



Dialogue on Youth: From Neuroscience to Effective Service



Account of a meeting of the National Institute of Mental Health in partnership with the Community Mental Health Council, Inc., and the Mental Health Association in Illinois ¹

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TABLE OF CONTENTS

- Summary
- Setting the Stage
- Suicide and Youth: The Mounting Crisis
- Psychiatric Disorders Among Delinquent Youth
- What Do Neighborhoods Contribute to the Well-Being of Children and Youth?
- Family Voices
- Genetics and Psychiatric Disorders of Childhood
- Which Treatment for Which Youngster?
- The Audience Speaks
- Wrapping Up the Day
- Conversation with the Black Community
- Agenda

Summary

The National Institute of Mental Health (NIMH), the Community Mental Health Council, Inc., and the Mental Health Association in Illinois hosted an all-day meeting to discuss the research needs of children with brain and behavioral disorders, especially in the African-American community. More than 700 stakeholders—including patients and their family members, health care providers, teachers, policy makers, advocates, and researchers—listened to reports about research progress and provided input about the goals we have yet to attain. Invited speakers—public stakeholders as well as scientists who work in the Chicago area—documented the extent and impact of brain and behavioral disorders on young people. Topics of discussion ranged from current understanding of the genetics of many behavioral disorders to effective treatments for these disorders and the importance of social and community factors in supporting children and adolescents. A major theme of the day was the need to bridge the chasm that often separates African-American communities from research and treatment enterprises.

Discussions highlighted issues common to those in attendance. Many spoke of the need for continued scientific progress toward finding the causes of and safe, effective treatments for bipolar disorder, autism, and attention deficit hyperactivity disorder (ADHD). Many expressed the need for more and better information on the best current treatment for dealing with these conditions. Participants also voiced the need for holistic approaches that treat the whole child, not just the illness, and that support the family as well. A dominant concern was the need for appropriate educational interventions for children with behavioral, emotional, and cognitive disorders.

Two issues were foremost on the minds of the public stakeholders who participated in the meeting: (1) the crucial need to involve the public, especially the African-American community, in research in order to diminish public mistrust of research motives and to make research more relevant; and (2) the failure of research findings being translated into treatment practice in a timely manner.

Setting the Stage

The urgent health care needs of the estimated 8 million American children and adolescents with serious behavioral, emotional, and cognitive disorders were the focus of this day-long NIMH conference, which sought to evaluate the current status of research on these disorders and its impact on treatment protocols. Dr. Steven E. Hyman, director of NIMH, began the proceedings with a discussion of the power, complexity, and fragility of the human brain—a 3-pound organ embedded with 100 million neurons that collectively make 100 hundred trillion connections. Dr. Hyman remarked that the on-off states of each of these quadrillion communication points total more than all of the elementary particles in the universe. "Can you imagine keeping 10,000 conversations straight?" he asked. The most powerful computer operations pale in comparison. Dr. Hyman elaborated:

The brain communicates with chemicals called neurotransmitters—more than a hundred different ones—and each one has different receptors and they're all connected to complex biochemistry.... This complex organ is built from before we're born until well into adolescence and beyond by an interaction of the majority of our genes with complex environmental factors and experiences.

The brain's magnificence begs these questions, he continued: What happens when something goes drastically awry, as in bipolar disorder, depressive illness, autism, attention deficit hyperactivity disorder, or suicide? How does the brain respond to stressful and even noxious psychological and social factors? To answer these questions and find successful interventions, NIMH, the Nation's leading supporter of research on brain and behavioral disorders, spends about 90 percent of its nearly \$1 billion annual budget at universities and research hospitals around the country.

Despite this huge investment, a gap persists between research findings and the treatment regimens of those who stand to benefit. NIMH called this conference to determine how to bridge the gap between findings and treatment protocols, and to ensure that the research it funds is focused on issues that will yield positive differences for the public. Dr. Hyman asked conferees the following questions:

What are the problems that kids face in your community? What outcomes do they experience? Yearn for? If we were to say that a treatment was successful, what would it look like to you as parents and teachers? What do we expect our kids to be able to do? What is it that we don't know that we need to know? Even if you hear from us about what we know, what are the gaps between what we say we know and what's actually happening in treatment settings? Finally, how can we better engage you in research—so that we improve treatment? Are the proposed studies welcoming? Would you put your child in such a study, or is it forbidding or even frightening?

Hyman ended his questions by acknowledging that research on children, especially minority children, with brain and behavioral disorders has been minimal, largely because children are harder to diagnose than adults and because children's rapidly developing brains and behaviors are moving targets for study. Furthermore, research has been retarded by the lack of consensus around research ethics and informed consent. By the same token, advances in treatments for youth of color have been hampered by the pervasive mistrust of biomedical research that exists in the African-American community. Attention to these research and treatment issues and dialogue

with the African-American community are certainly long overdue.

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Dr. Hyman turned the podium to Carl C. Bell, M.D., president and CEO of the Community Mental Health Council, Inc., in Chicago, and a clinical professor of psychiatry and public health at the University of Illinois. Dr. Bell agreed with Dr. Hyman's assessment of the paucity of research on mental disorders among minority youth.

Dr. Bell attributed this history of neglect partly to racism in the research and medical fields. Compounding the problem, Dr. Bell noted, is the suspicion among African Americans that medical research targets and exploits them, a perception fostered by the infamous Tuskegee experiments. Indeed, to this day, Dr. Bell said, inappropriate or inadequate medical treatment is rampant in the African-American community. For example, African-American males with bipolar disorder are less likely to be properly diagnosed and treated than are their white counterparts. Dr. Bell noted that the proliferation of antipsychiatry propaganda targeted at blacks has further undermined the health of African Americans.

