Kristien Hens succeeds in weaving together experiential expertise of both people with autism and their parents, scientific insights and ethics, and does so with great passion and affection for people with autism (with or without mental or other disabilities). In this book she not only asks pertinent questions, but also critically examines established claims that fail to take into account the criticism and experiences of people with autism.

Sam Peeters, author of *Autistisch Gelukkig* and *Gedurfde vragen*; blog @ Tistje.com

What does it mean to say that someone is autistic? *Dynamics of Autism* explores this question and many more. Kristien Hens conducts a thoughtful, wide-ranging examination of psychiatric, biological, and philosophical perspectives on autism, as well as its meanings to those who experience it, diagnose it, and research it. Hens delves into the history of autism to inform a contemporary ethical analysis of the models we use to understand autism and explores the various impacts of a diagnosis on autistic people and their families, the relevance of disability studies, the need to include autistic people fully in discussions about (and research on) autism, and the significance of epigenetics to future work on autism.

Rich, accessible, and multi-layered, this essential reading for philosophers, educational scientists, and psychologists who are interested in philosophical-ethical questions related to autism, but it also has much to offer to teachers, allied health professionals, and autistic people themselves.

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Cover Design by Anna Gaëlle.
In February 2020, three doctors stood trial for performing euthanasia in 2017 on Tine Nys, a thirty-eight-year-old woman with severe mental illness. Two months before her death, she had been diagnosed with autism. For the purposes of my account, it is irrelevant whether one approves of euthanasia for unbearable mental suffering, which is, in principle, legal in Belgium. The trial, the media, and the public reactions can shed some light on how autism has many meanings that we cannot merely reduce to one single meaning. For some commentators, many of them psychiatrists, it was bad practice to allow euthanasia to be performed a mere two months after the diagnosis. A psychiatric diagnosis, they said, is meant to provide a clinical image of a person’s (dys)functioning, and as such, it is a starting point for clinical care. Two months is far too short to be able to assess the effectiveness of diagnosis and treatment. Others suggested that it is precisely this diagnosis that gave weight to the claim that Tine was suffering incurably and unbearably. Autism is, after all, a lifelong and incurable disorder, they argued. Still others, often parents of autistic children and autistic adults, took issue with the automatic link between autism and suffering. For them, autism is perhaps indeed something that one has from birth and until death, but it is by no means intrinsically and automatically linked with suffering and a worse life. All these different conceptions of autism: from a clinical presentation, a lifelong disorder to a neutral neurological difference, exist simultaneously. Nevertheless, the case of Tine Nys shows us that how we conceive of autism can have far-reaching normative consequences.

In this chapter, I shall investigate how at least three meanings of autism have existed from its inception as a concept and a term: autism as a (child) psychiatric disorder, autism as an innate and lifelong character trait, and autism as a developmental phenomenon. To do
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so, I will return to what can be considered the original writings about autism: the English text from 1943 by Leo Kanner (1894–1981), ‘Autistic Disturbances of Affective Contact’ and the German article from 1944 by Hans Asperger (1906–1980), ‘Die “Autistischen Psychopathen” im Kindesalter’. Both texts shed valuable light on what autism is and how it is seen today: on the one hand, a familial condition that is innate and probably lifelong, on the other hand, a developmental disorder that child psychiatrists can treat. Kanner’s text anchored the concept of autism in the clinic, research, and the broader public. However, the word autism had already been used to refer to introverted children. For example, historical educational scientist Annemieke Van Drenth describes the work of Sister Gaudia (full name: Ida Frye (1909–2003). In the 1930s, Sister Gaudia was involved in the case of a boy called Siem. She encountered the four-year-old Siem (a pseudonym) at the Paedological Institute in Nijmegen, which she founded. Siem had difficulties maintaining social contact, as well as language difficulties. Sister Gaudia suggested using the word ‘autistic’ to describe Siem’s behaviour. Siem remained at the institute for eight years. After that, he was enrolled at a regular school and eventually took up a job as an accountant. However, for the actual origin of the term autism, we have to go back to the Swiss psychiatrist Eugen Bleuler (1857–1939), who used it to denote a specific symptom of schizophrenia: the withdrawal of reality. In this context, it was primarily used to describe adults.

Leo Kanner has made history as the researcher who gave child psychiatry a jump-start in the United States with his description of autism. The work of the other founding father of current thinking about autism, Hans Asperger, was less well known for several decades, until Lorna Wing (1928–2014) discovered and translated it in the 1970s.

