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The Long Battle to Rethink Mental Illness in Children

By SHIRLEY S. WANG



Since infancy, Max Brown, 11, has flown into a rage at the smallest of slights, such as being told 'no.'

Holed up in windowless hotel conference rooms near Washington, D.C., scientists have been busy rewriting the bible of American mental illness.

It is the first revision of the nearly 1,000-page tome in 15 years, and one of the top priorities of the insular conclave is to rethink some children's disorders, particularly bipolar disorder. The fear is that too many treatable children are slipping between the cracks, either because of misdiagnosis or—more controversially—because they suffer from a disease that hasn't even been defined yet.



His emotions change quickly throughout the day.

Pediatric bipolar illness is one of the most significant categories of psychiatric ailments in children, even though it came into existence as a diagnosis only in the mid-1990s. Hundreds of thousands of U.S. children are estimated to have been diagnosed with it. Many are heavily medicated.

The process of adding or subtracting diseases from the Diagnostic and Statistical Manual of Mental Disorders, the "DSM," can get contentious. In July, two committee members quit over disagreements about how to reclassify various disorders. Final decisions are expected this year.

At one of the closed-door meetings at the Hotel Palomar in Arlington in 2008 about a dozen psychiatry experts gathered to zero in on one sticky issue: Whether to define a new children's disease called Disruptive Mood Dysregulation Disorder—a condition characterized by children who are constantly irritable and can be explosive. This differs from bipolar disorder, which is characterized by periods of depression and "manic" episodes—extreme swings of happiness or irritability.

"We can't 'do nothing,'" said, Charles Zeanah, a committee member and Tulane University professor. He calls it "perhaps the most important child issue" in the revision of the massive manual.



Max loses his temper in a park, near Cincinnati, Ohio, where he lives.

The concern is that these kids are potentially being overmedicated with psychiatric drugs that cause severe side effects—including weight gain that increases diabetes risk—but which are ineffective for their condition.

Based on committee documents, conference presentations and interviews with dozens of experts involved in or familiar with the revision, The Wall Street Journal reconstructed the long-running process of defining a new disease.

Inclusion of a condition in the manual is often followed by increases in the use of medicines to treat it. New research in August showed a sevenfold increase in doctor visits for antipsychotic medications in children 13 and under, which treat bipolar disorder and others, between 1993 (the year before that disease entered the manual) and 2009.

Even the naming of ailments can ignite passions. When the proposed new disorder was announced, public criticism of its name was fierce. Initially it was dubbed Temper Dysregulation Disorder, "But when you say 'temper,'" people think temper tantrums, says Dr. Zeanah. "They think of their own toddler, and you're pathologizing everyone. TDD was such a fiasco."

One child who might benefit from new disease categories is Heidi Willoughby's 12-year-old daughter, whose emotions can careen quickly between giddiness and fury. "It's like walking around with an arm full of explosives," says Ms. Willoughby, of Boston, Mass. "You hope that you don't trip."

Melissa Brown tells a similar story about her son, 11-year-old Max. Since infancy, Max has flown into a rage at the smallest of slights, such as being told "no." He sent one child to the hospital during a play session, and has drawn blood a few other times, says Ms. Brown, who lives in Cincinnati, Ohio. "In his baby book, I wrote 'wild baby,'" she says.

At age 4, Max was diagnosed with bipolar disorder. But several clinicians think that is wrong. He has never been treated successfully, says his mother, a 40-year-old sales rep.



His mother, Melissa, comforts him.

Inclusion of a new disease in the DSM has potential to affect millions of patients and billions of health-care dollars. Some 30% or more of Americans are diagnosed with at least one mental illness in their lifetimes, and psychiatric drugs are among the most prescribed medicines in the U.S. Nearly \$40 billion was spent last year on the top three types—antipsychotics, antidepressants and medication for attention-deficit, hyperactivity disorder—according to IMS Health.

More than that, the DSM, published by the American Psychiatric Association, serves as a road map to rapidly changing scientific views of mental health. For instance, only in 1980 did the manual elevate autism to the level of psychiatric disorders, and strike homosexuality from its disease list.

