

## CHAPTER NINE

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# A Conspicuous Absence of Scientific Leadership The Illusory Epidemic of Autism

MORTON A. GERNSBACHER

If you're a scientist working for private industry, it helps to invent something useful. But if you're a scientist trying to get funding from the government, you're better off telling the world how horrible things are. And once people are scared, they pay attention. They may even demand the government give you more money to solve the problem.<sup>1</sup>

On the presidential campaign trail in 2007, Hillary Clinton decreed, "We have an epidemic, and it is time that we recognized the seriousness of it." On congressional letterhead that June, Congressman Dan Burton, former Chair of the Committee on Oversight and Government Reform, proclaimed, "We are literally in the midst of a nationwide epidemic." On posh Nantucket Island that August, Suzanne Wright, wife of former GE vice chairman and NBC CEO, Bob Wright, declared, "It's a health crisis... an epidemic that has to be stopped."

To what epidemic were these public figures referring? The AIDS epidemic? An epidemic of avian flu? An epidemic of SARS? No, as Suzanne Wright lamented to a group of school-age children: "I don't want you growing up, getting married and having a baby with autism."

Autism is a human variation characterized by atypical social interaction, atypical communication, and more focused-than-average interests. Autistic traits have most likely existed since humanity's origin and are woven throughout the biographies of numerous historical figures: Hugh Blair of Bogue, the eighteenth-century Scottish landowner, Henry Cavendish, the eighteenth-century British scientist, Nikola Tesla, the prolific inventor, Glenn Gould, the Canadian pianist, Moe Norman, the Canadian golfer, Michael Ventris, the English architect, Albert Einstein, Thomas Jefferson, and Isaac Newton.<sup>2</sup>

With the exception of Moe Norman, none of these influential individuals could ever have been diagnosed as autistic because the diagnosis of autism did not exist during their lifetime. Not until the 1940s would the constellation of atypical social interaction, atypical communication, and more focused-than-average interests be known, as Leo Kanner deemed it, as autism. And, as Gernsbacher, Dawson, and Goldsmith have reported, standardized criteria for diagnosing autism did not make their way into American psychiatry until forty more years had passed.<sup>3</sup>

Therefore, as Gernsbacher and her colleagues have noted, any estimate of the prevalence of autistic persons prior to 1980 would be based solely on an individual clinician's or a specific researcher's conception.<sup>4</sup> Moreover, such early estimates would be prone to methodological and epidemiological variations that continue to complicate current estimates, such as the sample's size and how it was ascertained. Furthermore, it would be impossible to reverse time and apply any era's diagnostic criteria without that era's accompanying societal context.<sup>5</sup> For example, the advent of social justice movements, such as that which bore the Americans with Disabilities Act in 1990, diminished the stigma and enhanced the opportunities available to persons with diagnosed disabilities.

Autism remains in the most recent edition of the APA's *Diagnostic and Statistical Manual*, but the diagnostic criteria have undergone significant changes, particularly between 1980 and 1994.<sup>6</sup> For example, a diagnosis according to the criteria published in 1980 required satisfying six mandatory stipulations, but a diagnosis according to the criteria published in 1994 involved simply meeting half the options on a branching menu. Moreover, one need not be a semanticist to discern the contrast between the mandatory criteria published in 1980 and optional criteria published in 1994.

For example, the *Diagnostic and Statistical Manual* criteria published in 1980 required "a pervasive lack of responsiveness to other people"; in

contrast, the criteria published in 1994 involved only “a lack of spontaneous seeking to share achievements with other people,” or peer relationships “less sophisticated” than developmental level would predict. As another example, the criteria published in 1980 required “gross deficits in language development”; the criteria published in 1994 involved simply experiencing difficulty “sustaining a conversation.”<sup>7</sup>

Furthermore, whereas the 1980 diagnostic criteria were organized into only two diagnostic categories (infantile and childhood onset), the 1994 criteria were expanded into five diagnostic categories, of which three connote what we commonly refer to as autism: Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Whereas Autistic Disorder requires meeting half the criteria, Asperger’s Disorder, for which criteria didn’t exist prior to the 1994 *Diagnostic and Statistical Manual* publication, requires meeting only two-thirds of that half. PDD-NOS, for which criteria didn’t exist prior to the 1987 *Diagnostic and Statistical Manual* publication, is defined by subthreshold symptoms. Thus, PDD-NOS and Asperger’s, which didn’t gain diagnostic status until 1987 and 1994, are less obvious phenotypes.

