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The push to label Many drugs aren’t well-studied in children Revise standards, critics say

By Melissa Healy
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Katie’s middle child “has always had a lot going on in her head,” says her mother. And much of it has been a mystery to Katie, who has coped with her daughter’s escalating tantrums, combative behavior, bouts of fearfulness and just-plain-oddity since the 11-year-old was a toddler.

A month ago, Katie, a 38-year-old L.A.-area mother of three, brought the child to a psychiatrist. The child’s behavior and performance in school were exemplary, but an ill-tempered outburst had gotten the preteen kicked out of a Girl Scout troop she had joined at age 5. The girl was confused and heartbroken over her ejection.

The daughter came away from the appointment with a diagnosis of bipolar disorder. Katie, who asked that her full name be withheld to protect her daughter’s privacy, came away with a list of 10 powerful psychiatric medicines and a momentous decision to make. Some combination of these mood-stabilizing, anticonvulsive and antipsychotic drugs, Katie was told, would probably control her daughter’s problematic behaviors, referred to by her psychiatrist as symptoms of a disease.

Now it’s Katie who has the racing thoughts and the alternating bouts of fear, anxiety, relief and anger. As she ponders whether her daughter’s strange behavior really amounts to mental illness – and whether medication is the answer – she says, “I feel like I’m flying blind.”

And she’s not reassured by the suspicion that the psychiatric profession is as confused about diagnosing and treating mental illness in children as she is.

All these psychiatric labels and pills may keep many kids on track and even save lives, Katie says. But both seem to be dispensed with little certainty as to what they mean and how they work – and even less debate over their long-term consequences for children.

In 2005, the latest year for which statistics are available, at least 2.2 million American children over the age of 4 were being treated for serious difficulties with emotion, concentration, behavior or ability to get along with others. It’s a figure mental-health professionals say has exploded in the last decade and a half, along with sales of a wide range of psychiatric medications for use by children.

A welter of studies has shown that kids are being diagnosed at younger ages, with a wider range of disorders and with more severe disorders than ever before. And in growing numbers, they are being medicated with drugs whose safety, effectiveness and long-range effects on children have not been demonstrated by extensive research.

A study published in September found that the diagnosis among children of bipolar disorder, a mental illness long thought not to exist in kids, grew 40-fold over the last decade. The prescribing to kids of antipsychotic drugs typically used to treat the symptoms of bipolar illness have soared as well, despite continuing concerns over side effects such as weight gain, metabolic changes that can lead to diabetes, and tremors.

Psychiatrists admit they haven't drawn clear lines between problem behaviors and mental illness, especially in kids, and they are debating future fixes. But until those fixes are made, parents – with their kids' futures on the line – are left with little to guide them when a child is tagged with a psychiatric label.

Katie's maternal instincts tell her she must protect her child. But from what, she asks – a disease that threatens health, happiness and future? A bogus label applied to an admittedly challenging kid? Or drugs with potentially harmful and little-studied side effects?

And protect her exactly how – by resisting or by medicating?

"I don't want to face her as an adult and say I didn't do everything I could to make her well. I feel like I'm answering to her future self," Katie says. "But so much of this is a crapshoot. No one wants to feel that their child is a guinea pig."

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Perception of kids changes

Mental-health professionals have long warned that the stigma of mental illness and the cost of its treatment have left millions of Americans with psychiatric disorders to suffer untreated. But as childhood diagnoses of mental illness have surged, some in the profession charge the field of child psychiatry with the opposite problem. A scourge of overdiagnosis, says a growing body of critics, has come to child psychiatry.

The trend, say these critics, threatens to turn kids like Katie's daughter – a preteen whose behavior is certainly odd but whose school life remains on track – into potentially lifelong patients.

And, they add, it has changed the way Americans think about children. Critics warn that as psychiatric diagnosis and medication of children becomes more widespread, teachers, well-meaning neighbors and relatives, and parents themselves are becoming less willing to accept youthful misfits for who they are and to help them adapt without prescribing drugs or attaching labels.

"We are suffering … from a shrinking tolerance for the broad limits of normality," says. Dr. Stanley Turecki, author of "The Difficult Child" and a practicing psychiatrist in New York and Massachusetts.