Drawing on his quarter-century of experience as a practicing psychiatrist, researcher, and advocate, Dr. Bell emphasized the urgency of expanding research in black America, at public schools, among increasingly suicide-prone African-American youth, in community treatment, and in juvenile detention centers. He spoke of the need for culturally sensitive policies aimed at minority populations that would ensure them appropriate treatment and be mindful of any physiological and cultural differences that may exist among them. To develop such policies, researchers must conduct studies that focus specifically on the health interests of African Americans. To promote these interests—and to bridge the gap in trust—Dr. Bell said that representatives of the African-American community must be seated at the research and health care policy-making tables.

Drs. Bell and Hyman agreed that research has taught us much about effective treatments for brain and behavior disorders in youth, but that translating these findings into practice to promote better outcomes for patients sorely lags behind. Both concurred that accelerating this process to benefit youngsters in need is a national priority. Research findings gathering dust on a library shelf do not serve public health interests. "We've got to connect the dots," Dr. Bell said, "to forge an important link between researchers and the community members who can turn results into reality and improve public health."

Suicide and Youth: The Mounting Crisis

Dr. Jan Fawcett, chair of the Psychiatry Department at Chicago's Rush-Presbyterian St. Luke's Medical Center and director of The Rush Institute for Mental Well-Being, launched the public discussion of suicide among youth—a problem that has grown significantly in recent years. Suicide among youth is too often the tragic result of depression, alcohol or drug abuse, disruptive behavior, anxiety, and other serious disorders. More teenagers and young adults die from suicide than from all natural causes combined, Dr. Fawcett reported. During the past 10 years, suicides among young black males have increased by an alarming 300 percent. Dr. Fawcett ranked suicide as the Nation's eighth most common cause of death, the third leading cause of death among persons aged 15 to 24, and the third leading cause among African Americans aged 15 to 24.

Dr. Fawcett noted that more than half of all individuals who committed suicide had had no recent contact with mental health professionals, who might have helped prevent the suicide by treating underlying depression, bipolar disorder, drug abuse, or conduct disorder. Research has shown that certain stressors, which clinicians can look for—such as a recent arrest or the loss of an important relationship or job—often presage a suicide attempt. Improving access to treatment is critical to preventing these needless deaths, but achieving this goal is formidable: nearly 50 percent of individuals with these illnesses currently receive no treatment.

Make no mistake, Dr. Fawcett sadly observed, there is much that we do not know about suicide and its prevention. Research is critical if we are to improve our understanding of the factors that represent imminent risk of suicide. "The standard behaviors used to identify persons at risk fall seriously short of the task of identifying individuals in the days and weeks leading up to their suicidal behavior," acceded Fawcett. And perhaps one-third of those who commit suicide do so even while they are receiving treatment. Clearly, research

is needed to improve interventions that can prevent this tragedy.

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Jade Smalls, the 22-year-old "Miss Illinois" and first-runner up in last year's Miss America pageant, underscored Dr. Fawcett's presentation with remarks about her own efforts on behalf of preventing teen suicide. "I speak at about one to three schools daily," she said. Invariably, after each presentation, a few teens approach her to tell about their own suicide attempts or the suicides or attempted suicides of their friends. "I'm wondering what kind of treatment the kids are receiving," Smalls declared. "Is there any follow-up or supportive service after I leave the school?"

Smalls spoke of the public stigma attached to mental illness, of her empathy for mothers who confess—with guilt and pain—that they never saw the suicide of their deceased children coming. Like fellow conferees, Smalls stressed the need for research to (1) improve counseling for suicide-prone persons, (2) make prescription medicine a more acceptable treatment protocol for young people, and (3) answer the question that so many students and family members ask: "What can we do to help?"

Psychiatric Disorders Among Delinquent Youth

Dr. Linda A. Teplin, professor of psychiatry and behavioral sciences and director of the Psycho-Legal Studies Program at Northwestern University Medical School, presented research about a very important and growing minority group—young people with mental disorders in the juvenile justice system. Dr. Teplin has spent two decades studying incarcerated adults with mental illnesses. She turned her research attention to juveniles because it is a natural extension of her previous work, but more important, because she is worried that mentally ill youths—like their adult counterparts—are receiving prison terms without benefit of treatment:

I'm very worried that the detention center has become the poor kids' mental hospital—and because so many poor kids are from minority groups, that means (the) minority kids' hospital. I'm worried about this because of the changes that we've made in the mental health system. I'm concerned that kids with psychiatric disorders [are more likely to] be... arrested... than treated.

Using research as the sword, Dr. Teplin spoke of striking a blow against public policies that imprison rather than treat young people with mental disorders. The Northwestern Juvenile Project, headed by Dr. Teplin, is the first large study of the mental health of delinquent youth that it is hoped will affect these policies. The project is following the paths of 1,830 juveniles in the Cook County Detention Center. Many of the participants in the study are eager to be involved, saying "You don't have to pay me for the interview. It's just enough that you listen to me." Teplin's staff sends them birthday cards and receives thank-you notes in return. One juvenile wrote, "Thank you for remembering my birthday. You were the only person who did."

