

Sula Wolff

The history of autism

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Sula Wolff, FRCP, FRCPsych (✉)
38 Blacket Place
Edinburgh EH9 1RL, UK

■ **Abstract** Autism remains a fascinating condition, perhaps the most prolifically researched of all child psychiatric disorders. Its history yields many lessons: early accounts of possible autism are, with one exception, unclear; the greatest contributions to our understanding have come from individual clinicians and researchers; the concept and definition of the disorder have changed greatly over the years;

some ideas once held with conviction, were later proved to be unfounded; and socio-political shifts as well as research findings have radically altered our understanding of the syndrome as well as the care and treatment offered to people with autism.

■ **Key words** autism – Asperger syndrome – history

Introduction

Since its discovery 60 years ago, autism has been puzzling, fascinating and massively researched. It has generated two international Journals: *The Journal of Autism and Developmental Disorders*, which started life in 1971 as *The Journal of Autism and Childhood Schizophrenia*, with Leo Kanner and Stella Chess as its foundation editors; and *Autism: the International Journal of Research and Practice* which first appeared in 1997. A further two journals dedicated to autism are *Focus on Autism and other Developmental Disabilities*, first published in 1985, offering practical articles on care, treatment and education for a multidisciplinary readership and *The International Autism Research Review* started in 1987. In 2001 the University of Birmingham in collaboration with the West Midlands Autistic Society and the Autism Services Accreditation Programme initiated the journal *Good Autism Practice*. All this in addition to many publications by parent organizations!

Announcing the change of title and scope of the *Journal of Autism and Developmental Disorders* in 1979, its then editors, Eric Schopler, Michael Rutter and Stella Chess, stressed Kanner's emphasis on developmental

distortions in autism, the increasing evidence of links between autism and other developmental disorders, as well as the association of autism with specific medical conditions. While it was at first thought that autism might be an early form of childhood schizophrenia, by 1979 this idea had been abandoned. The Journal henceforth was to be concerned with a wider range of developmental issues to clarify the similarities and differences between the various distortions of the developmental process [69].

The main aim of the editors of *Autism: the International Journal of Research and Practice* (published in association with the UK National Autistic Society) was to strengthen the interface between research and practice, in the belief that new treatments are often inadequately evaluated and that researchers need more regularly to clarify the implications of their findings for practice [40].

Early accounts of children with possible autism

Surprisingly, in view of its striking clinical features, few early accounts of psychiatric disorders of children fulfil the classical criteria for Kanner's syndrome. There are

descriptions of conditions allied to autism, and of intelligent and gifted children and adults who would now be diagnosed as having Asperger syndrome. But there is only one report of autism without associated brain damage, mental retardation, possible developmental language disorder or severe early social deprivation.

This is Uta Frith's analysis of the depositions of 29 witnesses in the legal case of Hugh Blair, son of a Scottish landowner, who in 1747 at the age of 39 appeared in an Edinburgh court for a decision on his mental capacity to contract a marriage [31, 20]. His younger brother successfully petitioned for annulment of the marriage to gain his brother's inheritance. In a beguiling book, entitled "Autism in History", written with the social historian Rab Houston, Frith convincingly argues for a diagnosis of autism, despite the lack of a developmental history. All we know is that Hugh Blair had not been exposed to early privations or serious illnesses. The deficits in his social relationships included tactlessness and abnormal gaze, although in adult life he was friendly and affectionate. There was severe retardation and abnormality of language, including echolalia ("he was in the habit of repeating simple phrases") and, while able to write out the Lord's prayer faultlessly, when examined on the catechism at school, he would always reply with both question and answer. His obsessive and repetitive behaviour included odd motor mannerisms, collecting feathers and sticks, always sitting in the same seat in church and insisting that domestic objects retained their same place. At the time he was described as lacking common sense and having a "silent madness".

Until then, John Haslam had been credited with anticipating Kanner by 140 years [73]. In his "Observations on Madness and Melancholy" published in 1809, in a chapter entitled "Cases of insane children", Haslam described a boy of nearly 7 who had had infantile convulsions, severe measles as well as a small pox inoculation. He was slow to walk and very late to talk. In hospital he was restless and inattentive, but curious about his environment, and he lied to cover up misdeeds. He had a poor grasp of distance, attempting to reach the ceiling. When seen again at 13 his language had progressed but he spoke of himself in the third person and pulled his mother's arm to gain her attention. No echolalia or abnormal gaze are recorded. He recognised Dr Haslam and was friendly. He was solitary (watching other boys at play, but never joining in) and had a number of obsessive preoccupations (he loved going to church, without understanding its purpose; he never used a closet, only a bowl as when he was in hospital; he talked only about toy soldiers and loved martial music) [26]. Vaillant, rightly, suggested the possibility of a post-encephalitic syndrome [73].

