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Should I

LABEL

My Kid?

BY TERI CETTINE

For some, it's a godsend. For others, it's a stigmatizing—and sometimes incorrect—professional opinion. Read about kids who were labeled with a disorder, and what it meant, for better and for worse.

When Oliver Winslow's* pre-school teacher suggested that something was "off" with him, his parents were ticked. Yes, he had trouble sitting still and focusing, but what 4-year-old boy doesn't?

Oliver's teachers and a developmental pediatrician (a specialist in developmental disorders) started tossing around names for his difficulties. He could have attention deficit hyperactivity disorder (ADHD). But then again, he also had difficulty communicating clearly. Maybe he had an auditory or sensory processing disorder?

Madeline Winslow* and her husband, Kevin*, who live in Portland, OR, pushed back. "We weren't about to slap an acronym on a kid that young," she says. "We worried that could stigmatize him."

Now, four years and many evaluations later, the Winslows feel just the opposite. Oliver, now 8, appears

to have Asperger's syndrome, a high-functioning form of autism. They're willing to have it noted on Oliver's medical and school records. It's not easy, of course. They alternate between heartbreak and gratitude that they finally know what's going on. "For him to get help, like behavioral therapy and special education classes, he has to have an official label. We can't just keep saying 'he's a little quirky.' It's more than that, and we're coming to terms with it."

For parents like the Winslows, the question of whether or not to label young kids with Asperger's, ADHD, or bipolar or other disorders has become hotly—and often tearfully—debated. One reason: The sheer number of kids we're talking about. Autism diagnoses, for instance, have increased 78 percent in the past decade. According to Medco Health Solutions, Inc., the biggest U.S. pharmacy-benefit manager, use

**Names have been changed.*



MIKE KEMP/CGETTY IMAGES

of psychiatric medications in U.S. children has increased 15 percent since 2001.

Those in favor of labeling point out that the best treatment starts early: The quicker you pinpoint what's ailing your child, the faster you can get him extra support or even medication. "If having a diagnosis is going to get your child the help he needs, go for it," says pediatrician Ari Brown, M.D., author of *Toddler 411*. Even so, getting some diagnoses may soon get harder: The American Psychiatric Association is tightening its pediatric autism

Usually, parents themselves fill out assessments. "There were a zillion questions, and many of them seemed repetitive," recalls Christina Lauro*, a mom in Babylon, NY. "I sweated that Aiden's* diagnosis hinged on my answers." For example, was Aiden "angry and frustrated," or did he "express frustration in an aggressive way"?

When a diagnosis like ADHD is stamped on a

"When your kid has a diagnosis, you're not judged as much."

guidelines in May 2013, which means fewer kids may qualify for intervention services.

There's also a relief that comes with being able to "blame" a medical disorder. "People are a lot less likely to be judgmental of your child's odd behavior, and your parenting skills, if they know your child has something definable," says Ivy Chong, Ph.D., director of autism services and training at the Scott Center for Autism Treatment at the Florida Institute of Technology, in Melbourne, FL.

But diagnosis is subjective. There's no blood or tissue test for autism, bipolar disorder, ADHD, or any developmental or mental health disorder, for that matter. "These illnesses exist, but diagnosing them can be a professional judgment call—and doctors can be wrong," says Scott Shannon, M.D., a child psychiatrist, founder of the Wholeness Center in Fort Collins, CO, and author of *Please Don't Label My Child*.

folder, Dr. Shannon says parents and professionals may stop looking for other solutions. And that's many parents' biggest fear: that future teachers will only see an ADHD case, and not their child. Dr. Shannon believes there are many ways to help such kids—from dietary to sleep changes. "But once a kid is labeled, parents accept that something's 'wrong' with her, the child feels 'broken,' and families tend to turn too quickly to meds."

If you're torn, you're in good company. **Here, four families' experiences:**

"WE'RE GLAD WE SAID NO"

"THE TRUTH SHOCKED US"

Diane Lansing's* youngest son, Colin*, first showed behavior issues and speech problems at age 2. Over the next two years, a dozen doctors gave him ever-changing diagnoses: ADHD, PDD-NOS (pervasive developmental

disorder—not otherwise specified, which relates to socializing and communicating), mixed receptive/expressive language disorder, SID (sensory integration disorder). All the possibilities gave Lansing a headache. Literally. "How could one kid have so much wrong?" wondered Lansing.

The San Diego mom declined the ADHD meds Colin's physician suggested. Eighteen months later, however, another doctor recommended lead testing, as symptoms of lead poisoning can mimic ADHD. They discovered that the entire family (both parents, Colin, and his older brother) had contracted lead poisoning from their dinnerware.

Because he was so young, it hit Colin hardest.