The data from the study thus far paint a gloomy picture: Two-thirds of the detainees have tested positive for one drug or more; 25 of the participants have died, all violently; mood disorders run rampant. Twenty-two percent of the female participants suffer from major depression—an extremely high rate. Two-thirds of the participants with an affective disorder also abuse alcohol or drugs. Clearly, many of these young people have very serious problems and have been failed by the treatment system; the data from this large study will be used to help make the case for improved screening and for greater availability of treatment and interventions.

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The next speaker, the Honorable Curtis Heaston, offered a unique perspective and follow-up to the remarks of Dr. Teplin. Judge Heaston is presiding judge, Cook County Juvenile Court, Juvenile Justice Division for the Circuit Court of Cook County. He has witnessed first-hand the alarming increase in the number of incarcerated young people who have serious behavioral and emotional disorders, but for whom no treatment is available.

"No, we have not picked up the slack for treating children with mental illness who come into the juvenile justice

system," Judge Heaston said, noting that a major barrier to providing appropriate services is the lack of a screening tool for mental illness when a child enters the system. That no such tool exists "is shocking to me," he added. (Following the NIMH meeting, Judge Heaston convened an advisory group to help him develop and implement a screening program for young people coming into the system so that those who need treatment for a serious behavioral or emotional disorder are identified up front and appropriately handled.)

The judge's words conveyed the magnitude and desperation of the problems that pervade the juvenile justice system and hamper its ability to provide appropriate services—not only in Illinois but throughout the Nation: Thousands of juveniles are under the Illinois courts' domain—no one knows how many of them are in need of mental health services. Hundreds of them are sent to faraway states because of the lack of secure facilities in Illinois—an exile that assures virtually no contact with family members, even though such contact is critical to the rehabilitative/treatment process. Judge Heaston observed with sad irony, "A mass murderer who is on death row gets more family contact than a child in residence placement who has stolen a car."

Dr. Hyman commented that "people who say it's too expensive to screen youth with mental illness in the justice system that Judge Heaston oversees or [who say it's] too expensive to supervise them in the afternoons must realize that, actually, it's much [more] expensive not to."

What Do Neighborhoods Contribute to the Well-Being of Children and Youth?

Conference participants next turned their attention to a holistic approach to understanding the causes of and pathways to juvenile delinquency, adult crime, substance abuse, violence, and mental disorders. Although the brain is the ultimate control center of cognition, behavior, and emotion, it is not the only component, nor is it the only appropriate target of research into the public health problems that young people face and the factors that may protect them from these problems. To understand the entire sequence of factors and events that "make" people, we must study their physiology as well as their community, family, peers, and individual characteristics over time. Dr. Felton Earls, professor of child psychiatry at Harvard Medical School and professor of human behavior and development at the Harvard School of Public Health, is conducting such a study—the Project on Human Development in Chicago Neighborhoods, which is following the paths of 7,000 young people over the course of 8 years.

Dr. Earls explained the study's guiding philosophy:

There are two extremely important and novel aspects to our project. One is its longitudinal, life-course perspective, which gives us the opportunity to look at human development as a dynamic, evolving process. That perspective will enable us to study the course of social and behavioral development in individuals—where antisocial behaviors begin and whether they persist, as happens in a small percentage of youth, or end, as is usually the case. It will let us see the connections between different stages of development, so that we can begin to unravel causes and effects.

The other—and this may be the most important aspect—is that we're studying development in the settings in which it naturally occurs: family, school, neighborhood, and the community at large. We're looking not only at how individuals shape their environments, but how their changing social and physical environments shape them. What opportunities and resources does a neighborhood make available to an individual? What kinds of barriers and constraints must a person overcome?

By looking at individuals and their communities—and individuals *in* their communities—as both change over time, the project seeks to identify the complex influences of community, family, and individual factors on human development. Why does one community have a high rate of crime, violence, and substance abuse, while a similar community nearby is relatively safe? What factors enable some individuals to live successful, productive lives, even in high-risk neighborhoods? Why does one young person experiment only briefly with delinquency, while another goes on to become a "career criminal"?

While low income and residential instability are both known to relate to violence, Dr. Earls' research has uncovered another contributing factor—the "collective efficacy" of a neighborhood, that is, how neighbors work together to solve problems and thereby create a healthy environment for children's growth. As the levels of collective efficacy increase, Dr. Earls has found, the levels of violence decrease. However, Dr. Earls noted that the world isn't quite so simple: Because neighborhoods are not isolated from one another, as children get older, they are exposed to the influences of other neighborhoods. What, then, is the impact of this exposure? Dr. Earls' project is considering this issue as well in an attempt to develop a comprehensive picture of the factors that put young people at risk.

Family Voices

The presentations that followed—the real-life experiences of two mothers of children with brain/behavioral disorders—humanized the many issues that had thus far been discussed in abstract terms and captured the close attention of participants.

The first speaker was Martha Hellander, J.D., author and executive director of the Child & Adolescent Bipolar Foundation, a national, not-for-profit organization of families raising children diagnosed with, or at risk for, early-onset bipolar disorder. Hellander described the nightmare experienced by children and teens with malfunctioning regulatory systems that govern mood and energy.

...[T]hink back to when you were first learning how to drive a car. It's a real exciting time of life... your mom is there with you... You put on your seat belt and you check the mirrors and you get everything all set and your mom says "start up the car." It starts up real good and your mom says, "OK! Now give it a little gas." So you step on the gas pedal and nothing happens. You just sit there. So you try again and the next time you put your foot on the gas pedal it sticks down... So your mom at this point is screaming, "Slam on the brakes! Hit the brakes! So you hit the brake pedal and it goes to the floor... and there's a bus coming toward you!... Your mom grabs the steering wheel and...you're trying to steer out of the path of the bus. But the steering wheel is loose, it's not working well...And on that bus heading straight for you are things like teen smoking, school failure, substance abuse, and maybe even suicide...

