

Who Owns Asperger's Syndrome?

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On the evening of 15 November 2005, shortly after nine, in the Dutch city of Nijmegen, a man was killed by gunfire. The victim, Louis Sévèke, was shot at close range. There were several witnesses and the police distributed a drawing of a caucasian male, between thirty and forty years of age. Despite the efforts of a team of thirty detectives, the murder case remained unsolved for over a year.

At a moment when the investigation seemed completely stuck, justice announced that it was looking for a person who had tried to contact Sévèke in the weeks before the killing. He seemed to have used an alias: 'Edmund Dantes'. This was obviously a reference to the main character in a novel by Alexandre Dumas *père*, *The Count of Monte Cristo*, published in 1844. In this novel Edmund Dantes lands in jail, innocently, as a result of the betrayal by friends. After a miraculous escape he takes revenge.

In March 2007 38-year-old Marcel T. was arrested in a Barcelona internet-café. The next day he made a full confession. The police found some sort of autobiography/diary in which T. described a series of bank robberies with violence and bomb attacks. This document also contained a hitlist of persons who had wronged him in one way or the other. It became clear that killing Sévèke was motivated by intense feelings of revenge: in the 1990s T. had been removed from the squatter's movement that he and Sévèke had been part of and T. felt that Sévèke was the person responsible for his expulsion.

In July 2007 there was a first hearing in the case against T. It appeared that experts from the Forensic Psychiatric Service (FPS) had established that T. suffered

from Asperger's Syndrome. These psychiatrists also felt that Asperger's Syndrome was causally linked to his crimes, and, therefore, T. could not be held fully accountable. T. fiercely opposed the Asperger diagnosis, and indeed *any* diagnosis of mental disorder. He argued he was completely sane, refused further psychiatric examination, saying something to the effect that he hated the idea of spending the rest of his life discussing his mental state with psychiatrists. Several commentators argued that this would be just the kind of thing a person with Asperger's Syndrome would hate to do. The court's president ruled that T. be subjected to further examination and observation in the Pieter Baan Centre (PBC), the institute responsible for forensic-psychiatric assessments in The Netherlands.

According to the PBC-report, discussed during the final court session, T. did *not* suffer from Asperger's Syndrome. This was not to say that there were no disorders at all, but these were only minor disorders and the report concluded that T. was fully accountable for his crimes. The verdict, ruled by a court that had to deal with contradictory expert reports, was a life sentence. Marcel T. refused to appeal.

Marcel T. was not the first defendant to be associated with Asperger's Syndrome. A few years ago we have seen a more or less public discussion on the question whether Volkert van der G., convicted for the assassination of Pim Fortuyn, suffers from Asperger's Syndrome and since this case there is a steadily growing number of forensic cases linking Asperger's Syndrome to a variety of crimes. A famous example, at least in the Netherlands, is a murder case known as the 'Peanut Butter Murder'. It involved a young woman who became very ill halfway eating her lunch. She was taken to hospital and struggled for a few more hours before she died. Both her parents and her partner were present, the partner showing no emotion at all. No immediate cause of death was found, but in a later investigation it turned out that the peanut butter on the bread she had for lunch, prepared by her partner, contained theobromide. This is a type of poison

only a chemist can lay his hands on, and this focussed attention on the partner of the victim, who was a chemist by profession. He confessed to having poisoned her.

During the preparation of the trial two reports were made by experts in forensic psychiatry. A psychologist concluded that the chemist suffered from PDD-NOS (a slightly different disorder within the autism spectrum); a psychiatrist concluded he had Asperger's Syndrome. It turned out that the future victim had repeatedly raised with her partner her wish to have children. As this wish intensified, the man felt cornered, and finally he became obsessed with the thought that there was only one way out: her disappearance. His lack of overt emotions during the final hours of his partner's life was seen as a consequence of his condition. Both reports claimed that his disorder implied the inability to consider other options. Since both PDD-NOS and Asperger's Syndrome are considered to be irreversible disorders the risk of relapse was deemed high. The man was sentenced to 6 years plus preventive detention.

Cases like these make clear that Asperger's Syndrome has found its place among – and partly at the expense of – forensic-psychiatric diagnoses like paranoid disorder or personality disorders like the psychopath, the sociopath, the narcissist or the borderliner. This has been a relatively recent development: less than ten years ago, a man watching his partner die without any signs of distress, would probably have been diagnosed as a psychopath. Today, lack of emotion or limited empathy has become an indication for a disorder in the autism spectrum.

If we take the broader view, outside the courtroom, we find that the number of Asperger patients – or, perhaps put more carefully – the number of Asperger *diagnoses*, is rising quickly. To mention but a few indications: there are discussions whether the high incidence of Asperger patients in the Eindhoven region could be related to an overrepresentation of parents in technical or scientific professions, working either at Philips or the Technical University. There are discussions on the need for special

education for children diagnosed with Asperger's Syndrome. There are the kinds of diagnoses that turn parents of Asperger children, fathers mostly, retrospectively into Asperger patients. There are posthumous diagnoses indicating that Einstein, Bartók, Wittgenstein and perhaps even Hans Asperger himself, were suffering from Asperger's Syndrome. Among historians of literature there is a controversy on the question whether Jane Austen may have modelled her Mr. Darcy from *Pride and Prejudice* after an Asperger patient in her circle of friends or relatives.

