Autism's anatomy
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1 | Introduction

A focus on autism

Autism makes an appealing case as a way to explore the structure and development of psychiatric knowledge. When I started my psychiatry residency training program, more than a decade ago, the phenomenon of autism had not yet been fully settled in the minds of mental health professionals, especially not in adult mental health. I remember visiting a middle aged man who had been a patient in an ambulatory psychiatric service for people with enduring psychiatric problems. He received psychiatric support from a multidisciplinary team for many years and he had seen many psychiatrists and medical doctors who had formally diagnosed him with a DSM-IV anxiety disorder not otherwise specified (NOS). When I visited him at the request of his psychiatric nurse and case manager, I saw an anxious and lonely man in an extremely dusty apartment. He never cleaned, never cooked, only left his house for vital necessities, collected war documentaries, hardly talked, and, apart from the mental health professionals, he only had social contact with his sister. When I visited him, he suffered from panic attacks since his landlord had threatened to remove him from his apartment due to nuisance and contamination. At that time, my colleagues and I saw a suffering man in desperate need of care and support, but we did not see a man suffering from autism. We still had to learn to perceive autism. Certainly, he was not the typical Rain Man, but with autism-specific diagnostic questions, a developmental biography, and an autism-trained

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1 This case has been slightly modified to prevent any type of recognition of the particular patient.
psychiatric gaze, the chances are high that he would now be diagnosed with an autism spectrum disorder.

Today, autism is harder to miss. In a relatively short period, autism has become one of the most diagnosed, researched, and discussed psychiatric disorders. Estimated prevalence rates went from about 1 in 2500 (Wing et al., 1976) to 1 in 68 (CDC, 2014) in less than forty years. The possible existence of a real ‘autism epidemic’ is widely discussed among autism researchers (Leonard et al., 2010), and, the ‘dramatic increase in autism prevalence parallels [an] explosion of research into its biology and causes’ (Dawson, 2013). In 2010, federal and private foundation funding for autism research in the US exceeded US$400 million (Pellicano et al., 2014). In 2000, funding for autism research in the US was approximately US$50 million and compared to other developmental disorders (for example, ADHD, Down syndrome, Tourette syndrome, Fragile X syndrome and Fetal alcohol syndrome) autism research receives the most funding and has the highest annual rate of increase in funding in the US (US$50 million annual increase between 2000 and 2010, Bishop, 2010). Even though the severity of the disorder cannot explain this growth in research funding, more and more of the NIMH and charity pie goes to autism research (ibid.). Within the UK, more than half of all autism research funding awards were given to projects in basic research areas of biology, brain and cognition. Cortical development, social cognition and animal models of autism were the most significant areas of funding between 2007 and 2011 (Pellicano et al., 2014). All this research needs to be published in scientific journals. *Molecular Autism, Autism Research, Research in Autism Spectrum Disorder, Good Autism Practice, and Autism Research and Treatment*, are all full-fledged and autism-specific international peer-reviewed journals that have only emerged over the last couple of years.

Next to all sorts of scientists and mental health workers who organize their research, clinics, careers, institutes and journals around the disorder of autism, the interest in autism has spread to the social sciences. As social scientist Chloe Silverman expressed it, ‘the idea of autism – as a metaphor, a neurological disorder, a mental state, an increasingly prevalent diagnostic category, or a species of neurological difference – has an almost ready-made appeal for social scientists, concerned as they are with questions of human identity, difference, perception and subjectivity within a social and cultural context’ (Silverman, 2008: 325). An example of a product of this appeal is *The Autism Matrix* by Eyal
et al. (2010). They give a sociological explanation for the dramatic rise in autism diagnoses. For Eyal et al., the prime suspects of the ‘autism epidemic’ are not the much-discussed mercury-based vaccine preservatives, old fathers, or the use of antidepressants during pregnancy. Instead, their explanation of the epidemic involves the emergence of autism parent organizations since the 1960s, the extensive deinstitutionalization of intellectually disabled children since the 1970s, and in greater benefits for those diagnosed with autism due to the growing availability of special services from 1991 onwards when autism was added to the Individuals with Disabilities in Education Act (IDEA).

The remarkable surge in autism prevalence also paralleled a rapid growth in popular awareness, visibility and concern regarding autism. Mark Haddon’s *The Curious Incident of the Dog in the Night-time* (2003) and an ever-growing collection of ‘autistic fiction,’ autobiographies, biographies, movies, documentaries, stories for children, stage plays and graphic novels have certainly contributed to the popular recognition of autism (see Hacking, 2009). In less than three decades, autism transformed from a rare and largely unknown syndrome into an almost inescapable cultural experience and fascination. For three more specific reasons autism makes a good case to explore the structure and development of psychiatric disease concepts – the central entities that shape both psychiatric practice and research.

