Kristi  en Hens succeeds in weaving together experienti  al experti  se of both people with auti  sm and their parents, scienti  fi  c insights and ethics, and does so with great passion and aff  ecti  on for people with auti  sm (with or without mental or other disabiliti  es). In this book she not only asks perti  nent questi  ons, but also critically examines established claims that fail to take into account the criti  cism and experiences of people with auti  sm.

Sam Peeters, author of Auti  sti  c Gelukkig and Gedurfde vragen; blog @ Tistje.com

What does it mean to say that someone is au�  s�  c? Dynamics of Auti  sm explores this ques  on and many more. Kris  ten Hens conducts a thoughtul, wide-ranging examina  on of psychiatric, biological, and philosophical perspec  ves on auti  sm, as well as its meanings to those who experience it, diagnose it, and research it. Hens delves into the history of auti  sm to inform a contemporary ethical analysis of the models we use to understand auti  sm and explores the various impacts of a diagnosis on auti  s�  c people and their families, the relevance of disability studies, the need to include auti  s�  c people fully in discussions about (and research on) auti  sm, and the signifi  cance of epigene  cs to future work on auti  sm.

Rich, accessible, and mul  -layered, this essen  al reading for philosophers, educa  onal scien  sts, and psychologists who are interested in philosophical-ethical ques  ons related to auti  sm, but it also has much to off  er to teachers, allied health professionals, and auti  s�  c people themselves.

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Cover Design by Anna Ga  .
In chapter seven, we encountered Sandra, an autistic woman who experienced how her coworkers treated her differently after she received her diagnosis. She was given a different job that did not involve customer contact and was given a desk in a quiet office without coworkers, where she felt lonely. When we investigate the experiences of the parents of autistic children, we often notice similar dynamics. Child psychiatrist Delphine Jacobs performed an interview study with parents seeking a diagnostic assessment for their young children as part of her PhD. Although the parents thought that such a diagnosis would provide insight into their child’s functioning, they also feared that teachers and other people’s attitudes towards their child would change and that these people would consider their child as completely reduced to the label.\(^1\) Professionals responsible for diagnoses also often talk about the uncertainties they experience regarding the impact of the label on children and adults.\(^2\) Autistic adults, children, and parents of autistic children describe how a diagnostic label can provide insight and a better understanding of challenges. Nevertheless, Sandra’s story and many parents’ fears show that others can look at you differently


when they know that you have a diagnosis. In this chapter, we shall
discuss the impact of classifications on people and the impact of people
on classifications. We will do so with the help of sociologist Erving
Goffman and philosopher of science Ian Hacking.

Stigma and Looping:
The Thoughts of Erving Goffman and Ian Hacking

Many scholars have investigated the phenomenon of stigma that
accompanies being labelled with a psychiatric diagnosis. The impact of
a diagnosis, and hence of classification, has been elaborately described
in labelling theory. Ian Hacking describes labelling theory as follows:
‘[it] asserts that social reality is conditioned, stabilized, or even created
by the labels we apply to people, actions, and communities.’\(^3\)
One of
the most well-known sociologists who has written about labelling
of Spoiled Identity}, he defines stigma as ‘the situation of the individual
who is disqualified from full social acceptance.’\(^4\) The examples he gives
are those of homosexuality, women in prostitution, drug addicts, or
people who have been in a psychiatric institution or belong to a minority
religion. Having a psychiatric label can also lead to stigma.

Such a stigma, according to Goffman, spoils someone’s social
identity: ‘normals’ do not take you seriously anymore. Even benevolent
others or allies have difficulty seeing the person in question as more
than their label, and one has to make an immense effort to encourage
those people to do so again. The person who is labelled is considered
different, expelled, and has to seek connection again. People who are
benevolent towards outsiders may function as go-betweens between
those stigmatised people and ‘ordinary’ people. People with a specific
stigma also have similar learning experiences, a similar moral career.
They start to see themselves in the same way as others see them and
start to interpret past experiences in the same way. They start to behave
like someone with a stigma. The fact that one is seen as different changes

\(^3\) Ian Hacking, \textit{Historical Ontology} (Cambridge, Mass: Harvard University Press,
2004), p.103.

