

## Chapter Six

### We Mislabeled and Misdiagnosed Stress

Excessive stress in children can mimic a host of psychiatric conditions. I have seen stressed children express symptoms of depression, anxiety, attention deficit and hyperactivity disorder, and oppositional/defiant disorder. I see severely stressed children in the clinic and also in the hospital, where they have been admitted because of out-of-control behavior. Often they come to the hospital with various diagnostic labels: attention deficit and hyperactivity disorder, bipolar disorder, obsessive compulsive disorder (a type of anxiety disorder), oppositional/defiant disorder, posttraumatic stress disorder, and others. Some of these children are so disturbed they move from the hospital to a residential treatment center. After a year or two in a stable and caring environment (a new experience for many of these kids), the diagnostic labels no longer apply. Depending upon the trauma they have endured, they may continue to feel sad and anxious, which are natural responses to the early childhood horrors.

Catastrophic or repeated trauma disrupts the exquisite child's balance and drive toward complete healing. When the stressor is less earth-shaking, a child can usually resume a state of mental and emotional health, as long as the noxious thing is removed from her life and adults give the child acceptance, love, and security. Unfortunately, our mental health system diagnoses illness, not stress. The following story illustrates this tendency.

*Not long ago, Annette Wilson, one of the best family doctors in my community, phoned me. "Scott," she said, "I know your practice is closed. But I have a sixteen-year-old patient I want you to see. Her name's Lauren Macky. Another psychiatrist diagnosed her with bipolar disorder. I know this girl and her family well, and I think the diagnosis is way off track."*

*I agreed to make time for Lauren the following week. Before then, I telephoned Sue Macky, Lauren's mother, to gather some background*

*information. Sue told me that Lauren had been an easy baby and had always been a good student. Now a sophomore in high school, she continued to keep up her grades, had many friends, and was involved in several after-school activities. Only two things stood out as unusual. She had some compulsive behaviors (checking things over and over) that resolved without treatment, and, a few years ago, she developed symptoms of spastic colon, a stress-related condition. When I asked about Lauren's, Sue granted that her daughter could be moody and was sometimes "a real drama queen. "*

*Sue went on to tell me that, about two years ago, Lauren worried she was overweight, went on a diet, and lost twenty pounds. Sue didn't think Lauren had a bona fide eating disorder. She said Lauren was "big-boned and full-figured," but not fat. However, she didn't look emaciated after losing weight.*

*About a year ago, Lauren started cutting on her arms. As with most kids who cut themselves, she hid both the act and the bloody results. When the weather grew warm and sleeve lengths grew short, Sue noticed the cuts and asked about them. Lauren admitted she made them herself. When asked why, she said the act seemed to release sadness, frustration and tension.*

*At this point, her parents sent her to see a counselor, who met with her weekly with some benefit. Then, six months ago, Lauren's mood took a nosedive. She felt despondent and told the counselor that she wanted to die.*

*The counselor notified the parents and referred her to an adult psychiatrist. The psychiatrist diagnosed bipolar disorder and told Lauren she would need to be on medicine for the rest of her life. He prescribed Depakote, a mood stabilizer, and Seroquel, an anti-psychotic.*

*Lauren and her parents were hesitant about using medication, but, given the severity of Lauren's symptoms, they relented. During the ensuing three weeks, she gained nine pounds – a common side effect [xx for which drug? Yy] and a mortification for someone already conscious of her weight. At the next appointment, the psychiatrist added a medicine called Topamax, an anti-convulsant that suppresses appetite. This new drug made Lauren feel cloudy-headed and dopey, which she hated.*

*After three days, she announced she wasn't going to take any of the medicines. "And," she added, "I am never going to see that shrink again."*

*Soon thereafter, they met with Dr. Wilson, who prescribed a mild, low-dose tranquilizer to help Lauren hold things together until I could see her.*

*On the day of the appointment, Sue and Lauren came together. Both women were tall and big-framed. Clad in jeans and a letter jacket, Lauren strode right up to me, looked me in the eyes, and firmly shook my hand.*

*For a few minutes, we all chatted together. When we got to the topic of family history of psychiatric disease, I found out that no one besides Lauren had ever been suspected of having bipolar disorder, but that Sue had panic attacks. Next I asked about any recent traumatic events and learned that a close friend of Lauren's had died in a car accident two years earlier.*

*Alone, Lauren told me about her concerns, chief of which was her weight. "I'm fat," she said, "and I hate it."*

*I thought she looked muscular, but by no means fat. I began to suspect that this sort of harsh self-criticism drove her mood swings.*

