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 auti  sm? Dynamics of Auti  sm explores this ques  on and many more. Krisi  en Hens conducts a thoughtul, wide-ranging examine 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  sm people and their families, the relevance of disability studies, the need to include auti  sm 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 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  sm people themselves. 

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Cover Design by Anna Ga  .
6. Epistemic Injustice and Language

In previous chapters, I talked about specific models and conceptions of autism. I also discussed the impact of specific approaches on the ethics of autism. For example, it is entirely different to consider autism primarily as a deficit of Theory of Mind and social functioning, rather than attributing the social challenges of autistic people to an overload of sensory experience. Thinking about autism as primarily a genetic condition is different from stating that the characteristics of someone we would consider autistic are only a dysfunction because Western society has narrowed our concept of normality. If we look at autism purely through a biomedical lens, we may consider it to be an individual’s problem that needs to be detected and solved early. If we look at autism through the lens of Crip Theory, we notice that many stories are possible about people with a diagnosis. These stories do not eliminate one another but supplement and challenge each other. The neurodiversity movement gives people a voice and states that autism does not have to be a disorder at all. It can be part of someone’s identity that does not need to be cured or prevented. The neurodiversity movement is a reaction to the often primarily medical discourse of many parents and autism professionals. It demonstrates that it is essential that many behaviours that we might consider as disruptive, non-adaptive or meaningless have a meaning for the autistic person.

Testimony from autistic people can give us a lot of sensitive information. Think about the significance of certain stims. Stims are repetitive movements, such as flapping one’s hands. Autistic people often describe these as a way to deal with stressful situations. They also explain why they have difficulty looking other people in the eyes: they experience eye contact as very intrusive. Such an explanation is
entirely different from stating that autistic people do not understand that eyes are the windows to the soul, as has sometimes been suggested. Nevertheless, autism researchers have long neglected such evidence. In this chapter, I discuss why it took a long time before people considered it to be valuable information. I analyse this as an example of epistemic injustice. I will also elaborate on what it means to incorporate the experiences of those who cannot express themselves very well in words, such as autistic people who do not use verbal language or people with an intellectual disability. I will argue that this does not mean that this testimony should be valued less, but that it is the moral duty of researchers, clinicians, and ethicists to actively search for ways to take seriously evidence that is harder to understand or collect.

A Sense of Self

In chapter three, I discussed what autistic persons often describe as one of the most important or challenging characteristics of autism: a different way of perceiving the world in sensory terms. Noises can be experienced as very loud, and smells can be overwhelming and sometimes even sickening. Some autistic people experience pain less frequently than people without autism. Such different sensory experiences have only been taken up in DSM-5 as diagnostic criteria since 2013.¹ How is it possible that this has been neglected for so long by autism researchers? To explain this, we can perhaps look at explanations given by some autism researchers themselves. One of the big names in the autism world, Uta Frith, describes in her book *Autism: Explaining the Enigma* how autistic people have a deficient sense of self and insight into their own self. ² She makes a distinction between the experiences themselves and being introspectively conscious of these experiences. Becoming conscious of an experience happens, in our brains, at a different moment than the experience itself. The experience itself is thus the first level, while becoming conscious of it is the second. According to this theory, autistic people probably experience the same levels of pain, and hear

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or smell similarly to non-autistic people. However, they find it difficult to represent these experiences to themselves. Autistic people, because of their impaired sense of self, can misconstrue their own experiences. Hence, the argument goes, we should take the personal testimony of autistic people with a grain of salt.  

This idea has engendered many reactions. For example, Roberta Schriber and colleagues have found that, overall, autistic people have different personality types from non-autistic people, but their insights about their own personality are equally adequate.  

A philosophical critique of the idea of a deficient insight in the autistic self comes from Victoria McGeer. In her article ‘Autistic Self-Awareness’, she gives different reasons why this way of thinking is wrong. She argues that autistic people, in their autobiographies, want to make sure that others understand them. They understand that non-autistic people have different experiences and would like to share their own. Moreover, these autobiographies are often very precise and demonstrate that the authors want respect as people. This also sheds a different light on the problematic philosophical assumptions made by Utah Frith. The fact that autistic authors do talk clearly about their so-called misguided interpretation of their underlying perceptions and thoughts presupposes a third level on top of the levels of experience and perception of senses and thoughts, which would necessarily have to function well, as, at this level, the autistic person can talk clearly about their experiences, although the latter have been misinterpreted on the second level. McGeer states that it is perhaps better to assume that people who talk about their sensations do not talk about the perception of these sensations but the sensations themselves, an approach McGeer calls direct expressivist. If this is true, autistic accounts about sensations are precisely that: the expression of atypical sensations, rather than inaccurate expressions of typical sensations. We are best to take such accounts seriously.

