Kristiën 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. Kristiën 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 Gacel.
In the first part of this book, we discussed the different levels of meaning of autism. Autism is a psychiatric diagnosis that is given based on criteria in diagnostic manuals such as the DSM. Autism can be considered a disability and identity. Autism is a phenomenon that is also historical: the diagnosis has come into being in a specific place and time. Simultaneously, autism is also a set of characteristics that some people probably always had, fixed in their biology. Crip Theory offered a vision of disability that made space for polysemous and often shifting meanings. According to this vision, we can think of disability as something corporeal and something that is socially constructed. Labelling theory and Ian Hacking’s dynamic nominalism demonstrate how diagnoses can change a specific diagnosed individual and the group of diagnosed people, and how they can change the diagnosis. This chapter will describe how, in other fields, such as biology, we can use more dynamic concepts. I will use the ideas of doctor and philosopher Georges Canguilhem (1904–1995), who called for a more dynamic conception of pathology as early as the middle of the last century. Then I will explain enactivist approaches of the human mind and their application to autism, before concluding with a short description of new materialism and the ideas of Karen Barad.

Dynamics of Health and Disease:
Georges Canguilhem

It is perhaps not a particularly radical idea that autism should not solely be seen as a problem within the individual, but also always in relation to others. We have, however, already discussed that autism is also seen as one of the more biological psychiatric diagnoses. This confers certain
advantages: the more biologically anchored something is thought to be, the more real it is deemed to be: the person with a diagnosis of autism receives the recognition that the challenges he or she experiences are real, that they are not imaginary, and that they are unavoidable. The biological conception is deculpabilising. People will tolerate particular behaviour more readily from someone diagnosed with autism than from someone without such a diagnosis. A diagnosis that we think about as biological also has the advantage that one is more forgiving about one’s own failures. A disadvantage of such a physical conception of psychiatric diagnosis is that it often leads to reductionism: the person is reduced to their genes. There is not much room for development or their own agency. However, it is possible that the association between biologically fixed and psychological malleable, which is often assumed in many conceptions about autism, is not warranted. I will describe some thinkers who have developed dynamic conceptions of biology and the human mind in what follows.

Georges Canguilhem may be one of the most original thinkers about life and health as dynamic and interactive. He was a medical doctor and philosopher and has gained some fame as Michel Foucault’s tutor. Nevertheless, he deserves some attention himself, as he has a refreshing and modern view of pathologies. Canguilhem has a biological conception of pathology, but argues that illness and pathology have to do with the individual’s experiences of suffering related to their relationship with their environment. With Canguilhem, we return to a discussion introduced in chapter two: what is a disease, and when is something a disease, and to what extent can our intuitions say something about this? We have seen that Christopher Boorse tried to pin this down objectively by referring to the concept of species-typical functioning.¹ Jerome Wakefield thought that psychiatric conditions resulted from an evolutionary function that has gone awry and is now considered disordered.² We asked ourselves to what extent we can offer a naturalistic explanation of the difference between suffering and health. Perhaps calling something a disease is, in the first place, something normative.

Canguilhem approaches this question using empirical data about how organisms function. His most famous work is *The Normal and the Pathological* (1943). He argues that the pathological is not merely a quantitative deviation from the normal situation but a qualitative one: all functions work differently in a pathological condition. He concedes that looking at the pathological as a broken version of the normal has certain advantages: it suggests that we must try to repair the statistically normal by targeted interventions with medication. However, this is not correct. If we want to know what is pathological, we have to look for what is going on in the state of the disease. We cannot merely extrapolate this state from the normal condition:

There is no objective pathology. Structures or behaviours can be objectively described but they cannot be called “pathological” on the strength of some purely objective criterion. Objectively, only varieties or differences can be defined with positive or negative vital values.

Canguilhem gives the example of diabetes: this is not merely the presence of statistically higher glucose, but the cooperation of different factors: the circulatory system, the nervous system, the endocrine system; they all work differently as a reaction to changes in movement or food. We have to look at the pathological as a different kind of ‘normal’, a condition that can stand on its own and where other norms prevail. As a result, the normal state can no longer function as the reference point to see whether something is normal or pathological:

if the normal does not have the rigidity of a fact of collective constraint, but rather the flexibility of a norm which is transformed in its relation to individual conditions, it is clear that the boundary between the normal and the pathological becomes imprecise.

