



# AUTISM: DISORDER OR IDENTITY?

*AN ARGUMENT IN FAVOR OF A NEW UNDERSTANDING OF AUTISM*

MASTER THESIS APPLIED ETHICS

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## Summary

Autism is a diagnosis described in the DSM-5, the diagnostic handbook of psychiatrists, with symptoms mostly in the fields of social communication and behavior. Nevertheless, there are people who strongly disagree with autism understood as a psychiatric disorder and claim that autism should be seen as an identity. The consequences of defining autism as a disorder or as an identity have an effect on the probability that someone receives medical care and on the level of stigmatization a person experiences. These two prominent explanations of how we should understand autism, as a disorder or as an identity, seem to be mutually exclusive. I will argue that it is possible to conceptualize autism as simultaneously a disorder and an identity. I will first explain the purpose of the search for a new understanding of autism by introducing the ameliorative approach for conceptual analysis by Sally Haslanger. Following a moral analysis of the two main ways to understand autism, I will provide an in-depth investigation of the concept of psychiatric disorder in order to decide whether autism belongs to this category. Finally, I will conclude that autism should be understood as simultaneously a disorder and an identity. This new understanding will result in a decrease in the stigmatization of people with autism, without taking away the beneficial medical aspects.

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## Introduction

Autism is a diagnosis described in the DSM-5, the diagnostic handbook of psychiatrists, with symptoms mostly in the fields of social communication and behavior. Nevertheless, there are people who strongly disagree with the claim that autism is a psychiatric disorder. According to them, autism should not be seen as a disease that is supposed to be cured, because it is part of a person's identity. This view contrasts strongly with, for instance, the anti-vaccination movement which claims that vaccines cause autism<sup>1</sup> or the organization 'Autism Speaks' that sponsors autism research.<sup>2</sup> People holding these conflicting views have not reached a consensus on how to understand autism.<sup>3</sup>

This thesis will address the issue of what autism is. Whilst seemingly an easy question to answer, as the debate described above shows, apparently autism is not merely the psychiatric diagnosis as described in the DSM-5. Having a disorder implies that there is something abnormal about a person, which conflicts with the strong conviction of people with autism who say that they are part of the normal variation. Therefore, using one concept of autism over another will have normative implications. To name a few things, the consequences of defining autism as a disorder or as an identity have an effect on the probability that someone receives medical care and on the level of stigmatization a person experiences. Autism conceived of as a disorder may result in stigmatization, while using the notion of autism seen as an identity might decrease one's chances to receive medical care.

The two main explanations of how we should understand autism, as a disorder or as an identity, seem to be mutually exclusive. However, we should ask ourselves whether there are ways in which those two views are compatible. The aim of this thesis is to answer precisely that question: *Is it possible to conceptualize autism simultaneously as a disorder and an identity?* In answering this question, I will provide an account of autism that is a helpful conceptualization for those people that are affected by it, because it will reduce stigmatization

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<sup>1</sup> Michael Davidson, "Vaccination as a Cause of Autism-Myths and Controversies," *Dialogues in Clinical Neuroscience* 19, no. 4 (December 2017): 403–7.

<sup>2</sup> "Autism Speaks," Autism Speaks, 2019, <https://www.autismspeaks.org>.

<sup>3</sup> Kristien Hens, Ingrid Robeyns, and Katrien Schaubroeck, "The Ethics of Autism," *Philosophy Compass* 0, no. 0 (October 24, 2018): e12559, <https://doi.org/10.1111/phc3.12559>; Francisco Ortega, "The Cerebral Subject and the Challenge of Neurodiversity," *BioSocieties* 4, no. 4 (December 2009): 425–45, <https://doi.org/10.1017/S1745855209990287>; Nancy Bagatell, "From Cure to Community: Transforming Notions of Autism," *Ethos* 38, no. 1 (March 2010): 33–55, <https://doi.org/10.1111/j.1548-1352.2009.01080.x>; Pier Jaarsma and Stellan Welin, "Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement," *Health Care Analysis* 20, no. 1 (March 2012): 20–30, <https://doi.org/10.1007/s10728-011-0169-9>.

without taking away the beneficial medical aspects. For this conceptual analysis, I will use Sally Haslanger's ameliorative approach. This means that I will describe why we need an understanding of autism in the first place and find out what concept would serve those purposes best.

I am aware that the use of certain expressions in this thesis, for instance, 'people with autism' or 'autistic person', might offend others with strong ideas about how they should be referred to. This debate about language is also known as the Person-First vs. Identity-First discussion. I deliberately use both terms interchangeably in order to signal the lack of consensus about the nature of autism and the appropriate language for referring to those persons diagnosed with it.

Following an explanation of why we need a new understanding of autism and what I aim to do by investigating the concept of autism in Chapter 1, I will describe six concepts of autism that are currently used. I will analyze the two main understandings of autism, namely autism as a disorder and autism as an identity. Their moral consequences will be investigated by exploring them from different ethical perspectives. I will do so by making analogies with debates about disability and homosexuality, thereby investigating whether topics of debate and lines of reasoning in those spheres can be applied to the debate on autism. Subsequently, in Chapter 3, I will investigate what exactly a psychiatric disorder is, by examining different definitions and the historical development of the concept that shaped our current definitions. In the last chapter, I will address whether the view of autism as an identity proves to be a more realistic understanding of autism. Ultimately, I will answer the research question of this thesis, namely whether it is possible to conceptualize autism simultaneously as a disorder and an identity. My hypothesis is that there is an acceptable way in which autism can be perceived as both.

Before proceeding, it is important to highlight that autism can manifest itself in many different ways. All forms are remarkably different from each other with regard to both severity and characteristics.<sup>4</sup> Besides that, autism often occurs together with other disorders, thereby making the group of autistic people even more heterogeneous.<sup>5</sup> During the process of writing

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<sup>4</sup> Ian Hacking, "Humans, Aliens & Autism," *Daedalus* 138, no. 3 (July 2009): 44–59, <https://doi.org/10.1162/daed.2009.138.3.44>.

