History of autism and aspergers

Pandora’s Box

During World War II, the large-scale involvement of US psychiatrists in the required a common language and standard criteria for the classification of mental disorders. This prompted the American Psychiatric Association (APA) to publish the Diagnostic and Statistical Manual of Mental Disorders (DSM)

The first edition, DSM-I, published in 1952, included autism as “ schizophrenic reaction, childhood type,” but provided no guidance on diagnosis.

In DSM-III, published in 1980, infantile autism was lifted from schizophrenia and established as the core of a new category of “ pervasive developmental disorders,” based on Kanner’s two cardinal signs: “ pervasive lack of responsiveness to other people” and “ resistance to change.” The age of onset was specified as “ before 30 months,” which would rule out all kids who would later be diagnosed with Asperger syndrome. To accommodate kids who suffered a loss of skills after thirty months, there was “ Childhood Onset Pervasive Developmental Disorder” (COPDD).

In DSM-III-R, published in 1987, the manual was revised to improve the criteria for autism based on recommendations of a task force, comprising Lorna Wing, Lynn Waterhouse, and Bryna Siegel. In this revision, the word “ infantile” was deleted, and “ Kanner’s syndrome” was rechristened “ autistic disorder.” There was no age-of-onset, and the COPDD diagnosis was dropped. It also added a new criterion “ Pervasive Developmental Disorder – Not Otherwise Specified” (PDD-NOS). This label turned out to be the most commonly used PDD diagnosis.

Estimates of autism prevalence increased worldwide after DSM-III and DSM-III-R was published. The overall trend was clear: “ Autism spectrum disorder might be as prevalent as 1 in 100 children.” After a comprehensive analysis of the Family Fund database for the UK Department of Education and Skills, PricewaterhouseCoopers concluded that the increase in autism resulted from improved diagnosis and recognition of the disability.

A similar evolution was taking place in the United States, prompted by a set of amendments to the Individuals with Disabilities Education Act (IDEA). In 1991, autism was included in IDEA as its own category of disability, which enabled children with a diagnosis to gain access to individualized instructions and other services. In tandem with IDEA, state legislators passed laws making public funds available to families for early intervention therapy.

The first standardized clinical instruments to screen for autism were becoming available. The first attempt to develop and popularize such a tool was Rimland’s E-1, and E-2 behavioral checklists. But the checklists depended entirely on parental recall rather than direct clinical observation. A child’s score could differ depending on which parent filled in the checklist. In 1980, Eric Schopler and his TEACCH colleagues introduced the *Child Autism Rating Scale* (CARS), which was good at distinguishing autism from other forms of developmental delays, such as intellectual disability. After observing the child engage in a structured interaction through a one-way mirror, the rater scored the child on a seven-point continuum along several dimensions such as verbal and nonverbal communication, interaction with people and objects, sensory responsiveness, intellectual functioning. CARS used the spectrum model of autism in the DSM-III-R to score behaviors.

Independent analyses showed that the scale was reliable and consistent, and that its score matched well with assessment by other means. In 1988, Schopler issued a second edition of CARS that could diagnose teenagers and adults. After reading the manual and watching a 30-minute video, a novice could produce ratings that were as accurate as those of seasoned clinical observers.

Then, six months after *Rain Man* opened, an international team of researchers introduced a comprehensive tool called the *Autism Diagnostic Observation Schedule* (ADOS). Based on the criteria that would appear in the upcoming DSM-IV, the ADOS and a companion tool called the *Autism Diagnostic Interview* became the gold standard of autism assessment.

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The first international conference on Asperger syndrome was held in 1988, and Lorne Wing had lobbied the *World Health Organization* (WHO) to include Asperger Syndrome in the 10th edition of the *International Classification of Disease* (ICD), published in 1990. In 1994, Asperger syndrome was included in DSM-IV.

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Leominster, the birthplace of Johnny Appleseed, is forty-five miles northeast of Boston. In the 1940s, it was called “ the Plastic City” as one in five residents worked for plastics manufacturers like Foster Grant, the company that turned sunglasses into a fashion. Soon it became the Pollution City as the waters of the Nashua flowed red, white, and blue. Then Foster Grant

outsourced its frame manufacturing to Mexico. The defunct plant was declared a hazardous-waste site by state authorities.