For such parents as Katie, that shrinking tolerance seems to have seeped into places like her daughter's Girl Scout troop as well as her own extended family, where her daughter's belligerent challenges of strangers and unpredictable episodes of fearfulness have long been a source of critical commentary. They have even seeped into Katie's heart.

“I find myself saying, ‘Geez, this is not normal,’ ” she says. But she’s equally unsure that her daughter’s perplexing behavior rises to the level of mental illness. “Are people,” she wonders, “just haphazardly sticking labels on kids?”

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Definitions remain fuzzy

There once was a time when a pocketful of well-worn adjectives, accompanied by a shrug, would have been sufficient to describe American kids at the outer reaches of normal: shy, spirited, combative, dreamy, sensitive, fretful – even odd. All were qualities a child might readily grow out of with guidance or a few years to mature.

The descriptors for such youthful outliers have undergone a linguistic overhaul in recent years, says Ross W. Greene of Harvard Medical School’s department of psychiatry. Increasingly, talk of temperamental extremes or social skills that need to be taught or strengthened has given way to the assignment of disorders, deficits and dysfunctions. Nowadays, a kid whose behavior is problematic has to have something – a diagnosis – which energizes school administrators, absolves parents of guilt and too often, Greene says, dictates medicating the child with powerful drugs.

In at least four in 10 cases, according to data from the Centers for Disease Control and Prevention, parents who seek professional help for their troubled children come away with at least one prescription medication.

These diagnoses suggest clear evidence that a malfunction of the brain is the cause of the problematic behavior. But despite dramatic advances in neuroscience, that presumption still cannot be verified by a blood test or brain scan. Mental-health professionals instead must base their diagnoses on the presence of a certain number of symptoms, and on a judgment – by teachers, parents and the professional evaluator – that the problem behaviors impair a child’s ability to function.

The boundary between troublesome behavior and mental illness is indistinct in adults, psychiatrists acknowledge; in children, whose brains are still a work in progress, it is fuzzier still.

“To tell the truth, I feel bad for parents,” says Greene, who directs the Institute for Collaborative Problem Solving at Massachusetts General Hospital. “I don’t think diagnoses help us understand how to help the kid.”

It’s a frustration felt by Katie. At times, she welcomes the diagnosis that tells her she’s not a bad parent or that might solve the riddle that is her middle child. But rather than a golden ticket to a fix, she says, it feels like a can of worms.

“What is a diagnosis?” she says. “All it is is permission to medicate. We could try this drug – and then what, if it doesn’t work? Do you go to the next drug, up the dose, decide the diagnosis was wrong?”

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Profession in transition

By the mid-1990s, the effort to prevent or mitigate mental illness began to focus on kids, who had long been considered too young, before adolescence, to treat with anything but love, time and therapy aimed at redirecting their behavior.

The profession's new focus would require a few leaps of faith and some significant reinterpretation of its diagnostic formulas, says Dr. Lawrence Diller, author of "Running on Ritalin" and "The Last Normal Child," two books that are critical of the trend.

Conditions such as bipolar disorder and schizophrenia were long thought so unlikely to appear in children that they were almost never diagnosed. If psychiatrists were going to start, they needed to fathom how symptoms of adult psychiatric illness might look in kids, whose brains are developing and whose social skills are immature.

For instance, troublesome behaviors stemming from extreme shyness, inflexibility, impulsiveness – even stuttering or tics – might prompt a diagnosis of anxiety disorder, bipolar disorder or attention-deficit hyperactivity disorder, even though those problems will recede or disappear with age for many children.

And a psychiatrist might have to reinterpret, in a child, the classic pattern of "cycling" between manic and depressive episodes that is the hallmark of bipolar disorder in grown-ups. Instead of taking months to swing from high to low, a mercurial, expressive child such as Katie's daughter might be seen as "ultra-rapidly-cycling" between mania and depression.

Thomas Insel, director of the National Institute of Mental Health, acknowledges that these translations may often be imperfect. Responding in September to the report of a 40-fold increase in bipolar diagnoses among kids, Insel warned that overdiagnosis and misdiagnosis probably accounted for some of the surge.

