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### Autism's anatomy

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### 3 | Autism in flux<sup>25</sup>

Autism is not a modern phenomenon, even though it has only been recognized in modern times. In view of the short history of psychiatry, and the even shorter history of child psychiatry, we know that a disorder recently described is not necessarily a recent disorder. An increase in diagnosed cases does not necessarily mean an increase in cases. There are tantalizing hints of Autism in the medical records of history.

A case description by the apothecary of Bethlem Hospital, the London mental asylum, often been quoted and never contested, as early evidence of Autism. The case was that of a five-year old boy who was admitted in 1799. It was particularly noted that this boy never engaged in play with other children or became attached to them, but played in an absorbed, isolated way with toy soldiers. (Frith, 1989: 16)

Since 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits – and, I hope, will eventually receive – a detailed consideration of its fascinating peculiarities. (Kanner, 1943: 217)

#### **Abstract**

This chapter argues that a new relation between past and present – a supposed historical continuity in the meaning of autism – is created by histories written by the discipline itself. In histories of autism written by ‘practitioner-historians,’ a sense of scientific progress and an essentialist understanding of autism legitimize and reinforce current understandings and research directions in the

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field of autism. Conceptual discontinuities and earlier complexities and disputes concerning classifying and delineating autism are usually left out of the positivist narrative of autism. In an alternative history of the concept of autism, I demonstrate that there have been major shifts in the type of symptoms, signs and impairments that were – and are – thought to be essential and specific for autism.

## Introduction

With the latest version of the American Psychiatric Association’s *Diagnostic and Statistical Manual for Mental Disorders* (APA, 2013), the history of autism enters a new era. The Neurodevelopmental Disorders (ND) Work Group – responsible for the formation of criteria and diagnostic categories of autism and related disorders – folded Asperger’s disorder, along with PDD-NOS<sup>26</sup> and autistic disorder, into the new category of *autism spectrum disorder* (ASD). The main argument for the creation of one ASD category was that ‘there is little evidence to support the current diagnostic distinction between Asperger disorder and high-functioning autism’ (Happé, 2011: 541). Studies that compared clinical and demographic characteristics, neuropsychological profiles, comorbidity and prognosis between autism and Asperger’s disorder largely did not support a diagnostic distinction between the two diagnostic categories (Witwer and Lecavalier, 2008). As stated by one of its prominent members, the *DSM-5* ND Work Group’s aim in proposing the new ASD category was to ‘recognize the *essential* shared features of the autism spectrum’ (Happé, 2011: 541, emphasis added).

In the Work Group’s reflection on the current state of autism research, autism is depicted as a discoverable entity with particular transhistorical essential features and autism research is presented as a growing body of scientific knowledge in relation to that particular entity. With this conception of autism and autism research, current developments and decisions concerning autism in *DSM-5* have become a logical and inevitable outcome of the present state of autism research. Furthermore, the dominant positivist understanding of autism underlies recent debates on the existence or non-existence of an autism

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<sup>26</sup> Pervasive Developmental Disorder Not Otherwise Specified, also considered part of the autism spectrum.

epidemic and it underlies the current tenacious search for autism's neurobiological essence (see Verhoeff, 2012/Chapter 2). This particular understanding of autism is being reinforced by the histories written by the discipline itself, depicting a more or less chronological, linear and progressive development towards current understandings of autism. However, this chapter illustrates that this is a limited representation of autism and its history.

For a better understanding of what is happening in the field of autism today, it is essential to explore its historical development in more detail. As stated by Polish medical doctor and philosopher of science Ludwik Fleck, 'at least three-quarters if not the entire content of science is conditioned by the history of ideas, psychology, and the sociology of ideas and is thus explicable in these terms' (Fleck, 1935/1979: 21). The primary aim of this chapter is exactly to explore the historical development of scientific ideas about autism in more detail, with a particular focus on how autism has been conceptualized since Leo Kanner (1894-1981) first described autism as a distinct nosological entity. Thereby, a new perspective on the idea of an autism spectrum and on the rise and fall of Asperger's disorder emerges.

In the first part of this chapter, some historiographical points are made and I demonstrate a specific way in which the discipline's history is being reorganized according to current understandings of autism. I argue that a new relation between past and present – a supposed historical continuity in the meaning of autism – is created through historical perceptions and references to classic autism studies. The second part of this chapter presents an alternative history of the concept of autism that challenges the general sense of continuity and progress. Instead of emphasizing the widely presumed historical stability of the core meaning of autism, I focus on these historical irregularities that are often overlooked, denied or misunderstood.

Even so, it is often noted that autism has gone through major changes since Leo Kanner first described the syndrome in 1943. Explanatory theories, interventions, public awareness and specialist services have changed considerably over the past seventy years. In addition, a progressive broadening of the concept of autism is generally accounted for in, for instance, explanations for the extraordinary rise in people diagnosed with autism (see, for example, Fombonne, 2005; Wing and Potter, 2002). As is visible through an evident widening of diagnostic criteria for autistic disorder in subsequent versions of the DSM, the broadening of the concept of autism is unambiguous.

However, the exact nature and scope of this broadening remain largely opaque and unexplored. I suggest that there has not just been a dimensional broadening, but that there have been major shifts in the specific type of symptoms, signs and impairments that were – and are – thought to be essential and specific for autism.