The family underwent chelation therapy to remove the lead from their bodies, and Colin needed speech and occupational therapy for several more years. During that time, the Lansings were shocked at how little teachers expected of Colin. He was automatically assigned to the remedial math group (despite having always done fine in math), and during class storytimes, Colin wasn't encouraged to join in. "They didn't expect him to be interested, so they didn't bother," says Lansing. His mom still wonders what would have happened had his condition been lifelong, rather than just temporary.

Now 11, Colin excels in school, football, and basketball. "But if we had accepted any one of those diagnoses, who knows?" says Lansing.



How do you know if your child is just a little off...or has a disorder?



Take the Time to Dive Deep

Most university medical centers do full-day developmental evaluations. Ask your pediatrician which one to call.

FROM TOP: MAHIE-REINE MATTERA/CORBIS, JON WHITTLE

"OUR DOC WAS WRONG"

Bridget James took her then 2-year-old son, Park, to the doctor because she thought he had strep throat. The pediatrician noted his language delays. He commented on the way he played with a toy he'd brought. Then he said Park was likely autistic.

After this visit, his parents enrolled him in early-intervention services near their Salt Lake City home. However, their gut told them the doc was wrong. James, who read that diet can affect kids' behavior, had him tested for food intolerances. Sure enough, food dyes and dairy popped up. And Park lived on cheese and yogurt.

Within five days of going dairy-free, "I kid you not, Park began looking in my eyes again. He wanted to read books together—something he hadn't done in a year," she recalls.

"A LABEL CHANGED OUR LIFE"

"MY 'BRAT' HAD AUTISM"

When 3-year-old Courtney Bourque of Loreauville, LA, has one of her meltdowns, Lacey Bourque knows how to handle the disapproving stares: She offers a card.

The card directs them to www.meetcourtney.org, where they can learn more about her, and autism, which now affects one in 88 children.

Bourque wasn't always this open with Courtney's illness. She and her husband, Bart, argued at first about whether it was possible to know for sure what was up with her. "But I never doubted the diagnosis," says Bourque. "I just wanted her to get help. Fast."

Hold On to Hope

Aspects of some disorders—like ADHD—can lessen as kids pass puberty.

Although the diagnosis was crushing, Bourque says it was also a huge help. "We came up with ways to make her life easier," she says. "She's calmer now, as we know what she needs." And the insurance company approved her therapy.

"IT OPENED HIS EYES TO THE WORLD AROUND HIM"

Cooper Windsor's kindergarten teacher had been the first to suggest he might have

"I finally knew why life was so chaotic. And it wasn't my fault."

ADHD. The day he took his first dose of Ritalin, he ran over to her after discovering his classroom's Home Life Zone. "This is fun! When did you put these toys here?" Upon hearing this, his mom, Amy Windsor, sobbed in relief. The toy zone had been there all along, but before he began the medication for ADHD, Cooper wasn't focused enough to notice them. "We knew it was working," Windsor recalls.

"I finally knew why our home life was so chaotic. And it wasn't my fault."

Cooper's parents disagreed at first about the label and medication. His dad worried the label would be a license to coast—that he'd get used to special treatment. But mostly, it provides a frame of reference. For instance, now they know Cooper can't sit still all the time, so they don't hound him. "We set goals he's capable of meeting," says Windsor.

Many parents

point to the lens that finally swayed them one way or the other: their child's self-esteem. "I understand when parents say they don't want to put a 'ceiling' on their child's potential by labeling them. But older kids tell me 'I always knew I was different. Now I know why,'" says Chong. A diagnosis can put a new structure in place that can make all the difference. "Self-esteem is the critical part of good mental health,"

says Dr. Brown. Lauro, the mom who stressed over the assessments, saw self-image as the missing piece in Aiden's puzzle. "Post-diagnosis, he has more confidence," she says. "He's not as hesitant to join in. He'd gotten to an age where it was sink or swim, and without the label...I think it could've been sink." 

TERI CETTINA is a freelance writer and mother of two daughters in Portland, OR.

Quirky or something more?

Child psychiatrist Scott Shannon, M.D., offers a checklist for sorting out the big question.

1. One visit won't cut it. *A 15-minute office visit with your family doc isn't enough to diagnose a developmental delay or ADHD. Get a referral to a developmental pediatrician, or a child psychiatrist or psychologist. If you're in a small town, you may need to travel to a university medical center for expert help.*

2. Put them to the test. *Professionals should spend an hour or two (perhaps over several visits) doing activity and observation-based testing. "If a diagnosis is handed down, get another opinion if your gut says it's wrong."*

3. Take advantage of help. *If therapy (speech, occupational, social skills) is suggested, it can't hurt—even if your child doesn't end up diagnosed. Some kids develop slowly, and that support can turn things around.*

GET A LEG UP

School districts often offer free early-intervention services for future students as young as 2, sometimes even in your own home. Call your district's special education office to see what your options are.

