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Children with Mental Disorders: Making Sense of Their Needs and the Systems That Help Them

Jane Koppelman, *Consultant*

OVERVIEW — *This paper examines the nature, severity, and prevalence of mental, behavioral, and emotional disorders among children, as well as the types of services that could help them. It looks at how they are served by the education, health care, and child welfare systems, and it identifies the gaps in these systems of care. It also examines the extent to which Medicaid, SCHIP, and private health insurance finance mental health care services for children.*

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Children with Mental Disorders: Making Sense of Their Needs and the Systems That Help Them

From a typical classroom of 25 children, a savvy elementary school teacher will usually be able to point to five children who are different from the rest. They may be overly sad, anxious, distractible, antsy, impulsive, defiant, withdrawn, combative, or some mix thereof. Two of the five may be close enough to the norm to go undetected as “troubled,” but they may struggle, to some degree, or underachieve. Another two may be more clearly troubled and performing more marginally. The last of the five is virtually unreachable by the teacher, who may lack the skills and/or time to deal with that level of disruption or withdrawal.

About one in five children suffers from an emotional or behavioral problem in which their symptoms meet the psychiatric community’s criteria for a diagnosable disorder. Half of this group lives with a disorder that is significantly impairing. One in 20, or about 5 percent of all children, have serious dysfunction.¹

All of these children have a harder than average time trying to enjoy life, do well in school, and form relationships with others. The disorders range from mild to severe, and their effect on children—if left untreated—can be life-limiting or crippling.

Untreated mental disorders tend to become more severe, and their behavioral effects spiral, when compounded by years of the frustration of failing grades and negative feedback from family members, peers, and authority figures. As youth, and later as adults, those with mental, emotional, and behavioral disorders are more likely to use alcohol and drugs—both because they may be more biologically vulnerable to chemical dependence and more likely to want to alter their moods to blunt their distress. More than half of those with a lifetime mental disorder also have a substance abuse disorder. The rates are highest for 15- to 24-year-olds.² In addition, the failure to identify and treat depression can result in suicide, which is the third leading cause of death among all teens and young adults.³

School performance is often another casualty for children with mild to severe disorders. Of all children with disabilities, those with serious emotional disturbance have the highest high school drop out rate. They also have the highest likelihood of landing in jail. Between 60 and 70 percent of children in the juvenile justice system have a psychiatric disorder.⁴ The cost of incarceration for one year is upwards of \$35,000.⁵

National Health Policy Forum

2131 K Street NW, Suite 500
Washington DC 20037

202/872-1390

202/862-9837 [fax]

nHPF@gwu.edu [e-mail]

www.nHPF.org [web]

Judith Miller Jones

Director

Sally Coberly

Deputy Director

Monique Martineau

Publications Director

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Over the past few decades, knowledge of the human brain and its development has increased exponentially. Researchers can predict with better accuracy which preschool-aged children have or are at risk of developing mental disorders; they know how to mute the effects of the disorders and, in some cases, prevent them from developing altogether.

Progress in delivering and financing mental health services over the past decade is evident. Visits of children to psychiatrists have doubled; more children are publicly insured and have mental health coverage; and public policies have begun to design community-based systems of care for children with serious emotional disturbance as an alternative to institutionalization.⁶ Despite these improvements, studies find that most children with mental disorders usually don't get the treatment they need. An estimated 70 to 80 percent of them go without care.

Obstacles to care are numerous. Mental disorders in children are often unidentified or diagnosed too late. Once identified, the child's family must sort through service and payment systems that include private and public insurance, schools, primary care doctors' offices, community mental health centers, and in some cases the child welfare and juvenile justice systems. Most of these systems will not offer a complete package of care, or offer it too late, when serious problems have developed. Often, the care these children do receive does not match with what research has shown to be effective. The combination of these factors led the surgeon general to label children's mental health needs a national health crisis in 2000.

This paper is the first of two produced by the National Health Policy Forum to examine the needs of children with mental health disorders, the systems that care for them, and directions for ensuring that public policies are not only connecting children to needed care, but that the care that children receive is effective.

This issue brief will examine the range of childhood disorders, describe where children fall on the intensity scale, and highlight the services from which they could benefit. It will also look at the various education and health systems that either provide or finance care for these children, and the limitations on eligibility and services.

The forthcoming paper will provide a brief summary of the current science in early detection and treatment of children's mental health problems. It will examine the workforce capacity in both the public and private mental health care systems and the extent to which professional training produces providers that know the most effective techniques for preventing and treating mental disorders in children. It will also discuss ways in which public policies—both in the financing and delivery of care—can promote prevention-oriented, evidence-based systems of care.

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PREVALENCE AND PROFILES

For a number of reasons, mental and behavioral disorders are arguably the most difficult of all childhood conditions to diagnose. Though screening tools are increasingly reliable, accuracy of diagnosis rests not on a lab test but on the reports of feelings and behaviors offered by children, parents, physicians, and teachers. To complicate matters, a number of disorders share common symptoms. Fear of stigma also plays a role; adults tend to resist labeling children for fear of damaging their own or their children's self-image and treatment by society. (There is a lingering public perception that children with mental disorders are bad, not sick, and that either they or their parents are to blame for their behaviors.) Equally challenging is the murkiness that exists between the symptoms of mental disorders and normal adolescent behavior. Adolescents often experience moodiness and outbursts of anger as well as experiment with alcohol and drugs.

