

## The Creation of Autism

## Bonnie Evans on how autism became such an important psychological concept

The diagnosis of autistic spectrum disorders in children and adults has rapidly increased in the last twenty years. A growing number of people also now self-identify as an 'Aspie' or someone 'on the spectrum'. Autism has become part of our common language for describing and understanding human individuality and self-identity. We live in a culture in which many of us think about the meaning of autism and its relation to ourselves, or someone we may know. The NHS website and other online medical resources enable parents to reflect on whether their child has autism. Support groups and online forums flourish in which people can tackle such challenging topics as 'I think I may have autism' and 'is my husband autistic?'. On a slightly more frivolous note, a growing line of T-shirt merchandise enables individuals to wear clothes with printed statements such as 'I had Asperger's before it was cool', 'Autistic Pride', and 'Kiss my Asperger's', confirming the acceptance and appreciation of autism within wider youth culture.

Statistics present a similar picture. The very first epidemiological study of autism in the world, conducted in England in the 1960s, generated a rate of 4.5 per 10,000 children. More recent UK studies put the rate of autistic spectrum disorder at around 1 in 100 children or even as high as 1 in 64. These figures mask the *critical* fact that autism has now become a 'spectrum' and that it currently encompasses much behaviour and thought that was not considered within its purview in the 1960s. Many medical and psychological researchers have bent themselves over backwards in order to understand the meaning of these quantitative changes, sometimes leading them to chase up blind alleys or towards precarious convictions. Although scientific enquiry obviously has its place, the more important question in relation to the growing significance of autism within our culture, I think, is: Why did autism become a spectrum? And the answer to that can be found in history. Good, solid history.

In order to understand how autism became a spectrum, it is necessary to return to the origins of our modern concepts of psychological development and self-identity. You may think that autism is a shiny new category, but in fact it has been around for as long as developmental psychology

itself. Despite popular belief, it was not the American psychiatrist Leo Kanner who first described autism in children, but rather the Swiss developmental psychologist Jean Piaget who used it to describe pre-social states of child thought in the early 1920s. Piaget drew from the leading gurus of descriptive psychopathology at the time: Eugen Bleuler (who invented the words autism and schizophrenia), and Sigmund Freud. Developmental psychologists in the 1920s wrote frequently about autism and related kinds of thinking, such as 'primary narcissism' and 'symbolic' thinking. Autism was regarded as part of a normal range of thinking that some people were more prone towards and it was associated with an interest in fantasy, imagination, and day-dreaming, coupled with a disinterest in relationships and social engagement.

There were several attempts to isolate autism as a specific medical condition in the 1940s and 1950s, most notably by Leo Kanner (see here, for example), and it was this that led to the limited model of autism that produced such low rates in the first epidemiological study in the 1960s. However, this attempt to narrow the category of autism was relatively short lived. By the 1970s, autism was already entering into a new field of child development research. The impetus for this was actually the closure in Britain and in many other parts of the Western world, from the late 1950s onwards, of institutions for children and adults with what was then called 'mental deficiency' or 'mental retardation'. The closure of 'mental deficiency' institutions encouraged radical overhauls of the techniques for measuring and understanding child development. This generated new scales of 'social impairment' that fed into the creation of new models of autism.

These changes led to a transformation in the meaning of autism. Piaget and others thought that pre-social, asocial, or autistic thinking was associated with a creative, symbolic, dreamlike world, characterized by fantasies and hallucinations. However, the newly quantified, epidemiologically defined autism of the 1960s redefined autism as a measurable entity that had nothing to do with imaginative thinking or inner fantasies. By the start of the 1970s, autism had come to mean the exact opposite of what it had previously meant. Although both autisms described pre-social or asocial states of mind, autism in the 1950s and 1960s referred to fantastical, hallucinatory thinking, whereas by the 1970s and 1980s, autism referred to a lack of fantasy, a lack of hallucination, and a lack of imagination. This was the birth of the 'social impairment' model of autism and the idea that non-social styles of thought could be measured, quantified, calculated, and tabulated.

Autism researchers of the 1970s and 1980s had new models of social justice on their side. The most important, persuasive, commanding, and formidable person responsible for transforming the meaning of autism and creating the current autism 'spectrum' was a British woman named Lorna Wing. Wing was the mother of a child diagnosed with autism and also a tireless campaigner, lobbying the British government to establish appropriate educational services for children who

were no longer institutionalized under the 'mental deficiency' law. She was also a trained **#FORUM** gist who organized the first population-wide study of 'social impairment' in England in the late 1970s. Wing argued that autism was *not* a unique medical condition but rather part of a

spectrum of conditions in which children showed a triad of impairments: In social interaction, in communication, and in symbolic play. This description of autism, based on a total population sample, was the one that made it into the 1987 Diagnostic and Statistical Manual of Mental Horsorders (CSM) For the best of interpretation of the fautistic spectrum. Wing was also the person who introduced the category of 'Asperger's syndrome', citing the work of a little-known Austrian physician from the 1940s, in order to build what was essentially her own psychological category. Contact Us

When doctors, psychologists, parents, 'Aspies', and others wonder about the ubiquity and prevalence of autism, they would do well to remember that our current categories and descriptions of autism are, and will always be, related to a more general, common, broad-scale understanding of human development, even though the meaning of that scale has changed. There are historical reasons for this change, the closure of 'mental deficiency' institutions being the most important. These changes in meaning should not be a source of confusion, as they sometimes have been, but should rather push us towards acknowledging the importance of history when it comes to comprehending the pervasiveness of autism. Lorna Wing's work, and British research in general, has been hugely influential in generating an international category of autism. The reasons for this

can be understood by studying British culture from the 1960s to the 1980s. These are historical reason.

In the early 1990s, as diagnoses of autism began to rise worldwide, the 'neurodiversity' movement also began to form, with adherents arguing that autism wasn't an illness, nor even always a disability, but merely a different kind of thinking. In fact, if you think about the history, this was almost inevitable. Although some autism researchers first admitted to being flummoxed by the 'neurodiversity' movement, there has recently been a change in approach. For example, British researchers Simon Baron Cohen and Francesca Happé have started to employ the language of 'neurodiversity' themselves, arguing that most of us are just 'neurotypical' and that autism may not always be a disability, merely another way to think. That doesn't compromise their research, they say, it merely affirms its importance as *the* new model for thinking about early development and the formation of social life. They are right about that. Autism has become part of our language for understanding modern selfhood and self-identity. There is no turning back now. But it is important to know how we got here.

Bonnie Evans is a Wellcome Trust Postdoctoral Fellow at Queen Mary, University of London. This blog is a summary of some of the arguments presented her articles 'How Autism Became Autism: The Radical Transformation of a Central Concept of Child Development', published in the History of the Human Sciences, 'The Foundations of Autism: The Law Concerning Psychotic, Schizophrenic, and Autistic Children in 1950s and 1960s Britain', published in the Bulletin of the History of Medicine, and her forthcoming book The Metamorphosis of Autism: A History of Child Development in England (Manchester University Press).

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