Towards an Ethics of Autism

Epistemic Injustice

Can a scientific theory that discredits the accounts of individual people be ethical? I think that not taking the stories of autistic people seriously is a form of epistemic injustice. This is a concept that Miranda Fricker develops in her book, *Epistemic Injustice*. Epistemic injustice is the injustice that is inflicted on someone in their capacity as someone who knows. The person suffering epistemic injustice is not believed because they have a particular social identity.

An example is that many women will recognize that sometimes, when a woman proposes an idea in a meeting, this will be less readily acknowledged than when a man proposes the same idea later. Because we do not have reasons to assume that women propose less promising ideas, this is an injustice. Fricker distinguishes between two types of epistemic injustice: testimonial injustice and hermeneutic injustice. Testimonial injustice refers to the injustice done to an individual when others do not hear her testimony because she has a social role associated with less credibility. Women and people of colour are examples singled out by Fricker, but autistic autobiographers can also be victims of testimonial injustice if we assume that the autobiography cannot be a truthful representation of authentic experiences. That such injustice is dangerous goes without saying. Not only is it fundamentally unjust, but the victims also risk seeing themselves as someone who has less of a right to speak.

Fricker also describes a more structural form of epistemic injustice, hermeneutic injustice. She describes this as: ‘The injustice of having some significant area of one’s social experience obscured from collective understanding owing to structural identity prejudice in the collective hermeneutical resource.’ In her book, she gives an example of a woman in the mid-twentieth century who systematically suffered from sexual intimidation by her boss. Because experiences of such intimidation were not systematically shared, as people did not take women seriously, women felt alone with their experiences. Thus, hermeneutic injustice means that specific experiences of suppressed groups are not available

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in the public domain as an expression of social injustice. This can lead to human beings who belong to this group considering their own experiences as unimportant and marginal.

Moreover, as some of these experiences are crucial for one’s own identity, hermeneutic injustice could lead to individual human beings being unable to develop themselves fully and be who they are or want to be. This form of epistemic injustice seems to apply to autism; for example, if the experiences of autistic people are not part of scientific research into autism. Considering the existence of the neurodiversity movement and the growing corpus of ‘auti-biographies’, this seems to be changing: autistic people are able to define what it is to experience autism more than they were before. It is essential to consider these experiences in research and clinical practice too. Moreover, we must not only consider one version of autistic experience. If we only consider the experiences of those with whom we share a common verbal language, we also do an injustice.

We could also ask ourselves whether the fact that autism as a diagnosis only became generally accessible to adults in recent decades is not an injustice in itself. I described in chapter four how autism as a named phenomenon only recently came about. This is perhaps because, previously, the challenges that autistic people experienced were not perceived as salient, so there was no need to name it. In this respect, speculation that historical figures such as the philosopher Jeremy Bentham may have been autistic make no sense. We cannot know for sure whether Bentham suffered from the fact that he was eccentric. Perhaps he lived in an environment in which that was not, by definition, a drawback. It could also be the case that these historical figures felt that they were different and felt alone in their difference. The fact that in the past — and perhaps also in the present, in countries where a diagnosis is not widely available — shared experiences of being autistic were not available could be considered as hermeneutic injustice.

We can look from two different perspectives at the post-factum diagnosis of historical figures. If the peculiarities and behaviour of, for example, Jeremy Bentham were not problematic in his time and did not cause him suffering, they probably did not need a name. This view

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corresponds to the idea of autism as a clinical diagnosis, a phenomenon that requires intervention and support. Nevertheless, this does not take away from the fact that Bentham and others could have had specific characteristics associated with autism. However, at that time, this was not sufficient to be considered a psychiatric condition. Let us assume that Bentham was aware that he was somewhat atypical and that this caused him suffering. We could state that the absence of the diagnostic category of autism, or even the lack of acknowledgement that certain people are different and should receive support for their specific difference, is a kind of hermeneutic injustice. Fricker herself might call this bad luck: the science about autism that would allow the creation of shared stories was simply not available. Nevertheless, the difference between bad luck and injustice is difficult to draw post factum. When looking at the examples Fricker gives that relate to women, we could play devil’s advocate and suggest that the science to say that women are equally valid human beings just was not there. Fricker states that there has to be social injustice, as in the case of oppressed women, in order to be able to talk about hermeneutic injustice. In the case of the diagnosis of historical figures, it is difficult to know whether social injustice was at play and whether Bentham suffered from the fact that he may have been considered unusual or peculiar by his community.

