

History of autism identification



**ASSIGN
BUSTER**

Nature's Smudged Lines

When Kanner published his autism paper in 1943, he felt it was premature at that point to propose a set of criteria for diagnosing the condition he described. To make the pattern visible to his peers, he proposed two “essential common characteristics” shared by all children with this syndrome. The first was a will to self-isolation, present from birth. The second was a fear of change and surprise. These two characteristics became the diagnostic basis known as “classic autism,” or “Kanner’s syndrome.”

In 1961, a British psychiatrist named Mildred Creak led a working party that established a nine-point criteria for the diagnosis of autism, based in part on studies of 100 children she herself had collected. The nine points were:

1. Sustained impairment of interpersonal relationships
2. Unawareness of personal identity
3. Preoccupation with particular objects
4. Striving to maintain sameness
5. Acute anxiety produced by change
6. Abnormal perceptual experience (hearing and vision)
7. Failure to develop speech beyond a limited level
8. Distortion of movement
9. Some learning difficulty, but some islets of particular skills or abilities or knowledge

These criteria represented the first set of standardized criteria for the diagnosis of autism, which she called “schizophrenic syndrome in

childhood.” They differed significantly from Kanner’s two-point criteria and were more difficult to apply in practice.

In the late 1960s, a young British psychiatrist name Lorna Wing set out to help her husband, John, a schizophrenia researcher at the University of London, compile a database of case records in Camberwell to determine if the National Health Service was providing the families of cognitively disabled children with adequate resources.

John and Lorna had a daughter Susie, who was diagnosed with autism when she was three years old in 1959. It didn’t take long for John and Lorna to figure out that there were almost no resources in place to support the families of children like their daughter. But fortunately they could send Susie to Sybil Elgar’s school.

Sybil Elgar was a school secretary who was taking a correspondence course to become a Montessori teacher. After visiting an institution for “ severely and emotionally disturbed children” in London in 1958, she started teaching classes for a small group of autistic children in the basement of her house in London. Susie Wing became one of her early students. In 1962, a group of parents from the National Autistic Society converted an old railway hostel in Ealing into the Sybil Elgar School using the money they raised. The Beatles visited the school one afternoon, and John Lennon became one of the school’s first major donors and attracted other celebrities to the cause.

In the late 1960s, when the Medical Research Council (MRC) asked John Wing to examine the prevalence of autism, he put a graduate student named Victor Lotter on the case. They sent out thousands of questionnaires to schoolteachers, training center supervisors, nurses, and parents in Middlesex and screened the entire population of eight- to ten-year-olds. Basing his selection criteria for autism on Kanner's Nine Points, Lotter calculated a prevalence estimate of 4.5 cases of autism in 10,000.

A closer look at the numbers reveals several problems. They found that several children had been screened out because they didn't fit Kanner's criteria. Suspicious of the validity of Kanner's criteria, Lorna Wing took a different approach in analyzing the data. Rather than using a top-down method as Lotter had done, she employed a bottom-up approach, searching for aspects of autistic behavior among children in Camberwell who were already identified as cognitively disabled. She and another MRC researcher named Judith Gould reached out to everyone whose job might bring them in contact with a child with special needs. Just as the Middlesex study predicted, they found only a handful of children in Camberwell – 4.9 in 10,000 – who met Kanner's criteria. But Lorna and Judith didn't stop there. As they made their rounds of the neighborhood, they noticed a much larger group of children who had signs of his syndrome, but were not eligible for a diagnosis under his guidelines.

While Lorna was trying to make sense of what she was seeing, she came across a paper by Dirk Arn Can Krevelen arguing that Kanner's autism and Asperger syndrome were distinct conditions. After John (who can speak

German) translated Asperger's paper for her, she realized that Asperger had seen the same thing in Vienna that she was seeing in Camberwell.

Lorna began a quiet but determined campaign to expand the concept of autism to include people who had been excluded from Kanner's. To replace Kanner's unified syndrome, she proposed the term *the autistic continuum*. While there were clearly many shades and hues along this continuum, all autistic people seemed to benefit from the same highly structured and supportive educational approaches, just as Asperger predicted.

It was apparent that a person could occupy one point on the continuum at a given point in their lives and another point later. Some children, like Susie, would remain disabled into middle age and beyond. But others blossomed in unexpected ways when given an accommodating environment and special consideration by their teachers. In 1981, Lorna codified the condition for Asperger syndrome by writing a case series of her own called "*Asperger's Syndrome: A Clinical Account.*"

Over time, Lorna would lose her taste for the word continuum and adopted the term autism spectrum.