Asperger was subsequently discredited in 2018 because of the discovery of his links to the Nazi regime;\footnote{Herwig Czech, ‘Hans Asperger, National Socialism, and “Race Hygiene” in Nazi-Era Vienna’, \textit{Molecular Autism}, 9 (2018), 29, \url{https://doi.org/10.1186/s13229-018-0208-6}} nonetheless, his work is essential to an understanding of the evolution of the concept of autism. It is worth noting that both Leo Kanner and Hans Asperger may have had the same influence for their conceptualisation of autism. Indeed, historical circumstances may have caused Kanner’s and Asperger’s predecessor, Georg Frankl, and his role in the early history of autism, to be forgotten. In a 2020 article, Filippo Muratori, Sara Calderoni, and Valeria Bizzari describe how Georg Frankl was a senior psychiatrist working in Vienna in the 1930s when Asperger was a postdoctoral researcher.\footnote{Filippo Muratori, Sara Calderoni and Valeria Bizzari, ‘George Frankl: an undervalued voice in the history of autism’, \textit{Eur Child Adolesc Psychiatry} (2020), \url{http://www.doi.org/10.1007/s00787-020-01622-4} (published online ahead of print).} Frankl wrote an unpublished work on autism, in which he attributed the phenomenon to a child’s poor understanding of the emotional content of words. It is very likely that Asperger knew of this work. Moreover, the authors describe how the well-known Russian psychiatrist Grunya Sukhareva had already published a paper on children with schizoid personality disorders in 1926. The description of the children was remarkably similar to the now famous description of autism by Hans Asperger. George Frankl, being Jewish, was forced to emigrate to the United States. It is certain that Leo Kanner knew Frankl and had read his work. Hence, the authors of the article argue, it is not the case that Frankl brought Asperger’s ideas to the United States and to Leo Kanner as it is often believed. Instead, he may well have been the source of these ideas. Below, I will focus on the texts by Kanner and Asperger, because they are the best known in the field, and because they reflect different conceptualisations of autism that are relevant for my account. But the stories of Sister Gaudia, Grunya Sukhareva, and George Frankl should serve as a warning that reading history as a succession of individuals of genius and of founding fathers is wrong: many thinkers contribute to important ideas, and the reasons why some thinkers are installed in the canon cannot merely be attributed to merit. We can only guess how many great thinkers and ideas are forgotten by history because of their gender or because they belonged to a minority.
Kanner’s Autism:
Kick-Starting the Field of Child Psychiatry

Leo Kanner was a psychiatrist of Austrian descent, who founded the department of child psychiatry at the Johns Hopkins Hospital in Baltimore, Maryland, in the 1930s. He thus became the first official child psychiatrist in the United States. The history of autism as a child psychiatric condition starts in 1943 with Kanner’s text, ‘Autistic Disturbances of Affective Contact’, in which he describes eleven children who have one specific characteristic in common:

The outstanding, “pathognomonic,” fundamental disorder is the children’s inability to relate themselves in the ordinary way to people and situations from the beginning of life. Their parents referred to them as having always been “self-sufficient”; “like in a shell”; “happiest when left alone”; “acting as if people weren’t there”; “perfectly oblivious to everything about him”; “giving the impression of silent wisdom”; “failing to develop the usual amount of social awareness”; “acting almost as if hypnotised.” This is not, as in schizophrenic children or adults, a departure from an initially present relationship; it is not a “withdrawal” from formerly existing participation. There is from the start an extreme autisticaloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside.8

Each person interested in autism should read this paper, if only to understand the context in which the discipline of child psychiatry was born. We find many characteristics still associated with autism: the children almost all mix up their pronouns and use ‘you’ rather than ‘I’ when they refer to themselves. Echolalia, repeating the words or sentences of an interlocutor, is mentioned several times. Kanner describes insistence on sameness to stress that these children are averse to change, a characteristic that is still frequently associated with autism today. Furthermore, we read that the children described by Kanner often experience sound and noise as disturbing and too intense. This hypersensitivity to sound is a characteristic that autistic persons often use to describe their experiences, but which has only just been taken up as a diagnostic criterion in DSM-5.