We arrive here at the fundamental question of who can say something about autism. I have no diagnosis, and although there are more and more autistic autism researchers, they are still a minority. Can I, as a non-diagnosed researcher, say something meaningful about the ethics of autism? Is that in itself not a form of normative violence? If we would oppose feminist ethics that are solely devised by men, perhaps we should have the same reservations about autistic ethics developed by people without a diagnosis. I do not have a straightforward answer to this question, and I feel some discomfort about it. I think it is essential to research autism in a spirit of openness towards, and with input from the autistic community. Autistic researchers are often an essential source of information about autism. This can take the form of an autoethnography, such as in the paper ‘Aut-ors of our Experience’ by Jessica Benham and James Kizer. This essay is a somewhat subversive but simultaneously clarifying and direct source of information.\footnote{Jessica L. Benham and James S. Kizer, ‘Aut-ors of Our Experience: Interrogating Intersections of Autistic Identity’, \textit{Canadian Journal of Disability Studies}, 5.3 (2016), 77–113.}
an autism diagnosis, talk about their experiences as autistic researchers and lecturers in short fragments. A recurrent theme is their attempts to pass as ‘normal’, while at the same time recognising that this was not wholly possible and also perhaps not desirable. It struck me that their experiences as junior lecturers, together with all the insecurities attached to this, was also readily recognizable, even for someone without a diagnosis. In their text, the authors explicitly aim to be disruptive: with the fragmentary layout of the text, using different fonts, they want to create a jarring experience for the reader. In this way, they want to relay the particular and different nature of the autistic experience. My students wondered whether this actually conveyed the message better or whether it would scare readers away. However, such a disruptive approach makes sense, especially if we keep in mind that non-autistic researchers write the vast majority of literature about autism.

Language and Autism

There is something particular to each experience, autistic or not, and although autistic researchers may be better suited to represent autistic experiences correctly, these findings cannot be generalized either. Many autistic people do not use verbal language, for example, but we do need to devise methods to incorporate the experiences of those who do not do so or who have cognitive challenges. Scientific research is primarily language-based, and even research that puts the experiences of autistic people at the centre will often be based on spoken or written communication. Nevertheless, autism is also associated with challenges in communication and language.

The following paragraphs are based on a talk I gave about autism and multilingualism in autumn 2017 in the Dutch town of Sittard. Based on my research into the experiences of adults with an autism diagnosis, I discussed the relationship between autism and language. On the one hand, spoken language is the most prevalent means of communication. However, this is often not how an autistic person prefers to communicate. Communication should be shared between autistic people and non-autistic people, and we should strive to come to a common method of communicating. I applied my ideas to the question of what multilingualism means for autistic people as an illustration:
what can we learn from autistic people themselves, and what does this imply for learning and speaking different languages?

Autism and language have been linked from autism’s conceptualisation as a child psychiatric disorder onwards—the earliest diagnostic instruments mentioned communication challenges. Kanner’s original article describes several children that either used minimal language or used language in a particular way: they changed pronouns. They often repeated words that were said by others, a phenomenon called echolalia. For a long time, diagnosticians distinguished between Asperger syndrome and classic autism by using mastery of language. People with Asperger syndrome have typical language development, although they may experience challenges in understanding what someone intends. People with ‘classic autism’ develop language late or never. The DSM-5 gathers all these phenomena under the name Autism Spectrum Disorder (ASD), and communication challenges can become apparent in different ways. A new classification has also been added: Social (Pragmatic) Communication Disorder (SCD), which includes the social challenges that define ASD, but without the second criterion (limited and repetitive patterns of behaviour and interests and activities). It is a diagnosis that can be made after ASD has been ruled out.

Nevertheless, diagnostic criteria are elaborated in observations of behaviour. Autism is diagnosed based on these observations and on the assessment of whether the behaviour leads to certain problems. According to Laurent Mottron, an autism expert from Canada, there is a link between the specific intelligence of autistic children, who, according to him, have strong visual intelligence, and their use of language. He points out that many autistic children are hyperlexic: their interests in images and written language occur before their interest in oral language.