Indeed, to some in mental health the behavior of Katie's daughter might be a classic presentation of pediatric bipolar disorder; others might see a strong-willed child who needs to learn better to recognize and cope with powerful emotions.

Katie says that when her daughter was a toddler, the girl's tantrums were frequent and stormy. As she grew, she picked fights with strangers and dreamed up projects too big for a little girl to accomplish.

Now, her mother says, the preteen's raging episodes are briefer but more intense and that she hates herself afterward. During a recent trip to an amusement park, the child stormed away from her mother and deliberately, it seemed, got herself lost. During the school day, she seems able to hold herself in check and works well in class. At home, she can be unpredictable. She'll fight with her little brother one minute and fawn over him the next.

"I've had this idea that if I can just get her through being a child, that she'll be fine, that she'll be high-achieving," Katie says. Her daughter's ambitious ideas, strong will, assertiveness with authority figures: Katie had long believed that in adulthood, these exasperating traits might make her a leader.

Now that they've been cast as symptoms of early mental illness, she's not so sure. Perhaps, she thinks, it would be better to curb them with medications.

"I don't want her to be some kind of crazy loner," Katie says.

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Medication grows popular

In spite of the questions about diagnosing mental illness in children, the medication of children for psychiatric conditions has shot up. At three major U.S. medical centers studied in the early 1990s,

antidepressant use among children aged 2 to 19 increased 2.9-fold, 4.6-fold, and 3.6-fold, according to a study published in 2002 in Pediatrics.

Another study found that among low-income children insured by the state of Tennessee, the use of new antipsychotic medications doubled in a five-year period in the late 1990s.

And in the seven years leading up to 2001, researchers at Brandeis University, reporting in 2006, found that prescriptions for psychiatric drugs for teenagers (ages 14 to 18) increased 250%. By 2001, one in every 10 medical office visits by teenage boys resulted in a prescription for a psychiatric drug, according to the study in the journal Psychiatric Services.

There's also evidence that such diagnoses and their medication are being dispensed at younger and younger ages. The study of Tennessee children found hikes in antipsychotic use even in preschoolers.

After a 4-year-old Massachusetts girl died of a psychiatric drug overdose in December 2006, the state undertook a first-of-its-kind review of medication records for children in its insurance program for low-income families. It found that nearly 1,000 children under 7 were taking Clonidine, a drug used to treat anxiety and hyperactivity that was found in lethal doses in the body of the Massachusetts 4-year-old. More than 500 kids under 7 were taking antipsychotic drugs.

The state is now investigating 33 cases in which a child under 5 is taking at least three psychiatric drugs on a regular basis, and more such cases are expected to surface.

That growth is taking place amid a debate over the safety and effectiveness in children of many widely prescribed drugs and drug combinations that have not been extensively tested on them.

All told, only 12 medications have been approved by the Food and Drug Administration for treatment of psychiatric disorders in children under 18. Six – mostly stimulants – are used by an estimated 3.5 million kids to treat ADHD, a condition estimated by the government to affect 2.2 million to 3.7 million American children. Six – fluoxetine (Prozac), sertraline (Zoloft), clomipramine (Anafranil), fluvoxamine (Luvox), lithium and risperidone (Risperdal) – are used to treat symptoms of "mood disorders," including depression, anxiety disorders and bipolar disorder, in kids.

But psychiatrists have also tapped extensively into the formulary of psychotropic medications FDA-approved only for adults. They often prescribe them in combinations that have been the subject of few trials for safety and effectiveness. Such "off-label" prescribing, which is legal, is done often, but not exclusively, when drugs approved for kids don't provide satisfactory results.

The dearth of approved drugs for pediatric use has prompted the two largest groups of mental-health professionals who treat children – the American Psychological Assn. and the American Academy of Child and Adolescent Psychiatry – to recommend that the FDA establish a new panel of independent experts to advise the agency on the safety and effectiveness of psychotropic drugs for children and adolescents. The AACAP has established a special working group to conduct and track research on preschool psychopharmacology, and another to focus on childhood bipolar disorder.

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Wary of early intervention

Northwestern University's Christopher Lane, author of a new book, "Shyness: How Normal Behavior Became a Sickness," calls psychiatry's growing focus on children "the perfect storm" for overdiagnosis.

