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A Powerful Identity, a Vanishing Diagnosis

By CLAUDIA WALLIS

It is one of the most intriguing labels in psychiatry. Children with Asperger's syndrome, a mild form of autism, are socially awkward and often physically clumsy, but many are verbal prodigies, speaking in complex sentences at early ages, reading newspapers fluently by age 5 or 6 and acquiring expertise in some preferred topic — stegosaurs, clipper ships, Interstate highways — that will astonish adults and bore their playmates to tears.

In recent years, this once obscure diagnosis, given to more than four times as many boys as girls, has become increasingly common.

Much of the growing prevalence of autism, which now affects about 1 percent of American children, according to federal data, can be attributed to Asperger’s and other mild forms of the disorder. And Asperger’s has exploded into popular culture through books and films depicting it as the realm of brilliant nerds and savantlike geniuses.

But no sooner has Asperger consciousness awakened than the disorder seems headed for psychiatric obsolescence.

Though it became an official part of the medical lexicon only in 1994, the experts who are revising psychiatry’s diagnostic manual have proposed to eliminate it from the new edition, due out in 2012.

If these experts have their way, Asperger’s syndrome and another mild form of autism, pervasive developmental disorder not otherwise specified (P.D.D.-N.O.S. for short), will be folded into a single broad diagnosis, autism spectrum disorder — a category that encompasses autism’s entire range, or spectrum, from high-functioning to profoundly disabling.

“Nobody has been able to show consistent differences between what clinicians diagnose as Asperger’s syndrome and what they diagnose as mild autistic disorder,” said Catherine Lord, director of the Autism and Communication Disorders Centers at the University of Michigan, one of 13 members of a group evaluating autism and other neurodevelopmental disorders for the manual.

“Asperger’s means a lot of different things to different people,” Dr. Lord said. “It’s confusing and not terribly useful.”

Taking Asperger’s out of the manual, known as D.S.M.-V for the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, does not mean the term will disappear. “We don’t want to say that no one can ever use this word,” Dr. Lord said, adding: “It’s not an evidence-based term. It may be something people would like to use to describe how they see themselves fitting into the spectrum.”

But the change, if approved by the manual’s editors and consultants, is likely to be controversial. The Asperger’s diagnosis is used by health insurers, researchers, state agencies and schools — not to mention people with the disorder, many of whom proudly call themselves Aspies.

Some experts worry that the loss of the label will inhibit mildly affected people from being assessed for autism. “The general public has either a neutral or fairly positive view of the term Asperger’s syndrome,” said Tony Attwood, a psychologist based in Australia who wrote “The Complete Guide to Asperger’s Syndrome” (Jessica Kingsley
Publishers, 2006). But if people are told they should be evaluated for autism, he went on, “they will say: ‘No, no, no. I can talk. I have a friend. What a ridiculous suggestion!’ So we will miss the opportunity to assess people.”

The proposed changes to the autism category are part of a bigger overhaul that will largely replace the old “you have it or you don’t” model of mental illness with a more modern view — that psychiatric disorders should be seen as a continuum, with many degrees of severity. The goal is to develop “severity measures within each diagnosis,” said Dr. Darrel A. Regier, research director at the American Psychiatric Association and vice chairman of the diagnostic manual’s task force.

Another broad change is to better recognize that psychiatric patients often have many health problems affecting mind and body and that clinicians need to evaluate and treat the whole patient.

Historically, Dr. Regier said, the diagnostic manual was used to sort hospital patients based on what was judged to be their most serious problem. A patient with a primary diagnosis of major depression would not be evaluated for anxiety, for example, even though the two disorders often go hand in hand.

Similarly, a child with the autism label could not also have a diagnosis of attention deficit hyperactivity disorder, because attention problems are considered secondary to the autism. Thus, they might go untreated, or the treatment would not be covered by insurance.

The new edition, by contrast, will list not only the core issues that characterize a given diagnosis but also an array of other health problems that commonly accompany the disorder. For autism, this would most likely include anxiety, attention disorders, gastrointestinal problems, seizures and sensory differences like extreme sensitivity to noise.

