



TOWARDS AN ETHICS OF AUTISM

**A Philosophical
Exploration**

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7. Experiences of Autism

(written with Raymond Langenberg)

It is a form of epistemic injustice to not engage with the experiences of autistic people in scientific research and ethical reflection. A book that claims to research the conditions of possibility of an ethics of autism should pay attention to these experiences. In the last years, the research into autistic experiences has taken a significant leap forward.¹ Autistic researchers wrote books about their own experiences and that of other autistic adults.² For example, the book *Aquamarine Blue 5* describes the experience of autistic students at university.³ There are more and more initiatives in different countries that enable autistic people to have a say in agenda-setting research, such as PARC (Participatory Autism Research Collective) in the United Kingdom and LAVA (Lees-en Adviesgroep Volwassenen met Autisme), a Belgian initiative of autistic people who share input, advice, and priorities with Belgian autism researchers.

What follows is a reflection of my study into adults' experiences with a diagnosis of autism. I conducted this study with Raymond Langenberg, who was diagnosed with Asperger syndrome fifteen years ago. We interviewed twenty-two adults. One of them decided to withdraw from the study for personal reasons. We got approval for the study from the ethics committee of the University of Antwerp, the ethische adviescommissie voor sociale en humane wetenschappen (EA

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- 1 Jaci C. Huws, and Robert S. P. Jones, 'Diagnosis, Disclosure, and Having Autism: An Interpretative Phenomenological Analysis of the Perceptions of Young People with Autism', *Journal of Intellectual & Developmental Disability*, 33 (2008), 99–107.
 - 2 Damian Milton, *A Mismatch of Salience: Explorations of the Nature of Autism from Theory to Practice* (London: Pavillion, 2017).
 - 3 Dawn Prince-Hughes, *Aquamarine Blue 5: Personal Stories of College Students with Autism* (Athens: Ohio University Press, 2002).

SHW). Participants signed a form to demonstrate informed consent and chose a pseudonym that we used in the reports. For our research, we chose to use Interpretative Phenomenological Analysis as the approach.⁴ This method is characterized by an emphasis on idiography, describing and appreciating particular cases and experiences, and on a double hermeneutics: participants themselves give meaning to their experiences. Researchers interpret this attribution of meaning. This meant that participants could read their quotes and our interpretation of these quotes and comment on them. We recruited via the Vlaamse Vereniging voor Autisme and on social media such as Facebook and Twitter. Two participants were personal acquaintances of the authors. In order to consider the stories in as unbiased a manner as possible, we did not ask to look at the participants' diagnostic reports, nor did we want to know their IQ. All had an official diagnosis given at a diagnostic centre. Participants could choose from an oral interview, a chat session or an email conversation. Some requested to look at the interview guide in advance because they would like to know what they would be asked. Our respondents shared with us their life trajectories before the diagnosis, as well as the diagnostic process itself, and life after the diagnosis.

After the interviews, we first did an inductive analysis of the themes. We did not use any software, but we noted themes separately in the margins of the transcript. We met every two weeks to check our findings and uncover common categories. In a later phase, we laid down the story of our book. *Experiences of Adults Following an Autism Diagnosis* is a descriptive text subdivided into seven broader themes.⁵ Another text, which was published in 2017 as a separate chapter in a volume on citizenship, contains a summary of the research.⁶ We presented the research findings at four different conferences and we took suggestions into account during the interpretation of our findings. In what follows, I present a couple of quotes and their interpretations. They demonstrate

4 Jonathan Smith, *Interpretative Phenomenological Analysis: Theory, Method and Research*, 1st edition (Los Angeles: SAGE Publications Ltd, 2009).

5 Kristien Hens and Raymond Langenberg, *Experiences of Adults Following an Autism Diagnosis* (Cham: Palgrave Macmillan, 2018).