According to a 1999 report by the surgeon general, it is estimated that nearly 21 percent of 9- to 17-year-olds has a diagnosable mental disorder.⁷ This means that they meet criteria established by the American Psychiatric Association as having moods or behaviors that are outside of the norm. The most common disorders in children are anxiety, depression, conduct disorder, learning disorders, and attention deficit hyperactivity disorder (ADHD) (Figure 1). A brief description of each follows. (Note: Combined percentages listed below exceed 21 percent because many children have multiple diagnoses.)

■ **Anxiety disorders** are the most common group of mental disorder among children, affecting about 13 percent of 9- to 17-year-olds.⁸ This category includes panic disorder, post-traumatic stress disorder, obsessive-compulsive disorder, and generalized anxiety disorder. Youth with these problems worry excessively about events that require their performance, such as homework, tests, participating in class, and forming and keeping relationships. They sometimes feel driven to perform rituals that seem to serve no purpose, or are immobilized by past traumatic events.

■ Four to 6 percent of 9- to 17-year-olds meet the criteria for **oppositional defiant** and **conduct disorders**. These disorders manifest themselves through a variety of behaviors. These children seem in constant conflict with authority, have a general disregard for the rules of society, perform destructive acts such as vandalism and theft, or "lash out" at adults and peers.⁹

■ **Learning disorders**, commonly called **learning disabilities**, affect about 5 percent of children, causing problems with the way they receive, process, and express information. They can range from mild language and reading problems to decreased mental capacity. Learning disorders make it difficult for a child to learn to read, spell, and do basic math.¹⁰

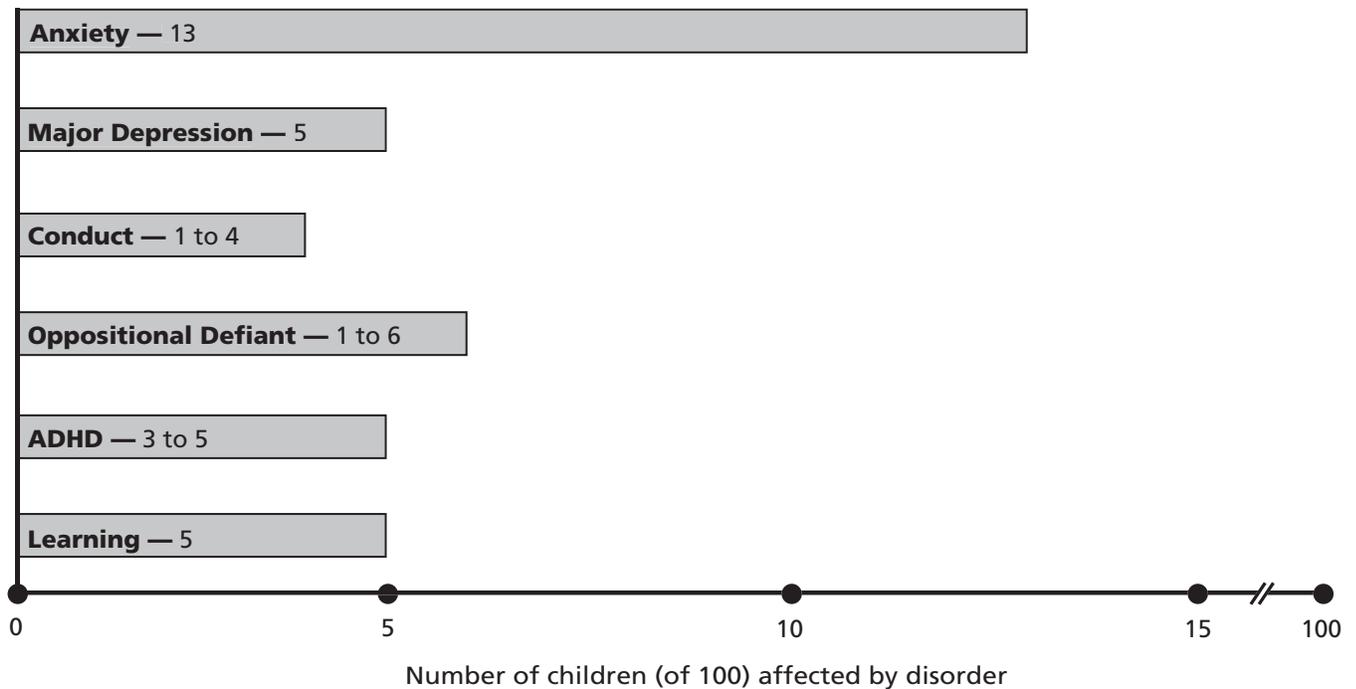
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■ Children with **attention disorders**, such as ADHD, often have difficulty concentrating in school, can be impulsive and distractible, and have problems getting along with—and being liked by—their peers. About 3 to 5 percent of children are estimated to have ADHD.¹¹

Affective disorders, which include major depressive disorder, dysthymia, and bipolar disorder, impair mood, energy, interest, sleep, appetite, and overall functioning. According to the National Institute of Mental Health (NIMH), more than 6 percent of children suffer with affective disorders; about 5 percent of them have major depressive disorder.¹²

All children will experience moments of sadness, feelings of loss, and mood changes as a result of life’s difficulties. Those with depressive disorders have extreme and persistent symptoms. Children with major depressive disorder can seem sad or irritable, lose interest in activities once enjoyed, eat and sleep too little or too much, be lethargic, feel worthless and inappropriately guilty, and, in some cases, think often about death or