Henry Maudsley in his 1879 edition of *The Pathology of Mind*, includes a chapter on "The insanity of early life" which was greatly respected by Kanner. Although Maudsley mentioned affective insanity and moral insanity,

recording here in some detail a 13-year old boy who may have had Asperger syndrome, he did not describe any child with classical autism [54].

Early accounts of the history of child psychiatry also fail to mention childhood autism [12, 51, 25].

There has been much speculation about the possible disabilities of "wolf children", that is children discovered in the wild, who had supposedly been reared by wolves or other wild animals [59]. When found, they were mute, tended to walk on all fours, were insensitive to cold, and ate only raw foods. Numerous cases were described over time, especially in India. Ireland in 1875 thought most of them were idiots, who had been abandoned by their impoverished parents and that the idea that cruel animals would spare the innocents was an "agreeable myth" [37]. But Malson in 1972 dismissed this notion because, he argued, how could such backward children survive on their own in the wild [53]? He preferred Tredgold's idea of "isolation dementia" [72].

The most celebrated *enfant sauvage* was Victor, "the wild boy of Aveyron", found naked and covered with scars, in the woods in 1798 aged about 11 or 12. An earlier sighting and failed capture when he was 6 is described by Jean Itard [53]. Victor's fame rests on the dedicated, ingenious and affectionate attempts over a 5 year period of this young French physician to educate and humanise him [53, 42, 47].

At first, Victor's gaze was shifting and expressionless; he was insensitive to loud or pleasing noise and indifferent to smells, but sniffed at every object; he made only guttural sounds; did not imitate; attended only to objects he wanted; could not climb a chair to reach what he wanted; and he rocked to and fro. He seemed profoundly melancholy but had outbursts of laughter and responded with joy to the sun, a bright moon, the snow. He was gluttonous, although at first eating only acorns, potatoes and raw chestnuts. Itard devised a carefully graded behavioural programme whose goals were first, to help Victor form social attachments, then to awaken his nervous sensibilities, to extend the range of his ideas, and finally to induce speech via imitation. Victor had a good memory and a great sense of order. Within 9 months he was able to match letters of the alphabet. At this time he had one convulsion. Five years later, he had learnt to distinguish emotions expressed by different tones of voice; he had become genuinely affectionate and loved helping people; he enjoyed his lessons; used objects imaginatively; could bring objects whose names were written down and could ask for things in primitive writing, but his spoken language never progressed beyond meaningless monosyllables.

Itard thereafter devoted his life to the education of mute children, both deaf mute and children with hearing, and he devised teaching methods still relevant today in the education of children with autism and with other language and intellectual disabilities.

John and Lorna Wing held “there can be no doubt that Victor was autistic” [78, 81]. This view is shared by Uta Frith [20] and others. Itard worked for over 20 years with 40 language disabled children whom he distinguished from the mentally retarded. A late report, which Kanner may not have seen [7], suggests that some (mute children without deafness or mental retardation, with poor peer relationships, specific difficulties with pronouns and a fugitive gaze) might now be diagnosed as within the autistic spectrum but without all the features Kanner described (there was no mention of stereotypic, obsessional behaviours) and some may have had developmental language disorders. Victor may have been autistic or dysphasic [6] but the picture is obscured by his past total social isolation, which we now know can cause “quasi-autistic patterns” when it begins in very early infancy [20, 66].

Moreover, in his history of the mentally retarded, Kanner described Itard’s work with Victor without mentioning the possibility of early infantile autism [42]. It is also surprising that Itard, that superb observer, did not single out this syndrome among the mute children he saw. Perhaps the fact that he concentrated on children without mental handicap may help to account for this.

Of the syndromes allied to early childhood autism the most clear cut is Heller’s “Dementia Infantilis” [27, 36], a condition now recognised as disintegrative disorder and known to be very rare [18, 52]. Heller had seen 28 children with a very similar symptomatology among a much larger group of mentally retarded children. They had developed normally until their 3rd or 4th year when a regression occurred affecting first mood with irritability, weepiness, anxiety, negativity and temper outbursts, followed by apparent hallucinations and a progressive dementia so that within a few months all language and self care skills were lost, there was incontinence and, while motor functions were preserved and there were no abnormal neurological signs, the children had tic-like movements. But their facial expression remained intelligent, their gaze clear and they appeared to be attentive to their surroundings. At follow-up, they remained demented but, because they looked so intelligent, many of their parents never gave up seeking a cure. Heller tells us he saw only a single case of schizophrenia in 35 years of practice: a girl aged 5. He too, excellent observer as he clearly was, does not describe early infantile autism.

