



TOWARDS AN ETHICS OF AUTISM

**A Philosophical
Exploration**

KRISTIEN HENS



<https://www.openbookpublishers.com>

© 2021 Kristien Hens



This work is licensed under a Creative Commons Attribution 4.0 International license (CC BY 4.0). This license allows you to share, copy, distribute and transmit the text; to adapt the text and to make commercial use of the text providing attribution is made to the authors (but not in any way that suggests that they endorse you or your use of the work). Attribution should include the following information:

Kristien Hens, *Towards an Ethics of Autism: A Philosophical Exploration*. Cambridge, UK: Open Book Publishers, 2021, <https://doi.org/10.11647/OBP.0261>

Copyright and permissions for the reuse of many of the images included in this publication differ from the above. This information is provided in the captions and in the list of illustrations.

In order to access detailed and updated information on the license, please visit, <https://doi.org/10.11647/OBP.0261#copyright>

Further details about CC BY licenses are available at <https://creativecommons.org/licenses/by/4.0/>

All external links were active at the time of publication unless otherwise stated and have been archived via the Internet Archive Wayback Machine at <https://archive.org/web>

Updated digital material and resources associated with this volume are available at <https://doi.org/10.11647/OBP.0261#resources>

Every effort has been made to identify and contact copyright holders and any omission or error will be corrected if notification is made to the publisher.

ISBN Paperback: 9781800642300

ISBN Hardback: 9781800642317

ISBN Digital (PDF): 9781800642324

ISBN Digital ebook (epub): 9781800642331

ISBN Digital ebook (mobi): 9781800642348

ISBN XML: 9781800642355

DOI: 10.11647/OBP.0261

Cover image: Photo by Mika Baumeister on Unsplash at <https://unsplash.com/photos/40HCUdMcHiw>

Cover design by Anna Gatti.

4. Sociological and Historical Explanations of Autism

We can interpret ‘understanding autism’ in different ways and on different levels. In the previous chapter, I described how people have tried to explain autistic behaviour based on specific cognitive models. I explained the most prevalent of these models, and demonstrated how some philosophers have used them in particular arguments about morality. I discussed two texts that show how the explanatory model we choose also has practical and ethical consequences for how we look at responsibility. Accepting the Theory of Mind hypothesis without further reflection may lead to autistic people not being taken seriously when they speak about their own experiences. It is striking how often these theories explain the challenges that autistic people face by pointing out a deficiency in the *individual*. Just as explanations of autism that primarily point to its genetic origins, this can encourage us to consider autism first and foremost as a medical problem, to be diagnosed and solved. However, we can also explain autism differently. We can ask ourselves why autism has become so visible from the 1940s onwards, and, more specifically, during recent decades.

Cross-culturally, it seems to be the case that behaviour considered typical in children in one culture is judged elsewhere in a wholly different way. In March 2017, I attended a conference in London entitled *The Globalization of Autism*, organized by Bonnie Evans, a historian of science. There we discussed whether autism means different things in different contexts. We may wonder whether it is not colonial to use diagnostic toolkits developed in a specific cultural context to detect autism in other cultures. One researcher, Tyler Zoanni of New York University, talked about how in Uganda, the primary criterion to diagnose autism is delay or absence of speech. Other behaviours, such as not looking in adults’

eyes, are expected of local children and cannot be used in diagnostics. In a presentation about the history of autism in Taiwan, researcher Lai Pin Yu provided insight into the difficulties diagnosticians face when diagnosing autism in Taiwan through a Western lens. In Taiwan, speaking at a later age is not always experienced as problematic but is sometimes considered a sign that the child could be brilliant. What Western clinicians would consider an eating disorder is often not experienced as such: Taiwanese mothers have far more patience with picky eaters. What we consider a disorder that needs intervention is, therefore, dependent on time and location, as it is closely linked to what we consider to be normal behaviour.¹

Explaining the Rise of the Phenomenon of Autism

Some have suggested explanations for the rise of diagnoses of autism that have been quickly disproven, although they had far-reaching consequences. A small study conducted by Andrew Wakefield suggested a link between autism and the vaccination for measles/ mumps/rubella (the MMR vaccine) in the 1990s. This paper, first published in *The Lancet*, was later withdrawn. Other studies debunked, once and for all, the link between autism and vaccines. Nevertheless, some people still believe that there is a causal link between the two, which resulted in an increasing number of parents choosing not to vaccinate their children. People might still believe this for many reasons. Perhaps one of them is that the first signs of autism in a young child often become apparent at approximately the same age as the vaccination is administered. The desire for a simple explanation for autism may be another reason.

