Troubled Children: Diagnosing, Treating, and Attending to Context

A HASTINGS CENTER SPECIAL REPORT

ERIK PARENS AND JOSEPHINE JOHNSTON
THE PROJECT

To better understand the controversies surrounding the diagnosis of mental disorders in children and recent increases in the use of medications to treat these disorders, The Hastings Center, with a grant from the National Institute of Mental Health, conducted a series of five workshops over the course of three years that brought together clinicians, researchers, scholars, and advocates from a variety of disciplinary backgrounds with widely diverse views. The first and last workshops considered the controversies generally, while each of the middle three workshops considered the debates in the context of one diagnosis—attention deficit hyperactivity disorder, depression, and bipolar disorder, respectively.

This report draws on what we, the authors, learned from these five workshops and from our reading of the scientific and scholarly literature. While it is the work of its authors, it grows out of the project’s final workshop, to whose participants we are deeply grateful for their insights and willingness to engage us and each other: Mary G. Burke (Sutter Pacific Medical Center and University of California, San Francisco), William B. Carey (University of Pennsylvania), Gabrielle A. Carlson (Stony Brook University School of Medicine), Peter Conrad (Brandeis University), Lawrence Diller (University of California, San Francisco), Jörg Fegert (University of Ulm), Michael B. First (New York Psychiatric Institute and Columbia University), Karen Harkness (University of Connecticut), Kelly J. Kelleher (Ohio State University), Roy P. Martin (University of Georgia), Jon McClellan (University of Washington), Sara Maschke (The Hastings Center), William E. Pelham, Jr. (State University of New York at Buffalo), Susan Resko (Child and Adolescent Bipolar Foundation), John Z. Sadler (University of Texas at Dallas), Ilina Singh (London School of Economics and Political Science), Bonnie Steinbock (State University of New York at Albany), Charles M. Super (University of Connecticut), Benedetto Vitiello (National Institute of Mental Health), and Julie Magno Zito (University of Maryland).

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Troubled Children: Diagnosing, Treating, and Attending to Context

BY ERIK PARENS AND JOSEPHINE JOHNSTON

More and more children in the United States receive psychiatric diagnoses and psychotropic medications—this is not news. With those increased rates of diagnosis and pharmacological treatment come sometimes intense debates about whether those increases are appropriate, or whether healthy children are being mislabeled as sick and inappropriately given medications to alter their moods and behaviors.

Some of these debates are inevitable, given the conceptual issues surrounding the diagnosis and treatment of psychiatric disorders in general and the application of these diagnostic categories and treatment modalities to children in particular. In this report, we will describe many of those complexities, paying close attention to the ineradicable role that value commitments play not only in decisions about the appropriate modes of treatment, but also in diagnosis.

Because psychiatric diagnoses are judgments—first of the panels of experts who draft the descriptions of the disorders and then of individual clinicians matching diagnostic categories to the child in front of them—they are necessarily influenced by cultural and individual value commitments. The exact boundaries between, for example, healthy and unhealthy anxiety or healthy and unhealthy aggression are not written in nature; they are articulated by human beings living and working in particular places and times. While the extreme end of mood and behavioral continua may be clear to almost everyone, there will always be some disagreement about whether a given cluster of moods and behaviors is best understood as disordered, about how exactly to describe some symptoms of disorder, about which particular diagnosis or diagnoses an individual warrants, and about whether some mildly affected individuals are best served by receiving no diagnosis at all. Those disagreements will be influenced by different but reasonable understandings of, for example, the proper obligations of parents and the proper goals of medicine. The fact that children are developing organisms on whose behalf adults are acting—sometimes with and sometimes without the participation of the children themselves—and the fact that the safety and efficacy of treatments is not always clear increase both the stakes and the complexity of the debates.

In this report we will suggest that where disagreements are reasonable, they should be tolerated, given the fundamental ethical commitment to respect for persons. And we will insist that it is important to distinguish between reasonable disagreements and diagnostic mistakes, including over-, under-, and misdiagnosis.

As important as it is to recognize reasonable disagreements, so, too, it is important to recognize how much we can and do agree. Unsurprisingly, everyone who participated in the workshops we conducted agreed that we share a fundamental obligation to promote the flourishing of children, that careful diagnosis takes time, and that treatments should be monitored for safety and effectiveness. No one rejected medication treatments in all cases, nor did anyone believe that severely impaired children would be better off undiagnosed and untreated.

More surprisingly, however, we found wide agreement around the disturbing conclusion that the United States’ mental health care system, educational system, and aspects of its shared culture too often fail children whose moods and behaviors are patently problematic for those children. In these systems, most children suffering mood and behavior problems fail to receive the kind of care that experts recommend; far too often they are not diagnosed at all or are not diagnosed carefully enough. Moreover, these systemic and cultural pressures constrain the treatment choices of clinicians and parents and make it difficult for them to deliver optimal care. Treatment is often only pharmacological, even where a nonpharmacological intervention or a combination of medication and psychosocial intervention would have fewer side effects, be more effective in the long run, and better reflect the parents’ and clinicians’ value commitments.

Too often, little is done to improve children’s environments, even where it is clear that these environments are an important source of the child’s problems or are key to securing lasting improvements. As important and inevitable as our disagreements are regarding the boundaries of “normal” in children, we make a profound mistake if we let them distract us from agreeing that we need to remove the barriers that stand in the way of optimal care for those children who are suffering from moods and behaviors that no one would consider normal or healthy.

Our report is divided into three major parts. In the first, we describe the conceptual and practical complexities associated with defining and diagnosing mental disorders in children. In the second, we describe the complexities associated with deciding whether and, if so, how to treat. Finally, we describe how our current ways of delivering mental health care fail to promote the welfare of children and families.
I. Defining Psychiatric Disorders and Assessing Individual Children Are Complex Activities

Individual clinicians in the United States are supposed to make psychiatric diagnoses based on their determination that a cluster of symptoms described in the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM) is present in the child in front of them and that those symptoms significantly impair the child’s functioning. The DSM’s diagnostic categories are created by committees of experts, drawing on clinical experience and published research. Because those categories are not based on an understanding of the pathophysiology of the clusters of symptoms they name, diagnoses cannot be based on physiological tests. (This situation, though, is not unique to psychiatry; many diagnoses throughout medicine are not moored in an understanding of the underlying pathophysiology.) Today, a psychiatric diagnosis is a judgment based on the clinician’s interpretation of the disorder’s diagnostic criteria, the clinician’s training and clinical experience, the clinician’s observations of the child during the appointment, parents’ and possibly teachers’ and school psychologists’ reports of the child’s moods and behaviors, and often the results of a diagnostic instrument like a symptom checklist or structured interview.

Recognizing the role of judgment in defining psychiatric disorders and making individual diagnoses does not, however, undermine the potential harmfulness of the moods and behaviors at issue, nor imply that modern psychiatry’s diagnostic categories are arbitrary or useless. Across cultures and over time, observers have noticed that some emotional and behavioral traits cluster in fairly typical ways and that extreme versions of some of these trait clusters can make it difficult for individuals to flourish. Hippocrates described melancholia and mania more than two millennia ago. In our own time, anthropologist Arthur Kleinman has found that what we call depression and schizophrenia can be found across cultures, and WHO researchers have shown that forms of schizophrenia are “ubiquitous, appear with similar incidence in different cultures, and have clinical features that are more remarkable by their similarity across cultures than by their difference.” That some of these clusters of traits have been described across time and place suggests the extent to which our environments do not affect the rates at which some mental disorders emerge in populations.

Equally important, however, is the extent to which our environments do matter—in at least two ways. First, some
BY MARY G. BURKE

In the 1990s, internist Vincent Felitti observed that, when asked, his adult patients with chronic diseases tended to report high levels of adverse childhood experiences. His analysis of a large database found that "persons who had experienced four or more adverse childhood experiences" had a four- to twelvefold greater risk for serious adult disease, from depression and drug abuse to cancer, heart, and liver disease. In 2010, The National Comorbidity Survey Replication reported that maladaptive family function (parental mental illness, substance abuse, or criminality; family violence; physical abuse; sexual abuse; and neglect) significantly increases the risk for mental illness, especially in childhood.

In the last decade, molecular scientists have begun to identify mechanisms by which these adverse environmental inputs affect gene expression. Neuroscientists have begun to understand the mechanisms by which environmental toxins affect the brain during gestation and early life. We now know that stress can be one of the most potent toxins of all. Much research has focused on changes to the hippocampus (site of memory storage) and the hypothalamic-pituitary-adrenal axis (site of the flight or fight system). It has illuminated why the combination of chronic poverty, racism, and early, interpersonal violence or neglect is so detrimental to mental health and adult function.

While small and episodic stresses in an otherwise nurturing environment tend to produce healthy adaptation and growth, stresses that occur during a critical developmental window, that are prolonged or severe, or that are multiple and cumulative can overwhelm the brain’s capacity to adapt and survive at full function. This situation of “allostatic overload” leads to a compromised brain, or to one that is especially vulnerable to later life stresses, or to both. It is important to note that, while stress can play an important role in the emergence of psychopathology, it is neither a necessary nor a sufficient cause. Mental illness can develop in children born into stable families and environments, and some children born into chaos can grow up to be stable, loving adults.