Two years after the plant closed, a couple in Leominster named Lori and Larry Altobelli had their second child, Joshua. When he was three, he was diagnosed with PDD-NOS. His younger brother, Jay, was also eventually diagnosed with PDD-NOS. Later on, Larry Altobelli realized that two of his friends grew up from the same neighborhood also had autistic kids. Lori, who had a master's degree in health care administration, asked parents at autism support group meetings if they had ever lived in her husband's old neighborhood. She was shocked by how many said yes.

On March 25, 1990, Lori sent a letter to the CDC headquarters in Atlanta demanding an investigation. An epidemiologist arrived in town two months later to collect data. Lori had promised to keep the investigation secret to avert mass panic until she heard the city was planning to build a playground next to the old factory. She called and complained to the mayor who promised to postpone the playground. But an anonymous caller tipped off local reporters and the news went national, appearing at ABC News's 20/20 on March 13, 1992.

A graduate student named Martha Lang from Brown University found from Lori's files that the number of confirmed autisms in town was lower than she had been led to believe. Some of the kids were misdiagnosed, and some parents in Lori's files had never lived in Leominster at all. After failing to find evidence of genetic abnormalities in the community, the team of geneticists from Stanford suggested that the rise in autism was driven by the change in

the diagnostic criteria for autism rather than a true increase in prevalence. But the media circus had long ago moved on.

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In 1995, after a torrent of inquiries from parents, Rimland ran a banner headline in his newsletter, “ Is There an Autism Epidemic?” His answer was yes. But instead of focusing on the changes in the diagnostic criteria, he raised the possibilities that pollution, antibiotics, and vaccines were triggering the increase in new cases, citing the Leominster “ cluster” as an example. Rimland made that statement after he read the book called *DPT: A Shot in the Dark* , written by Harris Coulter and Barbara Loe Fisher. Rimland’s endorsement helped to spread Coulter’s ideas within the autistic parents’ community.

Meanwhile, a young gastroenterologist in England named Andrew Wakefield introduced Coulter’s ideas into the mainstream by claiming to have discovered a potential mechanism by which the combination measles-mumps-rubella (MMR) vaccine causes brain injury.

In the mid 1990s, Wakefield published a series of studies in which he concluded that measles virus might cause Crohn’s disease and inflammatory bowel disease (IBD). The studies were considered groundbreaking, but subsequent research failed to confirm the hypothesis.

In 1995, while conducting research into Crohn’s disease, a mother of an autistic child approach Wakefield seeking help with her son’s bowel

problems. That prompted him researching for possible connections between the MMR vaccine and autism.

On February 28, 1998, Wakefield held a press conference at Royal Free Hospital in Hampstead, North London, on his new studies published in The Lancet. The paper, written by Wakefield and twelve other authors, claimed to have identified a new syndrome, raising the possibility of a link between autism, the MMR vaccine, and a novel form of bowel disease. Although the paper said no causal connection had been proven, Wakefield made statements at a press conference calling for suspension of the MMR vaccine until further research.

This press coverage sent shock waves through the autism parents' community. In the coming years, many members of Rimland's network would become convinced that autism was caused by damage to the child's developing brain from from vaccines, vaccine preservatives, or both.

Meanwhile, other researchers could not reproduce Wakefield's findings or confirm his hypothesis. In 2004, Brian Deer, a Sunday Times reporter, discovered that Wakefield had failed to disclose its financial conflicts of interest; ten of the study's co-authors took their names off the paper; and Lancet retracted the study in 2004. Wakefield was stripped of his medical license in England in 2010, and the editors of the British Medical Journal denounced his study as " an elaborate fraud" in 2011.

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There was no question in Lorna Wing’s mind that the changes she brought to the DSM criteria were the primary factor responsible for the rise in autism cases. Her daughter, Suzie died of a heart attack in 2005 at age forty-nine, and her husband died of Alzheimer’s disease five years later. She died in 2014 at age eighty-five.