Not all of these debates and discussions have serious consequences, but many have – most of them, in courtrooms, classrooms, mental health care institutions, and so on. And certainly Asperger's Syndrome holds consequences for those so diagnosed, as well as for their parents, children, husbands, spouses, colleagues, teachers, employers. This lends a certain urgency to the question who is in charge of the Asperger diagnosis. Who or what defines the criteria? Who or what is in the position to delineate this label? The question, to summarize, is *who owns the diagnosis of Asperger's Syndrome?*

A first answer could be that Asperger's Syndrome belongs to Asperger. After all, he is the eponymist, he is the one who discovered the syndrome named after him, and clearly he knew what he discovered. If we select this option we will just have to check what exactly it was that Asperger discovered. Hans Asperger (1906-1980), a Viennese paediatrician, described the disorder named after him in his 1944 *Habilitationsschrift*.² For a period of almost ten years Asperger had been observing children that entered the Paediatric Clinic of Vienna University, many of them with severe disorders. About 200 of them, he claimed, shared a disorder he called 'autism'. If one reads Asperger's original publication to find out how he characterized this disorder, one is immediately struck by the fact that he worked within a scientific paradigm that has no connection whatsoever

² H. Asperger, 'Die 'autistischen Psychopathen' im Kindesalter', *Archiv für Psychiatrie und Nervenkrankheiten*, 117 (1944), 76-136.

with today's psychiatric conventions. His report on the new disorder has an introduction in which he describes his thoughts on methodology in paediatrics and child psychiatry. From this introduction – which was left out when Asperger's article appeared in English translation – it is clear that Asperger was influenced by Gestalt psychology. He felt that clinical observation was the art of being sensitive to the Gestalt of the other person: voice, face, body language, intonation, gestures, gaze, expression, diction and so on. He stated that the clinician needs to hear what he called the 'Zusammenklang' of the person under observation. But how to present to your readers such an encompassing notion as this 'Zusammenklang'? This is an element of his methodology that remains largely implicit and is perhaps best characterized as the method of family likeness or family resemblance, articulated, of course, by Wittgenstein, also from Vienna. What Asperger did was to write three psychiatric profiles of boys that belonged to this category or family of 'autism'. These three boys were Fritz V., Harro L. and Ernst K. Fritz V., born in 1933, was admitted for observation at the age of six. His motor development proceeded somewhat more slowly than normal, while his speech was advanced for his age: indeed, he spoke 'like an adult'.³ Fritz was totally unfit for school. He never completed an assignment, and he'd grab things and smash them to bits, or hit the other children with toys, without ever stopping to think about whether he was hurting them. At the clinic, he never entered into an affective relationship with anyone. In addressing adults, he never used the formal *Sie*. For him, everyone was *Du*.

In his case study, Asperger tries to summon up a graphic image of Fritz, as if he invites his readers to join him in the act of clinical observation. Fritz is tall for his age: he slouches and his movements are clumsy. But his facial features are strikingly delicate: Asperger refers to 'fine and aristocratic features'.⁴ His gaze is vacant, travelling swiftly

³ Quoted from the translation by U. Frith: H. Asperger, 'Autistic psychopathy in childhood', U. Frith (ed.), *Autism and Asperger syndrome*, Cambridge 1991, 37-92, 86.

⁴ Asperger, 'Autistic psychopathy', 87.

and absently over people and objects. His voice is thin and high-pitched, with a strange lilting intonation. He speaks slowly, dragging out the words. When he replies, it is seldom an answer to the question. Sometimes he repeats the entire question, or only a word. Fritz has a peculiar relationship with noise: he throws toys, apparently because he likes the sound they make, and sometimes he starts drumming rhythmically on his thigh or the table or a wall, and sometimes another child – as if they are all the same to him. The most paradoxical aspect of his behaviour is that his impulsive actions are invariably so unpleasant, painful, or dangerous that he must know that his behaviour is disagreeable, even though he doesn't appear to be taking any notice of his immediate surroundings. He'll sit there with an absent, sleepy look on his face, and then suddenly jump up and sweep all the teacups from the table or give another child a box on the ears.

This peculiar behaviour also manifests itself during testing. One of the items involves copying a geometric pattern of sticks laid on the table. Fritz barely glances at the example, but lays the sticks down in the correct pattern, and more accurately than the other children in his age group. But with the exception of this example, he is impossible to test. He deliberately falls out of his chair, slaps the teacher on the hand, and gives nonsense answers. When asked what the difference is between glass and wood, he says 'Because the glass is more glassy and the wood is more woody.'⁵ It is only when it comes to figures and arithmetic that he is able to hold his own. He can remember a sequence of six numbers and repeat them, which according to Binet's intelligence test is equivalent to the level of a child of ten. Like almost all children of this type, according to Asperger, Fritz has one specific talent, or *Sonderinteresse*, and that is arithmetic.⁶ He taught himself to count to a hundred and within that range he knows his way around, not only numbers over ten but also fractions. Fritz can ask himself

⁵ Asperger, 'Autistic psychopathy', 89.