### **Recurrent histories of autism**

Books on the history of autism are not as numerous as autism novels, parent guides, autobiographies or textbooks. Of the small number of histories that are available, there is a wide variety in depth and specific focus of historical attention. Some recent histories of autism have as their object the pioneers in research, treatment and care (Feinstein, 2010), the role of parents and parent organizations (Silverman, 2011), or the social and cultural conditions of possibility for autism to emerge (Eyal et al., 2010; Nadesan, 2005). However, most histories of autism have been written by autism researchers and experts – or ‘practitioner-historians’ – often as an introductory first chapter to the topic in text- and handbooks, or as a short introduction in review articles or empirical studies. A common denominator of these latter histories is that they approach their main object – autism – as a static, decontextualized ‘thing’, discoverable by science. Moreover, these histories present a more or less chronological, linear and progressive development towards an ‘inevitable’ current understanding of autism, while mentioning the myths, mistakes, struggles and scientifically unsound convictions of earlier darker periods. For example:

We have come a long way from the era of myths and legends, through the unhappy deviation into psychoanalysis, to the practical realism of the present day that is accepted by most, though sadly not all, professionals in the field. We now know that there is a wide spectrum of autistic conditions, with Kanner’s and Asperger syndromes each forming only a part of these. (Wing, 1997: 20)

Such histories might seem to be little more than the memory of a science and a subordinate distraction from what the topic is really about, but if we follow the French historians and philosophers of science, particularly Gaston

Bachelard (Gutting, 1987) and Georges Canguilhem (1994), a discipline's history has become a central part of the discipline itself. In a discipline's history there is 'the tendency to see the history of the subject in the light of today's truth, which is easily confused with eternal truth.' (Canguilhem, 1994: 42). A discipline's history serves as an important legitimization of a science with the current knowledge about a subject matter as a necessary endpoint of scientific development; it confirms the idea, favorable to the discipline, of a science as a rational inquiry with a coherent accumulation of knowledge through history. The historical awareness of scientists is 'recurrent' in a sense that:

The history they construct for themselves is always constructed from the present and its criteria for truth. The perspective of the present reorganizes the past according to its own relevances. A mutation in current conceptions of scientific truth brings elements from past and present into new relations ... Hence, as science corrects its errors, it rewrites its history. (Rose, 1998: 166)

In the field of autism, two types of frequently combined 'recurrent histories' can be distinguished. The first one I call 'positivist histories'. These emphasize the progressive and cumulative nature of knowledge about autism and the maturation of the research field, while judging earlier theories, interventions and perspectives in the light of current expert convictions.

'The history of ideas on autism; Legends, myths and reality' (1997) by Lorna Wing, British psychiatrist and autism expert, makes a clear example of a positivist history of autism. She depicts the idea of a spectrum of autistic conditions as something in nature that was out there waiting to be discovered through a laborious process in which plain myths and Freudian mistakes had to be defeated by proper science. This resulted in 'the increasing knowledge of the nature of autistic disorders' (ibid.: 20). Earlier etiological hypotheses of autism attributing an important role to psychogenic causes, of which the infamous 'refrigerator mother'<sup>27</sup> received most attention, are discarded as 'unhappy deviations' since current research has shown that 'complex genetic factors are important in the causation but there are other physical causes that can lead to

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<sup>27</sup> The creation and popularization of this term 'refrigerator mother' is often attributed to the for many years most popular public autism expert Bruno Bettelheim and his widely read book *The Empty Fortress* (1967).

autistic conditions' (ibid.). Earlier ideas on autism are neatly divided into plain myths or reality, and earlier legends in the field are deemed either right or wrong. Current knowledge about autism acts as an endpoint and norm to judge history, while knowledge about autism cumulated in a linear and chronological way towards the contemporary view that 'autistic spectrum conditions are developmental disorders caused by physical abnormalities in parts of the brain' (ibid.: 20).

The recursive process in positivist histories of autism can be noticed by focusing on how autism researchers refer to earlier criteria and understandings of autism. In choosing the diagnostic criteria for autism in *DSM-IV* (APA, 1994), Lynn Waterhouse et al. (1992) provide a history of the development of the *DSM-III-R* (APA, 1987) criteria for autism. They state that the *DSM-III-R* criteria 'represent a reorganization and elaboration of *DSM-III* criteria that reflect a return to the criteria of Kanner's (1943) original case study descriptive accounts of impaired sociability, impaired social communication, and the presence of stereotypies or repetitive behaviors' (Waterhouse et al., 1992: 531). Besides the suggested fundamental continuity in diagnostic criteria for autism, the 'triad of autistic impairments' popularized by Wing and Gould (1979), is rather unproblematically projected onto Kanner's original description of early infantile autism. The '*extreme autistic aloneness*' mentioned by Kanner (1943: 242) is nevertheless quite different from impaired sociability, just as impaired social communication is different from the severe deficits in language development that were illustrated by Kanner, such as complete muteness and (delayed) echolalia. In addition, for Kanner, 'the child's behavior is governed by an *anxiously obsessive desire for the maintenance of sameness* that nobody but the child himself may disrupt' (ibid.: 245). An extreme resistance to changes in restricted routines and rituals or changes in furniture arrangements is again in many ways distinct from the 'presence of stereotypies or repetitive behaviors'.

The point here is that in a brief historical reference, Kanner's work is confidently connected to recent criteria of autism, with a suggestion of both continuity and refinement. Fred Volkmar (1998: 46) similarly claims that the *DSM-IV* (APA, 1994) and *ICD-10* (WHO, 1993) diagnostic systems have a 'fundamental continuity with the original description of autism made by Leo Kanner (1943)'. Volkmar suggests that Kanner emphasized as central to the definition of autism: 'the characteristic impairment of social interaction' (ibid.). Earlier 'truth' about autism is thus colored in the light of current 'truth' and the

connections between them are being reinterpreted to legitimize and reinforce the current status of autism research.

The increasingly popular practice of retrospectively diagnosing historical figures with autism is part of what I call ‘essentializing histories’ of autism. These particular histories are not primarily concerned with the development of the scientific field, but above all with affirming the validity and trans-historical continuity of the specific object under study: autism. Apart from being a recognizable disorder (Frith, 1989; Volkmar, 1998), autism is currently first and foremost ‘a highly heritable neurodevelopmental disorder’ (Mosconi et al., 2010) and ‘among the most heritable of all mental disorders’ (Lichtenstein et al., 2010). If autism is such a recognizable phenomenon and if it is a current fact that autism is a heritable brain disorder, traces of autism must be found in distant pre-Kannerian times.