\(^4\) Erving Goffman, \textit{Notes on the Management of Spoiled Identity} (New Jersey: Prentice
Hall, 2009), p i.
one’s self-insight, and the classification to which one belongs becomes an irrevocable part of one’s identity. If you are labelled, you become your label.

A philosopher inspired by the work of Erving Goffman and Michel Foucault, and who has used autism extensively as an example, is Ian Hacking. Throughout his career, he has tried to position himself in his work relative to nominalism on the one hand and realism on the other. He describes this as follows:

A traditional nominalist says that stars (or algae, or justice) have nothing in common with others of their kind except our names for them (“stars”, “algae”, “justice”). The traditional realist, in contrast, finds it amazing that the world could so kindly sort itself into our categories. He protests that there are definite sorts of objects in it, at least stars and algae, which we have painstakingly come to recognize and classify correctly.\(^5\)

In an early paper, ‘Making up People’, that has been reworked and published as part of the book *Historical Ontology*, he suggests a dynamic nominalism:

I believe that this sort of static nominalism is doubly wrong: I think that many categories come from nature, not from the human mind, and I think our categories are not static. A different kind of nominalism — I call it dynamic nominalism — attracts my realist self, spurred on by theories about the making of the homosexual and the heterosexual as kinds of persons or by my observations about official statistics. The claim of dynamic nominalism is not that there was a kind of person who was increasingly to be recognized by bureaucrats or by students of human nature, but rather that a kind of person came into being at the same time as the kind itself was invented.\(^6\)

Hacking tells us that kinds of people started to exist at specific points in history and that they could disappear later on. The hysteric, as she was considered in the nineteenth century, is probably an excellent example of this. Considering what we have investigated in chapter four about the origins of autism in the middle of the previous century, it is not difficult to see why the concept of autism has drawn Hacking’s attention.

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\(^5\) Hacking, *Historical Ontology*, p. 104.

\(^6\) Ibid., p. 106.
How does this dynamic nominalism work? In his chapter ‘The Looping Effects of Human Kinds’, Hacking elaborates on this further. By ‘human kinds’, a term he will abandon later on, he means kinds of people (not individual people): their behaviour, types of emotions, experiences, etc. These kinds are defined and studied in the human sciences. We would like to have exact information about these kinds, but we do not have it. Human kinds are, therefore, different from genes or quarks. These we could call, with American philosopher Willard Quine (1908–2000), natural kinds. However, we might prefer it if human kinds corresponded to natural kinds—for example, it might make some discussions easier if we could map the human kind called ‘woman’ one-on-one with a natural (and biological) kind. However, we have known for a long time that this is not possible. Autism is a human kind: psychologists and psychiatrists study it. It seems that scientific researchers of autism are eager to make sure that it will become a natural kind, but human kinds are not mere natural kinds of which we do not know the cause yet. They are also not necessarily social constructs that we mix up with kinds. As with natural kinds, we try to look for the causes of human kinds, and we try to explain them.

Still, human kinds are different from natural kinds. They are not value-free. People do not wish to be human kinds because they have moral import. Hacking gives the example of ‘child abuser’ as an example of such a human kind to which we do not want to belong. Nevertheless, by offering biological explanations for them, human kinds are often reduced to natural kinds, and people belonging to a certain kind are ‘exculpated’. Think, for example, about genetic explanations for addiction. Hacking’s most notable contribution to understanding human kinds is probably his remark that human kinds are subject to what Hacking calls looping effects. Being classified changes people in the future, but the past of the classified person also becomes reinterpreted. ‘Being classified’ changes how people think about themselves and how they will act. Because classified people change, this will eventually mean that the classification itself will also change. If what we know about a classification changes, this will, in turn, have consequences for people belonging to the classification: the looping will go on and on.