For what percentage of contemporary autism diagnoses do these less obvious phenotypes account? One of the largest epidemiological studies to date, published in the *Journal of the American Medical Association*, estimated that the less obvious phenotypes, Asperger’s and PDD-NOS, account for nearly 75 percent of current diagnoses.<sup>8</sup> Moreover, current diagnostic practices allow, whereas previous diagnostic practices prohibited, codiagnosing autism alongside known medical and genetic conditions, such as Down syndrome or cerebral palsy.

Keep in mind the purposeful broadening of the diagnostic criteria during the past two decades, the deliberate expansion of the diagnostic categories (to include less obvious phenotypes, which account for 75 percent of contemporary diagnoses), the contemporary recognition that autistic individuals can present with every level of measured intelligence, and the intentional effort to identify autistic children as young as possible. Now, consider the definitional criteria for an epidemic: an increase beyond a rate that is likely or expectable. It should be clear that the term *autism epidemic* does not meet these criteria.

How did the infelicitous term *autism epidemic* arise and why have so many scientists allowed the term to remain uncorrected? This chapter provides that narrative, related in order to illustrate a critical lesson in scientific leadership: “Leadership is most conspicuous by its absence.”<sup>9</sup> Thus, the vast majority of scientists—the leaders of the scientific

community—failed to quash the inaccurate coinage of the term *autism epidemic*. The vast majority of scientific leaders failed to educate the public as to why the rate with which individuals were being diagnosed with autism was increasing (e.g., due to purposefully broadened diagnostic criteria). The vast majority of scientists failed to lead.

### **How California Coined the Autism Epidemic**

In early 1998, four California fathers of autistic children dreamt of founding a joint research and clinical center to focus on autism. They would call it the MIND Institute and site it at the University of California-Davis Medical School. By June of 1998, the four California fathers had raised over \$2.5 million from private donors. Courtesy of one of the four founding fathers, Rick Rollens, a former state senate secretary turned high powered lobbyist, the four fathers and their fledgling center received an additional boost directly from the California state legislature: A line item of \$2 million was added to California's annual budget—without a sunset clause.

In November of 1998, the founding fathers gathered an extensive who's who of California-based biological and behavioral scientists, most of whom had never researched autism. They dangled before the scientists \$1 million of their kitty, to be awarded via fast-tracked competition, and they planned the construction of a new facility, which would carry a \$28 million price tag. Clearly, the founding fathers needed more funds.

The California Department of Developmental Services, a statewide collection of agencies that provides services for individuals with developmental disabilities, was one of lobbyist founding father Rick Rollens's clients. Because the diagnostic criteria for autism had been broadened a few years before,<sup>10</sup> it was only to be expected that more autistic individuals were qualifying for services. Rollens encouraged the California Department of Developmental Services to document those increases, which they did in a study released with fanfare in April 1999.

“State Study Finds Sharp Rise in Autism Rate,” shouted the headline of the *LA Times*; “Autism Spike Sets off Alarms,” alerted the *San Jose Mercury News*.<sup>11</sup> The increased number of individuals who qualified for services was described as “huge and unexpected,” a description propelled both by the authors of the study (“autism is increasing at an alarming rate”) and by the newly appointed director of the MIND Institute (“it's a dramatic report, but what's shocking is that it's not clear

what the cause is”). Bernard Rimland, a longtime California autism advocate who had founded the Autism Society of America but whose later interests had turned to questionable treatments, such as megadoses of vitamin B6 and the dubious, if not harmful, peptide hormone Secretin, proclaimed, “We’re in the middle of an autism epidemic.”

The next week, Edward Ritvo, Professor Emeritus of UCLA Medical School and venerable autism researcher, attempted to douse the panic. In a newsletter article titled, “No Epidemic of Autism,”<sup>12</sup> Ritvo stated that the results of the California Department of Developmental Services study were cause for cheer not fear; the increase reflected the successful efforts of previous autism researchers to broaden the diagnostic criteria so as to identify less obvious phenotypes. Ritvo outlined three additional, encouraging reasons for the increase: (a) the success of efforts to increase awareness of autism by physicians and the public, (b) the increased availability of public agencies and schools that provide necessary services, and (c) the fortunate closure of state and private “warehouses” [institutions] in which many autistic people had previously been “improperly diagnosed and housed.”