⁶ Asperger, 'Autistic psychopathy', 90.

which is larger, one-sixteenth or one-eighteenth, and come up with the right answer. As a joke, someone once asked him what two-thirds of 120 was, and the answer came back in a flash: 80. No wonder the assessments of such children range from genius to mentally retarded.

Asperger explains that while this isolated intellectual skill is intact, Fritz's emotional life is severely disturbed. Even before a 'normal' child – the quotation marks are Asperger's – has any knowledge of words, it learns to obey the look, the gestures and the tone accompanying what the father or mother is saying. It learns how to interpret the facial expressions, body language and voice, via a process which is entirely unconscious. In Fritz's case, it is as if the ability to make contact with others by means of such non-verbal communication is lacking. Conversely, no one can empathize with Fritz. No one knows why he's laughing or hopping around on one foot, why he turns angry, or suddenly starts hitting another child. His feelings are unrelated to the situation, and his mood swings are so abrupt that it is almost impossible to make contact with him. Any show of affection is counterproductive and seems to irritate him.

The case study of Fritz is much longer than can be presented within the compass of this lecture. The second case study, on eight-year-old Harro L., just as aggressive as Fritz and just as clumsy, is considerably shorter, as if Asperger trusts that the prototype is already taking shape. Harro has the same vacant expression, the smile that no one understands, the strange answers: 'Glass is transparent. Wood – if you want to look through it, you have to make a hole.'⁷ His *Sonderinteresse* is doing sums, and he has developed his own systems which are totally different from the conventional methods, so original and yet often so complicated that he ends up making mistakes. Harro is incapable of learning via the normal and much simpler methods. On the ward Harro avoids all contact with the other children in his group. He reads a great deal and when

⁷ Asperger, 'Autistic psychopathy', 99.

he is absorbed in a book, he is oblivious to everything around him. His verbal powers of expression are downright precocious, comparable to that of an adult: he takes pleasure in recounting fantastic stories which go on and on, gradually becoming incoherent.

After Fritz and Harro, the case of seven-year-old Ernst K. conforms to a by now familiar pattern: he cannot abide other children, makes a scene if things are not lying or standing in the same place as he wants or is used to, and he is so clumsy that he has to be helped with the simplest procedures, such as eating and dressing himself. Ernst also does sums according to his own methods. He seems to be looking straight past objects and people. His voice is high and nasal. Like Fritz, he is lanky, with delicate features.

According to Asperger, the differences between Fritz, Harro and Ernst were variations within a common profile. Their voices – to take an example – were often very high or shrill, or by contrast excessively soft or monotonous; in both cases they were unusual enough to invite derisive imitations. Although their special skills and interests were wide-ranging, they were all eccentric. The profile begins to take shape quite early in life, often from the age of about two. As the child grows up, there may be many changes in the expression of the disorder, but it will never go away. When they look at something, their gaze seems to glance off the object, as if they see it only on the periphery of their field of vision: ‘One can never be sure whether their glance goes into the far distance or is turned inwards, just as one never knows what the children are occupied with at a particular moment or what is going on in their minds.’⁸ Their intellectual skills are also different. In ‘normal’ children, intelligence takes shape between two poles: at one end the spontaneous original expressions, at the other end the copying activities, imitation, the learning from others. The latter without the former is empty and mechanical. But the former without the latter is a true handicap: children with this disturbance are incapable of being anything but original, spontaneous and

⁸ Asperger, ‘Autistic psychopathy’, 68-69.

impulsive. They dream up new words that no one understands, design worlds known only to them. The transfer of knowledge via normal learning channels is impossible. The children are totally egocentric. They have no respect whatsoever for others: this is not the reflection of a conscious insolence, but rather a defect in their understanding of other people. They have no sense of social distance: they touch people as they would a piece of furniture. Young or old, acquaintance or strangers – these are not considerations which govern the way they respond to others. Lessons in social mores will have to be explicitly taught. It is only via the intellectual route that these ‘intelligent automata’ are able to internalize behaviour patterns.⁹

Asperger finishes his article with a discussion of the prognosis of these ‘difficult children’, as he calls them with consideration. A great deal depends on the level of their intelligence. Autistic children with sub-normal intelligence have the poorest prospects. Children with a normal or above-normal intelligence have better chances. Once they have chosen a profession, some of them succeed in achieving a remarkably good social integration. In the experience of Asperger, almost all autistic children with a normal intelligence ultimately found a suitable job, often thanks to their prowess in subjects like maths, technology, or chemistry. The one-sidedness, the limited interest, the blinkers – these were qualities eminently suited to such professions. ‘We are convinced, then, that autistic people have their place in the organism of the social community. They fulfil their role well, perhaps better than anyone else could, and we are talking of people who as children had the greatest difficulties and caused untold worries to their care-givers.’¹⁰

⁹ Asperger, ‘Autistic psychopathy’, 58.

