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 crici  cally examines established claims that fail to take into account the crici  cism and experiences of people with auti  sm.

Sam Peeters, author of

Dynamics of Auti  sm

explores this ques  on and many more. Krisi  en Hens conducts a though  ul, 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 epigeneti  cs to future work on auti  sm.

Rich, accessible, and muli-layered, this essen  al reading for 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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In April 2018, I led a workshop for educational scientists, psychologists, and child psychiatrists who were autism experts. I started this workshop by lecturing about certain concepts, such as the looping effects of Ian Hacking, and by asking questions related to the ontological status of autism. Subsequently, I interacted with the participants: I asked them how psychiatric diagnoses are different from somatic diagnoses. After that, I presented our phenomenological study with autistic adults. We also discussed some of the ethical questions that participants had sent me beforehand. Such questions included the following: What to do with an adolescent who refuses a diagnosis? Can we force them to take on and accept the diagnosis, as you would if an adolescent refused a diagnosis of diabetes? Who is best to inform a child about her diagnosis—autism professionals or the parents? What if, primarily, the parents want a diagnosis because they are looking for an explanation for specific challenges they face, but the child herself is doing well? A recurring question in many discussions about autism is how to explain the diagnosis. Autism professionals ask themselves how they should respond to the fact that descriptions that represent autism as something inherent in the brain, such as the idea that neurons in autistic brains are hyperconnected, actually help people understand their diagnosis. Such explanations are not completely established as universal scientific facts but help the person who is confronted with specific challenges. Autism is conceived as real if one suspects a biological cause. It means that the person in question is no longer merely unwilling to cooperate, or bothersome. The clinical professionals in the workshop asked me whether it would be acceptable to use such brain analogies, even if they
are just that, analogies. This may imply tweaking the truth a bit in order to give their clients the clarity they seek.

From the literature and bioethical discussions about autism, we know that, as well as these questions clinicians may have, there are other issues regarding autism. Is autism something we should cure or prevent? Can we develop prenatal tests to detect autism in unborn foetuses? Do we have a duty to adapt society so that autistic people can feel at home? Perhaps autism is an invention of language, a social construct, and we should do away with a diagnosis, as some have suggested. We have arrived at the end of this book about the dynamics and ethics of autism. Those who expect a ready-made answer to these clinical and bioethical questions come home empty-handed. Rather than answering ethical questions, we have described different ways we might look at autism. To arrive at such a framework, we had to make a long journey. We saw that autism is a layered and polysemous concept and that it is perhaps senseless to try to bring back autism to a single biological or cognitive explanatory model.

In chapter one, I demonstrated that the ambiguities of the meaning of autism are already present in the descriptions by the two alleged founding fathers of autism, Leo Kanner and Hans Asperger. Leo Kanner described autism as a childhood developmental disorder. In his first paper, he assumed that autism is something innate but that the affected children do evolve after a period of time to have more social contact. Hans Asperger considered autism to be a personality disorder, lifelong, and with positive and negative sides—although in discussions of Asperger syndrome, scholars mostly talk about it being a developmental disorder. Today, people regard autism as an intrinsic property of a person, a certain way of thinking or feeling with which one is born and dies. Autism, or Autism Spectrum Disorder, is also a psychiatric diagnosis that a multidisciplinary team attributes to someone. Besides certain behavioural characteristics, this team determines whether the person suffers from these characteristics or whether they affect daily functioning. Indeed, it is not sufficient to have certain characteristics; these characteristics have to lead to certain types of challenges.

In chapter two, we tackled the question of what psychiatric diagnoses are. We investigated what it means for a phenomenon to be considered a mental disorder. Taking Nomy Arpaly’s paper as a starting point,
I described how it is wrong to think that psychiatric diagnoses are merely somatic diagnoses of which we have yet to discover the cause. Psychiatric diagnoses have content; they are about something. If we neglect that content in favour of mere etiological description, we are making a mistake. We also investigated the extent to which categories in the DSM correspond to real, underlying biological essences. I described how psychiatric diagnoses are collections of behaviours that often co-occur but for which we have not necessarily found a single biological cause. Nevertheless, a definition in the DSM often also leads to reification. Reification is the idea that there must be some biological essence underneath. This does not imply that we can unmask categories such as autism as being unscientific and not real. It still is the case that a diagnosis of autism often corresponds to an experience shared by the clinician and the person diagnosed.