We may wonder, then, what makes something pathological if we cannot deduce it by measurements alone? Here, Canguilhem introduces the concept of biological normativity, a normativity in relation to the adaptation to the environment: it is their relationship that makes them

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6 Ibid., p. 182.
such. Organisms adapt to their environment or try to adapt to their environment to survive in it. Health means being able to dynamically adjust to the current situation, but also to changing situations. Health is therefore the margin of tolerance to change:

Being healthy means being not only normal in a given situation, but also normative in this and other eventual [sic] situations. What characterizes health is the possibility of transcending the norm, which defines the momentary normal, the possibility of tolerating infractions of the habitual normal and instituting new norms in new situations. (…) Health is a margin of tolerance for the inconstancies of the environment.\(^7\)

The norms Canguilhem talks about are biological. They are the adaptations that the individual makes to itself or to its milieu in order to survive. They are, therefore, temporary norms. They can be propulsive if the organism can define new norms and adapt to new circumstances, or repulsive if the organism has to do everything in its power to maintain the current situation. Because of this combination of propulsivity and repulsivity, we consider things to be normal or pathological. An organism is in a dynamic interaction with its environment, and within this interaction, new situations occur that we consider ‘ill’ or ‘healthy’. We consider disease to be a negative biological experience: we perceive ourselves as healthy if our organism is resilient to change in the environment (propulsive). We perceive ourselves as ill if our organism is less resilient to changes (repulsive). Pathology and health are hence systemic properties. It is an individual assessment of the current situation in which one suffers. This does not mean that the pathology is actually ‘in’ the individual. Pathology arises when there is a mismatch between the individual and their environment, and if the individual cannot repair this mismatch by itself. For example, someone with low blood pressure at sea level is healthy when they are in the mountains because they will experience no suffering. Science may explain a specific experience of illness by pointing out where the mismatch lies. But medicine, as it deals with disease and health, operates at the level of experience, not merely at the level of causation.\(^8\)

\(^7\) Ibid.
\(^8\) Anna M. T. Bosman, ‘Disorders Are Reduced Normativity Emerging from the Relationship Between Organisms and Their Environment’, in Parental Responsibility in the Context of Neuroscience and Genetics, International Library of Ethics,
In her paper ‘Disorders Are Reduced Normativity Emerging from the Relationship Between Organisms and Their Environment,’ Anna Bosman applies Canguilhem’s ideas to psychiatric illness. She starts her paper by explaining what a correct measurement is, referring here to an article about validity by Denny Borsboom and colleagues. Measuring temperature is, for example, proper if the measurement denotes a change in kinetic energy in the environment. But what does this mean for psychological tests such as IQ tests or ADOS-2 that try to measure autistic traits? Firstly, we have to know what is measured. We have already discussed at length that this is not entirely clear in the case of autism. It is not hard to understand that it is probably also difficult in the case of intelligence. Firstly, then, we need a theory of what autism is.

Nevertheless, even if we take a simple view about, for example, autism or intelligence, Bosman states that we still have a problem. How can we decide whether something is too high or too low? How can we decide in psychiatry when phenomena deviate from the standard to such a degree that they become disorders? If we talk about temperature, this always happens in a specific situation: fifty degrees Celsius is too hot for your bath but too cold to cook potatoes. In IQ tests, the norms are already built in: below a certain point (seventy), it is assumed that you cannot easily take part in general education. With a high ADOS score, we believe that the person in question will experience some difficulties in social situations. The person is then considered ‘not normal’ in that respect.

Statistics cannot help us to decide at which point someone is objectively too intelligent or insufficiently intelligent. It is crucial here to return to Canguilhem’s idea: a healthy organism is an organism that can adapt itself dynamically and with a certain freedom to the environment, and that can adjust the milieu to its norms. Pathology means not being able to adapt and not being able to tolerate change. It is perhaps tempting to link this to the idea that autistic people cannot tolerate change and are intrinsically pathological. However, such

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Law, and the New Medicine (Cham: Springer, 2017), pp. 35–54, https://doi.org/10.1007/978-3-319-42834-5_3

9 Bosman, ‘Disorders Are Reduced Normativity’, pp. 35–54.

an argument goes against the views of Canguilhem, who explicitly considered pathology and health in relation to the environment. Hence, an autistic person who does not tolerate change very well is perfectly healthy in a predictable environment. Someone with ADHD is perfectly healthy in an environment in which they do not have to sit still. Healthy organisms are also organisms that can create new norms and adapt their environment to their own needs. Someone susceptible to sensory stimuli is healthy in an environment where they can shut down these stimuli. Children having difficulties sitting still are perfectly healthy if they can control when they can sit still and when they need to stand up or move. Being introverted is only pathological in a classroom where a teacher expects you to talk every morning. Therefore, medical professionals must listen to a patient’s experiences of suffering in his or her environment rather than simply examining the physical condition of the individual. A doctor, according to Canguilhem, should first and foremost take care of the suffering person.