"That's how it feels to be a child or teenager with bipolar disorder and to [lack] the self-control that everybody else has," Hellander said. Children with this illness act in ways that cause us to ask, "Why did you do that?" They don't know why they did that. They don't know why they can't control their behavior. Treatment gives them the tools to allow them to accelerate, brake, and steer."

Hellander pointed out that children with undetected or untreated bipolar disorder are at greater risk than other children for problems with alcohol, drugs, and tobacco, and are more likely to attempt suicide. Early diagnosis may spare them from these problems. They need flexible accommodations at school to meet their unique educational needs. Their medical treatment, their education, and the parenting they receive must take into account their neurobiological condition. "As parents, we want to give these kids a working vehicle before they drive off into the sunset, out of our power to help them." The goal of research must be to identify these children while "they're young enough that we can still make a difference," she said.

Hellander enumerated some of the many research priorities that are critical to improving their outcomes:

- Improving understanding of the diagnosis and long-term course of bipolar disorder in young people.
- Developing better diagnostic tools, including biological measures.
- Developing and demonstrating the safety of effective treatments.
- Promoting better understanding of both the strengths and disabilities suffered by these children and adolescents.
- Showing what settings are best for the delivery of psychosocial and educational services.
- Developing and disseminating the best educational practices for schools.
- Finding tools that help families provide the best possible support to their children with bipolar

- disorder.
- Understanding the effectiveness of nondrug treatments that attend to the needs and strengths of the whole child in everyday environments.

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Hellander yielded the podium to Evelyn Green, founder of the Chicago chapter of Children and Adults with Attention Deficit/Hyperactivity Disorder (CHADD), who chronicled her experiences parenting a child with ADHD.

"Correct identification of a brain disorder is difficult at best," she began. "In my community (Chicago's far South Side) a proper diagnosis is often impossible to attain. Minority populations, African Americans in particular, and the poor do not seek or receive adequate levels of diagnosis and treatment for mental illness."

After their son's diagnosis, the Greens opted for treatments that included behavioral modification, social skills training, and parent training. Reluctantly, they also agreed to meet with a physician to discuss medication. They were very wary about medicating their son and agonized about the decision. Was it the right thing to do? Were they bad parents because they could not control him themselves? Would the medicine turn him into a zombie and cause him to lose all of his creativity and spontaneity? Would there be long-term side effects? Cautiously, the Greens began the medication trial, pledging to stop if there were adverse effects or no effects at all.

However, the medicine did help—tremendously, and Green told participants that to this day she and her husband rue the painful struggle they underwent to obtain effective medical treatment:

In retrospect, I am very angry that we even had to experience those doubts and confusion over the medication. Medicating children is not an easy decision for any parent to make, especially when we don't even have a definitive means of diagnosis. We naturally recoil from the idea that young children need medical intervention to control their behavior. Yet if our children were diabetic and needed insulin, or needed cancer treatment, or even needed glasses or hearing aids, we would not hesitate to provide them. ADHD, depression, bipolar illness, and other similar disorders MUST be brought out of the dark closet, labeled mental illness, which is full of shame and fear.

Green cautioned that medication was not a silver bullet. Her son still had some lingering inattentiveness and distractibility, which, during his early school years, were accommodated by understanding teachers, who recognized and appreciated his intelligence and helped him succeed. All of his progress, however, was undone by what Green called "the teacher from hell." This fifth grade teacher had no tolerance for a child who was different. Quickly, her son was transformed from an engaged and confident young person to one who was depressed and increasingly antisocial. He stopped believing in himself and his parents' ability to protect him. Constantly acting out, he got into fights both at home and at school. His once healthy self-esteem disappeared, and by the age of 11 he was threatening suicide.

The audience was gripped by Green's story and audibly empathized with her suffering. Green stressed that she was lucky that her son had made his threat openly, enabling her and her husband to intervene. They traversed the treacherous path of special education—a path they found fraught with the stigma of mental illness and incredibly difficult to access. Today, Green's son is a freshman in one of Chicago's top college prep schools. He participates in school debates and youth programs and, while still struggling academically, has fully regained his self-esteem. "It is imperative that we find ways to help classroom teachers understand how to identify and work with ADHD children and maximize their educational experience without worsening their condition," Green said, and she listed the following areas as top research priorities:

- Discovery of a biologically based diagnosis.
- Availability of better medical treatments.
- Increased knowledge about the long-term effects of medication.
- Development and wide dissemination of better tools and services to help families and educators

best support and nurture these children in their journey to adulthood.

Genetics and Psychiatric Disorders of Childhood

As if in response to Hellander and Green's desire for scientific advances that would improve diagnosis and treatment, the next speaker, Edwin H. Cook, Jr., M.D., director of the Laboratory of Developmental Neuroscience and associate professor of psychiatry and pediatrics, University of Chicago, detailed the promise, confusion, and perils of genetics research.

According to Dr. Cook, "genes importantly influence autism, attention deficit hyperactivity disorder, obsessive-compulsive disorder, Tourette's syndrome, bipolar illness, and schizophrenia.... Like diabetes and asthma and hypertension, these conditions are characterized by a complex genetic underpinning." Dr. Cook attempted to root out the common and often damaging perceptions of these psychiatric conditions: They are not caused by bad parenting, nor are they the result of a single, simple genetic defect. In fact, as with other medical conditions, the complex interplay of various genes likely increases one's vulnerability to or protection against various mental conditions.