Those of us who work with families living in dire poverty, or with foster children who have experienced multiple losses and maltreatment, have found little room to talk about what we see as the underlying causes of children’s stress in the ongoing debate about the role of medications. Indeed, it seems to me that the question whether medications are overused can actually distract us from the other important question: how do we alleviate stress in families?

If exposure to stress increases a child’s chances of developing a mental illness, does that mean we are blaming parents? Of course not. But no medication can remedy the unjust social structures that produce those stresses. Those of us committed to serving socially disadvantaged children have to be able to talk about the sometimes devastating psychological effects attendant on poverty and early maltreatment, and we have to be able to ask policymakers to address that disadvantage. As Felitti has pointed out, it is a public health issue.


environments are more likely than others to contribute to the emergence of particular emotional and behavioral disturbances. Perhaps the most dramatic examples are the traumatic stresses associated with abuse, neglect, and poverty, which we have long known put children at significantly increased risk of some mental disorders. See Mary Burke’s sidebar for more on stress and mental illness.) Research in genetics, epigenetics, and neuroscience over the last decade shows that psychopathology results from exceedingly complex and ever-changing interactions among biological and environmental variables. This research expands our conception of environment beyond the old-fashioned notions of culture, neighborhood, school, peers, and family to include the intrauterine environment and even the cellular environment in which genes are expressed.

It is not, however, only abuse, neglect, and trauma that can affect rates of mental illness. Environments can also matter in the sense that some are more likely than others to predispose parents to prize and cultivate some sorts of moods and behaviors that can look similar to symptoms of psychiatric pathology. More specifically,
Because psychiatric diagnoses are judgments—first of the panels of experts who draft the descriptions of the disorders and then of individual clinicians matching diagnostic categories to the child in front of them—they are necessarily influenced by cultural and individual value commitments.

Some biologically oriented researchers have, however, sought to demonstrate that interpretation or “social construction” does not really matter when it comes to recognizing psychiatric disorders. One group collected studies from across the world reporting huge variation in the prevalence of ADHD—from 1 percent to 20 percent—seeming to confirm that the diagnostician’s interpretation or “construction” is very significant in determining what counts as ADHD.10 They argued, however, that by controlling for methodological differences among the investigators in the different countries they could effectively apply the same diagnostic criteria across the different data sets, which revealed a consistent prevalence rate of ADHD at a little over 5 percent. They then inferred that, as two commentators on their analysis frankly put it, ADHD is “a bona fide mental disorder (as opposed to a social construction).”11

While we accept that ADHD can name a cluster of impairing symptoms, we do not accept that research such as that we just mentioned can by itself show its “bona fide” core. We can imagine, for example, a carefully described cluster of behavioral traits constituting what a panel of experts called Contented Child Syndrome, and that diagnosticians trained to recognize that cluster would find similar prevalence rates across different countries. But that would not alone show that Contented Child Syndrome is a “bona fide” psychiatric disorder, or that “social construction” plays no role in determining which clusters of moods and behaviors are mental disorders.

In view of the ways in which interpretation or “social construction” can affect the diagnosis of psychiatric disorders, researchers in the United States and elsewhere have over the last few decades aspired to put psychiatry on a firmer scientific footing. According to Robins and Guze’s famous criteria, valid psychiatric disorders should have clear clinical descriptions, be distinguishable from other disorders, have a predictable clinical trajectory, aggregate in families, and be identifiable by laboratory studies.14 Biologically oriented researchers have for the last few decades thus searched for the sorts of genetic or neurological markers that a standardized laboratory procedure could
readily analyze to determine a diagnosis. These efforts to “cut nature at its joints” have yielded some intriguing findings. But we do not yet have a genetic or neuroimaging test to diagnose disorders like ADHD or depression, much less their subtypes. Indeed, geneticists increasingly grapple with the fact that, in general, identifying single gene variants—and even identifying patterns of multiple genetic variants—do not yield as much insight into the emergence of these common, complex disorders as was once hoped.

Similarly, neurobiologists grapple with the fact that variations in single neural circuits do not by themselves explain the emergence of common psychiatric disorders. It is increasingly accepted that for a biologically informed system of diagnosis to work, we will need to understand a great deal more than we do today about how myriad genes, multiple neural circuits, and myriad environmental variables all interact over time and in a developing organism to produce complex behaviors.

Former NIMH director Steven Hyman said at one of our workshops that those who seek a thorough understanding of the causes of psychiatric disorders were born too soon. He is hopeful that biological investigation will eventually lead to diagnoses that are valid (or “bona fide”) in Robins and Guze’s sense. In the meantime, though, diagnostic categories of some kind are necessary for clinicians and researchers to communicate with one another about similarly affected individuals, and for children and parents to access treatments and other services. The following six issues begin to explain the respect in which our current diagnostic system can result in disagreements about whether a psychiatric disorder is present, and if there is one, which one.

1) Heterogeneity within diagnostic categories. Children with different symptoms can receive the same diagnosis. For example, according to DSM-IV (the most recent version), the essential feature of ADHD is “a persistent pattern of inattention and/or hyperactivity-impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development.” To receive the ADHD diagnosis, children must exhibit at least six of the eighteen core symptoms listed in DSM-IV. The symptoms are divided into two major behavioral domains: inattention and impulsivity-hyperactivity. Among the nine symptoms of inattention: often making careless mistakes, often having difficulty sustaining attention in play or other activities, and often not seeming to listen when spoken to directly. A child exhibits some of the nine symptoms of hyperactivity-impulsivity if the child often fidgets or squirms, often cannot stay seated, blurts out, and has difficulty awaiting a turn. Different children can exhibit a different cluster of these eighteen behaviors, but receive the same diagnosis.

2) Overlap between diagnostic categories. Children with some of the same symptoms can also receive different
It is increasingly accepted that for a biologically informed system of diagnosis to work, we will need to understand a great deal more than we do today about how myriad genes, multiple neural circuits, and myriad environmental variables all interact over time and in a developing organism to produce complex behaviors.

diagnoses. Consider bipolar disorder. According to DSM-IV, to receive a diagnosis of classic or full-blown bipolar disorder (bipolar I), the individual must experience a manic episode, which is “a distinct period of abnormally and persistently elevated, expansive, or irritable mood” lasting for at least one week. If the patient’s mood is elevated or expansive she must exhibit at least three of the following seven symptoms: (1) grandiosity, (2) decreased need for sleep, (3) pressure to keep talking, (4) flight of ideas and racing thoughts, (5) distractibility, (6) increased goal-directed activity and psychomotor agitation, or (7) excessive involvement in pleasurable activities that have a high potential for painful consequences. If the patient presents with irritability, she must exhibit at least four of those seven symptoms. At a minimum, three of the symptoms used to diagnose bipolar disorder are very similar to those used to diagnose ADHD: pressure to keep talking, psychomotor agitation, and distractibility.

If one adds into the mix the symptoms of oppositional defiant disorder (ODD), which is frequently characterized by irritable mood, it can be difficult to determine whether bipolar disorder, ADHD, or ODD is the best-fitting diagnosis. In practice, children showing a mix of symptoms often receive more than one diagnosis (and are treated with more than one medication).

3) Symptoms of the same disorder can look different in children and adults. DSM-IV contains a special section of disorders usually first diagnosed in infancy, childhood, or adolescence, which includes ADHD. However, clinicians sometimes also diagnose children with disorders listed in other sections of the manual by adapting the diagnostic criteria. Before the 1970s, clinicians theorized that, while children could experience transient sadness, they were not sufficiently emotionally developed to experience clinical depression. By the 1980s, researchers argued that depressive symptoms can take slightly different forms in adults and children. For example, while adults may experience depressed mood and significant loss of interest in activities, small children may be more inclined to show particularly severe separation anxiety, and restlessness, sulkiness, and withdrawal from social activities might be more pronounced in adolescents. Today, the idea that children can experience depression and that their symptoms may be different from those seen in adults is fairly uncontroversial within psychiatry, even if there remains some debate about how best to treat it.

The situation with the diagnosis of bipolar disorder in children is currently quite different. While it is widely agreed within pediatric psychiatry that some rare children exhibit discrete episodes of mania and meet full DSM criteria for bipolar disorder, much of the recent controversy in the United States has been rooted in disagreements about whether it can look quite different in children and adults. Beginning in 1995, some researchers began to argue that chronic irritability (or raging) was a symptom of mania in children, even though in adults clinicians look for distinct episodes of “abnormally and persistently elevated, expansive or irritable mood.” That argument is highly contested, but not implausible. If we take at their word that subset of adults with bipolar who say that their symptoms went unnoticed when they were children, and if we remember that children’s bodies are developing and are different from adults’, it is conceivable that prodromal symptoms of bipolar or symptoms of the full-blown disorder could simply look quite different in children and adults. However, some researchers argue that the symptoms at issue, in particular chronic irritability, are best understood as markers of a different disorder altogether. In 2003, one team began using the term “severe mood dysregulation” to describe these children, and in early 2010 the committee charged with drafting DSM-V proposed a new diagnosis called “temper dysregulation disorder with dysphoria” for children exhibiting severe recurrent temper outbursts in response to common stressors.