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7 Kanner, ‘Autistic Disturbances of Affective Contact’.
8 Ibid., p. 242.
Kanner wanted to distinguish the phenomenon of infantile autism from childhood schizophrenia. As mentioned before, he did not invent the term autism, but we have to look for its origin in theories about schizophrenia. Kanner, however, introduced a marked difference between what he calls autism and how the term was used in the context of schizophrenia. He suggested that autistic children, unlike children with childhood schizophrenia, do not withdraw from the world but are born with the condition. It is striking how he describes the way that these children, born autistic, in fact gradually come out, from themselves towards the world:

While the schizophrenic tries to solve the problem by stepping out of the world of which he has been a part and with which he has been in touch, our children gradually compromise by extending cautious feelers into a world in which they have been total strangers from the beginning.9

Kanner describes the phenomenon as infantile autism. From this text alone, it is unclear what his prognosis was for the children he examined and what he would call the condition when it manifested in adults. He later described eleven adults that had been under his care as children.10 Some of them had been sent to Devereux schools (schools for special education). Some had overcome some of their previous challenges. About Don, who was first seen by Kanner when he was five years old, Kanner wrote that in a letter from Don’s mother, Don was described as working at a bank and having hobbies at age thirty-eight. Kanner and colleagues later researched how some of the children he had examined in his clinical practice fared once they were adults. He described how these children had learned social behaviour during adolescence and how many would earn degrees and find a job, although often they were loners.11 Although Kanner suggested that these children often come from detached and individualistic families, and although he invented the term ‘refrigerator mother’, a label for mothers of autistic children, whose so-called coldness he considered to be the cause of

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9 Ibid., p. 249.
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their children’s predicament, he did not state anywhere in the original paper that parents cause their children’s autism. He ended his article by stating that autism is an innate disturbance, hence biological, and not a psychological reaction to suboptimal circumstances. It was only later, in the book *The Empty Fortress* (1967), that the psychoanalyst Bruno Bettelheim (1903–1990) made a causal link between autism and distant parents, more specifically mothers. However, eventually Kanner did come to believe, under the influence of psychoanalytic explanations of autism, that there could be psychological as well as biological causes of autism.

Asperger’s Autism: A Lifelong Characteristic

Simultaneously, on the other side of the world, the paediatrician Hans Asperger described a similar pediatric phenomenon in his dissertation ‘Die “Autistischen Psychopathen” im Kindesalter’. In this text, written to obtain the degree of Habilitation, a postdoctoral German academic degree, Asperger described in four extensive case studies his ten-year-long observations of children in Vienna’s pediatric hospital. Comparable to Kanner’s statements, he offered an image of these children as being withdrawn and set apart from others: ‘The autistic is only “himself” (hence the word auto), not a lively part of a bigger organism, not constantly influenced by such an organism, and constantly influencing the greater whole.’

Famously, Asperger describes very bright but odd children, whom he calls little professors. However, in the text itself, Asperger states that the pathology also occurs in children who are less intellectually gifted. Moreover, the level of intelligence influences how well these children

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15 ‘Der Autistische ist nur ‘er Selbst’ (daher das Wort auto), nicht ein lebendiger Teil eines größeren Organismus, von diesem ständig beeinflußt und ständig auf diesen wirkend.’ (p. 9)
can adapt: ‘Now one does not find the autistic character solely with the intellectually gifted, but also with the less gifted, yes even with the very intellectually disabled. That adaptation with the latter is much more difficult is clear.’ Indeed, one of the children from the text, Ernst K., seven years old, is explicitly described as cognitively disabled. For Asperger, the ‘autistic psychopathy’, as he calls the phenomenon, is lifelong and would also impact one’s functioning lifelong. Although the condition is permanent, Asperger also thought that the unique gifts and skills that these children demonstrated also had advantages, as long as they ended up in the right place and the right circumstances. Just like Kanner, Asperger identified that the defining area in which the children struggled was their relationships with others. Through his description of the sometimes tricky and, from time to time, even cruel behaviour exhibited by some, he tells a nuanced story about their emotional lives and also recounts how the children sometimes exhibited deep emotions, such as terrible homesickness. Based on the following quote from his paper, I presume that Asperger would not agree with some present-day descriptions of autistic people which suggest that they do not have empathy:

Given these facts, the question about the emotional lives of these children has become very complicated. We cannot merely understand it as a “poverty of emotions” from a quantitative perspective. Instead, it is a qualitatively different way of being, a disharmony of sentiment, of mental state, full of surprising contradictions by which these children are characterised and which causes their disordered adaptability.