Dr. Cook tried to clarify what complex genetics might mean for autism. For example, five genes may be involved in the development of autism, but the illness will result only when all five of the susceptibility genes are present. Perhaps one version of one of these genes enhances anxiety. Another may influence intensity of focus—a trait that may result in some very positive outcomes (such as the tenacious pursuit of a research question, he said with a hint of self-mockery). It is likely that many people have some form of one or more of these genes. Rare individuals have the necessary form of all five of them, and thus have autism.

Dr. Cook noted that genes are not the only actors. Because so many genes—perhaps 50,000—principally act in the brain and because the brain's complexity unfolds over an extended period of development, there are many opportunities for genetic and environmental players to influence one another.

All of this information places disorders such as ADHD and autism firmly in the realm of medical illnesses such as asthma or diabetes. All are serious conditions and all require medical treatment. All have complex and only partially understood genetic inputs, and there is currently no cure for any of them. Thus, Dr. Cook argued that "stigmatizing mental illness is illogical." As his own family has been touched by both autism and diabetes, he understands all too well the shared pain and common pathways necessary for improved treatment and ultimate cure.

Dr. Cook expressed optimism about the medical impact of genetic research. "We know that better treatments are needed for these illnesses. A better understanding of the genes that contribute to the disorders will permit fundamental improvements in drug developments so that the roots of the illnesses are targeted." But he strongly cautioned all to stand firm against discrimination that may crop up in the future against persons with genetic illnesses.

Dr. Hyman joined Dr. Cook at the podium and urged participants to remember the following: "Each of us, by virtue of being human, has some risk genes for mental illness...." It is only when these genes "come together in an unfortunate combination with other nongenetic factors about which we are not yet fully informed [that] we get such illnesses." Dr. Hyman spoke of the problem of using genetics to stigmatize some ethnic groups. He cited a recent study of risk genes for breast cancer in Ashkenazic Jews that resulted in some health insurance companies denying coverage for treatment of breast cancer among all women of this ethnic descent. "One reason we need to be in a dialogue with the public," Dr. Hyman said, "is so that people do not fear [properly conducted] genetic studies." He urged policy makers, employers, and health insurers to resist the temptation to misuse genetic information, but to use it instead to create new and better diagnostic tools and therapeutic interventions.

Which Treatment for Which Youngster?

Finding an appropriate and effective treatment that will improve the lives of youngsters with a brain or behavioral disorder is the ultimate goal of researchers and families alike. John S. March, M.D., associate professor of psychiatry and behavioral science at Duke University, addressed this most salient topic with the assertion that much progress has been made in understanding childhood psychiatric conditions and in treating them effectively. The challenge today is to further expand this knowledge base and make it relevant and accessible to all children in every community via an informed and ethical care-delivery system.

This goal is achieved through what Dr. March calls "evidence-based medicine"—a process by which treatments are developed and tested under relatively pristine conditions, and then in more real-world studies. New interventions are tested on small groups of patients. If the treatments have a positive effect (and are safe) for the small test group, treatment research enters the "boutique phase"—a very carefully selected group of patients is treated under the supervision of highly trained providers. These studies are required to show whether an intervention has a positive impact in small settings. If it does, larger populations of patients—males and females of every color and ethnic group who possess more complicated as well as more common symptoms—are treated under real-world conditions by real-world providers.

The interventions that are generally developed or adapted today are either a form of psychotherapy, called cognitive-behavioral therapy, or medication management, or some combination of the two. Both medication regimens and psychotherapies are effective because they work on the brain.

Dr. March went on to describe the progress made in treating a variety of childhood psychiatric disorders. He first discussed post-traumatic stress disorder (PTSD), a condition that can develop when a child is involved in or witness to a terrible event, such as a car accident or a murder. Some of these children become withdrawn and frightened all the time; they are plagued by nightmares that replay the tragedy in their minds.

To treat PTSD, Dr. March and his colleagues developed a short-term cognitive-behavioral treatment program. Preliminary results from a study of the approach showed that children in the program got better and stayed better. Building on this work, Dr. March is now pursuing a larger study to confirm this positive effect.

Dr. March's research team is also examining the impact of medication and psychotherapy, alone and in combination, for treating obsessive-compulsive disorder (OCD) in a large efficacy trial. He and his colleagues had previously shown the benefits of using cognitive-behavioral therapy to treat children with this condition. Medications such as Zoloft also have been shown to help many with OCD. The question Dr. March is now considering is, how do these various approaches stack up against each other and in combination?

Research to understand and treat ADHD in children has made even greater strides, particularly with publication of the findings of the landmark NIMH Multi-Modal Treatment Assessment (MTA). This large-scale community trial showed that stimulant medication alone was quite effective in treating most children with ADHD. However, the study found that a subpopulation of youngsters benefited from added psychosocial interventions.

Dr. March mentioned his team's latest research project, which is examining the impact of cognitive-behavioral psychotherapy and medication on adolescents with depressive illness. Relatively little is known about effective treatment for depression in young people—clearly an important public health issue, given the prevalence of this disorder in youth, the fairly widespread use of medications among this population, and the mounting youth suicide crisis.