Enactivist Approaches to Autism

Anna Bosman describes Canguilhem as a precursor of complex adaptive systems thinking. Complex adaptive systems are systems such as organisms, immune systems, brains, and insect colonies: they can learn and adapt and are emergent: we cannot reduce them to their parts. In *Mind in Life: Biology, Phenomenology, and the Sciences of Mind*, Evan Thompson describes an ‘enactive’ approach to the mind.\(^{11}\) In such a system, the human mind emerges from processes that organise themselves and connect the brain, body, and environment on different levels. A human being is just like other living creatures, and their parts are a self-determining system that creates a dynamic relationship to the environment, creating and maintaining its own identity. In such ‘autopoiesis’ the embodied self appears, and together with it the world with which it interacts. This process of autopoiesis is a process of sense-making, giving meaning to oneself and the world. Furthermore, this sense-making is ‘enaction’: it is oriented to and subject to the environment. This approach explicitly opposes the idea

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of human beings as atomistic and isolated, against the idea of brains as computers and genes as blueprints. Our consciousness is embodied and exists in relation to the environment. This creates and is created in a dynamic process. Suppose we assume that life and consciousness are indeed dynamic processes that generate meaning and receive meaning. In that case, we can also understand the importance of phenomenology, studying experiences and sense-making, if we want to study the human mind.\textsuperscript{12}

Hanne De Jaegher has applied this line of thinking to autism in her paper ‘Embodiment and Sense-Making in Autism’.\textsuperscript{13} According to this approach, embodiment, experience, and social interaction are the key to understanding autism. The approach is also comprehensive; she tries to bring together senso-motoric, cognitive, sensory, and affective aspects of autism in a framework. This approach aims to build bridges between autistic people and their environment and ameliorate their quality of life. She refers to research that does not consider autism solely as a social and communicative challenge. She also defines autism as a different way of perceiving and moving. In this way, she wants to put the experience of autistic people at the centre of her work, and to investigate how autistic people create sense in the world.

She talks about participatory sense-making: individual sense-making is influenced by coordination with other individuals. By aligning our movements, emotions, and interactions with others, and by being thus coupled, we are part of each other’s sense-making. We are in sync. Think about musicians who automatically synchronize and coordinate their play. The interaction itself makes sense-making possible. We can then see autism as a difference in embodiment. Autistic people sometimes react more slowly or less visibly when viewing a movement. It feels to them that the world goes too fast. Some have suggested that autistic people have heightened perception. Because there are motor and sensory differences in autistic people, this will influence their participatory sense-making. If autistic people react more slowly to certain behaviours than their non-autistic respondents, it will be more challenging to become in


sync. However, they can acquire a rhythm of participatory sense-making with other autistic people. This allows us to understand that certain autistic behaviours, for example, repetitive behaviours such as flapping hands, which in the context of autism are often called stimming, are part of the way autistic people generate meaning. Echolalia, repeating another person’s expressions, can be a way to maintain oneself as an autonomous individual in a conversation.

This approach to autism also has ethical consequences. Rather than considering specific behaviour to be disturbing or abnormal, we have to assume that it has a meaning for the person in question and that we have to try to grasp this meaning. The use of music can, for example, enable autistic children and their non-autistic respondents to find the right rhythm in social interaction and communication. In any case, De Jaegher ends by saying: ‘Ethically, the point forward is not one of laissez-faire. On the contrary, it is one that starts from also taking the perspective and subjectivity of autistic people themselves seriously, in a principled, coherent, and comprehensive way. It is then that we can expect to be able to build bridges that are well-informed by both autistic and non-autistic experience.’

Karen Barad and New Materialism

Dynamic and enactivist models of life and mind offer us the opportunity to look differently at autism. If we take them seriously, we are no longer talking about autistic people as individuals with fundamental shortcomings in their genes or the software or hardware of their brain. On the one hand, this allows us to conceive of autism as a phenomenon that appears in interaction with a given context, as a meaningful reaction to specific environments. On the other hand, it also provides us with a guideline for sensible research. The experiences of autistic people become equally important to those approaches as those of non-autistic people. However, looking dynamically at a phenomenon that we have long considered static also has ethical consequences. I shall come back to this later.

One thinker who views ontology, epistemology, and ethics as inextricably intertwined is Karen Barad. She is a professor in feminist

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studies, philosophy, and history of consciousness at the University of California in Santa Cruz and one of the most well-known theoreticians of new materialism. New materialism is a line of thought in a philosophy that tries to transcend the dichotomy between language and reality. This dichotomy is not solved by more traditional materialist approaches nor by poststructuralist methods. The approach is interdisciplinary and has affinities with gender studies, disability studies, and environmental studies, and it reconceptualises nature and matter as dynamic and agentic. Barad is a physicist by training and has a PhD in quantum physics. In her book *Meeting the Universe Halfway* (2007), she describes one of the starting points of new materialism. New materialists do not continue to wrestle with nominalism and essentialism, with social constructionism and biological realness. Instead, they state that everything is matter: matter is what matters. There is no difference between representation and underlying matter. However, contrary to more traditional forms of materialism, this vision does not lead to naive reductionism or determinism.