Some studies have tried to demonstrate a connection between autism and particulate matter. This may lead some to conclude that the increasing number of children diagnosed is due to decreased air quality in recent decades. The assortative mating theory suggests that parents with specific joint interests, such as mathematics, science, or technology, would, by bringing together their genes, more often have children with autism.² Descriptions of historical figures, such as those by Uta Frith

1 Hyun Uk Kim, 'Autism across Cultures: Rethinking Autism', *Disability & Society*, 27:4 (2012), 535–45, <https://doi.org/10.1080/09687599.2012.659463>

2 Simon Baron-Cohen, 'Two New Theories of Autism: Hyper-systemising and Assortative Mating', *Archives of Disease in Childhood*, 91:1 (2006), 2–5, <https://doi.org/10.1136/adc.2005.075846>

in *Autism: Explaining the Enigma*, suggest that there has always been autism.³ We are just now starting to notice it. To engage with these discussions, we must first pry some issues apart.

Firstly, there is a distinction between autism as a kind of innate personality trait and autism as a clinical diagnosis, a clinical presentation of someone who visits the (child) psychiatrist with specific challenges that need answers and solutions. We can assume that there have always been persons with certain personality traits that we would now call autistic. Still, the need to diagnose such people and give a DSM label is relatively recent. People often refer to aspects of current Western society to explain the prevalence of autism and other so-called developmental disorders such as ADHD. Social behaviour is regarded highly, and the loner with a fanatical hobby is doomed to lead a lonely life filled with misunderstanding by others. However, the fact that we live in an autismogenic society, in which an ever smaller group of smooth operators is considered normal, is in itself not a sufficient reason why the diagnosis of autism, something previously thought of as a rare paediatric disorder, has taken flight in the last decades.

Measuring Selves

In the spirit of Michel Foucault's work, the British sociologist Nikolas Rose and colleagues tried to answer a similar question in the context of psychology, neuroscience, and psychiatry in general. Rose states in his book *Inventing Our Selves: Psychology, Power and Personhood* how psychology, as a new science in the twentieth century, has invented the concept of the average individual.⁴ Thus this discipline has played an essential role in engendering the terminology we use when we think about ourselves:

For it is only at this historical moment, and in a limited and localized geographical space, that human being is understood in terms of individuals who are selves, each equipped with an inner domain, a 'psychology', which is structured by the interaction between a particular

3 Uta Frith, *Autism: Explaining the Enigma*, 2nd ed. (Malden, MA: Blackwell Pub, 2003).

4 Nikolas Rose, *Inventing Our Selves: Psychology, Power, and Personhood* (Cambridge: Cambridge University Press, 1998).

biographical experience and certain general laws or processes of the human animal.⁵

Hence, according to psychology, some general rules structure how we are selves are shaped: we can measure these processes and statistical deviations. Because variations are now objectively measured, they can also be named: the disorder has an objective basis, and we can demonstrate it through measurement. The instruments of psychology have made psychiatry into an exact science. Rose calls this 'govern[ing] subjectivity according to norms claiming the status of science, by professionals grounding their authority in an esoteric but objective knowledge.'⁶ Furthermore, he states that psychology becomes expertise: 'It is in this fashion that psychological ways of thinking and acting have come to infuse the practices of other social actors such as doctors, social workers, managers, nurses, even accountants.'⁷ We can see this mechanism also in the diagnosis of autism. Although this is a psychiatric diagnosis, it is, in optimal circumstances, given after an extensive and multidisciplinary investigation that includes educational scientists and psychologists. The so-called *praecox*-feeling of the psychiatrist, a sensing of the correct diagnosis when she first encounters her patient, is not sufficient. The psychiatrist no longer merely relies on her expertise and experience in attributing a diagnosis but is supported by a vast scale of tests that substantiate the scientific validity of the diagnosis.