“You’ve got a constituency – children – who cannot make informed medical decisions for themselves,” Lane says. In a fast-moving culture that heaps stress and high expectations on children, “parents are in many cases under great pressure to ensure their child succeeds and is socially proficient. A child that doesn’t negotiate rapidly those hurdles can look very quickly as if he or she is falling behind, or displaying behavior that warrants medical concern.”

Some mental-health professionals are wary, too, of the implied promise of early intervention. In fact, whether, how or in how many cases a child’s problematic behavior leads to full-blown mental illness – what health professionals call the “progression” of the disease – is in many cases not well understood, especially when the patient is not even a teenager yet.

As to the claim that early treatment will lessen symptoms or prevent mental illness later, there is growing evidence, but it is hardly a slam-dunk. And it doesn’t address which kids will benefit from pharmacological treatment and which won’t.

As the mental-health profession begins debate over how to update its diagnostic manual, the Diagnostic and Statistical Manual of Mental Disorders, or DSM, which is set for reissue in 2012, it is debating whether it has gone too far. The recent publication of two books critical of the expansion of psychiatric diagnoses – Lane’s “Shyness” and “The Loss of Sadness,” by Allan V. Horwitz and Jerome C. Wakefield – have touched off a flurry of discussion.

In a foreword to “The Loss of Sadness,” Dr. Robert L. Spitzer, a leading figure in psychiatry, acknowledges the imprecision of the DSM, “especially the question of how to distinguish disorder from normal suffering.” But he also defends the widening of psychiatry’s safety net.

“I’m more concerned with people who could benefit from treatment not getting diagnosed – with under-treatment – than with overdiagnosis,” he says. “If you need the drug, it’s pretty awful if you don’t get it.”

If notions of what’s normal for kids have changed, he adds, “I don’t know that that’s necessarily bad.” More is known now, he says, about how things can go wrong with human functioning.

Dr. Robert Hendren, president of the American Academy of Child and Adolescent Psychiatry, says he is acutely aware of the overdiagnosis debate. Among the many possible explanations, he says, is that many psychiatric drugs appear effective in treating kids’ problematic behavior. “When you believe the medications work, you’re awfully tempted,” he says. “But we must not be seen as pill-pushers.”

The profession, he adds, will need better research to justify the growth in diagnoses.

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Making a decision

That research will come too late to help Katie judge what’s best for her daughter.

She fears that the proposed antipsychotic medication will exacerbate the child’s weight problem and “deaden her spirit.”

She looks up bipolar disorder on the Internet and sees that while many of the symptoms described are “spot on,” many don’t fit her daughter at all – or worse, could fit any child with a difficult temperament, a flair for drama or a challenging family situation.

As she wavers at the threshold of a decision, Katie leans toward acceptance of her daughter's diagnosis and the pills that will probably come with it. "I've struggled to come up with an answer. This is at least something I can do," she says.

She is sad but resigned to choosing without full information. "All I can do, in the end, is love her and make the best decisions I can at the time," she says. "That's the blessing and curse of being a parent. It's never going to be perfect."

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Fine-tuning all those labels

A project that could help rewrite psychiatrists' diagnostic guidebook is underway at UCLA. The work, launched this summer by the National Institutes of Health, aims to put the diagnosis of several major psychiatric conditions – including attention deficit hyperactivity disorder, bipolar disorder and schizophrenia – on a more rigorous footing by identifying and mapping the biological processes that may link these diseases or distinguish them from one another.

Under the $22.5-million project, UCLA neuroscientists expect to explore how weakness in two cognitive skills – working memory (sometimes called short-term memory) and impulse control – may better identify people who have, or are developing, psychiatric disease. If clinicians can test patients for such measurable deficits, they might one day abandon the imprecise diagnostic labels and the trial-and-error medication decisions that characterize psychiatry today, says UCLA neuroscientist Robert Bilder, who leads the project.

Until then, it's hard to know whether mental-health professionals are overdiagnosing or underdiagnosing psychiatric disorders in kids or adults, Bilder says. Instead, he says, "there's an implicit misdiagnosis, since we don't know what we're doing."

– Melissa Healy

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