<sup>5</sup> Ingrid Robeyns, "Conceptualising Well-Being for Autistic Persons," *Journal of Medical Ethics* 42, no. 6 (June 2016): 383–90, <https://doi.org/10.1136/medethics-2016-103508>; Marilyn Augustyn and L Erik von Hahn, "Autism Spectrum Disorder: Clinical Features," in *UpToDate*, ed. Mary M Torchia, Marc C Patterson, and Carolyn Bridgemohan (Waltham, MA: UpToDate Inc., 2019), [https://www.uptodate.com/contents/autism-spectrum-disorder-clinical-features?search=autism%20spectrum%20disorder&topicRef=595&source=see\\_link](https://www.uptodate.com/contents/autism-spectrum-disorder-clinical-features?search=autism%20spectrum%20disorder&topicRef=595&source=see_link).

this thesis, I therefore realized that it is not possible to answer the question of what autism is to everyone's complete satisfaction, given the heterogeneity of the concept and the many diverging opinions. Since I am aware of this, I will try to formulate an answer that is acceptable for as many people as possible, mainly focusing on giving an account of autism that is a helpful conceptualization for those that are affected by it.

## Chapter 1 – The purpose of a new understanding of autism

Prior to the search for a new conception of autism, I will explain the aim and motivation of this entire project. In this chapter, I will investigate what it means to give an account of autism and what the purpose of a new understanding of autism is. Answering these questions will improve our concrete understanding of what this conceptual analysis aims to achieve.

### 1.1 Concepts & conceptualizations

Concepts are used to describe the world around us and to draw distinctions between things. Terms can refer to biological kinds, to social kinds or to nothing at all. Sometimes, people disagree about the nature of a concept, such as the concept of autism. Sally Haslanger notes that these disagreements could possibly stem from a fundamental different understanding of the concept, but it might also be a result of talking about different things.<sup>6</sup> Haslanger focused in her work on the concepts of gender and race, but her argumentation can also be applied to the topic of autism. Haslanger states: “In developing constructionist accounts of race and gender, I’ve maintained that my goal is not to capture the ordinary meanings of ‘race’ or ‘man’ or ‘woman’, nor is it to capture our ordinary race and gender concepts. I’ve cast my inquiry as an analytical - or what I here call an ameliorative - project that seeks to identify what legitimate purposes we might have (if any) in categorizing people on the basis of race or gender, and to develop concepts that would help us achieve these ends.”<sup>7</sup> Like Haslanger for race and gender, I’m not concerned with finding out what autism truly is, but I aim for a new concept that promotes social justice for autistic people.

Haslanger distinguishes three existing methods that we can use to answer what ‘race’ and ‘gender’ are, and which I aim to use in addressing the question *What is autism?*. These three approaches are the conceptual approach, the descriptive approach and the ameliorative approach. When using the conceptual approach, the underlying question would be: what is our concept of autism? The investigator uses introspection and looks at our intuitions about cases and principles. When using the descriptive approach, the investigator wants to develop a more precise concept by looking at phenomena, using an empirical method. The ameliorative approach, however, starts from a different kind of enquiry: what is the point of having the

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<sup>6</sup> Sally Haslanger, “What Are We Talking About? The Semantics and Politics of Social Kinds,” *Hypatia* 20, no. 4 (November 2005): 10, <https://doi.org/10.1111/j.1527-2001.2005.tb00533.x>.

<sup>7</sup> Haslanger, 11.

concept in question? Thus, in our case, why do we have a concept of autism? And following from that; what concept would do the work best? For this approach, normative input is necessary to find out what our legitimate purposes are for having the concept in the first place and what concept would serve those purposes best.

After this explanation of the three approaches, Haslanger mentions that these approaches cannot be seen entirely distinct from each other. They will always be (at least partly) intertwined, but have nevertheless different subject matters and different purposes. According to Haslanger, the disagreements about the nature of a concept often stem from a different approach to conceptual analysis, either conceptual, descriptive or ameliorative, and not from a fundamental different understanding of the concept.

Additionally, Haslanger introduces a fourth approach: genealogy, based on the philosophy of Friedrich Nietzsche and Michel Foucault. When using this approach, a concept is described by investigating its history to understand how the concept is rooted in transforming social practices. This approach assumes a tight connection between concepts and social practices. It is a symbiosis in which concepts are shaped by social practices, but these social practices may in turn be influenced by those concepts. Besides that, the genealogical approach also acknowledges a large gap between the dominant understandings of concepts and how concepts are perceived in society. In practice, concepts can play out differently when compared to their ‘official’, dominant understanding. Haslanger uses the example of tardiness to further clarify this. Imagine a school setting where being tardy is defined as entering the classroom later than 8:25 AM. The attendance sheet is passed around and everyone that is not on it, is late. Everybody knows this, and in this local setting of the school, that is the official definition of tardiness. However, in one of the classes, a certain teacher always passes the attendance sheet around at the end of first period. This means that students who enter the classroom after 8:25 AM, but before 9:15 AM, can still write their name down, and will not be reported as tardy. Tardiness in that specific class with that specific teacher is different in practice compared to the official understanding of tardiness. Moreover, there is a difference in ‘what something really is’ versus how something is used in everyday life. The genealogical approach circumvents this problem by describing both uses of the concept, practical and official, as equal parts.

Haslanger explains that genealogy can be connected to the three approaches described above. For example, ameliorative genealogy is a way of investigating different ideas and practices to evaluate the point of having that particular concept, and to come up with ways to



improve it. Because of the presupposed tight connection between concepts and social practices, endorse this approach and consider it to be useful for the conceptual analysis of ‘autism’.

Haslanger elaborates on how these approaches to conceptual analysis would affect the debate on what the concept of race should be: “I would not argue that there is one thing that race really is or one thing that “we” mean by “race.” Nevertheless, in developing an account of race we should be attentive to our manifest, operative, and target concepts and, if there is a legitimate target notion, have them coincide.”<sup>8</sup> The manifest concept is the official one, the operative concept is the practical one and the target concept is the one that would serve our purposes of having the concept best. In other words, she claims that there is not one thing that we mean by race. This insight could also be applied to the concept of autism. According to this line of reasoning, there is not one concept of autism. It is only possible to try and identify the manifest, operative and target concept of autism. Only then is it possible to discover which of the three concepts is ‘flawed’. For instance, it could be possible that the manifest concept and the target concept coincide. Thus, both the ‘official’ concept and the concept that would be the best possible concept are the same. However, the operative, ‘practical’, concept appears to be different. In that case, it would be sensible to change practice in order to make the operative concept match the manifest and target concept.

I agree with Haslanger that it might not be possible to describe *the* concept of autism. In formulating a target concept for autism, I will try to describe one of the concepts of autism one can make use of. In practice, it may take time to make the target concept coincide with the operative concept. The target concept is an ideal to strive for, while the operative concept is the one actually used in society.