*When she talked about her friends, however, her face glowed and her tone of voice grew warm. On this subject and others, she sounded confident and optimistic. She admitted that, when she was alone, she tended to ruminate on her failings (her weight, test scores lower than an A, moodiness around her parents, etc.). The more she ruminated, the more she felt unhappy, frustrated, and disgusted with herself.*

*At this point, I became certain Lauren didn't have bipolar disorder. This condition runs in families (and Lauren had no family history). As the older term for the illness – manic-depressive disease – suggests, the moods are intense, unpredictable, and uncontrollable. In Lauren's case, her judgmental thoughts and self-loathing seemed to shape her moods. Furthermore, any number of things (hanging out with friends, seeing a good movie, going for a run) could pull her out of a dark mood. I decided that Dr. Wilson's impression was, as usual, correct.*

*With Sue back in the room, I told her and Lauren that I did not think Lauren had bipolar disorder. I didn't even think Lauren was truly depressed. Rather, I thought Lauren was an emotionally vulnerable and self-critical girl, who needed help redefining her self-image, shoring up a somewhat fragile self-esteem, and managing her moods. It was her overly negative thoughts about herself that blackened her moods. Plus, she was exquisitely sensitive to emotional stress. Although the patterns she had gotten into were difficult and even dangerous, they were a long way from the lifelong seriousness of bipolar disorder. I told them I had every confidence Lauren could turn things around.*

*We began a program to help Lauren stabilize her moods, identify and halt negative thought patterns, and reduce psychological tension. She gradually learned to view herself in a kinder light, to feel gratitude for the good things in her life, and to find the deeper lessons in difficult issues. Two and one half years have passed. She is about to graduate from high school. She is not on any medication. She has not cut herself again. Though still sensitive about size, she no longer hates her body and likes herself much more. In essence, she has learned to monitor the emotional stresses in her life and take them on directly without spiraling down into despair and hopelessness*

Lauren's story ends on a happy note. However, had she not received a second opinion (and one that nixed the notion that she was bipolar), Lauren would likely still be carrying this label. She would still be on several medications. Worst of all, she might not have grown to understand herself. Had no one pointed out her underlying self-esteem issues, she would still be in a destructive cycle wherein negative thinking begat unhappy and tumultuous emotions. She would not have been able to develop to her highest potential.

Millions of other kids do find themselves in the situation Lauren managed to avoid. These kids have been labeled with a psychiatric diagnosis. And these labels, whether or not they're correct, can limit and damage children. Any kind of label, including a diagnostic label, is incomplete.

Diagnostic labels, however, are a fact of life. They drive the mental health care industry. Insurance companies require them. Without the diagnostic code, they don't reimburse. Furthermore, doctors are trained to come to a tidy conclusion about what ails a patient. It is intellectually satisfying to see how a person's symptoms fit the criteria for a particular illness.

Parents also want a diagnosis because it answers the question, "What's wrong with my child." They also want a solution to the problem at hand, and identifying and naming the problem is the first step in that process. Also, schools and social service agencies can provide additional supportive services, once these institutions know the diagnosis. Along the same line, social security may provide disability based on an evaluation and the resultant diagnosis.

When the diagnosis is correct, then the elements mentioned above fall satisfactorily into place. For instance, had Lauren really had bipolar disorder, appropriate medications, psychotherapy, and other supportive services would have done her much good and prevented disastrous events such as mania, severe depression, and suicide.

Here's the hitch: The process of evaluating a child is complex and requires considerable time, patience, and skill. Getting a clear picture of Lauren's thought and emotional patterns took time and a willingness to consider many aspects of her existence. I'm not saying I have any extraordinary diagnostic acumen, only that a perspective that honors the roll of stress and regards the whole child is more likely to uncover the root cause of symptoms.

*Here is an instance wherein a hastily obtained and inaccurate diagnosis equaled calamity for a child. There once was a six-year-old boy named Nick. His mother struggled to manage a busy job as an administrative assistant and three children: Nick, a needy and sad eight-year-old sister, and an energetic*

*three-year-old brother. His father, a bright but underachieving computer programmer, drank too much and argued with and occasionally struck his mother. After divorcing Nick's mother, he didn't bother to stay in touch with his kids and ex-wife. Nick's mother, who had moved to a small town in the rural south for her husband's work, had few friends. The divorce left her feeling isolated and hurt.*

*Not long after the divorce, Nick's first-grade teacher called to complain to the mother that Nick would not sit still and pay attention. He said and did things impulsively. Relentlessly inquisitive, Nick roamed the classroom, pulling things out of drawers and off of shelves.*