4) Careful diagnosis requires identification of symptoms and evaluation of impairment. DSM-IV is clear that the presence of symptoms alone does not warrant a diagnosis; a diagnosis is warranted only when symptoms
create significant impairment. Some impairment might be inferred from the fact that parents make appointments with health professionals, but impairment assessments are unfortunately not always included in diagnostic workups. When they are included, diagnostic rates are lower. In one study, researchers assessing a sample of children for serious emotional disturbances found prevalence rates of between 4 percent and 8 percent, depending on which of three different impairment measures was used, and a prevalence rate of 20 percent when impairment was ignored. Reimbursement systems, which require a DSM diagnosis, may encourage clinicians to record a diagnosis even when the severity criteria are not fully met, in order to justify the provision of services.

5) The diagnostic system does not encourage assessment of the child’s context. Allan Horwitz and Jerome Wakefield have argued that “the basic flaw” of the DSM approach to major depression is that, with rare exception, it “fails to take into account the context of the symptoms.” For example, while DSM-IV indicates that intense sadness in response to the death of a loved one should not be considered a symptom of depression, it does not mention the myriad other sorts of normal human problems that can trigger intense sadness—from the lack of strong, meaningful attachments to job loss (in adults) to being bullied or neglected (in children). As a result, Horwitz and Wakefield argue, people who are intensely but appropriately sad due to life events or circumstances can mistakenly receive a diagnosis of depression. (They are thinking primarily of adults, but the same analysis applies to children.)

It is perhaps not surprising that Horwitz, a sociologist, and Wakefield, a philosopher, would lament the lack of attention to social context. The foreword to their book, however, was written by Robert Spitzer, the head of the American Psychiatric Association’s DSM-III task force. Spitzer notes that the definition of mental disorder involved dysfunction or impairment. This brings us to a second deep tension in the diagnostic manual. Whereas the introduction to DSM-IV acknowledges that psychiatric diagnoses refer to phenomena that are dimensional, the body of the text uses categories to name them.

When the DSM-IV authors use “dimensional” in the introduction, they refer to the fact that symptoms appear on a continuum of expression or intensity, and that so, too, can disorders. Individuals who, for example, exhibit a single symptom such as sadness can do so to different degrees. And individuals who exhibit a cluster of symptoms indicative of clinical depression can also do so to different degrees, which can produce different degrees of impairment. (The authors of DSM-V are working to incorporate the fundamental fact of dimensionality into the next version of the manual.) Determining whether a given child’s moods and behaviors are intense enough to be labeled disordered is further complicated by the fact that, as still-developing organisms, their moods and behaviors can be very different from those we see in adults and can vary greatly depending on the age of the child (it may be normal for a four-year-old child to talk with an imaginary friend, but not for a fourteen-year-old or an adult). Indeed, the experiences of children who do and do not live “under the description of” a psychiatric disorder, as the anthropologist Emily Martin would say, are
Recognizing the role of judgment in defining psychiatric disorders and making individual diagnoses does not deny the potential harmfulness of the moods and behaviors at issue, nor imply that modern psychiatry's diagnostic categories are arbitrary or useless.

not always as radically different as the categorical labels can seem to suggest. There is, for example, a continuum between children who do and do not warrant the diagnosis of depression: most children, after all, at some time experience sadness, or sleep disturbance, or eating disturbance. This dimensionality is not unique to children or to psychiatry. There is also a continuum between adults who do and do not warrant a diagnosis of, for example, hypertension. But because a trait like mood is closer to our sense of identity than a trait like blood pressure, and because recognizing these traits as symptoms of a disorder requires greater observer interpretation than reading blood pressure results, our values play a bigger role in determining where to draw the line on the depression continuum than on the blood pressure continuum.

Individual and Cultural Values Influence Diagnostic Systems and Diagnosis in Practice

These potential disagreements about whether (and which) disorder is present do not imply that childhood psychiatric diagnoses are not real. The clusters of moods and behaviors described in the DSM can cause real—and significant—suffering in children, creating significant costs to families, the health care system, the education system, the juvenile justice system, and employers (through parental work loss). Nor does the possibility of disagreement suggest that DSM diagnoses are arbitrary or hopelessly imprecise. Instead, it urges us to remember that psychiatric diagnoses are tools that physicians have created to think about the very real, varied, and sometimes deeply difficult lived experience of adults and children. Wielded thoughtfully, those categories can help to identify children who can benefit from intervention. But wielding those tools thoughtfully requires remembering that human beings created them, based on their interpretation of the varied and complex moods and behaviors they observe or that are reported to them.

If, further, we remember the fundamental fact of dimensionality, two important features of the discussion about childhood emotional and behavioral disturbances are highlighted. First, there will actually be significant agreement that some children are on one end of a continuum and need help in changing their impairing moods and behaviors, and that other children are closer to the middle of that continuum and deserve to be affirmed in their atypical-but-not-impairing ways of being. Or, in more colloquial parlance, there will be ready agreement that some atypical children are sick and that other atypical children are healthy. Second, there will be a zone of ambiguity between those uncontested regions of the continuum, in which reasonable people will disagree about whether or not a given child is suffering from a disorder. Because observers will bring different value commitments to their diagnostic analyses, some will have an expansive conception of disordered behavior, and others will have an expansive conception of normal variation. Acknowledging the existence of a zone of ambiguity and the role of value commitments in this zone does not undermine the seriousness of the problems that families and children experience, although as Susan Resko shows in her sidebar (see page S12), it can sound that way to some who deal with these problems day to day.

Given the ineradicable role of value commitments both in principle (in the DSM, diagnostic guidelines, and diagnostic instruments) and in practice (does the child in front of me warrant a diagnosis?) it is, at least for now, inevitable that reasonable people will sometimes disagree about how to define mental disorders and about whether a given child would be harmed or helped by living under the description of a particular psychiatric diagnosis.

Reasonable disagreements. Psychiatry is not unique in harboring disagreements about how narrow or broad our conceptions of illness and health should be—or about how cautious or aggressive our treatment approaches should be. Some observers are untroubled by the tendency of medicine in general—and psychiatry
Values Talk Exacerbates Discrimination

BY SUSAN RESKO

It’s all well and good for academics to write about the role that “values” play in the diagnosis and treatment of childhood mental illness. However, as executive director of the Child and Adolescent Bipolar Foundation (which, I should note, does not seek or receive financial support from the pharmaceutical industry), I represent the voice of parents who love and care for these children. I want to share our perspective.

Merely debating the use of pharmacological treatments in children rubs salt in the open wounds of affected families—it feels like an accusation that parents are irresponsibly drugging children when there are other, better treatments available. Children need access to all forms of treatment: therapy, school accommodations, and, yes, medication. To debate the merits of only one leg of the treatment triangle is shortsighted. It vilifies that intervention and implies that it’s not necessary.

Suggesting that parents’ or physicians’ values play a role in driving up diagnostic rates aggravates that wound even more—people who make that suggestion sound like they think there really is nothing going wrong with these children, even though some of these children try to harm or even kill themselves. Others cannot function in mainstream classrooms, and they cannot interact with family and friends.

I can’t imagine anyone seriously discussing the role that “values” play in diagnosing cancer or suggesting that medications that shrink cancers are just tools to force people who are different to be like everyone else. In my opinion, anybody who said such things would be ridiculed or ignored. When a child undergoes chemotherapy, no one asks why parents would allow their child to risk nausea, hair loss, a compromised immune system, and even death. No one accuses drug companies of pumping our children with poisons in the name of profit. Instead, we set up care pages, car pools, and prayer chains for these children and families. However, when a child suffers from a psychiatric illness, friends and neighbors turn a blind eye and society maligns parents, doctors, and industry for intervening with lifesaving medications.

The theory of “medicalization” that is used to describe increased rates of diagnosis (and that is advanced by Peter Conrad in his sidebar and is discussed in the main article) makes parents into scapegoats instead of grasping the real problem. Families of yesteryear were encouraged to write off their children as bad seeds because physicians did not understand the nature of mental illness. Does anyone really want to go back to the days of punishing children for their illnesses and blaming parents for causing them? Does anyone really want to revert back to the days when “refrigerator mothers” were blamed for creating autistic children due to their cold and unfeeling demeanor?

In fact, many children who live with serious psychiatric illnesses also live in loving, stable homes. Parents do the best they can to use whatever tools are available to help their children flourish. These families deserve the same respect and support as families afflicted with cancer.

BY SUSAN RESKO

in particular—to treat problems that seem to have their proximate cause in educational, social, or cultural mores rather than in pathophysiological dysfunctions. Such observers have an expansive conception of the proper goals of medicine and psychiatry. They can argue that, insofar as the goal of medicine and psychiatry is to promote the well-being of persons, and insofar as what counts as well-being is expanded and the thresholds for diagnosis lowered, poses risks to individuals and society. As Peter Conrad explains in his sidebar (see page S13), some critics are concerned that the medicalization process—which locates the child’s problem in her body rather than her context—is fueled not by the needs of patients, but by drug companies, which profit by creating or expanding disorders for which they then market medication treatments, even where the medications have limited efficacy and carry the risk of serious side effects. As William Carey explains in his sidebar (see page S14), other critics are concerned that we are losing touch with what is normal for children.

Conrad, Carey, and others demand that we recognize that a wide range of human temperaments and behaviors are compatible with a healthy human life. Surely this is right. Nonetheless, it can also be true that many of the children diagnosed with mental disorders can be helped by a medical understanding of their problems. Some of
these children have been traumatized or deprived, some have a poor fit between their strengths and weaknesses and the qualities it takes to succeed in our society, some have “wiring” that predisposes them to problematic moods and behaviors, and the most unlucky have all three. Whatever the causes of their symptoms and impairment, these children are suffering now and need help. Many would once have been dismissed as “stupid” or “bad,” institutionalized, or left alone to fail. In our culture and within the constraints of our institutions and systems, one—though not the only—important way to help these children can be to recognize their behaviors and moods as symptoms of a mental disorder and to offer them evidence-based treatments.

Whether one has a narrow or broad conception of the goals of psychiatry, or of medicine in general, and whether one is more or less distressed by medicalization of children’s moods and behaviors, can partly depend upon the

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**Medicalization**

**BY PETER CONRAD**

The increasing number of psychiatric diagnoses in children and the rising use of psychotropic medications described in this report are part of a larger trend toward the medicalization of society. Over the past four decades, an increasing number of human conditions have been medicalized, including alcoholism, obesity, anorexia, erectile dysfunction, menopause, Alzheimer disease, and sleep disorders. To these we can add the increased diagnoses of attention deficit hyperactivity disorder (ADHD), Asperger syndrome, and childhood bipolar disorder. The broad expansion of medical categories and their subsequent treatment have brought more individuals and life conditions and problems into medical jurisdiction.

Medicalization occurs when previously nonmedical problems become defined (and treated) as medical problems, usually as an illness or disorder. The main concern about medicalization is how something becomes defined as medical and with what consequences. While one commonly expressed concern is “overmedicalization,” the social process itself, like urbanization or secularization, is not necessarily either good or bad. Medicalization is on a continuum, with some conditions more medicalized than others, and we can also speak of demedicalization (which has happened with masturbation and homosexuality)—although many more conditions have been medicalized. Medical categories can expand or contract. When ADHD was first diagnosed and treated, it was seen as a disorder for children, mainly boys. But as the focus of the definition shifted to attention and away from hyperactivity, an increasing number of girls were diagnosed with it. Soon we began to see adolescents diagnosed with ADHD, and in the past two decades we have seen the rise of adult ADHD. The thresholds for ADHD, both in terms of age and behavior, have shifted so that now it can be deemed a lifetime disorder affecting a far larger number of people.

The engines underlying medicalization have shifted as well. In the 1970s, physicians were key, but currently the pharmaceutical industry, consumer and advocacy groups, and the health insurance industry have become more powerful engines. Physicians are now sometimes just gatekeepers for medicalization, as exemplified in the pharmaceutical mantra, “Ask your doctor if (name of drug) is right for you.” Direct-to-consumer advertising has become an important vehicle for medicalizing new categories and their drug treatments.

What are the problems with medicalization? I can list just a few here: (1) everything becomes pathologized, turning all human difference into medical problems; (2) medicine gets to define what is normal, whether it is behavior, body shape, or learning ability; (3) attention is focused on the individual and away from the social context, which may be the primary source of the problem; (4) medicine is viewed as a commodity; and (5) “consumers” are at risk for the adverse side effects associated with the powerful medications often used to respond to medicalized problems. For these reasons, it is important to recognize medicalization when it is occurring.

Primary Care Physicians Need a Better Understanding of Temperamental Variation

BY WILLIAM B. CAREY

Primary care clinicians and educators are usually the first stop for parents concerned about their child’s moods and behaviors. It is important, therefore, that they can distinguish annoying-but-normal variations in behavioral style or content from true dysfunction or “disorders,” and that they can distinguish problematic behaviors that warrant medical intervention from those that do not.

Variation in children’s temperament is a fundamental fact of nature. Atypical but perfectly healthy styles of behaving may arouse concern and conflict with the caregivers when the child does not fit the adults’ expectations or preferences. Behavioral styles like low adaptability, shyness, negative mood, or high intensity, when they do not lead to true behavioral dysfunction, require understanding, tolerance, and better accommodation by the child’s caregivers. Medications are inappropriate for these often unpopular, innate, normal traits.

Dysfunctions in behaviors can take many forms, have many different causes, and warrant different responses. Behavioral, emotional, and functional problems or “disorders” can arise in the six “BASICS” areas: behavior competence in social relationships, achievements (task performance and mastery), self-relations (esteem, care, and regulation), internal status (feelings and thinking), coping (problem-solving patterns), and symptoms of physical functioning (eating, sleeping, elimination, and so forth). If a child exhibits a problem with one of those behaviors, and if the problem can be determined to arise as the result of a conflict between the child’s temperament and her environment, then, again, accommodation (not medication) is called for. What needs to be altered here is not the child’s biochemistry, but the caregiver’s unsuitable response to the child’s individuality. For example, poorly managed low adaptability may result in the development of an unacceptable pattern of opposition. Intervention should include both behavioral management of the reactive opposition and instruction for caregivers and teachers on how to handle the temperamental inflexibility.

Physicians can help to educate parents about temperamental variation, though this will not always be easy. Sometimes parents simply lack knowledge of how wide the range of normal temperamental variation is; for example, it can be surprising for some parents to see the intensity of their infant’s stranger anxiety or to accept their toddler’s distressing but normal testing of limits. Physicians can also help parents to recognize that their own psychosocial problems may contribute to a distorted view of their children’s behavior; sometimes the parents need psychiatric help more than the child.

Primary care physicians, psychologists, and educators must be instructed in their initial training and continuing education to be aware of the full range of normal behavior. Better education would surely lead to better research and care and to less overdiagnosis of pathology.


extent to which one emphasizes one of two deep obligations that parents must constantly balance. On the one hand, parents have an obligation to let their children unfold in their own ways, to affirm their children as individuals, to let them be who they are. The violin-loving father who pushes his football-loving son to play the violin fails to accept his son and affirm his son’s pursuit of what seems good to him. On the other hand, parents have an obligation to shape their children through discipline, education, and adherence to traditions. A parent who lets his child stay home all day every day and play for as long as, and at whatever, suits him violates his obligation to shape his child.

Though both obligations are fundamentally important, it is inevitable that in particular situations some parents will emphasize the obligation to let children be, and others will emphasize the obligation to shape them. Which obligation one is prone to emphasize may help to explain one’s decision in the zone of ambiguity. Parents who emphasize their obligation to shape their children may be fairly quick to see intervention in the zone of ambiguity as just one more instance of fulfilling that obligation—even though they accept that they also have an obligation to let their children unfold in their own way. If a choice has to be made between promoting a child’s flourishing in our society as it is and affirming her in her behavioral or temperamental differences, these parents might choose the former. Other parents will be more inclined to let their children unfold in their own ways and will therefore be reluctant to see their children’s moods and behaviors as potentially “disordered” and in need of psychiatric assessment.
Whether one is distressed by medicalization can partly depend on how one balances two deep parental obligations. On the one hand, parents have an obligation to let their children unfold in their own ways. On the other, parents have an obligation to shape their children.

One of us (EP) has elsewhere emphasized that medical professionals have traditionally underestimated the capacity of children to participate in making decisions about their own care, and that medical professionals and parents have an obligation to include children in those discussions—to the extent that the children are able to participate in light of their age, maturity, condition, and the nature of the decision. That obligation seems likely to obtain across pediatric medicine, although establishing how much capacity a given child has to participate in decisions about her own care may be more complex in the psychiatric context than in others. The appropriate role of children in making decisions about their own psychiatric care is a hard and important issue. Our working group did not pursue it, but we agree that it warrants further attention.

Recognizing that some disagreements about how to diagnose or treat a given child can arise because reasonable people emphasize different but equally respectable values in no way minimizes the enormous social and economic pressures bearing on families to emphasize some value commitments rather than others. Nor does it in any way minimize the need to distinguish between reasonable disagreements and mistakes.

**Diagnostic mistakes.** Clinicians, teachers, and parents—all of whom may be pressed for time and burdened by cultural, systemic, and resource pressures—can make at least three sorts of diagnostic mistakes. The first sort entails overdiagnosis: clinicians can diagnose (or if they are nonclinicians, they can think they see) a disorder on the basis of observed behaviors or moods but fail to recognize that those symptoms are not associated with impaired functioning, or they can fail to consider the possibility that the observed behaviors or moods are better understood as manifestations of a difficult but healthy temperament. The second sort of mistake entails misdiagnosis—a failure to diagnose the “right” disorder. In this case, the child has symptoms associated with a DSM-defined disorder, but the symptoms are a better match for some other diagnosis than the one the child has received. The third mistake entails underdiagnosis: failing to diagnose a disorder when one is present.

The Great Smoky Mountain study illustrates that these mistakes can take place simultaneously. Researchers in this study examined a representative sample of 1,422 children in the western region of North Carolina. Trained interviewers applied DSM criteria, including the requirement for impaired functioning, from which they estimated that about 6.2 percent of children in the community met the criteria for ADHD. (A greater number exhibited one or more ADHD symptoms but fell short of the diagnosis.) The researchers then looked at rates of stimulant use and found that 7.3 percent of children in the study had received stimulants at some time during the four-year study period.

At first glance, it might appear that just slightly more children received stimulants than met the DSM criteria for ADHD, implying mild overdiagnosis. But the numbers actually revealed a more complicated situation. The researchers found that not all of the children who warrant an ADHD diagnosis had received stimulants—that is, they found undertreatment, implying underdiagnosis of ADHD. And they found that 4.5 percent of children who did not warrant an ADHD diagnosis had nevertheless received stimulants—that is, they found overtreatment, implying either overdiagnosis or misdiagnosis. While this is a small percentage, it is 4.5 percent of all the nonaffected children in the study, and so amounts to a large absolute number. In terms of absolute numbers, the study found that more children without ADHD received stimulants than did children with ADHD.

So how do we know when we have a reasonable disagreement and when we have a diagnostic mistake? In the beginning, a reasonable disagreement and a diagnostic mistake may be indistinguishable. But there is an important difference. Mistakes can be fixed with more time or information. Reasonable disagreements, however, persist, even after careful reflection and discussion, and are due to
There are many possible responses to mood and behavioral disturbances, from changing the child's sleeping and eating patterns to classroom interventions, family therapy, cognitive behavioral therapy, parent training, and medication. Here we discuss two broad kinds of treatment: medication and psychosocial interventions.

Medication Treatments

All medications carry a risk of adverse reactions. For example, some of the new antipsychotics introduced primarily during the 1990s and 2000s have been shown to cause severe weight gain and metabolic and endocrine disorders, and the antidepressants known as selective serotonin reuptake inhibitors (SSRIs) have been linked to increases in suicidal thinking in some children. A decision to medicate therefore always asks parents and clinicians to weigh the benefits of symptom relief against the risks. In addition, parents and clinicians must assess whether psychosocial treatments can be used instead of, or in conjunction with, medication treatments. Unfortunately for parents and clinicians, it is often quite difficult to work out which treatment or treatment combination has the best chance of helping a child diagnosed with a mental disorder.

Treatment for ADHD, one of the most studied and established pediatric mental disorders, illustrates this complexity. In the 1990s, the National Institute of Mental Health funded a large randomized clinical trial comparing the efficacy of pharmacological and behavioral treatments for ADHD. Over fourteen months, researchers compared children with ADHD treated with either: (1) carefully managed medication; (2) intensive behavioral treatment (with responsibilities for the child, parents, teachers and teacher aids, and therapists); (3) combined medication and behavioral treatment; or (4) standard community care (that is, whatever providers in that child's community happened to offer).

After fourteen months, the Multimodal Treatment Study of Children with ADHD (known simply as “MTA”) reported that carefully managed medication alone was superior to the other three arms of the study at reducing ADHD symptoms. If one provides carefully monitored medication treatment similar to that used in this study as the first line of treatment, our results suggest that many treated children may not require intensive behavioral interventions.

Although this finding might at first sound like an unequivocal endorsement of a medication-only treatment plan, MTA researchers recognized that medication treatment was superior only at reducing the severity of ADHD’s official symptoms. For some outcomes that will reach different conclusions about how best to understand particular clusters of moods and behaviors, where to draw the line, and whether a particular child in the zone of ambiguity would be helped by a diagnosis. In making these judgments, all parties will be influenced by their different (usually unarticulated) conceptions of the goals of psychiatry and parenting, which can result in different but equally reasonable decisions about whether to intervene. Neither critics of, nor enthusiasts about, intervention proceed from facts alone to the decision about whether diagnosis and treatment are warranted; value commitments play an ineradicable role.

II. If Diagnosis Is Warranted, Which Treatments Are Best?

There are many possible responses to mood and behavioral disturbances, from changing the child's sleeping and eating patterns to classroom interventions, family therapy, cognitive behavioral therapy, parent training, and medication. Here we discuss two broad kinds of treatment: medication and psychosocial interventions.

Deeply held value differences. Disagreements are “reasonable” when, after learning all I can about your position, my response to you is not “you’re mistaken about a fact” or “you didn’t look carefully enough” or “you did this too quickly,” but “you and I disagree about the goals of medicine or the goals of parenting or about what will promote my child’s flourishing.”

What, then, is the upshot of the diagnostic complexities and value differences that we have begun to explicate? In some cases it will be possible to reach easy consensus about how to describe a disorder, where to set diagnostic thresholds, and whether a given child has a psychiatric disorder. In other cases, clinicians, teachers, and parents will reach different conclusions about how best to understand particular clusters of moods and behaviors, where to draw the line, and whether a particular child in the zone of ambiguity would be helped by a diagnosis. In making these judgments, all parties will be influenced by their different (usually unarticulated) conceptions of the goals of psychiatry and parenting, which can result in different but equally reasonable decisions about whether to intervene. Neither critics of, nor enthusiasts about, intervention proceed from facts alone to the decision about whether diagnosis and treatment are warranted; value commitments play an ineradicable role.
Clinicians, teachers, and parents can make at least three sorts of diagnostic mistakes—overdiagnosis, misdiagnosis, and underdiagnosis. The Great Smoky Mountain study illustrates that all three can take place simultaneously.

are important in the daily functioning of these children (e.g., academic performance, family relations),” they said, “the combination of behavior therapy and medication was necessary to produce improvements, and families and teachers reported somewhat higher levels of consumer satisfaction for those treatments that included behavioral therapy components.” The researchers also noted that children receiving combined medication and behavioral therapy were able to take lower doses of medication, which had fewer side effects and a better safety profile. Nevertheless, following publication of these initial findings, medication alone was widely regarded as an acceptable and effective first-line treatment for ADHD.

Yet when MTA researchers followed up with their participants ten months after the study ended, those in the medication and combined arms of the study were showing superior reduction in ADHD symptoms and superior improvement in reading, social skills, and functional impairment. Two years after the study ended, researchers found that, on average, children originally enrolled in each of the four arms of the study had improved to the same degree; that is, even though the group of children originally assigned medication management or combined treatment had shown superior improvement after fourteen months in the study and ten months after the study ended, no treatment group outshone any other two years after the study finished. Some children had improved more than others, but the differences did not correspond to the mode of treatment they received.

To further confuse matters, there is insufficient evidence that stimulant medication improves learning or overall academic achievement. Like many medications used in pediatric psychiatry, stimulants can reduce the severity of symptoms, or even eliminate them, but they do not “repair” the underlying causes of those symptoms. They can reduce a child’s inattentiveness and hyperactivity, but cannot teach the child to pay attention or to control his or her activity levels. Further, while one might assume that, by reducing symptoms, stimulants make it easier for children to concentrate and thus learn, current data do not bear that intuition out. Medication can “produce acute, short-term improvements in on-task behavior, compliance with teacher requests, classroom disruptiveness, and parent and teacher ratings of ADHD symptoms,” and there is some evidence that stimulants help improve school-work accuracy and productivity. But researchers do not currently have sufficient data to conclude that these improvements translate into long-term improvements in learning.

ADHD is one of the best-studied childhood mental disorders, yet as the MTA and other studies of the effectiveness of medication and behavioral treatments for ADHD show, the data are both complex and potentially confusing. The data on the effectiveness of treatments for other disorders are equally if not more difficult to assess—even though, as Benedetto Vitiello observes in his sidebar (see page S18), we know far more now than we did a decade ago. Most studies still look at the impact of treatments on symptoms only, excluding other treatment goals, like educational achievement and parent-child relations, that are important to children and families. Few studies follow children over many years. Few studies compare medication treatments to evidence-based psychosocial treatments or a combination of both.

Yet in the face of very difficult and damaging emotions and behaviors, treatment decisions must be made. For them to be made well, there is increasing agreement that psychosocial (behavioral) interventions should also be considered.

Psychosocial Interventions

The potential for adverse drug reactions, no matter how small, is one reason people sometimes invoke the principle of “do no harm”—and urge beginning with psychosocial treatments and home and school-based interventions. These interventions include teaching teachers how to better teach children with the particular disorder, teaching parents how to better parent children with the particular disorder, and helping children to monitor and
Research Can Help Clarify the Benefits and Limitations of Psychiatric Medications in Children

BY BENEDETTO VITIELLO

The main article has a somewhat glass-half-empty view of the evidence regarding psychiatric medications in children. It’s important to remember that the glass is much fuller now than it was just a few years ago, and that this bodes well for solving the current conundrum through further research.