Less convincing is De Sanctis’ *Dementia Praecoxissima* [13, 14]. Of the 3 children aged 6, 7 and 10 years he described, one seems to have had mental retardation with autistic features and two had been traumatised and deprived.

There is also an account of what might be symptoms of autism by Earl in children diagnosed as having “primitive catatonia of idiocy” [15]. Severe motor stereotypies, self-injurious behaviour and mutism occurred in se-

verely retarded children, whose clinical picture is obscured by prolonged institutionalisation. One mute boy once uttered a complete and pertinent sentence under stress, a feature of autism described by Kanner [41].

The contributions of individual clinicians and researchers

Eisenberg, in his preface to Kanner’s writings, described him as self-educated, irresistible to children like a piper, and recalled his clinical interviews as “moving human encounters” [44]. He was clearly a wonderful clinician, and widely read. His papers are extraordinarily well written and, unusual for the time, well referenced. In his original description, in 1943, of a unique syndrome, not previously identified: “Autistic disturbances of affective contact”, he stressed its emotional basis, now upheld by Peter Hobson [30], and its presence since the beginning of life. He thought it was probably rare and may in the past have been confused with feeble-mindedness or schizophrenia. He listed as the crucial symptoms an “extreme autistic aloneness”; abnormal speech with echolalia, pronominal reversal, literalness and inability to use language for communication; and monotonous, repetitive behaviours with an “anxiously obsessive desire for the maintenance of sameness”. Three of his first 11 children were mute. From the start he noticed the skewed sex ratio (3 of the 11 were girls); the enlarged heads of 5 of the 11, now rediscovered [3]; and, although he wavered about this in later years, he stressed the distinction from schizophrenia, later demonstrated by Kolvin [45, 46]; as well as the constitutional basis of the disorder, now amply confirmed. The children, he wrote “have come into the world with innate inability to form the usual, biologically provided affective contact with people” [41]. He considered the disorder to be a psychosis, and indeed this view was still held by Rutter in his foreword to the 1973 volume of Kanner’s writings [64]. On follow-up, he found the children’s solitariness and language to improve with age [44].

Kanner described the parents as highly intelligent, preoccupied with abstractions of a scientific, literary or artistic nature, limited in genuine interest in people. Later he wrote: “There is a resemblance between their make-up and that of their children, except that their aloofness has not reached the gross proportions of a psychotic illness” [44]. The special features of parents of autistic children have also now been amply confirmed by comparative studies [86, 3] and strengthen the notion of a genetic causation. Kanner thought that mild autistic traits may lead to success in a “non-psychotic existence”. What he failed to spot was the children’s selective referral: 4 of the first 11 had fathers who were themselves psychiatrists. Over the next 30 years Kanner and Eisenberg followed up more than 100 affected children. They dif-

ferred from children with aphasia, later confirmed by comparative studies [6] and language competence at 5 years was a good prognostic sign. Where Kanner failed was to stress the contributory effects of parental lack of warmth on constitutionally predisposed children. And this was congruent with the then current ethos of parent blame which was to last for some decades. We should never underestimate the effects on scientific thinking of the prevailing beliefs and culture.

Curiously, in his comprehensive literature reviews, Kanner made no mention of Hans Asperger. This Viennese paediatrician in 1944 described 4 cases of "autistic psychopathy of childhood" and summarised the features of other similar children [1, 19]. They were often able, some with extraordinary gifts in mathematics or natural science with creative, original modes of thinking and objective self-appraisal. But their social and emotional relationships were poor and they were sometimes malicious. Themselves highly sensitive, they lacked feelings for others, had stereotypic behaviours as well as pervasive special interests and were clumsy. Language acquisition was not usually delayed, but language use was idiosyncratic. The condition could be recognised in early childhood and was life long. Later work adjustment was often good but the social handicaps endured. Asperger stressed the constitutional basis of the condition: many parents had similar personality traits, and he suggested that these might be an extreme variant of the male intelligence [19]. Baron-Cohen has recently provided evidence that this could indeed be so [4].

Asperger's work was less systematic than Kanner's and his prognostic conclusions impressionistic. His literature review too was incomplete. He failed to mention the marvellous German account of 6 cases exactly like his own, described by Ssucharewa as "schizoid personality of childhood" in 1926 [71, 84]. But he offered devoted care and treatment to affected children in a special unit and had much to say about how they can best be educated [19].

