

The Science and Fiction of Autism

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Autistic Disorder, or autism, is a severe form of psychopathology evident before the age of three years. It is a disorder characterized by a unique constellation of severe and pervasive behavioral deficits and excesses, which have challenged and captivated professionals and lay personnel for over 50 years. Because of the unusual and interesting characteristics of the disorder and the all-encompassing nature of its effects autism has attracted a tremendous amount of attention from psychologists, psychiatrists, pediatricians, neurologists, speech and language specialists, educators, parents, and others whose responsibility it is to understand and help these children and adults.

Autism is unique not only in its constellation of symptoms but in the extent to which it has generated controversy and strong competing factions among those professionally concerned with its understanding and treatment. Ever since Leo Kanner first described autism in 1943, controversies have raged. Many aspects of the disorder remain highly controversial to this day, and new issues arise regularly. There is almost nothing concerning autism about which everyone agrees except for the fact that it is a seriously debilitating disorder pervasively affecting almost all aspects of behavior.

Why the controversies? Controversies are most likely to arise when things are poorly understood and this is certainly the case with autism. While we are much further along in our understanding of the disorder than we were even only a few years ago, there is still a great deal we do not know. This poses a tremendous challenge to all those interested in, or responsible for, the care of these affected individuals.

So what are the main controversies in the field today? Oh, where to begin! Let's look at a few of the more high-profile past and current debates.

1) *What is the cause of autism?*

When autism was first identified as a distinct disorder in 1943, the predominant theoretical orientation was psychodynamic. Thus if there was a problem with a child that could not be tied to some specific biological or environmental origin, bad parenting was usually considered the cause. Thus Bruno Bettelheim and others blamed autism on the parents, considering them to be cold, logical, and unaffectionate (e.g., "refrigerator mothers") such that their children withdrew into autism. Various versions of this theory were influential until the 1960's when people such as Bernard Rimland proposed the origin was physiological. After many years of research autism is now

considered to be a neurodevelopmental disorder and one that is frequently genetic in origin. Parents are definitely no longer implicated as causative agents.

While on the subject of etiology, it is perhaps important to point out here that one of the most furious debates in the area in recent years is whether the childhood vaccines containing thimerosal (a mercury based preservative), such as the Measles, Mumps, and Rubella vaccine cause autism. While still hotly contested by some in the autism community, the fact is that at this point in time there is no scientifically substantiated evidence of a causal relationship.

2) *Is there an autism epidemic?*

The reported incidence of autism has increased from 4-5 in 10,000 cited in the 1960s/1970s to 1 in 166 cited today. The California State Department of Developmental Services has reported that between 1988 and 1998 there was a 610% increase in autism cases. Dramatic numbers indeed. But is this “epidemic” real or the result of other factors? Potential contributors to this reported increase include raised public awareness of the disorder, increased awareness by professionals (e.g., pediatricians), broader diagnostic definitions, better diagnostic instruments, and the ability to diagnose the disorder much earlier. In addition, in many places, including California, it is the case that children are likely to get better and more intensive services if they carry an autism diagnosis instead of another diagnosis such as mental retardation. This may serve to increase the likelihood that a professional will provide an autism diagnosis if at all possible so the child may have access to better services. However, even considering all of these factors, the fact remains that there may indeed be an increase in the incidence of autism and some have speculated that the increase may be due to environmental toxins affecting a genetically predisposed child and that these toxins may not have existed in the past. In sum, there may be a real increase in the incidence of autism but it is unlikely that the “real” increase is as dramatic as numbers may suggest.

3) *What are the most effective treatments for autism?*

This is perhaps one of the most contentious areas in the field and we have been down so many blind alleys over the years. Since autism was first identified there have been innumerable “treatments” proposed but until the appearance of behavioral treatments, none was truly effective. Despite all the arguments over the years it is now widely accepted that behavioral treatment (in its various forms) is the only form of treatment that has been *empirically* shown to lead to major improvement in individuals with autism. This form of treatment is based upon the principles of learning and goes by names such as Discrete Trial Training, Pivotal Response Training, and Incidental Teaching. While not a cure for autism, it is the best treatment we have at this point in time.

Further, it is important to identify which treatments have *not* been shown to be effective as treatments for autism. Some of the more popular of these include casein-gluten free diets, megavitamins, any form of pharmacological therapy (although some specific drugs may assist with specific behaviors such as anxiety and obsessive compulsive behavior), and sensory integration training. While these treatments may not be effective, in most cases they are not harmful. However, there are some basically bogus treatments out there that may indeed be harmful in that they include unnecessary aversive procedures (e.g., Holding Therapy), take up time that may be better spent in effective treatment (e.g., psychodynamic therapies, Facilitated Communication), or are unproven and very expensive (e.g., Options Therapy). Perhaps Facilitated Communication (FC; wherein a facilitator “assists” the individual by holding their hand as they type on a keyboard or point to letters on a letter display) is the best example of what can go tragically wrong in using scientifically unsubstantiated therapies. Research has determined that in FC the communication typically comes from the facilitator, not the autistic individual. Further, FC has led to false accusations of physical or sexual abuse. Then of course there are whatever new snake-oil treatments that have been proposed since I have written this paragraph. Indeed it is the case that new “treatments” for autism seem to arise daily.

Controversies are not necessarily problematic; in fact they often can be just the engines that keep discovery moving forward. If they promote the conduct of sound science to advance our knowledge in the area of autism, we can welcome them. If we do adhere to sound science to address controversies, we may be assured we will keep headed in a forward direction.

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