## 1.2 Criteria for a better understanding

Why do we need an understanding of autism in the first place? For analogous topics such as gender and race, the necessity mostly comes from the fact that it is politically essential to have a definition in order to refer to undesirable patterns of oppression or negative stereotypes.<sup>9</sup> By putting a label on a minority, injustices can be made visible and (hopefully) addressed. This applies to autism as well. The autistic community can be considered as a minority in society. Autistic people who do not agree with the common notion of autism as a disorder, do not feel

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<sup>8</sup> Haslanger, 21.

<sup>9</sup> Kathleen Stock, “Doing Better in Arguments about Sex, Gender, and Trans Rights,” *Medium*, May 2019, <https://medium.com/@kathleenstock/doing-better-in-arguments-about-sex-and-gender-3bec3fc4bdb6>.

heard and respected. Stigmatization of psychiatric disorders can therefore lead to similar situations as the patterns referred to in relation to gender and race.

In order to know which concept of autism would be the most desirable, we need to know what the purpose is of having a concept of autism. Additionally, in order to address the injustices such as stigmatization, we need conceptual categories that make it possible to describe the unjust systems and their effects. To make it more tangible, I will list several requirements a concept of autism should comprise in my opinion.

First of all, the understanding of autism should lead to increased levels of well-being for people with autism. Stigmatization of people with psychiatric diseases in general, and autism in particular, is one of the main issues for autistic people. People diagnosed with a mental disorder are socially stigmatized because they are considered to be ‘crazy’ or ‘weird’ and are therefore not accepted as fully equal members of society. Crichton, Carel & Kidd describe that sometimes people experience the effects of the stigma as more burdensome than the mental disorder itself.<sup>10</sup> They distinguish three types of stigma and explain their effects. The first type is the *general stigma*. This type causes potential patients to refrain from consulting a psychiatrist because they fear the consequences of being labelled with a psychiatric diagnosis. Therefore, this general stigma negatively effects the prevention and early treatment of mental disorders. The second type of stigma is the *self-stigma*, which is the process of internalization of the general stigma. People diagnosed with a mental disorder often start to identify with the negative stereotype associated with it and consequently suffer from a low self-esteem and loss of confidence. The third type of stigma is the *structural stigma and discrimination*. In surveys, psychiatric patients have stated that they feel their views are not sufficiently regarded. Psychiatric services are often structurally based on a single model of psychiatric diseases (mostly the biological model), which is according to patients too narrow of a view. This third type of stigma already shows how the concept of autism is linked to the occurrence of a stigma. How one understands autism has an effect on how psychiatric services are arranged and therefore on how people with autism are treated. It seems clear to me that in order to improve the level of well-being of autistic people, we will have to get rid of (or at least minimize) the stigma on autism.

Secondly, notwithstanding the risk of stigmatization, the new understanding of autism should remain relatable to the field of mental health care. If autism is judged to be just a natural

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<sup>10</sup> Paul Crichton, Havi Carel, and Ian James Kidd, “Epistemic Injustice in Psychiatry,” *BJPsych Bulletin* 41, no. 2 (April 2017): 68, <https://doi.org/10.1192/pb.bp.115.050682>.

variation, it would no longer fall under the scope of psychiatry. Some people with autism simply need the label of mental disorder to receive the help they require. This might be largely a practical issue, since most contemporary health care systems rely on diagnoses to distribute care, but that does not make it less important for the concept. Besides that, as I will describe in Chapter 2, there are people with autism or caregivers of autistic people who strongly feel that autism is a disease that should be cured. If we lose the aspect of disorder completely, their opinions will be disregarded.

Finally, the concept of autism should be accepted by at least the majority of people with autism. Ideally it would be accepted by all, but given the heterogeneity of the spectrum and the diverging ideas amongst autistic people and their families, this may be unfeasible. I would suggest that autistic people are the first group to have a say in what a concept of autism should entail. However, in order to have any effect, the new understanding of autism should become a widely supported concept by the entire society. Without this, other understandings of autism will still be used, which might be powerful enough to keep the stigma of autism alive. If the majority of the people uses the new concept, gradually, this concept will become the dominant understanding of autism in society. Especially professionals in mental health care should use the new concept, since those working in this field are often regarded as an authority on the topic of autism. In order to be accepted by these professionals, autism should probably still be understood as some kind of disorder. Yet, there are autistic people who claim that psychiatrists and therapists are not the ones with the best knowledge of autism.<sup>11</sup> However, they feel as if, in our current society, psychiatrists and therapists have more power to claim knowledge about autism. Therefore, it might still be useful, even for the one's that do not agree about psychiatrists and therapists being authorities in this field, to support a new concept that is also accepted by the mental health care professionals.

Having seen these diverging views, my hypothesis is that in order to be accepted by the majority, a conception of autism should allow autism to be both an identity and a disorder at the same time.

### 1.3 What is a good life for people with autism?

As described above, a requirement of a new understanding of autism is that it would result in a better world for autistic people to live in, and enhance their well-being. But what constitutes

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<sup>11</sup> "About AUTCOM - The Autism National Committee," The Autism National Committee, 2011, <https://www.autcom.org/about.html>.

well-being for autistic people? This topic might lead us too far away from the central question of this thesis, yet, it makes sense to mention a few things about it.

Scott Michael Robertson argues that the research on autism is mainly focused on finding the origin of the disorder, while more research should be directed towards the quality of life of autistic people. If we want to improve the quality of life, researchers will have to shift their focus.<sup>12</sup>

Rodogno, Krause-Jensen and Ashcroft did research on the topic of well-being for autistic people, but argue that our present-day approach to studying well-being is not apt to answer the question of what well-being is for autistic people.<sup>13</sup> This is the case because of a crucial step every philosopher takes when describing a theory on well-being: ‘pre-theoretical’ knowledge on the topic or intuitions on what well-being is, are presupposed. But that is exactly the problem when discussing the well-being of autistic people; we do not know what increases their happiness and what is bad for them. Rodogno et al. propose a new epistemology of well-being, which is more sensitive to the needs of people with autism. The diversity of autism makes collecting the required data difficult, but Rodogno et al. encourage parents of children with autism to observe and learn from the things that evoke happiness and unhappiness in their children to gain a better understanding of what promotes their well-being. Unlike Rodogno et al., Robeyns did use a conventional theory of well-being to try to better understand well-being for autistic people: the capability approach.<sup>14</sup> In short, the capability approach is a theoretical framework that relies on two normative claims: “[F]irst, the claim that the freedom to achieve well-being is of primary moral importance, and second, that freedom to achieve well-being is to be understood in terms of people's capabilities, that is, their real opportunities to do and be what they have reason to value.”<sup>15</sup> Robeyns is optimistic about the use of the capability approach for developing an account of well-being for autistic people. The other way around, investigating an autistic account of well-being can teach us something about which items are relevant for all people to be included in the capabilitarian account of well-being.