*Nick's mother brought him to the family doctor, where the boy promptly annoyed the doctor by getting into his equipment and supplies. The doctor diagnosed ADHD and prescribed Ritalin. The medication seemed to help Nick to sit still and focus – for a few days. Then things got worse. The mother became too depressed to be emotionally available to her children. Nick began to act out at home and at school. The doctor raised his Ritalin dose, and after Nick failed to improve over the next few weeks, raised it again. Nick began to hit kids at school and his siblings at home. When teachers and his mother asked him to do something, he did the opposite. Or he threw things and screamed. He became a tempest of a boy. In response, the doctor added the anti-psychotic drug Risperdal to control the aggressive behavior.*

*On high-dose Ritalin and Risperdal, Nick was somewhat more manageable, though lethargic and gaining weight. Because of his severe behavior and aggression, the school moved him into a classroom with other "high-needs" kids, most of whom had learning difficulties and poor social skills.*

*Meantime, Nick's mother began taking antidepressants and receiving counseling. Once her head was above water, she decided to move back to Colorado, where she had family and other social supports. Soon after she arrived, she phoned me. I made time to see Nick.*

*By this time, Nick was nine. He had gone from thin to obese. His clothes and hair were disheveled. He didn't seem to care about his appearance, nor*

*social conventions in general. To my astonishment, he related to me on the intellectual level of a teen. He could discuss politics and philosophy, electronics and computer programming. He compensated for an overall lack in social skills with a sharp and sarcastic sense of humor. When I asked about his medications, he jokingly compared himself to Jack Nicholson in One Flew Over The Cuckoo's Nest. He was observant, intelligent, and a bit eccentric, but clearly his own person. I liked him.*

*As we talked, I picked up some mildly compulsive traits. Specifically, he liked to order and count some of his possessions. I decided to taper his medications and do some testing. His IQ was over 140 for analytic skills, higher than mine and all but about one percent of the population. Although he lagged in some academic areas, his greatest shortfall was in social skills. The bottom line was that Nick didn't have ADHD; he was bored by school and extremely stressed by his family's turmoil.*

*Off medication, Nick was a handful: energetic, talkative, sarcastic, curious, testy and stubborn. However, the mother now had more psychological ballast and generally felt better able to cope with him. She realized his hyperactivity surfaced mainly when he was bored or upset. The mother and I placed him in a twice exception program -- a program for kids with two areas of uniqueness, in Nick's case high IQ and poor social skills. His teachers encouraged his curiosity and intellect, provided instruction in social skills, and tolerated his need for stimulation and movement.*

*Nick's now eleven. He has lost some weight and makes more effort towards his personal hygiene. He takes a low dose of a medication called Luvox to treat his compulsions. Relaxation training and calming herbs have helped him feel more even-keeled. He enjoys his home life and so does his mother.*

*Nick illustrates the concept that if we adults can just look beyond the way a child challenges us, we may find his greatest gift. In Nick's case, his hyperactive and frustrated behavior blinded adults from his high intelligence and thirst for knowledge. Labels tend to make us stop looking for the gem inside the*

*rough stone. For a while, Nick became “that ADHD kid.” Now he’s a complex individual known as Nick.*

My goal in discussing the potential problems of labels is not to alarm you but rather to instill you with a healthy skepticism about the reliability of psychiatric diagnoses in children. It puts me in mind of the old bumper sticker, “Question Authority.” If you question a doctor’s diagnosis, get a second opinion. All of us – health professionals, parents, and educators -- could stand to learn to be more cautious about how we label kids.

### **Advantages of Diagnostic Labels**

Before I begin to sound totally down on diagnostic labels, I must point out that they do have some important advantages. For one, they provide parents with a sense of relief. After all, parents come to the psychiatrist desperate to know what in the world is wrong with their child. Once named, their struggles no longer seem vague and inexplicable. Plus their child’s problems are not simply a result of inept parenting. And the child may understand that he is not just a naughty kid. In other words, parents and child alike can stop feeling guilty.

Once the problem is identified, everyone involved – doctor, family, teachers -- has an idea what to do. Granted, some of them may need some education to know how to handle the problems. Family members, knowing that various treatments can improve symptoms, feel hopeful. They can read about the condition and contact local support groups, thereby ceasing to feel alone in their problem.

### **Negative Consequences of Diagnostic Labels**

Of course, there are negative consequences of a diagnostic label, even if it’s correct. For one, the physician may cease looking for other causes of a child’s symptoms. For instance, if a child is labeled ADHD, adults may miss his stress

reaction to some traumatic situation or his learning disability. In general, the typical child referred for psychiatric evaluation has two to three problems at once. Missed diagnosis is more common when professionals without specialty training in child psychiatry or psychology do the evaluation. In contrast, children's mental health specialists are more likely to make more than one diagnosis and recommend broader treatment (e.g., medication + therapy + lifestyle changes + educational supports).