In chapter three, we discussed the main cognitive explanatory models of autism. We tackled the question of how people have tried to explain the behaviours associated with autism. I used one example, that of a deficient Theory of Mind, to demonstrate how scholars in meta-ethics have often used autism to test the validity of certain moral theories. A lesson we drew from this is that we have to test the extent to which explanatory models correspond to the experiences of autistic people. Autistic people have criticized the deficient ToM model because they do often do not recognize themselves in the description. Moreover, sometimes this has engendered the idea that autistic people are less human. Non-autistic people often have similar difficulties with understanding autistic people’s minds. In chapter four, I dealt with sociological explanatory models of autism. We investigated how, in recent decades, the diagnosis of autism has expanded greatly and how this is not merely due to new scientific insights. Some scholars have described the specific circumstances in which the diagnosis of autism has come to exist. For example, they describe how children with an intellectual disability were no longer automatically sent to institutions in the second half of the twentieth century. Subsequently, their parents actively sought solutions and treatments for their children, whom they now raised at home. They often found these solutions in therapies available for autism. The discovery of the Broader Autism Phenotype made it possible for us to identify people exhibiting less
striking autistic features in the context of autism. Moreover, the advent of child psychology and child psychiatry led to children becoming the subjects of psychological measurements and discussions about typical development.

In chapter five, I discussed different models of disability. Is disability, as bioethical discourse often presumes, by definition something we should avoid? Is it merely located in the individual? Certain models of disability, such as the social model, will claim that disability arises from social institutions, behaviours, and practices that make life difficult for people with certain bodily or cognitive characteristics. It is therefore important to change the context rather than cure the individual. However, a model that emphasises institutions and the environment could also neglect the individual experiences of a person with an atypical body or brain. Crip Theory tries to look at the different narratives of disability in a polysemous way and encourages us to take the stories of people with a disability seriously.

Chapter six then asks why it has been the case that researchers have not always taken the stories of autistic people seriously. For a long time, some scholars assumed that autistic people had a diminished sense of self, and therefore researchers did not take their accounts seriously. I analysed this as a form of epistemic injustice. We are doing an injustice to autistic people if we do not listen to their stories, and if we see them as less reliable narrators. I also described here the problems that can arise if preferences about communication differ. Suppose we consider it our moral duty to engage with autistic people. In that case, it is also our moral duty to look for ways to include those who use different communication methods or those who have an intellectual disability. Chapter seven sketched some of the conclusions of the interview study that Raymond Langenberg and I did with adults with a recent diagnosis of autism. We described how autistic people still dynamically interacted with their environment, although people often see them as inflexible. By having conversations and by double-checking their experiences with others, they understood themselves better. In chapter eight, I reflected, by way of interlude, on autism and time, and what it means to have a different sense of time.

In chapter nine, we returned to questions about the nature of psychiatric diagnoses. Using ideas from labelling theory and Ian Hacking’s looping effects, I clarified how diagnostic labels influence
how people look at themselves and how the environment looks at them. Both classified persons and the diagnostic criteria change during this process. The concept of autism and the group classified as autistic people are, therefore, always changing. In chapter ten, I continued to describe dynamic models of biology itself. Based on the previous discussions, I do not consider it desirable to conclude that autism does not exist or that it is purely in someone’s mind. Autistic people share experiences, and these shared experiences are real and give meaning to autism. Moreover, a strict division between mental and somatic phenomena is hard to maintain, and looking at autism as a fundamentally biological condition also has certain advantages. People testify that they feel relieved from blame by a diagnosis, enabling them to let go of their perfectionism. This is also the case for the parents of autistic children. Nevertheless, thinking about a condition as something biological or genetic also has certain disadvantages. People often consider a biological cause to be static and unchangeable, and something one has simply to accept. I use the ideas of Georges Canguilhem to demonstrate that it is also possible to think about biology and pathology more dynamically and interactively. Enactivism achieves this for the human mind. Furthermore, Karen Barad’s new materialism demonstrates that materialism does not necessarily have to be synonymous with reductionism and determinism.