In *The Social Construction of What?* Hacking describes social constructionism: in chapter four (‘Madness: Biological or Constructed?’); he discusses autism to illustrate the effect of classifications. He states that we cannot quickly answer what has an essence and what is construed by language. He uses the words of Hillary Putnam to express that

> [...] a *common* philosophical error of supposing that ‘reality’ must refer to a single super thing, instead of looking at the ways we endlessly renegotiate and are *forced* to renegotiate — our notion of reality as our language and our life develops.

Hacking himself looks for a more nuanced approach to what exists solely in language and what is real. Instead of using human kinds, he uses the term interactive kinds in this chapter, in contrast to things like quarks, which he calls indifferent kinds. The term interactive applies to the people categorised and the classifications, the kinds to which they belong. They interact with what they classify. This can imply that people who belong to a particular classification will start to behave according to the classification’s descriptions. However, we must be aware that classification also occurs in a larger context of institutions and practices. Children with ADHD are, for example, put in a room without much distraction. The classification ‘hyperactive’ not only influences these children because they are aware that they are considered to be so, but also because they are put in an environment for hyperactive children. If these children were not aware of their diagnosis, this diagnosis would still influence their environment and thus their behaviour.

Hacking is very interested in the example of autism, precisely because you could consider it as an interactive and an indifferent kind at the same time. I have already described autism as a striking example of the tension between ‘real’ and ‘a social construct’. For Hacking, autism is undoubtedly also a biological-neurological condition. He states that autistic children are, at first glance, perhaps a problematic example of an interactive kind. Autistic children often have communication challenges, and some may not be aware that they are classified as autistic. Nevertheless, just as with the example of ADHD, the fact that they are put in a specific setting deemed appropriate for autistic children

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influences them. They often receive special education, and when they attend regular classes, from the moment they are diagnosed they are often assigned someone who helps them and suggests appropriate support. The matrix of practices in which the child is put, regardless of whether she is aware of her diagnosis, changes irrevocably, and this will affect the child herself.

Hacking later describes a thought experiment. What if we, at a specific moment, discover pathology $P$, the biological essence of autism. This could be a gene or something in the brain:

How would the discovery of $P$ affect how autistic children and their families conceive of themselves; how would it affect their behaviour? What would be the looping affect [sic] on the stereotype of autistic children? Which children, formerly classified as autistic, would now be excluded, and what would that do to them?  

There is indeed something inherently dangerous in wanting to fix autism within a yet-to-be-discovered biological reality. Some children and adults who were previously considered autistic or who considered themselves to be autistic would probably be excluded from this diagnosis. We can only wonder what that would do to people who have come to see autism as an appropriate way to think about their own functioning. If we were to discover pathology $P$ and pin this down as the essence of autism, we would fundamentally change what autism is now: a diagnosis based on behavioural characteristics, flexible, and hence workable.

In a later article, ‘Kinds of People: Moving Targets,’ Ian Hacking refers again to the example of autism. In this article, Hacking wants to provide a framework about how we should think about the fact that classifications create new kinds of people and about the fact that classifications and those classified are susceptible to the looping effect. He abandons the idea of natural versus human kinds and talks instead about kinds of people. We often assume that kinds of people are predefined categories with fixed characteristics. If we get to know these characteristics better, we can control and adjust them. However, that is not how it works, according to Hacking. Kinds of people are moving targets: we interact with them as we study them, and therefore they change. They are no

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*10* Ibid., p. 121.
longer the same kinds of people as before. This is the looping effect: the science we undertake also creates kinds of people. Human sciences such as psychology and psychiatry study kinds of people. We want to measure and know and hopefully find biological causes. Nevertheless, it is not only by giving kinds of people a classification that dynamics of looping come to exist. The people classified, the experts who do the classification, and the institutions and knowledge about classifications: all of these interact with and contribute to creating kinds of people. Therefore, Hacking’s nominalism is dynamic.