Indeed, traces have been found. Historical accounts of feral children, eccentric geniuses, religious figures and even fictional literary protagonists have proven productive for retrospectively diagnosing autism. To name only some of those diagnosed, there are *The Blessed Fools of Old Russia* (Challis and Dewey, 1974), the extraordinary case of Hugh Blair of Borgue in eighteenth-century Scotland (Houston and Frith, 2000) and – according to Michael Fitzgerald’s (2005) endless list – Isaac Newton, Michelangelo, Ludwig Wittgenstein and Albert Einstein.<sup>28</sup> According to Frith (1989: 17), retrospective diagnosing helps to ‘distil those features that are the essence of the disorder beyond our immediate time and cultural context’. She points out that ‘autism is not a modern phenomenon, even though it has only been recognized in modern times’ (Frith, 1989: 16) and she and Houston try to find what they call ‘the unchanging core of autism’ (Houston and Frith, 2000: 4). However, it is this assumed trans-historical, essential core of today’s autism that is being recognized in the many recent examples of peculiar historical figures, and these historical cases, in turn, support the legitimization of the current ‘tenacious search for autism’s essence’ (Verhoeff, 2012/Chapter 2) at neurobiological

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<sup>28</sup> Michael Fitzgerald, professor of Child and Adolescent Psychiatry, diagnosed most of these historical geniuses with Asperger’s disorder. From the perspective of ‘recurrent histories’ of autism, it will be interesting to follow up on what will happen with his huge amount of retrospective diagnoses of Asperger’s disorder now that Asperger’s disorder stops being an official diagnosis in *DSM-5*.

levels. It is only in present times that these peculiar historical figures have become part of the history of autism.

### **Three phases in the history of the concept of autism**

The following history of autism will not explicitly search for explanations, causes, events, decisive scientific moments or the final truth about autism. Nor will it trace, like the histories of Nadesan (2005) and Eyal et al. (2010), the socio-political, economic, ideological or technical factors that might have made the emergence and reshaping of autism possible. These histories give important and detailed accounts of the role of parental activism; the availability of new treatments and services; the demand for educable conditions; and the reorganization of expertise, in understanding shifts in thinking about autism. However, the aims for the second part of the present chapter are different, and the primary aim of the following history of autism is to give a basic description of the development of scientific notions of autism.

With landmark scientific articles, definitions, diagnostic criteria, case studies and descriptions of characteristic phenomena, ideas about what makes a typical case of autism will be reviewed. However, a straightforward and unambiguous identification of earlier notions of autism is a chimera. Ideas about autism are not fixed but constantly in flux. There is not a single test, definition, article or researcher that marks a definite idea of autism in a specific period. Hence, a history of the concept of autism always remains an imperfect approximation of a general (scientific) sense of the meaning of autism at a particular moment in time. Yet in the history of ideas about the characteristic features of autism three periods can be distinguished. However, these periods are not marked by clear events and probably reflect more gradual and partial – rather than radical or revolutionary – changes, and they are above all a heuristic for structuring the historical analysis and for helping to bring to light important modifications in thinking about autism.

#### **Phase I**

##### **Extreme autistic aloneness and insistence on sameness (1943-1965)**

Most histories of autism start with Leo Kanner, a pioneer in the field of child psychiatry and the founder of the first clinic for children with psychiatric

problems at Johns Hopkins University in Baltimore. He introduced the diagnostic category of childhood autism in his famous and canonical case series of eleven children with ‘autistic disturbances of affective contact’ (1943). This was indeed the moment that autism, as a separate and unique psychiatric entity, became visible for the first time. However, if we want to retrieve the specific meaning of this new disorder, it might be better to start with the well-known Swiss psychiatrist Eugen Bleuler. Bleuler had already coined the term ‘schizophrenia’ in 1908, and was the first to use the word ‘autism’ somewhere around 1910 (Kuhn, 2004). Bleuler began using the term ‘autism’ to refer to what he considered to be one of the most important symptoms of schizophrenia.<sup>29</sup> Next to association loosening, ambivalence and affect inappropriateness (Berrios, 1996), autism was one of the primary symptoms of schizophrenia, and it was characterized by ‘a definite withdrawal from the external world’ (Bleuler quoted in Kanner, 1973: 94).<sup>30</sup> In the decade after its introduction Bleuler’s use of the term started to develop and expand to include a more moderate and non-pathological form of ‘autistic thinking’ that included daydreaming and fantasy (see Bleuler, 1919).

For Frith (1991), and for many other contemporary autism researchers, Bleuler’s schizophrenic autism and autistic thinking are unrelated to the disorder that came to be referred to by the same name. As Frith notes, ‘autistic thinking in Bleuler’s sense has nothing to do with autism as we know it’ (1991: 38). Maybe, if we think of the recursive processes that are active in rewriting the history of autism, it is because of the current disconnection between autism and schizophrenia, that Bleuler seems to have disappeared from the discipline’s history of itself.<sup>31</sup> However, it was not without reason that Kanner borrowed Bleuler’s by then popular term.<sup>32</sup> As Nadesan (2005: 40) notes, it is not surprising that ‘Leo Kanner and Hans Asperger elected to describe their patients in terms of the concept of autism. Autism was a phrase with wide

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<sup>29</sup> Bleuler looked upon schizophrenia not as a distinct disease entity but as a common name for a group of particular symptoms. He referred to this group by speaking of the ‘group of the schizophrenias’ and not of schizophrenia in singular.

<sup>30</sup> For more on Bleuler’s conception of schizophrenia and autism, see, for example, Bleuler (1911); Berrios (1996); Gundel and Rudolf (1993).