Pediatric bipolar disorder, the condition 11-year-old Max is diagnosed with, is a serious illness characterized by swings between depression and mania. Up to 3% of children are estimated to have it, according to the National Institute of Mental Health.

Many children respond to treatment, but others struggle. Their behaviors may get them booted from mainstream classrooms. In extreme situations, such as with Max, they must move to a residential facility for care.

But some experts feel many children are misdiagnosed and in fact suffer from Disruptive Mood Dysregulation Disorder, the new, still-unofficial disease currently being debated for inclusion in the manual. Wrong diagnoses can lead to inappropriate drug treatment. There is no treatment regimen yet for DMDD.

Changing Diagnoses in the DSM

Take a look back over some of the language that has been used in the DSM to describe common mental-health diagnoses and how it has changed.



"We want to be sure we're using [antipsychotics] in the right patients when they're needed," says Ellen Leibenluft, chief of the bipolar spectrum disorders section at the National Institute of Mental Health, who is involved in the revision process.

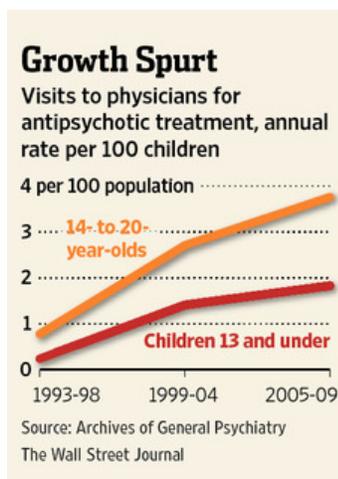
There is no way to know precisely how many children currently diagnosed with bipolar disorder might have instead have DMDD. However, one of Dr. Leibenluft's studies found that 60% or so of children who are likely candidates for the new diagnosis are currently diagnosed with bipolar disorder.

The revised manual, expected next year, could have far-reaching effects. Inclusion of a new disease means researchers can attract funding and patients can obtain insurance reimbursements. The Food and Drug Administration primarily approves drugs only for listed diseases or symptoms.

Created by a small group of clinicians in 1952, the manual was largely ignored by the wider medical field until 1980, when it was greatly expanded and formalized. The revision process relies on experts, mostly researchers, to comb through scientific papers and presentations looking to clarify or improve diagnoses.

Researchers aren't paid for their work. The APA pays for the book and has co-hosted several research conferences about the DSM with government partners and public-health organizations. There is no drug-company, insurer or hospital participation.

This scholarly process is sometimes at odds with the emotionally charged nature of what psychiatric labels mean to the public. For instance, a proposal to eliminate the category for Asperger's syndrome and instead subsume it under a broader umbrella term of autism disorders prompted protests from "Aspies" (people diagnosed with Asperger's) who identify themselves as distinct from people with autism. Some parents also protested, fearing their children might be denied services.



Groups like the Global and Regional Asperger Syndrome Partnership Inc. encouraged members to complain to the manual committee. And Aspies discussed on message boards whether they should start describing themselves as having "high-functioning autism."

"A Hifunctie?" one person suggested on the Aspies for Freedom website.

"What about haughty," quipped another.

Classifying mental illness is an imperfect science. The DSM task force defines mental illness as a condition that causes disruption in people's daily functioning. But setting a threshold for disruption is a judgment call.

It is a level of disability "that really necessitates intervention," says David Kupfer, chairman of the DSM task force that oversees the process. "The problem is, just listing a series of symptoms is not sufficient to call it a disorder."

The current DSM revision began in 1999. For the first seven years, a steering committee fine-tuned a priority list by holding several research conferences.

Starting in 2006, 13 "work groups" of a dozen or so experts were established to review batches of new and existing conditions, overseen by an overarching task force of 29 members. For years, these groups have met in person or talked on the phone at least monthly, according to Dr. Kupfer, a psychiatry professor at the University of Pittsburgh.

Each expert must agree to limit their involvement with drug companies to \$10,000 over the duration of the revision. About a third of the experts invited to join committees declined to do so for this reason, Dr. Kupfer says. The APA covers the cost of hotel and conference rooms.