FIGURE 1
Common Mental Disorders of Children and Adolescents, Ages 9 to 17



Source: Extrapolated from data included in U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General* (Rockville, MD: National Institute of Mental Health, 1999). Data on learning disorders taken from Reid Lyon, "Learning Disabilities," *The Future of Children*, Special Education for Students with Disabilities, 6, no. 1 (Spring 1996): 54, and from The David and Lucile Packard Foundation.

suicide. Their symptoms last at least two weeks, although usually continue for much longer. Children with dysthymic disorder have less severe symptoms, but their conditions are more chronic, with episodes lasting an average of four years.¹³

■ **Bipolar disorder**, a combination of changing manic and depressive episodes, usually surfaces around adolescence, though it can develop earlier. Depressive symptoms are similar to those of major depressive disorder. When children cycle into their manic phase, they can seem either extremely irritable or overly silly and elated, have an overly inflated ego, exaggerate their abilities, be overly energetic, need little sleep, talk a lot, and engage excessively in risky behaviors. About 1 percent of teens are estimated to suffer from bipolar disorder.¹⁴

■ **Schizophrenia** is a chronic, severe, and disabling brain disease that causes terrifying symptoms, including hallucinations and delusional thinking. People with schizophrenia often hear internal voices not heard by others and believe that people are reading their minds, controlling their thoughts, or plotting to harm them. These symptoms may make them feel afraid and withdrawn. The disease rarely emerges in childhood: the average age of onset is 18 among men and 25 among women. About 1 percent of the adult population suffers with schizophrenia; 1 in every 40,000 children is affected.¹⁵

■ **Autism** is a lifelong neurological disorder that severely impairs one's ability to communicate and interact socially with others. The condition appears before age three. Children with autism generally display little interest in the world or the people around them. They often repeat behaviors over long periods of time, such as banging their heads or rocking. They are also at increased risk of having other mental disorders. Over the past few years, estimates of the prevalence rates of childhood autism have soared.¹⁶ In 1999, the NIMH suggested that 10 to 12 of every 10,000 children are affected.¹⁷ In 2001, the U.S. Department of Health and Human Services (DHHS) reported that as many as one in 500 children could have autism.¹⁸

LEVEL OF SEVERITY AND THE NEED FOR SERVICES

While about one in five children has a mental disorder, the extent to which it interferes with living and learning and the intensity of help children could use to feel and perform better varies dramatically. According to the surgeon general's report, about half of all children with a mental disorder are impaired mildly. The other half—1 in 10 children—are significantly impaired, and 1 in 20 children is considered severely impaired by their disorder (Figure 2). What does this mean?

Experts say that the 10 percent of children with mild disorders display symptoms that are not immediately obvious and, therefore, often go undetected. For example, children with mild depression "might be quiet and withdrawn, they might go home and go to bed. They have a lot of

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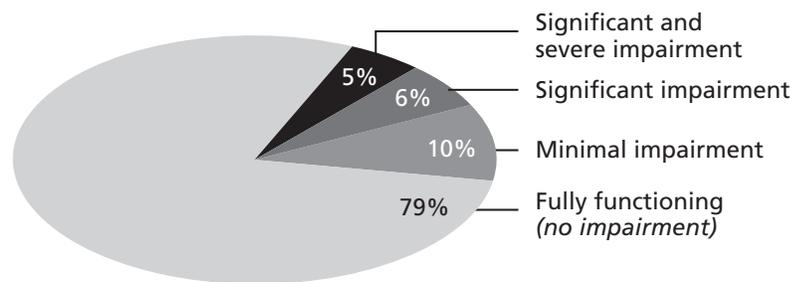
personal distress and often are under performing,” says Steven Forness, a psychologist with the University of California at Los Angeles. Children with mild ADHD “will have trouble getting it together, getting their homework done. Children with borderline anxiety disorders will find it hard to get up in front of class.... These kids drift along and are often ignored or tolerated rather than being fully engaged in their school or family lives,” he says.¹⁹

Experts say that most children with mild mental disorders could benefit from some form of treatment, whether medication, behavioral or behavioral cognitive therapy, family counseling, or some combination thereof. According to Forness, many of these children require limited school accommodations. That is, rather than categorizing such children as needing special education, modest classroom accommodations may suffice, as provided under Section 504 of the Vocational Rehabilitation Act—the same act that offers workplace accommodations to adults with disabilities.

If their disorders are left untreated, children with these mild to moderate impairments often make it through school, because they have supportive families, the will to carry on despite emotional pain, the intelligence to advance in the face of being disorganized and distracted, luck, or some mix. “After they leave school, they’ll probably develop a lifestyle that takes account of their limitations,” says David Shaffer, MD. Schaffer is director of the Adolescent and Child Psychiatry Department at Columbia University’s College of Physicians and Surgeons. For example, people with mood disorders who do well as adults “are those who form very tight marriages...and engage in jobs that don’t overexpose themselves to the potential for embarrassment,” he says.²⁰ “If they do get divorced or if their partner dies, they may do very badly.”

The other half of children with mental disorders who are significantly impaired have a much tougher time dealing with family, school, and peers. For the most part, they are extremely withdrawn or extremely disruptive. “Just about anybody would notice and say something is wrong with these children,” says Richard Mattison, MD, a child psychiatrist and professor at Stony Brook School of Medicine in New York. “The key is that they’re very dysfunctional in school and at home. Many also have learning disorders, which is part of the reason they’re doing so poorly in school,” he says.²¹ Experts agree that the 10 percent of children who are significantly impaired all need some form of mental health treatment: medication, behavioral or cognitive therapies, family counseling, or some combination.