However, we might wonder about the relationship between what we test (for example, autism or intelligence) and the tests themselves. Do they test the phenomenon itself, and are they, therefore, valid?⁸ Or are we talking primarily about reliability? A measurement is reliable if, when different people measure something, they will come to the same conclusion. If we take the example of intelligence, we might wonder what intelligence is: does the IQ test measure intelligence, or do we define intelligence as the IQ test outcome? The former seems to be problematic: IQ tests are also context-sensitive, and as there appears to

5 Rose, *Inventing Our Selves*, p. 23.

6 *Ibid.*, p. 75.

7 *Ibid.*, p. 86.

8 Denny Borsboom, Gideon J. Mellenbergh, and Jaap van Heerden, 'The Concept of Validity', *Psychological Review*, 111.4 (2004), 1061–71, <https://doi.org/10.1037/0033-295X.111.4.1061>

be no agreement about the ontological status of intelligence. The latter suggests that such tests are merely social constructs and conventions, without actual truth status. We could follow the same reasoning for autism. Diagnostic instruments such as ADOS-2 are based on the criteria for Autism Spectrum Disorder, as described in DSM-5.⁹ Do we then test to what extent someone satisfies these criteria or to what extent someone has an underlying condition ('autism')? In later work, Nikolas Rose, together with Joelle M. Abi-Rached, has also applied these ideas to neuroscience. They argue that psychiatry has increasingly become neurology, and we think about ourselves more and more in terms of the brain. However, according to them, this does not lead to defeatist thinking about ourselves: our brain does not merely control us, but we are deemed responsible for improving ourselves, as brains, employing medical and other techniques.¹⁰

A Different View of Childhood

Several sociologists and philosophers of science have explored why autism appeared in the middle of the previous century. One of the first comprehensive sociological explanations of autism can be found in *Constructing Autism. Unravelling the 'Truth' and Understanding the Social* by Majia Holmer Nadesan.¹¹ Nadesan, a mother of a child with a diagnosis of autism, describes how autism is the result of several practices in the twentieth century. In the nineteenth century and before that, autism was unthinkable. Not only was there no such concept, but people also did not consider children as interesting enough for psychiatry or a clinic. At a particular moment, the conditions of possibility were created for autism as a phenomenon, in need of a name and a diagnosis:

However, the question typically arising in discussions on the relationship between culture and illness (in all of its forms including mental illness)

9 Adam McCrimmon and Kristin Rostad, 'Test Review: Autism Diagnostic Observation Schedule, Second Edition (ADOS-2) Manual (Part II): Toddler Module', *Journal of Psychoeducational Assessment*, 32:1 (2014), 88–92, <https://doi.org/10.1177/0734282913490916>

10 Nikolas Rose and Joelle M. Abi-Rached, *Neuro: The New Brain Sciences and the Management of the Mind* (Princeton: Princeton University Press, 2013).

11 Majia Holmer Nadesan, *Constructing Autism: Unravelling the 'truth' and Understanding the Social* (London; New York: Routledge, 2005).

is whether the cultural component is simply built upon a foundational and determining biological component or, conversely, whether the biological component exists at all. Is culture merely the clothing within which the diseased body appears? Or, does culture—through its practices of hygiene and diet and through its medical vocabularies and institutions—produce disease in its entirety? For those versed in academic debates, one can easily recognize the eternal battle between realists in the materialist camp and nominalists in the idealist camp having their say about the nature and origins of health and disease. At issue here are the seemingly inescapable dualisms in western thought between mind and body, culture and biology.¹²