¹⁰ Asperger, ‘Autistic psychopathy’, 89-90.

Let's remind ourselves of the courage needed to publish these words in Vienna, 1944.¹¹ Let's remind ourselves also that in Asperger's article there is not a trace of the disorder being connected to crime.

It is clear from his way of presenting his observations that Asperger expected that we, his readers, would form some sort of mental image of the disorder, not as an explicit list of criteria, but more or less as you would recognize someone from a particular family. Each of these three boys is a unique person, yet, as members of a particular psychiatric category they share a profile. Once this profile has been pointed out to you, Asperger claimed, you will recognize it at first sight, as soon as the boy enters, as soon as he starts talking. The sixty densely printed pages of his article are an extremely rich source of observations and reflections. With him, one already finds the idea that the disorder is the result of an extreme type of male intelligence, focussed on facts rather than emotions, more on literalness than the overtones in conversation. It is also a rich source because Asperger makes a serious effort to describe things imponderable in dealing with these children: the emptiness in their gaze, the traits of their faces, the quaint, pedantic choice of words. But this very same sensitivity to the Gestalt of the child typifies Asperger as a representative of a scientific style that is long since gone. What's lacking in his report is the reduction of his observations to a list of specific, verifiable criteria – criteria of inclusion and criteria of exclusion, a list that indicates who suffers from this disorder and who doesn't. The answer to the question who's in charge of Asperger's Syndrome, therefore, is *not*: Hans Asperger.

A second option could be that the criteria are not laid down by the eponymist himself, but by the person *proposing* the eponym who will then have to specify what exactly it is that should be so named. In the case of Asperger's Syndrome this was done by Lorna

¹¹ In the Vienna hospital 'Am Spiegelgrund', some 800 mentally and physically handicapped children died as a result of Nazi experiments.

Wing, a British autism expert. In 1981 she argued that the disorder described by Asperger should have a separate status within the autism spectrum and successfully proposed to label the disorder 'Asperger's Syndrome'.¹² It is only since 1981 that there is such a thing as Asperger's Syndrome. Sadly, Hans Asperger didn't live to see this, he died the year before.

Lorna Wing represented a new generation of scientists. She worked in a methodological style that was radically different from that of Asperger. She too presented case studies, but these were not in the heart of the article (where Asperger had them), but followed the article as an appendix. They were illustrations, rather than constitutive of the new psychiatric category. The focus of her article is an explicit discussion of the classification and differential diagnosis of the syndrome. She separated the disorder from normal variation between individuals in personality, from schizophrenia, obsessive neurosis and in particular from classical autism, the type of disorder that Leo Kanner had described in 1943, one year before Asperger, and that had come to dominate the notion of autism. Wing proposed to apply the label Asperger's Syndrome to a person showing autistic traits, but with preserved grammatically correct use of language and a certain degree of social skills. This moved the syndrome in the direction of a disorder with clearer specifications than in the description by Asperger, even if this clarity came at the expense of an immense reduction in the richness of Asperger's clinical profiles.

Are we to say, then, that the criteria for the application of the Asperger label have been laid down by Lorna Wing and that we will simply have to check her article? Unfortunately, this is not the case. Lorna Wing too was a passing phase in the classification process. This leads us to a third option to consider as an answer to the question who is in charge of Asperger's Syndrome.

¹² L. Wing, 'Asperger's syndrome: a clinical account', *Psychological Medicine*, 11 (1981), 115-129.

Surely an orderly science such as psychiatry, you may think to yourself, will have instruments and institutions to regulate discussions on criteria for classification and labels? Certainly. The most important one is the *Diagnostic and Statistical Manual (DSM)*, issued by the American Psychiatric Association. In ever revised editions it attempts to list inclusive and exclusive criteria for a range of psychiatric and neurological disorders. In 1980 Kanner type autism was included in *DSM-III*. It was only in 1994 that Asperger's Syndrome appeared in *DSM-IV*. For the Asperger diagnosis to apply there have to be severe impairments in the use of nonverbal means of communication, such as eye-to-eye gaze, facial expression or body posture, a lack of spontaneous seeking to share interests and activities, as well as a lack of emotional reciprocity. Indicative of the Asperger diagnosis are also stereotyped patterns of behaviour or interests, such as intense preoccupations, non-functional routines and motor mannerisms. As an excluding criterion there should be no significant delay in language or cognitive development.

Does this point-for-point diagnostic directive nail down unambiguously who suffers from Asperger's Syndrome and who doesn't? Can we say now that *DSM* is in charge of the diagnostic process, or, in a wider sense, the psychiatric community that accepts *DSM* as its diagnostic guide? There are two reasons why this is not the case.