In fact, a considerable expansion has occurred in research to evaluate the efficacy and safety of commonly used medications in children. Legislative initiatives, such as the Best Pharmaceuticals for Children Act, have induced industry to conduct pediatric studies. Several medications are now approved by the Food and Drug Administration for pediatric use, including those for the treatment of depression, schizophrenia, bipolar disorder, and autism-related behavioral problems. At the same time, publicly funded studies have compared the effectiveness of different medications and evaluated the potential benefits of combining medication with psychotherapy. A number of evidence-based conclusions can now be drawn.

Stimulants decrease the symptoms of attention deficit hyperactivity disorder in the short and middle term, but they do not appear to substantially change the course of the disorder. While symptomatic improvement is very important, especially for children at risk for academic failure and social isolation, the ultimate goal is to avert the negative impact of ADHD on academic achievement and social functioning. It appears that medications alone cannot accomplish this task.

Antidepressants decrease depressive and anxiety symptoms and speed up recovery, but their overall effect is modest. Of greater concern, in some cases, is that through still-unexplained mechanisms, they increase the risk of suicidal ideation and behavior.

Antipsychotics help control psychotic and manic symptoms in some youths, but many others do not improve. More troubling, children are more sensitive than adults to the metabolic adverse effects of antipsychotics.

Compared with just a few years ago, we have now a better understanding of what medications can—and cannot—do for children suffering from mental disorders when used carefully under controlled conditions. The main limitation is that most studies of these medications are focused on symptomatic improvement. We still lack sufficient information on the long-term effects of treatments, and we cannot explain or predict why some children respond well, but others do not. Personalized treatment is now a research priority in medicine, and it will be the focus of future investigations in child psychiatry.


There is sometimes significant disagreement among clinicians about whether medication, behavior therapy, or the combination should be the first line of treatment. In the face of this disagreement, parents and clinicians may prefer a treatment because, in addition to what they know about its safety and effectiveness, it best fits their values.
A number of social and economic forces heavily influence the creation and use of diagnostic categories and decisions about which treatments are used. These forces help to explain why many children do not receive careful diagnoses, why evidence-based treatments are often not available, and why promising changes to children’s environments are not made. Many systems and institutions play a role in shaping diagnoses, diagnostic practices, and treatment choices. For example, to be diagnosed in our educational system with a “serious emotional disturbance” is one way to qualify for special education services under the Individuals with Disabilities Education Act; thus, the price of accessing these services can be to accept an ill-fitting diagnosis. (For more on the roles of schools and teachers, see Lawrence Diller’s sidebar on page S21.) Here, however, we will focus on how the system for the discovery and development of treatments and the system devoted to the delivery of mental health care can influence diagnostic and treatment decisions.

**III. Our Treatment Development and Health Care Systems Constrain Diagnostic and Treatment Choices in Ways That Are Bad for Children**

Psychotropic Treatments Dominate the Treatment Marketplace

Despite data supporting the safety and effectiveness of some psychosocial treatments for particular disorders, drug treatments are more readily accessible to most patients. One reason for this enhanced availability is that psychotropic drug treatments are more aggressively marketed to practitioners and patients than psychosocial treatments (see John Sadler’s sidebar on page S22).

The National Institute of Mental Health has funded or conducted research to evaluate the efficacy of a variety of psychosocial interventions for adult mental disorders and to compare the effectiveness of drug, psychosocial, and combination treatment programs for ADHD and adolescent depression. NIMH has also indicated that it intends to support curriculum development to train clinician-scientists to develop, test, and translate into practice innovative psychosocial treatments for mental disorders.

This significant federal investment is, however, dwarfed by the amount of money private companies invest in basic and translational science aimed at producing new drug treatments for psychiatric disorders.

While estimates of pharmaceutical industry spending on research and development vary greatly, overall industry spending is in the tens of billions of dollars per year. An analysis published in 2003 estimated that for each new drug treatment approved by the FDA, pharmaceutical companies spend an average of $403 million to bring a new drug to market ($800 million when adjusted for opportunity cost), while another published in 2006 estimated the cost at between $500 million and $2 billion dollars for every new drug approved. Additional funds are then spent marketing approved drugs to physicians.
and consumers, from direct-to-consumer advertising to
physician detailing to efforts to essentially create or ex-
and development.\textsuperscript{68} Although the data are not broken
down by specific drug class, psychotropic medications,
including antidepressants and antipsychotics, are among
the most profitable drug classes\textsuperscript{69} and are therefore likely
to be aggressively marketed. Some of the increase in the
diagnosis of bipolar disorder in children surely results

\begin{quote}
\textbf{The Role of Schools in Fostering a Bias toward Efficiency
over Engagement}
\end{quote}

\textsc{By Lawrence Diller}

While the behavioral health
system undeniably promotes
a medication solution to children's
behavioral problem, our education-
al system also plays an enormous
role. Schools generate most of the
referrals to doctors in the first place.
Children, parents, and teachers are
all under pressure to meet the in-
creased educational demands of the
past thirty years.\textsuperscript{1} While most teach-
ers are loathe to "diagnose" children
with attention deficit hyperactivity
disorder, and the Individuals with
Disabilities Act prohibits teachers
from directly recommending med-
cation, many teachers interpret poor
student performance as a "lack of fo-
cus" and recommend that the child
undergo a medical evaluation—a
form of "teacher speak" suggesting
that parents consider medication.

In some cases, medication \textit{will
be} a very reasonable intervention.
But too often, no prior develop-
mental or educational assessment
is made first, so that learning dis-
orders can go undiscovered and
untreated. Some school districts
actually \textit{require} parents to address
any ADHD behaviors medically
before considering an evaluation
for learning problems; if the child’s
performance improves sufficiently
on medication, the school can avoid
providing the time-intensive special
services required to address learning
disorders.

Stimulant medication will
improve the performance of all
children on difficult, boring, or re-
petitive tasks. But medication will
neither teach a child how to com-
pensate for a learning weakness nor
how to cope with a challenge by
sticking to it. To invoke a distinc-
tion that appears in the main article,
the medication-first approach em-
phasizes the value of "efficiency" at
reducing symptoms over the value
of "engagement" (with teachers) to
cultivate skills.

My intent is not to blame teach-
ers or schools for promoting medi-
cation interventions. They are also
under pressure to perform (to main-
tain or improve students’ achieve-
ments) with decreased funding,
increased classroom size, and fewer
special education supports. Teach-
ers receive professional education
on ADHD and stimulant drugs
similar to the information provided
to medical doctors, which has been
influenced and promoted by drug
companies’ money.

To highlight the values at issue,
I offer a “modest proposal.” With
three million children currently
taking stimulant medications in
our country and classroom size av-
eraging thirty children per class, I
propose we increase the number of
children on drugs to four and half
million, allowing us to increase
classroom size to forty—and thereby
save taxpayers huge sums on teacher
salaries and classrooms.

No reasonable leader or politi-
cian would ever promote such a
proposal. But we—parents, teach-
ers, clinicians, citizens—have, in es-
ence, allowed a system to develop
that operates within the spirit of it.
Too many of us are not cognizant
of the ethical values attached to the
“to medicate or not to medicate”
choice. The job of clinicians, re-
searchers, and scholars is to create
an awareness of these ethical choices
so that we can make informed de-
cisions about our children’s educa-
tion. We must understand that our
educational institutions, along with
the mental health delivery system,
foster a bias toward medication in
the classroom over practices that
engage the child but potentially cost
more money and time.

1. L. Diller, \textit{Remembering Ritalin: A
Physician and Generation Rx Reflect on Life
and Psychiatric Drugs} (New York: Perigee,
forthcoming May 2011).
**Pharmaceutical Company Influence**

**BY JOHN Z. SADLER**

Does the pharmaceutical industry influence medicine in general and psychiatry in particular? A direct assessment of physicians’ and researchers’ motivations requires “getting into people’s heads”—an impossible task. Instead, beginning mainly in the 1990s, studies have looked for correlations between interactions or relationships with industry and the outcome of research or patterns of physician prescribing. This research yielded four relatively uncontroversial conclusions: (1) Direct-to-physician pharmaceutical marketing works: physicians tend to prescribe promoted products more than standard compounds. (2) Offering samples increases prescriptions. (3) Outcomes of research performed with industry sponsorship usually favor the sponsor. (4) Physician financial relationships with industry are ubiquitous.

These findings apply to psychiatry as well. For example, Lisa Cosgrove and colleagues researched financial ties to industry for authors of the DSM in 2006 and found that 56 percent of 170 DSM panelists had one or more financial associations with the pharmaceutical industry. Within the Mood Disorders and Schizophrenia and Other Psychotic Disorders groups, 100 percent had industry ties. A 2003 analysis of pharmacoeconomic studies of antidepressants found “clear associations” between industry sponsorship and outcomes that favor the sponsor, and a review of ten studies comparing clozapine with conventional antipsychotic drugs for treatment-resistant schizophrenia cast doubt on the superiority of clozapine and found an association between a favorable clozapine study outcome and drug company sponsorship of the research. Commentaries and newspaper articles have described financial links between drug companies and some mental illness support groups as well as between drug companies and influential physician-researchers.

Unfortunately, psychiatry is not yet doing enough to address these financial conflicts of interest. In 2007, the DSM-V Task Force crafted conflict-of-interest rules for membership in the committees that will write DSM-V. Two years after those rules were announced, Cosgrove’s group examined the financial ties of the authors of the American Psychiatric Association’s Clinical Practice Guidelines for treatment of schizophrenia, bipolar disorder, and major depressive disorder. They found that 90 percent of the authors had at least one financial tie to companies whose products were specifically considered or included in the guideline they authored. None of these financial relationships were disclosed in the practice guidelines. Medicine’s—including child/adolescent psychiatry’s—dependence upon industry runs deep, and its influence through marketing and other financial mechanisms is powerful. Alas, the recent rejection by the American Psychiatric Association of stiffer conflict-of-interest rules makes it unlikely that the pharmaceutical industry’s undue influence will diminish anytime soon.


from an honest belief that the moods and behaviors of the children at issue are what bipolar disorder looks like in children. But some of the research supporting this expansion was supported by pharmaceutical companies, which stand to gain financially if increased diagnosis of bipolar disorder in children is followed, as it seems to be, by increased use of antipsychotics and mood stabilizers in children. One result of the enormous financial investment in developing and marketing medication treatments and the comparatively small investment in psychosocial treatments is that medication is more familiar and readily accessible to practitioners and patients.
Despite data supporting the safety and effectiveness of some psychosocial treatments for particular disorders, drug treatments are more readily accessible to most patients. They are more aggressively marketed to practitioners and patients, and there is much more money invested in the basic and translational science aimed at producing them.

The research, development, and marketing emphasis on medications would be less concerning were it clear that these treatments are safer and more effective than psychosocial alternatives or than medication and psychosocial treatments in combination. Medications are approved only after the FDA is satisfied that sufficient data shows they are safe and effective for the named indications, so they come with some data to support their safety and efficacy, and they are subject to laws regarding truth in marketing. Psychosocial treatments, by contrast, are not subject to FDA approval, and though the efficacy of certain treatments is well established, some are supported by little or no evidence. Nevertheless, we note ongoing concerns about the drug approval process and, therefore, about drug safety and effectiveness. These concerns are not limited to drugs used to treat children diagnosed with mental disorders, but given underlying worries about the impact of medication on the developing brains and bodies of children and the heightened ethical obligations that physicians and parents have to minors for whom—or with whom—they are making treatment decisions, the concerns take on a particular urgency in this context.

One concern is about the generalizability of safety and effectiveness findings. Designing feasible, affordable clinical trials often entails selecting patients who are less “complicated”—less likely to have additional diagnoses or to be taking more than one psychotropic medication—than those that clinicians usually encounter. Research populations can therefore be quite different from patient populations. Further, clinical trials seldom do head-to-head comparisons with existing medications or with psychosocial treatments—which makes comparing available treatment modalities difficult—and they seldom include patients who are taking multiple medications at once.

Perhaps most importantly, as Julie Zito details in her sidebar (see page S24), few incentives exist to conduct extended, postapproval studies on drug safety and effectiveness. It may not be possible or desirable to dramatically rethink the kind of data required for FDA approval, but once medications are approved for use, new data on their safety and effectiveness should be collected. This data would be particularly important for medications that we know are likely to be used off-label in children for months or years of their lives, in combination with other medications, and with a known risk of serious adverse effects, as has been the case with the newer, so-called atypical antipsychotics. Surely we owe it to these and future children to monitor the safety and effectiveness of these medications in real time. Finally, there are ongoing concerns that conflicts of interest pose significant risks to the quality and trustworthiness of human subjects research.

Changes that would begin to redress the imbalance between investments in the development of new pharmacological compared with psychosocial treatments include sustained or increased government and philanthropic funding of basic research likely to lead to new psychosocial interventions, and of clinical research to test their effectiveness once developed. Once new, evidence-based psychosocial treatments are available, funds will be required to market these treatments and to train practitioners to use them effectively. Specifically, NIMH could proceed with its plan to fund centers of excellence in psychosocial treatments, which would develop curricula for and train physicians in the delivery of scientifically validated psychosocial treatments. Certification programs could provide quality assurance for these therapies. Changes that would begin to improve the information available about medication treatments as they are actually used in the community include enabling the FDA to require robust postmarketing registries on selected medications that are used in children.

The U.S. Mental Health Care System Constrains Choices

Several features of U.S. health care increase the likelihood that diagnostic mistakes will occur and that psychotropic medications alone will be the default treatment
for children’s mood and behavioral disturbances. Several of these features are causes for concern in themselves because in addition to limiting clinicians and parents’ choices, they suggest that children are not receiving recommended care.60

In general, visits to medical practitioners are very brief. Although one study showed that pediatricians spent an average of between five and nearly seven minutes longer with patients when behavioral health concerns were raised than when they were not,61 visits including behavioral health concerns are still likely to last less than twenty minutes. It is extremely difficult in such a limited time for practitioners to undertake careful mental health diagnoses; reassess these diagnoses periodically; discuss, carefully monitor; and reassess medication treatments; or provide and monitor psychosocial interventions. Not only are these visits of short duration, but they are less frequent than is necessary for optimal treatment management. One study of adults and children treated with antidepressants reported that just under 15 percent of patients received recommended follow-up care in the first four weeks of treatment.62 As Gabrielle Carlson argues in her sidebar (see page S25), these economic pressures also undermine the quality of clinician training.

From a provider perspective, the system is fragmented among primary care physicians, hospitals, and various other mental health care providers, with little cross-communication or coordination following referrals and limited interaction with other systems that care for children, including child protective services, juvenile justice, and schools.63 Practitioners and parents seeking psychosocial interventions have limited ability to identify services, judge their quality, or assess the expertise of individual practitioners. Primary care providers have limited ability...
to monitor the costs and outcomes of any psychosocial interventions they recommend. When psychosocial services are identified, long waiting lists often delay access, and high rates of staff turnover among mental health providers can disrupt continuity of care. This fragmentation is very likely driven by time and cost concerns—payers are not willing to reimburse professionals for consulting with one another or developing systems that streamline communication and coordinate care. As a result, pediatricians may feel unable or unwilling to recommend psychosocial treatments to their patients or to manage behavioral health care issues as part of their practice. This leaves families who are committed to psychosocial treatments to identify, access, and navigate them alone. 

Where mental health care is funded through private insurance, coverage for psychosocial treatments is often more limited than for medication treatments, despite new legislation. Under managed care plans, medication treatments for emotional and behavioral disorders do not count as behavioral health care costs, but instead fall under the plan’s general prescription drug coverage. Behavioral health care management organizations, therefore, have an incentive to reduce utilization of psychosocial treatments. 

**Clinician Training Programs in Disarray**

BY GABRIELLE A. CARLSON

One of the most devastating blows inflicted by our current health care system has been the crippling of our training programs. When economic pressures force clinicians to spend ever-less time with patients, patients no longer receive the careful assessments they need and deserve. It takes time to gain trust, obtain an accurate history from a parent and child, ascertain current mental status, and solicit information from other sources such as teachers.

The mad whirl of the revolving door that occurs if the child is unfortunate enough to need hospitalization precludes safely discontinuing the myriad medications that desperate doctors have prescribed in trying to staunch her behavioral or emotional hemorrhage. It also precludes knowing how much of the problem is rooted in the child, the family, or the interaction between them.

If a new drug is not administered immediately upon hospitalization, managed care gatekeepers do not pay for the hospitalization. Although some fields of medicine have developed effective procedures to shorten patient contact time or hospital stays while improving patient care, psychiatry has not. We cannot speed up brain development, nor can we spontaneously create self-control in children or cure their severe psychopathology.

How does all of this affect the training of young mental health clinicians? If a young resident does not know what a condition looks like clinically, if there is not adequate time to obtain accurate information from relevant sources and to integrate them, or to observe firsthand the effects of various treatments, then that career has started off on the wrong foot. The clinician is never able to make accurate diagnoses and has no idea that she is wrong.

If the only medication management a young resident has seen is a fifteen-minute “med-check,” executed without eye contact with the patient or without the use of systematic data acquisition and rating scales, she will be learning shoddy practice and never even know that it is shoddy. As the Multimodal Treatment of ADHD study (discussed in the main article) showed, not all medication delivery is created equal. In standard practice, children are often given medications and not seen again for weeks; drugs are started and stopped with a minimum of information; doses are haphazard.

For those poorly trained clinicians who remain in academic settings, the only information and skills they will have to impart to their students will be equally poor. Most teachers in medical settings are paid either by the clinical income they generate or by research grants. Because time for teaching is not subsidized, even those who—miraculously—were well trained cannot afford to take the time to teach well.