When the "child and adolescent" work group first convened in early 2008, bipolar disorder was a top priority. "It would be impossible not to be aware that there's a major issue with the diagnosis of bipolar disorder," says Dr. Zeanah, the Tulane professor and group member.

At one of his group's first in-person meetings, the NIMH's Dr. Leibenluft, an expert on bipolar disorder in children, gave a 20-minute PowerPoint presentation with evidence for a potential new disease. She called it Severe Mood Dysregulation.

She described a decade of studying children with severe mood problems that don't fit neatly into current illnesses. Thus began a cerebral process to decide what these kids might be suffering from.

The two main options: Create a new disease, or create a variant to an existing disorder. The discussions ran for years.

Members disagreed on how much evidence was needed to create a new disease. They debated whether the new ailment could be sufficiently distinguished from others. But work-group members didn't break into separate camps, they recall. Instead, they tended to play devils' advocate.

The group grappled for "a long time" with making the ailment a severe subtype of a current diagnosis, Oppositional Defiant Disorder, says Dr. Leibenluft. But ultimately, in 2010, they decided to recommend creation of a new illness instead. (A broader APA committee will make the final decision on that and all other recommendations later this year.)

Dr. Leibenluft, who works at the NIMH, described the research but declined to go into detail about committee discussions.

One of the more emotionally charged exchanges occurred months in. Once again, the group was sequestered in a hotel meeting room and having another lengthy chat about whether these explosive children should be tagged with a new disorder.

Dr. Leibenluft suggested that perhaps the right thing to do was to not make any changes and to drop the idea of a new illness. Suddenly, Dr. Zeanah spoke up, arguing with intensity that the issue was tremendously important to children's health and that to "do nothing" shouldn't be an option.

His reaction surprised some group members, who recall Dr. Zeanah as being soft-spoken and relatively quiet throughout the process.

"I was never persuaded that a new disorder was unjustified, but I tried to listen fairly to contrary evidence," Dr. Zeanah said recently when asked about the meeting. He said he felt that doing nothing, or adding the disease to an existing disorder, wouldn't help the children.

In spring 2010, the panel's recommendation of a new disease was made public. In contrast to the intellectual ruminations inside the work group, public criticism was fierce, particularly against the proposed name, Temper Dysregulation Disorder.

Susan Resko of the Balanced Mind Foundation, an advocacy group for kids with serious mental illness, said that though she didn't conduct a formal poll of her members, "Those that heard about it and voiced their opinion, hated it, across the board." One mother emailed Ms. Resko to say: "The use of the term 'temper' in the diagnosis connotes a bad personality," when what the child actually suffers is a "severe condition resulting from a dysfunction in the brain."

In response to the criticism, the group decided to change the name. After months of further deliberation, the deed was done and the name became "Disruptive Mood Dysregulation Disorder," or DMDD.

Many critics zeroed in on the very issue that consumed the group for so many years: Are there enough data to justify a new disease?

"I don't think we solved the overdiagnosing and overprescribing of psychiatric drugs for children by inventing another category that may unintentionally catch even more children," says David Elkins, president of the American Psychological Association's Society for Humanistic Psychology, who has criticized the manual-revision process.

Some advocacy groups voice measured support for creating a new illness. "The concern is that DMDD hasn't been studied well enough," says Ms. Resko. But "from a parent-advocacy perspective, we hope that its inclusion will encourage more research" into children with severe mood problems.

The latest challenge in the making of the new illness: Determining whether the definition is reliable enough to use in diagnosing actual patients. DMDD was one of dozens of disorders tested in "field trials" begun in 2010. The trials used the proposed criteria on real patients nationwide.

In May, early results indicated that the condition is relatively rare, and that clinicians don't always share strong agreement about which children have DMDD, according to work-group members. That could limit its clinical usefulness.

But for the time being, the new disease is expected to appear in the revised manual in some form—either as an official new illness, or as one that needs more research, Dr. Kupfer says. The final decision is expected in December.

Ms. Willoughby, the mother of the explosive 12-year-old girl, says her family has a good team of doctors, but "even with people so terrific, we still don't know if we have [the treatment] right." She says she and her husband are "open and flexible" to the idea of a new diagnosis if it will help their daughter. "None of it is a bloody science," Ms. Willoughby says.