FIGURE 2
Severity of Children’s Disorders (Ages 9 to 17)



Source: Extrapolated from data in U.S. Department of Health and Human Services, Mental Health: A Report of the Surgeon General, (Rockville, MD: National Institute of Mental Health, 1999).

According to Forness, about half to two-thirds of these significantly impaired children also need extra help in school, but not necessarily special education. Teachers can use different strategies to keep them on track. With depressed and anxious children, for instance, teachers can be more sensitive as to how much pressure to apply in class. For students with disruptive behaviors, they can diffuse outbursts by anticipating the child's disruptive behavior before it escalates, perhaps by placing a hand on the shoulder of an antsy child or by sending them on an errand to the office to expend excess energy. School personnel also need to communicate more with parents about how the child is faring at home and at school. "These are not huge interventions," says Forness.²²

The remaining one-third to one-half of significantly impaired children—about 3 to 5 percent of all children—are severely affected by their disorder. Data find that these children, grouped under the umbrella category of serious or severe emotional disturbance, often have more than one disorder combined with a troubled environment. A profile of children with serious emotional disturbance served under a program run by the Substance Abuse and Mental Health Services Administration (SAMHSA) found that 43 percent had disruptive disorders, 35 percent had either depression or anxiety, and one-third had two coexisting diagnoses. More than half had experienced physical or sexual abuse.²³ In another study mapping a similar sample of children, Mattison found that 60 percent had experienced abuse.²⁴ In addition, 90 percent of his sample had one parent with a mental disorder, and most had more than one psychiatric disorder as well as a learning disability.

Children with serious emotional disturbance have staggeringly large high school drop-out rates: 50 percent compared with 30 percent of all students with disabilities.²⁵ If these students with significant emotional disturbance do drop out, they often fare poorly. One study in 1991 found that 73 percent of students with serious emotional disturbance who quit high school were arrested within five years.²⁶

Of all children with mental disorders, those with serious emotional disturbance need the most, and the most intensive, services. Caring for them usually requires a host of individual and family therapy, medication, intensive classroom support, and help during nonschool hours, such as respite care for parents, therapeutic camps, and, in some cases, residential care or partial hospitalization (day treatment).

ARE SERVICE NEEDS MET?

Though estimates vary, studies concur that most children with mental disorders of any severity go without treatment. A major report issued by the Office of Technology Assessment in 1986 found that about 70 percent of children who needed mental health care went without.²⁷ A landmark study released in 1995 by Barbara Burns and colleagues at Duke University found

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that 16 percent of children with diagnoses received some type of care. For children with serious emotional disturbance, 40 percent got some type of care but only 20 percent received specialty mental health services.²⁸

Since the late 1990s, a number of large-scale federal government reports have called attention to the mental health needs of children and the inadequacy of systems designed to serve them. "There is broad evidence that the nation lacks a unified infrastructure to help these children, many of whom are falling through the cracks," notes a 2001 action agenda on children's mental health issued by the surgeon general.²⁹ In 2002, a report released by the President's New Freedom Commission on Mental Health, which assessed the public and private mental health delivery systems in the United States, made a similar observation with regard to children with serious emotional disturbance. According to the report, "Currently, no agency or system is clearly responsible or accountable for young people with serious emotional disturbances. They are invariably involved with more than one specialized service system, including mental health, special education, child welfare, juvenile justice, substance abuse, and health."³⁰ The commission was part of a larger initiative launched by President Bush to promote full access to community life for people with disabilities.

FRAGMENTED SYSTEMS OF CARE

Families turn to a variety of systems to get and help pay for care, yet they often face challenges in qualifying for and receiving the help that their children need. Although data are not available on the exact nature and volume of care provided to children across different service systems, a number of general statements can be made. Overall, in 1998 (the most recent year for which data exist), public and private expenditures on children's mental health services totaled about \$12 billion.³¹ Most of the funding was provided by state and local governments; education and Medicaid dollars were major sources of this revenue.³²

Most public and private mental health dollars spent on children are for those with severe, pervasive, and chronic problems. And, interestingly, school systems are found to be the largest source of mental health services for children.

Schools

Of all sectors, schools play the largest role in serving youth with mental and emotional disorders, ranging from mild to severe. "For the majority of children who received any mental health care, the education sector was the sole source of care," Burns' 1995 study concluded.³³ While schools are by no means serving all children with mental disorders, they are a prominent source of care for two reasons.

First, under the federal special education law schools are mandated to help children with emotional disturbance. The special education criteria,

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however, are narrow enough so that only those with the most serious dysfunction qualify. Second, over the last 20 years, as leaders have focused on the connection between emotional well-being and school performance and as political pressure for academic achievement has mounted, there has been a striking growth in the number and variety of mental health services offered by schools for students with problems not severe enough to warrant, or qualify for, special education. These services are for students at risk for or diagnosed with mild to moderate disorders. In some cases, funding can be used for prevention programs for the entire student body.

Special Education — The Education for All Handicapped Children Act, created in 1975 (now Part B of the Individuals with Disabilities Education Act [IDEA]), requires that all handicapped children aged 3 to 21 receive a free, appropriate education in the least restrictive environment. Instruction is to be provided alongside their nonhandicapped peers when possible and according to the terms of an individualized education plan drafted by school administrators with input from teachers, parents, and physicians.