Firstly, the inclusion of both syndromes, Asperger's and Kanner's, has not ended the controversy on the relation between them. The criteria for the diagnosis 'Autistic disorder' overlap those of Asperger's Syndrome. When a child meets six or more of the criteria for autism, the diagnosis will be 'Autistic disorder'. In order to avoid double diagnoses, *DSM* users are instructed to consider the diagnosis Asperger's Syndrome only in those cases where the child meets fewer than six of the autism criteria and, moreover, has no language deficiency. This diagnostic procedure has led to a paradoxical situation: according to a recent analysis, Fritz, Harro and Ernst met so

many criteria for autism that the diagnosis Asperger's Syndrome shouldn't even be considered.¹³ Thus the conclusion would have to be that the children whom Asperger himself described did not have Asperger. Some researchers maintain that this result is proof that there is no essential difference between the two syndromes, while others conclude that the *DSM* is apparently incapable of describing Asperger's Syndrome in the manner intended by Asperger.

The second reason why we shouldn't agree that the *DSM* is in charge of Asperger's Syndrome requires a digression – a rather lengthy digression, I'm afraid – on one of the theories put forward to explain the central defect in this disorder.

In the 1980's the notion that autism is caused by a severe contact disorder gained support from a theory inspired by a combination of developmental psychology and philosophy. It maintained that the core of the defect was the inability to see the world from someone else's perspective. As the British psychologist Simon Baron-Cohen and his colleagues put it in 1985, an autistic has no *theory of mind*, no sense of the inner life of others, possibly because he has no access to his own mental life.¹⁴ In a series of tests, he demonstrated that it is difficult for autistic children to work with mental representations of objects. Ordinary children learn at a young age to distinguish between a real cookie and a remembered, imagined, or promised cookie. Autistic children apparently find it difficult to imagine that an object which is not present in a concrete form, but exists in – say – someone's memory can still influence behaviour. Take this simple experiment. There are two dolls, Sam and Kate, the experimenter says. Now both of them feel like having a cookie, but unfortunately only Sam gets a cookie from his mother, since Kate's mother isn't home. Of course, all this is 'make-

¹³ J.N. Miller & S. Ozonoff, 'Did Asperger's cases have Asperger Disorder? A research note', *Journal of Child Psychology and Psychiatry*, 38 (1997) 2, 247-251.

¹⁴ S. Baron-Cohen, A. J. Leslie & U. Frith, 'Does the autistic child have a "theory of mind"', *Cognition*, 21 (1985), 37-46.

believe': Sam doesn't really get a cookie. Children aged around five and children with Down syndrome feel sorry for Kate because Sam got a cookie and she didn't. The autistic children show no sign of sympathy. Why should they? In their literal world, there are just two dolls, and neither one gets a cookie.

Because of the absence of a theory of mind, autists live in a social world inhabited by individuals with an inaccessible inner world: in other words, they live among people who will never become another 'I', but will always be an external 'he' or 'she'. This implies that children with Asperger's Syndrome will always have difficulties with tasks that require insight in what other persons think, want or know. Many tests from the literature on Asperger's Syndrome focus on dealing with so-called 'false beliefs'. A fifteen-year-old boy, Christopher, took a test at his school for special education. His teacher put a tube of Smarties on his desk and asked him what he thinks is inside. 'Smarties', Christopher said. Then she picked up the tube, opened it and pulled out a little red pencil. She put it back in, closed the tube and asked Christopher: 'If your mummy came in now and we asked her what was inside the Smarties tube, what do you think she would say?' 'A pencil', Christopher said.

Some of you may recognize this scene. It is not from the scientific literature, but from a precious little novel, *The curious incident of the dog in the night-time*, by Mark Haddon.¹⁵ Christopher is the main character of a novel that attempts to give an impression of the inner world of someone who has no sense of the inner world of others. Haddon gave the boy a profile that resembles the Gestalt that Hans Asperger tried to summon up sixty years ago. Christopher has a long history of behavioural problems. Although he is of normal intelligence and in some categories, such as mathematical insight and spatial puzzles, far above normal, he attends a school for children with learning difficulties. On a test measuring the interpretation of emotions on

¹⁵ M. Haddon, *The curious incident of the dog in the night-time*, New York 2003, 116.

the basis of facial expression, he scored very low. He recognized the expressions denoting happiness and sadness, but not those for perplexed or surprise. His inability to 'read' emotions often leads to conflicts with other children. On the playground he tends to stay close to the adults.

His interests are monomaniacal. He knows all the prime numbers up to 7057 and has learned the names of all the countries of the world by heart, together with their capitals. His use of language is literal and concrete. He does not understand metaphors. The same is true of humour. Christopher's behaviour is highly ritualized. He will only eat when the various foods on his plate do not touch each other. Colours have a distinct emotional value: red is good, yellow and brown are bad. He doesn't eat brown food. He wants his surroundings to remain constant: he moves pieces of furniture back into their old position. He does not like to be touched.

It is striking that Christopher describes his own mental processes invariably in mechanical terms. He compares his memory to a video recorder, and the reproduction of facts to the processes *rewind*, *play* and *fast forward*. In new surroundings, where there is too much new information to cope with, he feels like a crashing computer. Christopher shuts out the world around him by putting his hands over his ears, and begins to moan softly. He compares this to shutting down the computer by means of *control-alt-delete*.