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<sup>12</sup> “About AUTCOM - The Autism National Committee,” The Autism National Committee, 2011, <https://www.autcom.org/about.html>.

<sup>13</sup> Raffaele Rodogno, Katrine Krause-Jensen, and Richard E Ashcroft, “‘Autism and the Good Life’: A New Approach to the Study of Well-Being,” *Journal of Medical Ethics* 42, no. 6 (June 2016): 401–8, <https://doi.org/10.1136/medethics-2016-103595>.

<sup>14</sup> Robeyns, “Conceptualising Well-Being for Autistic Persons.”

<sup>15</sup> Ingrid Robeyns, “The Capability Approach,” in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (Metaphysics Research Lab, Stanford University, 2016), <https://plato.stanford.edu/archives/win2016/entries/capability-approach/>.

The conclusion of this digression is that defining what well-being is for autistic people remains a difficult undertaking. In spite of that, we may assume that in order to answer this question, it is necessary to consult people with autism about this, as well as those who take care of them (since not every person with autism is able to express him- or herself). Without their perspective, trying to decide what constitutes well-being for autistic people is not possible. Since autism is such a complex concept, every view is valuable, especially of those who have autism themselves, in order to grasp all the nuances of the concept.<sup>16</sup> This claim also raises a new question: are autistic people the only people that can say something about what constitutes well-being for autistic people? This epistemological question is related to one of the problems encountered by autistic people in society: epistemic injustice.

#### 1.4 Epistemic injustice

Who is to say what a good life for people with autism is? Is it only justified for autistic people to say something about that? And who is to say what autism is? Doctors or people with autism? The Autism National Committee argues that the real experts on autism are autistic people.<sup>17</sup> However, one could refute this claim by stating that autistic people are not necessarily the real experts. What about mental health care professionals or care givers with years of training and experience? It is not inconceivable that it sometimes might be the case that an autistic person lacks insight in his or her own preferences and experiences.

Epistemic injustice occurs when a listener does not take the speaker seriously. Injustice is done to the speaker that is not considered an epistemic subject with knowledge of the topic he or she is conversing about. It is argued by Crichton, Carel and Kidd that patients suffering from mental diseases are more vulnerable to epistemic injustice than those with somatic diseases and that many psychiatric patients express that they do not feel heard by their psychiatrist.<sup>18</sup> The credibility of the patient is for some reason questioned by the psychiatrist and the therapists. According to Crichton, Carel and Kidd, because of the persistent negative stereotypes that exist about psychiatric patients, epistemic injustice remains a problem. However, patients are the only ones that really know what is going on in their mind, while precisely that mind is possibly affected. The psychiatrist or therapist is therefore not entirely wrong by (sometimes) questioning the credibility of the patient's story. This is a complicated

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<sup>16</sup> Hens, Robeyns, and Schaubroeck, "The Ethics of Autism."

<sup>17</sup> Hacking, "Humans, Aliens & Autism," 47.

<sup>18</sup> Crichton, Carel, and Kidd, "Epistemic Injustice in Psychiatry," 68.

issue to which I cannot do justice considering the scope of this thesis. Mentioning it might bring up many questions which will remain unanswered, but the value of mentioning this issue is that it clearly shows how complex the problem of epistemic injustice in psychiatry is.

### Self-identification

Related to the topic of epistemic injustice is the work of Kathleen Stock on gender identity.<sup>19</sup> Stock wonders who gets to define whether someone has a certain identity. Writing about gender, she is concerned with whether someone can identify as a woman, focusing on the case of transwomen. This can also be applied to the question of whether someone can identify as autistic. We can question self-identification in the case of autism. Is it sufficient for being autistic that one self-identifies as autistic? This reasoning is quite the opposite way of what I have been doing until now. Instead of asking what autism is, the question is now whether one can be autistic on the basis of self-identification. Is it even legitimate to contest such statement?

However, since being diagnosed by a psychiatrist is a necessary tool in our current society for receiving mental health care, in a practical sense, self-identification would not be accepted as a sufficient ground to be labelled ‘autistic’ by the medical establishment. Yet let us put aside the practical side of this question and focus on the claim itself. One could argue that self-identification is automatically self-verifying; who knows better who you are than yourself? On the other hand, one could claim that self-identifying as an autistic person should not be seen as a truth claim, but as an expressive appeal. This is similar to the issue described above, about the credibility of a psychiatric patient. Who has the epistemic authority to decide on these issues? So far, this question remains unanswered.

To conclude this chapter, the purpose for a new understanding of autism is to promote well-being for autistic people. The question we now remain with: how should we conceptualize autism in order to reach this goal? For this ameliorative approach, normative input is needed to find out what our purposes are for having the concept of autism in the first place and what concept would serve those purposes best. This ‘target concept’ is formed by the list of requirements, focusing on what would be a good life for people with autism. Now, we can move on and take a look at the existing views on autism and analyze how these views would fulfill the requirements of the target concept.

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<sup>19</sup> Stock, “Doing Better in Arguments about Sex, Gender, and Trans Rights”; Kathleen Stock, “Why Self-Identification Should Not Legally Make You a Woman,” *The Conversation*, October 2018, <http://theconversation.com/why-self-identification-should-not-legally-make-you-a-woman-103372>.

## Chapter 2 – Different understandings of autism

In the previous chapter, I have given an outline of what the aim of this thesis is: conceptual analysis with an ameliorative approach. The current concept of autism does not satisfy all parties involved in the field. Stigmatization and epistemic injustice are two examples of the problems that occur as a result of the current principal understanding of autism. But what is the current principal understanding of autism? Is it a disease, a disorder, a condition or something else? First, I will give an overview of the phenomenology of autism. Subsequently, I will explain the six dominant views on what autism is. There are, without a doubt, many more views on autism, because everyone can experience it in their own personal way. However, for this thesis I will focus on the following six perspectives, which are, to the best of my knowledge, the most widely used views: autism as a psychiatric diagnosis, autism as a neurocognitive reality, the neurodiversity movement, the pro-cure movement, the deficit view and autism as a social construct. Following this account of the six views, I will analyze and assess the two main views on autism: autism as a disorder and autism understood as an identity.