For school year 2000–2001, IDEA served about 5.7 million 6- to 21-year-olds, or about 11.5 percent of the student population at a total cost of about \$50 billion.³⁴ (The program also served an additional 600,000 3- to 5-year-olds, or 5 percent of the total preschool population.)

Eligibility for IDEA is divided into 13 categories: specific learning disabilities, speech or language impairments, mental retardation, emotional disturbance, multiple disabilities, hearing impairments, orthopedic impairments, other health impairments, visual impairments, autism, deaf/blindness, traumatic brain injury, and developmental delay.

Three of these categories are most applicable to children with mental disorders: specific learning disabilities (SLD), other health impairments (OHI), and emotional disturbance (ED). The SLD category is most appropriate for children with learning disabilities alone. Children qualify if they have problems understanding written or spoken language which, in turn, impairs their ability to listen, think, speak, read, write, spell, or do math.³⁵ Most services provided to SLD students are classroom-based. SLD is the largest category under IDEA. In school year 2000–2001, more than half of all children enrolled in IDEA programs (2.8 million) came under this category.³⁶

In 1991, IDEA was revised to allow children with ADHD to qualify for special education under the category of OHI. Most children with a sole diagnosis of ADHD who qualify for special education are placed in OHI. They qualify if they have a diagnosis of ADHD that harms school performance by causing limited alertness to academic tasks.³⁷ Under OHI, students are eligible for classroom and test accommodations, as well as therapies.³⁸ According to the Department of Education, the number of children served in the OHI category has increased by more than 300 percent since 1991, due in part to the inclusion of ADHD.³⁹ In school

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year 2000–2001, nearly 292,000 children were served under the OHI category, some with conditions other than ADHD. Although about 3 to 5 percent of all children are estimated to have ADHD, the portion served under the OHI category represents less than 1 percent.

Children with serious emotional disturbance (those with the most severe forms of mental disorders or with multiple disorders) can qualify for special education services under the ED category. To qualify, the law requires that students have a psychiatric diagnosis and that their school performance be impaired by one or more of the following: an inability to learn that cannot be explained by intellectual, sensory, or health deficits; an inability to form and maintain good relationships with teachers and peers; general depression; inappropriate behavior or feelings; and physical symptoms or fears resulting from personal or school problems.⁴⁰ In school year 2000–2001, 474,000 children qualified under the ED category.⁴¹

Qualifying under the ED category entitles children to intensive classroom help, usually provided in separate classrooms and, in some cases, separate schools. Because their conditions significantly impair their functioning, ED students can also receive a range of free services outside the classroom, including therapies, day treatment, and residential care. (Under IDEA, schools are not required to provide students with any needed medications.)

These related services, however, are restricted to those that are essential for the child's learning. Over the past 25 years, the limits of schools' responsibility for providing services have been tested in the courts. With some exceptions, schools can usually make the case against providing family therapy, respite care, and other non-school-based services. According to mental health advocates and experts, this is often insufficient, especially for children who are seriously acting out. Mattison says that parents also need to be taught ways to manage their child's behavior. "If you want to help kids with temper [problems] and you're not helping the parent, you're not providing what the students need," he says.⁴²

Because qualifying as emotionally disturbed under IDEA is the door to intensive school help, including some free supportive services, it is critical to note that most children who have a severe emotional disturbance do not receive special education. Although experts find that about 5 percent of all students have serious emotional disturbance, less than 1 percent qualified in 2001 for the ED category under IDEA, and most could have benefited from its services.⁴³

There are a number of reasons why this group is so underserved by special education. In many cases, schools misidentify them as learning disabled under IDEA. One research study published by Forness and his colleagues in 2002 found that nearly half of a group of children with emotional disturbance were labeled by schools as learning disabled.⁴⁴

According to Forness, some schools are mislabeling these children because of they are not usually required to offer therapies or other nonclassroom services to learning disabled students under IDEA. (Residential care, for

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example, used when there are no intensive community-based services for some children with severe emotional disturbance, can cost upwards of \$250,000 a year.)⁴⁵ Thus, learning disabled students are less costly to serve. In school year 1999–2000, the average cost of educating a learning disabled child in special education was \$4,100; for an emotionally disturbed child, it was \$7,700.⁴⁶ “Data suggests that as many as one-third of all learning disabled kids may have either ED or at least have co-morbid ED,” says Forness.⁴⁷

In 2003, testifying before Congress on a General Accounting Office (GAO) study of children who enter the juvenile justice and child welfare systems solely to access mental health care, GAO official Cornelia Ashby told a similar story:

Almost all the parents that we interviewed said that school officials were reluctant to evaluate their children to determine eligibility for special education services or provide specialized services for them. For example, a parent of a child with a mental illness in Kansas said officials in her daughter’s school refused to evaluate the child for a year and a half. After the evaluation, the school recommended that the child work with a learning disability specialist for 30 minutes a week, even though the parent said this service was insufficient and did not address her daughter’s destructive, violent, and aggressive behavior.⁴⁸

Schools may also want to avoid stigmatizing a child by labeling them emotionally disturbed—so they either do not enroll them in IDEA or only do so under the learning disabled category. In addition, they may assume that the public or private mental health systems will provide the care these children require. Interestingly, seriously emotionally disturbed children are likely to come into contact with numerous service systems, although most who get any services get them through special education.⁴⁹

In addition, children with severe emotional disturbance are often extremely disruptive. For years, children’s advocates and researchers have argued that schools prefer to expel rather than serve them under IDEA. They claim that the federal definition of emotional disturbance under IDEA is vague and offers schools a loophole for excluding many children with behavior problems by asserting that their problems are not caused by a mental disorder. Specifically, advocates oppose a clause in the IDEA that excludes children from ED services if they have a social maladjustment. The IDEA does not define this term, but school officials often interpret it to apply to students who consistently break rules.