At the beginning of the book Christopher is fifteen years, three months and two days old. Christopher imparts this information to a policeman who has been summoned in the middle of the night, and is now squatting next to Christopher, staring at the neighbour's poodle, cruelly impaled on a pitchfork. The novel centres on the efforts to solve this cowardly murder, as experienced and recounted by Christopher.

Reading Haddon's novel, one experiences something which does not occur when reading the Asperger case in the *Casebook* that comes with *DSM-IV*. After ten or twelve

pages, you feel yourself being drawn into Christopher's mind. Another ten pages, and you find yourself in an inner world which is at once bizarre and ordered, exotic and logical, eccentric and straightforward. As the story unfolds, you begin to see the world through his eyes and process information through his brain. One of the paradoxes of this strange book is that you begin to experience the inner life of someone who has no notion of the inner life of others. As a reader, you find yourself slipping into the first-person perspective of someone who sees the world from a third-person perspective. At the end of the book, it is difficult to dispel the feeling that you have just experienced something which is impossible, as if you've caught a glimpse of the dark side of the moon.

This is what creates such an intriguing tension in the description of Christopher. A 'normal' first-person narrator allows the reader access to two worlds at once: the world of outward behaviour and acts, and the world of inner experience. With Christopher part of this latter, private world disappears. In the novel one finds some fine examples of the 'translations' he needs to keep out of trouble in the world of acts now that the world of inner experience is inaccessible. His teacher has explained that when someone shuts his mouth and breathes loudly through his nose, this may mean that he is losing his patience. A few pages later Christopher is being interrogated by a policeman who shows precisely this combination of behaviours. Christopher understands that he has to be careful now. The teacher must also explain to him other people's feelings in reaction to what he says or does. When he tells her that some dogs are smarter than Steve, who needs help with eating and can't even retrieve a stick, the teacher asks Christopher not to say this to Steve's mum.

Anyone enjoying the full command of his senses can, by closing his eyes, try to form an impression of what it means to be blind. It will be a clumsy and no doubt misleading

impression, but it is an impression nevertheless. Someone who has been born blind will not have a clumsy impression of what it means to be able to see, he will have no impression at all, any more than a seeing person would have an impression of what it means to have an extra sense. In the eighteenth century persons with a sensory handicap were discovered as epistemological 'experiments of nature'. In 1749 Diderot wrote his *Lettre sur les aveugles* and in 1754 Condillac devised his thought experiment on a statue gaining ever richer knowledge by opening, one by one, its senses. What does a blind man 'see' of reality? What is his experience of space? What kind of knowledge may a deaf man acquire without access to language?

In our time we seem fascinated by a different category of 'experiments of nature', those of persons in a deviating state of mind. How does a person with manic depression experience his world? What is it like to suffer from schizophrenia? How does it feel to live with delusions? Or with a dense amnesia? The literature that tries to find an answer to these questions has something in common with the eighteenth century literature on sense and knowledge: the authors are themselves in full command of the faculties they take away from their characters. This is a fundamental asymmetry. If Bernlef had suffered from even the earliest signs of Alzheimer's, he wouldn't have been able to write *Hersenschimmen*, his celebrated novel about a character experiencing the first symptoms of Alzheimer's. *Hersenschimmen* is the result of imagining the absence of something that has to be there in the first place.

The same asymmetry characterizes the relationship between someone with and someone without a 'theory of mind'. Mark Haddon has tried to imagine a self that doesn't contain the usual interior of feelings, much less the usual instruments for self-observation. Christopher is a thought experiment. Haddon provides his inner world with little more than a few primary emotions, the emotions he recognized in the facial recognition test, like sad or happy. With these poor instruments Haddon lets him

navigate a world inhabited by people who fine-tune their behaviour to the feelings and expectations of other people, or at least have the ability to do so. Such a world, you will find, empathizing with Christopher, is confusing. You come to understand why he hates lies and fantasies, his world is complicated enough as it is, he has little use for alternative versions of reality.

And so we see Christopher in the classroom and we see Christopher living with his dad, we see how his conversation with the policeman derails and Christopher hits the policeman when he tries to grab him. These are the dozens and dozens of situations and Christopher's reactions to them from which the reader begins to spin, thread for thread, something like insight and empathy. This empathy quickly changes into sympathy and pity, because it gradually turns out that he has been told many a lie, by people who *can* operate with alternative versions of reality – if that suits them better. In this respect, *The curious incident of the dog in the night-time* is also a novel on the defects in non-autistic lives.