Although van Krevelen [75] and others [85] attempted to put Asperger's work on the map, it was not until Lorna Wing's seminal paper of 1981, that Asperger's syndrome as we now know it was born [80].

Michael Rutter's comparative studies in the 1960s validated the syndrome and features of autism [62, 68] which a previous working party [10, 11] had not achieved; uncovered the high frequency of epilepsy at adolescence and confirmed the prognostic significance of early language and intelligence [63]. In a landmark study with Bartak [67] he found behavioural approaches the best teaching method and with Pat Howlin he evaluated a home treatment programme for young children with autism [35]. But most important, his twin and family studies proved once and for all that autism has a strong genetic basis and that an excess of relatives have lesser variants of the autistic syndrome [17, 3]. The

Autism Diagnostic Interview [48] and the Autism Diagnostic Observation Schedule [50] now enable researchers to define their study populations accurately while circumventing the changing definitions of DSM and ICD over the years. A summary of Rutter's views on autism appear in his recent Festschrift [65].

Stella Chess was the first to discover that autism can be associated with neurological disease, in a series of children with congenital rubella [9].

Kolvin's comparative studies distinguishing early childhood autism from childhood schizophrenia, by age of onset, phenomenology, family history and associated symptoms, are now rightly regarded as classics in the history of autism [45, 46].

Beate Hermelin's innovative controlled studies together with Neil O'Connor [29] of the psychological features of children with autism, culminated in her more recent explorations of the "savant" phenomenon [28] and set the scene for the ground-breaking studies of Uta Frith [19, 20] and Francesca Happé [24] of the psychological deficits of autism and now, via brain imaging, of their neurological basis [20].

Lorna Wing, who put Asperger's syndrome on the map in 1981 [80], has greatly contributed over the years to the epidemiology of autistic conditions [82]; to changing concepts of autism (we owe the "Autistic Spectrum" largely to her influence); to the birth of parent organisations; to the literature on autism for parents [79]; and to the diagnosis, treatment and care of affected people and their families.

Finally, Gillberg's wide ranging studies have added to our knowledge of the epidemiology, genetics, outcome and clinical management of children with autistic conditions and have helpfully clarified the diagnostic features of Asperger syndrome [21, 22].

Changes in the concept and definition of the disorder over the years

Kanner defined autism narrowly and was dismayed by its widening "almost over night" to include children with isolated autistic symptoms on the basis of brain damage and mental retardation. Suddenly, in the 1950s, "the country was populated by a multitude of autistic children" [44]. Moreover, in the 1950s and 1960s, especially in the US, schizophrenia was everywhere and in children it included autism [5]. Schizophrenia was often held to be psychogenic [49] and the psychoanalytic theories which then prevailed, often led to wasted and painful years of expensive psychotherapy for affected children and their parents.

As a result of Rutter's and Kolvin's studies in the 1960s and 1970s, the concept was again restricted only to widen once more in the 1980s.

This wider concept took off from Wing and Gould's

[82] epidemiological study which was based on children with special educational needs and included many with brain syndromes and learning disabilities. From a therapeutic stand point, this was helpful because when such children have autistic features, they benefit from exactly the same educational and therapeutic methods as other children with autism. It was also helpful that the US Developmental Disability Act of 1975 [74] included them along with other people with severe and chronic developmental disabilities and mental retardation, because of the similarities of their administrative needs for financial support and for special educational services.

In addition, Wing's rediscovery of Asperger's work [80] drew attention to high functioning autism with which Asperger syndrome, as currently defined, is often equated [19, 24, 34], and this culminated in the birth of the autistic spectrum which has been useful both clinically and as a basis for genetic and other studies.

More debatable is the widening of the concept to include exceptionally gifted people with Asperger syndrome, such as philosophers and mathematicians, for example, Wittgenstein [83] and the Nobel prize winner, John Nash prior to his schizophrenic illness [57] whose therapeutic needs, if any, are very different.

Ideas once held with conviction, which proved to be unfounded

The first, and most malignant was that autism is caused by poor parenting, when now we know that the unusual features of parents of autistic children are due to shared genes [65]. The second is that autism is among the group of schizophrenias, disproved by Kolvin [45, 46]. Here the idea that autism is a developmental disorder rather than a psychosis has been helpful. The third, that autistic symptoms are secondary to a developmental receptive language disorder, once held by Rutter, was disproved by his own researches into autism and language disorders [6]. The fourth, that the incidence of the condition in siblings of affected children is not raised, was disproved by comparisons of the population and family incidence of autism [65].