In summary, Dr. March reiterated that much has been learned in the last decade about treating children with various cognitive, emotional, and behavioral disorders, but much remains to be done. Testing our knowledge among broader and more diverse populations in the real world is just the first step.

Translating our findings into practice remains a major hurdle to helping young people with brain and behavioral disorders. Dr. March put it this way:

[T]hese disorders are, in fact, common. They're relatively easy to diagnose using available tools. They're complicated by comorbidity, not only with respect to diagnosis, but also treatment. The treatments that we have, that we know work, involve cognitive-behavioral psychotherapy [and] medications, either alone or in combination. These treatments need to be well delivered and they need to be delivered over the long-term to be maximally effective. And as I think you've seen, we need much more research in order to answer the question we started with: "Which treatment is best for which child?"

The Audience Speaks

After a morning of presentations from scientists and public stakeholders, the audience of health care providers, educators, policy makers, community advocates, family members, and consumers were invited to give their views about the research questions and issues that were most pressing for them. Dr. Hyman stated that "NIMH is ready to hear from patients and others in the community, particularly African Americans, in real health care settings, telling us what treatments have some intrinsic ability to make patients well. What more must we do?" The ensuing discussions were wide-ranging—touching on broad issues, such as the impact of race on research, as well as more specialized concerns, such as the specific disorders that afflict young people. The major themes that emerged are highlighted below.

Inadequate and inappropriate treatment of African Americans was a constant theme in a discussion of race and research. An African-American mother pleaded, "I have a schizophrenic son...he'll take his medicine for a while, then he'll come off of it and come down. He wants to be self-sufficient. He wants to get better. But the medicines, even if they are helpful, are also so depressing and suppressing, filled with side effects. Is there more he can do to get back his life? Are there better medicines or ways to control the side effects?" While the gap between knowledge and practice is wide in many communities, regardless of their demographics, the disparity in treatment is greatest in African-American communities, a fact that caused Dr. Bell to cry out, "Too often, African Americans are given the wrong diagnosis, the wrong medicines, or too much medicine. Yes, there are new drugs. Yes, there are better treatments." Another practicing African-American psychiatrist noted that the problems facing African Americans are compounded by the lack of black doctors, psychiatrists, and psychologists serving their community.

I think part of what the problem is for a lot of my patients is that they go to someone who doesn't look like them, doesn't talk like them, doesn't listen like them, and has had none of their experiences. They believe that providers of different backgrounds don't understand their illness, their neighborhood, their struggles. I think there need to be more people who look like us in our communities taking care of our people. And if not looking like us, at least understanding and being willing to understand.

Participants agreed that redressing the chronic shortage of African-American psychologists, psychiatrists, and social workers is a clear need, as is creating true partnerships between researchers and minorities in the community. Monica Hewitt, a community advocate from Chicago's South Side, reiterated how essential it was to involve communities in research from the start of a project until its finish. "Research has got to be designed to fit our communities; to answer the questions we know are important; to engage members of the minority population in a way that builds trust." This is no small challenge, given the complexity of issues confronting these families as well as the poverty, lack of services, and mistrust that is rampant in parts of the inner city and in many African-American communities.

A discussion of bipolar and depressive illness in children brought forth the commonly expressed need for more treatment professionals, more minority professionals, more bilingual professionals, more professionals who are better trained in the latest research, as well as for more and better coordinated treatments. Jane Boyd, a special educator of children with emotional disturbances who supervises special education programming in a large, suburban Chicago school district, is the mother of two young children with bipolar illness. Boyd stressed the many research questions that are so important if children

with these illnesses are going to get well and develop into productive, happy adults. "The research needs are significant, including a better understanding of what bipolar disorder in youth really is, and how to better identify and diagnose the illness as well as knowing what treatments work and are safe."

Families confronting a variety of illnesses in their children—bipolar disorder, autism, and ADHD—agreed on the need for improved diagnostic methods, better and safer treatments, and improved service delivery. They expressed interest in research that focuses on the whole child—not on just a few symptoms or a medication regimen. Many family members and patients or consumers were put off by a reductionist approach to these illnesses. They want to know, for example, what part nutrition plays in the various illnesses and what they can do to promote a healthful diet in loved ones facing a serious illness. They have questions about alternative medicines and therapies that they hear about in the media. Parents asked time and again how they can promote both the treatment of illness and the recovery and educational and social development of their children.

Providers and parents from poor urban neighborhoods in Chicago also eschewed a reductionist approach. Their children often face multiple barriers: the impairment resulting from a brain disorder as well as poverty, violence, and other privations. They demanded that research take into account the child's whole environment.

In addition to discussing their children's current needs, parents were anxious about the future. They asked again and again, What will be the long-term outcomes for our children with these brain and behavioral disorders? What are the long-term effects of medicines? How will our children with severe disabilities be cared for when we are gone? Linking these concerns to research brought calls for longitudinal studies from Boyd, who represented participants in the bipolar and depressive disorder breakout session, and from Dr. Seth Harkins, assistant superintendent for curriculum and instruction for the North Shore School District 112, who represented the autism breakout group. The goal of such studies would be to improve understanding of the nature of these illnesses and the long-term outcomes for those who are afflicted. Boyd, Dr. Harkins, and Matthew Cohen, then-president of CHADD and rapporteur from the discussion group on ADHD, also requested long-term studies of the impact of medication.

An equally important concern was the need to improve the educational opportunities for children with brain and behavioral disorders. As Cohen stated:

There is a very clear perception that the public schools are not doing an adequate job of addressing these disorders, and that for many children, schools are a hostile environment [that] aggravates the conditions they are experiencing by virtue of the disorder itself.

