

November 10, 2009

OP-ED CONTRIBUTOR

The Short Life of a Diagnosis

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THE Diagnostic and Statistical Manual of Mental Disorders, published by the American Psychiatric Association, is the bible of diagnosis in psychiatry, and is used not just by doctors around the world but also by health insurers.

Changing any such central document is complicated. It should therefore come as no surprise that a committee of experts charged with revising the manual has caused consternation by considering removing Asperger syndrome from the next edition, scheduled to appear in 2012. The committee argues that the syndrome should be deleted because there is no clear separation between it and its close neighbor, autism.

The experts propose that both conditions should be subsumed under the term “autism spectrum disorder,” with individuals differentiated by levels of severity. It may be true that there is no hard and fast separation between Asperger syndrome and classic autism, since they are currently differentiated only by intelligence and onset of language. Both classic autism and Asperger syndrome involve difficulties with social interaction and communication, alongside unusually narrow interests and a strong desire for repetition, but in Asperger syndrome, the person has good intelligence and language acquisition.

The question of whether Asperger syndrome should be included or excluded is the latest example of dramatic changes in history of the diagnostic manual. The first manual, published in 1952, listed 106 “mental disorders.” The second (1968), listed 182, and famously removed homosexuality as a disorder in a later printing. The third (1980) listed 265 disorders, taking out “neurosis.” The revised third version (1987) listed 292 disorders, while the current fourth version cut the list of disorders back to 283.

This history reminds us that psychiatric diagnoses are not set in stone. They are “manmade,” and different generations of doctors sit around the committee table and change how we think about “mental disorders.”

This in turn reminds us to set aside any assumption that the diagnostic manual is a taxonomic system. Maybe one day it will achieve this scientific value, but a classification system that can be changed so freely and so frequently can't be close to following Plato's recommendation of “carving nature at its joints.”

Part of the reason the diagnostic manual can move the boundaries and add or remove “mental disorders” so easily is that it focuses on surface appearances or behavior (symptoms) and is silent about causes. Symptoms can be arranged into groups in many ways, and there is no single right way to cluster them. Psychiatry is not at the stage of other branches of medicine, where a diagnostic category depends on a known biological mechanism. An example of where this does occur is Down syndrome, where surface appearances are irrelevant. Instead the cause — an extra copy of Chromosome 21 — is the sole determinant to obtain a diagnosis. Psychiatry, in contrast, does not yet have any diagnostic blood tests with which to reveal a biological mechanism.

So what should we do about Asperger syndrome? Although originally described in German in 1944, the first article about it in English was published in 1981, and Asperger syndrome made it only into the fourth version of the manual, in 1994. That is, the international medical community took 50 years to acknowledge it. In the last decade thousands of people have been given the diagnosis. Seen through this historical lens, it seems a very short time frame to be considering removing Asperger syndrome from the manual.

We also need to be aware of the consequences of removing it. First, what happens to those people and their families who waited so long for a diagnostic label that does a good job of describing their profile? Will they have to go back to the clinics to get their diagnoses changed? The likelihood of causing them confusion and upset seems high.

Second, science hasn’t had a proper chance to test if there is a biological difference between Asperger syndrome and classic autism. My colleagues and I recently published the first candidate gene study of Asperger syndrome, which identified 14 genes associated with the condition.

We don’t yet know if Asperger syndrome is genetically identical or distinct from classic autism, but surely it makes scientific sense to wait until these two subgroups have been thoroughly tested before lumping them together in the diagnostic manual. I am the first to agree with the concept of an autistic spectrum, but there may be important differences between subgroups that the psychiatric association should not blur too hastily.

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