<sup>31</sup> For instance, Bleuler is not mentioned in the history of autism by Wing (1997).

<sup>32</sup> The nature of autism as a symptom of schizophrenia and the nature of autistic thinking were actively debated in psychiatric circles in the 1920s and 1930s, for example by Ernst Kretschmer and Hans Gruhle (Gundel and Rudolf, 1993).

currency and applicability, particularly in German psychiatry'.<sup>33</sup> Bleuler's autism, which describes a certain break with reality combined with other dissociations of affect, provided the framework for Kanner to introduce a new diagnostic category.

In a discussion on the problems of nosology and psychodynamics of early infantile autism, Kanner (1949: 418) considers that 'the extreme isolation from other people, which is the foremost characteristic of early infantile autism, bears so close a resemblance to schizophrenic withdrawal that the relationship between the two conditions deserves serious consideration' and early infantile autism 'may be looked upon as the earliest possible manifestation of childhood schizophrenia' (p. 419). In one of his later articles, Kanner (1973: 94, original italics) explains that 'in my search for an appropriate designation, I decided on the term *early infantile autism*, thus accentuating the time of the first manifestations and the children's limited accessibility'. Kanner recognized in his autistic patients a remoteness from affective contact with other people, similar to the remoteness of Bleuler's schizophrenic patients.

However, unlike Bleuler's schizophrenic patients, who withdrew from previous participation, Kanner's children never participated in the first place. They began 'their existence without the universal signs of infantile response' (ibid.). Furthermore, as Kanner pointed out, 'they develop a remarkable and not unskillful relationship to the inanimate environment' (ibid.: 95). Instead of a turning away from the external world, Kanner's autistic patients 'can cling to things tenaciously, ... They are so concerned with the external world that they watch with tense alertness to make sure that their surroundings remain static' (ibid.). Despite a fundamental *aloofness* that relates the two autisms, and despite Kanner's explicit recognition of an intrinsic relationship between his autism and

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<sup>33</sup> Hans Asperger (1944) introduced the term 'autistic psychopathy' only one year after Leo Kanner (1943) introduced his 'early infantile autism' and there is lots of speculation and debate (for example in Feinstein, 2010; and Eyal et al., 2010) about how it is possible that these two clinicians came up with very similar and new childhood disorders almost at the same time, while they were 'separated by an ocean and a war'. Hacking (2006: 4) argues that this is certainly not a coincidence, as 'Asperger, a generation younger than Kanner, had trained under August Homburger, the author of one of Kanner's main German textbooks, who wrote about childhood schizophrenia and other developmental disorders. They came from the same medical culture (each had served in the Austrian army, although in different wars)'.

Bleuler's (group of) schizophrenia(s), he concluded that his early infantile autism 'does not seem to fit in with Bleuler's criteria for autism' (ibid.).

Let us get back to Kanner's landmark case series that for the first time illustrated the new psychiatric condition he designated *early infantile autism*. Donald T. – his first and most detailed case – was a remarkable little boy who was happiest when left alone. He didn't seem to notice when someone entered or left the room he was in, and he was indifferent to visiting relatives, potential playmates, and he even failed to pay the slightest attention to Santa Claus in his full regalia. When petted he showed no apparent affection and he gave the impression to be self-sufficient. At the age of two he developed an obsession for spinning blocks and pans and virtually all round objects that could be spun. A spinning pan for instance, could keep him fascinated for hours and, when interfered with, he had destructive temper tantrums. The majority of his actions were endless repetitions performed in exactly the same way in which they had been carried out originally. Furthermore, he never spontaneously spoke just to chat or to share his thoughts. When he spoke, he seemed either to ejaculate irrelevant utterances randomly, such as 'chrysanthemum' or to parrot what he had heard said to him at some other time (Kanner, 1943).

After the description of ten more cases, Kanner's article (1943) ends with a discussion of a number of common characteristics of early infantile autism that appear essential. Among them are:

*an extreme autistic aloneness ... [a] limitation in the variety of spontaneous activity ... performances [and verbal utterances that] are monotonously repetitious ... the child's behavior is governed by an anxiously obsessive desire for the maintenance of sameness ... [the child has] excellent rote memory.* (Kanner, 1943: 242-243, original italics)

Certain language problems are also mentioned. In later articles, Kanner and Eisenberg (1956: 557) present a somewhat stricter definition of early infantile autism:

In the light of experience with a tenfold increase in clinical material, we would now isolate these two pathognomonic features, both of which must be present: extreme self-isolation and the obsessive insistence on the preservation of sameness, features that may be regarded as primary,

employing the term as Bleuler did in grouping the symptoms of schizophrenia.

Kanner investigated the phenomenon – fundamental for autism – of ‘obsessive desire for the preservation of sameness’ in more detail in a separate study (Kanner, 1951). He argued that the autistic child desires ‘to live in a static world, a world in which no change is tolerated ... The slightest change of arrangements, sometimes so minute that it is hardly perceived by others, may evoke a violent outburst of rage’ (1951: 23). Furniture arrangements, the arrangement of toy building blocks, beads or sticks, the precise route to school, and the position of the dishes on the table are typical examples of things that must not be changed. Autistic children, Kanner concluded, find ‘security in sameness, a security that is very tenuous because changes do occur constantly and the children are therefore threatened perpetually and try tensely to ward off this threat to their security’ (p. 26).

The frequently described problems with language and speech were not considered to be core features of autism. Although they are ‘often the most striking and challenging of the presenting phenomena, [they] may be seen as derivatives of the basic disturbance in human relatedness’ (Eisenberg and Kanner, 1956: 557). Furthermore, they argued that simple repetitive activities may be seen in severely retarded children and may offer a diagnostic problem, but ‘the presence of elaborately conceived rituals together with the characteristic aloneness serves to differentiate the autistic patients’ (ibid.: 558).