Nadesan points to an important fact here: often, a sociological or social-constructivist approach to autism is confused with a denial of the biological or phenomenological reality of autism. However, this is not what she argues (nor do I in this book). To understand a phenomenon such as autism, and to be able to reflect on it ethically and philosophically, we need to understand the different aspects of it. Nadesan investigates how autism in the first part of the twentieth century arose as a phenomenon. How is it possible that at that given moment, a pattern of behaviour did catch the attention of the medical profession? Nadesan explains this firstly by referring to the changing status of the child. Only in the nineteenth century, when child mortality was decreasing, was childhood considered to be a separate stage, qualitatively speaking, in human life. People no longer believed children should become wage-earners as soon as was practicable; rather, childhood was seen as a distinct period of one's life for which the state could set specific conditions. In different countries, official education became compulsory. Because children were now under the scrutiny of educators, teachers, and researchers, their psyche also became an object of study. Psychoanalysis, as invented by Sigmund Freud, stressed the influence of what happens in the first years of life upon later mental development. Researchers such as Jean Piaget and later Lawrence Kohlberg dedicated their lives to studying the different phases of childhood.

Because of these developments, children became interesting for psychiatry: the clinical gaze was turned on them. Clinicians and doctors thought about normal development, and because of that, those who

12 Nadesan, *Constructing Autism*, pp. 21–22.

deviated from normal development stood out. In the thirties and forties, child psychiatry developed under the impulse of Leo Kanner and others, and at the same time, the diagnosis of autism was born. The concept of autism could only find acceptance from the moment that these institutions (compulsory education, child psychiatry, psychological research laying down the contours of normality) had acquired an influential role in society. Nadesan also describes how the development of computational analogies influenced the shaping of the meaning of autism. Ideas such as Theory of Mind — or the lack thereof — and the corresponding modules in our brain only work if we conceptualize our brain as a kind of central processing unit, consisting of parts that can be broken. Furthermore, although Asperger considered autism to be a personality disorder, the idea of autism as a developmental disorder has been retained. Autism is now primarily conceived as the atypical course of the biological development of a child, beginning before birth:

The ascendancy of the cognitive paradigm thereby produced significant effects for the study of 'abnormal' child psychology. As delineated above, it led to more interest in, research about, and surveillance over very early processes of cognitive development in infants. The paradigm both telescopes for scrutiny and fragments the mind as it seeks to identify the various components of cognitive development. Accordingly, I believe it has contributed to the increased rate of diagnoses of high-functioning forms of autism including PDD, Asperger's syndrome, as well as partially explaining the increased diagnoses of ADD and ADHD (Croen et al. 2002). On the other hand, it has also destigmatized, to a certain degree, a psychological diagnosis because it replaced molar categories of normalcy and pathology with a multitude of developmental continua used to describe the acquisition of a considerable range of intellectual and social skills and abilities.¹³

The emphasis on autism being a developmental disorder also suggests that it is a medical problem. On the one hand, it is situated in the biology of individuals. On the other hand, it is responsive to interventions. In English speaking countries in particular, there is a proliferation of therapies — especially behavioural therapies — that try to bring the atypical development of the autistic child back on track.

13 Ibid., p. 113.

Deinstitutionalisation and Expertise

Gil Eyal and his colleagues at Columbia University in New York discuss the rise of autism diagnoses in their book *The Autism Matrix* and the article 'For a Sociology of Expertise: The Social Origins of the Autism Epidemic'.¹⁴ They claim that this rise is due to the deinstitutionalisation of children who would previously have been considered intellectually disabled. This is partly explained by the availability of services and therapies for autism, and the fact that intellectual disability carried greater connotations of being insurmountable.¹⁵ Eyal juxtaposes naturalistic and social-constructivist explanations. According to naturalistic explanations, there are now truly more cases of autism. Nevertheless, according to social-constructivist explanations, there are no more cases: we can explain the rise of cases by referring to the broadening of diagnostic criteria or the pressure by parents' organisations to receive a less stigmatizing diagnosis than mental retardation. Neither one of these explanations is sufficient according to Eyal, who asks: if the rise is due to a greater availability of diagnostic criteria, why were these broadened in the first place?