Indeed, as Ritvo calmly concluded, “The prevalence figures that are emerging just now from California and Illinois are in line with recent figures from Japan and other countries that have recognized the existence of milder cases of autism for several years. Thus, the increased figures come as no surprise to those following the international epidemiological literature.”<sup>13</sup>

However, once spawned into the popular vernacular, the term *autism epidemic* proliferated. The term recurred almost weekly in the California-based Families for Effective Autism Treatment newsletter, which was electronically distributed to 7,000 readers. News items were glossed by the editor: “Rising rate of autism in state” was relabeled “*San Jose Mercury News* reports on the California autism epidemic,” and an article in *The New York Times* about AIDS was relabeled, “A look at AIDS—that other immune disease epidemic.”<sup>14</sup>

In another attempt to stem the tide, similar to Edward Ritvo’s earlier attempt, Canadian researcher Eric Fombonne published in the journal *Pediatrics* a critique of the California Department of Developmental Services’ report. Noting first that “the report . . . has been, and still is, widely quoted as evidence for an epidemic of autism,” Fombonne concluded that the data “provide no basis for the claim” and “there is no need to raise false alarms on putative epidemics or to practice poor science.”<sup>15</sup>

When interviewed in the prestigious journal *Science*, Fombonne responded even more frankly: “The grounds for an increase [are]

completely nonexistent . . . The rise in demand for services can probably be traced to an increased awareness of the condition, more common referrals due to the availability of better services, and an ever-broadening definition of just what constitutes autism.”<sup>16</sup> Fombonne’s reasoning corroborated perfectly that of longtime autism researcher Edward Ritvo. David Amaral, a behavioral neuroscientist who by then had been appointed Research Director of the MIND Institute, objected. “I’m still not convinced that there hasn’t been an [actual] increase,” he demurred.

Apart from Canadian researcher Fombonne and emeritus California researcher Ritvo, the rest of the scientific field remained publicly silent. No other scientist attempted to calm the storm, to extinguish the wildfire of a false epidemic. In June 1999, lobbyist and founding father Rick Rollens reported that the California legislature would be contributing another \$2 million to the MIND Institute and an additional \$1 million would be given to the MIND Institute to study “the epidemic of autism in California.”

### **The Illusory Epidemic Goes National**

At the federal level, the Advancement in Pediatric Autism Research Act, introduced by Senator Slade Gorton, had been languishing for over a year. Although read twice, it had not yet been scheduled for senatorial debate. During the summer of 1999, buoyed by the California Department of Developmental Services report of increased services attached to the indelible term *autism epidemic*, Jon Shestack, cofounder of the California-based foundation, Cure Autism Now, rallied the troops.

Shestack, a Hollywood producer, and his wife, Portia Iverson, an Emmy-winning set designer, had become well known for their dramatic rhetoric about autism. Iverson likened being a parent of an autistic child to “the Village of the Damned,” and Shestack reiterated in several major media outlets—*Newsweek*, *Sixty Minutes II*, even the August *Journal of the American Medical Association*—that having an autistic child was “one of the worst nightmares a parent can imagine [because] without warning, a child is abducted from his bed in the middle of the night, never to return. Now, imagine that instead of taking the whole child, only his mind is stolen and his body—the hollow shell of his being—is left behind. If one in every 250 children in America were actually being abducted, that would be a national emergency,” Shestack said. “But that is what is happening with autism.”

Shestack's refrain of his autistic child as a mindless hollow shell and his repeated allusion to an Elizabeth Short-like abduction epitomized John Stossel's facetious advice for crow-barring government funding: "You're better off telling the world how horrible things are. And once people are scared, they pay attention. They may even demand the government give you more money to solve the problem."<sup>17</sup>

To power the passage of the Advancement in Pediatric Autism Research Act, Shestack's organization directed parents to call their Congress members and "tell them that autism is a truly devastating disorder. While it will not affect the life-span of those with autism, individuals with autism require a lifetime of services, interventions, and struggles, all of which are a tremendous financial and emotional drain on not just families, but our nation as a whole."