Barad developed her ideas based on her reading of Niels Bohr’s interpretation of quantum theory and states that ‘quantum theory leads us out of the morass that takes absolutism and relativism to be the only two possibilities’. The uncertainty principle states that particles may have a locality and momentum, but we cannot know them. Barad says that for Bohr, it is more than that; it is uncertainty and indeterminacy. Particles do not have momentum and location simultaneously, and the fact that we cannot perceive these characteristics simultaneously is not only the result of our observation. The act of knowing itself will determine one of the features (location/momentum). There is, besides an epistemic uncertainty, also an ontological indeterminacy. There is no original object with inaccessible characteristics, only phenomena. Furthermore, these phenomena are continuously produced at the quantum level and the macro level. It is, according to Barad, absurd to think that the quantum world is ruled by other physical laws than our

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17 Barad, *Meeting the Universe Halfway*, p. 18.
visible world. She suggests because these ideas come from quantum physics does not mean that they do not apply to our world.

With our practices in our daily lives, we can make things real, and we produce bodies and meanings: matter comes to matter. Differences and categories come into existence by the daily practice in which we use them. By labelling someone autistic, we also create the autistic person, and this has always been the case. However, contrary to Bohr and later quantum physicists, who have sometimes assigned a special status to the human mind, Barad is no strict humanist. In this process of creating differences and meanings, the human being has no special status. Barad considers herself to be a posthumanist, not in the sense of transhumanist, but in the sense that people are not exceptional. Human beings are also emerging phenomena of the world, a world that is continuously becoming. We are part of the nature we try to understand. She uses the term agential realism. This is realism, not in the sense that words and things map one-on-one, but as an explanation of how discursive practices are linked to material phenomena. She states that ‘practices of knowing are specific material entanglements that participate in reconfiguring the world.’ For her, theoretical concepts are specific physical arrangements. If we refer back to Hacking’s description of looping effects, we can understand this: by mattering (which gives meaning to something), we create boundaries and realise phenomena. Barad transcends Hacking’s distinction between human kind and natural kind: all phenomena are materialist and dynamic, always becoming through intra-action with one another. Barad uses the term intra-action rather than interaction. With this term, she tries to explain that pairs such as subject/object, thing/word, ontology/epistemology are not independent because they act upon each other from the beginning. They bring each other into being in and through the intra-actions between and inside of the action.

We bring into being the autistic child or the autistic adult through diagnosis, and through this, the other path (the future without a diagnosis) is closed off. It is not merely a name or a description that we give to someone. For Barad, it is also intrinsically an ethical act: we make realities and close down other possibilities by our practices. We have to account for that. This is ethics situated in praxis. In this regard,

18 Ibid., p. 91.
in their edited volume, *Material Feminisms*, Stacy Alaimo and Susan Hekman say:

A material ethics entails, on the contrary, that we can compare the very real material consequences of ethical positions and draw conclusions from those comparisons. We can, for example, argue that the material consequences of one ethics is more conclusive to human and nonhuman flourishing than that of another. Furthermore, material ethics allows us to shift the focus from ethical principles to ethical practices. Practices are, by nature, *embodied, situated actions*.19

Barad and others leave the discussion of nominalism/representationalism/essentialism behind, favouring a dynamic and not deterministic materialism, which is at the same time normative. This approach seems a valuable way to look at diagnoses as well. It allows us to look at autism simultaneously as a historical and lived experience and as something real. Thus, we can leave behind ethics that one-sidedly uses generally applicable principles, instead favouring ethics embedded in concrete clinical and scientific practice.

In the previous chapter, we explored dynamic approaches on different levels. With the help of George Canguilhem, we described a dynamic and context-sensitive approach to pathology. Something becomes pathological in relation to an environment in which it cannot maintain itself. This leads to the experience of suffering. With the help of Hanne De Jaegher, we explored an enactive approach to the mind in general, and autism in particular: sense-making happens in coordination with others and should not be considered individualistically. With Karen Barad, matter itself becomes dynamic, and the distinction of language versus essence or word versus thing stops making sense. Our words, our praxis matter, even literally. This has profound ethical consequences. With our words and praxis, we enable or disable possible futures. Hence, they require careful consideration. In the next chapter, I will return to what has historically been conceived of as the matter, the static and unmoveable essence of autism: the gene. I will explore how we can also think of genes as dynamic.

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