Why should we pay this much attention to a boy who is merely a character in a novel? And what has all of this to do with the question who's in charge of Asperger's Syndrome? The answer will lead us to a few peculiarities of classification in general and psychiatric classification in particular. Historian of science and philosopher Ian Hacking has argued that classifications are never in any immediate sense an unambiguous reflection of reality.¹⁶ He favours a more relativistic view in which classifications are the result of interpretations that in different circumstances might have been otherwise, leading to different classifications. This is a view on classification that lends psychiatric classifications a certain leeway. It does *not* mean that there are no disorders in reality; the point is, rather, that symptoms and syndromes, deviations and abnormalities, could have been grouped in completely different classifications. This is an important

¹⁶ I. Hacking, *Rewriting the soul: multiple personality and the sciences of memory*, Princeton 1995.

philosophical point of view, not restricted, incidentally, to psychiatric labels. In 1906 Alois Alzheimer found microscopic abnormalities in the brain of Auguste D., a patient with severe amnesia that had entered his ward a few years earlier. These abnormalities included plaques and tangles. Alzheimer held these abnormalities responsible for the woman's memory disorder. It remained to be seen, Alzheimer thought, whether he had discovered a new disease. Emil Kraepelin, his chief, was more straightforward and proposed to label the memory disorder in combination with plaques and tangles 'Alzheimer's Disease'. Not much later Alzheimer was confronted with a patient that showed the same clinical symptoms of memory loss and after an autopsy also the plaques, but not the tangles. Did this constitute a new disease? Or was it a variant of the first disease? A few years later his colleagues decided to choose the latter option, which is why there exists a 'plaques-only' variant of Alzheimer's Disease. It is important to consider that even in classifications that are ostensibly more clear-cut than Asperger's Syndrome and moreover have a neurological substrate that can be unambiguously demonstrated in microscopic research, it is still a matter of choice to order symptoms under the label Alzheimer.

Perhaps an analogy is helpful. The relation between psychiatric disorders and their labels resembles the signs of the Zodiac. No-one doubts that the stars that combine to form Scorpio really exist; it is equally indisputable that they could have been ordered in different constellations.

Writing on psychiatric classifications, Hacking also identified a mechanism that pertains in particular to diagnoses like Asperger's Syndrome. The crater on the moon that was named after George Sarton hasn't changed because of this. A child that is diagnosed with Asperger does change. Asperger changes something in the life of the child itself, in the life of its parents, in the life of its siblings, its teachers. A label like Asperger carries connotations and consequences, and these, in turn, will influence the

way the child is raised, educated, played with. Hacking called this the *looping effect*: the diagnosis initiates a complicated interaction between the label and the person so labelled. To the person himself, once capable of reflecting on the meaning of the label, on what it stands for, there is now a *relation* to the label, he may – to mention but a few options – decide to live ‘after the label’, to accept what present wisdom decrees to be the limits of his condition. He may also decide that particular elements from the disorder don’t apply to him. He may use the label to explain to others what is wrong with him. He may accept the label and say that he has a mild form of the syndrome. He may find that he has learned to overcome or compensate the challenges of his condition. He may – the options are too numerous to be listed. And these are merely the options for the person so diagnosed. To parents, friends, teachers, roommates, colleagues there is equally a new spectrum of potential relations to the label.

These relations take shape in a world in which psychiatry is not the only force of influence. To someone who has read *The curious incident of the dog in the night-time*, Asperger’s Syndrome is already slightly different and in this sense Mark Haddon is partly in charge of the Asperger label. The same goes for lawyers who appeal to Asperger’s Syndrome in their pleas, or judges who accept or reject this appeal. Or for teachers who tune their lessons to what they have read or heard about Asperger. In this sense Asperger’s Syndrome belongs to each and anyone, because the processes that shape the syndrome have come to be distributed over persons and institutions, literature and film, education and media. Each movie, like *Ben X*, on the life and premature death of a boy suffering from Asperger’s Syndrome, changes something in our ideas of what it means to suffer from this condition. Each book written by parents on what it means to raise a child with Asperger, each course for remedial teaching, every instructional guide for employers’ changes something in the general perception of Asperger’s Syndrome and is, therefore, part and parcel of the looping effect.

But doesn't Asperger's Syndrome belong, first and foremost, to the *persons* so diagnosed? Perhaps the most convincing sources are letters, diaries or autobiographies. In 2006 Daniel Tammet, diagnosed with Asperger's Syndrome, published his autobiography *Born on a blue day*.¹⁷ Its title refers to the colour associations called up by words: in Daniel's synaesthetic mind the initial letter 'w' turns words into blue, including the Wednesday that he was born. He describes the rigid obsessions implied in his disorder, the ritualistic acts and compulsions, the intense fascination with simple movements like a spinning coin, the peculiar preference for lists of facts, like the capitals of the world or the presidents of America, the equally miraculous talent for calculation and the love of prime numbers, all those traits that ever since the work of Hans Asperger have shaped the family likeness of this syndrome. His autobiography is also a tribute to his parents, who managed to raise a baby that cried almost incessantly for over eighteen months, had to deal with a toddler that was extremely to himself and reacted with a tantrum at the slightest change in his surroundings. Later, in school, at a time when precious little was known about Asperger's Syndrome, Daniel ran into trouble on a daily basis. It was only in his twenties that he slowly adjusted.

What is especially touching in his book are the examples of ways of thinking that one ordinarily finds in the professional literature only in the shape of test results. Lacking a 'theory of mind', children with Asperger's Syndrome find it difficult to handle 'pretend' situations, as in the case of the imaginary cookie of Sam and Kate. Daniel Tammet relates a story that was completely incomprehensible to him at the time. It was called 'Stone Soup'. A soldier wanders into a village and asks for food. The greedy villagers provide none and the soldier offers to make 'stone soup'. All he needs are a

¹⁷ D. Tammet, *Born on a blue day. A memoir of Asperger's and an extraordinary mind*, London 2006.

cauldron, water and a stone. Tammet: 'The villagers huddle round as the soldier begins to cook his dish, licking his lips in anticipation. 'Of course, stone soup with cabbage is hard to beat,' says the soldier to himself in a loud voice. One of the villagers approaches and puts one of his cabbages into the pot. Then the soldier says: 'Once I had stonessoup with cabbage and a bit of salt beef and it was fit for a king!' Sure enough, the village butcher brings some salt beef and one by one the other villagers provide potatoes, onions, carrots, mushrooms, and so on until a delicious meal is ready for the entire village. I found the story very puzzling at the time because I had no concept of deception and did not understand that the soldier was pretending to make a soup from a stone in order to trick the villagers into contributing to it. Only many years later did I finally understand what the story was about.'¹⁸

This is a multi-layered passage. It is a convincing demonstration of the difficulties a child with Asperger will have understanding what is going on in other people's minds. But by writing about his difficulty in figuring out the soldier's intention, Daniel Tammet also relates himself to the hypothesis that persons suffering from Asperger's have no 'theory of mind'. We may even say that without such a 'theory of mind', Tammet wouldn't have been able to write about his failure to understand the story as a child, nor about his present interpretation of his earlier lack of understanding. Hacking would be delighted by this instance of the looping effect: a scientific hypothesis on a central defect in the mental functioning of a person with Asperger's explains to Daniel Tammet why he didn't understand the gist of the story at the time, and at the same time he proves with this passage that this is a handicap than can be overcome. In this way, Tammet's autobiography is a clear demonstration of yet a third important notion derived from the work of Hacking: Asperger's Syndrome is an example of a 'fuzzy concept'. The

¹⁸ Tammet, *Born*, 64-65.

very fact that limits may shift as a consequence of looping effects characterizes Asperger's Syndrome as the type of diagnosis with uncertain boundaries.

Ladies and gentlemen, it's time to see what we may conclude from our considerations. The present developments in thinking on Asperger's Syndrome confirm what historical investigation into this syndrome already suggested: its limits are diffuse, they are constantly changing and have done so since the earliest publications by Hans Asperger. In this respect, history of science has a benevolent, relativizing effect: it is simply not true that psychiatry has a golden standard somewhere to separate those who suffer from Asperger's Syndrome from those that don't. The criteria listed in *DSM-IV* are admittedly an attempt to specify such a diagnostic standard, but the acceptance of a standard depends on its actual use and since this actual use varies considerably, one can hardly grant these criteria standard status. To a large degree, Asperger's Syndrome is what is made of it in day to day dealing with this disorder, in the way it is handled in families, in schools, in court rooms.

To be fair, the notion of Asperger's Syndrome as a 'fuzzy concept' has downsides as well. Sometimes decisions have to be taken or verdicts have to be passed that require a yes or no outcome. Should this child receive special education? Is this man accountable for his crime? In cases like these a clear-cut diagnostic protocol is dearly missed. But in different circumstances the diffuseness of limits may be a blessing in disguise. No doubt it is partly by the dedication of his parents and teachers that Daniel Tammet has been able to expand the limits of his condition. In his book he uses metaphors, he makes jokes, he analyzes his inner life – he does all kinds of things a person with Asperger's Syndrome isn't supposed to do. That's the inspiring consequence of limits that aren't nailed down in a standard: they invite patients, parents and teachers to test whether these limits are permanent, whether handicaps can be

compensated, whether the special abilities and talents one so often finds with them may be a key to better social integration. So, who's in charge of Asperger's Syndrome? Many different people and many institutions, no doubt. But most importantly: the persons so diagnosed and their loved ones. They are the ones who may push limits, transforming the disorder in the process.

Let me finish by thanking Ghent University and the members of the Sarton Committee for the honour of inviting me to such a distinguished position as the Sarton Chair for the History of Science. George Sarton specialized in the early history of physics and his work doesn't intersect with my main interests, but I did read his 1947 essay 'The tower of Babel', in which he pleads that international scientific communication should not be narrowed down to *one* lingua franca, i.e. English, but to English *and* three or four main languages, while simultaneously nurturing national languages. I was struck by his sensitivity to the consequences implied by the choice of language. Hardly a minor consequence is a typical historian's concern: choosing English as the exclusive language for publication and education will gradually but inevitably close the access to the knowledge and experience laid down in the past in other languages. A man after my own heart, your Sarton.

I would also like to thank my colleague and friend Jürgen Pieters for his good care and for his Laudatio – which was grossly exaggerated, but enjoyable nevertheless.

Ladies and gentlemen, this is not the first time that we visit the fairest city of Belgium and it will not be the last, but the occasion for *this* visit pleased us very much indeed. Thank you.¹⁹

¹⁹ I would like to express my gratitude to my colleagues Anne Beaulieu and Maarten Derksen, who gave the manuscript of this lecture a thorough reading.