To better understand how autistic people experience the world, I have interviewed adults with a diagnosis of autism together with Raymond Langenberg, who himself has a diagnosis of Asperger syndrome. Because some people with autism are not comfortable using spoken language, we asked our respondents whether they would like to do these interviews via chat, email or live. We talked about the following:

feeling different and the suffering that sensory overload sometimes causes, the importance of language, and the feeling of having one’s own way of communicating that is not understood or appreciated by others. For example, one participant, Nora, describes how she had communicated with another autistic person via cards and images rather than words. She experienced this way of communicating as much more expressive than merely using spoken words. Nora loves to dance, and dancing allows her to express her deepest feelings. Another respondent, Bas, has found that ways of expressing himself that differ from standard verbal communication are not considered fully valid by therapists. Bas is a musician; he has played music since he was a child and he only plays his own compositions. He also ran a music shop for a while. Music is a natural way for him to express himself, but therapists attributed to him a ‘minimal inner world’ because he could not express that inner world very well in standard language.

In the video In My Language (2007), Mel Baggs (1980–2020) shows strikingly how verbal communication is not the only way to relate to reality. Baggs had been diagnosed with low-functioning autism’ because she did not speak. Via the video, she questions what it means to be ‘low-functioning’. She shows her own language: a more direct way of dealing with reality by humming and feeling. Her method of communicating was not lesser, but different. That human beings are linguistic beings is frequently stated. Often, we automatically assume that others use oral language. However, through our interviews, I wondered why other ways of expression would not be equally valid. We might consider the other means of expression by autistic people as a different language, such as Baggs explicitly did by referring to her ‘own language’.

Nevertheless, communication is always mutual. People who prefer a language that most people do not share, either because they speak a different language or prefer a different way of expressing themselves, have a disadvantage. If we consider language in an extended sense, perhaps autistic children and adults have always been bilingual. During my interviews, something that also struck me is that these autistic adults often wanted to write about their experiences: they kept diaries.

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wrote books, and documented their experiences. There was a great wish to communicate, although not always in the standard way. Autobiographies also demonstrate a different way of being in the world, albeit one that can be communicated. Somewhere in the middle, it must be possible for typical and less typical people to relate to one another.

What does this mean for multilingualism and autism, the subject of the conference at which I gave this presentation? Some autism professionals argue that autistic children may be overburdened by learning another language because they already experience challenges with their mother tongue. Research has demonstrated that there is no proof that this is so: autistic children can be fluent in multiple languages. At the same time, being able to speak multiple languages might improve their executive functioning. It may be the case that autistic adults have always been multilingual in a certain sense. The methods of communicating they prefer are perhaps different from the preferences of their close contacts. They have to translate their natural way of dealing with communication into something more standard. It would be interesting to learn more about what this means for the acquisition of an additional language.

Of course, autism is a heterogeneous phenomenon. There is probably something atypical in the autistic use of language, as this is one of the diagnostic criteria for autism. However, this is hard to pin down to one single cause or to one single way of expression. Laurent Mottron, who is perhaps overly restrictive in applying the term autism to a specific conception of autism—that of visual intelligence—states that we should not force autistic children into using common means of communication. Instead, we should work with their interests and ways of expressing themselves. We can use this approach to communicate with children who do not talk but are interested in reading and visual images from an early age.

Nevertheless, it remains the case that this atypical communication also makes people vulnerable: you become vulnerable if you are unable to express yourself in the same way as the majority, and consequently it is often necessary to have a common language and learn a more widely-used method of communicating. However, if we want to understand the

relationship between language acquisition, communication preference, and autism better, we should probably first gain insight into what it means for autistic people to experience language differently. Together with them, we should look for alternative communication methods if they are uncomfortable with spoken language, and come to a mutual understanding. Although we may be expecting too much from autistic children if we ask them to learn yet another language, it may be an opportunity.

An example of this approach can be found in the movie *Life, Animated* (2016), in which the parents of the autistic main character discover that they can communicate with their son via the dialogue of Disney characters, and, in this way, share a common language. Perhaps some children are very visual thinkers, or like to learn many different languages. There is perhaps no readily available answer to the question of whether multilingualism and autism go well together. We must learn from the child herself. Is she a visual thinker, and what are her interests? What is her preferred way of communication? What can we learn from her?

In this chapter, I have described how not taking the experiences and testimony of autistic people seriously can be considered epistemic injustice. This is relevant to ethics research, but I would contend it is also important for scientific research. Research that tries to explain a behavioural phenomenon linked to a specific experience of the world would do well to incorporate an understanding of this experience. Granted, this may be complicated because some autistic people may have different communication preferences or not use verbal language at all. Nonetheless, this does not make research into people’s experiences less important. It only means that we may have to try harder. In the next chapter, I will put this conclusion into practice and present some of the research that Raymond Langenberg and I did with adults who had received a recent diagnosis of autism.