Chapter eleven zoomed in on the relationship between autism and genetics. Since the first descriptions of autism, there has been a tension between autism as something innate and genetic, and autism as psychogenic. The former approach has become dominant in most countries. As a result, there has been a proliferation of genetic studies into the causes of autism. Conceptualising autism as genetic has certain advantages: even more than the diagnostic label alone, the fact that autism is seen as a genetic phenomenon works to relieve people from blame. Because of our prejudices regarding genetics, autism may be considered a problem located in the individual, which must be prevented or cured. In this chapter, I used epigenetics as an example of a more dynamic view of human biology, and I sketched the possibilities of this approach in the context of autism. Such dynamic approaches may lead to the search for simplistic etiological explanations for autism being given less weight. There is more space for considering an individual in her context and at a certain point in her life. The importance of an
individual’s own experience can then become an integral part of clinical care and scientific research. In this way, we can look at autism as a truly epigenetic or developmental phenomenon, which is inherently connected with the contexts and circumstances people encounter on their life path.

Such an approach may help us to tackle specific clinical-ethical dilemmas. Let us go back to the questions that were raised by the participants of the workshop I mentioned above, regarding diagnosis in children and adolescents. Often, clinicians state that it is of the utmost importance that autism is detected early to prevent specific problems later on. Autism is then presented as a reality to be discovered, like diabetes. It is striking that it is often not specified what exactly is discovered, as at a very early age there is often no dysfunctioning. It is often also unclear which problems people want to (or can) prevent. Are we talking about learning how to support the child better? Do we want to encourage their development towards a more typical path, if that is even possible? For many autistic people, the prevention of autism is not a worthwhile goal. They consider their specific way of being to be inextricably linked to their identity. Nevertheless, of course, some children can indeed suffer from specific characteristics that are associated with autism. Preventing suffering seems to be a good aim.

When talking about diagnoses and tests in childhood, we often refer to the child’s right to an open future, a principle that was first laid down by Joel Feinberg, a philosopher of law.¹ Children are becoming gradually more autonomous as they grow older: we should not make decisions that would impair children’s future autonomy unless this has immediate benefits for the child. For example, ethicists often assume that parents do not have the right to know specific genetic facts about their child if that knowledge is not immediately practical. Children should be allowed to decide for themselves what information they want to know and what they do not. Parents can find out about genetic conditions that require preventive intervention from an early age onwards. How does this translate to diagnostics? At first sight, a diagnosis opens up certain opportunities for the child that they would otherwise miss. A diagnosis can improve the relationship between

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parent and child and give parents guidelines on how to raise their child. Still, it may also be that something is taken away from a child by giving a diagnosis: if we interpret autism as a lifelong condition, it means that the child does not have any choice other than to accept autism as an intricate part of her identity. But we have discussed how a psychiatric diagnosis is not only a mere description of a disorder in the individual. Such a diagnosis must actively be incorporated into one’s own identity. Is that something we can decide for the child? What if an adolescent decides not to see herself as autistic anymore? Do we have to force her to accept the diagnosis at all costs?

This is not a plea for or against early diagnosis. We cannot predict the future. I think that a contextual, dynamic approach can offer some relief here. A diagnosis of autism can help parents and their children. It can lead to a better understanding of specific challenges. We must consider these challenges in the specific context and milieu of the individual. Whether a young adolescent who no longer views certain cognitive peculiarities as a limitation should consider herself as autistic or not must be discussed with them at an appropriate time. For some, autism will be an inextricable identity. Others will identify differently. Therefore, it is important to continue talking to clients about their relationship to their challenges and their diagnosis, and not to view diagnosis as a singular event, but as something that can be dynamically renegotiated. I want to refer back to Karl Jaspers here: Jaspers advocated for a phenomenological-hermeneutic approach to psychiatry. This entails an empathic understanding of the other, and requires us to look at problems from different perspectives, including biological perspectives. We should not consider autism as static and deterministic, but we should look at all levels of functioning as dynamic and context-sensitive. If we take autism seriously as a developmental phenomenon, this means acknowledging the many meanings it can have, and appreciating the relevance of the person’s experiences throughout their lifetime, including in relation to the diagnosis itself.