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# The History of Autism

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## **The History of Autism**

Since the first description of autistic tendencies in the early 1800s, the definition and diagnostic criteria for autism have changed radically. The first Diagnostic Statistical Manual (DSM) categorized autism as a childhood subtype of schizophrenia (American Psychiatric Association, 1952) though autism was eventually separated from schizophrenia, becoming its own diagnosis. Over time autism evolved into a diagnostic spectrum by the time the DSM-5 was published in 2013. Autism is becoming more prevalent, and the diagnostic criteria and definition are likely to continue to change in the future.

### **Early Conceptualizations of Autism**

In 1798 before the first use of the word autism, French physician Jean-Marc Gaspard Itard described Victor the Wild Boy of Aveyron, a young boy who was found after being isolated in the woods for 11 years, as being socially withdrawn in addition to having language and intellectual disabilities. He recognized Victor as being developmentally different from other children his age. Itard's description of Victor's tendencies would later be formally characterized as autistic (Itard, 1932).

Over a hundred years later, in 1910, Paul Eugen Bleuler, a Swiss psychiatrist, used the word 'autism' for the first time when describing specific symptoms of schizophrenic patients where they became withdrawn from others (Greydanus & Toledo-Pereyra, 2012). Later in 1927, a student of Bleuler, Eugene Minkowski, described autism as the "trouble generator" of schizophrenia (Minkowski, 2001).

### **Shifting Perspectives on the Origins of Autism.**

### *Psychogenic perspectives of autism*

In the early 20<sup>th</sup> century, the predominant theories on autism adopted a psychogenic approach, according to which autism is caused by emotional or psychological factors rather than ones that are biological or physical. Some of this was grounded in Freudian psychoanalytic theory, which was popular at the time. These psychogenic explanations for autism were widely accepted among the medical field and persisted due to a lack of medical research investigating the cause of autism.

Researchers who were proponents of the psychogenic approach focused specifically on parenting styles as the underlying cause of autistic behaviors in children. In the 1940s, Kanner described autism as the “children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life,” and separated autism from a subtype of schizophrenia into its own category as “infantile autism” (Kanner, 1943). Kanner continued to describe autism as “an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside” (Kanner, 1943). One of the most interesting aspects of Kanner’s view of autism was his theory of “refrigerator mothers,” which states the cause of autism as “lack of maternal warmth.” Though Kanner believed in some innate properties, this would be his main argument for the cause of autism (Kanner, 1943).

After Kanner’s separation of infantile autism and childhood type schizophrenia, Hans Asperger, a German pediatrician, identified a milder form of autism. In 1944 he highlighted this milder form of autism in his study of boys all of higher intelligence who suffered from trouble with social interaction and obsessive interests (Asperger & Frith, 1991).

Following Asperger in the 1950s, the “refrigerator mothers” theory was popularized by childhood psychologist, Bruno Bettelheim, through his use of the media to perpetuate the idea

that parents were the cause of autism (History of Autism, 2010). Bettelheim's further blame of parents for causing autism resulted in the psychogenic perspective creating a range of therapeutic approaches. Most notable was Bettelheim's approach that included removing children from the negative influence of their parents to live in residential treatment facilities (Mesibov, Shea, & Schopler, 2005). He compared parents of autistic children to concentration camp guards and their children to prisoners and victims saying, "emotionally cold parents had produced the autistic features in their children through unconscious feelings of hostility and rejection." Children were even encouraged to play on a large stone sculpture of a woman to learn that their mother had a "heart cold as stone" (Mesibov, Shea, & Schopler, 2005).

#### *A shift toward biological explanations of autism*

The idea that parents were the cause of autism was controversial. Beginning in the 1960s, a different approach to autism research began to take shape. Instead of focusing solely on psychogenic and emotional causes of autism, researchers began to shift their focus toward understanding the biological and behavioral mechanisms of autism. Early biological research started with Stella Chess in the 1960s and her research of autism as a neurological disease (Pearce, 2007).

In 1964, Bernard Rimland founded the Autism Society of America. Rimland was also a proponent in refuting Bettelheim's 'refrigerator mother' theory; instead extending the theory that autism had a biological basis. In his book, *Infantile autism: The syndrome and its implications for a neural theory of behavior*, Rimland disproved the "refrigerator mothers" theory and proposed that there was a genetic component responsible for autism (Edelson, 2014).