**A genetic brain disease**

To begin with, autism is often seen as a paradigmatic (child) psychiatric disorder. It is thought to have a large genetic component. Concordance rates among monozygotic and dizygotic twins are 50-90 percent and 0-30 percent, respectively, supporting a large genetic contribution (Berg and Geschwind, 2012). The genes or genetic variances associated with the disorder are assumed to be involved in the development of our brains. Almost without exception, autism researchers and mental health professionals see autism as a highly heritable and lifelong *neurodevelopmental* disorder. Probably more than depressive disorder, ADHD, anxiety disorders, conduct disorders or even schizophrenia, autism is primarily understood as a brain disease with which one is born and dies. Furthermore, many researchers and clinicians acknowledge the

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2 See Draaisma (2009) for an analysis of how popular representations of autism in novels, TV-series or movies can contribute to a harmful divergence between the popular image of autism and the clinical reality of autism.
distinctiveness and recognizability of autism. For autism expert Fred Volkmar, autism is one of the better examples of a disorder ‘that is distinctive and does not just shade off into normalcy’ (Volkmar, 1998: 45). Uta Frith, another well-known autism expert, also considers it a recognizable entity (Frith, 1989) and Leo Kanner himself, autism’s founding father, stated unreservedly that the disorder represents a ‘definitely distinguishable disease’ (Kanner, 1965: 418). Moreover, many parents of autistic children and professionals who observe, treat and interact with a lot of children diagnosed with autism develop a certain readiness to quickly perceive and recognize an autistic child as somehow different from a ‘normal’ or non-autistic child (see Chapter 2).

Against the background of psychiatry’s preferred identity as a medical specialty, autism’s neurobiological and distinctive image are expected to be promising for making successful translations from the biomedical sciences and the neurosciences to the clinic. Psychiatry’s need for successful translations ‘from bench to bedside’ is not particularly recent. In 1973, the historian of medicine Charles Rosenberg presented a lecture – The crisis in psychiatric legitimacy: Reflections on psychiatry, medicine, and public policy – that would not appear obsolete or irrelevant from a present-day perspective (published in Rosenberg, 1975). Rosenberg noticed a growing gap between the performance of psychiatry as a medical specialty, and the expectations from society and psychiatry itself, regarding successful psychiatric care, treatments, and (brain-based) explanations of deviant sexual, moral and social behavior. Psychiatry’s responsibilities to cure and illuminate – in Rosenberg’s prose of the antipsychiatry movement of the 1970s – ‘the clinical burdens of a society which “produces” vast numbers of individuals whose behavior is stigmatized by that society as mental illness,’ (ibid.: 249) contrasted with the sparse technical means and the lack of insight into the pathophysiological processes of these particular clinical burdens. The identification of psychiatry as a medical specialty was ambiguous, and psychiatry, while resting on its status and authority of a medical profession, was at least an unusual medical specialty. Many other areas in clinical medicine had been able to link understandings of pathological mechanisms with specific

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3 As I explain later on, the work of Charles Rosenberg has been an important source of inspiration for this dissertation. Rosenberg wrote his essay The crisis in psychiatric legitimacy, for a meeting in Williamsburg, Virginia, in 1973 ‘to commemorate the bicentennial of the British North American colonies’ first public hospital for the mentally ill’ (Rosenberg, 1975: 245). The essay was published in 1975 in an edited book containing all the papers that were presented at this particular meeting.
therapeutic interventions that structured and defined the boundaries within which clinical decisions were being made. This was not the case for psychiatry, whose theoretical foundations were based on the analysis of clinical experiences, and who struggled to substantiate their claim to exclusive (medical) care and control – against ‘rival schools of emotional healing’ – of those defined as mentally disordered. For Rosenberg, the crisis in psychiatric legitimacy was exactly this gap ‘between the demands of medical exclusivity and the inability of psychiatry to provide either understanding or relief consistent with the pretentiousness of such demands’ (ibid.: 250). These considerations are – more than forty years and heaps of neuroscientific, epidemiological, clinical and psychopharmacological research later – still valid.