The resulting application of the ED categorization, to some, seems haphazard. “In fact, the majority of students who have been identified as emotionally disturbed by their school have a conduct disorder and thus exhibit some of the behaviors for which others are suspended or expelled. Sorting students into two groups—suspending one group and giving the other access to special education...cannot be justified from the research,” according to the Bazelon Center on Mental Health Law.⁵⁰

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A number of studies show that, even when children are served under the ED category of IDEA, they do not receive all of the services needed for improvement. Mattison conducted a study over a three-year period in the early 1990s of the St. Louis, MO, special education system, which found that 40 percent of ED children were not receiving any therapy or medication.⁵¹ Another study conducted in 1992 by Pelavin Associates found that only 25 percent of ED children (then categorized as seriously emotionally disturbed) were receiving therapy.⁵²

Non-IDEA Mental Health Services — There is rising consensus in the children's mental health field that schools are the optimal place for reaching out to children. School is the predominant social environment for young people. Here, providers can get to know the students' teachers and peers as well as the way the youths behave in their surroundings and be poised to detect problems early. And the location means that students are much less likely to miss programs or appointments. Increasing the number of school-based mental health services was among the chief recommendations made by the President's New Freedom Commission on Mental Health to help improve access to care for children.⁵³

For the past two decades, the number and variety of school-based programs to address the mental health needs of students has risen dramatically. (SAMHSA will soon be releasing findings from the first national survey that attempts to quantify the amount and type of non-IDEA mental health services provided in schools.) For instance, schools are increasingly partnering with local mental health agencies to place mental health professionals on site. In addition, about 1,500 public schools across 45 states house school-based health centers that staff primary care providers to meet the physical and mental health needs of students. Such centers are usually located in low-income neighborhoods. About 60 percent of these centers employ mental health staff and 80 percent offer crisis intervention services.⁵⁴ In surveys of students who use the centers, mental health is cited as the leading reason for visits.⁵⁵

A variation on this model is the school-based mental health center, a separate clinic on school grounds that solely addresses the mental health—not physical—needs of the students. A number of states, such as New York and Connecticut, as well as the city of Baltimore have provided funding for such centers.

There has also been a steep rise in the number of school-based mental health promotion and prevention programs. Programs include school-wide discipline, violence, teen pregnancy, gang involvement, and substance abuse prevention, as well as self-esteem promotion. They are funded by a variety of sources, including the federal Centers for Disease Control and Prevention, SAMHSA, the federal Maternal and Child Health Block Grant, the Departments of Education and Justice, state and local substance abuse, mental health, and education agencies, and private foundations.

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An example of federal collaboration in violence prevention is the Safe Schools/Healthy Students Initiative, a grant program run jointly by SAMHSA and the Departments of Education and Justice. Designed to prevent youth violence, the Initiative gives about \$145 million to nearly 80 local school districts to encourage partnerships between schools and local law enforcement and mental health agencies. The agencies work together to create a range of violence prevention services for local youth.⁵⁶

Private Insurance

Because nearly 70 percent of children are privately insured,⁵⁷ private health insurance pays a major portion of children's mental health services. Most privately insured children are covered through either health maintenance organizations (HMOs) or preferred provider organizations (PPOs).

Parents of children with serious emotional disturbance who are enrolled in IDEA turn to their plans to provide what schools will not (often times family or individual therapy, respite care, etc.). And for the majority of children with serious emotional disturbance whom the IDEA does not serve, parents also look to private coverage when expensive services are called for, such as residential care.

Private insurance is also an important source for children with more moderate disorders. Parents of these children usually turn to their plans first to seek coverage for individual and family therapy and medications.

Most plans, however, place limits on mental health visits, and some either exclude or limit coverage for certain mental disorders, so children with mental health problems rarely get all the care they need from private insurance.⁵⁸ Though privately insured children accounted for nearly half of the \$12 billion spent on children's mental health in 1998, much of the care they received was paid for by other sources. According to the National Conference of State Legislatures, "A relatively large portion of specialty care is not paid for by [private] insurance; instead, the out-of-plan specialty care is often provided through the education system."⁵⁹

In 1996, Congress passed the Mental Health Parity Act, which eliminated annual and lifetime dollar limits that private plans can place on mental health care services. (The law applies to companies with 50 or more employees and excludes self-insured plans.) The law, however, does not prohibit plans from placing limits on numbers of outpatient visits and inpatient days or from excluding treatment for certain diagnoses. Although 33 states have passed their own mental health parity laws, many of which exceed the federal standard, serious emotional disturbance is a category commonly not included.⁶⁰

In 2002, the Maternal and Child Health Policy Research Center released a study assessing children's mental health care coverage in 98 of the most commonly sold HMO and PPO plans across the country. It found that prescription drug benefits were not covered by about 20 percent of