The German term ‘Psychopaten’ that Asperger uses sounds odd to contemporary ears and reminds us of psychopathy. However, Autistischen Psychopathen refers to someone with an ‘autistic personality disorder’. Asperger considered autism in the first place as

16 ‘Nun findet sich der autistische Charakter keineswegs nur bei intellektuell Hochwertigen, sondern auch bei Minderbegabten, ja bei tiefstehend Schwachsinnigen. Daß in diesen letzteren Fällen eine Anpassung noch viel schwerer zu erzielen sein wird, ist klar.’ (p. 31)

17 ‘Angesichts dieser Tatsachen ist uns das Problem der Gefühlsseite dieser Kinder sehr kompliziert geworden. Es ist jedenfalls nicht einfach nach dem Begriff „Gefühlsarmut“ zu verstehen, also nach quantitativen Gesichtspunkten, es ist vielmehr ein qualitatives Anderssein, eine Disharmonie an Gefühl, an Gemüt, oft voll überraschender Widersprüche, wodurch diese Kinder charakterisiert sind, wodurch ihre Anpassungstörung verursacht wird.’ (p. 56)
something innate and permanent, which is part of one’s personality and identity.

The British psychiatrist Lorna Wing rediscovered the work of Asperger: she renamed the phenomenon ‘Asperger syndrome’ in her article from 1981, which offers a reinterpretation of the original text. For Wing, Asperger syndrome is not a personality disorder but a developmental disorder. Since Wing’s rediscovery, people have questioned whether Asperger syndrome is a separate entity from autistic disorder. The primary distinction would be that children with Asperger syndrome do not have a delay in language development. Wing herself proposed a spectrum of disorders with a triad of deficits: in social interaction, communication, and imagination. This triad would form the basis for later descriptions in different versions of the DSM.

Even today, the concepts of Kanner’s autism and Asperger syndrome evoke other images, which might not meet with the complete approval of the authors of the original texts.

Autism’s Past and Present

There is much more to say about the history of autism. For example, I did not elaborate on the psychogenic explanation by Bruno Bettelheim and the spread of the harmful idea of the ‘refrigerator mother’. This idea primarily blamed mothers for their children’s autism and resulted in the institutionalisation of many children. In response to (and reaction against) this idea, a new era dawned, ushered in by people such as Bernard Rimland (1928–2006), a psychologist with an autistic son. In this era, autism was primarily understood as being innate and neurobiological. This shift in understanding autism led to decades of scientific research into the genes and neurology of autism. Rimland,
however, still understood autism as a rare condition, which occurs in children without intellectual disability.

The growth in diagnoses of autism over recent decades is well documented. Many explanations have been given for this, some more plausible than others. Some people argue that the expansion is due to the broadening of diagnostic criteria. Some say that there has been a diagnostic substitution of intellectual disability with autism because people consider the latter to be a less “severe” diagnosis and because there are treatments for autism that are not available for intellectual disability. Some point to environmental pollution, whereas others suggest that our society is very autismogenic: today, there is much more stress on autonomous and social functioning and far less tolerance for those who do not fit in easily. Sebastian Lundström and colleagues have suggested that it is not a question of the greater prevalence of autism traits but of diagnoses of autism.\textsuperscript{21} The reason why such a diagnosis has become more commonplace can be attributed to the fact that doctors are more familiar with the characteristics of autism. However, another explanation may be that society has changed: flexibility and social communication is valued more, which means that people with characteristics of autism stand out more often and experience challenges in their daily functioning.\textsuperscript{22}

For those wanting to understand autism as a phenomenon, it is essential to read the original texts by Kanner and Asperger. A crucial difference between Kanner and Asperger lies in their perspective on the nature of the condition, not the kind of people they described. Kanner suggested in his first text that infantile autism was innate, but whether it was also lifelong was less clear. He described, from a developmental perspective, how these children gradually acquired more social skills. Although, in his follow-up study, Kanner described the adults as unusual, many of them succeeded in finishing their education and established a place in society. Perhaps Kanner considered these adults

\begin{itemize}
\item \textsuperscript{22} Taskforce Autisme, ‘Naar Een Autismevriendelijk Vlaanderen. Aanbevelingen van de Taskforce Autisme in Opdracht van Minister Jo Vandeurzen’, 2016.
\end{itemize}
as autistic still. Nevertheless, as a child psychiatrist, he viewed autism primarily as a disorder of development.

However, for Asperger, autistic characteristics were lifelong characteristics of one’s personality. Both conceptions are still relevant: autism as a developmental condition, of which the course is not fixed, and autism as an innate neurological “difference” with strengths and weaknesses. Of relevance, also, is autism’s origins as firmly associated with the birth of child psychiatry. A diagnosis of autism is, therefore, also a diagnosis of a child psychiatric disorder. But what is a psychiatric diagnosis, and what is its relation with neurological development and with biology more generally? The next chapter will delve deeper into these questions.