Those who followed the fierce debates surrounding the publication of *DSM-5* (APA, 2013) must have noticed that the major themes of the discussion were the free-floating boundaries of psychiatry (for example, Frances, 2013); the ‘premature’ state of behavior-based classification and diagnosis; the dubious role of big pharmaceutical and biotechnology industries in shaping psychiatry; the complete absence of useful biomarkers for treatment and prediction; the non-specificity of psychopharmacological drugs and the ambiguous evidence for the beneficial effects of these drugs; and the use (or misuse) of the diagnostic manual and psychiatry for bureaucratic, juridical, educational, insurance, and other purposes. Of course, the forces and stakeholders that shape contemporary psychiatry have shifted since the 1970s, but the ‘crisis in psychiatric legitimacy’ still comes down to a tenacious discrepancy between the expectations from a truly *medical* specialty and the performance of that same specialty. These persistent uncertainties and fragilities of a medical specialty in search of its medical identity and legitimacy are part of the broader motivation behind this dissertation.

As I have said, autism’s neurobiological and distinctive image are promising for making successful translations from the biomedical sciences and the neurosciences to the clinic. Consequently, the expectations to develop a biotechnical armamentarium and close and successful connections between biomedical research and clinical practice are particularly high for the field of autism. The illumination of pathophysiological pathways, the identification of specific diagnostic markers, and the development of ‘normalizing’ interventions on the basis of these pathophysiological mechanisms are the promising prospects of a medical discipline specialized in emotional, behavioral and
cognitive maladies. The field of autism is one of those fields in which the medical identity and legitimacy of psychiatry is very much at stake. This is all the more urgent given the rising rates of autism diagnoses and the significant economic costs of autism – a person with autism without an intellectual disability costs US$1.4 million during her or his lifespan in the US (Buescher et al., 2014). By meeting societal and medico-techno-scientific expectations, autism could be a forerunner and important example for (child) psychiatry in general.

Attempts to fulfill these expectations are passionate and, given the considerable clinical and economic ‘burden’ of autism, it is no surprise that autism research is booming. Thousands of autism researchers worldwide devote their working days to ‘unraveling the mystery of autism’. Performance, however, is still far away from fulfilling the great expectations. Despite many premature claims of sensitive and specific diagnostic tests for autism – for instance by Duffy and Als (2012) who claimed to have developed an electroencephalogram (EEG) test that could distinguish autism from non-autism – there are no clinically useful biological tests or specific neurobiological treatments for autism on the basis of identified pathophysiological pathways.

**An elusive entity**

This is a second reason why autism makes a fascinating case for studying psychiatric disease concepts: autism is on the one hand culturally pervasive and an undeniable reality for patients, families, clinicians, researchers and even for social scientists while, on the other hand, it remains a big mystery in terms of its causes, its neurobiological underpinnings, its treatment, prognosis and prevention. In other words, the nature of autism remains disturbingly unknown. What is more, the idea of autism – or what is thought to be essential in autism – is far from stable. In its brief history, autism has been a disorder of affective contact (Kanner, 1943); a language disorder (Rutter and Bartak, 1971); a disorder in processing and integrating perceptual information (Wing and Wing, 1971); a disorder of executive functioning (Hill, 2004); a disorder of reading other people’s minds (Baron-Cohen, 1995); a disorder of weak central coherence (Happé and Frith, 2006); an excess of ‘systemizing’ drives at the expense of ‘empathizing’ drives (Baron-Cohen, 2002); a disorder of social motivation (Chevallier et al., 2012); a disorder of social cognition (Wing et al., 2011); and more. The core features of the concept of autism are not as stable as
many autism researchers presume. Nevertheless, the multiplicity of manifestations, cultural representations, explanatory frameworks and ‘essential’ characteristics of autism is, especially among social scientists of autism (for example, Murray, 2008; Fitzgerald, 2012), increasingly acknowledged. Given this multiplicity of autism realities, I suggest that if we want to understand how psychiatric knowledge develops, it is important to understand what it is that keeps the very idea of autism together and autism research thriving. That will be a central theme in this dissertation.

How is it possible to keep on talking about autism; to keep a stable image of autism; to keep on doing fundamental research on autism; to keep on perceiving clear cases of autism; and to keep on organizing psychiatric care around the category of autism, while the idea of autism is notoriously elusive, heterogeneous and variable in the way it is and has been conceptualized? How can autism be both a ‘successful,’ recognizable and well-researched disease, and yet be notoriously unstable at the same time? These questions kept on wafting into my mind during the process of thinking and writing about autism. Both constancy and change seem to characterize the entire historical trajectory of autism. One of the things I realized was that a certain degree of conceptual flexibility has been a prerequisite for a certain form of continuity, stability and unification among autism researchers, clinicians and other ‘exoteric’ communities in the broad field of autism (see Chapter 4). This dissertation argues that an exploration of the interactions between changing ideas of autism and the steady search for autism – that is, the search for behavioral, cognitive and biological common denominators or ‘the essence’ of autism – helps to understand one of the ways in which psychiatric knowledge develops.

