



What Autism Epidemic?

By Claudia Wallis

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Epidemic is a powerful word. It generates bold headlines, congressional hearings, research dollars and dramatic, high-stakes hunts for culprits. It's a word that has lately been attached to autism. How else to account for the fact that a disorder that before 1990 was reported to affect just 4.7 out of every 10,000 American children now strikes 60 per 10,000, according to many estimates--the equivalent of 1 in 166 kids?

But what if there is no epidemic? What if the apparent explosion in autism numbers is simply the unforeseen result of shifting definitions, policy changes and increased awareness among parents, educators and doctors? That's what George Washington University anthropologist Roy Richard Grinker persuasively argues in a new book sure to generate controversy. In *Unstrange Minds: Remapping the World of Autism*, Grinker uses the lens of anthropology to show how shifting cultural conditions change the way medical scientists do their work and how we perceive mental health.

In addition to rising awareness of autism, Grinker points to these factors:

BROADER DEFINITIONS Each successive edition of the Diagnostic and Statistical Manual of Mental Disorders--the bible of mental health--has revised the criteria for identifying autism in ways that tend to include more people. Two conditions on the milder end of the autistic spectrum--Asperger's syndrome and the awkwardly named PDD-NOS (pervasive developmental disorder, not otherwise specified)--were added to the DSM in 1994 and 1987, respectively. Grinker and others say 50% to 75% of the increase in diagnoses is coming in these milder categories.

SCHOOL POLICY U.S. schools are required to report data on kids who receive special-education services, but autism wasn't added as a category until the 1991-92 school year. No wonder the numbers exploded--from 22,445 receiving services for autism in 1995 to 140,254 in 2004. Grinker points out that "traumatic brain injury" also became one of the 13 reportable categories in 1992, and it had a similar spike.

MORE HELP, LESS STIGMA As services have become more available for kids with autism, more parents are seeking a diagnosis they would have shunned 30 years ago, when psychiatrists still blamed autism on chilly "refrigerator" mothers. Doctors are also more willing to apply the diagnosis to help a patient. "I'll call a kid a zebra if it will get him the educational services I think he needs," National Institute of Mental Health psychiatrist Judith Rapoport told Grinker.

FINANCIAL INCENTIVES In some states, parents of children with autism can apply for Medicaid even if they are not near the poverty line. A diagnosis of mental retardation doesn't always offer this advantage.

RELABELING For all the reasons above, many kids previously given other diagnoses are now called autistic. University of Wisconsin researcher Paul Shattuck has found that the number of kids getting special-ed services for retardation and learning disabilities declined in 47 states between 1994 and 2003, just as those getting help for autism was rising. In 44 states, the drop exceeded the rise in autism.

As convincing as Grinker's analysis seems, arguments about the apparent epidemic will probably continue. It's simply impossible to accurately reconstruct the past incidence of the disorder, given how radically definitions have changed. Those who believe the increase is real often focus on the mysterious paucity of autistic adults. With their conspicuous symptoms like hand flapping and little or no language, "I think we would be recognizing them in institutions," says Dr. Robert Hendren, executive director of the M.I.N.D. Institute at the University of California, Davis.

Grinker's answer is that autistic adults are out there but wearing other labels. "Where are all the adults with fetal alcohol syndrome?" he asks. No one over 40 has the condition, thought to affect up to 1 in 500 kids today, because it was not recognized until the mid-'70s. "But no one would say alcoholism among pregnant women just started," says Grinker.

Grinker, whose 15-year-old daughter is autistic, concedes that there's something reassuring about the idea of an epidemic: "Thinking about any disorder as an epidemic is easier than thinking about it in terms of multiple causes, shifting definitions and a scientific reality we are only just beginning to understand." Besides, if a disease suddenly spikes, it seems more plausible that the increase could be reversed--if only we could find the mysterious environmental trigger. With autism, though, that hopeful scenario seems just too simple.