth with SED is also associated with the growing problem of teen suicides and/or suicide attempts. If properly implemented, Medicaid's Early and Periodic Screening, Diagnosis, and Treatment Program (EPSDT) should assist parents of youth with SED and school personnel in identifying their disorders, providing the appropriate treatment, and preventing suicide.

The lack of home- and community-based services has still other negative consequences. The lack accounts for unnecessary hospitalization of children and youth with SED. It also contributes to readmission. Because of a lack of services that might ease the transition from hospital to home, including respite services for their families, these children cycle back and forth between hospital and the community without ever achieving stability. In turn, unnecessary hospitalization usurps the limited resources of state mental health budgets, thus obstructing the provision of services that might have prevented institutionalization and perpetuating an unproductive cycle.

If all aspects of the system — from assessment to treatment — took into account the long-term needs of children, rather than episodic or crisis occurrence, children's needs would be described in terms of their underlying issues and in the context of their family and living situation instead of mere documentation of short-term behavior or services available. For some children, the system must be prepared to make a commitment to serve the child for their entire childhood, with

³ See, e.g., Children's Defense Fund, Quick Facts: Mental Health and Juvenile Justice (CDF), at http://www.childrendefense.org/ss_jjfs_menthlthj.php.

easy entry and re-entry into the system. Outcome measures should reflect long-term goals — such as school attendance, living at home with family or independently, and working at a job.

Missed Opportunities for Prevention

Individuals with Disabilities Education Act: IDEA has long been the primary vehicle for securing mental health services and supports for children and youth with mental, emotional or behavioral disorders. The Act's basic tenet is that, until age 21, children and youth are entitled to "a free and appropriate public education." Under IDEA, children with emotional or behavioral disorders that interfere with their ability to learn are entitled to special education services, including any related mental health services and supports that enable them to benefit from their education. Yet despite the intent of this strong federal entitlement, parents and advocates report that children are not receiving many of the promised and needed services. Children and youth with emotional and behavioral disabilities are the least likely to receive the services and supports mandated by IDEA.

The 1997 IDEA amendments mandated that school systems provide two new services to address the needs of children and youth with behavioral problems that interfere with their learning or the learning of those around them. Schools must conduct "functional behavioral assessments" (FBA) to determine the causes of undesirable behavior and develop "positive behavioral interventions and supports" (PBIS) to address them. According to Robert Horner, Ph. D., of the University of Oregon faculty,

"research conducted over the past 15 years has demonstrated the effectiveness of strategies that foster positive behavior for individual students and for entire schools. Even schools with intense poverty, a history of violence and low student skills have demonstrated change in school climate when effective behavioral systems have been implemented."⁴

Despite this history of success, parents and school personnel report that schools are not implementing the provisions of the 1997 IDEA amendments. Some profess they don't understand the statute; others are ignoring or actively subverting the law. In almost all cases, it is apparent that school personnel are unaware of how effective (and relatively inexpensive) these interventions can be.

EPSDT and Medicaid: Medicaid-eligible children should also benefit from the early screening required under Medicaid's EPSDT mandate and a generally broader array of services in state Medicaid plans than is available in the private sector. Under EPSDT, all states must screen

⁴ Warren, J.S., Edmonson, H.M., Turnbull, A.P., Sailor, W., Wickham, D. & Griggs, P. (in press), *School-wide Application of Positive Behavioral Supports: Implementation and Preliminary Evaluation of PBS in an Urban Middle School*.

Medicaid-eligible children, diagnose any conditions found through a screen and then furnish appropriate medically necessary treatment to “correct or ameliorate defects and physical and mental illness and conditions discovered by the screening services.”⁵

Children and youth up to age 21 have a broader entitlement than adults who qualify for Medicaid. For adults, some services are mandatory, but some need only be provided at a state’s option. A state will list its “optional” services in its Medicaid plan, but must make available to children all services listed in federal Medicaid law “whether or not such services are covered under the state plan.”⁶ Few states have good tools to identify children with mental health needs and most fail to monitor providers or health plans to ensure that children receive behavioral health screens.

Medicaid’s EPSDT program, especially when used in conjunction with IDEA, is the ideal vehicle for meeting the comprehensive mental health needs of children and youth. The program requires that states conduct regularly scheduled examinations (screens) of all Medicaid-eligible children and youth under age 22 to identify physical and mental health problems. If a problem is detected and diagnosed, treatment must include any federally-authorized Medicaid service, whether or not the service is covered under the state plan. If problems are suspected, an “inter-periodic” screen is also required so the child need not wait for the next regularly scheduled checkup.

Child mental health services under Medicaid have undergone considerable change over the past decade. For many years, states had included more comprehensive mental health benefits for adults than for children and youth. After the enactment of legislation requiring coverage of all Medicaid-covered services for children through the EPSDT mandate in 1990, states began revising their rules and expanding coverage of child mental health services.

Shortly after these revisions began to occur, states also began to move the Medicaid population in need of mental health care into managed care, generally into separate “carved-out” specialized managed behavioral health care plans. By 1998, fifty-four percent of Medicaid beneficiaries were enrolled in managed care programs.⁷ (Health Care Financing Administration, 1998). Due to the rapid expansion of covered services early in the 1990s and the subsequent introduction of managed care, it is pertinent to question whether children and youth actually receive these community-based services and to determine the patterns of service use. Key stakeholders

⁵ 42 U.S.C. §1396d(a).

⁶ Social Security Act, Section 1905(r)(5). See also, Omnibus Budget Reconciliation Act, 1989, Public Law 101-239.

⁷ <http://www.hcfa.gov/medicaid/trends98.pdf>

continue to cite the lack of attention to the special needs of children and youth as the most serious problem with the public mental health system.⁸

By offering waivers and options Medicaid law also affords states other policy choices that could expand access to mental health services. The home- and community-based waiver allows states to provide alternatives to hospitalization to children with disabilities, including children and youth with SED. The waiver allows states to provide various community support services, but only three states have availed themselves of this waiver for children with SED. Significantly, however, a recent study indicates that the Medicaid home- and community-based waiver is effective in reducing the incidence of custody relinquishment and institutional placement in the three states where they are in use.⁹

However, Medicaid does not cover all low-income and other children and adolescents who have no access to mental health treatment. Moreover, while the array of covered services is fairly broad, some home- and community-based services are still excluded from coverage under many state Medicaid programs.

Denial and Inaccessibility of Services

Despite the IDEA and EPSDT entitlements, children and youth in many states fall through the cracks of the public systems of care. This happens even in states like California, with well-developed local government infrastructure:

“Despite the integrity of individual programs—and even with the extraordinary contributions of so many individual professionals—incremental efforts add up to less than the sum of their parts. The programs often fall short of providing the right services, in the right way, to the right children at the right time. Year after year, new commitments—even with additional funding—fail to achieve the goals so desperately desired.”¹⁰

⁸ Stroul, B.A., Pires, S.A., Armstrong, M.I., and Meyers, J.C. (1998). The impact of managed care on mental health services for children and their families. *The Future of Children: Children and Managed Health Care*, 8, 119-133.

⁹ Bazelon Center for Mental Health Law, *Relinquishing Custody, The Tragic Result of Failure to Meet Children's Mental Health Needs*. (Mar. 2000).

¹⁰ Little Hoover Commission, *Young Hearts & Minds: Making a Commitment to Children's Mental Health*, at iv (Report #161, October 2001), available at <http://www.lhc.ca.gov/lhcdir/report161.html>.

Services are often denied not out of malice, but because of the lack of coordination among systems of care and complexity of funding arrangements:

“Funding is restricted by complex rules that encourage communities to forsake those in the path of danger and focus only on those children who are physically bruised and emotionally broken.”¹¹

Moreover, the criteria that youth must meet before they can receive services can easily be interpreted to deny services.¹² In practice, many states do not have specific definitions of all covered services, so it is likely that many Medicaid-eligible children receive neither the mental health screens nor the mental health treatment to which they are entitled by EPSDT.¹³ The shortage of knowledgeable legal advocates virtually ensures that the rights of many children to EPSDT services will not be enforced.

Access to services is limited due to lack of insurance coverage for mental health services and inadequate access to the special education and related mental health services for which children and youth are eligible through IDEA. For example, ten million children and youth lack health insurance and many more are under-insured for mental health treatment and exhaust their

¹¹ Id.

¹² For example, to qualify for special education, the child’s mental disorder must affect educational performance to a marked degree and over a long period of time. The child must also exhibit one or more of the following characteristics:

- an inability to learn that cannot be explained by intellectual, sensory or health factors;
- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers;
- inappropriate types of behavior or feelings under normal circumstances;
- a general pervasive mood of unhappiness or depression ; or
- a tendency to develop physical symptoms or fears associated with personal or school problems.

¹³ Bazelon Center for Mental Health Law, *Making Sense of Medicaid for Children with Serious Emotional Disturbance* (1999).

benefits. An estimated 30 percent (3 million) of those 10 million are eligible for Medicaid, but their families are unaware that they qualify.¹⁴

As states have sought to “do more with less,” they have also sought out managed care approaches to limiting Medicaid expenditures. Instead of bridging the gap between child-serving agencies, however, states’ shift of Medicaid to managed care has stranded even more children with serious mental health needs.¹⁵

Tragic Consequences for Children, Youth and Society

Custody Relinquishment: Due to lack of community-based services and/or special education services, families of children with SED are often faced with the heart-wrenching choice of not receiving adequate mental health services for their children or relinquishing custody of their children in order to qualify for Medicaid. Child mental health advocates and professionals have recognized the issue of custody relinquishment for many years.¹⁶

¹⁴ The Kaiser Commission on the Future of Medicaid. Medicaid’s role for children. Medicaid Facts. Washington, DC (1997).

¹⁵ Bazelon Center for Mental Health Law, *Managed Behavioral Health Care for Children and Youth: A Family Advocate’s Guide* (1996).

¹⁶ Jane Knitzer first identified it in a ground-breaking 1978 study and elaborated on it in a 1982 publication, *Unclaimed Children: the Failure of Public Responsibility to Children and Adolescents in Need of Mental Health Services*. Several later studies confirm Knitzer’s findings.

- The Research and Training Center on Family Support and Children’s Mental Health found that 25 percent of parents whose children have SED received suggestions that they relinquish custody. One third of those parents receiving the suggestion gave up custody in order to get services.
- The Commonwealth Institute for Child and Family Studies conducted a survey of 45 states. In 28 states (62 percent), at least one agency used custody transfer to gain access to state funding for services for children with serious emotional and behavioral problems. Thirty-eight (32 percent) of the responding child-serving agencies used custody transfer to obtain funding for children’s treatment.
- A 1999 Bazelon Center study found that this problem continues to be pervasive in approximately half of the states. The fear of coerced relinquishment is so widespread that a major family advocacy organization, the Federation of Families for Children’s Mental Health, identifies this problem as one of its current top

Requiring families to give up custody:

- traumatizes both children and parents;
- limits family involvement in key decisions about their children's mental health, health and educational needs;
- undermines family integrity;
- unnecessarily burdens public agencies with children who are neither abandoned nor neglected, but whose families need services and support to raise them at home;
- penalizes families for the state's failure to develop adequate services and supports.

Requiring families to relinquish custody to the child welfare system in order to obtain essential mental health services and supports for their children wastes public funds and destroys families.

Inadequate funding of mental health services and supports for children and their families is the major reason families turn to the child welfare system for help. Private insurance plans often have limits on mental health benefits that can be quickly exhausted if the child has serious mental health needs. In addition, many private plans do not provide the home and community based services and supports that are needed to keep children at home. When their personal funds run out, families are forced to turn to the child welfare system.

Even families whose children are eligible for Medicaid face custody relinquishment. Although many of the needed services are covered, states fail to adequately define their rehabilitation services, to educate providers on how to bill for those services, or to make sure that Medicaid recipients know the array of services to which a child is entitled. When parents then turn to the child welfare agency, the agency often requires - as a non-negotiable condition for obtaining those services - relinquishment of custody to the state or county. In large part, this is driven by the child welfare agencies' mistaken belief that custody is required in order to draw federal matching funds under the Social Security Act.

Educational System/Special Education/Discipline: Due to the stresses of poverty, children and youth from low-income families are disproportionately represented in the young population with SED. The inequities of the neglect of these children by schools and the public mental health system are further compounded by racial discrimination.

The failure to provide early screening and mental health services has meant that as many as 35 percent of students entering school are considered to be at high risk for social and academic

priority areas.

- The National Alliance for the Mentally Ill surveyed parents of children with mental and emotional disorders and found nearly one-fourth of them had been told by public officials that they needed to relinquish custody to get needed services for the children.

failure.¹⁷ Once in school, the failure or refusal to provide IDEA services results in much greater drop-out rates for children and youth with SED.¹⁸ This has led researchers to recommend a new approach to screening, and to identifying a child's strengths rather than deficits.

In perhaps the classic attempt to blame the victim, school districts' failure or refusal to provide preventive services under IDEA has also led, inexorably, to treating children with SED as "discipline problems." In a series of attempts to amend the IDEA over the past three years, Congress has increasingly expanded the authority of school districts to exclude such children and youth from mainstream classrooms.

The techniques for supporting children with SED—known broadly as "positive behavioral supports"—in school are well documented.¹⁹ The use of punishment to correct behavior comes with negative consequences such as negative attitudes on the part of students toward school and school staff (which leads to increased antisocial acts and behavior problems). Punishment of children with SED is strongly correlated with dropping out of school.²⁰

Foster care: The child protective services and foster care system in the United States grew out of efforts by early religious and charitable organizations to serve orphans and "rescue" children and youth from abusive or neglectful families. Today's federally supported foster care system was created under the Social Security Act of 1935 as a last-resort attempt to protect children at risk of serious harm at home. The law obligated states to assume temporary custody of children whose parents were unable or unwilling to care for them.

¹⁷ Ruth Goldman, *Model Mental Health Programs and Educational Reform*, *American Journal of Orthopsychiatry*, (1997) p. 347.

¹⁸ ABC Project, *Staying in School: Strategies for Middle School Students with Learning and Emotional Disabilities* (1995), at p. 1: "Nationally, 35 percent of students with learning disabilities and 55 percent of students with emotional disabilities drop out of school as compared to about 25 percent of students without disabilities."

¹⁹ Among the most recognized of these are to:

- Personalize instruction through accommodating different learning styles and abilities;
- Create leadership opportunities for less-popular students (such as appointing as class helpers) ;
- Give student alternatives (such as self-imposed time-outs, relaxation techniques);
- Try to eliminate conditions that lead to reactive misbehavior (such as teasing from other students).

²⁰ *Id.* at 5.

By the early 1990s almost half a million children were in the custody of state child welfare systems. The U.S. Department of Health and Human Services estimated that at least one of every 10 babies born in poor urban areas in the '90s would be placed in foster care.²¹ Children with emotional or behavioral disorders made up 40 percent of the child welfare population and few resources were available for any type of treatment or support services.²² The steady increase in foster care placements is very troubling. Most children are deeply traumatized when they are separated from their families. Even when their family environment has been dangerous or unhealthy, studies have shown that a child often experiences separation from a primary care giver as a threat to survival.²³

Family disintegration and allegations of abuse are the most frequent reasons that children are placed in foster care, and these reasons are often rooted in the inability to get mental health services and support for parents and/or children.

According to the Annie E. Casey Foundation, every year 25,000 young people in foster care turn 18 and leave foster care. This means that young people in state-supervised programs must leave foster care whether or not they have the skills to maintain an apartment, seek and hold a job, or balance a checkbook. Too many 18-year-olds emerge without having had a stable foster-care environment or adequate mental-health services or a quality education. According to one recent study, 12 to 18 months after they left foster care, half of those who left were unemployed and a third were receiving public assistance. Clearly, youths who "age-out" of foster care are among the most vulnerable and the most at risk.

Juvenile Justice: Each year, more than one million youth come in contact with the juvenile justice system and more than 100,000 are placed in some type of correctional facility. Studies have consistently found the rate of mental and emotional disorders higher among the juvenile justice population than among youth in the general population. As many as 60-75 percent of incarcerated youth have a mental health disorder; 20 percent have a severe disorder and 50 percent have substance abuse problems.²⁴ The most common mental disorders are conduct disorder, depression, attention deficit/hyperactivity, learning disabilities and post traumatic

²¹ "Proposal to Preserve the Family," Associated Press, *The Wenatchee* (Alabama) *Daily World*, May 24, 1993.

²² Mental Health Law Project (now Bazelon Center for Mental Health Law), *The R.C. Case: Creating a New System of Care for Children*, 1991.

²³ Firman, C., *On Families, Foster Care, and the Prawning Industry*, *Family Resource Coalition Report*, No. 2, 1993.

²⁴ Cocozza, J.J. (ed.) *Responding to Youth With Mental Disorders in the Juvenile Justice System*. Seattle, WA, The National Coalition for the Mentally Ill in the Criminal Justice System, 1992.

stress.²⁵ According to a 1999 survey conducted by the National Mental Health Association (NMHA) and the GAINS Center, mental health problems typically are not identified until children are involved with the juvenile justice system, if at all.

Although African-American youth aged 10 to 17 constitute only 15 percent of their age group in the U.S. population, they account for 26 percent of juvenile arrests, 32 percent of delinquency referrals to juvenile court, 41 percent of juveniles detained in delinquency cases, 46 percent of juveniles in corrections institutions, and 52 percent of juveniles transferred to adult criminal court after judicial hearings. In 1996, secure detention was nearly twice as likely for cases involving black youth as for cases involving white youth, even after controlling for offenses.²⁶

Many youngsters have committed minor, nonviolent offenses or status offenses. The increase in their incarceration rates is a result of multiple systemic problems, including inadequate mental health services for children and more punitive state laws regarding juvenile offenders. These nonviolent offenders are better served by a system of closely supervised community-based services, including prevention, early identification and intervention, assessment, outpatient treatment, home-based services, wraparound services, family support groups, day treatment, residential treatment, crisis services and inpatient hospitalization.

Intensive work with families at the early stages of their children's behavioral problems can also strengthen their ability to care for their children at home. These services, which can prevent children from both committing delinquent offenses and from re-offending, are most effective when planned and integrated at the local level with other services provided by schools, child welfare agencies and community organizations.

More than one in three youths who enter correctional facilities "have previously received special education services, a considerably higher percentage of youths with disabilities than is found in public elementary and secondary schools."²⁷ Many children with emotional disorders end up in

²⁵ Garfinkel, Lili F., *Unique Challenges, Hopeful Responses: A Handbook for Professionals Working with Youth with Disabilities in the Juvenile Justice System*, PACER Center, 1997.

²⁶ 1999 National Report Series, Juvenile Justice Bulletin.

²⁷ "Special Education in Correctional Facilities," by the National Center on Education, Disability and Juvenile Justice (1990). Available at http://edjj.org/Publications/pub05_01_00.html.

detention facilities as a result of incidents at school and/or because they fail to receive special education and related mental health services. In addition, many juveniles are released from detention facilities without appropriate discharge services, and end up being re-incarcerated.

Young people with serious emotional disturbance are punished for the failure of systems designed to protect them. Because schools fail to identify and serve youth with serious emotional disorders (SED), these children miss out on much or all of the “free and appropriate public education” to which they are entitled under the federal Individuals with Disabilities Education Act (IDEA), even though IDEA funds services for such children.²⁸

Although IDEA requires educational plans to be in place prior to a young person’s release from juvenile detention, and a well-designed and implemented plan, coupled with connections to the services provided under Medicaid, can mean the difference between a successful transition to home and community or a repeat of the negative cycle that landed the juvenile in detention in the first place, few states implement this requirement. Thus, juvenile offenders with SED frequently fail to reconnect with the education system upon their release.

Without the appropriate intervention, students whose behavior could and should be addressed in school are ending up in juvenile detention. Each year over 100,000 youth are detained in correctional facilities. These institutions have been called the “de facto” psychiatric institutions for adolescents with mental health problems because they substitute incarceration for needed treatment. A recent survey by the Pittsburgh Post-Gazette found that 80 percent or more of the residents of Pennsylvania’s juvenile detention centers had a diagnosable psychiatric problem. Arkansas and New Mexico reported that 90 percent of their juvenile detainees were on psychotropic medication.

Effects of Welfare Reform: In the implementation of welfare reform, policy makers have, to date, focused rather narrowly on the needs of the adult recipients. In particular, reform efforts have concentrated on recipients who are relatively well-positioned to enter the workforce, that is, who do not have evident disabilities or special needs. States have declared remarkable success in their initial efforts to reduce welfare rolls, moving off welfare large numbers of individuals and capitalizing on the current demand for workers. Now, states are beginning to face some unanticipated consequences of return-to-work policies particularly on adults with significant

²⁸ Almost always for want of special education services, 55 percent of children with SED drop out — more than twice the rate of other students in the general population. Nearly 20 percent of students with SED have been arrested, compared with an arrest rate of nine percent for all students with disabilities. As these children age and leave school without adequate preparation or skills, the arrest rate climbs. Of youngsters with SED out of school for two years — more than a third had been arrested. By the time they had been out of school for five years, more than 70 percent had been arrested.

problems (such as those who have mental health and substance abuse issues) and on parents whose children have special needs. States are facing the reality that there is a residual population of welfare recipients whose capacities to work are challenged by these problems.

What might easily be overlooked in the debate on welfare reform is that the children of welfare recipients — both those who have already been counted as “successes” and those remaining on welfare due to special needs — may, themselves, have significant problems. Recipients who have successfully returned to work may have marginal work skills and find themselves in low-level jobs. When they have children with serious emotional disturbance, they may be confronted with parental demands that pull them away from already-precarious work situations. For example, school systems are often ill prepared to deal with special-needs children and seek to exclude them from the classroom. Child care centers are often not prepared to handle children with significant behavioral problems and these children may be expelled, creating significant job-related problems for the parent.

Those welfare recipients who have not yet entered the workforce include significant numbers of individuals with significant problems of their own, such as depression, post-traumatic stress disorder, and chemical dependency. These problems among parents have been identified as risk factors for serious emotional disturbance among their children. The movement of these adults into the workforce, which is already a formidable goal, may pose new problems for their high-risk children. For example, children with serious emotional disturbance who have been reliant on parental care and supervision within the home may, for the first time, be entering child care arrangements outside of the home. These settings must be prepared to offer special approaches appropriate to the needs of these children. In addition, it is likely that the work-place success of recipients who are already struggling to overcome their own problems will be compromised by the added stress of disruptions in their children’s functioning.

This array of factors suggests that the special needs of children do not simply co-exist with welfare reform; parental return-to-work has both an effect upon these children and is affected by these children. However, few policies thus far have considered the interaction of welfare reform and recipients’ children with serious emotional disturbance. Most states have not worked to ensure that the needs of these children are addressed. As the policy and legislative focus comes to be redirected to the hardest to serve welfare recipients (which may well include a significant number of parents of children with special needs), the well being of children will increasingly come to be an issue.

Psychiatric Hospitalization and Residential Care: Traditionally, the mental health services available to children with SED have tended to fall at two ends of a continuum: 1) treatment in a residential facility and 2) individual, usually once-a-week therapy. Yet youth with SED need one or more of a broad spectrum of therapeutic modalities between these two poles. These include ongoing intensive services in their home community and school. Additionally, their families need support services, education and training on how to best handle the youngster and his or her problems.

In many cases, the lack of home- and community-based mental health services results in unnecessary institutionalization. Deprived of services, the condition of many children and youth with SED worsens and reaches crisis proportions, leaving commitment to a residential treatment facility as the only option. Though residential treatment centers lack studies supporting their effectiveness, this treatment — which serves a small percentage of youth — consumes one-fourth the outlay on child mental health.²⁹ Referrals to residential treatment facilities — often unnecessary — remove the child far from home and community; sometimes out of the county or even the state for extended periods of time. Moreover, after leaving the hospital, the lack of transitional services and/or intensive in-home services and supports frequently results in children and adolescents cycling from home to hospital and back again without ever achieving stability.

However, effective home- and community-based services — such as in-home services, behavioral aides, intensive case management, day treatment, family support and respite care, parent education and training, and after-school and summer camp programs — do exist. Of these services, the Surgeon General's report found home-based services and therapeutic foster care to have the most convincing evidence of effectiveness.³⁰ These services are furnished in partnership between professionals and families, are clinically and fiscally flexible, and individually tailored for each child and family, providing whatever intensity of service is needed. Home- and community-based services build on strengths and normal development needs rather than just focus on problems, and provide continuity of care. They strive to be culturally competent and involve the family in the child's care. Evaluations of these community-based services have found them to be highly effective, less costly than the alternative residential services and much preferred by families.³¹

Delinquency Prevention and Juvenile Justice

On May 1, 2003, NCD released a research study entitled *Addressing the Needs of Youth with Disabilities in the Juvenile Justice System: The Status of Evidence-Based Research* (<http://www.ncd.gov/newsroom/publications/juvenile.html>). The report evaluates the emerging status of key policies and programs that affect children and youth with disabilities who have often been overlooked by service and research programs.

²⁹ U.S. Department of Health and Human Services. *Mental Health: A Report of the Surgeon General* (1999), at Chapter 3.

³⁰ Id.

³¹ Hyde, K. L., Burchard, J. D. & Woodworth, K. (1996). Wrapping services in an urban setting. *Journal of Child and Family Studies*, 5, 67-82; Yoe, J. T., Santarcangelo, S., Atkins, M. & Burchard, J. D. (1996). Wraparound care in Vermont: Program development, implementation, and evaluation of a statewide system of individualized services. *Journal of Child and Family Studies*, 5, 23-38.

The issues of delinquency prevention and juvenile justice as they relate to children and youth with disabilities are relatively new for policymakers, yet they present some of the most complex and challenging problems that policymakers must grapple with and resolve.

Over the past several years, NCD has recognized that children and youth with disabilities have increasingly become overrepresented in the juvenile justice system. A significant proportion of youth in the juvenile justice system have education related disabilities and are eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA). Factors associated with the disproportionate representation of youth with disabilities in juvenile corrections are complex — but the available information suggests that school failure, poorly developed social skills, and inadequate school and community supports greatly increase the risks for arrest and incarceration. NCD believes, therefore, that delinquency prevention is a critical feature of any service or support system that is used to address the needs of all youth, especially youth with disabilities and special education needs.

The major recommendations NCD makes are to:

- Identify a range of strategies to enforce and promote compliance with federal disability law as it relates to children and youth with disabilities who are at risk of delinquency. The strategies should include those that increase effective programming for youth with disabilities in schools and in juvenile justice settings.
- Increase funding and/or resources to schools and the juvenile justice system to ensure that youth with disabilities receive appropriate services.
- Designate a single federal agency whose sole focus is to ensure that the rights and needs of youth with disabilities entering or in the juvenile justice system are addressed. The Coordinating Council on Juvenile Justice and Delinquency Prevention and the President’s Task Force on Disadvantaged Youth may be well-suited to provide the direction and leadership to address this gap by helping to create a national commission focused explicitly on youth with disabilities at risk of entering or already in the juvenile justice system.
- Conduct research that focuses on establishing the true prevalence of youth with disabilities of different types among at-risk populations in schools and across all stages of the juvenile justice system; the needs/services gap, including compliance with disability law; the causes of overrepresentation, where it exists, of youth with disabilities in the juvenile justice system, especially correctional facilities; and effective systems level and program level approaches, including federal laws, for addressing the needs of these youth, including particular attention to the types of programming most effective for youth from diverse racial/ethnic and cultural backgrounds.
- Undertake a comprehensive assessment to determine what programs and policies are most effective in schools, communities, and the juvenile justice system. At the same time, ensure that there is a balanced approach to funding diverse programs and policies, coupled with evaluation research studies of their effectiveness. Such an approach will ensure that a more definitive body of knowledge can develop to determine “what works” and for whom.

Without a clear understanding of what works, communities can become awash in a maze of programs and services that claim effectiveness in deterring delinquency yet have no factual information or evidence supporting their effectiveness. NCD believes that policy makers can use the findings and recommendations from this research study to help shape the scope and direction of future federal initiatives designed to tackle delinquency prevention and juvenile justice. Such initiatives fall under the purview of the Department of Education and the Department of Justice.

NCD's study findings on the status of, and need for, improved, evidence-based research in the area of juvenile justice are consistent with those of two other federal level agency research endeavors, namely, the President's Mental Health Commission and the General Accounting Office (GAO).

In an April 3, 2003, draft outline of a final report from the President's Mental Health Commission, Goal No. 4 states: "Adults with serious mental illness and children with serious emotional disturbance will have ready access to the best treatments, services, and supports leading to recovery and cure. Accelerate research to enhance prevention of, recovery from and ultimate discovery of cures for mental illnesses." Recommendation No. 4 states: "Evidence-based practice interventions should be tested in demonstration projects with oversight by a public-private consortium of all stakeholders. The results of those demonstrations should form the basis for directing support of financing, dissemination and workforce development."

In an April 15, 2003, report *Child Welfare and Juvenile Justice*, officials in the states GAO visited identified practices that they believe may reduce the need for some child welfare or juvenile justice placements. These practices included finding new ways to reduce the cost of or to fund mental health services, improving access to mental health services, and expanding the array of available services. GAO reported, however, that few of these practices have been rigorously evaluated.

Conclusion

All too often, when it comes to addressing the needs of too many children and youth with mental health needs in this country, the human services system in this country is in crisis. For decades, state mental health systems have been burdened with ineffective service-delivery programs and stagnant bureaucracies.

At the same time, the complementary systems established to support children with mental health needs and their families (i.e., special education, welfare, juvenile justice) are themselves unable to operate efficiently and effectively individually, and together, on behalf of some of the most vulnerable members of society.

There is no single antidote for the current dysfunction of these service systems. Clearly, visionary leadership, adequate funding and meaningful collaboration are essential ingredients. More than

these, however, there needs to be a dramatic shift in our aspirations for children and youth with mental health needs and their families.

What is most needed now is a dramatically new vision of what children and youth with mental health needs can achieve, if given the supports they need to succeed. That vision must start with the premise that family should not have to relinquish custody of their sons or daughters for the same level of adequate support and services. The vision must also include an emphasis on public funding and utilization of what works with children and youth, as well as with their families. A third component of this vision requires a commitment to fund effective supports and services and to fund enforcement of the rights guaranteed under the Individuals with Disabilities Education Act, Medicaid, TANF, and other federal statutes.

The Federal Government can play an important role in establishing funding and other incentives for state human service systems to adopt new models that support this vision and that are consistent with President Bush's New Freedom Initiative.

**Testimony for Nowhere to Turn: Must Parents Relinquish Custody in Order to Secure Mental Health Services for Their Children?
July 15 & 17, 2003**

Good afternoon Chairperson Collins. Thank you for allowing Children's PressLine to testify. Children's PressLine is a New York-based youth journalism program that trains kids to be journalists who advocate on behalf of the peers. Our journalists are ages 8 to 18 and work together in small teams using a process of oral journalism to conduct their interviews. The interviews are digitally recorded. The interview was then transcribed and edited to retain the purity of the young people's experiences.

The following interview with 17-year-old Tiquita Robinson was conducted on the issue at hand at today's hearing: kids whose parents must give up custody of them so they can get proper treatment. CPL reporters Ramses Driskell, 10; Safiya Driskell, 8 and Janes Gregoire, 12, conducted the telephone interview. Gary Guzman, 18 and Miguel Tejada, 16, were their editors. Her words about her experience in a residential treatment facility ran in the Amsterdam News on Thursday, July 17, 2003, to coincide with this hearing.

Tiquita Robinson, 17

Department of Social Services got custody of me so they could pay for my placement [in the residential treatment facility]. They tried to charge my Mom with child abuse and neglect. The judge made the decision for me to go into a center.

I didn't want to go. I thought that maybe if I tried [suicide] someone would listen. I wasn't trying to kill myself. I just didn't want to leave home.

I didn't like the institution they put me in. I wanted to leave. I tried to run away several times, but I didn't succeed. I wanted to be home with my family. There wasn't much freedom where I was.

I slept in a room with a roommate. I didn't get along with a whole bunch of [the kids there] because my unit was girls only. When I went to a co-ed unit I got along better with them.

I don't like talking. I don't communicate a lot. But I did talk to some people there. We shared what we went through. We talked about it in group or in mediation or we talked amongst ourselves.

We had groups every day except for Friday and we went to the gym. We went out to the playground. We went on the green top where you can play basketball and run around. We went to Kings Dominion [amusement park], the zoo, a lot of different places.

At the facility there was a lot of other people around. A lot of people didn't think things were fair.

Sometimes I felt safe. There was one girl that I got in a fight with. She was crazy. She's had a lot of things happened to her. I thought if I went to sleep she would come in my room and try to do something to me.

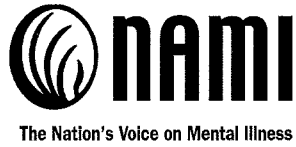
The building wasn't in good condition. A lot of the bathrooms were dirty. There was urine all over the toilet.

I didn't like the program. It was strict. You had to earn your freedom. You have to get the counselors to sign your paper and then you get the primary doctor, primary nurse to sign your paper. If you don't get one signature then you won't get your levels. You start out at level 1. Then it takes two weeks to get to level two, three weeks for level three.

I don't really think the institution helped me change. I was there for a year and two months. A person only changes when they want to. I disliked it because in there it's not like you learn to deal with your problems on your own. They force you to deal with it, so it wasn't really learning.

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STATEMENT OF RICHARD C. BIRKEL, PH.D
EXECUTIVE DIRECTOR OF NAMI

ON BEHALF OF NAMI –
THE NATIONAL ALLIANCE FOR THE
MENTALLY ILL

ON
"NOWHERE TO TURN: MUST PARENTS RELINQUISH CUSTODY IN
ORDER TO SECURE MENTAL HEALTH SERVICE FOR THEIR
CHILDREN?
PART 1: FAMILIES AND ADVOCATES
PART 2: GOVERNMENT RESPONSE"

SUBMITTED TO THE
SENATE COMMITTEE ON GOVERNMENTAL AFFAIRS

JULY 15 AND 17, 2003

Chairman Collins, Senator Lieberman and members of the Committee, NAMI would first like to thank you for holding this critically important hearing on the crisis of states forcing families to give up custody of their child with a mental illness to secure necessary services.

I am pleased today to submit the following testimony on behalf of the National Alliance for the Mentally Ill (NAMI) on the issue of custody relinquishment – the tragic practice of states and local governments forcing families to turn custody of their child with a mental illness over to the state to secure necessary treatment.

Who is NAMI?

NAMI is a nonprofit, grassroots support and advocacy organization of consumers, families (including parents and caregivers of children and adolescents with mental illnesses) and friends of people with serious mental illnesses. Founded in 1979, NAMI today works to achieve equitable services and treatment for more than 15 million Americans living with severe mental illnesses and their families. Hundreds of thousands

of volunteers participate in more than one thousand local affiliates and fifty state organizations to provide education and support, combat stigma, support increased funding for research, and advocate for adequate health insurance, housing, rehabilitation, and jobs for people with mental illnesses and their families.

NAMI applauds the leadership of Senator Collins (R-ME) – as Chair of the Senate Committee on Governmental Affairs -- for holding this hearing and for joining with other Congressional leaders -- Representatives Patrick Kennedy (D-RI) and Pete Stark (D-CA) – in asking the General Accounting Office (GAO) to report on this national tragedy. NAMI consumers, families and advocates are truly grateful that this committee is taking a close federal look at a system that forces families to be torn apart simply to access treatment and services for children – who often suffer from serious mental illnesses.

The GAO Report on Custody Relinquishment Documents the Struggles of Our Nation's Families

The GAO report – *Child Welfare and Juvenile Justice – Federal Agencies Could Play a Stronger Role in Helping States Reduce the Number of Children Placed Solely to Obtain Mental Health Services* – confirms that states and counties force families to give up custody of tens of thousands of children and adolescents with mental illnesses to the child welfare and juvenile justice systems to secure necessary treatment. This national tragedy exists even though those systems are not designed primarily to provide mental health care and often fail to represent a therapeutic environment for children with mental illnesses.

The GAO report supports NAMI's landmark study -- *Families on the Brink: The Impact of Ignoring Children with Serious Mental Illness*, published in 1999 by NAMI, in which 20% of families surveyed reported having to give up custody of children to the state to secure treatment for their mental illnesses.

NAMI is deeply concerned with both the findings in the GAO report **and** with the failure of states to track and report on the number of families that are forced to relinquish custody of their child because there simply is no other way for them to secure services. The report revealed that no formal or comprehensive federal or state system exists to track the number of families asked to relinquish custody of their child to secure mental health services. In fact, the GAO report admits that figures available from 2001 understate the problem. Of those states from which the GAO could not obtain estimates, five have the greatest populations of children in the nation.

Based on estimates provided in the report from 19 states and 30 counties, the GAO found that more than 12,700 children were placed in the child welfare or juvenile justice systems in 2001 for mental health treatment. That figure is likely a gross underestimate of the problem because most states failed to provide data -- including those

states with the largest population of children. Therefore, it seems quite safe to say that thousands of additional families have been impacted by this unthinkable practice.

According to the GAO report, families were forced to turn their children over to child welfare and juvenile justice systems even though none of the children had been abused or neglected – nor had they committed a delinquent act. It happened because necessary home and community based mental health services for children with mental illnesses are not available in most communities across the country.

Families from all financial levels may be forced to make the heart-wrenching decision to give up parental rights of their child in exchange for help, but the federal government picks up most of the tab for residential care for children from low-income families. In many cases, the cost runs as high as \$250,000 per year for a single child.

The report highlights something that NAMI families know all too well – the systems designed to serve families with children with mental illnesses are not family-friendly. This often overwhelms families who require immediate and intensive assistance. As the GAO report indicates, living with a child with a serious mental illness without appropriate treatment or services—without any support—strains a family’s ability to function.

The GAO report also highlighted other issues that are quite familiar to NAMI families including the fact that school personnel often do not understand basic facts about childhood mental illnesses and are unprepared to effectively teach children with them. Also, school officials continue to blame parents for a child’s mental illness. There are also numerous barriers to treatment and services, including discriminatory caps on mental health insurance coverage, strict Medicaid eligibility requirements, and a profound shortage of mental health specialists for children.

The tragic reality is that as a nation we abandon and neglect families with children with mental illnesses – driving them into the wrong systems. Those systems that do exist to serve children and adolescents with mental illnesses struggle with inadequate funding or budget cuts. They are fragmented and overly bureaucratic. Families in crisis are left on their own to navigate multiple, complex systems that do not work well.

Parent Testimony Presented at the Senate Hearing Gets to the Heart of the Crisis

The stories of the families testifying at the Senate hearing represent the stories of thousands of families from across the country. These stories are quite familiar to NAMI. They include parents being blamed for their child’s mental illnesses. Parents being told by multiple state or local mental health authorities and other agencies that they do not have the resources to address the child’s treatment needs, and referrals being provided to multiple state and local agencies, including the child welfare agency. The child welfare agency in turn frequently telling families that they cannot provide services unless the child is in state custody. Parents are also told to call the police because the juvenile

justice system is the only place for a child to secure treatment for a mental illness. The manner in which families – attempting to access services for their children – are being treated is truly unfortunate.

Families are also left without insurance coverage because their private insurance plan includes discriminatory and restrictive caps on mental health coverage – which families with a child with a severe mental illness quickly exhaust. Families in need of mental health treatment and services often do not qualify under the strict income and asset limits in the Medicaid programs. The testimony before the committee makes clear that families with children with mental illnesses – from across our nation -- are abandoned in their hour of greatest need.

In addition, the tragedy of custody relinquishment is well documented in numerous media accounts of families being torn apart to secure mental health services. These stories are powerful and share many of the same elements as families struggle to secure services for their child. In fact, Senator Collins decided to hold the custody relinquishment hearings after reading the Portland Press Herald/Maine Sunday Telegram series titled *Castaway Children: Maine's Most Vulnerable Kids*.

The Reality of Childhood Mental Illnesses for Families Across the Country

*The prevalence rates of youth with mental illnesses are staggering.
Approximately 7-9% of all children have a diagnosable serious mental disorder,
which translates into millions of youth and one or two of the children in every
classroom.*

--NEW FREEDOM COMMISSION'S INTERIM REPORT, OCTOBER 2002

NAMI is deeply concerned with the information reported to the President in the New Freedom Commission's Interim Report in October, 2002. It is consistent with the research and information in the Surgeon General's 2001 report on children's mental health and the seminal report released in 1999. According to the Surgeon General's report, 1 in 10 children and adolescents in the United States suffers from a mental illness severe enough to cause impairment while fewer than 1 in 5 of these children receives needed treatment. Moreover, the World Health Organization Global Burden of Disease Study indicates that by the year 2020, childhood neuropsychiatric disorders will rise proportionally by over 50% to become one of the five most common causes of morbidity, mortality, and disability among children. (WHO, 2001)

One thing is patently clear -- too many children with mental illnesses are not receiving any services. The circumstances are even worse for African-American, Latino and other youth from ethnically and culturally diverse communities. Tragically, they often bear a significantly greater burden from unmet mental health needs and thus suffer a greater loss in overall health and productivity. (Surgeon General 2001 Report on Mental Health: Culture, Race, and Ethnicity)

What are the consequences for the roughly 80% of youth with mental illnesses who fail to receive services? The long-term consequences are staggering in both human and fiscal terms. Suicide is the third leading cause of death in adolescents aged 15 to 24. (Centers for Disease Control, 1999) Over 30,000 lives are lost each year to suicide. (Commission's Interim Report, October 2002) The evidence is strong that as many as 90% of children and adolescents who commit suicide have a mental disorder (Institute of Medicine Report, 2002 and Surgeon General, 1999).

Youth with untreated mental illnesses also tragically end up in the criminal justice system. According to a recent study – the largest ever undertaken – an alarming 65% of boys and 75% of girls in juvenile detention have at least one psychiatric diagnosis. (Teplin, Archives of General Psychiatry, Vol. 59, December 2002). The prevalence rates of children and adolescents with mental illnesses in the juvenile justice system is a moral outrage and speaks to our nation's failure to build an effective mental health treatment system.

What is the impact of untreated and poorly treated mental illnesses in children on families? Simply put – devastating. Stigma and shame drive many families away from the treatment system. Suicide severely impacts the families left behind – who often wrongly live with extreme shame and guilt over not having prevented the death of their loved one.

NAMI is frequently contacted by families from across the country who have struggled to get treatment for their child, and in the process attempted to navigate a fragmented, broken and under-funded system. Often these families have long since exhausted their private insurance benefits for mental health coverage (90% of private health insurance plans place restrictive and discriminatory caps on mental health benefits) and paying for intensive services is simply not financially feasible. Most of these families do not qualify for Medicaid benefits. State agencies and others tell many families that the only way to access critically needed treatment is by relinquishing custody of their child to the state. This causes unthinkable stress for families, hit at their most vulnerable moment.

Some families also report being told that to access treatment or services for their child, they should either call the police and have their child arrested or leave the child at a hospital or treatment center. An arrest means that the child *may* receive services through the juvenile justice system and parental abandonment means that the child will be referred to the child welfare system for possible treatment. Families are suffering a great and unnecessary burden because of the lack of effective treatment for children with serious mental illnesses. We would not think to treat families with a child with another serious illness – like brain cancer – like this – it is fundamentally unjust to treat families with children with serious mental illnesses like this.

Federal Action Critically Necessary to Help Address the Crisis

Our nation's failure to prioritize mental health is a national tragedy.

--NEW FREEDOM COMMISSION'S INTERIM REPORT, OCTOBER 2002

NAMI applauds Senator Collins for proposing the introduction of federal legislation to address the custody relinquishment crisis in our nation. NAMI also applauds the Congressional leadership of Representatives Patrick Kennedy (D-RI) and Pete Stark (D-CA) in working to address the crisis in the children's mental health system. NAMI is also grateful to Senator Collins for her co-sponsorship of 3 critical pieces of legislation that, if enacted, will help to address custody relinquishment -- the Paul Wellstone Equitable Treatment Act (S. 486), the Family Opportunity Act (S. 622) and the Child Healthcare Crisis Relief Act (S. 1223).

Federal legislation and action is critically necessary to ensure that services are delivered to children with mental illnesses and their families and that families are no longer torn apart to secure services.

States clearly lack the resources and scope of understanding to do it alone. When the states cannot solve such problems, the federal government has a responsibility to act -- as a partner in our federal system.

Families suffer greatly from the lack of treatment options. The system for delivering mental health services to children and their families is complex; the patchwork of providers, interventions and funding streams contributes to the lack of treatment. There is a desperate need for appropriately trained child psychiatrists, psychologists and social workers.

In addition to support for the federal legislation addressing custody relinquishment -- that Senator Collins may introduce -- and in response to the GAO report -- NAMI asks for Congressional support of the following legislation pending in Congress that can make a difference in reversing the moral, economic and political scandal of child custody relinquishment--

- The Paul Wellstone Mental Health Equitable Treatment Act of 2003 (S. 486 and H.R. 953) -- parity legislation to end insurance discrimination in health insurance against children and adults with mental illnesses;
- The Family Opportunity Act of 2003 (S. 622) -- which allows states to expand Medicaid coverage to low and middle-income families, which are the ones most often forced to give up custody of children to states in exchange for treatment;
- The Child Healthcare Crisis Relief Act (S. 1223 and H.R. 1359) -- to address the national shortage of children's mental health specialists.

Federal action is also needed to encourage states to adopt Medicaid options that would help to eliminate the practice of states forcing families to give their child up to secure treatment for mental illnesses. The unfortunate reality is that only three states have adopted the first such option -- the Medicaid Home and Community-Based Waiver

option for children with mental illnesses. This option is only available to families in Kansas, Vermont and New York. It provides Medicaid funding for home and community based mental health services for children who require intensive and costly institutional care. The second Medicaid option is the TEFRA or Katie Beckett option – which is currently used by approximately 20 states, however in only 10 states for services for children with mental illnesses.

Both of these options are critically important for families with children with intensive service needs because families are not required to meet the income requirements for either of these Medicaid options. States need information and resources that will make it easier for them to adopt these options to help address this crisis.

Conclusion

The unthinkable practice of custody relinquishment is a national scandal. Federal legislation and action are critically necessary to help build a system that can provide appropriate treatment for children with mental illnesses. No child should be left behind. No parent should ever be forced to abandon their children to get the help they desperately need. Children and teenagers represent our nation's hope for the future. Those with mental illnesses deserve to receive treatment and services in their homes and communities and close to those who love them the most.

AMERICAN ACADEMY OF
CHILD & ADOLESCENT
PSYCHIATRY

American Academy of Child and Adolescent Psychiatry
Statement for the
Senate Governmental Affairs Committee Hearing on
Child Custody Relinquishment
July 15 and 17, 2003

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Introduction

The American Academy of Child and Adolescent Psychiatry (AACAP) is a medical membership association established by child and adolescent psychiatrists in 1954. Now over 6,700 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 Sen. Collins for holding this hearing and for her work in increasing access to treatment for children and adolescents with mental illnesses. We look forward to working with Sen. Collins to enable passage of legislation she is drafting with Reps. Kennedy (D-RI) and Stark (D-CA) to increase coordination across state service systems to prevent child custody relinquishment.

The Surgeon General's 2000 report on children's mental health estimated that about 13 million American children and adolescents have a diagnosable mental or emotional illness. Of this number, only about 20% 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. Over the last several decades, the suicide rate in young people has increased dramatically, according to the Surgeon General's *Call to Action to Prevent Suicide*. From 1980-1996, the rate of suicide among persons aged 15-19 years increased by 14% and among persons aged 10-14 years by 100%. For African-American males aged 15-19, the rate increased by a shocking 105%.

Early Intervention

The barriers to early identification and treatment are the critical areas of focus for children and adolescents with mental illnesses. Several 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 lifetime 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, possible custody relinquishment, and on into adulthood. The increased availability and affordability of treatment will enable earlier identification and interventions for children and adolescents suffering from mental illnesses.

Custody Relinquishment

There are a number of factors that contribute to the national tragedy of parents being forced to relinquish custody of their children to state child welfare or juvenile justice agencies in order to access mental health treatment. These include:

- The lack of parity in insurance coverage for mental illness
- The absence of coordinated systems of care across state health, social service, education and child welfare service systems
- The inability of some low-income families to qualify for Medicaid
- The shortage of child and adolescent psychiatrists and other children's mental health professionals

Parity in Insurance Coverage

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 the 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 two independent actuarial firms (Milliman & Robertson and Coopers & Lybrand) estimated that managed nondiscriminatory mental health benefits will increase average premiums by only 1.8% - 2.1% adding somewhere between \$2.32 and \$2.71 per child/per year to 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.

Health insurance 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. There should be no limit on inpatient or residential days or outpatient visits. Children and adolescents seldom need hospitalization, but when they do, it is extremely serious and should not be limited to the danger to self or others standard that is set for adults.

Today, approximately 85% 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. Discriminatory insurance coverage prevents many children and adolescents in middle-income families from accessing needed mental health treatment. The recent General Accounting Office (GAO) report on custody relinquishment showed that middle-income families whose health insurance does not cover mental health treatment are forced to consider custody relinquishment because their income level and assets make them ineligible for Medicaid coverage, leaving them with no way to pay for the intensive and expensive treatment that their children require. The AACAP

recommends enactment of the Paul Wellstone Mental Health Parity Act, S. 486 and H.R. 953, as one legislative step to prevent families from being forced to relinquish custody of their children to state child welfare and juvenile justice agencies.

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.

In addition to discriminatory coverage, children and adolescents with mental illness and their families are often faced 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

The absence of coordinated community-based systems of care for children and adolescents with mental illnesses is another key factor that forces parents to consider custody relinquishment. Currently, most state mental health, education, juvenile justice, social service and child welfare agencies do not provide coordinated treatment for children and adolescents 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.

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 community-based systems of care:

- reduce the number of costly hospital and out-of-home residential treatment placements;
- improve how children behave and function emotionally;
- improve school performance;
- reduce violations of the law; and provide services to more children and families who need them.

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 one 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 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%, with general psychiatry's increase at 19%. 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 nondiscriminatory 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. Parents should never be forced to consider giving up custody of their children to state child welfare and juvenile justice systems in order to access mental health treatment. The AACAP is confident that with further clarification from federal agencies, coordination of state service systems, and passage of mental health parity and Medicaid expansion legislation, this national problem that is devastating American families can be eradicated.

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 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).
- Federal, state and local interagency coordination to ensure that comprehensive treatment is provided to children with mental illnesses.
- 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 its support for access to treatment for children and adolescents with mental illness.

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JOSEPH F. EWA, M.D., P.C.
CHILD, ADOLESCENT, AND ADULT COUNSELING SERVICES

July 16, 2003

To: Senator Susan Collins

A presentation to Senator Susan Collins Chair Committee hearing the mental health needs of children and adolescents, and the need to ensure all efforts be made to preserve the supervisory role of parents so that their rights are not lost in order that their children receive mental health services.

I have just been made aware of this hearing Senator and I commend your efforts at trying to ensure children be able to get mental health services while their parents have rights to continue making decisions regarding their children's care and provide adequate supervision to the children at home, preferably.

I am a child, adolescent psychiatrist, trained in Columbia University at Harlem Hospital New York, New York. I worked as a Clinical instructor in Columbia University at Harlem Hospital, New York, New York for nine years while also providing services in Fort Greene and Bedford Stuyvesant Communities of Brooklyn, New York where I spend all my practicing hours presently at Child, Adolescent and Adult Counseling Services. We work as an interdisciplinary team of child psychiatrists, licensed psychologists and certified social workers to provide access to mental health services in this neighborhood which has very few resources/access to mental health clinicians. Over the last several years it is my professional experience that extremely limited access to mental health services has made it rather difficult for children and adolescents whose relatively minor to moderate symptoms went untreated and they developed into severe emotional and sometimes extremely disruptive behaviors. For example, an eight year old child who feels depressed, went untreated, exhibited very defiant and oppositional behavior to authority figures at home and school became belligerent and sometimes run away from home, then later became uncontrollable to his/her parents. Such a child a lot of the time ended up in court with the parents seeking a PINS (Persons in need of supervision) petition. This is often because access to mental health services are extremely limited, and it takes two or more months for such an eight year old child to receive any form of mental health services in this neighborhood and across the country, as other clinicians have shared with me during conferences.

Due to scarcity of preventive children's mental health and curative services, such a child ends up in court where attempts to get mental health services fail more often than not, the child's parents are then encouraged to give up their parental rights in order that the child be sent to a group home, or residential treatment center where funding by Medicaid becomes mandatory, due to the fact that many private insurances/HMO's have very limited or no coverage for mental health services for children and adolescents.

For our society to have healthy adults, we need to provide more mental health services for children and adolescents, and greater emphasis needs to be placed on the children residing with their parents while we de-emphasize parents losing their rights in order that their children get much needed mental health services away from home. Even when they need to be away from home, efforts should be made to preserve the rights of parents except when they are not in the child's best interest.

Here in Child, Adolescent Counseling Services because many parents, the schools, the family courts, foster care agency's and hospitals are aware of our services in the community for the last ten years children have been able to make early contacts with our clinicians (child psychiatrists, licensed psychologist and certified social workers) within one to three weeks which has been very beneficial to the community, as quick access to mental health services for children and adolescents has been our goal, but we too are overwhelmed and for all we do, it remains humbling and only a drop in the bucket in terms of the need for mental health services.

Therefore Senator Collins, children and adolescents will be helped more to become happier adults if they reside with their parents while receiving mental health services. Timely access to mental health services including prevention and treatment is the key to assuring the above goal.

Parity in mental health coverage will also reduce the rate at which mandated treatment through the courts will be sought for children, so parents may not have to lose their rights in order that their children receive much needed and good mental health treatment.

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