A social disorder
A third and final reason for me to focus on autism is that it is not only seen as a paradigmatic psychiatric disorder, but also widely contested as a medical category. As Rosenberg also pointed out in his 1975 article on psychiatric legitimacy, to a far greater degree than other medical specialties, psychiatry is shaped by social values and attitudes toward deviance, aging, child development, and ethnicity, as well as by the needs of social policy and by other decisions made outside the medical profession of psychiatry. The emergence of psychiatry in the nineteenth century, more recent trends toward deinstitutionalization, shifts in (psychoanalytical or biological) explanatory
frameworks, and a panoply of now-discarded treatments (of which lobotomy and insulin coma therapy are prominent examples), reflected specific social needs and shifting ideologies, rather than an outcome of an ‘expanding body of knowledge or the crystallization of particular techniques’ (Rosenberg, 1975: 247). Rosenberg held that despite the fact that psychiatry lacks the technical means and knowledge to delineate its field, it still needs to deal with a large variety of emotional pain and psychological disabilities. And because of the fact that psychiatry lacks the technical means and knowledge to delineate its field, it is prone to border disputes and it has a diffuse societal responsibility. In other words, the lack of technical means and knowledge to delineate the field makes psychiatry particularly vulnerable for all sorts of social influences.

Given that autism is currently characterized and diagnosed on the basis of deficits in social behavior (for example, deficits in social-emotional reciprocity, non-verbal communication and in developing relationships), it does not come as a surprise that some argue that the rising numbers of people with autism reflects social changes. Among other things, a growing medicalization and pathologization of diversity; increasingly narrow social norms; shifting educational ideals toward mental flexibility, teamwork and oral presentation; and growing expectations from and demands on children’s social skills, are potential causes for the ‘autism epidemic’. For example, Molloy and Vasil (2002) see Asperger syndrome – now incorporated into autism spectrum disorder (APA, 2013) – as a socially constructed category because of its value as a category for organizing special education. Fein (2015) argues that a changing sociocultural milieu ‘in which friendship and other extra-familial relationships are increasingly determined by individual choice, with affiliations formed around likeability and the negotiation of mutual positive affect’ contributed to the increase in autism diagnoses for those ‘who are slower to develop nonverbal awareness, perspective taking, and emotional self-regulation (Fein, 2015: 82).

Notwithstanding the value of these type of studies, I am not primarily interested in disentangling all the (social) factors that might have contributed to the ‘autism epidemic’. Instead, I am interested in what we can learn about the structure of psychiatric knowledge from the almost paradoxical situation in which autism can both be extremely prone to border disputes and vulnerable to socially-induced diagnostic expansion and yet simultaneously be a paradigmatic psychiatric disorder that awaits neuroscientific discovery. How does psychiatric
research deal with these social issues and the boundaries of mental (ab)normality? Why is it that certain forms of social interaction, eye-contact, body language, imaginative play, and so on, are considered deviant, and at what point do they become deviant? Again, due to its inherent social component, autism makes a rewarding case to explore these questions in this dissertation.

A historical approach

This PhD dissertation consists of seven independent articles that have been published in or were submitted for publication to diverse scientific journals in the fields of philosophy, history and sociology of medicine and biology. I tried to publish in autism journals, but my manuscripts never entered the peer review process. A common response I got from the editors was that they are ‘accepting very few review or conceptual articles, and those that are accepted are typically solicited by the editorial team’ (personal e-mail). With the prevailing idea of autism as a heritable brain disease, historical, philosophical and sociological studies of autism are indeed not very urgent for autism research itself. However, as I argue in this dissertation, a closer connection to and collaboration with social, historical and conceptual studies can be very valuable for the field of autism – even for the basic brain sciences that study autism. Hopefully, this collection of articles will support my future attempts to bring autism research and the human and social sciences closer together.