Nearly every parent and educator who spoke at the conference touched on the need for research that will help teachers and school officials educate children afflicted with these disorders—be it in the regular classroom or in more specialized environments. In so doing, participants voiced a universal desire of all parents and one that is crucial for the future of our society—the availability of a good education for our children.

Participants also expressed their desire that these children be seen as individuals with much potential. Children with brain and behavioral disorders are not just ill—they are developing humans who have strengths and talents beyond their disability. A mother of a child with bipolar illness noted, "My child is marvelously creative, very bright, as so many of the other children with this disorder seem to be. We must recognize and support these abilities." Parents also spoke of the need to eliminate the stigma of mental illness that is so hurtful for these children and their families. Many parents relayed experiences of being blamed by doctors and teachers for causing their children's difficulties. Parents warned time and again that their children, especially those in the African-American community, want research and its implementation to erase the hurtful stigma of being labeled as mentally ill.

Parents talked about the research needs that *they* have: How can they better support their children? How can they better deal with the stress of parenting a child with a serious condition? What can they do to forestall a suicide? What is the science-based information on interventions that really work? Clearly, the caregiver role is a difficult one that can be strengthened and supported with appropriate research

and information.

Perhaps the most consistent message to emerge from the meeting was concern about the inadequacy of current community-based treatment and services. Not only did public stakeholders express a desire for new knowledge, they also lamented the enormous gap between knowledge and practice that plagues poor urban districts and wealthy suburbs alike. The gap was attributed to discriminatory health insurance practices that hinder full and necessary treatment, and to a poorly funded public system of care. Managed care was decried for its focus on cost control rather than quality of services. Providers were criticized for lacking knowledge of the latest scientific findings. "How can we bring the best treatments and services to our children?" Boyd implored. The challenge for NIMH and researchers alike is to devise and test effective ways to bridge the gap so that research findings translate into improved public health practices. Furthermore, NIMH must effectively communicate and distribute the results of its research. As Cohen put it, "NIMH does not only need to do additional research but to more effectively disseminate what it already knows and issue a clear and decisive statement that 'these are real disorders...not subject to debate...not subject to dispute.'"

Wrapping Up the Day

The day's final gathering began with a summary of the information that had been exchanged throughout the day's sessions. James S. Jackson, Ph.D., professor of psychology at the University of Michigan, shared what he has learned from conducting the National Survey of African Americans. This study is a project of the Program for Research on Black Americans (at the University of Michigan Institute for Social Research), which for 25 years has collected, analyzed, and interpreted data on African Americans and addressed questions such as the following: What is the meaning of specific diagnoses in different racial and ethnic groups? How do people of different ethnic backgrounds perceive mental disorders? What do race and culture have to do with these disorders?

A revealing finding of the study, which has informed the current debate about disparities in medical treatment among ethnic groups, is this: "The ways in which black service providers thought of mental health, mental illness, was totally divergent from the ways in which it was [perceived] by white service providers." Dr. Jackson explained, "Our research has tried to document how racism and discrimination [have their] effects on individual health outcomes." How do we understand exactly the pathways by which discriminatory experiences affect mental disorders and other kinds of mental health outcomes? What are the effects over one's lifetime of being discriminated against, living in a society that indeed devalues you? "You cannot understand African Americans outside of the context in which these other things [the economic, social, biological nexus] occur."

Dr. Jackson, an African-American who grew up in a poor community and who worked as a probation counselor before getting his Ph.D., reiterated many of the comments from attending care providers, family members, and public advocates. He eschewed "research that doesn't inform" public health needs. "I think our work is informed by a notion that says we need to understand the context in which we study and provide services, especially to children and to adolescents."

Dr. Jackson described a new NIMH-supported study that he is heading up, which will examine the prevalence of mental disorders and disability in black adolescents and adults around the country and evaluate the context within which these factors occur in their everyday lives. This research should increase our understanding of the impact and many aspects of mental illness in the African-American population.

Katrina Gay of the National Alliance for the Mentally Ill illuminated the need for understanding these ethnic-related impacts by describing her own experiences as the parent of a child with bipolar illness. As an invited commentator on the meeting's breakout group reports, Gay pronounced herself humbled by what she had heard throughout the day. All too familiar with the difficulties of getting urgently needed treatment for her son, of the horror and fatigue of round-the-clock suicide watches, of the toll her son's disease has taken on her whole family, Gay commented that she had never before fathomed how these

difficulties are compounded for African-American families, who must deal with the poverty and strife of inner-city living; the even sparser service system; and the double stigma of race and mental illness. Gay echoed the sentiments of numerous other public stakeholders with these words: "Research is the essence of hope for our children. It is also the fuel for our fight against discrimination in our society."

Gay's remarks were followed by those of Peter Nierman, M.D., the final guest speaker of the day. Dr. Nierman is a board-certified child and adolescent psychiatrist who coordinates mental health services for children and families living in Cook County and in six surrounding counties. As such, he is all too familiar with the tremendous distance between the lofty towers of academic research and the poorly funded and sparsely staffed service centers that confront the tidal wave of human need every day. He began by expressing his hopes that the call to practically apply research findings, as voiced throughout the meeting, would indeed be heard by those who can make a difference:

Research is really good. I mean, the fact is, there's so much good research right now, it's almost unbelievable.... There's a tremendous amount of very good research [on] ADHD, [on] psychosis. What we know about affective disorders and OCD and post-traumatic stress disorder is voluminous compared to where we were 15 years ago. I mean we are in a whole new millennium, without a doubt.... But I must remind you that we are setting up a standard of care that has currently been received by 0.0001 percent of the population of kids who need services. Public and private funding for services has actually declined in the last decade, by 10, 20, even 40 percent.