### 2.1 Facts and figures: the phenomenology of autism

Autism was first conceptualized by Leo Kanner (1894-1981), who was the first to describe autism as a separate nosological entity.<sup>20</sup> Nowadays, 1 in 132 people in the world is diagnosed with autism, which is approximately 0.7% of the population.<sup>21</sup> In 2014, in the Netherlands, the estimated prevalence of autism amongst children between 4 and 12 years old was 2.8%.<sup>22</sup> These percentages differ, which might suggest that there are more children affected by autism in the Netherlands than elsewhere in the world. However, as suggested by the authors of the article, this questionnaire was filled in by parents and they were asked to say whether their child was affected. This could mean that the child was not officially diagnosed, but that the parents conceived the child's behavior as caused by a form of autism. This could have resulted in a reported higher percentage of children with autism in the Netherlands, while the actual

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<sup>20</sup> Berend Verhoeff, "Autism in Flux: A History of the Concept from Leo Kanner to *DSM-5*," *History of Psychiatry* 24, no. 4 (December 2013): 443, <https://doi.org/10.1177/0957154X13500584>.

<sup>21</sup> Marilyn Augustyn, "Autism Spectrum Disorder: Terminology, Epidemiology, and Pathogenesis," in *UpToDate*, ed. Mary M Torchia, Marc C Patterson, and Carolyn Bridgemohan (Waltham, MA: UpToDate Inc., 2019), [https://www.uptodate.com/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?search=autism%20spectrum%20disorder&source=search\\_result&selectedTitle=4~150&usage\\_type=default&display\\_rank=4](https://www.uptodate.com/contents/autism-spectrum-disorder-terminology-epidemiology-and-pathogenesis?search=autism%20spectrum%20disorder&source=search_result&selectedTitle=4~150&usage_type=default&display_rank=4).

<sup>22</sup> Hilde Geurts, Sander Begeer, and Rosa Hoekstra, "Prevalentiecijfers over Autisme," October 2014, <https://www.autisme.nl/over-autisme/onderzoek-naar-autisme/prevalentiecijfers-over-autisme/>.

difference is not that significant. Another reason for the discrepancy between the Netherlands and the rest of the world could be that in some countries there is probably underdiagnosis due to ignorance or due to a less developed mental health care system.

Autism is more common in boys than girls, and often goes together with intellectual disability (in 45% of the cases), attention deficit hyperactivity disorder (50%) and epilepsy (30%). Besides that, autism is often part of the variety of aspects of clinically defined syndromes such as Angelman syndrome and Rett syndrome.<sup>23</sup> Since autism is such a heterogeneous concept, the psychiatric association decided to use the term autism spectrum, in which all the different types of autism are placed. Those different forms of autism are categorized under the term Autism Spectrum Disorder (ASD). However, this new categorization was not to everyone's liking: "To subsume Asperger's Disorder into Autistic disorder in DSM-5 is a wrong way to go. To be put in the same category together with low-functioning autists may be regarded by some of the persons with Asperger's as an even worse stigmatization."<sup>24</sup> As illustrated by this quote by Jaarsma and Welin, the heterogeneity of the concept of autism is one of the main problems, since according to them, the new classification of the DSM-5 increases stigmatization.

The cause of autism is still unknown. "A strong genetic contribution to the development of ASD is supported by the unequal sex distribution, increased prevalence in siblings, high concordance in monozygotic twins, and increased risk of ASD with increased relatedness."<sup>25</sup> However, a single genetic defect as the cause of autism has not been identified. Much attention is also paid to neurobiological factors. People with autism are thought to have brain anomalies that play an important role in the development of ASD.

The most prominent features of ASD are impaired social communication skills and restricted and repetitive behavior, interests and activities. Children show limited interest in social interaction with other children or react inappropriately when someone tries to make contact with them. Many people with autism have difficulties in understanding non-verbal communication such as facial expression and body posture. Stereotyped behavior is a core symptom of autism, such as hand flapping or lining up toys repetitively in the same manner. Autistic people can also experience difficulty with changing circumstances. Furthermore, many people with autism are solely interested in one specific topic, such as children that are obsessed with trains or adults that are highly interested in computers. This preoccupation makes

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<sup>23</sup> Augustyn, "Autism Spectrum Disorder: Terminology, Epidemiology, and Pathogenesis."

<sup>24</sup> Jaarsma and Welin, "Autism as a Natural Human Variation," 25.

<sup>25</sup> Augustyn, "Autism Spectrum Disorder: Terminology, Epidemiology, and Pathogenesis."



it hard for autistic people to shift their attention to other things. Another feature of autism is atypical sensory perception, which can make an autistic person over- or under-responsive to stimuli. This sensory aspect can present itself in many different ways, by for instance a strong preference of certain textures, while having a strong aversion to others. Bright lights or loud music can be experienced as painful, while other autistic people do not seem to experience pain at all.<sup>26</sup>

Other characteristics that are not defining features are motor deficits such as clumsiness or an abnormal gait, increased head circumference and having special skills, for instance in memory, mathematics or solving puzzles.<sup>27</sup>

This phenomenology of autism is used in psychiatry. Autism as a psychiatric disorder is the first of six ways of understanding autism that I will describe. This will be explained in the next section.

## 2.2 Six ways to understand autism

### Psychiatric diagnosis

In the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) of the American Psychiatric Association, Autism Spectrum Disorder (ASD) is placed under the section of neurodevelopmental disorders. From this, we can conclude that autism is seen as a disorder that has to be present in a person from the early stages of life. From the fact that it has been named a spectrum disorder, we can derive that autism as a psychiatric diagnosis is not a singular, clearly defined disorder; it comes in many shapes and sizes. In the DSM-5, Autism Spectrum Disorders consist of five main criteria (see Box 1). In short, according to the DSM-5, ASD consists of specific symptoms (mostly in the fields of social communication and behavior), is an innate developmental disorder, causes significant difficulties in everyday life, and all of these aspects cannot be better explained by other disabilities or developmental problems a person may suffer from.

Even though the DSM is often criticized, it is the most widely used manual for the classification of psychiatric diseases and it has been extremely useful through formulating clear definitions that are used around the world to compare (groups of) patients. It allows psychiatrists to speak the same language and to have an international guide book to make reference to.

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<sup>26</sup> Augustyn and von Hahn, "Autism Spectrum Disorder: Clinical Features."

<sup>27</sup> Augustyn and von Hahn.