Socio-political shifts and research findings have radically changed the understanding of autism and the care and treatment offered to affected people

In a review of child and adolescent psychiatry over the past 50 years, Eisenberg [16], recollecting that he found 3 autistic siblings among 131 autistic children but failed to spot the genetic cause, stressed that our conclusions always reflect prevailing concepts and ideas. Cultural shifts as well as research findings have influenced our

concepts of autism and the education and treatment offered to affected people.

The period of long-term institutionalisation for psychiatric patients and for those with learning disabilities endured well into Kanner's lifetime and he realised that this "cut short any prospects of improvement" [44]. But even Kanner, who always stressed the constitutional basis of autism, was caught up in the era of psychoanalysis when all childhood disorders were attributed to poor parenting, and held that this was a contributory cause.

Reviews of the education and treatment of autistic children [33, 58] make clear that, while the behavioural adjustment of children with autism can be much improved with early intervention, there is no effect as yet on long-term prognosis. Interventions are also dependent on the administration of medical and educational services. In the US, for example, where managed care sets limits to the intensity and duration of psychiatric treatments, over 50 % of children with autism are taking drugs or vitamins, a situation very different from that in the UK. Here the educational policy of "inclusion", whereby children with disabilities attend main stream schools wherever possible, coupled with the widening of the concept of autism to include more able children, means that more affected children are now expected to cope, with special help, in ordinary classrooms and that more teachers are learning about the needs of autistic children [39].

The increased awareness of teachers, doctors and the general public as well as the widening of the concept have contributed to the fact that far more children are now recognised as having autistic spectrum disorders and the estimated prevalence of "autism" has increased over the years from around 4–5 per 10,000 to around 6 per 1,000 children [8]. The greater awareness of the condition is largely attributable to the activities of parent organisations.

These started in the 1960s and are now world wide. They provided information for policy makers and the public and established residential and day schools for children with autism, implementing evidence-based best practice [76]. In the 1970s and 1980s provisions were made for affected adults too and this coincided with the closing of long stay hospitals. In the UK, at least, few people with autism would now be found in institutions.

As parents of autistic children found their voice, and the boundaries of autism extended to include more able people with Asperger syndrome, published accounts by parents and affected people themselves enormously advanced the understanding of the general public, of professionals in education and health care, and of affected families. Among the best publications of this kind are Liane Willey's "Pretending to be Normal" [77], Kate Rankin's "Growing up Severely Autistic" [61], Temple Grandin's "An Inside View of Autism" [23], and Luke

Jackson's "Freaks, Geeks and Asperger Syndrome", a touching account of his own predicament by an adolescent boy [38].

Increasing awareness of autism has led to many innovative interventions and wider access to good care and education. But increasing public debate about autism has also had its down side. Desperate parents can be seduced by untested and often expensive treatments which later prove to be ineffective. They include facilitated communication, auditory integration, "holding" therapy, and a variety of dietary interventions [32, 56, 33].

Most worrying in the UK has been the furore over MMR vaccination. Parent organisations, the press and television were persuaded by a very small number of otherwise undistinguished doctors and psychologists that the triple vaccine induces bowel disorder in a proportion of children and that this can cause autism. Despite lack of evidence, the increasing prevalence of autistic disorders has also, by some, been attributed to changing vaccination policies. While the originators of this theory lay no claim to scientific proof for their beliefs, they have, via the media, persuaded many parents of children with autism to see their past vaccination as its cause and to seek legal redress and compensation from the UK government. Many parents in the general population now refuse the triple vaccine for their young children, lobby for the introduction of single vaccines, and thus put the population at risk of serious childhood infections. A recent review of the prevalence and causes of autism by an MRC committee [55], composed of ex-

perts, parents of affected people and representatives of parent organisations, found no link between MMR vaccination, bowel disease and autism, while of course recognising that a negative association can never be proven. This report has been largely ignored by the media and parent organisations and, in the present "post modernist" climate of "lay epidemiology", distrust of science, doctors and politicians, government reassurances have so far been ineffective [70, 60].

Conclusions

Exceptional clinicians such as Kanner and Asperger opened our eyes to clinical syndromes previously unseen. But, even at a time when most developmental disabilities were relegated to the general category of mental deficiency with the implication of a hopeless prognosis and institutionalisation as the outcome, an innovative therapist like Itard devised a method of remedial education and personal care that is still relevant today. Cultural and political shifts have profoundly affected how we view autism and its boundaries, the range of ability levels of people now included as within the autistic spectrum, and the range of interventions offered. Some of these are still untested and others remain popular despite their proven ineffectiveness. But on the whole, the power of parent organisations and the destigmatisation of disabilities, at least in childhood, have greatly improved the services for autistic people of all ages.

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