In September 1999, Shestack organized a rally on Capitol Hill. Geraldine Dawson, a longtime autism researcher, appeared before the Senate's Public Health Subcommittee, testifying that while autism was "once thought to be rare," the prevalence had increased so rapidly that it now affected more children than did cancer. Actress Rene Russo, who made personal visits to key senators' offices, testified that "we've lost a generation of children."

State by state, congressional votes were won, through parents' repetition that "autism is a truly devastating disorder." In October 2000, the Advancement of Pediatric Autism Research Act, relabeled the Children's Health Act, passed Congress. The \$75 million NIH pot was distributed among eight groups of researchers, five of whom had shared a \$45 million NIH pot three years earlier and would share another \$60 million NIH pot two years later. Not one researcher funded by the nearly quarter billion NIH dollars, including three researchers who had been directly responsible for purposely broadening the 1994 *Diagnostic and Statistical Manual* criteria,<sup>18</sup> ever publicly questioned the verity of the illusory autism epidemic.

### **A Tall Tale from California**

In October 2002, the results of the MIND Institute study, investigating the basis of the increasing number of autistic persons served by the California Department of Developmental Services, were released to state legislators. The study reported that 2,778 autistic individuals had received services in 1987, whereas 10,360 autistic individuals had received services in 1998. This 273 percent increase, the study

concluded, “could not be explained by loosening of criteria.”<sup>19</sup> This conclusion licensed *The New York Times* to label the autism epidemic “a mysterious upsurge,” CBS news to deem it a “baffling... outbreak,” and the *San Francisco Chronicle* to call it an “explosion.” This conclusion promulgated throughout the Internet, but as Gernsbacher and her colleagues noted, it was marred by a serious lapse of logic, as described next.<sup>20</sup>

The study had collected two samples of children: One comprised children born between 1983 and 1985 (the earlier cohort); the other sample comprised children born between 1993 and 1995 (the more recent cohort). Both cohorts were assessed using the same diagnostic instrument (a standardized diagnostic interview conducted with the child’s caregiver). However, the fatal flaw of the study was that the diagnostic instrument was based on only the more recent, purposely broadened criteria, which had not been published until 1994, many years after the earlier cohort had been originally diagnosed.

When the same percentage of children in the earlier and more recent cohort met the broader 1994 criteria, the researchers concluded that the 273 percent increase in persons served by the California Department of Developmental Services between 1987 and 1998 could not have been due to changes in diagnostic criteria. However, here is where the logic breaks down: A diagnostic instrument based on a broader criterion can easily identify the same percentage of individuals who meet a broader criterion and a more restricted criterion.

Consider the analogy forwarded by Gernsbacher and colleagues based on male height.<sup>21</sup> Suppose in the mid-1980s the criterion for tall was 74.5" and taller, but in the mid-1990s the criterion was broadened to 72" and taller. A diagnostic instrument based on the broader, more recent criterion of 72" would identify males who met the more restricted 74.5" criterion as well as males who met the broader 72" criterion: If a male is tall according to the 74.5" criterion, he is tall according to the 72" criterion. While a perfectly reliable diagnostic instrument based on a broader criterion would identify 100 percent of the individuals who meet the broader criterion along with 100 percent of the individuals who meet the more restricted criterion, a highly reliable instrument might identify about 90 percent of each group. This was the percentage of the MIND Institute’s early and more recent cohort who met the broader 1994 autism criteria. Thus, broadening a criterion results in a dramatic increase in diagnosed cases. As Gernsbacher and her colleagues calculated,<sup>22</sup> census data estimate that 2,778 males in McClennan County, Texas would be called tall by the more restricted



74.5" criterion, and 10,360 males would be called tall by the broader 72" criterion. If those two criteria for tallness had been applied a decade apart, a 273 percent increase in the number of males called tall would emerge—without any real increase in Texans' height. In the same way, the 273 percent increase from 2,778 versus 10,360 autistic individuals served by the California Department of Developmental Services in 1987 versus 1998 could well be a function of broadening the diagnostic criteria.