Box 1: Autism Spectrum Disorder, main aspects as described in the DSM-5<sup>28</sup>

- A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:**
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
  3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
- B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:**
1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
  2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
  3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
  4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
- C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).**
- D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.**
- E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.**

### Neurocognitive reality

Next to being a psychiatric diagnosis based on certain behavioral symptoms, autism is also a term used to describe a neurocognitive reality that could explain why someone shows those symptoms.<sup>29</sup> Various theories try to explain this, of which the *theory of mind* theory is the best known. *Theory of mind* refers to the ability developed in childhood to understand beliefs and intentions of others. This ability is impaired in most people diagnosed with autism, which could explain the difficulty autistic people experience in putting oneself in somebody else's position. However, the *theory of mind* theory is not the only way in which the phenomenon of autism is

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<sup>28</sup> American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (American Psychiatric Association, 2013), <https://doi.org/10.1176/appi.books.9780890425596>.

<sup>29</sup> Hens, Robeyns, and Schaubroeck, "The Ethics of Autism," 2.

explained. Other theories are for instance: *the weak central coherence theory*, *the weak executive function theory*, *the intense world theory* and the *HIPPEA (high, inflexible precision of prediction errors in autism)* theory.<sup>30</sup> Explaining these theories in detail is not necessary for understanding the point of view of people that see autism as a neurocognitive reality. Those who approach autism as a neurocognitive reality are mostly concerned with finding a (physical) explanation for the symptoms in autistic people, to be able to grasp the concept of the disorder and probably find a treatment for it.

### The neurodiversity movement

As opposed to the psychiatric diagnosis and the neurocognitive reality view, the neurodiversity movement advocates the position that neurodevelopmental disorders, such as ASD, should not be pathologized. Every human being is neurologically different. Differences in neurological ‘wiring’ that result in atypical behavior should be seen as merely a human variation, not as a disorder. ASD is one of those differences in ‘wiring’. Neurodiversity supporters plead for ‘neuro-equality’, in which they express the need to be understood by society as requiring equal opportunities and the acceptance that their condition is not something that they suffer from or that should be cured.<sup>31</sup>

Since its origin in the 1990s, the neurodiversity movement has been led mostly by people with so-called high-functioning forms of autism, but they stand up for the rights of all possible forms of autism in the spectrum. To them, autism is not a disorder, but an identity. Even further, some of them claim that if neurodiversity is considered a disease, ‘neurotypicality’ might as well. Who is to say what is normal and what is not?<sup>32</sup> The neurodiversity movement rejects the existence of neuro-normality.<sup>33</sup> It thus makes an ontological and a political claim: the former is the one of autism not being a disorder, whereas the latter is the need for similar rights, recognition and acceptance.<sup>34</sup>

Autism understood as an identity is a position taken by many autistic self-advocates. Nancy Bagatell explored how the autistic community tries to transform the dominant notion of autism as a neurobiological disorder.<sup>35</sup> In her work, Bagatell explains three historical trends in

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<sup>30</sup> Hens, Robeyns, and Schaubroeck, 2.

<sup>31</sup> Jaarsma and Welin, “Autism as a Natural Human Variation,” 23; Andrew Fenton and Timothy Krahn, “Autism, Neurodiversity and Equality Beyond the Normal,” *Journal of Ethics in Mental Health* 2 (November 1, 2007).

<sup>32</sup> Ortega, “The Cerebral Subject and the Challenge of Neurodiversity,” 431.

<sup>33</sup> Hacking, “Humans, Aliens & Autism,” 46.

<sup>34</sup> Jaarsma and Welin, “Autism as a Natural Human Variation,” 23–24.

<sup>35</sup> Bagatell, “From Cure to Community.”

the development of the concept of autism that influenced the emergence of an autistic community. The first trend is the broadening of the autism spectrum to include High Functioning Autism (HFA) and Asperger's disorder. People with these subcategories of autism often have better capacities to express themselves, giving the autism community a stronger voice. This broadening of the spectrum therefore led to the second trend: the emergence of the disability rights movement and, specifically, the self-advocacy movement. Self-advocacy, already successful in the civil-rights movement and disability movement, became important for autistic people as well. The third and last trend that fueled the emergence of autistic communities is the explosion of computer technology. Via the internet, autistic people are able to get in contact with each other: "The Internet has, in many ways, become an important tool of identity. Freed from the constraints of typical ways of perceiving and interacting, individuals with autism meet each other, share stories, and provide support."<sup>36</sup> Impaired social communication skills form no longer a boundary between autistic people and social interaction. Through the internet, communication has become easier and autistic people can surround themselves with like-minded people. These developments have made it possible for autistic people to form a community and voice their opinions and experiences on a larger scale.

In various blogs, autistic self-advocates give the autistic community a voice and share their experiences of being autistic. One of these bloggers is the Autistic Advocate, arguing that autism is an identity: "An Autistic Identity is integral to our well-being, physically and mentally, to our whole selves. Yet we are made to feel as though we have to suppress that. To go further we are actively told that our identity is wrong and broken. So we mask and create and build new ones, false ones, imperfect replicas of ourselves."<sup>37</sup> He also claims that most people in the Autistic community favor the Identity First Language. That is, people prefer to be called 'an autistic person' as opposed to 'a person with autism'. In Chapter 4, the topic of autism as an identity will be further addressed.

### The pro-cure movement

As the name reveals, the pro-cure movement does conceive of autism as a disease that should be cured. To them, autism is anything but part of the identity of a person. The etiology should be searched for, in order to develop treatment options for people suffering from this disease. The pride with which autistic persons of the neurodiversity movement claim their identity,

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<sup>36</sup> Bagatell, 36.

<sup>37</sup> Kieran Rose, "An Autistic Identity," *The Autistic Advocate* (blog), accessed June 6, 2019, <https://www.theautisticadvocate.com/2019/03/an-autistic-identity.html>.

differs largely from the misery people from the pro-cure movement express when talking about their experiences with autism. This also becomes clear when looking at the different ways in which the two groups use the term autism. For the pro-cure movement, people *have* autism—signifying something external that affects them—while in the neurodiversity movement, people *are* autistic, as part of who they are.<sup>38</sup> Unlike the Autistic Advocate, Jonathan Mitchell, who is (using his own words) affected by the disability autism, voices his worries on the effects of the neurodiversity movement: “Many parents of autistic persons and some autistic persons themselves (myself included) have expressed a desire for a cure for autism. This causes outrage among neurodiversity proponents. They equate a cure for autism with eugenics and genocide. (...) The only cure we need, they say, is an end to discrimination, which would solve, or at least greatly mitigate, the challenges and poor outcomes accompanying autism.”<sup>39</sup>

Mitchell sketches the sentiments of the neurodiversity as opposed to his own desire for a cure for autism. He also challenges the claims by neurodiversity proponents that the majority of people with autism agree with the views of the neurodiversity movement: “Many on the spectrum can’t speak or use a computer. They can’t argue against ‘neurodiversity’ because they can’t articulate their position. They’re too disabled, you might say. In the wider group of autistic people, there’s a 4:1 ratio of autistic males to females, yet the majority of neurodiversity proponents are women. Many of them have no overt disability whatsoever.”<sup>40</sup> The main worry Mitchell has, is that the neurodiversity movement will hinder the scientific research towards a cure for autism. A cure desired by him and many other, severely afflicted, individuals with autism.