Parents and advocates have been clamoring for an approach that addresses the multiple health problems that plague many children with autism. “Our kids will do much better if medical conditions like gut issues or allergies are treated,” said Lee Grossman, president of the Autism Society of America, a leading advocacy group.

The new diagnostic approach addresses another source of confusion: the current labels may change over time. “A child can look like they have P.D.D.-N.O.S., then Asperger’s, then back to autism,” Dr. Lord said. The inconsistent use of these labels has been a problem for researchers recruiting subjects for studies of autism spectrum disorder.

And it can be a problem for people seeking help. In some states, California and Texas, for example, people with traditional autistic disorder qualify for state services, while those with Asperger’s and pervasive developmental disorder do not.

A big challenge for the diagnostic manual team working on autism is how to measure severity in a condition that often causes a very uneven profile of abilities and disabilities. Mr. Grossman gives the example of a woman who serves on an advisory panel to his organization. She is nonverbal and depends on an electronic device to communicate, is prone to self-injury and relies on a personal aide. And yet “she’s absolutely brilliant, she runs a newsletter, and she’s up on all the science,” he said, adding, “Where would somebody like that come out on the rating scale?”

Recent books by people with Asperger’s give insights into the workings of some oddly beautiful minds. In “Embracing the Wide Sky” (Free Press, 2009), Daniel Tammet, a shy British math and linguistic savant, tells how he was able to learn enough Icelandic in a week to manage a television interview and how he could recite the value of pi to 22,514 decimal places by envisioning the digits “as a rolling numerical panorama” of colors, shapes and textures.

In “Look Me in the Eye” (Crown, 2007), John Elder Robison describes a painfully lonely childhood and an ability to look at a circuit design and imagine how it will transform sound — a talent he used to invent audio effects and exploding guitars for the rock band Kiss.
Not all people with Asperger’s have such extraordinary abilities, and some who do are so crippled by anxiety and social limitations that they cannot hold down a job or live on their own.

Dr. Susan E. Swedo, a senior investigator at the National Institute of Mental Health who heads the diagnostic manual group working on autism, acknowledges the difficulty of describing such a variable disorder. Dr. Swedo said the plan was to define autism by two core elements — impaired social communication and repetitive behaviors or fixated interests — and to score each of those elements for severity.

The trick is to “walk the tightrope of truth,” Dr. Swedo said, between providing clear, easily used diagnostic guidance to clinicians and capturing the individual variation that is relevant to treatment. “People say that in autism, everybody is a snowflake,” she said. “It’s the perfect analogy.”

The proposed elimination of autism subtypes comes at the very moment when research suggests that the disorder may have scores of varieties. Investigators have already identified more than a dozen gene patterns associated with autism, but Dr. Lord, of Michigan, said the genetic markers “don’t seem to map at all into what people currently call Asperger’s or P.D.D.”

Nor have many of these genes been linked to distinct sets of symptoms. Until research can identify reliable biological markers for autism subtypes, Dr. Lord and other experts say, it is better to have no subtypes than the wrong ones.

In interviews, people with Asperger’s and mild autism were divided on the prospect of losing the label. Temple Grandin, a Colorado State University animal scientist who is perhaps the best-known autistic American, said Asperger’s was too well established to be thrown overboard. “The Asperger community is a big vocal community,” Dr. Grandin said, “a reason in itself” to leave the diagnosis in place.


But some younger people involved in the growing autism self-advocacy movement see things differently.

“My identity is attached to being on the autism spectrum, not some superior Asperger’s identity,” said Ari Ne’eman, 21, an activist who founded the Autistic Self-Advocacy Network, a 15-chapter organization he has built while in college, adding, “I think the consolidation to one category of autism spectrum diagnosis will lead to better services.”

All interested parties will have an opportunity to weigh in on the proposed changes. The American Psychiatric Association is expected to post the working group’s final proposal on autism diagnostic criteria on the diagnostic manual’s Web site in January and invite comment from the public. Dr. Swedo and company are bracing for an earful.

This article has been revised to reflect the following correction:

**Correction: November 5, 2009**

An article on Tuesday about a proposal to remove Asperger’s syndrome from the next edition of psychiatry’s diagnostic manual misstated the educational affiliation for Temple Grandin, a well-known American with autism. She is a professor of animal science at Colorado State University, not the University of Colorado.