6 Kristien Hens and Raymond Langenberg, 'Immeasurability, Biology, Identity. Citizenship and the Meaning of a Diagnostic Label for Adults Diagnosed with Autism', in *Citizenship in Organizations. Practicing the Immeasurable.*, ed. by Suzan Langenberg and Fleur Beyers (London: Palgrave Macmillan, 2017), pp. 201–23.

how autism is not solely a static 'given' in the life of the individual, but instead how the meaning of autism and the diagnosis of autism changes throughout the individual's life. This discussion functions as an introduction to the final part of this book, which presents dynamic conceptions of autism.

Although autism has been initially conceived of as a childhood disorder, more and more adults receive the diagnosis. This is challenging in different ways. Firstly, to qualify for a diagnosis, the individual should be hampered in their everyday functioning, to such an extent that this poses insurmountable problems in their social or professional life. We could explain the fact that this person did not receive the diagnosis as a child or adolescent by stating that they were not dysfunctional at that moment, that they received a faulty diagnosis, or that their dysfunctioning was not obvious enough. Nevertheless, as soon as the diagnosis of autism is attributed, this implies that the condition has existed since birth. Secondly, clinicians consider diagnosis challenging in adults because they have learned to cope with their autism through a range of masking strategies.⁷ Therefore some suggest that autism is a lifelong condition, but it is visible or invisible depending on whether and how the individual can adapt. The question then arises: how does this relate to the idea that autism is a diagnosis given if there is evidence of dysfunctioning? Indeed, the case of adults without an intellectual disability who receive a diagnosis of autism implies a more dynamic understanding of autism. An understanding that explains dysfunctioning based on a specific vulnerability (whether it is genetic, neurological, or cognitive) in interaction with environmental and social factors seems adequate. Below, I describe confrontations with and learning from others. Such feedback is, in the first place, given by people with whom our participants interacted. It is also a mechanism of the diagnosis itself, a label that can be assimilated, rejected, or transcended.

Autism, as defined in DSM-5, is characterized by 'social and communicative problems'. Furthermore, our respondents described how they felt that their challenges were often linked to misunderstanding

7 Iliana Magiati, 'Assessment in Adulthood', in *Handbook of Assessment and Diagnosis of Autism Spectrum Disorder*, ed. by Johnny L. Matson, Autism and Child Psychopathology Series (New York: Springer International Publishing, 2016), pp. 191–207, https://doi.org/10.1007/978-3-319-27171-2_11

others or not being understood by others. This could happen, for example, because they took the words of others literally or could not detect deception. Baukis, who was sixty at the time of the interview and who had recently received her diagnosis, described how she was sexually abused on different occasions:

When I was between sixteen and twenty-six years of age, many things went wrong, specifically in the relationship with boys. It was a disaster. I was very gullible. I was a toy for many people. I was raped a couple of times because I did not understand the world.

On the one hand, I had an enormous need for connection. That is the thread in my life, and I think that is so for most people. But how do you do that without making yourself vulnerable, without being hurt?

Baukis' story, and specifically this quote, is illuminating for different reasons. Like many of our participants, she describes a heartfelt desire for connection with others. However, she is easily deceived into thinking that others have good intentions. For Baukis, these moments of deception and even abuse were not instructive. On the contrary, even if a simplistic reading of autism (as the inability to read the intentions of others) seems applicable here, the question remains where the problem lies: in the person who is gullible and looks for genuine connection, or in those who can 'read' such a vulnerability and abuse it? Baukis explains how her diagnosis has helped her to understand that she has experienced many challenges in her life.

Hanna, thirty-five, describes how the reactions of others have pushed her towards trying to fit in:

I was acutely aware that I was always left out. I remember that, from the age of three, that specific behaviour made other people uncomfortable. That meant that I shouldn't do that anymore. And each time I thought, that is not allowed, I should do this, I should do that. Thus, you learn not to do things anymore. I have learned that I should not shout: leave me alone. And if you are bizarre or act strange, this is also not good.