The pro-cure movement differs from the DSM-5 in the way autism is understood, because the classification and criteria as described in the DSM-5 are intended as neutral (as far as possible). The way pro-cure supporters look at autism, is with a strong aversion. This is related to the distinction between descriptive and normative conceptualization. The DSM-5 aims to give a descriptive definition of autism, whereas the pro-cure movement gives a normative definition. They make the concept of autism value-laden, in this case with a negative value. Pro-cure sentiments are often based on a ‘deficit view’ on autism. Janette Dinishak investigated this view in relation to the concept of autism.

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<sup>38</sup> Ortega, “The Cerebral Subject and the Challenge of Neurodiversity,” 427.

<sup>39</sup> Jonathan Mitchell, “The Dangers of ‘Neurodiversity’: Why Do People Want to Stop a Cure for Autism Being Found?,” *The Spectator*, January 17, 2019, <https://spectator.us/dangers-neurodiversity-cure-autism/>.

<sup>40</sup> Mitchell.

## Deficit view

One way to understand human differences is through the *deficit view*. Dinishak explains the deficit view as follows: “Roughly, to understand some phenomenon in terms of deficits is to (a) conceptualize the phenomenon as the lack or absence of some feature, trait, capacity, etc. and then (b) characterize this lack or absence as a deficit in the feature, trait, capacity, etc. in question—that is, as the lack or absence of some feature, trait, capacity, etc. that one ought to have. In short, labeling some feature a "deficit" serves a normative function.”<sup>41</sup>

This approach has been criticized on the grounds that it categorizes human beings mainly (or solely) in terms of their deficiencies. Janette Dinishak examines these critiques and uses autism as an example of a supposed deficit as a focus case. She explains the ways in which autism is mainly understood as a deficiency. An example is the *theory of mind* theory as described above. The ability developed in childhood to understand beliefs and intentions of others is impaired in most people diagnosed with autism. This lack of a *theory of mind* theory is one of the most influential deficit views on autism.

“Given that autism is classified as a disorder, it is not surprising that the bulk of autism research and intervention strategies have a largely negative emphasis. Researchers and practitioners aim to identify, characterize, and intervene on "what's wrong" with autistic individuals.”<sup>42</sup>

Even though, as stated by Dinishak, the negative connotations are not surprising, the deficit approach is highly criticized. The emphasis laid on the deficit aspect of autism leaves no room for the strengths or neutral aspects of autism to be recognized. As described earlier for the case of autism, the neurodiversity movement is against the conceptualization of autism as a disorder or deficiency. One of the main critiques on the deficit view is that it influences public opinion, policy and science in an undesirable way. As long as the deficit view is the predominant understanding of autism, the issue of stigmatization will remain.

Dinishak makes a distinction between the claim that current deficit views of autism are problematic and the claim that deficit views in general are objectionable. The first claim leaves room for the development of a deficit view of autism which stays away from the problematic aspects identified in the current deficit view. The second claim rejects the deficit view in every shape or form and from that point of view, there is no need for revising a current understanding of autism based on deficiencies.

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<sup>41</sup> Janette Dinishak, “The Deficit View and Its Critics,” *Disability Studies Quarterly* 36, no. 4 (December 2, 2016), <https://doi.org/10.18061/dsq.v36i4.5236>.

<sup>42</sup> Dinishak.

As to the current understanding of autism based on the deficit view, Dinishak describes three problematic aspects. First, the current understanding emphasizes the deficit aspects too much, which leads to overlooking other possible explanations for the phenomenon of autism. A second problem is the way in which deficit attributions are made. A deficit attribution is based on a standard of what is normal, but this requirement of a standard is attached to value judgements. It is one thing to notice a lack or absence of something in a person, but it is another step to call this a deficit. Dinishak adds: “Accepted values may be so entrenched that those making deficit determinations do not even recognize that they are making a choice to assign negative value to the deviation.”<sup>43</sup> This problem of using the deficit view might therefore be difficult to recognize for the ones using the concept based on the deficit view, but for the case of autism, examples are plenty. In the dominant narrative of autism, suffering from the condition is integral to the concept of autism. When people think of autism, they think of a condition that comes with problems and severe issues. However, many autistic people or parents of autistic children claim that this is not the case for them. The absence of a certain trait (the so-called deficit) does not automatically lead to suffering. The underlying value-judgement fostering this connection should be revised. Thirdly, whether a difference is judged as a deficit, depends (partly) on the label of autism that a person had already received. Dinishak gives the example of differences in intelligence test performances in children with and without the diagnosis of autism. There is a positive bias in favor of neurotypicality. The results of the autistic group are judged differently because of the label autism they already had. When non-autistic children perform worse compared to the autistic group, this is not perceived as a deficit in their intelligence. Moreover, when autistic children outperform the non-autistic group, for the autistic children, it is not seen as a strength, but merely a part of them being autistic, as a part of their deficit. Neurotypical children cannot fail, while every result of autistic children is ascribed to their autism.

### Social constructivism

Sally Haslanger, as referred to earlier, defends a social constructionist account of gender and race. She explains social constructivism as follows: “Social constructionists are interested in cases where there is a gap between manifest, operative, and target concepts, and in particular, where assumptions about what's natural are misleading us about what we're talking about. Constructionists come in many forms, of course, but at least a good number of us argue,

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<sup>43</sup> Dinishak.

concerning certain specific concepts, that contrary to common assumptions, we are tracking something social when we think we're tracking something natural, and pointing this out is a way of understanding what we're really talking about.”<sup>44</sup>

Autism is also considered to be a social construct by some.<sup>45</sup> Proponents of the neurodiversity movement have made the analogy that their struggle resembles that of the gay rights movement. Homosexuality was seen as a disorder in the past, yet, today it is seen as a form of being different in large parts of the world. Being gay is no longer considered to be a disease. According to Sarah Allred, the same could be the case for autism. In the same way that a society can be homophobic, our societies are ‘autism-phobic’. Having autism would not be pathologized if society would be more accepting of this form of being different.<sup>46</sup> However, this way of reasoning could potentially be disadvantageous to the people with autism that do need help from society. Because, as described earlier, if autism is judged to be just a natural variation and not a disorder, why would one need support?

