

University of Groningen

Autism's anatomy

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Document Version

Publisher's PDF, also known as Version of record

Publication date:

2015

[Link to publication in University of Groningen/UMCG research database](#)

Citation for published version (APA):

Verhoeff, B. (2015). *Autism's anatomy: A dissection of the structure and development of a psychiatric concept*. University of Groningen.

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Summary

This dissertation is a collection of seven independent historical and conceptual studies on the concept of autism. I use autism as a central case to gain a specific insight into the development of scientific knowledge in the field of psychiatry. There are several reasons why autism makes an interesting and important case, and why it is important to get a better insight into the structure and development of psychiatric disease concepts. I will briefly mention four important reasons.

Firstly, autism is one of the most diagnosed, researched and discussed psychiatric disorders. Certainly, that has not always been the case. In less than forty years, prevalence rates have increased dramatically from about 1 in 2500 in 1976 to 1 in 68 in 2014. Currently there is no clear explanation for this major increase in autism cases. Next to an increase in autism research, public concerns regarding autism and a wider awareness and recognition of autism have also risen exponentially. Films like *Rain Man* and, for instance, Mark Haddon's bestseller *The Curious Incident of the Dog in the Night-time* have contributed to this popularization of autism. In a relatively short period of time, autism not only became a common psychiatric disorder, but it also became an almost inescapable cultural phenomenon. An analysis of the development of the concept of autism offers new perspectives on this 'autism epidemic'.

Secondly, autism is generally viewed as a 'true' psychiatric disorder. This means that autism is a good example of a serious brain disease with a clear genetic component. Autism researchers and clinicians conceive of autism as a distinct and largely heritable neurodevelopmental disorder. More than with any other psychiatric disorder, expectations are high that neuroscientific research on the biological foundations of autism will become clinically relevant in the near

future. This is why a large part of autism research is directed at unraveling the neurobiological pathophysiology of autism. However, as of yet, there have been no clinically relevant findings or discoveries from autism neuroscience.

This fact brings us to the third reason why autism makes a good case to use to get a better understanding of the development of psychiatric disease concepts. On the one hand, autism is an undeniable reality for patients, families, mental health professionals and autism researchers, and, on the other hand, autism remains a big mystery in terms of its causes, neurobiological foundation, prognosis, course, early signs, prevention and adequate treatment.

In other words, autism's nature remains mysterious. In addition, the 'essential' characteristics of autism – the core symptoms or phenotype – are historically rather variable. Autism has been a disorder of affective contact, a language disorder, a disorder of integrating sensory information, a disorder in understanding the intentions of others, a disorder of executive functions, etcetera. The question that arises is how it is possible that autism can be a clear, recognizable and extensively researched brain disease, while, at the same time, autism is notoriously elusive, heterogeneous and historically variable. And how is it possible that autism is a neurodevelopmental disorder when no clear disturbances have been identified in the development of the 'autistic' brain? These paradoxes are a central theme in this dissertation.

Lastly, autism makes an interesting case because it is not only conceived of as a brain disease. Critics consider the rise of autism diagnoses as a consequence of increasing medicalization and pathologization of diversity. Critics argue that societal changes have resulted in increasing attention to and higher expectations of social skills of children. At school, teamwork, oral presentations and mental flexibility have become more and more important. Furthermore, an official diagnosis is often necessary in order to qualify for all sorts of special services. Thus it seems that there are several social factors involved in the emergence of the 'autism epidemic'. Given this obvious societal component, a study on the concept of autism can provide insight into how autism experts, researchers and clinicians deal with the boundaries of this particular disorder. How do they think about the role of social factors in diagnosing autism and how do they demarcate between, for instance, normal social interaction and pathological social behavior? Again, autism makes a good case for exploring these issues.

All these issues are addressed in this study and in Chapter 2 I focus on the question of the nature – or ontology – of autism from the perspective of autism experts and researchers. This chapter argues that the common belief about the ontological status of autism is that autism constitutes a *natural kind*. There are, however, two major difficulties with a natural kind approach in autism research. First, how can we continue to speak about autism as a distinct disease while the condition is marked by such a sheer diversity of symptoms, traits, biological markers and cognitive profiles? And second, recent historical works on autism illustrate that there is something fundamentally social and historical about how autism is defined, diagnosed and treated. I argue that the dominant natural kind approach in autism research is problematic, as autism can only be understood in relation to ideas about what kind of behavior is deviant and in need of correction or support. Furthermore, locating and maintaining autism within the biological realm of the individual obscures an array of social, cultural and psychological issues involved in understanding the contemporary phenomenon we call autism.

Chapter 3 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 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.

Using the conceptual tools of philosopher of science Ludwik Fleck, Chapter 4 argues that the reframing of autism as a neurodevelopmental spectrum disorder is constrained by two governing ‘styles of thought’ of contemporary psychiatry. The first is the historically conditioned ‘readiness for directed perception’ of, and thinking in terms of, ontologically distinct diseases. The clinical gaze of mental health professionals, the bureaucratic needs of health administration, the clinical and scientific utility of disease categories, and the practices of autism-oriented advocacy groups all imply a bias toward thinking about autism and related disorders as ontologically distinct psychiatric and

scientific entities. Second, within the ‘neuromolecular style of thought,’ mental disorders are more and more located at the neurobiological levels of the brain. In autism research, one of the biggest challenges is the identification of autism’s neurobiological singularity. However, at a moment when biological and categorical approaches toward autism face serious empirical difficulties, a balance is established that holds together these two styles of thought. With a need to account for some of the most persistent uncertainties and conflicts in autism research, namely ubiquitous heterogeneity and a failure to identify disease-specific biomarkers, the reframing of autism as a neurodevelopmental spectrum disorder satisfies the scientific, institutional and socio-political needs for stability and homogenization.