The adverse reactions of others taught Hanna to adapt. Although she does not suggest, at least in this quote, that this is something negative, it is evident in this interview and others that such compensating behaviour does help her to function better in society. However, it is at the same time felt as a loss of who one is. Moreover, it left participants with feelings of fatigue. Indeed, they often gave voice to the sense that

they could never be genuinely themselves, to the extent that, in the end, they did not know who they really were because of the strategies of compensation and camouflage they had taught themselves.

Others are often valuable sources of information, feedback, and opportunities to develop and learn. Karel was fifty-five when he was interviewed, and he had received his diagnosis of Asperger syndrome fifteen years before. In this study, he is the one who lived with his diagnosis the longest. He explained how he was somewhat isolated as a child and grew up in an environment that did not encourage him to break out of his isolation. Nevertheless, he says:

I think you can call it a kind of hunger, a feeling that I needed more than my own understanding of what was available in my direct environment. But on my own I was not able to open myself up.

Rather than an unwillingness to connect with others, or a lack of interest in such human contact, Karel experienced a desire for more that remained unsatisfied. He continues:

I was too isolated; I was too concerned about myself and got stuck. I could be very childish and provoke people, but I could not think about myself in these terms. So I confronted many people and tried to get in touch with them.

As a teenager, Karel wanted to learn more about himself and how to function in the world. He knew that he could only learn by communication and in relation to others. He felt, however, growing up in an environment that did not afford him many responses from others, that he did not receive the necessary feedback. He tells how he was sometimes so isolated that he got lost in his thoughts:

There were periods that I thought that I was not entirely there. I was semi-conscious. I was not entirely there, you know. I have it now, and I had it as a child. I can do things for hours or be immersed in something, but really deeply immersed. Does that mean I am different from others? You can only know that if someone talks to you or if you are in contact with the other.

You can only know if certain feelings of being *apart from your environment* are normal — or if you are different in some respects — when you are in contact with others who share or do not share similar experiences.

These others, whether they are friends or family, can also function as a touchstone. For example, Robyn, thirty, talks about how she was looking for a new job. She tells how her friends gave her feedback about what kind of job would be suitable for her. She says she had three job offers, and she had managed to choose 'the worst of all three', against the advice of her friends:

I had a choice between two different jobs, and everyone told me to take one specific, and I completely did not understand why. So finally they tried very hard their best to explain this to me, and then I understood. But I had managed to choose the job from all three with the lowest wages, the most stressful, farthest from home and with the vaguest job description.

She chose this job because the job title sounded interesting and the deal included a company car. She continues: 'I notice that that happens to me a lot, that I have to check twice with people because otherwise, I have a completely different and wrong idea of what something really is.' Even if Robyn admits that she probably made a mistake in choosing that job, she does understand, after consultation with her friends, why that was the case. She learns how to understand her own choices better and how to translate this into future decision-making.

Interview participants explained how they used input from others and confrontations with others to understand themselves and others better. For participants in a relationship, their partner often gave necessary feedback without wanting to change them. Some of our participants counted on friends. Those who had a joyous childhood stressed that their parents had understood their ways of being, and so they could grow into adults without at that point requiring a diagnosis.

At a certain point in their adult lives, all our respondents encountered specific challenges that proved to be insurmountable without professional help. In many cases, they took the initiative to ask for a diagnostic examination that eventually led to a diagnosis of autism or Asperger syndrome. With this diagnosis, a different kind of confrontation happened. They were confronted with the implications of the test results on the one hand, and with societal expectations about the meaning of such a diagnosis on the other. Our participants' reaction varied from an almost complete acceptance of the diagnosis to a rejection of the many associations of autism.

On the one hand, they accepted autism as an accurate description of their functioning. Some participants had previously received a diagnosis of personality disorder — such as Borderline Personality Disorder — and could relate much better to autism. On the other hand, our respondents stated that they did not entirely fit the stereotypical image of an autistic person. Many also contradicted the idea that autistic people are ‘loners’ or lack empathy. Nevertheless, overall our respondents did recognize themselves in a description of ‘autism’.

