By the time Sam reaches preschool, his parents can tell he lacks what we can only imprecisely term a developmentally appropriate social instinct. He might avoid speaking to others and probably misses social cues already natural to his peers. He likely hums, talks to himself, or is unusually sensitive to noise. His teachers criticize his “inappropriate” behavior, but Sam doesn’t necessarily grasp the concept of propriety. He has some psychological disorder; autism and Asperger’s are both likely guesses. As parents, teachers, and doctors settle on a correct diagnosis, they also choose the set of strategies Sam will use to navigate a healthy, adult world.

Autistic disorder, according to the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-IV*), comprises some combination of “qualitative impairment in social interaction,” or difficulty with non-verbal aspects of interaction like eye contact, body language, and gestures; “qualitative impairments in communication,” or difficulty with verbal communication (without non-verbal compensation); and “restricted repetitive and stereotyped patterns of behavior, interests, and activities,” such as “stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole body movements)” (APA 299.00). The manual’s unofficial but much more readable description tells us that autistic disorder consists of “markedly abnormal or impaired development in social interaction and communication and a markedly restricted repertoire of activity and interests” (APA 299.00).

While those who have autism are easily differentiated from the general public, the behaviors that distinguish them are markedly similar to behaviors caused by another disorder: Asperger’s. The *DSM-IV* distinguishes the two by stating that, for Asperger’s, “there are no clinically significant delays in language (e.g., single words are used by age 2 years, communicative phrases are used by age 3 years)” and “no clinically significant delays in cognitive development or in the development of age appropriate self-help skills, adaptive
behavior (other than in social interaction), and curiosity about the environment in childhood” (APA 299.80).

Though the two disorders share almost every symptom, they are currently considered distinct. Why? Because the DSM says so, and in the American psychiatric community, the DSM’s word is law. As Allen J. Frances and Thomas Widiger point out, the DSM “provides the authoritative list of what are considered to be mental disorders. This list has a tremendous impact on research, funding, and treatment” (109). Although researchers debate the accuracy of diagnostic criteria, it makes sense for them to put their differences aside and accept the DSM as the definitive source of standards: doing so allows for

A common language for clinicians, a tool for researchers, and a bridge across the clinical/research interface . . . ; a textbook of information for educators and students . . . ; [and] a coding system for statistical, insurance, and administrative purposes. (Frances and Widiger 110)

Agreeing upon a common set of standards to define disorders enables a vigorous national conversation about them. When the DSM is revised, though, both clinical knowledge and cultural norms change along with it, and disagreements among researchers, clinical doctors, patients, and families come again to the fore as DSM criteria are questioned anew.

Since the American Psychiatric Association (APA) released its proposed revisions to the DSM-IV, controversy has centered on its proposed designation of an “autism spectrum disorder,” a diagnosis that would subsume both autistic disorder and Asperger’s disorder, as well as childhood integrative disorder and pervasive developmental disorders not otherwise classified. These diagnoses would be eliminated in the DSM-V, becoming instead variations of “autism spectrum disorder.” The APA’s revision team states that the two disorders could be merged easily because “Asperger disorder is not substantially different from other forms of ‘high functioning’ autism; i.e. Asperger’s is the part of the autism spectrum with good formal language skills and good (at least Verbal) IQ.” They write that language acquisition, the main differentiator between the two disorders, has little effect on “trajectories and later outcomes” of children diagnosed with either disease. Furthermore, language acquisition is an unclear diagnostic criterion, as “[e]arly language details are hard to establish in retrospect, especially for older children and adults” (“Proposed”). This last point is generally considered the most important rationale, and is worthy of a more detailed and lucid explanation.
Lorna Wing et al. provide such an explanation, writing that

The problems of social interaction are present from birth in individuals with any autism spectrum disorder. However it needs an experienced observer (or a very observant parent) to recognize the earliest signs in infants . . . The problem in clinical work is that individuals presenting for the first time in later childhood, adolescence or adult life may not have anyone who knew them in early childhood to give an accurate history. If the DSM-V is accepted in its present form, individuals in this situation may be denied appropriate help. (770)

Many families of those diagnosed with Asperger’s disorder oppose the revision—not because they disagree with the medical evaluation, but because of “the possible loss of their label, which they much prefer to that of autism spectrum disorder or just ‘autism.’” The new, more encompassing “label” may also “make them ineligible for medical or social services” (771). In essence, those currently diagnosed with Asperger’s may no longer have a diagnosis, and may therefore be ineligible for the state aid they currently receive. To qualify for aid, they will need to be re-diagnosed, this time with autism spectrum disorder. Though there’s some debate over the numbers, a recent study found that many—perhaps as many as seventy-five percent of those currently diagnosed with Asperger’s—would fail to meet the stricter criteria for a diagnosis of autism spectrum disorder (Carey).

Despite the relatively narrow subject of this debate, there’s surprisingly little overlap between the concerns of the two sides. The APA revision committee and the parents of children with Asperger’s disorder do not, in most cases, interpret medical evidence differently. But they do have very different conceptions of a diagnosis’s purpose.