Chapter 5 argues that the history and philosophy of autism need to account for at least two different kinds of autism. As is argued in Chapter 4, contemporary autism research and practice is structured, directed and connected by an ‘ontological understanding of disease’. This implies that autism is understood as a disease like any other medical disease, existing independently of its particular manifestations in individual patients. In contrast, autism in the 1950s and 1960s was structured by a psychoanalytical framework and an ‘individual understanding of disease’. In contrast with the ontological understanding of disease, autism was not a distinct disease but an idiosyncratic and meaningful response of the child to a disturbed development of the ego. These two kinds of autism are embedded in and reveal two very different ‘styles of psychiatric thought’.

In Chapter 6 I argue that the persistent search for autism-specific pathophysiology has two fundamental difficulties. The first involves the growing gap between basic autism science and clinical practice. The second involves the difficulties researchers face with demarcating autism as a psychiatric condition. Instead of the unremitting search for the neurobiological basis of autism, I suggest that basic autism research should focus on experiences of impairment and distress, and on how these experiences relate to particular (autistic) behaviors in particular circumstances, regardless of whether we are dealing with an autism diagnosis or not.

Chapter 7 is an exploration of alternative disease concepts. One conceivable alternative framework for understanding disease and individuals we have come to call autistic can be found in the work of neurologist Kurt Goldstein (1878–1965). His person-centered approach provides radically new ways to investigate

and intervene with the behavior we are accustomed to explain as being caused by the elusive entity called autism.

In the conclusion in Chapter 8 I illustrate that Fleck's notion of thought styles makes it possible for autism to be both continuously in flux *and* a seemingly stable – albeit unknown – object with many true representations and consequences. Numerous factors including a particular medical tradition, the medically-educated and DSM-trained clinical gaze of psychiatrists and other mental health professionals, the clinical and scientific utility of disease categories, the bureaucratic needs of health administration, and the practices of autism-oriented advocacy groups all create a dense social, material and cognitive network in which autism achieves a seemingly inevitable stability. Autism has become a form to be directly perceived. This '*readiness for stylized (that is, directed and restricted) perception*' of autism makes it possible for scientists and clinicians to continue to perceive a variable mixture of seemingly independent signs and symptoms as expressions of a specific, identifiable disease. This 'readiness' explains the strong tendency to objectify and reify autism. From this Fleckian perspective, the persistent search for autism's neurobiological basis can be regarded as an intelligible consequence of the restricted and directed way of perceiving, thinking and acting in contemporary psychiatry.

Finally, I argue that the broad field of psychiatry will always depend on certain contingent ideas about the nature and boundaries of mental ailments. I suggest that a critical, reflective attitude towards these ideas (and the circumstances under which they emerge) should be an integral part of psychiatry. A psychiatry that is mainly focused on legitimizing its own *medical* identity does not leave much room for a contextualizing and historicizing critical attitude. However, if we start to acknowledge that psychiatry is always formed by social and cultural conditions, a critical reflection on these conditions will become accepted by and relevant for psychiatry itself. Psychiatry will be less inclined to reject a critical view of some of the fundamental assumptions in psychiatry. This is one of the reasons why I suggest that psychiatry should work more closely with the human and social sciences. A more active interaction with fields such as medical anthropology, sociology, medical history and disability studies will give psychiatry a better understanding of and grip on how society shapes psychiatry and vice versa. In this respect, the current partial focus on the brain sciences keeps psychiatry somewhat ignorant and powerless.

A second reason that there should be more ‘intercollective communication’ between psychiatry and the human and social sciences follows more directly from this study. As Chapter 6 argues, the gap between basic autism research and the everyday struggles of those diagnosed with autism seems to be widening. I have argued that current scientific perceptions of autism as a neurodevelopmental disorder drift away from the diversity of problems and experiences of those diagnosed with autism. In addition, the boundaries of autism are unlikely to be drawn by the brain sciences, while there are growing socio-cultural, economic and clinical concerns regarding the still growing ‘autism epidemic’. These worrying developments create opportunities for a more positive – instead of a merely critical – role for the human sciences. They can play a positive role in the development of new styles of psychiatric thought that explicitly take personal, social, cultural and historical context into account. I suggest that, at least for the field of autism, new styles of thinking about mental ailments should not conceive of the milieu as merely external to an abstract disorder, but as constitutive of the impairments and disruptive behaviors of an individual. This does not imply a neglect of the brain or body, but a recognition of the embeddedness of the human being that constantly shapes and is being shaped by its surrounding world. From this perspective, which is certainly not at odds with certain current developments in the neurosciences, it is by taking the individual in his or her particular situation into account that mental ailments can exist.

The human and social sciences can play an important and positive role in developing new ways of thinking about mental ailments that, for instance, put the troubles, impairments and adverse experiences, as well as the strengths and resiliencies of the entire human being at center stage. Undoubtedly, any new style of psychiatric thought will generate new types of problems and criticisms, but I expect that psychiatric research that manages to take the intricate relationship between human life and the surrounding milieu seriously has a better chance at translating into clinical practice.