Research examining biological and physical underpinnings of autism has not been without its share of controversy. The Lancet published an article in 1998 by Wakefield, Murch,

Anthony, Linnell, Casson, et al., which suggested that the Measles, Mumps and Rubella (MMR) vaccine was causing autism (Rao, 2011; Wakefield et al., 1998). This article argued that the preservative thimerosal in the vaccine was an underlying cause. Subsequent studies by the FDA and CDC found no evidence for the claim; however, in response to the article the preservative thimerosal was removed from vaccines in 1999 (Thimerosal in Vaccines, 2014). Furthermore, any existing vaccines that contained thimerosal expired in 2003 (Thimerosal in Vaccines, 2014). The Lancet article was finally retracted in 2010 after being exposed as fraudulent (Rao, 2011). To date there is no credible evidence that vaccines are a cause of autism.

Alongside a shift in focus away from psychogenic origins and toward biological origins, there was also a movement to focus on the treatment of autistic behaviors. This was guided by behaviorist principles, which were popularized in 1965 by Ole Ivar Lovaas, who developed Applied Behavior Analysis (ABA) therapy (Lovaas Institute, 2005). In ABA therapy “the overall goal is to break down skills into manageable pieces and then build upon those skills so that a child learns how to learn in a natural environment” (Lovaas Institute, 2005).

In 1972, Eric Schopler started another intervention program, the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) program at UNC Chapel Hill, a program that continues to this day. This program provides intervention, training, and other programs for individuals with autism, and uses parents as “co-therapists” to help treat autistic children (Mesibov et al., 2005). For more information about the TEACCH program visit the section of this FUSE page entitled “TEACCH Research.”

### **Summary of the Changing Definitions of Autism**

The definition of autism and the diagnostic criteria for autism have changed several times in the last hundred years. Autism was initially listed as a form of childhood schizophrenia in the DSM-I (American Psychiatric Association, 1952) and under this diagnostic criteria, the first epidemiological study was conducted in 1966 and found that 4.5/10,000 children had autism (Lotter, 1967), suggesting that it was a rare disorder. Autism was not officially separated from schizophrenia until 1980 when it was labeled infantile autism in the DSM-III and 6 main criteria were necessary for diagnosis (Gernsbacher, Dawson, & Goldsmith, 2005). In 1987, another revision occurred to the definition and diagnostic criteria and the “infantile autism” definition expanded to become “autism spectrum disorder” in the DSM-III-R (American Psychiatric Association, 1987). The clinical definition of autism changed yet again in 1994 when Pervasive Developmental Disorder-Not Otherwise Specified & Asperger’s syndrome were added to the DSM-IV through the expansion of the diagnostic criteria to include subtypes of autism (Baker, 2013). Another epidemiological study conducted by the Centers for Disease Control in 2009 estimated that 1 in 110 children have autism spectrum disorder, which was an increase from the 1 in 150 estimate calculated in 2007 (Baio, 2012). The CDC notes that prevalence rates increased partially from improved screening and diagnostic techniques. Finally, in 2013, the DSM-5 was published which again changed the definition of autism by consolidating the five subcategories of autism spectrum disorder (ASD) into one umbrella diagnosis of ASD with Asperger’s no longer being a separate condition. Autism Spectrum Disorder is now defined by two categories: impaired social communication and/or interaction and restricted and/or repetitive behaviors (American Psychological Association, 2013). As of 2014, the Centers for Disease Control and Prevention estimate that autism affects 1 in 68 children (CDC, 2014).

Along with the changes in the definition and diagnosis of autism and an increased prevalence of autism, autism research and advocacy groups have also increased. The Organization for Autism Research was created in 2001 by parents and grandparents of autistic children who believed that applied research could help answer many of the questions they encountered in their daily lives (Research Autism, 2001). Later in 2003, the National Autism Association, another parent run organization, formed to focus on issues related to severe autism such as safety and crisis prevention by providing family support (National Autism Association, 2015). Another organization also formed in 2005 when Autism Speaks was founded by Bob & Suzanne Wright to fund research, increase awareness, and advocate for autistic individuals and their families (Autism Speaks, 2013).

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