Robinson and Vitale (1954) discussed another diagnostic problem for autism at the annual meeting of the American Orthopsychiatric Association in 1953. They presented three cases of children with circumscribed interest patterns and ‘a limited establishment of interpersonal relationships’ (1954: 755). These children were all introvert, had average or above average intelligence, good language skills and circumscribed interests in rather unusual topics. Tom, for instance, was unable to participate in activities with other children, but developed an intense interest in and a hunger for knowledge about chemistry and finance by the age of eight years. Nine-year-old Billy had an ‘amazing knowledge of trolley routes and an unusual interest in and knowledge of calendars and maps’ and John, also nine years old, ‘preferred to play by himself and was ‘particularly interested in astronomy’ (pp. 758-759). The behavior of these children shows a striking similarity with that of the children described by

Hans Asperger (1944) and they would probably be diagnosed with Asperger's disorder or high-functioning autism in present times (Gillberg, 1998).

However, clearly unaware of Hans Asperger's earlier cases, Robinson and Vitale explicitly distinguished these children from autistic children in 'that they have not presented the early infantile incapacity for emotional responsiveness' (Robinson and Vitale, 1954: 760). Furthermore, they 'present a lesser degree of "withdrawal from contact with people" and a lesser measure of the "obsessive desire for the preservation of sameness"' (ibid.). In a response to their article, Leo Kanner himself agrees that autism is a different condition and he adds that the rituals and fixated patterns in autism are qualitatively and etiologically distinct from the circumscribed interest patterns described by Robinson and Vitale. For as far as autistic children exhibit a circumscribed interest, it 'has often been foisted on the children by their parents' (Kanner in Robinson and Vitale, 1954: 766) and is not seen as a core feature of the syndrome.

Debates on the possible causes of autism erupted soon after Kanner's original article was published. Initially, Kanner emphasized that autistic children 'have come into the world with innate inability to form the usual, biologically provided affective contact' (1943: 250). Somewhat later, with the growing psychoanalytic influence in American psychiatry, he came to place a greater emphasis on psychogenic factors like the obsessive traits, emotional coldness and lack of affection that he saw in the parents (Eisenberg and Kanner, 1956). Arguing that 'early infantile autism is a total psychobiological disorder', Kanner often defended a middle course between a psychogenic and an innate biogenic origin of autism, which required 'a comprehensive study of the dysfunction at each level of integration: biological, psychological, and social' (Eisenberg and Kanner, 1956: 564). Various psychiatrists and psychologists argued that autism was mainly a psychogenic disorder (for example, Bettelheim, 1967; Despert, 1951), whereas others regarded autism primarily as an organic brain disorder (Rimland, 1964; Rutter, 1968).

However, discussions on etiology aside, Kanner's first description of autism as a diagnostic entity characterized by extreme emotional withdrawal and tenacious insistence on sameness, remained largely unchallenged for approximately the first two decades after its introduction. Despite discussions on the possible nosological relations between early infantile autism and (childhood) schizophrenia (Kanner, 1965), and despite some unsuccessful proposals to lump autism together with childhood schizophrenia, mental

retardation and organic brain disease under the broad term ‘atypical child’ (see Rank, 1949; Szurek, 1956), it was not until the 1960s that the concept of autism started to change.

## **Phase II**

### **Language and other perceptual and cognitive abnormalities (1960-1980)**

From the 1960s on, as early infantile autism slowly entered the public arena and organized research communities started to replace the earlier observation-based case descriptions with the first epidemiological and experimental studies with autistic children, the concept of autism was altered significantly. Influenced by new types of investigation and new scientific methods, an important shift in emphasis occurred: from severe affective withdrawal as the essential defect in autism, towards language and other cognitive and perceptual abnormalities as essential and primary in autism. Whereas Eisenberg and Kanner (1956: 557) regarded ‘the vicissitudes of language development’ as derivatives of the fundamental disturbance in affective contact, many autism researchers in the 1960s and 1970s not only observed accurately, but also actively tried to engage with the autistic child. They argued that the basic defect in autism was the inability to develop a normal use and understanding of language, in combination with a global defect in the integration of other sensory stimuli. In spite of the popular but barely empirically studied, often vague and contradictory hypotheses that autism had a psychogenic basis, deficits in language, speech and cognition became fundamental features and key characteristics in diagnosing and recognizing autism.

This new way of thinking about autism was backed up by empirical evidence from several new studies and methods in autism research. For instance, the first longitudinal studies on autism (Lockyer and Rutter, 1969) showed that Kanner’s primary disturbance in affective contact and the profound withdrawal tend to lessen considerably as the autistic child grows older, while other symptoms like language deficits and intellectual shortcomings tend to persist. The first systematic psychological experiments with autistic children (for example by Frith, 1970; Hermelin and O’Connor, 1970) that tested intellectual (language and performance), receptive, integrative, and expressive abilities suggested that language and speech problems were not due to profound affective withdrawal or motivational failure, but instead due to a poor understanding of the meaning of spoken words.

Furthermore, these experimental studies showed that the autistic child: had difficulties with the use and understanding of gesture; was particularly unresponsive to verbal stimuli; lacked the ability to associate words semantically; had difficulties with grammatical aspects of language; and made little use of concepts in memorizing. Additional difficulties with the transformation of information from one sensory modality to another and in perceiving temporal patterns in visually presented stimuli ‘suggested a central defect in the processing of any sort of coded, meaningful, or temporally patterned stimuli’ (Rutter and Bartak, 1971: 27). A new discourse, which was profoundly influenced by the at that time emerging cognitive and computer sciences (see Gardner, 1987) and that made use of terms like codes, processing, stimuli and sensory modalities, became dominant in investigating, recognizing and thinking about autism. Furthermore, in addition to the familiar observations and parents’ descriptions of the child’s behavior, (neuro)psychological tests and experiments became an integral part of the diagnostic process.