A classification also enables people to think about themselves in a specific historical context. Hacking refers to Foucault’s example of homosexuality. There have always been homosexual acts, but only recently have people started to think about themselves as homosexual, and only recently has homosexuality become a sexual orientation and a way of being. The applicability of this way of thinking to autism is clear. It is only since Kanner and Asperger have started describing certain children as autistic that people have started to see them as autistic, and adults and children have been able to see themselves as autistic.

Furthermore, although there have always been people with what we now see as autistic traits, autism has only recently become a way of being. Moreover, the stories that autistic people tell about their own experiences change how autism is defined. Think about the specific sensory sensibilities of autistic people. For a long time they have not been considered as core symptoms. Since the DSM-5, however, they are included as a diagnostic criterion, probably because of the influence of autistic people themselves. The classification itself has changed by adding a new criterion: the collection of people classified now may not precisely overlap with the collection of people classified in the past.

In his writing, Hacking gives an original description of the relationship between language and reality, between classification and those classified. However, I believe he cannot wholly solve the dialectic between social construct and reality. He talks about biolooping, in which certain interactive and indifferent types interact with one another. Specific ideas about autism, the idea that it is a condition that we should treat with behavioural therapy, for example, will influence people’s brains through this behavioural therapy. Other ideas will have a different influence on the brain. But what happens when classifications change the classified?
Is the distinction between biolooping and classificatory looping useful? Could classificatory looping also change something in the biology of the person classified? Hacking leaves these questions open.

Looping Genomes

Hacking’s dynamic nominalism is an exciting way to reflect on autism. In a fascinating article by Daniel Navon and Gil Eyal, ‘Looping Genomes: Diagnostic Change and the Genetic Makeup of the Autism Population’, both authors describe how knowledge about the genetic origins of a diagnostic category interacts with the kinds of people that people believe fall under the diagnostic category. They demonstrate how the search for a genetic explanation of autism has contributed to the diagnostic expansion of autism. They do this by looking at the number of autism diagnoses in research cohorts that are selected based on genetic mutations. In this way, they seek to demonstrate that, at present, because the diagnostic criteria have changed, genetic mutations that previously did not fall under the diagnosis of autism now do so. It is a dynamic process: genetic findings have caused a shift in diagnostic criteria. People who clinicians and researchers previously considered to have a specific genetic mutation are now considered autistic. For example, people who were previously considered to have Phelan McDermid syndrome increasingly receive a diagnosis of autism. The authors describe four loops that have contributed to the fact that autism has transformed from a rare disorder to a frequent, heritable, and genetic heterogeneous spectrum of communicative and social disorders. They point at the importance of genetisation for the entire process of considering autism more and more as a genetic condition.

The first loop starts with Leo Kanner, who saw similarities between parents and their children. This has led to the fact that scholars primarily see autism as something genetic, especially thanks to Bernard Rimland (the second loop), who opposed psychogenic explanations of autism, and who found in genes the explanation for these intra-familial similarities. Nevertheless, autism being considered a genetic condition

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is also an attractive diagnosis for parents. If something is genetic, parents are not directly responsible for their children’s challenges. It has a destigmatising effect. Twin studies in the seventies formed the third loop, which indeed showed that autism was heritable. Through this, the Broader Autism Phenotype was discovered: people who had autistic traits but did not fulfil all diagnostic criteria. These were often family members of people with a diagnosis. Diagnostic criteria were widened to make autism into a broad spectrum. However, because more people fit the diagnostic criteria, autism became more heterogeneous with respect to the underlying genetics: the number of mutations detected in cohorts of people with a diagnosis rose.