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plans. Another 20 percent of plans offered drug coverage but not to those with ADHD in particular or a behavioral disorder in general. More than 20 percent of plans excluded coverage for residential treatment and partial hospitalizations. "Ancillary therapy and mental health therapy were the benefits least likely to be available in the amounts considered necessary by medical experts who routinely treat children with special needs," the study concluded.⁶¹

Medicaid

About 20 percent of children with a diagnosed mental health problem are publicly insured—most of them through Medicaid.⁶² In 1998, Medicaid covered 24 percent of all children's mental health care expenditures.⁶³

On paper, children covered by Medicaid have more generous mental health coverage than their privately insured peers, and Medicaid is required to pay schools for the costs of health-related IDEA services for such students. Under the Medicaid Early and Periodic Screening, Diagnosis and Treatment (EPSDT) benefit, children are entitled to medically necessary services to treat a condition. This includes mental disorders detected during a screening, which is intended to include an assessment of a child's mental health needs.⁶⁴ Depending on need, services covered can include inpatient and residential care, medications, and a range of outpatient therapies and support programs for the family.

The EPSDT benefit to treatment was strengthened in 1989, largely to better serve special needs children, because the services they required were too often optional under state Medicaid plans. Today, in practice, Medicaid children enjoy much fewer restrictions on length and types of mental health services than privately insured children. But there are still formidable barriers to care.

A number of studies have found that states, both through managed care and fee-for-service Medicaid, have come up short in fully implementing the EPSDT entitlement. Problems include low payment rates (one Minnesota psychologist told the GAO in 2003 that Medicaid reimbursement for a therapy session was about half the customary rate.⁶⁵), provider shortages, lack of parental awareness of the EPSDT screen, and concerns that managed care's capitation arrangement discourages plans from offering care. (More than half of Medicaid recipients are enrolled in managed care plans.) A 1999 report by GAO found that at least 28 states had been sued since 1995 by parents or advocates for failing to provide access to EPSDT services.⁶⁶

Because, in many states, decisions of what constitutes medically necessary care are still made on a case-by-case basis, accessing some services requires legal action by parents. According to the Bazelon Center for Mental Health Law, attorneys have had some success getting Medicaid to pay for in-home services and behavior management, services for ED children that IDEA usually does not cover.⁶⁷

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SCHIP

In 1997, Congress enacted SCHIP (State Children's Health Insurance Program) to provide health coverage to low-income children whose families' incomes are too high to qualify for Medicaid but too low to afford private coverage. States can choose to operate SCHIP as an extension of their Medicaid programs, as a separate program, or as some combination. For the 16 states that run SCHIP as a Medicaid extension, children's mental health benefits are as generous as those under Medicaid.⁶⁸ In the rest of the states, SCHIP mental health coverage is generally more restrictive than Medicaid's but, overall, more generous than what most private plans offer.

SCHIP programs operate separately from Medicaid do not have to follow Medicaid's coverage rules. These programs can charge premiums and copays and can offer fewer mental health services than what Medicaid requires. For example, non-Medicaid SCHIP programs in California and Utah are not required to cover residential care and targeted case management, nor do they have to provide EPSDT screens or coverage for care deemed necessary through a screen.⁶⁹ Most non-Medicaid SCHIP programs place limits on inpatient and outpatient mental health visits, and some limit inpatient substance abuse services.⁷⁰

Child Welfare and Juvenile Justice

A small but striking portion of families with children with serious emotional disturbance have relinquished custody of their children to either the child welfare or juvenile justice systems for the sole purpose of accessing mental health care, a circumstance the President's New Freedom Commission on Mental Health calls "appalling."⁷¹ Known as a custody for care trade, most families caught in this dilemma are middle class and do not qualify for Medicaid, which offers the best coverage for the array of intensive services their children need. Most often their private insurance does not cover such services, or they have exhausted their private coverage. Once placed in the custody of the foster care system (under Title IVB of the Social Security Act, the Child Welfare Services Program) children become eligible for Medicaid.

Through the juvenile justice system, mentally ill children arrested for certain crimes can receive residential treatment and partial hospitalization for free when it is ordered by the courts. Children with court-ordered treatment are also often given preference for care slots, which is why some families who have insurance but face long waits for services place their children in police custody.

A 1999 survey conducted by the National Alliance for the Mentally Ill of about 900 parents of children with serious emotional disturbance found that 20 percent of parents had relinquished custody to get intensive services that their children needed but could not get, either due to cost or availability.⁷² And a GAO study based on a sampling of 30 counties in 19

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states, found that, in fiscal year 2001, there were at least 12,700 cases of children placed in the custody of child welfare and juvenile justice systems so they could access needed mental health services. About 3,700 children went to child welfare systems; another 9,000 were placed in the juvenile justice system by police who had detained children—sometimes at parents' request—for delinquency related to their emotional disorders. Because less than half the states were surveyed, the GAO stated that the number was most likely an undercount.

Public System of Mental Health Care

The public mental health care system is an umbrella term for both public financing streams and direct service programs for low-income and uninsured children, as well as those in state custody. Medicaid is the largest public payer of mental health services. Other public funds mainly come from state and local mental health authorities, which receive some funding from SAMHSA (through block grants and discretionary programs) and other federal agencies. State and local child welfare and juvenile justice agencies fund mental health care for children in their custody.