Receiving a diagnosis and informing others about it changes one’s relationship with these others. The official diagnosis is, for many participants, a way to explain one’s particularities. Expectations become adjusted, and problems that would previously lead to conflict are now readily explained because of the diagnosis. Thus, Hanna states:

What is really nice, I have a really good bond with my parents, but we had always had so many conflicts in the past. [...] Since they know about my diagnosis, this is no longer so. They have found a different way to approach me, and I really appreciate that. Before, they would confront me and say, oh, Hanna, you shouldn’t do that, try to be a bit less black and white. And now they say, we know that we won’t let it explode, we tackle it, it is OK.

The diagnosis itself can also engender new expectations from others. What autism is, besides the stereotypes and in the specific context of a person, remains hard to grasp. Sandra (thirty-eight at the time of the interview) suffers from sensory hypersensitivity. Although she appreciates the insight offered by the diagnosis, she regrets that other people, especially in a professional context, conclude that she functions better in a job without contact with clients:

At the moment the diagnosis was given, I received a different job. I am now seated at a different desk; it is a desk without colleagues. It is a bit lonely. I know this works best for me, but sometimes they exaggerate. I know it is to protect me, but I do not think that I am a danger to other people.

Although, in her previous job, she suffered from extreme fatigue, Sandra thinks that sitting alone in a separate room is better in some ways, but on the other hand, it is lonely. In other parts of the interview, she stresses that the extra compensations she gets at work through her diagnosis

are based on a general feeling about what autism is rather than what it means specifically for her.

A formal diagnosis not only changes the relationship one has with others, but also how one understands oneself. The diagnosis is an external evaluation that influences one's self-image. It is true that some of our respondents automatically recognized themselves in their diagnosis, but they also each had to find out what the diagnosis meant for them. Karel explains this as follows:

It offers an insight that can inspire, that can help you reorient yourself. But you still have to make it your own so that you can build it into your own actions. For example, now I can accept that I may sometimes go into too much detail. But that is again simplifying it. A diagnosis offers focal points, which you can research. How does this fit into my own pattern of actions? It is an extra critical factor that can be confronting or can offer peace of mind and a way to think about it. That was not explained to me when I received my diagnosis because the world of diagnoses is hyper flat.

Hence a diagnosis can offer self-insight, but only after the person diagnosed comes to terms with it and integrates it in their self-image. This process is something that many adults we interviewed went through without external help. Some did receive therapy, but that therapy was often not aimed at the development of such self-insight. Another participant, BartDelam, explained how the insight given by the diagnosis helped him surpass the limitations of that diagnosis. He uses the example of how, before receiving the diagnosis, he became outraged when children were playing noisily in a playground close to his house because he is susceptible to noise. The diagnosis offered him insight into these emotions and allowed him to deal with them better:

Before the diagnosis, I would probably have been someone who would file a complaint about the noise if there had been a playground behind the house. Now I try to think, what can I do about it, put on headphones... Children play and make noise. Of course, looking at it differently does not help a lot because the noise is still there.

It is important to note that the diagnosis could have given him an extra reason to be even angrier. It is an acknowledgement that he experiences certain sounds more intensely than other people. Instead, the narrative

provided by the diagnosis offered him an opportunity to look at his functioning critically, from a distance.

Autism is considered a neurodevelopmental disorder present very early in life and persisting throughout the lifespan. Although many participants have experienced challenges in their lives and have felt different from others as a result, our study demonstrates that we cannot interpret their stories in a unidimensional and straightforward way. Perhaps they show how a vulnerability that might be neurological can lead to challenges later in life, and how these people have dealt with this vulnerability in their interaction with others. We suspect that there may indeed be a genetic or innate predisposition towards an atypical cognitive or social development that is not always translated into problems. Still, it is very enlightening to learn how people have dealt with their problems before and after the diagnosis. This suggests that an approach that exclusively targets problems and challenges within individuals is problematic and often futile.