Eyal then turns the question around: why was autism so rare before? According to him, this is because children with an intellectual disability usually lived in institutions. There, it did not matter whether they had a diagnosis of intellectual disability or autism. At a certain point in history, parents started to take care of these children at home, and something shifted in the locus of expertise. Expertise used to be solely attributed to the child psychiatrist. Now, parents are the experts regarding their child. Eyal looks at expertise (and diagnosis) through the lens of Actor-Network Theory, as Bruno Latour and others have devised and applied it. Expertise is a network that joins professional actors, and clients and their parents together with (diagnostic) instruments and institutions. These actors work together to create and maintain a specific phenomenon: in this case, the rise of diagnoses. Parents, now they had their child at home, went looking for professionals and therapists who

14 Gil Eyal, 'For a Sociology of Expertise: The Social Origins of the Autism Epidemic', *American Journal of Sociology*, 118:4 (2013), 863–907, <https://doi.org/10.1086/668448>

15 *The Autism Matrix: The Social Origins of the Autism Epidemic*, ed. by Gil Eyal (Cambridge, UK ; Malden, MA: Polity Press, 2010).

could help them raise their child, and, while raising them, they made use of their own experiences and expertise.

For example, in *Applied Behavioural Analysis (ABA)*, a therapy based on behaviourist principles (praise and, in the earlier versions, punishment), parents were actively enrolled as therapists for their children. The therapy was so time intensive that there was no other possibility. Eyal compares this evolution with the diagnosis of childhood schizophrenia: in the sixties, this diagnosis was also on the rise. However, the prescribed treatment was a six-month stay in the hospital, together with electroshock therapy. It is understandable that this kind of therapy was not popular with parents (and probably with their children). It was also not very efficient. This may have led to the fact that ultimately the diagnosis of schizophrenia became less and less popular. Behavioural therapies developed for autism likewise have not proven their effectiveness even today, and many autistic people consider them abusive. Nevertheless, for many parents, these therapies were an acceptable and understandable way to help their children, and they at least seemed practical.

Moreover, parents felt that they did not just impose the treatment on their children. They worked together with the child to improve the challenges that the family were experiencing. This might explain why parents more readily accept autism as a diagnosis. Furthermore, Eyal mentions the rise of self-advocacy: the stories of autistic adults who can talk knowledgeably about their own functioning, such as Temple Grandin. Because these adults became known to the general public, people could see autism as a different way of being, with which it is possible to live a fulfilling life. Eyal suggests that such examples of self-reliant adults have contributed to the fact that parents chose autism above so-called mental retardation as a diagnosis.

Shifting Autism

Maija Nadesan and Gil Eyal have tried to explain the birth and the expansion of autism as a diagnostic category. On the one hand, a different view of childhood was dawning. On the other hand, relations between parents and professionals were changing. However, we can ask ourselves whether, throughout the history of the concept of autism,

we are talking about the same phenomenon. Berend Verhoeff, a Dutch psychiatrist and philosopher, investigates this question in several publications.¹⁶ In 'Autism in Flux: a History of the Concept from Leo Kanner to DSM-5',¹⁷ he describes that the concept of autism as something that has expanded throughout history, but that fundamentally can be brought back to autism as described by Kanner and Asperger, is not correct. The idea of autism as a continuous phenomenon results from a rewriting of history by autism professionals. In research as well as in diagnostic practice, Verhoeff states, we often assume that autism is a natural essence that we can discover: the more biomedical research we do, the closer we will come to the truth of autism. He ascribes the idea of a discoverable essence of autism to the fact that autism professionals always interpret the history of autism in the light of that one essence.

Verhoeff suggests, however, that the diagnosis has not expanded, but that we are now talking about a different phenomenon from the one in Kanner's time. Kanner talks about extreme autistic aloneness. This may not be the same as experiencing challenges in social functioning or communication. In the first twenty years after Kanner's first paper about autism, his definition persisted: autistic children were aloof, extremely alone and insistent on sameness. However, later on, under the influence of developments in cognitive sciences and the idea that language is a code, autism came to be considered more and more as a communication problem. Autistic people had difficulties understanding the symbolism of language. Under Lorna Wing's influence in the eighties, issues with social interaction came to the foreground again. However, these issues were not the same as Kanner's autistic aloneness but referred to challenges in understanding the unwritten laws of social interaction. According to Verhoeff, these are two different things. It is probable, Verhoeff states, that we cannot talk about autism as a condition about which we gradually learn more, but about a shift in what we mean by