Jaarsma & Welin offer two strategies to overcome this problem. First, autistic persons may be considered as not having a disorder, yet they could still be seen as being vulnerable in general, and therefore in need of support. Vulnerability is a ground for special responsibilities towards a group. However, categorizing a minority as vulnerable is not always widely accepted as a positive thing, because it may lead to inequality between the group considered vulnerable and the group giving them that label. Jaarsma & Welin do not agree with this line of argument. According to them, vulnerability is something everyone experiences at least once, for instance as infants. Also other groups, such as the elderly, are vulnerable. Therefore, this label is not promoting inequality, but equality. The second strategy they propose, is to use the concept of neurodiversity only for those individuals that are high-functioning, because the low-functioning people with ASD are clearly in need of support and care. If society would accept certain traits of high-functioning autistic people as ‘normal’, they would be able to live in society without being judged as having a disorder. “So, disability in autism is always, at least partially, socially constructed disability”.<sup>47</sup>

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<sup>44</sup> Haslanger, “What Are We Talking About?,” 20.

<sup>45</sup> C.S. Wyatt, “Socially Constructed Autism,” *The Autistic Me* (blog), accessed June 18, 2019, <https://theautisticme.blogspot.com/2010/08/socially-constructed-autism.html>; Harvey Molloy and Latika Vasil, “The Social Construction of Asperger Syndrome: The Pathologising of Difference?,” *Disability & Society* 17, no. 6 (October 2002): 659–69, <https://doi.org/10.1080/0968759022000010434>.

<sup>46</sup> Jaarsma and Welin, “Autism as a Natural Human Variation,” 25.

<sup>47</sup> Jaarsma and Welin, 48.



To summarize, autism is a social construct that was invented by psychiatrists and it is not a natural kind. Even though I agree with Sarah Allred that having autism would not be pathologized if society would be more accepting of this form of being different, I do not agree with the claim that autism is a social construct in the sense that it does not really exist. The heterogeneity of the spectrum and the severity of some of the cases do not allow this rejection of the existence of autism.

The previously described six views on autism can be narrowed down to three main conceptualizations. Autism as a psychiatric diagnosis, autism as a neurocognitive reality, the pro-cure movement and the deficit view fall under the scope of *autism as a disorder*. The neurodiversity movement follows the perspective of *autism as an identity*. In the *social constructivism* view, autism is not something that really exists, but it is made up by society. In the following, I will focus on the views of autism as a disorder and as an identity. To regard autism as a disorder, is to treat someone with autism as if that person suffers. To see autism as an identity, is to treat someone with autism as if that person is (merely) different. Following this description of the different views on the nature of autism, I will analyze the practical and moral consequences of holding the two main views.

### 2.3 Moral analysis

Moral philosophy is concerned with what is right and what is wrong, and how people should act in relation to others. The search for an ideal concept of autism seems to stem from the conviction that the current conceptualizations are insufficient for creating a world for autistic people that is good for them to live in. Contemporary societies might accommodate autistic people (diagnosed with autism as a disorder) in certain needs, but when this unavoidably comes with a stigma, one might doubt whether understanding autism as a disorder is beneficial to them. The present uses of ‘autism’ might not be the way people should interact with each other. In the previous chapter, I explained through an ameliorative approach which aspects of an account of autism are desirable. Following that, the next step is to find out which concepts best serve the purposes as described earlier.

As a brief recap: firstly, the understanding of autism should lead to increased levels of well-being for people with autism. This can be achieved by removing the stigma on autism. Secondly, it should consist of certain aspects that relate the concept of autism to mental health care. Thirdly, it should be a concept accepted by at least the majority of people with autism. My hypothesis was that in order to be accepted by the majority, a conception of autism should

allow autism to be both an identity and a disorder at the same time. However, if the majority requirement is not immediately met, but the other two are, it could still be useful to endorse the new understanding. The endorsement by the majority might need more time and resources in order to convince them that this new understanding is better than the dominant one, but it might still be successful.

I will first explain which ethical perspectives I chose to use for the analysis. Subsequently, I will elaborate on the moral consequences of using the concept of autism as a disorder or as an identity.

### Different ethical perspectives

There are many different theories that could possibly be interesting in analyzing which concept of autism would be preferable. For this thesis, I chose three theories which I consider useful frameworks for the question concerning the concept of autism. Firstly, I will use utilitarianism, because this ethical theory is concerned with the greatest good for the greatest number of people. Increasing the well-being of autistic people is what I aim to achieve by formulating an understanding of autism, so this theory might help to reach that goal. Secondly, I will investigate the different concepts of autism by looking at disability theories. The comparison of autism and disability has been made by others.<sup>48</sup> Disabled people share many of the problems encountered in society by people with autism, which makes disability theories an interesting and helpful point of view. Thirdly, I will use virtue ethics for the analysis of the moral consequences. Virtue ethics is especially concerned with the individual and one's motives for one's acts, as opposed to utilitarianism, for which only the consequences of an act count.

For the analysis of moral consequences, I will use the paradigm cases of the understanding of autism as a disorder and as an identity as described above. The consequences of defining autism as a disorder have an effect on many different aspects of life, but mostly on the probability that someone receives medical care and on the level of stigmatization a person experiences. In cases where a child shows severe symptoms, the diagnosis of autism gives the child the possibility to receive the necessary care and it may result in acceptance of its deviant behavior.<sup>49</sup> However, on the other hand, as described earlier, receiving a label of a psychiatric

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<sup>48</sup> Berend Verhoeff, "The Autism Puzzle: Challenging a Mechanistic Model on Conceptual and Historical Grounds," *Philosophy, Ethics, and Humanities in Medicine* 8, no. 1 (2013): 17, <https://doi.org/10.1186/1747-5341-8-17>; Damian E.M. Milton, "On the Ontological Status of Autism: The 'Double Empathy Problem,'" *Disability & Society* 27, no. 6 (October 2012): 883–87, <https://doi.org/10.1080/09687599.2012.710008>.

<sup>49</sup> Geert Keil, Lara Keuck, and Rico Hauswald, eds., *Vagueness in Psychiatry*, First edition, International Perspectives in Philosophy and Psychiatry (Oxford: Oxford University Press, 2017); