



Patterns of Wholeness



Children's Mental Health:
Generating Hope Through Shared Responsibility

Rosalynn Carter
Georgia Mental Health Forum
The Carter Center
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Robert, do you have a message
for those who minister to people
with your sort of experience?

Always listen to your kid.
Because some kids think nobody listens to them.
Sometimes people do, but they don't read between the lines.
Some things I used to say, you had to read between the lines to understand,
and a lot of people really didn't understand me,
and I always wondered why that was.

I am Robert Martin and I am 18. I am graduating from North Clayton High School this year. A lot of people told me I wouldn't—I would never go to a public school because I've always been in alternative schools or in institutions. ❖ I have been in and out of institutions since I was 7. By the time I was 10 years old, I had been in Georgia mental health institutions 14 times. They told my mother that she should just leave me alone, whatever happens happens. I'm proud of my mother. She stuck by me. She fought for me. Whatever I've been through, she's been by my side. ❖ At 14, I was in an institution called Devereux. I went through a 10-level program in six months and was discharged. I still had problems. Hillside was my last institution. ❖ I've been out for three years. I go to therapy. Everybody says I am doing great. I do not take medication. I took myself off medication because it was not helping. Since I have been off medication, I have done better. ❖ I still thank my mother to this day.



Dannie, what is one thing that
has helped turn you around?

The light bulb finally turned on when I realized what it was that was wrong with me.
All those years, I thought, "Well, I'm crazy,"
until for once someone sat down and explained to me exactly what was wrong with me.
That is when I really started to change my life.
When I could see why my brain reacted the way it did,
then I could take steps to change that.
Different places, different hospitals, helped me in different ways.
And they all helped me in one way or another.
It was a combination of that and the love and support of my family and friends.
But basically, the turning point was knowing what was wrong with me.
Because a lot of kids don't. They're just told, "You're sick."
OK, I'm sick. What's wrong with me?
If I had cancer, they would say, "You've got cancer, and this is what's happening
and what you have to do; these are your options."
But with mental illness, it didn't work that way.

My name is Danielle Smith; everybody calls me Dannie. I have been diagnosed with a mental illness since I was about 6 or 7 years old. Through that time from then to now, there have been a lot of hardships and a lot of joy. ❖ One of my first doctors told my parents that they should beat the crud out of me, which we all know is not the way you do things. One of my doctors told my parents they should have left me alone and let me die. I'm glad that they didn't. ❖ I'm 22 years old. I own my own house. I have a good job. I drive a car. I graduated from high school and am close to graduating from college. Somewhere down the line, about two years before I graduated from high school, they told my parents, "She won't graduate, she won't go to college, she won't drive a car, she won't live on her own, she won't live outside of institutions, and she'll never hold a job." I defeated the odds and I did all those things—and that is probably the thing that most made me realize that I am finally normal. Throughout my whole life, all I ever really wanted was to be normal like everybody else. And I am.

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Robert, what has been your most frustrating time?
Could you have done anything to change that?

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When I was put in Georgia Regional Hospital my first time,
that was my longest stay. It was very frustrating.
[Friends and workers] tried to make it easy for me. My mom tried.

But six months was too long.

I forgot what the house I lived in looked like.
I didn't know anything from the outside.

I would change all of that, I would.

If I had known I would have been staying that long,
I would have changed it completely.

Dannie and Robert help us understand what young people face as they struggle with a challenge: Are we doing the best we can for the most vulnerable young people who need help in that process. Its contents are adapted from the annual Georgia Mental Health Forum, a scientific basis and background we need to help us shape our decisions and concerns of those who have experienced mental illness as patients and family members. Their needs are tremendous. We have had some success in working together. Through hard work, we have told many, many people—elected officials, the business and religious communities. Now our immediate focus is on keeping children and families at the center of our efforts. We've gotten all we wanted. So we will keep on moving ... generating hope, sharing



Dannie, what was most frustrating for you?
What would have improved your treatment?

The most important thing in services is for the professional—the doctor or staff person—to listen to us. Who knows better what I need than me?

Nobody. Nobody knows better what I need than I do.

A lot of times, because a child is under 18, they don't listen.

But the turning point, one of my turning points, was having people listen.

You've got to listen to what we think and what we want.

That takes a caring staff, a staff that isn't in it for the money, and there are places where some staff is.

A lot of staff is there because they want to help kids.

I would say 95 percent care. But some don't.

Caring staff, people who listen to what we want, what we think, and programs that are centered around our individual needs.

That can make a very big difference.

gle with mental illness. It's important to hear from them. They confront us
people among us? Most of us want to do more. This booklet is an attempt to
Health Forum, held at The Carter Center. It ranges from a discussion of the
collaborate with others who share our concerns, to the feelings and deep con-
members. Our common goal is to help our children, the children of Georgia.
We are headed in the right direction, we have made progress, we have worked
religious community, media and professional people—about mental health issues.
our efforts. In the past, we may have moved a few mountains. But we have not
responsibilities. — **Rosalynn Carter**, *Host, the Georgia Mental Health Forum*



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Passion for Action

DR. PETER JENSEN, *associate director of Child and Adolescent Research at the National Institute of Mental Health and the Chief of the Developmental PsychoPathology Research Branch at NIMH, is the author of more than 100 scientific articles and book chapters; he has edited two books on children's mental health research. For his writing, research, and teaching, he has received national awards that include the Norbett Ritcher Award from the American Academy of Child and Adolescence Psychiatry as well as awards from the American Psychological Association. He was formerly with Walter Reed Army Institute of Research. He also serves on a number of editorial and scientific advisory boards.*

One of the most touching moments in my life came shortly after I had begun work at the National Institute of Mental Health, when a young person—a courageous teenager—told me her story. Since then, I have felt a passion, not only to help others tell their stories, but also to spread the “gospel” of the new sciences that are helping us understand the disorders of brain and behavior.

We all have a role to play, to reach out to others, to teach others, to make a difference for the one.

I have a bumper sticker I treasure; it says, “Honk if you’re on lithium.” You’d be amazed how many honks I get: police cars, pickups, young teenage girls. One funny experience happened at a stoplight. The car behind me honked. I looked in my rearview mirror and the fellow behind was pointing at my car. I thought I must have a flat tire. I rolled down my window and saw nothing, rolled down the right window and saw nothing. I thought it must be a rear tire. So I got out of my car and walked back as the driver behind holds up his vial of lithium.

I said, “Yes.”

It is important to do everything we can to reduce stigma and spread the message of this new understanding

of the brain with the public and with policy makers.

The brain is a precious organ, the most complex organ of the body. Like any other organ, it can become ill. And like so much of the body’s mechanisms, the brain is mysterious. So it is no surprise that many newspapers and news magazines in the past few years have carried lead articles on our new discoveries of the brain.

We now see—literally—brain functions once thought impenetrable; we actually can identify parts of the brain that are responsible for specific functions. In the structural changes that take place with each new memory, we can see clear evidence of brain activity.

Not only can we pinpoint some brain functions, but also we can examine the brain’s chemical receptors to learn what is happening when the brain remembers, for example, or when the brain sends the hand a message to pick up a pen. Basically, the brain communicates by chemical messages. One neuron—separated from other neurons by a tiny space called a “synapse”—spurts out little chemicals—neurotransmitters—to a receiving neuron.

We have more than 30 different kinds of these neuron receptors. Re-

search further indicates specific receptors very likely are associated with specific mental illnesses, such as schizophrenia, attention deficit disorder, or obsessive compulsive disorder.

Once we locate receptors and pinpoint the disorders with which they are associated, we believe we will be able to design more appropriate—more effective and more efficient—techniques to treat those receptors that seem to be out of balance, over-active, under-active, or perhaps even missing.

Scientists are using neuro-imaging techniques to study the extent to which, when we treat a disorder or an illness, we can see changes in brain functioning. Such research is exciting, because it shows improvements in brain functioning with specifically targeted medications corresponding to those achieved through psychotherapy.

Investigator Bill Greenough has been studying the impact of early environments on mammals—specifically, on rats, with whom we humans share about 85 percent of our genes. (By the way, we share about 95 to 98 percent of the genes of primates.)

In a complex and stimulating environment—a kind of Disney World for rats of colors and shapes and things to do—rats are enriched, experiencing

mental and physical growth much like what occurs in their natural habitat.

However, when rats are isolated and their environment deprived, when they are locked in glass cages and given no stimuli, they become entirely different animals.

Is this difference stored in the brain? And can we “read” that behav-



ioral conditioning in the neurons? Dr. Greenough asked.

He discovered that, in fact, the stimulating environment did increase the cell sizes of the neurons, the capillary growth, and the complexity and number of connections among the neurons.

The implications on human maturation are clear: early enrichment’s demands on areas of the brain result in the body pumping more sugar and more oxygen to the growing, developing neurons, which in turn become stronger and bigger, very much like the muscles of a weight-lifter.

It is not news that a child who is stimulated, a child who is enriched by emotional and physical nurture, will grow into a being more healthy, mentally and physically, than one who is deprived of nurture and stimulation. That is not what makes Greenough’s study amazing.

What Greenough’s research

shows is that our neurons can sprout new connections and that this neuron growth continues—at least in rats—pretty much throughout life. In contrast, the ability to sprout new capillaries declines over time.

The importance of learning experiences at early ages cannot, these studies of the brain tell us, be overestimated. They are critical to human development. They lay down tracks in the brain that may be tapped later in life.

So what does this mean when we start to think about mental illness and mental health in children?

One implication is that all of the mental disorders that afflict adults—schizophrenia, bi-polar disorder, even Alzheimer’s—can afflict young children. In each of these disorder areas, we are now discovering what “treatment” works and what doesn’t work.

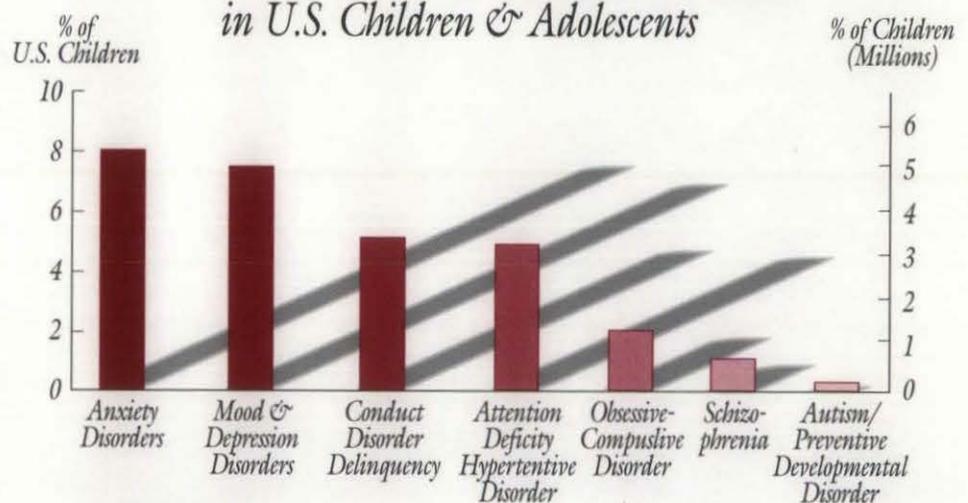
Among the most common childhood problems is anxiety disorder. One way it manifests itself is in “separation anxiety”—something more acute than a few tears on the first day of school. We now are learning that separation anxiety disorders are a harbinger, at least in some children, for later development of panic disorder.

Research reveals that children with separation anxiety disorder have

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Science is great, but can we improve children's lives with it?
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That's one of our big worries. As a result, we are forming an umbrella organization that is working to incorporate scientific findings into the training of medical students, mental health providers and psychiatrists. By teaching people about these new sciences, we hope to get our treatments out into the “real world.” We'll move from “efficacy studies” to “effectiveness studies” that can be replicated by real practitioners. That is going to be the issue: How do we get these treatments to work for clinicians and not be so difficult, so cumbersome, or so unaffordable they can't really be used?

Mental Illness and Behavior Disorders in U.S. Children & Adolescents



SOURCE: MECA AND RELATED SOURCES

family members with the same propensity. They, in effect, “inherit” the disorder—yet not all children with separation-anxiety-disorder parents follow in their parents’ mental/emotional footsteps. It is important to understand what aspects of the environment activate the genes and bring out this condition in some, but not in others, since we know genes alone do not automatically condemn one to this disorder. It is always some combination of genes and some aspect(s) of the environment (whether prenatal toxins, viral infection, stress, or trauma) that we must understand and appreciate.

In studying obsessive-compulsive disorder (OCD), we also are finding links between brain and behavior, and mental health and mental illness. A number of years back, Dr. Judy Rapaport, one of my colleagues at the National Institute of Mental Health, published *The Boy Who Couldn't Stop Washing*. A best seller, it sensitively described case reports of youngsters with obsessive-compulsive disorder.

Among the letters Dr. Rapaport received in response were about 50 from owners of Irish Setter dogs. They asked if their Setters’ propensity to lick their paws raw could be similar to these children’s obsessive-compulsive disorder. Other letters came from people, usually women, who were afraid to leave their homes and who couldn’t keep their hands out of their hair. They twirled it and twirled it until they pulled it out, a disorder in psychiatry called *tricotelomania*. The women asked, “Could this be similar to OCD?”

In her studies, Dr. Rapaport had found that the drug *clonipromine* seemed to be an effective treatment for OCD. She then tested it on dogs with the paw-licking disorder and with people who suffered obsessive hair-pulling, and found this agent was an effective remedy for both those conditions.

In a related OCD study, Dr. Susan Sweedo, another researcher at NIMH, has found a subset of persons who, after a strep infection, develop antibodies that—for reasons un-

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What happens to the developing brain when it is afflicted by disorders of feeling or behaving or thinking?

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The changes in brain neurons are as apparent visually as their outcomes are statistically. When someone says, “It’s all in your head,” the honest reply is, “That’s right, it is all in my head, it’s in my brain.” Who we are and what we do is all stored there. Everything—from early experiences to the action of genes and the actions of toxins, as well as good nutrition—affects the brain.

known—enter the brain. There these antibodies perceive brain tissue to be streptococcal bacteria and attack specific areas of the brain thought to be related to OCD. The tissues swell as an immune response occurs. Treatments that reduce the infection or reduce the body’s immune response produce a dramatic cure rate in children with a particular form of OCD.

We now have three agents approved by the Food and Drug Administration (FDA) for the use against OCD in children and adolescents.

Meanwhile, other studies underway are comparing the cognitive behavioral therapies—which can be effective for some anxiety disorders—and these special medications in OCD.

The unresolved issue is: which child needs which combination? How do you put the treatments together? Is it always the best strategy to put them together, or do some children respond best to one, some to the other? What if there are side effects? What if the child or adolescent or the family isn’t comfortable with medication?

We need the whole array of therapies to provide the most effective treatments that are also palatable and acceptable to the community.

To examine these and related questions, we have established seven new research units in pediatric psychopharmacology. While hundreds of psychopharmacologic studies have been done with adults, only three to four have taken place with children. Despite the increased attention to research, parents and clinicians remain in a real dilemma while waiting for research results. The question is: What do we do in the meantime, if we do not know if a medication is safe or effective?

Fortunately, President Clinton and the Federal Drug Administration have developed a new “pediatric labeling initiative” to encourage industry to be testing these agents in children and adolescents, so that parents can make sensible decisions about which treatments work best under which conditions. To date, we have been doing too much treating based on

"clinical wisdom" without solid evidence. That should be a great concern to all of us, but one which should improve with time.

Another area of mental illness that afflicts children is depression. Twenty-five years ago, we did not think depression could occur in children and adolescents. Now we know depression is not "just a stage" through which a young person is passing; it is a severe condition that must be taken seriously. One-third to 40 percent of children with depression go on to develop bipolar disorder. Because these children have fallen off a developmental train and are therefore at risk for other conditions, depression can be life threatening. We need to mainstream that idea so people appreciate the severity and complexity of the problem and the importance of early identification and effective treatment.

Five or six recent studies show that cognitive behavior therapies, as well as a new treatment called interpersonal therapy, are effective in treating depression. What are not necessarily effective are the traditional therapies available at a clinic or in a private practice setting. It is important, therefore, to train clinicians in these recently tested and proven therapies. Bringing them into the "real world" of mental health care is critical.

Other data suggests that some of the newer agents, such as Selective Serotonin Reuptake Inhibitors (SSRIs), also can be effective for treatment of depression. Many older antidepressants are no better than placebo.

The next step is to learn when and how to put these treatments, chemical and/or psychological, together, and who needs both treatments or a single treatment alone.

In the area of bi-polar disorder, where we are just beginning to understand the auto-immune, infectious, toxic, and other potential causes affecting the brain, we have evidence suggesting that lithium is effective for treatment of adolescents. But given the fact that it has probably been prescribed more

than a hundred thousand times in this country, it is amazing that there is only one study whose data shows that lithium works.

Part of the problem is that the pharmaceutical industry has been loath to conduct extensive patient-testing research, given its liability concerns. NIMH and the federal government have assumed the greater part of the responsibility here, reversing the percentages in the field of biomedical research—the development of products—where 60 to 70 percent is done by the pharmaceutical industry, with only 30 percent done by the federal government.

Researchers, armed with these recent understandings of the chemical reactions within the brain, are also exploring new treatments for some of the more common mental disorders. ADHD is probably the most common mental illness among children today. The disorder has been around a long time and we know an enormous amount about it. Three to five percent of all children have been clearly documented victims. Many experience difficulties and conditions that have adverse, long-term consequences.

Much of the public simply equates treatment of ADHD with prescriptions of stimulants. Indeed, we have to be concerned when medications are used without appropriate assessment and diagnosis. On the other hand, we must be aware that powerful people are willing to distort information for personal purposes, to unduly and unnecessarily frighten parents, children, and mental health professionals, away from effective treatments.

The real need is for data—solid information that the public can evaluate.

Fortunately, while we have good data indicating that many pharmaceutical treatments work, not only the psycho-stimulants, but also general types of anti-depressants. The cogent question, as in other cases, relates to our knowledge of when to prescribe what: how do we discover what to

offer in treatment—alone or in combination with psycho-therapy—and who needs which and what will work best over the long term.

One study recently compared medication alone with a combination of medication and psycho-social treatment. After 12 months, the study found the medication was powerful in improving the children's functioning in almost every area. The addition of intensive psychotherapy didn't yield a great deal more improvement. Therapy contributes to parental satisfaction and several other matters, including improved functioning. Yet the medication alone was powerful and effective up to 12 months..

Even though the study was done with only a small sample, when I look at that data, I still have to ask myself: is it ethical to withhold this medicine from a child who has ADHD? I think the answer is if the decision to withhold is made by a professional without fully involving the parents and child, it is unethical behavior and should be treated as such. On the other hand, a parent's choice concerning when to use a medication is a separate issue. But mental health professionals should be bound by data. And where the data are solid, we have to practice what according to the data seems the best treatment, ignoring personal preference, whim, or strong biases that go one direction or the other.

Because ADHD has been controversial and some groups are concerned that medications, including the psychotropic agents, "poison the brain," NIH is hosting a consensus development conference in late 1998. We are bringing many of the world's best scientists together to review the data objectively, impartially, and scientifically. Some of the questions for which they will be seeking answers include: what works, how well does it work, how to diagnose the condition, what are its long-term consequences, what are the costs of the disorder, what are the safety and efficacy of treatments, what are adverse consequences if the disorder remains untreated? If the conference succeeds,

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Do we know the toll of our failures to get across the message of early mental and physical nourishment of children?

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I'll give you a simple answer: Research shows perhaps 18 to 20 percent of children in the United States are victims of mental illness. What this means is that they did not get, or are not getting at this very moment, the right balance of enriching and nurturing experiences, good nutrition, and proper health care. The result: their brains evidence stunted neuron development and their actions reveal one or another form of mental illness.

the public will have a consensus statement by an impartial jury, so that practitioners can begin to change outdated clinical practices.

Several other disorder areas deserve attention as well. One is opposition defiant disorder or conduct disorder, where children have behavioral problems that often begin with parental and school difficulties and end in conflicts with law enforcement. In juvenile justice settings, about 50 percent or more of the children have a mental disorder that has gone untreated, usually for many years. Depression is frequent, as is early onset ADHD and anxiety disorders. Our system is seldom treating these children, and when they have had treatment, the results to date have not been good.

Some creative people, however, have questioned the way we deliver treatment in mental health settings for problems that require community-level interventions. In the neighborhoods and homes, these experts suggest, we could (and should) offer the supports appropriate to these children.

Investigator Scott Hangler at the University of South Carolina, Charleston, took kids in the juvenile justice system and randomly assigned some to traditional mental health treatment, other to his "multi-systemic therapy." Those having multi-systemic therapy didn't go to the mental health clinic, instead they got a caseworker. Each caseworker had four families and no office. The caseworker had a car and a beeper. The caseworker's job was to be in the homes, working with the families, suggesting principles of behavioral modification in a way that was palatable and acceptable and workable—and productive.

Of those who got Hangler's special kind of wrap-around therapy—in their homes, in their neighborhoods—few of them went back into the juvenile justice system; 75 to 90 percent succeeded. However, nearly 60 percent of those who went through the traditional routine ended up back in the juvenile justice system.

The multi-systemic therapy

proved not only good for the kids, it also was quite cost effective.

Other researchers have used similar principles to develop similar preventive intervention strategies based in the schools. They find that if one provides families intensive support and gives teachers special resources, high-risk children in kindergarten succeed much more often than children who have no additional or special resources.

There are things we know; these are things we can do. The problem is we are not doing them. We are not disseminating the findings of our research as we need to: We are neither talking to our legislators nor making the changes in policies that are increasingly warranted.

The last disorder areas to be mentioned are schizophrenia and autism, very severe disorders that have profound, life-long impairments.

Schizophrenia or autism in an adolescent or adult has a much more benign outcome than when it occurs in a six-, seven-, or eight-year old. We do not have as much research on these disorders as we need—the FDA is trying to instigate more on its own, based on the failure of the pharmaceutical industry to perform research. Although studies show medications can reduce some problems in autism and schizophrenia, they certainly do not cure these disorders. Children remain severely impaired. As with other disorder areas, we need to learn when, how, and with whom to combine treatments so they are most effective.

Science is great, but can we improve children's lives with it? That's one of our big worries. As a result, starting with all the major psychiatry training organizations, we are forming an umbrella organization that incorporates scientific findings into the training of medical students, mental health providers and psychiatrists.

We hope that we can get practitioners on board and bring the best of science and this new way of thinking

about mental health and mental illness into their training. Not only do we have to teach people about these new sciences, but also we have to get our treatments out into the "real world."

We will move from "efficacy studies" to "effectiveness studies." In doing so, we look to find a way to move efficacious treatments into the real world where they can be performed by real practitioners. That is going to be the issue: How do we get these treatments so they work for clinicians and that they are not so difficult, so cumbersome, or so unaffordable that they can really be done?

This is the area the Institute of Mental Health is staking out for the next decade.

If we are successful, we may be able to make the first steps toward a truly national, comprehensive and integrated approach to health care for children. We are seeing steps for children now, but we have a lot of work to do.

To be effective requires more than just a compassionate system. For example, some of the studies have tested model systems versus patchwork care. But these studies have shown no differences in outcomes each year for two years. The well designed study has been done and tested twice, so we cannot just make the mistake of arguing for an integrated system. We have to argue for effective, efficacious treatments and knowledgeable providers within those systems, who can make sure effective treatments are built into the system. We have to get into the

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How do we get treatments so they work for clinicians and are not so difficult, cumbersome or expensive they can't be done?

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The Institute of Mental Health is staking out for the next decade a transition from "efficacy studies" to "effectiveness studies." In doing so, we look to find a way to move efficacious treatments into the real world where they can be performed by real practitioners. If we are successful, we may be able to make the first steps toward a truly national, comprehensive and integrated approach to health care for children.

"black box." These new models impart understanding of the complex interplay of brain development and environments, and the importance of working with the family and the child to provide effective treatments (whether pharmacological, behavioral, or a combination of both).

While there has been major progress and we are seeing inroads being made, we have a long way to go to get everyone's attention focused on our children. That has to be the first step before our country can bring about a truly comprehensive, integrated, and effective mental health care system.

Not everyone agrees with my assessment that the "brain is the organ of the mind." Old, misleading dichotomies die hard. We used to ask about some aspects of human behavior, "Is it biological or is it psychological?" That is passe now. If you catch yourself asking, "Is it psychiatric or neurologic?" or "Is it nature or nurture," you're asking the wrong questions. It is like asking, "What's more important for the area of a triangle, its height or width?" Both dimensions are important. Similarly, what is more important, air or water? We must have both. That is really the issue here: how normal brain development and mental health unfolds, as well as when disorders emerge.

Increasingly, we have the tools necessary for understanding. What is needed is the political will and the moral passion to make a difference. Let's do it.

Problems & Potentials

CHRIS DENDY *has more than 30 years' experience as a teacher, mental health counselor, mental health administrator, lobbyist, and executive director of a statewide mental health advocacy organization. Perhaps more importantly, she is the mother of two sons with attention deficit disorder and author of the best-selling book, Teenagers with ADD. She has produced a videotape, Father to Father: The ADD Experience. Dendy has conducted trainings in more than 30 states for parents and professionals and has consulted with state and local mental health departments on children's issues. She presently serves on the board of a national research and training center for children's mental health, the advisory board of her local community mental health service board, and the board of directors of the Georgia Family Support Network.*

We have not been put on this earth just to look out for ourselves; we have been put here to make the world a better place.

That is the lesson of my childhood that molds my adulthood.

Forty years ago, my father, W.L. Ebney, a probate judge in Walker County, told me about the "lunacy hearings," when a lawyer and a doctor would talk to a person suspected of mental illness, and together decide if that person needed treatment. And I remember, even that long ago, feeling great sympathy for these people.

But in my ignorance, I thought it was a good thing to send these people away; we all thought Milledgeville State Hospital was best for them.

Fast-forward 10 years: I was director of child and adolescent services at a mental health center. The first child I saw there was probably one of the most complex children I have ever seen. Mental retardation,

probably schizophrenia, and no intelligible speech. He was accompanied by his mother.

I was impressed with that mother's devotion and love for her child. But when the child grew into his teen years and she could no longer control him, the mother had to send him to the state hospital.

In those days, when we sent people away, we had the out-of-sight, out-of-mind philosophy. When children were committed to state hospitals, we professionals never followed up, never went to see them. Sometimes they returned home and we didn't even know they were back.

So I did something unusual. I went to the state hospital to visit this complex teenager. It was my first time there and it was an eye opener.

The crowding. The rows of rocking chairs with the rockers almost flat, because people had spent their days rocking, rocking, rocking.

Children were put on the adult

ward in those dark ages.

I was leaving feeling a little anxious. But I had developed a nice rapport with the counselor, so I asked of my former patient, "How is he really doing?" The counselor confided that he suspected this young teenager may have been sexually assaulted at night.

I was stunned and horrified, and I was so naive; it had never occurred to me that bad things could happen to children who were in our care and under our protection.

I came away with a different thought: *Maybe this thing we do is not so good. We have to find a different way to serve our children.*

Move on to another decade: Around 1980, I was working in the Florida office of mental health and got a call from the governor's office.

The governor and his wife began telling me of a teenage girl who was institutionalized in South Florida. She had been abused by her family and had

been in multiple foster-homes failures—a not uncommon story. Now at 17, she was pregnant and had demolished a home for unwed mothers. What could be done for her?

As they told me the story, a wave of cold chills swept over me. I recognized this child; I had been her counselor when she was 12 years old.

In those days we did not have crisis services. We did not go into homes, we did not have day treatment, we did not have therapeutic foster care. The basic message we gave our patients was: "I'll give you one hour of counseling a week, and if you don't get better, I'm sorry. When you get sick enough, I'll send you to the state hospital or whatever.

I scheduled a trip to visit this young woman who was spiraling downward. But before I could go, I got word she had run away.

And where did she end up, after six years of being dragged through our system: Back home with the family that abused her in the first place.

It does not take a Ph.D. to figure out there's something wrong, terribly wrong, with that picture, or to realize we have to change the way we do business.

In the early years of my career, when I didn't know what to do with a child, I believed that somewhere out there, far away, was a wonderful psychiatrist who would magically cure these children I could not cure. And sometimes there was. But more often, there was not.

And as that reality seeped into my consciousness, I began to see, quite clearly, that our kids would be better off if we treated them and worked with them in their own communities.

No matter how bad a home situation is, home is where about 99 percent of all children still want to go, desperate for their mothers' love, even when their mothers lack the skills to provide nurturing care.

That being so, I concluded we professionals must build on the les-

sons that were obvious from the experiences we had had.

We must provide, for example, the support those mothers need to become the kind of mothers their children need.

We must understand, for example, that sometimes, when we think we are doing good, we are not. In spite of our best intentions, we actually are harming children. We must question old ways of doing business. And we must continually change the way we practice our profession.

We must accept, too, that if intensive services are provided in the community, these children can succeed; they can do well. For too long we have believed the opposite: Intensive care is exclusively residential care. It is not. Intensive services can be provided in the child's home. We must learn that we can serve children with severe problems in their communities as well as, if not better than, in distant institutions.

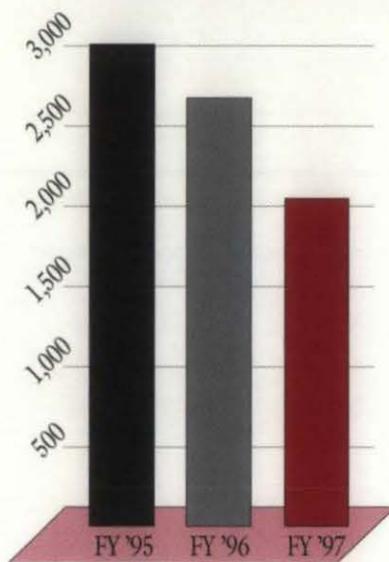
When I was director of children's services, we had a crisis. A child needed to be placed immediately in a 24-hour-care secure facility. There weren't any beds. We were forced to scramble, wrap people around him, put people in his home. People stayed with him 24 hours a day. He made it through the crisis and he did not need residential care.

Sometimes a crisis is of our own making. We get frightened and we do not know what to do, so we send the child somewhere else for someone else to fix. Often, if we would just ride out this turbulence, the child would do well.

When I was consulting in West Virginia, I met Roy. He was 17. He had had 12 placements in 11 months. He had been an arsonist. He had made a suicide attempt. The doctors and counselors and nurses in the psychiatric facility said, "We've helped him all we can, we want to send him home. We do not know what else to do."

So one of the facility's staff

Child-Adolescent Admissions to Georgia Hospitals



members and I went into this rural community, this little one-traffic-light village, and we gathered representatives of the residential program, the psychiatric program, the therapeutic foster home, all the local agencies. We sat down together and developed a treatment plan for this child.

He had multiple diagnoses: substance abuse, ADHD, bi-polar conduct disorder.

Three years later, Roy was still in the community. He wasn't well, but he was making progress. He was not in jail; he was not in a psychiatric hospital.

We had bettered that child's quality of life.

Roy is real. But his story is also a parable for our progress and our promise. In his journey is the transformation of methods of care-giving and the rebirth of hope in the treatment of mentally ill children.

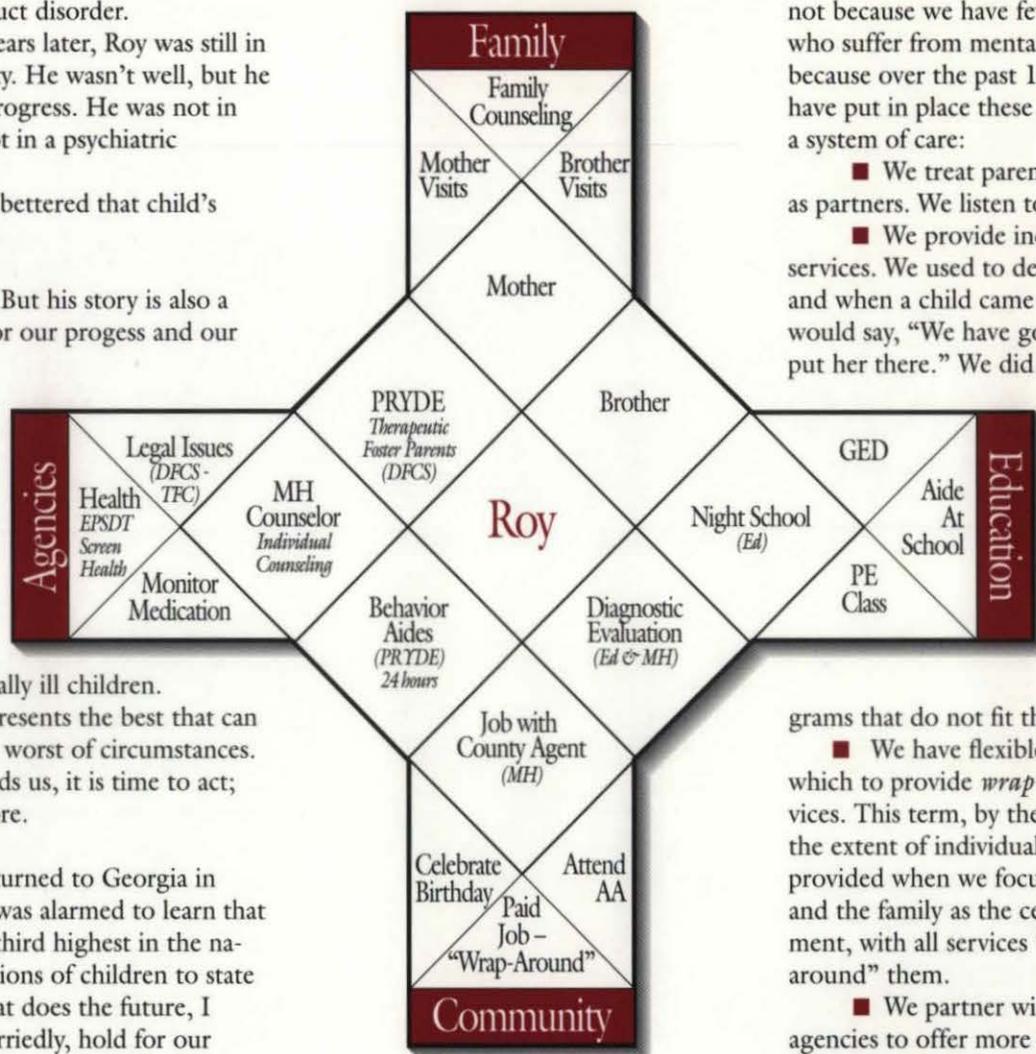
Roy represents the best that can happen in the worst of circumstances. And he reminds us, it is time to act; we can do more.

When I returned to Georgia in 1986, I was alarmed to learn that the state was third highest in the nation in admissions of children to state hospitals. What does the future, I wondered worriedly, hold for our children?

Today I have good news. Good things are happening to children in Georgia. The children's mental health system is more progressive and more responsive than ever.

With the statewide Seriously Emotionally Disturbed (SED) initiative, we are on the right track. We are consistent with the national trends for "wrap around" and individualized services, and for the development of

Roy's Quilt of Individualized Service



community-based services.

An example of this progress can be found in what we have done for children in Region 7, the Gwinnett, Rockdale, Newton Mental Health System. We have 7 or 8 percent of the state's population, about 176,000 people. In 1995, we placed 77 children in mental health institutions; in 1996, 50; in 1997, 37.

We have reduced the numbers not because we have fewer children who suffer from mental illness; but because over the past 11 years, we have put in place these key elements of a system of care:

- We treat parents and children as partners. We listen to both.
- We provide individualized services. We used to develop programs and when a child came to us, we would say, "We have got a bed, let's put her there." We did not ask, "What

does she need?" With individualized services, we no longer slip into the trap forcing children into pro-

grams that do not fit their needs.

- We have flexible funds with which to provide *wrap-around* services. This term, by the way, describes the extent of individualized services provided when we focus on the child and the family as the center of treatment, with all services "wrapped around" them.

■ We partner with other state agencies to offer more complete services. Interagency collaboration is working better than ever. The level of trust has increased and people are sharing what little money we have to spend. Our regional match committee has access to a modest amount of flexible funds. So any child coming through, regardless which agency brings him or her in, can access some of those funds.

- We provide an array of services, including going into the home.

We are there for the family when its members need us.

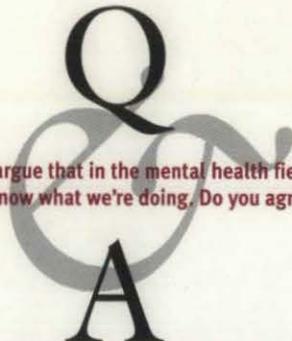
* * *

If I were to pick a symbol for our movement toward better mental health for children, I would choose a quilt, that familiar icon of love and care and warmth that literally wraps around us each night in the winter of our lives.

What better symbol of our work—especially its “wrap-around” nature—than a quilt, whose colored fabric pieces are stitched into a pattern; and that pattern pulls our eyes toward a central unity, like the arms of children reaching for the different state agencies that serve them: education, mental health, juvenile justice.

Like the quilt pieces, the organizations and agencies that touch this child’s life need to be stitched together, and in the sewing, these separate pieces are not only made much stronger, they also create a picture more complete, more beautiful, than any makes alone.

Emotionally, the quilt has great symbolism for me. My grandmother made a quilt for me. It is one of my greatest treasures. I quilt—I have been working on one, off and on, for about



Skeptics argue that in the mental health field, we don't know what we're doing. Do you agree?

Every day we are learning more and more about how to effectively meet and treat the needs of our children. We don't have to be apologetic. Treatments are effective. It's medicine and psychotherapy and behavioral intervention and psychosocial rehab—these things work.

three years; I hope one day to finish it, for my son.

My son was 12 when he was diagnosed with ADD, attention deficit disorder.

This experience in parenting has been the most humbling in my life. I had always been on the side of the table with the professionals, across from the poor parents, sitting there feeling so intimidated, frustrated and inadequate. Suddenly, I was trying to cope with my feelings. I was doing my best. I was not dysfunctional. And yet: here was my son, my child, who was struggling ... and we could not get his medication right.

The good news today is both my sons are young adults. One is a college graduate, gainfully employed and living on his own. Our youngest son is in college.

I have learned great patience. I used to be optimistic and to believe we would be on a four-to-six-year plan. Now I'm praying it's only six to eight years. But we will get there. As a family. And as a profession. I have learned, firsthand, sitting on both sides of the table, that these principles work.

They have worked for me.

Perspectives

Improving mental health care for children requires the collaborative effort of many participants in the health care field; advocacy of early intervention, funding, and other issues require unity. Without common understandings and commitments, little hope will be generated because few responsibilities will be shared.

The Business Perspective

Rick Woodham
Vice President
Human Resources
W.C. Bradley Company

The mental and emotional health issues of children and adolescents today affect every employer, regardless of where he or she is located, regardless of the size of the company, regardless of the type of industry it is in.

Employers hire the mothers and the fathers of children with problems. These parents are not thinking about work when they are on the job; they are thinking—as any of us would—about the mental and emotional health of their children.

Parents who have children suffering from mental problems are also away from work a significantly greater amount of time than those without children in such circumstances.

They have to attend parent-teacher conferences to address academic performance and behavioral issues. They have to take their children to medical appointments. Frequently, at least for parents at the Bradley Company, the children are seeing medical physicians rather than therapeutic care providers who

might offer better care.

And finally, and sadly, parents take time from work to visit children in the legal system.

What also affects employers, ultimately in greater force, is that these children become our future employees. If they don't get proper treatment for issues and problems that exist today, they end up having to deal with them as adults in the workplace.

Employers are frequently hesitant to provide benefits for mental health care services equal to those of medical services. This is true for many reasons. First, and perhaps most profound, is a concern that the assessment and treatment of mental and emotional problems are not as well defined as for physical illnesses. It is difficult to determine when someone is cured, when treatment is over. Because of that, employers frequently are unwilling to lock into an ongoing, long-term, expensive treatment program.

Second, although it may be less expensive in the long run to provide proper and effective therapeutic care, many employers choose less expensive immediate care, treating problems with medication.

Third, many employers feel their community does not have an adequate supply of qualified health care providers for children and adolescents. In

Columbus, Ga., a community with a population of some 200,000, we probably have five or less professionally trained mental health care providers with the skills and experience to deal with children and adolescents. So, lack of care availability is an issue.

Nevertheless, there are things that employers can do to help address some of these issues. In the Columbus community, we encourage employers, large and small, to get involved in the health care delivery system. Some may do so solely for the purpose of trying to reduce costs. But when we are trying to help address needs and provide education and assistance, the health care provider community appreciates employer involvement.

Employers also need to accept some responsibility for educating employees. We have to remove some of the stigma that is still attached to receiving mental health treatment. A lot of parents will not seek proper treatment for their children simply because of the negative perception attached to receiving mental health care. Employers can do a lot to help eliminate or minimize that.

We've done that in our company through on-the-job education. As a result, we probably have one of the highest utilization rates of health care services of any employer in our com-

munity. Our folks are not afraid. They do not sense a negative stigma.

We also support the parents, our employees, and have tried to eliminate policies and procedures that are in fact barriers to parents being parents.

For example, most absenteeism management programs penalize people when they are off work to attend school functions or meet other parental responsibilities. Companies could develop policies that allocate a specific amount of time each year for parents to be off the job to be parents, to participate with their children in school programs, educational programs, and the like.

In terms of schools, health care providers, parents, and employers can jointly address these problems. A lot of what needs to take place is simply one party asking the other party for assistance. In Columbus, we have an effective working relationship among parents, the school system, the health care providers, and the employers. This has led to some very effective programs.

Finally, perhaps most importantly, employers need to encourage our parents to be effective parents in all that they do, and that encompasses involving our children in every part of life: personal, spiritual, and vocational.

The Faith Community Perspective

Marshall Handon
Mercy Seat Ministries

The legacy of racism exacerbates the problems of mental illness within the African American community. Yet we as a society find it difficult to talk about present-day racism, and its subsequent behavior patterns on those who experience its evil.

African-Americans, denied other outlets, have traditionally and historically dealt with these cause-and-effect issues within the confines of religious faith. That faith—the belief in the God of justice and mercy—has sustained us.

It has also given us a clearer perspective in dealing with racism and its attendant behaviors. We see, for example, the insanity of investing huge resources in detention programs and prisons for young people, while providing a relatively minute amount of resources for preventive care of babies, children, and adolescents who need to be in the mainstream of public life before they engage in deviant behavior.

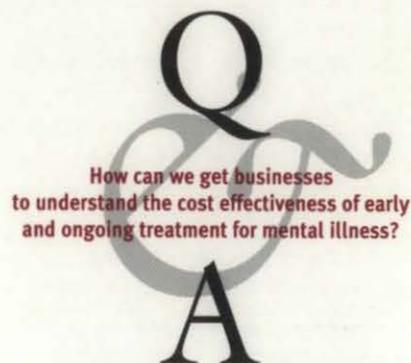
We also see parents, themselves the products of racism and a society unwilling to incorporate them as full-fledged members, who are intimidated and do not trust the system; their children often wind up self medicating or getting into serious trouble. Many do poorly in school.

Many African American youngsters exhibit symptoms of attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD). When I discuss the child's problem with these parents, and urge them to see a physician, basically they say, "These people don't care anything about my child. All they want to do is make money off me."

Children today—black, white, and polka-dot children—who have mental health problems suffer criticism and ridicule as a result of stereotypes.

When you add the issue of race, you have a potentially volatile situation for kids who are hurting, who have never been nurtured, never been loved, always been marginalized and cast out. It is difficult for them to meet the standards and expectations of society when they have not had proper nutrition, they have not been intellectually stimulated, they have not been given resources to learn, they have not experienced the love and acceptance of the entire community.

And the entire community ignores its responsibility. As a society, we are all in this together. We sink or swim together. And on the brink of a new millenium, we still delicately tip-toe around the serious questions of racism and neglect and the mental health of our children. It does not have to be so. We can do better to



How can we get businesses to understand the cost effectiveness of early and ongoing treatment for mental illness?

Unfortunately, we do not have data in our company that proves that point. It is our belief, however, that it is cost-efficient. Also, we know it is the right thing to do. Therefore, we have not spent time and money analyzing it. Maybe we need to challenge the academics to study it so we will have the data that will prove to a company that good mental health care works for the bottom line.

Our U.S. Declaration of Independence was not founded in research data, it was based on values. There are certain core values from which society should be constructed, and one of them is caring for children, providing a nurturing context in which they can grow up with equal opportunity to experience a full life.

make our children proud of us and of themselves.

The Health Insurance Perspective

Ron Bachman

Principal
Coopers & Lybrand

The hot topic today at federal and state levels is mental health parity laws. The first issue raised is that equity is not possible; mental health care is a black hole of expenses. Because it is risky and uncertain, no one wants to improve the benefits.

That is not so, however. Studies from independent organizations—the Congressional Budget Office, the Congressional Research Service, the Department of Health and Human Services, for example—as well as organizations like my own, Coopers and Lybrand, and other consultants like Mellman and Roberts, have all weighed in with the same basic numbers, even though we arrive at them differently.

Using conservative assumptions—assumptions perhaps higher than an advocate might make to force movement in a given direction—every study has agreed that to add mental health and substance abuse at parity with medical/surgical costs, will add between 3 and 5 percent in the health insurance marketplace. In some states, which have monitored costs closely, the actual figure is closer to 1 percent.

While not 10, 20 or 40 percent, as some opponents have argued, this is still a lot of money. So the debate now centers on whether the cost—to government and to business—is acceptable.

In that debate, in a rational discussion of the pros and cons and the sort of public policy that is appropriate, why can we not make a rational decision? What keeps us from bringing mental health care to equity with physical health care?

Two hurdles remain. One is historic, the other current.

The historical one is the memory of the excesses and abuses that have occurred. We tried a kind of unlimited treatment policy, but employers rebelled. They didn't know when somebody would be cured, or if they would be at all—whether they faced paying for a life-long dependency on a therapist or a brief period of counseling. They finally said, "We're not going to do it anymore. Prices are out of control and we must cut benefits."

That created the environment for the 30-day benefit. Basically, someone has 30 days in which to be cured. By the thirtieth day, all sorts of people have reviewed the case: a medical director, a case manager, a reinsurance manager, a utilization manager. All agree the individual has a medical need. But on the thirty-first day, pay for treatment is terminated.

It is an artificial limit that is a carry over from the days when we just arbitrarily cut back because we could do nothing else.

The second current hurdle is the concern about a mandate. That is the number one issue that surfaces time and again. We are in an environment where we do not want government to mandate anything. Yet, in this case, it is necessary, and here is why:

To create a cost that is reasonable for everybody, you have to pool risks. In other words, your insurable universe has to include those who may never use benefits and those who need them soon. To create that pool, you have to level the playing field for everybody. That means mandating the benefit.

There is, however, this knee-jerk reaction to the word "mandate." Nobody wants the government telling them what benefits they have to have or do not have to have.

This, I contend, is a mandate of a different nature. It is already covered by 98 percent of insurance policies. We are not adding new providers. We are not adding new benefits. We are merely covering mental health at a financial parity with physical health

and we are removing artificial limits. That makes it a different type of animal. It will be a tough sell and will take some time, but it is worth the effort, because the mandate creates a cost low enough to make coverage not only worthwhile, but affordable.

Five years ago, costs would have been much higher. The reason the numbers are now reasonable—at least in many people's minds—is that the delivery of mental health care has changed.

There are new medications, new treatments, new procedures, continuum of care options—lots of alternatives to in-patient care that make treatment much more affordable.

In the insurance world, adjusters use a term that defines what is covered: *medically necessary*. Government programs include other needs, and appropriately so. But no matter how you set benefits, mental health care is affordable: that is the big message.

The Balanced Budget Act of 1997 (BBA) created a new program for children's health care. It covered some uninsured children with both physical and mental health benefits.

In 1998, \$4.3 billion was available to the BBA's Children's Health Program, \$24 billion authorized over five years. Among the states taking advantage of that is Georgia, which is in the lead to establish a program for uninsured children that includes mental health benefits.

There are three ways to do this:

- Expand Medicaid;
- Create a separate children's

program and establish it in the private market place;

- Combine those two options.

The key to figuring benefits is complicated, but the BBA allows mental health benefits to be funded at 75 percent of the actuarial value of what is in three benefits funds. In Georgia, these would be the Federal Employees Health Benefit Plan, the state employees insurance plan, and the largest federally qualified HMO plan, Blue Cross/Blue Shield's Blue Choice pro-

gram. Those three benefits are not in parity now. So getting 75 percent is a funding benchmark—a floor—for something that ought to be higher to begin with.

Nevertheless, the Federal Employee Health Benefit Plan benchmark is about 3.7 percent of the premium for mental health. The state plan is about 4 percent, and for the largest HMO in the state, it is about 2.8 percent.

Nationwide, some 9.8 million children are uninsured. About one third of them are hard-core uninsured; another 3.3 million currently qualify for Medicaid, but have not enrolled.

One of the benefits of the Georgia children's program will be that when uninsured children are enrolled, they will also qualify for Medicaid benefits.

Of the estimated 2 to 5 million children newly insured under the Balanced Budget Act, approximately 50,000 to 100,000 Georgia children would be picked up in an insurance program.

Those numbers suggest how vital it is to increase the mental health benefits in all employer plans, because doing so would make a direct impact on the benchmarking for uninsured children, as well as for the adults who need mental health benefits.

The Family Member Perspective

Tara Norman
Parent

Jessica Marie Norman has Attention Deficit Disorder (ADD). In first grade, we noticed it. Jessica was a compliant child and not hard to deal with in class. At the same time, she could not keep up, could not pay attention in class, and could not finish her work.

To get her treatment, we had to talk to the principal. We had to have



Going to your pediatrician is a good first step. The school systems sometimes are able to help. The Georgia Parent Support Network is also available; its staff can tell you where to go for support and treatment.

psychiatric testing done through the school system to be recognized for insurance purposes and to be able to get medical help.

The principal did not want to do the testing. She said, "We do not test until the children are in the third grade. That is when we see if it is a pattern." I said, "Excuse me, you are not going to test my daughter in the third grade. She will be so far behind by then the problem will be far worse."

So we did get the testing.

Our pediatrician prescribed medication and within two weeks, Jessica could read enough and pay attention enough to be able to cope.

Today, she is just so different. We continue to progress, despite hitting some bumps occasionally.

We built a new home and the move to our new location necessitated a change in pediatricians and in the school my daughter attends.

Along the way, we found that neither the schools nor the parents can work alone. We have to work together because otherwise, effective recovery will not take place. You have to be a team.

Beth Perry

Teacher/Learner Support Strategist

I am an educator and a parent of a child with Attention Deficit Hyperactivity Disorder (ADHD) who is now an adult. I tease him and say, "I did a great job raising him," and he says back to me, "I did a better job raising you." I think that is true. We have to listen to our children. We need to work with parents, with teachers, with everyone in the community that is involved with the child.

My role as learner support strategist is to help bring those players together to come up with the best program for an individual child. The focus is on the child, not the program. The best place for the child is in the regular classroom, and that's where we try to do our interventions.

In the mid 1980s, the Georgia Department of Education mandated

that we have a Student Support Team process in every school. Cobb County now has a learner support strategist in every school. We know that interventions are important, and if we can reach children at a young age, we can prevent or deter problems later on.

In my strategist role, I help develop training for teachers and parents. We meet and decide ways to handle each child's problem: e.g., cut back the work assignment, give alternative assignments, or provide computers so the child won't have to write out assignments.

Behavior contracts are a big part of my day. Children come to me in the afternoon to get their rewards, or sometimes their consequences.

We are trying to identify and work with ADHD children, and help parents understand what they can do. Parents need to be the ones most informed about the child and the problems. As we become more informed, we will see improved results in the classroom.

The Juvenile Justice Perspective

Michelle Staples Horne

Medical Director

Georgia Department of Juvenile Justice

Most of us think of the Department of Juvenile Justice as razor-wire-surrounded facilities scattered across the state. But our department is responsible for all of the juvenile services that are provided to any child who is an offender within the state.

Most other states have divided that responsibility among local municipalities, local counties, and the state. In Georgia, we are responsible for detention, long-term secure confinement, probation and parole, and community placements.

Of the 35,000 children we serve on a daily basis, about 4,000 are in secure facilities. The rest are in group homes, therapeutic foster care, wilderness programs, and even specialized residential placement. These last are

particularly important for kids that have high mental health needs.

If you look at mental health needs among our population, you see a large number of conduct disorders. We also have many children with anxiety and mood disorders, ADHD, even mental retardation. The proportions of these problems that you see in the larger society are magnified by ten within our system.

Substance abuse treatment is a very critical part of our work.

Special education services for our young people have been an important part of the treatment we provide. We are a school system in ourselves, and the children tend to do much better in our schools than they have done in the community, perhaps because they attend every day, classes are usually smaller, and supervision is more intense.

Despite our successes, we face barriers to care:

First, children who are incarcerated are excluded from Medicaid eligibility. All funding for our department's services comes solely from the state. Consequently, some youth who could be best served through individualized treatment or alternative programs end up in juvenile justice, because of inadequate resources.

Second, many of our facilities are in rural areas, making it hard to find providers—there are not many child psychiatrists in Blakely, for example, where one of our facilities is located. And with very limited resources for that level of staffing, it is hard to hire people for all our facilities.

Third, we have a perception problem: people see *juvenile offenders*, not children of Georgia. If I had a magic wand, I would make people see that any child who enters our system at some point will return to our communities; to your community and to mine. What we do to make that child a better citizen will only enhance the community.

Fourth, I would wave my magic wand again to make everybody work together: local agencies, state agencies, the Department of Family and Chil-

Q
My husband and I pay \$1,200 every two months for my son's insurance; how can you say that insurance costs are reasonable?

A

They're not, as you prove. Only by making mental health insurance mandatory for the entire population, so that risks are spread equally, will insurance companies reduce their charges. Now you bear that risk alone, and that is not fair. You are paying because you are suffering the risk. When that risk is spread over a pool of people, everybody's shared portion becomes very small for the insurance carrier, who is then able to reduce premium costs. We all pay a little bit so that those who need the services are able to get the care they need for a price they can afford.

dren Services, the Department of Human Resources, the educational system, the faith communities, business partners—all those people who work independently would learn to work jointly to benefit that child.

Yes, we have children who have done some terrible things. But also, some terrible things have been done to them in their very short lives. And the most terrible thing of all is to identify those children and fail to address their needs, denying them the chance they need to be healthy human beings and productive citizens living among us.

The Foundation Perspective

Patrick McCarthy

Director

Policy Reform and Initiative

Management

Annie E. Casey Foundation

To do better for children with mental health problems, I suggest we make adjustments in three areas: frontline practice, neighborhoods, and managed care.

In frontline practice, I find that in communities of color—communities in which there is concentrated poverty and isolation—the quality of frontline practice, what happens between the persons who are supposed to help and the families and children who are looking for help, is nothing short of dismal.

The psychopharmacology is poor; it is the misuse of drugs. There is misdiagnosis—missing basic characteristics that suggest whether a child has an organic disorder or a post-traumatic stress disorder. There is inability to identify and use even the basics of “best practice” to help families. There is the inability to knit together a collaborative approach to complex problems. All these mean it is more likely a child will not get his or her first comprehensive review until we have locked the child up, rather than when the family first asks for help.

Part of the reason for this failure



Now it seems the system is so programmed to find out who's paying, and to make sure all the bills are going to be paid, there isn't much attention given to health care itself. Can managed care improve that situation?



Managed care, used well, offers an opportunity to shift incentives. The systems now are set up so that each has an incentive to shift part or all of the bill to someone else.

It is part of the political dynamic of financing. And that means, for example, that these kids—poor kids, kids of color—after they have been bounced around from special education to child welfare, from child mental health to foster homes, end up in juvenile justice, the final stop in bill-payment shifting.

Managed care gives us an opportunity to shift those incentives by pooling funds in a different way.

is that most of us do not care enough about these communities to invest the resources or energy to improve practice; it is simply a matter of weak public and political will.

What would frontline practice look like if it were improved? It would mean redefining what frontline practice is. It would mean putting family resources at the center of practice, and, where necessary, supplementing what is available to the family.

It means better training, both at the university level and in the field—professional development and support. Academia, with its book knowledge, could partner with families, who have experiential knowledge. Families know what happens, academia knows why those things happen. Together they could be powerful advocates with service providers, legislatures, the purchasers of services, and the public systems that finance frontline practice.

It would also mean that parents would be much more involved in the training and resource development that needs to occur.

The other piece of frontline practice that needs to be improved is the fit of needs, values, and cultural perspectives of the family and those who are providing help. Solving a tough problem is even tougher if my views of how the world works are totally disconnected from those of the person trying to help me.

Frontline practice also needs to improve its ability to draw from non-traditional supports. Partnering pure support of family connectedness with some clinical interventions is perhaps the more powerful approach.

Finally, frontline practice won't be improved until we have an absolutely rabid commitment to improving outcomes. That means getting clear about what we mean when we say that we want to make things better for our kids. How do we define that? How do we measure it? But most importantly, how do we measure outcomes to inform and improve frontline practice?

Even if frontline practice is improved, there remains a need to

Q
Do any of you foresee the time when the issue of insurance becomes secondary and the concern of the patient moves into the forefront, so that it isn't just "you've got 15 or 20 minutes and let's get on to the next case"?

A
Doctors swear in the Hippocratic oath not just to do no harm but also to render service where service is needed. Most physicians do that. But many do not see that service is needed in advocacy. Pediatricians are one exception; they have advocated interventions best—at least better than the mental health field. They push for seat belts, bicycle helmets—they speak strongly for the needs of children, for the need to protect children. That's where our hearts have to be and that's the leading edge for us. Parity issues, those are best born not by the self-serving medical or mental health professionals who want to bill. Clearly, parity's a pragmatic, dollars-and-cents issue that has to be addressed. But more important should be speaking on behalf of families and mental health needs. That's the issue. So a change in attitude and emphasis is clearly needed. Our voices have to be heard most loudly on behalf of children.

imbed mental health services into the fabric of neighborhoods. Why?

First, having parents from a community involved as designers and monitors of the group that purchases services means more effective outcomes. When purchasing and design decisions are made by a centralized bureaucracy, it is easy to incorporate a few parents into the process and claim parental involvement. In fact, it is not parent involvement. Parent involvement means neighborhood level involvement.

Second, partnerships of agencies, providers, and residents have to occur to build a responsive mental health system. It is melding large systems and the agencies with neighborhood schools and churches and institutions.

Third, at the neighborhood level we have a better opportunity to redefine what is meant by mental health services: each particular neighborhood has its own definition of mental health, family support, youth development, family resource centers, and so on.

Finally, improved frontline practice and redefined, neighborhood-oriented managed care also need a redesign of health care financial systems. We are in the midst of huge changes in health care financing. The way that managed care has been implemented has been inadequate and piecemeal in terms of its effect on child welfare and behavioral health.

But there are also opportunities. To take advantage of them, we again must clearly define outcomes and values, so that those who purchase managed care—business or government—are not focused solely on cost containment. That approach neither saves costs nor improves care.

Managed care offers, among other things, good data to inform our decisions, as well as incentives to focus more intently on health than worrying about who pays the bills.

Foundations such as mine believe that our job is to publicize the conditions of children and youth so we

can build public will to do a better job in providing the resources necessary to better their lives. It is our job to find and provide expertise to those who are trying to change systems. It is our job to encourage new kinds of partnerships. It is our job to find ways to support the voice of consumers in the system. And, finally, it is our job to serve as research and development units that take on the tough issues—issues like race, culture, power that are part of the broader dynamic of poverty and isolation in this country—and in redefining them, help forge solutions for—among other things—better frontline practice, better neighborhood involvement, and better financing of health care.

The Clinical Perspective

Eva Nemeth

Middleton & Fey

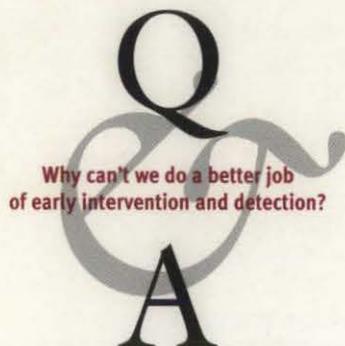
Private Practice Psychiatry, Psychology, and Psychotherapy

Among the most important issues facing us as we consider ways to improve mental health care for children, is early detection and early intervention of childhood mental illnesses.

Recently, I took my 14-month-old to the doctor for a checkup. Waiting to get on the elevator, I saw a large sign that announced free skin cancer screenings at the dermatology clinic. At the pharmacist section I saw another sign announcing free blood pressure screening.

On the way out, we passed the mental hygiene clinic. What was notably absent from its wall was a sign advertising, "Free childhood mental illness screening day." Instead, all we saw was a mental *hygiene* clinic, which gave me this sense of going in there dirty and coming out clean, or getting your brain flossed, or having fluoride treatment of your psyche.

Unfortunately, the stigma of mental illness frequently keeps people from recognizing that there is a prob-



Why can't we do a better job of early intervention and detection?

In the field of physical illness early intervention and early detection are common because everyone realizes the benefit, not only in treatment but also in prevention, of discovering skin cancer or hypertension early, before it is too late to save one's life. Unfortunately, that is not yet true in the field of mental illness. Too few recognize the benefits.

lem, and it certainly keeps people from going early to get help. Yet it really is cost effective—as well as health effective—to have early mental health treatment for children.

To illustrate this point, I present two hypothetical youngsters, both composites of kids I have seen through the years.

The first child did not have early detection and early intervention; the second one did.

Paul can not sit still, blurts out in kindergarten class, and never follows sequential orders. If his mother says, "Paul, take your shoes off before you come in, go upstairs, put your play clothes on, and put your school clothes in the laundry," he will not make it up the steps.

Paul sometimes hits other kids. When he is four, he breaks his arm doing a dare-devil stunt on his bicycle.

Paul has no early detection—or, more accurately, the early detection he has is his teachers thinking he is another misbehaving child, and they discipline him accordingly. His early intervention consists mostly of sitting with his school desk facing the wall.

His parents work long hours and by the time they get home, they are too tired to deal with his behaviors, much less get help for him.

Paul's pediatrician and the staff in the pediatrician's office dislike him so much that when he comes, they just hurry him out and never recognize his Attention Deficit Hyperactivity Disorder (ADHD) symptoms.

His grandparents suggest that his parents duct tape him to a chair so he will sit still.

Paul at first hides how bad he feels about himself by being the class clown. Slowly he starts to identify with bad kids because they are the only kids who will hang out with him. He becomes known as a fighter; he begins being suspended from school. By the age of 10, he is stealing small items from home and stores. By 12, he has joined a gang because nobody else likes him.

At 15, he is sent by the courts to

Georgia Regional Hospital for an inpatient evaluation. This is the first time he has ever laid eyes on a psychiatrist.

In the hospital, Paul is a nice kid. Attractive, pleasant, polite, but constantly moving. He has made it through the ninth grade and cannot read third-grade level. His spelling, math, and achievement tests are second grade level. He is very honest and forthright; he tells me proudly that he has already stolen 15 cars.

Paul has had ADHD symptoms since he was four or five; no one has taken the time to notice until now.

Henry is the second child. When I see him, he is also 15 years old. He, too, has exhibited ADHD symptoms since age five.

His behavior patterns go like this: He refuses to do work. He spits. He kicks. He screams at teachers. He uses profanity, pushes other kids. Henry cannot complete assignments. He is accident-prone, a dare-devil who will try anything. He has a short attention span and cannot sit still.

What distinguishes Henry from Paul is by the middle of kindergarten year, his teacher recognizes that Henry has a problem. She discusses it with his parents, who agree to get help.

Henry is diagnosed with ADHD and placed on medication.

His parents get training. Now they understand what their son is going through and how they can best help him.

Henry has appropriate school resources. At 15, he is a ninth-grade student with a B average. He still procrastinates on assignments, but is planning to go to college. He has never been in trouble with the law. He gets along with his family reasonably well—for a 15-year-old. He has friends his parents like. His girlfriend is an honor student.

What makes these two kids turn out so differently when they were so similar to begin with?

Paul had a lifetime of failures. A hundred times a day somebody was saying, "Paul, sit still," "Paul, stop fidgeting," "Paul, do your work,"



**Schools teach physical fitness.
Businesses encourage physical fitness
because they know it's cost-efficient.
Why can't we get businesses and the
education system and others to give
parenting classes or support classes
where people can learn to recognize symptoms
of mental illness so they can respond to their
children's needs in time?**



**Educational opportunities are available.
A lot of hospitals offer those classes.
Libraries are a good source of information.
Many employers sponsor educational
programs. Employee assistance programs
(EAPs) often deal with parental management
and parental development topics.
Yet more could be done earlier,
perhaps in the high schools,
to prepare young people to recognize
and cope with the problems of mental illness.
Why can't the health community establish
a partnership with the schools?
Why can't psychiatrists or counselors
come into the school to talk about
mental illness like pediatricians
talk about bike helmets?
Why can't they explain chemical disorders in
the brain, just as disabled people explain
physical handicaps?
There clearly are things we could do
in the schools of Georgia.
Only through early intervention will
young people, who will soon be parents, learn
the signs of mental illness.
By the time they turn to the hospital
programs, the library, or the EAPs for help and
understanding, it may be too late.**

"Paul, you're being bad." Over time, Paul learned he could not be successful at the things other kids were doing; he started to try succeeding at other things. He succeeded at being the class clown, he succeeded at being a gang member, he succeeded at being the best car thief among all his friends.

How might Paul's situation have turned out better? If he had had early intervention, if people had recognized there was a problem ... he might have turned out differently.

Instead, Paul is sitting in the Georgia Regional Hospital, and it is difficult, perhaps impossible, to measure the loss of productivity and the loss of quality of life. But as a small indication, right now he is costing maybe \$120 a day in the youth detention center and about \$400 a day for a court-ordered evaluation. And all this could lead to \$100,000 a year for several years in residential treatment. Even then, the prognosis is uncertain and the additional costs unknown.

Henry cost about \$200 for the initial evaluation and about \$15 a month for medication. To make sure everything went well, he cost an additional \$85 a month for a counseling session, where he got supportive therapy and medication management, and his parents got a "booster shot" to help them continue to understand and cope.

The point of my illustrations is this: if we don't invest in our kids, if we don't share the responsibility to provide them the mental health care they need when they first need it, we will have to pay a lot more later on, in loss of productivity and loss of quality of life, but also in increased costs to society.

And there is a role for all of us:
For clinicians, the responsibility

is to move beyond treatment of individual clients to be part of the system, taking time to help people recognize that we need early detection and early intervention if we are to be successful.

For parents, the responsibility is to seek help early on; do not be afraid. Just because your child acts like the Tasmanian devil, it does not mean he is evil or you are doing something wrong. Do not be embarrassed to seek help for your child.

For educators and childcare workers, watch for early signs of mental illness and, when behavior is questionable, bring the symptoms of trouble to people's attention.

For clergy, the responsibility is to be courageous and act in the family's best interest, the child's best interest. Frequently, the first person parents turn to is their clergyperson. Clergy can be instrumental in guiding parents to get help before things start to go downhill for their child.

For employers, the responsibility is to support employees in their efforts to raise and get help for their children.

For health care financiers and policy makers, the responsibility is to move money and policy toward prevention and, in effect, stop giving all the grease to the squeaking wheel. It may be more popular to focus on detention, but what is needed is intervention and prevention. Do not allocate all the money to all the services that aren't part of the solution.

For those in the juvenile justice system, your responsibility is to demand more resources for youngsters who come into the system early with status offenses. By doing so, maybe you can make it more likely they will not return as more serious offenders.

And for the advocates of improved mental health care for children—for, in fact, all of us—the responsibility is to do all of the above for our kids.

Actions

SUE SMITH, *executive director of the Georgia Parent Support Network and president of the Federation of Families for Children's Mental Health, is also the parent of a child who has experienced mental illness. In her challenge, she sums up the needs and concerns of those involved in the struggle to gain parity in mental health care for children.*

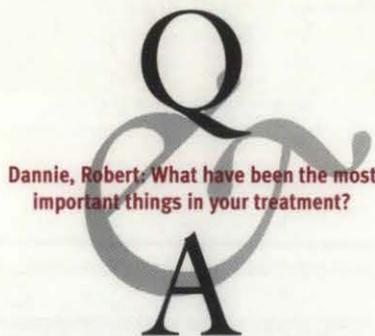
Health care and mental health care in Georgia and the nation present a very complex set of problems and challenges.

In Georgia, we are less than 50 percent funded for children living in poverty in 1990. We serve 13 percent of the children in need with some service, in some areas. It varies. We have barely begun to address the needs of African American children in this state. By 2003, the dominant minority population in the state will be Hispanic. We have not even begun to think about what this population shift will mean.

It is time we thought long and hard about what we want in terms of mental health care for our children and families. Then we need to advocate our position. We cannot stop until we achieve our goals.

And to do that, we may have to study more about health care issues. Talk to experts. Visit the library. Many hospitals offer services to people in the communities. We get a lot of assistance from the United Way Help Book. Surf the Internet. It is worldwide and offers more information than you can imagine. We must be able to defend our positions with facts and logic.

The things that are happening in juvenile justice give us hope. On the other hand, to downsize hospitals and fail to provide services is discouraging.



Dannie, Robert: What have been the most important things in your treatment?

Dannie: It is important to tell me the truth. Do not lie about what is wrong with me. Do not lie to me about what a medication will do to me. Tell me the truth. It is easier for me to understand the truth. It is.

Robert: Family therapy has always been big with me. But every time I was in an institution, they put me on medication. Always. I've wondered, "What is this medication supposed to do?" When I got of age, I asked, "What are the side effects? How does it work with the brain?" They could not tell me.

So I have wondered, if they gave therapy without the medication, how would it turn out? That is just something I have always wondered.

We are improving community-based services—a good sign. But in the process, our funds are limited to those *most* in need. There needs to be funding for a broader spectrum of our people.

The number of parents who need help has been escalating. More people are getting poor services. If they don't happen to be in the right place at the right time, they might get better services in the juvenile justice system, at a greater cost to themselves and society.

Children with mental illnesses ought to have better resources. It will not happen until we vote change in.

It is a complex puzzle. A lot of players have a lot of different views on it and they are influenced by a lot of different things.

But some pieces of the puzzle are on the table. We need a Medicaid rehabilitation option. We need full parenting. We need legislation that makes it possible for every eligible child in Georgia to be covered by Medicaid.

More than those details, we need a new mindset. We need education. We need involved parents. We need partnerships. We need to stop turf guarding and work together, cooperatively and energetically, for the mental health of our children. We need, in short, to generate hope through shared responsibility.

Positive Messages

JOHN GATES, Ph.D., is director of The Carter Center Mental Health Program. He was formerly Director of the Division of Mental Health Mental Retardation, and Substance Abuse of the Georgia Department of Human Resources and he currently serves on the boards of directors for the National Mental Health Association and the World Federation for Mental Health.

There were some clear messages conveyed by the keynote speakers and panelists at the *Third Annual Rosalynn Carter Georgia Mental Health Forum*. These messages will be disseminated throughout Georgia to consumers and family members, and to practitioners, business leaders, faith leaders, and key policy-makers at local and state levels.

The messages are primarily positive ones conveying confidence that Georgia can achieve a system of accessible and effective services. We are hopeful the result will be enhanced efforts to build upon the progress already achieved in serving the mental health needs of Georgia's children and families.

Perhaps the most important message is that *effective treatments for many disorders already exist*, and that ongoing research on brain/behavior relationships is teaching us more every day. In carefully controlled studies, both psychopharmacological and behavioral treatments (broadly conceived) have been shown to produce positive outcomes for a variety of disorders, including depression, anxiety, and obsessive-compulsive disorder. In some cases, psychopharmacological treatment is sufficient, while in others behavioral treatment produces the positive result. In yet other cases, a combination of the two is best.

This confirmation that we can help children through careful attention

to their internal environment (*i.e.*, improving their physiological functioning with medications) and to their external environment (*i.e.*, improving their behavioral functioning through various behavioral interventions such as multi-systemic case management, wrap-around services, cognitive therapy, etc.) conveys the message that continued support for both types of interventions is needed.

In short, *there is need for more support for both behavioral and psychopharmacological research, training, and practice.*

The pursuit of both should not be interpreted as a continuation of the old dualism of mind and body, but rather as a recognition that the functioning of our brain—with attendant thoughts and feelings—and our behavioral functioning are integrated. It is a reciprocal relationship of mutual influence of behavior and physiology. The electrical and chemical processes in our brain affect our perceptions, thoughts and feelings, and thus how we learn and react to daily events.

Similarly, our daily experiences at home, in school, on the job, in our places of worship and in the relationships we have with others influence the chemical and electrical activity of our brain. The evidence suggests that it is not only physiological processes that are affected, but also physiological structures. Peter Jensen's citation of

research comparing the effect of deprived and enriched environments on the brains of rats is an example: the brains of rats exposed to an enriched environment had larger nerve cells, with an increased number and complexity of connections to other nerve cells, and increased capillary growth to provide energy in response to the increased metabolic demand.

These exciting developments deliver another positive message: *we can enrich child development by careful attention to early experiences.*

The sooner we can attend to children's experiences, the better the outcome is likely to be. In an effort to give every child the fullest opportunity for success, *we need support for a system of early interventions both physiological and behavioral in nature.* For example, proper nutrition and medical care for pregnant women and newborns, and the provision of nurturing contact and appropriate stimulation can combine to give each child the opportunity for his or her optimal development.

While there is still much to be learned, we now know that poor nutrition or the use of alcohol or tobacco during pregnancy negatively affects development, as does the absence of a warm, nurturing adult or an environment lacking in diverse stimulation of a child's senses and the opportunity for positive interactions with others. The availability of a comprehensive

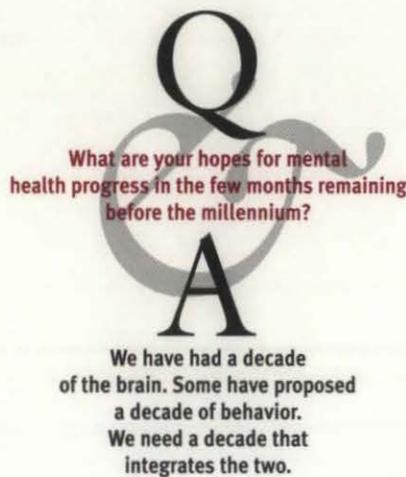
system of early interventions would give us the opportunity to promote the development of each child's assets, strengths, and abilities, and thus prevent many future problems. Accepting, however, that such a system would not prevent all problems, we would still have the ability to detect early on when physiology or behavior goes awry. We could then develop plans to address such problems earlier rather than later, when chances of success are likely to be greater.

The evidence of the differential effect of various treatments upon different problems conveys another positive message: *our arsenal of interventions is robust, containing an array of techniques that can produce positive outcomes.* We need not—should not—restrict our efforts to only medicinal or only behavioral or only social efforts. It is to the advantage of our children and their families that there be an array of techniques from which to choose, guided by the evidence of which ones work for which problems.

The message is further confirmation of the need to plan around the strengths and needs of each child and that child's circumstances.

And there is yet another message embedded in this one, a message probably most relevant to practitioners and service administrators. It is this: As we learn more about which treatments work best with which problems, *we must become deliberate in using only those treatments that produce the positive outcomes desired.*

This is already well-established practice with the physiological aspect of functioning. We know a good deal, for example, about which medications are effective for which problems, and physicians prescribe those medications and not others. We have begun to attend to differential practices with respect to the behavioral aspect of functioning. Fortunately, we are now much beyond the days when some behavioral practitioners (broadly conceived as analysts, or behavior modifiers, or rational-emotive therapists, etc.) learned and practiced one par-



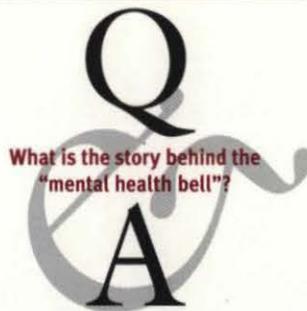
ticular technique and applied it to all, or nearly all, problems. Like the proverbial craftsman with only a hammer who saw the world as consisting of nails, these therapists viewed the plethora of human problems as due to either Oedipal mishaps or faulty contingencies or inappropriate ideas we kept repeating to ourselves.

The evidence suggests a need for more differentiation and precision in our practices. One implication for individual practitioners is the need to master a variety of behavioral and psychotherapeutic techniques and to use them selectively. For human service administrators, an implication is to develop staffing patterns—for a clinic, hospital, or service region—that ensure the availability of staff that collectively have at their disposal the full array of effective techniques. The recognition that one size will not fit all has implications for research and training programs. We need more research focused on the effects of medications on children specifically and better ways to translate the knowledge of the laboratory into the practices of those on the front-lines of care.

A final, positive message has to do with the strength and resiliency of children and their parents, especially in view of the problems they encounter, and the courage and determination they display to overcome those problems. Robert and Danielle shared their journeys of challenge and triumph. Their stories reinforce all the other messages. *Success can be achieved by working in partnership with children and their families,* as much as possible in their homes and communities, offering the appropriate treatments and supports, being sensitive to cultural variations, with an eye to what works and what does not, and changing our efforts as needed.

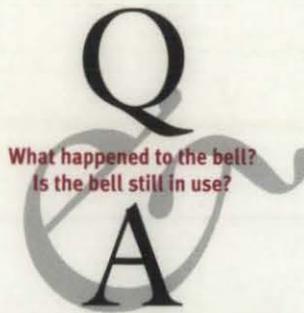
Most of what is achieved will be due to the efforts of the children and their families themselves. We need only provide an array of services and supports to build upon, supplement, and support those efforts.

Georgia has begun, but there is more to do.



During World War II and the Korean Conflict, a number of conscientious objectors served with the National Mental Health Association. As they traveled the country, they encountered horrible conditions in state mental hospitals. Spontaneously, they began sending back to association headquarters the cuffs and chains that were used to bind people with mental illness. These shackles were displayed in a room called the chamber of horrors until 1953, when they were taken to the McShane Bell Foundry in Baltimore and, in a ceremony, melted down into a special bell.

Our challenge now is to put what we've learned into practice. To do that, work of children and adolescents and their families are too great for any one group of life for children. ❖ I was in Goshen, Ind., speaking on mental illnesses and didn't look more than 20 years old—said to me, “In the last couple of years, I was overwhelmed me. I could not believe that in Goshen, in a place that people have brought home dramatically the need for collaboration among the education and care of their children. ❖ With all of us working together, there is so much we can accomplish that is unmountable when we work in isolation. But together, we can succeed. Why do we do this for our children. And the best way to get that is for all of us to join together for



What happened to the bell?
Is the bell still in use?

The inscription on the bell reads:

*"Cast from the shackles and chains that bound them,
this bell shall ring out hope for the mentally ill
and for victory over mental illness."*

The bell has been rung only on special occasions.

At the closing of the Rosalynn Carter Georgia
Mental Health Forum, Rosalynn Carter and Sue Smith—
acting for all those who have struggled with mental illness,
those who struggle with mental illness now,
and for all those who will struggle with mental illness—
again rang the bell.

we have to work together; we have to collaborate. We realize that. The needs
group to tackle alone. ❖ We have a long way to go to have the best quality
and mental health to about 1,000 people. A young school teacher—she
years, I have had six of my students commit suicide. Six of them.” That
ified the ethic of middle America, a “cluster suicide” could happen. ❖ But it
network, the business community, the juvenile justice system, the families and
accomplish. There are so many needs and so many problems, they seem insur-
not? We all want the same thing. We all want the best care we can get for
the good of all. — **Rosalynn Carter**, *former first lady of the United States*



*1998
 Rosalynn
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 Georgia
 Mental Health
 Forum
 Planning
 Committee*

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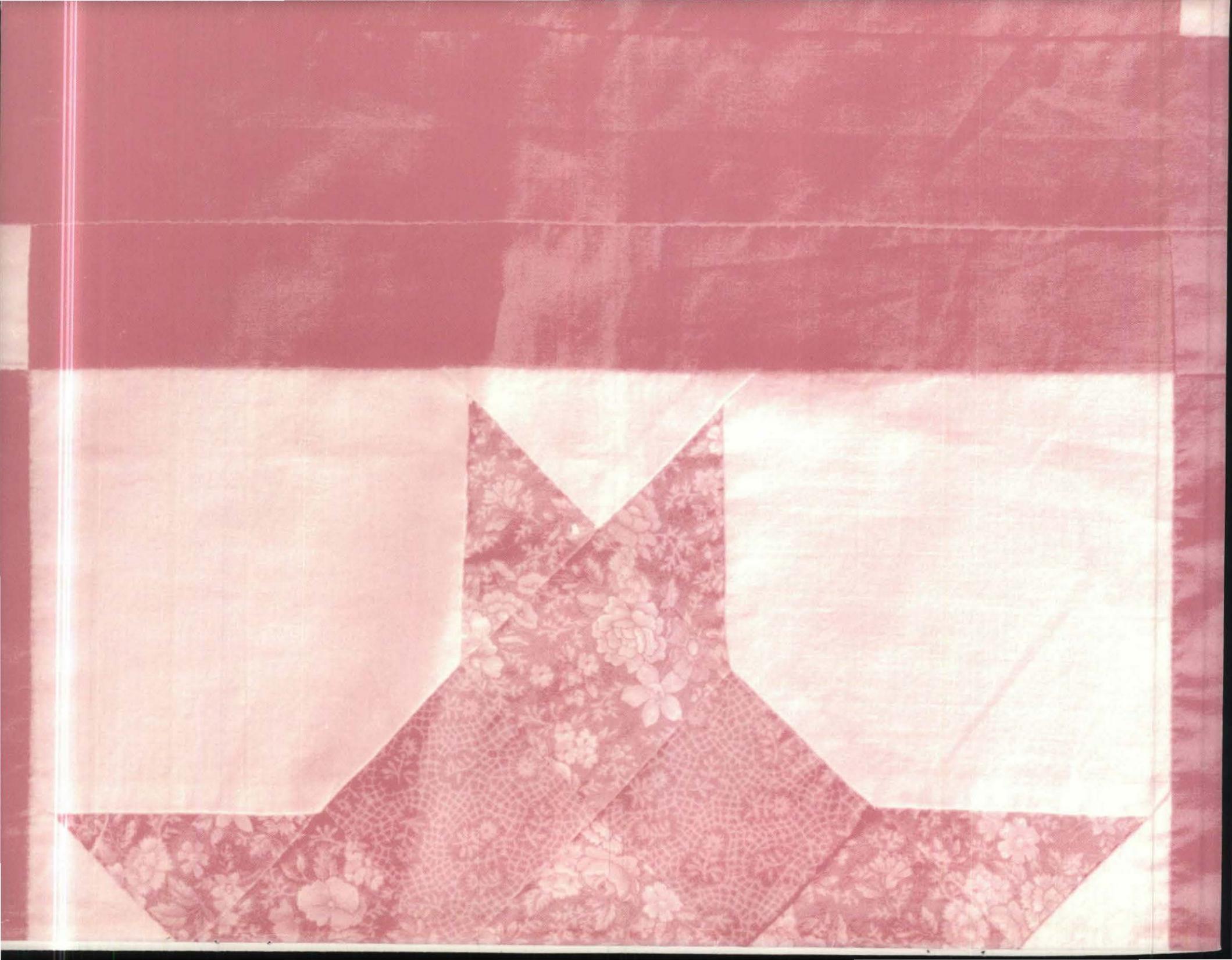
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