Qualitative research that is geared at investigating lived experiences and evaluating how people interpret their own experiences is also relevant to judge the appropriateness of specific explanatory models. For example, in the year 2000, Robert Jones, Andrew Zahl, and Jaci Huws used the first-person narratives of autistic people to demonstrate that — contrary to prevailing theories — autistic people have strong emotions.⁸ David Trembath and colleagues used focus groups to research how young adults diagnosed with autism experience feelings of fear: what are the occasions for this, the consequences of it, and which solutions do these young people use to deal with it?⁹ Our respondents have demonstrated that they interact dynamically with others to build their own stories. Confrontation and contact with others can be a source of suffering but also a learning opportunity.

We gave an example of how challenges with interaction can lead to deception and even abuse. Such challenges are not (only) related to a difficulty within the autistic person him- or herself. Abuse is the result of

8 Robert S. P. Jones, Andrew Zahl, and Jaci C. Huws, 'First-Hand Accounts of Emotional Experiences in Autism: A Qualitative Analysis', *Disability & Society*, 16:3 (2001), 393–401, <https://doi.org/10.1080/09687590120045950>

9 David Trembath and others, 'The Experience of Anxiety in Young Adults With Autism Spectrum Disorders', *Focus on Autism and Other Developmental Disabilities*, 27:4 (2012), 213–24, <https://doi.org/10.1177/1088357612454916>

deception by another. Trying to conform to social expectations can also lead to interactions going awry, as this involves ‘giving something up’ to ‘belong’. Sarah Bargiela and her colleagues described these mechanisms in fourteen women who received their diagnoses when they were adults. They described how nine out of the fourteen women experienced a form of abuse, and felt that they applied a masking strategy and camouflaged themselves in order to belong to a group. The authors describe how the diagnosis gave these women a way to create a narrative within which their differences and communication styles could fit, and how this eased communication.¹⁰

Laura Hannah and Steven Stagg described negative sexual experiences following an abuse of trust.¹¹ Besides these breaches of trust to which autistic persons, often women, are subjected, social interaction can also become a learning opportunity. Our respondents expressed a genuine desire to learn from others and improve their social interactions. This is in line with the findings of Fleur Wiorkowski, who interviewed twelve participants who had a diagnosis of autism about their experiences during higher education. She found that her respondents enjoyed social interaction, mostly when they met people with similar interests. This enabled them to learn from their interactions. She explains that, although we may expect group assignments to be less than ideal for students with this diagnosis, her participants stated that they saw it as an opportunity to learn.¹²

In this and other research into the experiences of autistic people, it becomes apparent that autism is not solely a fixed identity that is persistent throughout one’s life. We have described how the diagnosis is a description of one’s functioning and can form the basis of how others understand you. As such, it is often a welcome explanation of the challenges that people with autism experience. Nonetheless, the

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- 10 Sarah Bargiela, Robyn Steward, and William Mandy, ‘The Experiences of Late-Diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype’, *Journal of Autism and Developmental Disorders*, 46:10 (2016), 3281–94, <https://doi.org/10.1007/s10803-016-2872-8>
 - 11 Laura A. Hannah and Steven D. Stagg, ‘Experiences of Sex Education and Sexual Awareness in Young Adults with Autism Spectrum Disorder’, *Journal of Autism and Developmental Disorders*, 46:12 (2016), 3678–87, <https://doi.org/10.1007/s10803-016-2906-2>
 - 12 Fleur Wiorkowski, ‘The Experiences of Students with Autism Spectrum Disorders in College: A Heuristic Exploration’, *The Qualitative Report*, 20:6 (2015), 847.

meaning of autism and of the diagnosis of autism changes. There are possibilities for learning and misunderstanding in interactions with others, and even when answering the question of what it means to be autistic. In the last part of the book, I will suggest how we can conceive of autism as a biologically real yet dynamic phenomenon. But firstly the next chapter, an interlude, will offer some speculative reflections on autism and time.