16 Berend Verhoeff, 'The autism puzzle: challenging a mechanistic model on conceptual and historical grounds,' *Philos Ethics Humanit Med*, 8:17 (2013), <https://doi.org/10.1186/1747-5341-8-17>; Berend Verhoeff, 'Fundamental Challenges for Autism Research: The Science-Practice Gap, Demarcating Autism and the Unsuccessful Search for the Neurobiological Basis of Autism', *Medicine, Health Care, and Philosophy*, 18:3 (2015), 443–47, <https://doi.org/10.1007/s11019-015-9636-7>

17 Berend Verhoeff, 'Autism in Flux: A History of the Concept from Leo Kanner to DSM-5', *History of Psychiatry*, 24:4 (2013), 442–58, <https://doi.org/10.1177/0957154X13500584>

autism. The children that Kanner described may have had a different disorder from those who receive this diagnosis today.

Abandoning the Label

How should we respond to the idea that autism as a phenomenon is dependent on time and place, and that it may not refer to a single biological essence that we can discover if we look hard enough? Autism researcher Lynn Waterhouse suggests that we should stop using 'autism' as a concept in research: autism is a description of two symptoms that happen to occur together, but that do not correspond to an underlying biological cause that we can research. Research that tries to find the neurological, genetic or cognitive explanation is hence doomed to fail.¹⁸ Does this mean that it does not make sense anymore to use autism as a diagnostic label? Maybe we have to look for something that approaches the underlying biological truth more closely, and start using that in the clinic. Alternatively, perhaps we should stop labelling children with disorders such as autism. The British psychiatrist Sami Timimi thinks so. Together with Neil Gardner and Brian McCabe, two adults who rejected their autism or Asperger syndrome diagnoses, he wrote *The Myth of Autism: Medicalising Men's and Boys' Social and Emotional Competence*.¹⁹ In this book, the authors argue that we should abandon the concept of autism, as it is not based on scientific fact. In the paper 'Children's Mental Health: Time to Stop Using Psychiatric Diagnoses',²⁰ he follows the same line. There is no proof of a biological cause of autism, and the effectiveness of existing therapies is not proven either. On the contrary, labelling leads to stigmatisation and medicalisation. We should no longer try to diagnose children with labels that are not supported by scientific proof. We have to engage in a different form of clinical practice,

18 Lynn Waterhouse, Lynn Eric London, and Christopher Gillberg, 'ASD Validity', *Review Journal of Autism and Developmental Disorders* (2016), 1–28; Lynn Waterhouse, *Rethinking Autism: Variation and Complexity* (Cambridge: Academic Press, 2013).

19 Sami Timimi, Neil Gardner, and Brian McCabe, *The Myth of Autism: Medicalising Men's and Boys' Social and Emotional Competence* (London: Macmillan Education UK, 2010).

20 Sami Timimi, 'Children's Mental Health: Time to Stop Using Psychiatric Diagnosis', *European Journal of Psychotherapy & Counselling*, 17:4 (2015), 342–58, <https://doi.org/10.1080/13642537.2015.1094500>

one that puts the experiences and feedback of clients at the centre and looks at them in their specific contexts.

This chapter has explored how autism as a phenomenon in the clinic arose over the last century. Although the kinds of people we now call autistic may always have existed, they have been given this specific diagnosis only recently. Moreover, autism is a biologically heterogeneous condition. It may be impossible to find one specific biological cause. This has led scholars such as Sami Timimi to reject DSM diagnoses such as autism in the clinic. They argue that there is no reason to keep diagnoses that can lead to stigma and have no underlying biological essence.

Nevertheless, many adults with a recent diagnosis of autism claim that this diagnosis helps them, gives them insight into their everyday functioning and allows them finally to understand themselves. Autism is real as a shared experience for autistic adults and for parents and psychiatrists. We can concede that the phenotype of autism is heterogeneous, perhaps even on a biological level, but that it is at the same time recognizable. Moreover, the concept of autism creates a common language that is understandable and recognizable for those diagnosed and for those in their environment. We could also consider autism as a disability, one that is not straightforwardly associated with lesser wellbeing but that is an integral part of one's identity. In the next chapter, we will explore concepts of disability and suggest how these can accommodate diverse experiences.