For example, a primary care doctor diagnosed eleven-year-old Josh with ADHD and prescribed stimulants. A year-and-a-half later, the school counselor met with Josh, detected suicidal thinking, and referred him to me. My evaluation revealed that, when Josh was eleven, his parents' frequent squabbles caused him to become depressed, and the depression aggravated a very mild case of ADHD. Because Josh kept his depressed feelings locked up inside, adults in his life didn't notice. The main outward sign of his depression was a dramatic fall in school performance, which was chalked up to ADHD. Although Josh did have mild ADHD, this condition was not the most important diagnosis. The ADHD label narrowed everyone's view of him and delayed treatment of his more pressing problem – depression. So you see, even a correct diagnosis can put blinders on us adults, limiting our view of the whole child and halting a deeper exploration of other underlying issues.

Another problem with a diagnostic label is that they can make a child feel defective or even "bad." He may come to see himself as problem to be solved. It's as though the label becomes a funhouse mirror reflecting a distorted child. The child no longer sees his true self, but only the representation the world casts back to him. This stigmatization occurs in spite of how positively parents and professionals frame the diagnosis.

I find the ADHD label can be particularly noxious for kids. Take Johnny, a pleasant and playful nine-year-old who came to me for an ADHD evaluation. His

parents were appropriately concerned and attentive to his needs. I confirmed the diagnosis. Stimulant medication abated his symptoms. During one session, I was exploring why he continued to struggle with math, even though other subjects had improved. For a moment, he sat silently. Then, his eyes on the floor, he said quietly, “You know why I can’t do it. My brain is broken. I’ve got ADHD.”

Labels also create a legacy, enduring after the child has shed the original problem. One of the most remarkable things about children is their plasticity, their ability to adapt and change. And many psychiatric conditions run a variable course, waxing and waning, and sometimes disappearing altogether. Unfortunately, labels are not nearly as flexible. Like tattoos, they often endure and outlive their usefulness. And if the label persists, no one may ever stop the medication the child is taking, to see whether there’s any reason to continue treatment.

Another downside with labels has to do with the continued stigma mental health diagnoses carry. Anyone who knows of a diagnosis – parents, friends, teachers, future employers, doctors – may react with expectations born of prejudice. For instance, a teacher, upon hearing that a child coming into her class has ADHD, may brace herself for unruly behavior and poor academic performance. The child may live up (or down) to those expectations. The child may also feel that the problem is outside his control, that he is a victim of his illness. People around him may stop seeing him as the multi-faceted person he really is. Samuel becomes “the ADHD kid,” instead of a boy who rides a unicycle, collects Pez dispensers, plays the penny whistle, and knows the names of every dog in the neighborhood.

If the label isn’t even correct, then you have a real mess on your hands, including all the problems inherent in a correct diagnosis. In addition, the child probably won’t get the treatment she needs. Her continued suffering will make her feel

despairing and damage her self-esteem. Her treatment failure will also frustrate and worry her parents.

The off-target treatment she does receive may not help and may aggravate symptoms. Take the all too common situation of the child overwhelmed by stress who is misdiagnosed with ADHD. If he's anxious, stimulants may make him more so. If he suffered an unspoken trauma, no one may help him come to terms with that horror. All doctors, myself included, make such errors. When a missed diagnosis misdirects treatment, I feel foolish and regretful, but try to learn from the experience.

*One case that comes to mind is that of Micky, an explosive, difficult, extremely energetic nine-year-old boy. His mother, upon arrival at my office, appeared frustrated, overwhelmed, emotionally drained, and at wit's end. She demanded that I do something to help. Micky's inability to express his feelings made me feel as though I'd been handed the Rosetta Stone. He was too kinetic for thoughtful conversation. He moved quickly from trains to puppets and back again. He pushed the toys into my face and bopped me on the head with them. Despite my repeated requests that he stop, he went through my desk drawers.*

*When he did speak, he acknowledged some symptoms that sounded like hallucinations. Specifically, he said he sometimes heard someone calling his name at night. The mother said there was a family history of mood disorder. Indeed, Micky appeared unhappy. His school reports spoke of problems with aggression, violence, explosive behavior, and inattention.*

*Thinking that Micky had a mood disorder marked by rapid swings in emotion, I prescribed a mood stabilizer and a very low dose of an anti-psychotic medication for this child. A few weeks later, his mother phoned to report that the medications had had remarkably positive effects on his behavior. Micky and his mother failed to keep their follow-up appointment.*