What can be done? Dr. Nierman identified several priorities that he believes would help close this gap:

1. Develop and implement treatment protocols in partnership with community partners.
2. Use research to show the long-term cost savings of appropriate treatment for these disorders to help advocates access increased funding for these conditions.
3. Develop a workable model for the interface between schools and mental health centers.

The afternoon session concluded with a symbolic coda, as a woman from the audience approached the microphone and said, "I have bipolar disorder. I can tell you from personal experience that having a mental illness makes one a member of a discriminated minority. It's so isolating, so painful, so horrible. I would like for all of you, no matter what your ethnic heritage, to work together to find ways to stop the pain, to find a cure, and to help everyone achieve recovery."

Conversation with the Black Community

The events of the day were capped off with an evening session that shifted in both focus and venue. The NIMH staff, researchers, and public stakeholders in attendance took their forum to the University of Illinois in Chicago—a centralized spot convenient to a variety of black neighborhoods. The evening session focused on the needs and perspectives of the African-American community, and sought to involve local residents in the exchange. The meeting had an open microphone format to encourage questions to and comments from the assembled group of officials, experts, and community representatives—Drs. Steven Hyman, Carl Bell, and James Jackson; Jade Smalls (Miss Illinois); U.S. Congressman Danny Davis; Jan Holcomb (executive director, Mental Health Association in Illinois); Leigh Steiner, Ph.D. (associate director, Office of Mental Health, Illinois Department of Human Services); and Master of Ceremonies Clifford Kelly, a local radio talk show host.

The evening commenced with a welcome and challenge, via videotape, from the U.S. Surgeon General, Dr. David Satcher. It was under Dr. Satcher's leadership that the first Surgeon General's Report on Mental Health was issued earlier this year—a report that urged improved access to treatment for all people with cognitive, emotional, and behavioral disorders. "We know more today about how to treat mental illness effectively and appropriately than ever before. We must turn that knowledge into practice," said Dr. Satcher. He stated that his concern about the lack of appropriate treatment for mental illness redoubles in light of the clear disparities that minority communities face in finding and accessing services and in dealing with poverty, racism, and disease-related stigmatization. "We have allowed stigma and a

now-unwarranted sense of hopelessness about the opportunities for recovery from mental illness to erect these barriers," Satcher said. "It is time to take them down."

Satcher noted that racial and ethnic minorities have enjoyed some favorable disparities over the decades, but these have dissipated in recent years. For example, it is only recently that African-American youths seem to be at increasing risk of suicide; they were much less susceptible to this problem in previous decades. What is it that protected these young people? Spirituality? Strong family and community ties? Many participants urged that researchers study the impact of these factors on outcomes for youth with brain disorders and behavioral problems. One young participant—a boy in treatment for ADHD—reminded those in attendance of the important role that family members play in helping young people get the treatment they need and move forward toward their goals and aspirations.

The dearth of community-based treatment was a constant theme of the evening. One mother recounted the experience of her 22-year-old son who has schizophrenia. "There was no place for him to get intensive treatment in our own community.... He ended up having to go out to a suburb because [there wasn't] enough room in the hospital.... [He was in] a place I couldn't get to...I couldn't visit him during this crisis."

Dr. Bell spoke of his determination to fix this lack of services by improving the child psychiatric infrastructure in Illinois. He said that he wants to connect the dots between science, practice, and policy; between providers, administrators, and agencies; between patients, their families, and positive outcomes. "We do not have a system.... It is horrible...and our children are dying. We need to fix that."

Other speakers commented that stigmatization, lack of funding, and lack of services are not the only factors that deplete the futures of many African-American youth with cognitive, emotional, and behavioral disorders, but that researchers' and treatment providers' lack of connection with these communities is also to blame. "We need to have folks who live in those neighborhoods help us interpret what we are finding," declared Sybil Madison, an African-American researcher at the University of Illinois (Chicago). "If you're experiencing a lot of gang violence, then what you think is ADHD might actually be post-traumatic stress disorder."

Participants at the evening session issued a clear mandate for improved medical services and supports in the African-American community—improvements that build on the strengths of that community—its families and other institutions. They called for a true partnership between the research enterprise and the service delivery system to ensure the successful translation of research findings into treatment protocols. The Honorable Danny K. Davis, a U.S. Congressman from the area who eloquently participated throughout the meeting, encouraged the community to enthusiastically assume partnerships if they hope to see better services. Jan Holcomb, the executive director of the Mental Health Association in Illinois and co-sponsor of the event, made clear throughout the day the need for researchers and NIMH to work with providers and advocates in the community to improve services, especially for underserved children. Indeed, Ms. Holcomb succeeded in translating the NIMH meeting into effective advocacy for increased resources for children's services this year.

Dr. Hyman summarized that only through such partnerships can recovery become a reality for all of America's youth who suffer from these illnesses. In pursuit of this goal, he added, "NIMH will continue to dialogue with communities around the country to assure that this federal agency will listen to the needs of the American taxpayers and stakeholders whose lives are deeply touched by brain and behavioral disorders and work with you to assure access to effective services in every community."

¹ This document was developed from a write-up of the meeting prepared by Alex Poinsett, a writer from Chicago, IL.