The official, medical conception of a diagnosis’s function is not necessarily the right one—the APA’s stance is just one of several valid ways of seeing diagnosis. Frances and Widiger, in a reflective discussion of the epistemology of mental disorder, write that “there are four ways of depicting how we understand mental disorder,” and use a metaphorical baseball umpire to explain each one—“The first umpire believes that mental disorders are real things existing ‘out there’ that will soon reveal their secrets through scientific study.” This umpire believes that “[t]here are balls and there are strikes, and I call them as they are”. Because balls and strikes have inherent differences, it’s always possible to call them accurately. On the other end of the spectrum, their fourth umpire believes that “[m]ental disorders are no more than useful constructs—they are not real and independent psychiatric illnesses with clear
boundaries.” The diagnostic cutoff separating an individual with a disorder from an individual without one is arbitrary, a product of society’s expectations of what it means to be functional within that society. This umpire, therefore, says, “I call balls and strikes according to how I need to use them” (112-13). In this view, the differences between balls and strikes come not from the throw itself, but from the game’s rules—rules the umpire creates and enforces to ensure a fair game.

The APA revision committee seems to share the first umpire’s perspective. Their understanding of mental disorder focuses on the neurological and assumes that unknown structural mutations in the brain cause distinct mental disorders. Because each disorder can therefore be understood, and because that understanding would further human knowledge and potentially lead to discovering a new treatment or cure, the APA revision committee designs diagnostic criteria based solely on symptoms and treatment options. They see diagnosis as the accurate assessment of a patient’s place in the medical hierarchy.

But parents whose children suffer from Asperger’s disorder tend to agree with Frances and Widiger’s fourth umpire. These parents believe mental disorders stem from the same murky process that produces normal personalities, not from biological flaws in that process. Because there isn’t a root cause to discover, just the extremes of normal variation, a diagnosis should serve some other useful purpose. Parents don’t typically publish in scientific journals, but many use blogs to share their experiences and consult with other parents. Heather K. Adams, the mother of a child with Asperger’s, exemplifies the fourth umpire’s attitude in an article on Yahoo! Voices. She writes: “When I first suspected my son had Asperger’s Syndrome, I spoke with an administrator at his preschool. She told me very plainly that I did not want a diagnosis of Asperger’s Syndrome because it wasn’t officially considered a form of Autism. She told me that a diagnosis of Autism would be better for Sam because then I would get more assistance.” Yahoo! Voices isn’t peer reviewed or fact checked. It’s essentially a collection of blog posts from Yahoo’s associated content that meet a series of requirements such as “Don’t rant.” But the lax publishing requirements have allowed parents whose children have autism to form an online community that offers an unfiltered account of parents’ search for information. In her post, Heather isn’t trying to discover the neurological mechanisms of Sam’s problem. She is a mother who wants good things for her struggling child, who thinks the most useful diagnosis is the one that will give her child the help he needs to function. Any change to diagnostic criteria that
eliminates that help, whether it’s classroom aid or one-on-one tutoring sessions, dilutes the diagnosis’s power.

Neuroscience has developed significantly in recent years, but scientists still understand very little about the brain. Basic questions, like why people sleep or what causes emotion, remain unanswered. We know little about how neurons communicate with each other and less about how these communications can go awry. It’s possible that every trait and disorder can be understood on the neurological level. Alternatively, consciousness might be irreducible to simple, deterministic cause and effect. Both the APA revision committee and the parents of autistic children base their conceptions of diagnosis on the need it fills for them, ignoring its function in other contexts.

We have known for decades that diagnostic accuracy is limited. In 1973, almost twenty years after the APA published the first edition of its Diagnostic Statistical Manual of Mental Disorders, D. L. Rosenhan embarrassed psychiatrists with an experiment he describes in an essay titled, “On Being Sane in Insane Places.” His experiment consisted of “getting normal people (that is, people who do not have, and have never suffered, symptoms of serious psychiatric disorders) admitted to psychiatric hospitals and then determining whether they were discovered to be sane and, if so, how” (251). But Rosenhan never got to the “how” part: none of his “patients” were discovered. One might have expected the whole field to be discredited, but it persists unscathed.

That we did not force psychiatrists out of the medical community, dismissing them as junk scientists, suggests that diagnosis serves a purpose apart from accuracy. Splitting diagnostic criteria into four sets—one for clinicians, one for researchers, one for parents, and another for dividing up government aid money—is clearly not viable, and would likely harm the interests of those who occupy the intersection of these competing concerns: the children who have any of the disorders currently up for debate. But the often contradictory purposes of medicine, research, childcare, and aid allocation are at the heart of diagnosis’s fifth and most important role, one that transcends the others. Diagnosis acts as a conversational bridge for groups whose distinct objectives would otherwise separate them, and the interdisciplinary argument forces each group to add nuance to its conception of mental disorder.

This interdisciplinary conversation becomes increasingly important as we move from a system that segregates people with mental disorders to one that understands mental disorders well enough to serve those who suffer from them and encourage their social participation. Enhancing our understanding of those disorders allows us to better guide both our division of medical
resources and our most basic interactions with a population that must not be ignored. The only way to pursue this understanding, though, is to continue the conversation that this shared vocabulary of diagnosis allows. No Diagnostic and Statistical Manual of Mental Disorders criteria can satisfy every need, so we must settle for an imperfect one; by facilitating interdisciplinary interaction, we facilitate the nuanced understanding that comes from argument. But we also make sure that those struggling with mental disorders, on the autism spectrum and beyond, get the help they deserve.

WORKS CITED