Managed care has not only subverted the delivery of mental health care, it has created a situation where, even if all of a sudden money were available to allow clinicians to spend more time with patients, the clinicians would not know how to use that time.
Listening to Children with ADHD

BY ILINA SINGH

Between 2006 and 2010, I conducted interviews with approximately two hundred children in the United States and United Kingdom who had been diagnosed with attention deficit hyperactivity disorder. Both boys in the excerpts below are American, ten years old, and being treated with stimulants. Neither receives behavioral treatments or formal school-based services. According to their parents, both are responding well to medication.

Doug: I get in trouble when I argue with my brother and sister and when I don’t get good grades. My mom might yell at me and that makes me angry sometimes. In school I get in trouble if I come out of my seat a lot. I guess I do that sometimes, like, if I need to talk to my friends. That’s a little bit part of having ADHD. But sometimes I, um, can, um, think before it happens. ADHD makes my brain think faster. I know answers to questions really quicker, so that is the good part of having a fast brain. [But] I might do something I think is good, but I didn’t think what would happen if I do it . . . like talk to my friends and not think what the teacher will say. Then I get in trouble for that.

When I don’t take my medication my head hurts a little bit because my brain thinks too fast and I get a headache. If I didn’t take my medication it might be harder to do good things, like help people, because I’d be messing up or something. I’d be, like, yelling more or angry more, and I would be, like, getting in trouble a little bit more than I do [without medication].

Toby: At home I got two dogs, boxers, and I got [five siblings], and my mom and dad. My house okay. Most parents don’t let kids go outside every day because they be fighting. In my neighborhood they shoot people. . . .

I feel happy when I get things right at school, like my spelling test. Right now my grades bad because everybody keeps picking on me. . . . This kid, [B], he be pushing me, and we hit each other. I got bit in my face. He run away and I get punished. Then I have to stay home, do chores, my mom get mad at me. I tell my teacher [about kids picking on me] but she don’t do nothing about it. . . .

I know a kid brought a gun to school. He said he was going to shoot us. . . . One girl, she bad, she tripped this dude in the class and kicked him in the shoulder. He was leaking blood.

I don’t know what [ADHD] is but I know we talked to the doctors about how my grades are and what I was doing in class. Like, do you riff or stuff like that. [It makes me sad] that I can’t learn nothing and I forget stuff. My mom took me to the doctor to help my act get better. I want to act, like, good and get good grades.

In many ways, Doug, the boy in the first excerpt, sounds like the classic ADHD patient—a child whose brain works too fast, making it difficult for him to pay attention and behave appropriately in school. Pharmacological treatment helps him to meet home and school expectations and to feel better about himself as a person.

The second boy, Toby, also has trouble in school, and medication may help reduce his symptoms, but he describes a home, school, and neighborhood that would challenge most children with or without ADHD. Medication alone is unlikely to help him succeed in school or to feel better about himself.

While Doug may benefit in the long term from medication alone because of all the social structures already in place to support him, Toby needs more than medication to achieve freedom of opportunity and long-term well-being. A psychiatric diagnosis should not distract us from addressing the broad spectrum of risk factors that contribute to disordered behavior. To support Toby’s capacity to realize his social and behavioral goals, it will be necessary to integrate medical treatment with the design of more just and equitable social arrangements.

Claims for psychosocial interventions, unless covered by recent parity legislation, usually carry higher copays and deductibles than visits for medication management, and may be subject to annual limitations. Behavioral HMOs may further restrict reimbursement for psychosocial interventions by requiring the presence of the patient at each treatment session, which means that they do not cover parent training, for example, which is known to be effective but does not require the
presence of the child. They may also disallow reimbursement for case management and rehabilitative services. Finally, few incentives exist for payers to cover long-term, large-scale prevention programs—from interventions for high-risk families to programs specifically targeting children who have experienced trauma—despite strong effectiveness data for these programs.

The result of this fragmentation and these restrictions on treatment availability and coverage is that every step in children's mental health care is compromised, from assessing the child's needs to providing information on treatment choices, accessing treatments, and monitoring the effectiveness of whichever treatments are provided.

What's the Result of This Compromised System?

The United States' system for developing treatments results in far more medication than psychosocial treatments entering the marketplace. Medication treatments are also better advertised, and clinicians are more familiar with them, although they may still not be sufficiently trained in their use. At the same time, the country's mental health care system makes it difficult for children to access psychosocial care, but relatively straightforward to access medication treatments (even if those treatments are not monitored or reassessed as recommended). The result is that even where psychosocial treatments have proven efficacy, they may be difficult or impossible to access, and where a combination of medication and psychosocial treatments is recommended, many children will not receive it.

While it is important to acknowledge that pharmacological treatments are a highly imperfect tool, we need to acknowledge the respect in which they can nonetheless be valuable. Medications are often one of the few tools clinicians have to reduce the ferocity of impairing moods and behaviors so that they can begin to help children and families address the causes of these problems and prevent future crises, so that children and families can get on with living their lives as they see fit. And we need to acknowledge that it would be bad if medication became the default mode of treatment for each and every child with any mood or behavioral problem. Systems, institutions, and cultures that restrict treatment choices not only prevent families from choosing some treatment programs with a strong evidence base, but prevent them from accessing—and clinicians from offering or recommending—treatments that reflect their value commitments.

Making pharmacological treatments the default option also risks encouraging an erroneous habit of thinking. Even where medications are safe and effective at addressing symptoms of concern, they are seldom the only intervention worth pursuing. Parents, teachers, clinicians, and even children themselves need to pay attention to additional steps that may be taken to help children learn to manage their emotional distress and problematic behaviors, including taking steps to change children's environments. One risk of focusing solely on the pharmacological mode of treatment is that the more we use medication to change children, the less likely we are to remember that we can also change parenting practices, classroom structures, school routines, neighborhoods, cultural expectations, and other aspects of children's contexts. In some cases, these changes may be the sources of children's distress, and in many cases, they will be key to lasting improvements in their mental health. (See Ilina Singh's sidebar on page S26 for more on the relevance of context.) Our current ways of delivering mental health care to children stack the deck against engaging with children's contexts, and this needs to change.

Disagreement and Consensus

We have described some of the complexities associated with the current approach to diagnosing emotional and behavioral disturbances in children. Most of the diagnoses articulated in the DSM were based on observation of symptoms in adults, but symptoms of what psychiatrists consider to be the same disorder may look different in adults and children. Also, the DSM's categories capture heterogeneous phenomena, and they overlap; further, because symptoms and impairments are expressed along continua, there are no bright lines between healthy children and those who warrant diagnoses.

Informed, trained, caring people will thus sometimes have reasonable disagreements about where to set
diagnostic thresholds and about whether a mildly affected child—a child in the “zone of ambiguity”—would benefit from a diagnosis. These disagreements can occur when people have different value commitments or just give different emphases to shared value commitments (regarding, for example, the goals of psychiatry or the goals of parenting). Such value differences or emphases can play out in the context of treatment decisions as well.

As important as it is to recognize such disagreements, it is also important to recognize how much agreement there can be among people as diverse as those who constituted our working group. For one thing, there is agreement that children can indeed have serious psychiatric disorders and that medications can be an essential part of appropriate treatment plans. For another, no matter how important it is to tolerate reasonable disagreements, it is essential to avoid the sorts of mistakes that involve patent overdiagnosis, misdiagnosis, and underdiagnosis, which result in many children not receiving the care they need. These mistakes are facilitated by systemic forces that bear on clinicians and families and restrict the time available for careful diagnoses. Specifically, these forces can make it tempting to base a diagnosis on the presence of symptoms alone, as opposed to doing the sort of careful evaluation that can determine whether those symptoms impair the child. Those same systemic forces strongly favor medication treatments over psychosocial ones, so that children too often receive pharmacological treatment only, even when other treatment plans are supported by evidence and reflect their or their family’s deepest value commitments.

Improving the quality of the U.S. pediatric mental health care system would include supporting the development of psychosocial treatments, comparative effectiveness and postmarketing research on approved treatments, training clinicians in sophisticated medication management and delivery of psychosocial interventions, and instituting reimbursement policies that enable clinicians and families to access both treatment modalities. As all members of our working group could readily agree, children deserve “developmentally appropriate and comprehensive assessments” to determine whether a psychiatric diagnosis is appropriate. Moreover, if children are diagnosed with emotional and behavioral disturbances, they should have access not only to medication treatments but also to “empirically supported psychosocial and behavioral services.”

As we attempt to improve our systems of delivering mental health care to children, we should remember that, even though some disagreements about diagnostic and treatment decisions will persist, there is fundamental agreement that children and families deserve access to careful diagnosis and multimodal treatment approaches that are safe, effective, and reflect their value commitments. Our ethical obligations to children require that we—including policy-makers, educators, medical professionals, and parents—remember that in addition to changing children (by pharmacological or psychosocial means), we also have the power to change the contexts in which children are embedded, which can be key to lasting improvements in their mental health.

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