More than a disorder of language, ‘the central problem, present in even the most mildly handicapped autistic people, appears to be a specific difficulty in handling symbols, which affects language, nonverbal communication, and many other aspects of cognitive and social activity’ (Ricks and Wing, 1975: 214). In a review of concepts of autism, Rutter (1968: 21) explicitly states that ‘contrary to earlier views, infantile autism is *not* anything to do with schizophrenia, and is *not* primarily a disorder of social relationships’. Language and cognitive defects were thought to constitute the primary handicap in autism, with ‘the social and behavioral abnormalities arising as secondary consequences’ (Rutter and Bartak, 1971: 29). Kanner’s cardinal resistance to change and insistence on routines were also thought to be secondary and were explained by deficits in processing and integrating visual perceptual information (Wing and Wing, 1971).

This major shift in thinking about autism was reflected in the first formal diagnostic criteria for autism in *DSM-III* (APA, 1980). Besides a ‘pervasive lack of responsiveness to other people’, the second cardinal criterion became ‘gross deficits in language development’, and ‘if speech is present, peculiar speech patterns such as immediate and delayed echolalia, metaphorical language, [and] pronominal reversal’ were central in diagnosing autism (p. 89). The third and final criterion became ‘bizarre responses to various aspects of the environment, for example, resistance to change, peculiar interest in or attachments to animate

or inanimate objects' (ibid.: 90). The dominant theory of a basic defect in the use and understanding of language, in combination with a global defect in the integration of other sensory stimuli caused by deficits in processing and integrating perceptual information, reshaped and redefined how autism could be detected, recognized and how the stereotypical autistic child was imagined. In spite of the ambition (of those involved in putting together the *DSM-III*) to produce 'theory neutral' descriptions of observable behavior distinctive for each disorder (Spitzer and Cantwell, 1980), autism's diagnostic criteria undeniably reflected theoretical commitments.

### Phase III

#### Deficits in social cognition and instinct (1980-present)

A second major shift in thinking about autism started somewhere in the early 1980s. I will highlight two events in the autism research field – with Lorna Wing playing a significant role in both of them – that anticipated, influenced and illustrate this second shift.

The first event is one of the first epidemiological studies on autism, which was carried out in London. This study investigated the prevalence of social, language, and cognitive impairments found in intellectually disabled children, and it investigated to what extent these distinct impairments tended to occur together (Wing and Gould, 1979; Wing, 1981b). From a larger sample, 132 children were selected on the basis of exhibiting at least one impairment in social interaction, language development, intellectual functioning, or repetitive stereotyped behaviors. The value of this epidemiological approach, Wing (1981b: 32) argued, 'was that it allowed the examination not only of "pure" syndromes but also of borderline and partial forms, within the context of a larger, geographically defined population'. The children were split into two groups. The first group consisted of sociable children 'in whom social interaction was lively, positive, and a source of great pleasure' and the second group consisted of socially impaired children 'who were inappropriate in their social interaction' (ibid.: 34). This second group consisted not only of socially aloof and unresponsive children, but also included children who interacted passively and 'amiably accepted approaches from others without initiating ... [and children who] made peculiar one-sided approaches to others, approaches that were not adapted to the responses of the person approached' (ibid.). The study subsequently demonstrated that the children with social impairments, the

second group, all had ‘repetitive stereotyped behavior and almost all had absence or abnormalities of language and symbolic activities. Thus, the study showed a marked tendency for these problems to occur together’ (Wing and Gould, 1979: 25). In contrast, most of the children in the first sociable group had symbolic pretend play, and repetitive activities and language impairment were found in a minority of the sociable and severely retarded children (*ibid.*).

Wing argued that ‘the abnormalities of social interaction, verbal and nonverbal communication, and imaginative activities so consistently occurred together ... that they could be referred to as “the triad of social and language impairment”’ (1981b: 37) and she suggested that there was no clear division between Kanner’s autism and other less severe forms of social impairment. The nature of autism, Wing (1981b: 38) suggested, can only be understood ‘in the wider context of the triad of language and social impairment’ and Wing and Gould (1979: 25) argued that ‘the clustering of the social, language, and behavioral abnormalities ... provided support for the main division into the socially impaired and the sociable though severely retarded groups’. This somewhat circularly justified division between ‘socially impaired’ and ‘sociable’ now provided a new basis for categorization, and social impairment became a central distinguishing aspect in the study of autism. Furthermore, social impairment was not understood as ‘extreme autistic aloneness’ but as a subtle deficit in the use and understanding of the ‘unwritten rules of social behavior’ (Wing, 1981b: 42).

The second important event was the introduction of the work of the Austrian pediatrician Hans Asperger (1906-1980) into the Anglo-Saxon autism literature. Although Van Krevelen (1971) and a few others had already discussed Asperger’s cases of *Autistische Psychopathie* (Asperger, 1944) in English, an article by Wing (1981a) followed by Frith’s 1991 translation of Asperger’s original cases aroused substantial international interest in what became known as Asperger’s syndrome. Based on four cases, Asperger (1944/1991) described a ‘particularly interesting and highly recognizable type of child’ (p. 37). This type of child exhibited ‘the essential feature of ... a disturbance of adaptation to the social environment’ (*ibid.*: 87). Apart from this essential feature, Asperger described a variety of behavioral and physical peculiarities in his cases, such as: odd, idiosyncratic or pedantic speech; absence of a sense of humor; little facial expression and limited gestures; an almost ‘aristocratic’ appearance; an over-sensitivity to criticism; manipulative, vindictive and antisocial acts; difficulties in

learning simple practical skills; an absence of feelings of shame or guilt; hyper- or hyposensitivity for noise; extreme egocentrism; a lack of affection; clumsy movements; single-mindedness, as manifested in peculiar and limited interests; a gift for logical, abstract and original thinking; and more. Despite acknowledging certain similarities, Asperger considered his autistic personality disorder to be basically different from Kanner's autism:

Kanner's early infantile autism is a near psychotic or even a psychotic state, though not identical with schizophrenia. Asperger's typical cases are very intelligent children with extraordinary originality of thought and spontaneity of activity though their actions are not always the right response to the prevailing situation. (Asperger, 1979: 48)

Furthermore, Asperger argued that his children developed highly grammatical speech, while Kanner's children 'generally avoid communication ... [and] do not develop speech or develop it very late' (*ibid.*). In contrast, Wing (1981a) argued that Asperger's cases and Kanner's cases were essentially similar. Despite the variations in terms of severity of impairments, Wing argued that both disorders shared a common and essential characteristic: the impairment of two-way social interaction.<sup>34</sup> This impairment:

is not due primarily to a desire to withdraw from social contact. The problem arises from a lack of ability to understand and use the rules governing social behaviour. These rules are unwritten and unstated, complex, constantly changing, and affect speech, gesture, posture, movement, eye contact, choice of clothing, proximity to others, and many other aspects of behavior. (Wing, 1981a: 116)

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<sup>34</sup> Timimi et al. (2011) highlight the differences between Asperger's cases and Wing's (1981a) case descriptions of children she diagnosed with Asperger's syndrome. For example, most of Wing's cases spoke late, whereas Asperger's cases spoke early. Furthermore, 'most of Wing's cases were described as having little capacity for analytical thought whereas Asperger's cases were thought by him to be highly analytical. None of Wing's cases could be described as manipulative, mendacious, cheeky, confrontational or vindictive (terms of description used by Asperger about his cases)' (p. 61). Timimi et al. (2011) argue that Wing's understanding of Asperger's syndrome was fundamentally different from Asperger's own understanding of the condition he delineated. This created a misleading link between Asperger's and Kanner's cases.

A new way of distinguishing and thinking about autism arose, influenced by: an international introduction of Asperger's work; a growing awareness of the existence of Asperger's new 'type of child'; the recognized and emphasized similarities between Kanner's and Asperger's cases; and by Wing's epidemiological study that argued that certain problems affecting early child development tend to cluster together. From a rare disorder characterized by a pervasive lack of responsiveness and gross deficits in language development, autism became first and foremost a disorder of sociality. The lack of intuitive skills that make complex social interaction possible is now central in yet again a new way of conceptualizing autism. Next to psychiatric and psychological assessments and tests, information on a child's (dys)functioning at school, among peers and in other social activities gets a central position in diagnosing autism.

This way of thinking about autism became more explicit and formalized in the revised version of *DSM-III*. In only seven years, the criteria for autistic disorder in *DSM-III-R* (APA, 1987) changed remarkably compared to the earlier criteria for autism in *DSM-III* (APA, 1980). A 'pervasive lack of responsiveness to other people' (*DSM-III*) changed into 'qualitative impairment in reciprocal social interaction' as, for instance, manifested by 'no or abnormal seeking of comfort at times of distress' or 'gross impairment in ability to make peer friendships' (*DSM-III-R*). Likewise, 'gross deficits in language development' were no longer central to or necessary for an autism diagnosis and were replaced by a new domain of 'qualitative impairments in verbal and nonverbal communication'. This domain included 'marked abnormal nonverbal communication' and 'marked impairment in the ability to initiate or sustain a conversation with others, despite adequate speech' (*DSM-III-R*). Furthermore, whereas *DSM-III* required an onset before 30 months of age, autism lost its adjective 'infantile' and became 'autistic disorder' in *DSM-III-R*. Autistic disorder could now be diagnosed not only during infancy but also during childhood when (latent) more subtle problems with social interaction and communication become visible.

### ***DSM-5* and the short life of Asperger's Disorder**

Debates about whether Asperger's disorder is a distinct nosological entity, identical with 'high-functioning' autism or part of a broader autism spectrum started right after the publication of Wing's (1981a) influential article (see Macintosh and Dissanayake, 2004). On the eve of the publication of *DSM-IV* (APA, 1994), Rutter and Schopler (1992: 476) argued: 'As there is an obvious research need to compare autism with Asperger syndrome, we suggest that there is a need for a ... category for Asperger syndrome in order to encourage and facilitate that research'. Mainly for research purposes, Asperger's disorder became a distinct DSM diagnostic category in 1994 (Szatmari, 1992). However, the concept of autism had already been influenced by Asperger's 'type of child', and the essential 'disturbance of adaptation to the social environment' (Asperger, 1944: 87) of Asperger's children had become *the* central characteristic of autism in the 1980s.

In order to assess the validity of viewing Asperger's disorder as a distinct category and to compare Asperger's disorder with autistic disorder on multiple characteristics such as course, prognosis, neuropsychological profiles and underlying neurobiological markers, Rutter and Schopler (1992: 476) acknowledged that it would be necessary 'to define the syndrome in such a way that there is no overlap with autism'. However, despite the fact that Michael Rutter was a member of the Work Group responsible for creating criteria for autism and related disorders in *DSM-IV*, criteria for Asperger's disorder and autistic disorder hardly differ in *DSM-IV*. Both disorders require 'qualitative impairment in social interaction' and 'restricted repetitive and stereotyped patterns of behavior, interest, and activities'. The major differences are that for a diagnosis of Asperger's disorder 'there are no clinically significant delays in language' (APA, 1994: 75) and that for autistic disorder 'qualitative impairments in communication' are required. But, as we have seen, delays in language were no longer at the core of or necessary for a diagnosis of autistic disorder, and most people who meet criteria for Asperger's disorder also show 'marked impairment in the ability to initiate or sustain a conversation' sufficient to meet the impairments in communication criteria for autistic disorder. Because of this significant overlap of the two disorders, in combination with 'the precedence rule: diagnose Asperger disorder only if criteria for autistic disorder are not met' (Happé, 2011: 541), several autism researchers even concluded that a diagnosis

of Asperger's disorder is impossible using *DSM-IV* criteria (Mayes et al., 2001; Szatmari et al., 1995).

The problems with applying the *DSM-IV* Asperger's disorder criteria resulted in wide variation in how the term Asperger's disorder was, and still is, used in clinical practice and research (Happé, 2011). Lord and colleagues (2012) recently argued that the best predictor of an Asperger's disorder diagnosis is not the characteristics of the individual, but the specific clinic the individual goes to. In defense of the decision to fold Asperger's disorder into the new category of *autism spectrum disorder* (ASD), Work Group member Happé explains that 'There is no evidence of differential treatment response or etiology to date, and claims for a distinct neurocognitive profile in Asperger disorder have received mixed results' (Happé, 2011: 540). Happé concludes that 'there is little evidence to support the current diagnostic distinction between Asperger's disorder and high-functioning autism' (Happé, 2011: 541).

However, as the history of the concept of autism reveals, even before Asperger's disorder became an official diagnostic category in the 1990s, Hans Asperger's 'autistic psychopathy' and Lorna Wing's interpretation of it, influenced a shift in thinking about autism in the early 1980s. Wing (2005: 198) later acknowledged that she 'always considered Asperger's syndrome to be part of the autistic spectrum. It shares the impairments of social interaction, social communication and social imagination and the repetitive pattern of activities and interests that characterize the spectrum'. It is not just the lack of empirical 'evidence to support the diagnostic distinction' between autistic disorder and Asperger's disorder, but this earlier broad interpretation of autism as 'the absence or impairment of the social instinct' (ibid.: 201) that made the separate category of Asperger's disorder scientifically fragile. The impossible task of contrasting a new category with an already very broad conceptualization of autism made defining Asperger's disorder as a distinct diagnostic category rather prospectless even before it officially existed. Additionally, the seemingly recent introduction of an 'autism spectrum' is not as new as it might seem, but just a new term for an already accepted and established understanding of autism as a wide and heterogeneous disorder of social contact.

The *DSM-5* Work Group for neurodevelopmental disorders might make history repeat itself by the introduction of, next to ASD, a new category of *Social Communication Disorder* (SCD). Even though history is often unsuited for predicting future developments, the introduction of this category resembles the

introduction of Asperger's disorder in *DSM-IV* and PDD-NOS in *DSM-III-R*. As a residual category for those who did not fully fit the autistic disorder category, PDD-NOS was thought 'to describe the (*very rare*) children who appear to merit special diagnostic notation' (Cohen et al., 1986: 217, emphasis added), but PDD-NOS became far more commonly diagnosed than autistic disorder (Chakrabarti and Fombonne, 2001). Today, the *DSM-5* will include SCD 'to describe the *rare* individuals who display significant social/communication impairments of ASDs without restrictive/repetitive behaviors' (Mahjouri and Lord, 2012, emphasis added). However, Lord argues elsewhere that 'How many individuals fall into this group is not clear ... No data are yet available about its reliability, validity or prevalence' (Lord and Jones, 2012: 499). It is unclear if and how SCD is different from ASD, for instance, in terms of etiology, symptom profile and management. Furthermore, as Ozonoff (2012) pointed out, it seems 'logically and internally inconsistent for the *DSM-5*, so pioneering in its dimensional approach, to introduce a *separate category* that is so qualitatively similar to another condition' (original italics). The way in which SCD enters the *DSM-5* is highly reminiscent of the way in which Asperger's disorder entered *DSM-IV*, and I will not be surprised if it becomes far more commonly diagnosed than ASD and if it then – just like Asperger's disorder – disappears again to be incorporated into the qualitatively similar autism spectrum.

## Conclusions

This historical analysis of the concept of autism might not be directly helpful for a deeper understanding of *why* ideas about autism have changed, but it is a necessary first step towards such an understanding as it illustrates how autism as an object of scientific inquiry and clinical practice evolved and mutated. More than just a broadening of the concept or an inclusion of milder forms of an essentially similar deficit, what is considered essential in autism has gone through major changes, from profound affective withdrawal and aloofness, to language and other perceptual and cognitive abnormalities, to deficits in social cognition and intuition. In addition, the rise and fall of Asperger's disorder is not an inevitable result of scientific scrutiny, but deeply bound to earlier conceptualizations of autism and Asperger's disorder.

Contrary to the assertions of ‘practitioner-historians’ who argue that ‘Ever since Kanner’s first descriptions in 1943 ... there has been agreement on the core symptoms’ (Sponheim, 1996: 513), this history makes room for unacknowledged discontinuities and irregularities, which are often found in the same canonical texts that are used for the positivist and essentialist narrative of autism. In this narrative, a sense of progress indirectly legitimizes current understandings, research directions, and decisions concerning classifying autism in *DSM-5*, while conceptual discontinuities and earlier complexities and disputes concerning classifying and delineating autism are left out. One tends to see and describe those aspects of earlier accounts of autism that corroborate current views of autism and thereby confirm the validity of autism as a recognizable disease characterized by a particular essential or core deficit.

However, in describing the reshaping of the concept of autism, the historicity, provisionality and plurality of knowledge and truth about autism becomes apparent. As a consequence, such a historical reflection destabilizes the present ‘truth’ about autism as a neurodevelopmental spectrum disorder of social cognition localized in an individual’s brain, and as it destabilizes the present ‘truth’ it creates space for other possible perspectives and conceptualizations of autism in the present and future. The point is, however, not to dismantle the very idea of autism, but merely to correct a positivist and essentialist understanding of autism as a discrete and stable entity in nature that we get to know and understand better and better as science progresses and knowledge accumulates.

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