From the 1990s onwards, fundamental research into autism genes took off. This was partly due to parents’ organisations, to whom it was essential that researchers discovered genetic causes of autism. They subsequently found more genetic mutations because these were actively sought after and because the population of diagnosed people became more heterogeneous. Navon and Eyal give the example of Fragile-X. This is a genetic condition that is today associated with autism. However, this has not always been the case: in the early days of research, a diagnosis of autism and Fragile-X were mutually exclusive. Only in DSM-III did it become possible to diagnose intellectual impairment and autism together. Because people could now think of these two as being linked, and because clinicians no longer considered autistic aloneness as a base characteristic of autism but rather spoke in terms of social and communicative problems, autism as a diagnosis could also apply to persons with Fragile-X syndrome. And indeed, children with Fragile-X do sometimes exhibit repetitive behaviour and experience challenges with language development. However, they also have strong social awareness, which we might not have expected in the original children Kanner observed. By linking Fragile-X and autism, the genetic research into both phenomena was connected: researchers could work together on theories about the pathways from genetics to behaviour. The autism community could hope that there would eventually be a biological explanation for autistic behaviour.

Moreover, parents of children with Fragile-X gained access to therapies that were aimed at autistic people. Simultaneously, Fragile-X researchers gained access to research funding that was intended for
research into autism genes. Fragile-X became a biological model for autism. Other examples are Phelan-McDermid syndrome, which is caused by a deletion in chromosome 22. These people have mild to severe cognitive disability and language impairment. Until recently, the syndrome was not associated with autism. Furthermore, because these people were often cognitively challenged, it was argued that — although they might have some autistic traits — it was not meaningful to talk about ‘real’ autism in these cases. In 2008, autism was seen as an adequate diagnosis for people with this syndrome, long after the diagnostic criteria for autism were extended in DSM-IV. This shift is probably due to the example of Fragile-X. If a genetic syndrome is associated with autism, it gives syndrome researchers access to a broad community of autism researchers, with efficient access to research funding for autism research. Moreover, people with family members with Phelan-McDermid were motivated to contribute to autism research. There was something in it for both sides.

One of the most striking examples is Williams syndrome. Until 2000, this syndrome was positioned as the opposite of autism. People with Williams syndrome are hypersocial and have strong communicative skills. However, today, more and more people with Williams syndrome are diagnosed with autism. Diagnosticians interpret their social skills as only superficial: being too social can be seen as a social deficit as well. Besides these examples that Navon and Eyal have described, I think we will see these mechanisms increasingly at work with ADHD and autism. ADHD and autism sometimes occur together, but ADHD is more readily seen as a behavioural problem. Often people with ADHD are very social and communicative. Anecdotal evidence suggests that some psychiatrists look for a more in-depth explanation for ADHD, and, in some cases, they consider ADHD to be an expression of underlying autism. If you have ADHD, you can also be ‘too social’. Autism as a diagnosis may be preferable for some parents: to the outside world, ADHD is still often seen essentially as annoying behaviour; autism is a way of being that is perceived to have good and bad sides. Time will tell if my prediction is correct.

At the beginning of this book, I described how autism, which we conceive of as a neurobiological phenomenon, has acquired different meanings throughout its history. I also suggested that autism is more
than a condition. For many people, it is part of their identity. In this chapter, I have discussed several authors who have investigated these mechanisms. Erving Goffman described the phenomenon of stigma: how a label becomes part of how you and others understand yourself. Ian Hacking has investigated how classifications alter those classified, and how those classified alter the classifications themselves. Gil Eyal and Dan Navon have applied this idea to the association between genetic syndromes and autism. Although the relationship between genes and autism seems straightforward — genes ‘explain’ autism — their paper demonstrates that other mechanisms contribute to classifications and objects of study. Erving Goffman was a sociologist; Ian Hacking is a philosopher of science. If the classification has such a profound effect on people, what kind of ethical implications does this have? We might ask ourselves if we should make these decisions for other people, specifically for young children. How do we weigh the advantages of a diagnosis with the disadvantages of stigma? Perhaps diagnosticians have a duty to communities as a whole and to actively strive to educate the greater public to remove the stigma, so that the association between specific diagnoses and stigma is no longer there. However, even without stigma, having a specific label also changes the ways other people look at and treat those who are classified. It is a life-course-changing event. I will later come back to the question of how we should deal with this. In the next chapter, we will further investigate dynamic conceptions of the relationship between people, between organism and environment, and between language and reality.