The largest federal direct service program for children's mental health is the Children's Services Program funded by SAMHSA. At a fiscal year 2004 budget of \$102 million, it offers grants to localities to develop community-based systems of care for children with serious emotional disturbance. The goal is for communities to develop an infrastructure of high-end care—case management, respite care, family counseling, and day treatment—so that children with serious emotional disturbance get the support they need to be able to live at home. With grants to about 40 to 60 communities a year, the program serves about 6,000 children annually.⁷³

Other direct service programs include federally funded community mental health centers, which also receive substantial third-party revenues from Medicaid, and a range of clinics and programs supported by state and local mental health authorities. Some jurisdictions offer a generous array of in-home therapy, day programs, and intensive case management for children with serious emotional disturbance. However, the surgeon general's report notes, "since there has never been a mandate to states to provide mental health services to children and adolescents, the state or local support for such services has been variable."⁷⁴

Thus, the strength of the public mental health care system relies on the strength of Medicaid funding and the well-being of state and local economies. Due to problems in both arenas, public funding for mental health care over the past three years has been cut. In 2002, according to the National Mental Health Association, nearly two-thirds of states cut mental health services through their state mental health budgets, Medicaid, or both.⁷⁵ Between 2000 and 2002, 16 states instituted rules to restrict access to psychotropic medications.⁷⁶ Budget cuts have yielded a variety of shortfalls. In Arkansas, for example, private, nonprofit mental health providers

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that contract with the state have had to reduce the length of treatment sessions and increase the length of waiting lists.⁷⁷ Oregon cut community mental health funding in 2003 for nearly 4,000 non-Medicaid children and eliminated 164 psychiatric day treatment slots for youth.⁷⁸ That same year, in response to budget cuts, the Missouri Department of Mental Health decided to close a 12-bed children's unit.⁷⁹

EARLY IDENTIFICATION AND TREATMENT

Studies find that the earlier that emotional and behavioral problems are addressed, the better the outcomes. According to a Department of Education report on special education, "Emerging research indicates that intervening early can interrupt the negative course of some mental illnesses and may, in some cases, lessen long-term disability...longer periods of abnormal thoughts and behavior have cumulative effects and can limit capacity for recovery."⁸⁰

A number of studies find that prevalence rates for mental disorders are about the same in young children as in older children. You just have to look harder to find them, explains Neil Halfon, MD, a child development expert based at the University of California, Los Angeles.⁸¹ The rates are particularly constant for children with disorders that cause disruptive behaviors.⁸² For example, one study involving 3,800 preschools found that 21 percent of the children showed signs of a psychiatric disorder, 9 percent of them severe. Research done on local Head Start programs shows a prevalence range of between 5 and 33 percent.⁸³ In particular, behavior problems that cause later school problems can be picked up early. In one study of 22,000 children entering kindergarten, about 10 percent showed behaviors "predictive of early school failure. For low-income children, the estimates are usually two or three times as high," according to a report issued by the National Center for Children in Poverty.⁸⁴

There are a number of known risk factors for developing emotional problems and disorders: biological factors (prematurity, traumatic brain injury, prenatal exposure to alcohol and cigarette smoke), family factors (resources, capacity, and stresses), and parenting factors (responsiveness, sensitivity, and parental mental health). Poverty is known as an indirect risk factor because it can cause behavioral problems among parents, facilitate chronic stressful environments, and increase the risk of child abuse.⁸⁵

Some of Mattison's research on children with emotional disturbance found that early intervention improves outcomes. In one study, he and his colleagues followed 150 children receiving ED services in public school. Success was measured by rates of mainstreaming and high school completion. Students with unsuccessful outcomes were those who were placed in residential care, dropped out of high school, or spent time in a corrections or substance abuse facility.⁸⁶ "The most powerful predictor of success was age," says Mattison.⁸⁷ "The younger the kids were referred for ED services, the higher their chances were of having a successful outcome."

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Mounting evidence suggests that pediatricians, usually the first nonfamily members to assess a child's health, are missing an opportunity to flag these children early. According to the American Academy of Pediatrics (AAP), there are a number of screening tools that pediatricians can use to assess children through age eight that can identify 70 to 80 percent of children with problems. But a new AAP study finds that only 15 percent of pediatricians always use a screening tool.⁸⁸ Parents are also failing to follow up on problems that come to light. One major study of primary care physicians found that 59 percent of children referred to a mental health specialist never went for treatment.⁸⁹

Schools are also doing a poor job of identifying these children. One study by Forness found that parents of ED children first noticed a problem at age 3.5. By age 5, these children were first noticed by outside agencies—either physicians or child care providers. On average, they were first assessed for special education at the end of second grade and, in more than half of the cases, were misplaced into a learning disabled category. Not until fifth grade did the children in Forness's study receive the appropriate services.⁹⁰

CONCLUSION

About 20 percent of all children have an emotional, mental, or behavioral disorder; about half of them are significantly impaired in their ability to function at school, at home, and in society. Yet between 70 and 80 percent of these children receive no help.

The service systems designed to help these children are riddled with gaps. These children are underidentified and underserved by the education system, one of the few public systems mandated to serve them. Private insurance coverage often falls short, and Medicaid, a major payer of care for children's mental health services, is often underutilized. The need for counseling, family supports, and intensive intervention services for mild to seriously disturbed children far exceeds the supply offered by the public mental health system. Families are too often forced to relinquish custody of their children to the child welfare and juvenile justice systems solely to access mental health care that they otherwise could not find or afford.

Part II of this series will discuss mental health professional workforce issues and ways that public policies—both in the financing and service delivery—can promote prevention-oriented, evidence-based systems of care.

Mounting evidence suggests that pediatricians are missing an opportunity to flag these children early.

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