For those who will read the entire dissertation, I apologize for quite a bit of overlap between the chapters. Nevertheless, the diversity in journals reflects the diversity of the perspectives that I have tried to incorporate in exploring expert ways of thinking about autism and what these ways of thinking might tell us about the structure and development of psychiatric knowledge. The seven articles, diverse and autonomous as they are, are tied together by the aim to render present knowledge and practices in the field of autism intelligible. Unfortunately, studies that try to understand the social, cultural, political, historical and economic determinants of current psychiatric thought (for example, Dehue, 2008; 2014; Young, 1997) are sometimes equated with radical constructionist accounts that see psychiatry as a pathologizing and medicalizing vehicle for social control (Szasz, 1972). I want to make clear that, similar to the work of above-mentioned authors, this dissertation is not a discourse of
suspicion that tries to underplay the seriousness of psychiatric problems or that tries to uncover malicious practices or conspiracies between medical imperialists and Big Pharma. Nor is it a critical reflection that tries to uncover ‘bad’ psychiatric research. Lastly, I do not attempt to present abstract philosophical reflections on the nature or social construction of psychiatric disease, on a general distinction between health and disease, or on something like the mind-body problem in mental health. Instead, my aim is to present an anatomy of the notion of autism – a critical reflection that recognizes and explores the often implicit philosophies that are operative in the field of autism itself.

To achieve this aim, one of the assumptions guiding this dissertation is that it is necessary to elucidate the past in order to understand the concepts and traditions that determine our current ways of seeing and knowing. People did not simply open their eyes and notice autism all around them. Being able to see autism requires much more than that. It would be overambitious to analyze all the historical conditions that make it possible to perceive autism, to talk about autism, to shape ‘autistic’ identities and experiences, and to investigate, discover and know autism in a particular way. Besides, some of the important social and cultural spaces that made it possible for autism to emerge as a distinct disorder – for instance, compulsory education and the rise of mental hygiene movements in the early twentieth century – have already been scrutinized (see Nadesan, 2005). Nonetheless, the importance and role of underlying concepts of disease and the ways in which actual research findings effect new conceptualizations of autism are often overlooked in historical and sociological studies of autism. These aspects will get substantial attention in this study and I took inspiration from a combination of works of several distinguished theorists, historians and philosophers of science.

Specifically, I draw on the works, concepts and methods of Ludwik Fleck (1935/1979), Georges Canguilhem (1966/1991), Charles Rosenberg (2007), Ian Hacking (2002) and Nikolas Rose (2013). Apart from the fact that they explore similar themes in the fields of medicine and the life sciences, these authors share a sincere interest in and profound knowledge of the field they reflect upon. They all want the objects of their own discussions to do well and they do not merely attempt to dismantle the hidden premises and assumptions that support particular scientific practices and truth claims. Most of these authors share the assumption that internal and external aspects of science can only
artificially be disconnected. Scientific ideas and results are always connected to the societal context in which they appear and they inherently depend upon collaborations and communicative interactions between scientists, scientific communities, and external groups of people. Furthermore, these authors theorize that epistemological and ontological matters cannot be easily distinguished. Scientists not only try to discover the world or produce knowledge of the world, but they also bring novelty to the world. It is in the spirit of these authors, who are sometimes grouped as ‘historical epistemologists’ (Rheinberger, 2010), that this dissertation is written.

The next six chapters contain several conceptual histories of autism (Chapters 3, 4 and 5) and analyses of the often implicit philosophies that are operative in the field of autism today (Chapters 2 and 4). Chapter 3 argues that the histories written by the discipline itself play a significant epistemological role and the chapter demonstrates – in an alternative history of the concept of autism – that there have been major shifts in the type of symptoms, signs and impairments that were thought to be essential for autism. Chapter 4 offers an account of the reframing of autism as a neurodevelopmental spectrum disorder by using the conceptual tools of philosopher of science Ludwik Fleck. In Chapter 5 I compare current understandings of autism with psychoanalytical understanding of autism, and I argue that the history of autism needs to account for two rather different kinds of autism, which are based on different understandings of psychiatric disease. These two kinds of autism are embedded in and reveal two very different ‘styles of psychiatric thought’. As I have said, my aim is not to reject present ways of thinking about autism or recent aims of autism research, but I do point out some difficulties that I think are inherent in current ways of thinking about psychiatric ailments. For a substantial part, these difficulties will be discussed in Chapters 2 and 6. In addition, I do hope to open up new ways to investigate and intervene with the behavior we are accustomed to explain by the elusive entity called autism, even when new conceptualizations of autistic behavior will certainly generate new problems. Chapter 7 offers a concrete attempt to explore new ways of thinking about psychiatric disease through the work of neurologist Kurt Goldstein.

Generally, I hope that *Autism’s Anatomy* will contribute to the awareness of the contingency of psychiatric concepts that guide and shape everyday practices, both in the lab, in the clinic, and in society at large. This will create space for possible alternatives in thinking about psychiatric disease. In the final
chapter (Chapter 8), I draw conclusions about the structure and development of the concept of autism and I come back to the larger motivation behind this study: the issues regarding the objectives, preferred medical identity and legitimacy of contemporary psychiatry.

References