*Nine months later, the mother phoned to say Micky had gained 25 pounds. (Weight gain is a side effect of one of his medications.) She also told*

*me that she had separated from Micky's stepfather, and that she had learned that this man had physically and possibly sexually abused Micky. I had never met with the stepfather, though even if I had, I don't know whether I would have learned of the abuse. Shortly thereafter, Micky began therapy to help him cope with the abuse. He was able to gradually withdraw from his medications and lose some weight. His twisted course and ultimate recovery taught me a lesson I won't forget.*

### **What Can We Do?**

Clearly, we can't change the insurance industry, the medical profession, and societal attitudes about mental health issues. Not overnight, anyway. What we can do is temper the negative consequences of labels with a more holistic evaluation and treatment process. This model recognizes inherent limitations in the diagnostic process and counters these shortcomings with the strengths, capabilities, and positive potential of the child.

*Sometimes I find things work best when I don't even apply a diagnostic label. That's what I did when Melanie's parents came to see me. I had already spent two sessions trying to understand their complex nine-year-old daughter. Both parents are engineers who work long hours but are devoted to their only child. Melanie has struggled with anxiety, sad moods, and a volatile temper. On the one hand, she could be intense, defiant, and contrary; on the other she could be needy, weepy, and generally emotionally fragile.*

*Previous evaluations by two other mental health professionals had yielded two different diagnostic labels (depression and intermittent explosive disorder by a family doc and a psychologist respectively). The parents hoped I could resolve this confusion and help Melanie feel better. I shared my understanding of Melanie with them as a needy somewhat fragile girl who needed lots of support and attention. Then, I outlined my treatment recommendations. They seemed pleased by the breadth of this plan. However, I could sense some hesitation.*

*Finally the mother spoke up, "What is her diagnosis?"*

*I realizing they were too focused on the label and at times missing the girl underneath. My view was that Melanie was stressed by the relative lack of steady emotional connection to her busy, distracted and intellectual parent*

*I said, "Melanie is a complex girl. I am going to need your help to make the final diagnosis. Melanie could fit into one of five different labels: mood disorder, anxiety disorder, oppositional-defiant disorder, intermittent explosive disorder, or parent-child conflict. I need both of you to learn about these labels, watch her very closely and then at the end of every day sit down with Melanie and decide which of these five was most accurate that day. All three of you need to agree. Keep a log and bring it in each time we meet."*

*I gave them a mental health book that outlined the various diagnostic criteria. They got into this project with gusto. Both parents spent time watching her emotions and talking about them with her.*

*After five sessions, my undisclosed strategy bore fruit. The parents were spending more time really connecting with Melanie and seemed less preoccupied with their work. Melanie seemed happier, more relaxed and fought with them much less. We continued some of her treatment plan but all four of us agreed that none of the labels really described her all that well.*

This broader approach helps practitioners and parents view a child as a multifaceted individual with many connections to things and people in her environment. In Melanie's case, it helped the parents see these relationships (especially the relationships between the family members) and understand their importance and their constant evolution. To understand Melanie intimately, they had to spend lots of relaxed time with her. And that time made Melanie feel valued and gave her the positive attention (rather than negative attention in the form of reprimands) she craved. Had I given her a diagnostic label, her parents (and maybe Melanie as well) would have focused on the pathology, the thing that was wrong with this girl. By widening the lens to look at the whole girl, we were able to remain flexible and optimistic, while giving Melanie what she needed to heal. Melanie became not just a girl with oppositional-defiant disorder, but a girl

who collects unicorns, dreams of owning three cats, fears spiders, hates sandwich condiments, and loves having her feet massaged. When she's upset, a hug from her parents and the music of Debussy makes her feel better. When she's happy, she wants to share it. She wants her parents to listen to her sing for joy and watch her turn cartwheels. The more her parents take note of all the many things it means to be Melanie, the smoother and more fulfilling their family relationships become and the better they can help her when her emotions run wild.

While respecting the realistic impact of genetics and biology, this model does not reduce all of the struggles of our children to "a biochemical imbalance." For instance, I could have easily (and accurately) diagnosed Melanie with a mood disorder and prescribed an anti-depressant. Many of Melanie's symptoms would have improved, but the disturbance at the heart of Melanie's struggle – the emotional distance from her parents, a loss she felt but could not articulate -- would never have been resolved. That Melanie and her parents did achieve that kind of deeper healing will make their lives better in the present and also help them cope with any hardships the future might hold.