### Limitations of the IDEA Data

In addition to California-based claims of an autism epidemic, based on increasing numbers of autistic individuals in the California Department of Developmental Services system, country-wide claims of an autism epidemic were made, based on increasing numbers of autistic children in the country-wide special education system. As Gernsbacher and her colleagues reported, in October 2003, the Autism Society of America sent its 20,000 members the following electronic message: "Figures from the most recent U.S. Department of Education's 2002 Report to Congress on IDEA reveal that the number of students with autism in America's schools *jumped an alarming 1,354% in the eight-year period from the school year 1991–92 to 2000–01.*"<sup>23</sup>

However, as Gernsbacher and her colleagues noted, the Autism Society of America failed to note the following important fact: Before 1991–92, autism didn't exist as an IDEA reporting category. Autism was a new, and optional, reporting category in 1991–92.<sup>24</sup> Whenever a new category is introduced, if it is viable, increases in its usage will ensue. For example, as also noted by Gernsbacher and her colleagues, the reporting category, traumatic brain injury, was also a new IDEA reporting category in 1991–92.<sup>25</sup> The reporting category of traumatic brain injury soared an astronomical 5,059 percent from 1991–92 to 2000–01. Similarly, the IDEA reporting category, developmental delay, was introduced only in 1997–98, and from 1997 to 1998 it grew 663 percent in only those three years.

After the initial year, the number of autistic school children reported through IDEA has increased by approximately 23 percent per annum—and most likely will continue to increase. Why? As with cellular phones and high-speed Internet, new options are not capitalized upon instantaneously; they require incrementally magnified awareness and augmentation or reallocation of resources. Moreover, no state currently

reports the number of autistic children who would be expected based on large-scaled epidemiological studies,<sup>26</sup> namely, 6.0 to 6.6 children per 1,000. Thus, the number of autistic children served by the IDEA will most likely continue to increase until each state reports the number of autistic children identified in the epidemiological studies. As Massachusetts state officials have stated, increases in their reporting of autism will continue for several more years until “districts better understand how to submit their data at the student level,” and “all districts comply completely with the new reporting methods.”<sup>27</sup>

### An Epidemic of Hype

Despite growing awareness of the purposeful broadening of diagnostic criteria, increased understanding of the limitations of the country-wide IDEA data, and more logical consideration of the MIND Institute’s time-trend study, alarmist rhetoric continues. Two weeks after the December 2004 catastrophic Sumatra-Andaman earthquake triggered the devastating tsunamis that killed nearly a quarter million people, Rick Rollens, MIND Institute founding father and lobbyist, likened the increasing number of autistic individuals receiving California Department of Developmental Services to a “tsunami rapidly growing.”

Tom Insel, Director of the National Institute of Mental Health, which has become the primary NIH institute for funding autism research, described autism in *Newsweek* as an “astonishingly devastating disease” and in *USA Today* as a “tremendously disabling brain disease, which really robs a child and a family of the personhood of this child.”<sup>28</sup> When a community member questioned the ethics of describing any group of children with such dehumanizing terms, Insel replied that he had modeled his rhetoric after Jon Shestack, who “has been very eloquent” on the subject of autistic children.<sup>29</sup>

At a large professional conference in 2005, NIMH Director Tom Insel used the country-wide IDEA data to suggest that autistic school children are a rapidly growing “public health challenge.”<sup>30</sup> However, a recent editorial in the prestigious journal *Nature* provided a different and even more sobering perspective.<sup>31</sup> As the editorial noted, while the myth of the autism epidemic has successfully helped NIMH increase its funding, the often forgotten “dark side” of such manipulation is the fixed sum of NIH’s budget. For example, as NIH’s funding of autism has dramatically increased, NIH’s funding of other critically important

areas, such as childhood leukemia and cystic fibrosis, has dramatically diminished.

### Pulling the Curtain on the Wizard of Oz

Albert Szent-Gyorgyi, the Hungarian biochemist and 1937 Nobel Laureate, defined discovery as “seeing what everyone else has seen” but “thinking what no one else has thought.” I submit that leadership in scientific discovery also involves saying what no one else has said. Recall the fabled young boy, who distinguished himself from the obsequious masses, by announcing not the presence, but absence, of the emperor’s new clothes. Scientific leadership requires the same earnest courage.

With regard to the illusory autism epidemic, only a handful of scientists have shown such leadership: Canadian researcher Eric Fombonne, British researcher Lorna Wing, and U.S. and Canadian researchers Lisa Croen, James Laidler, Morton Gernsbacher and her colleagues, Paul Shattuck, and Roy Richard Grinker.<sup>32</sup> A majority of these researchers are also parents of autistic children, and one is autistic. As Robert Crease aptly articulated, “Leadership is most conspicuous by its absence.”<sup>33</sup>

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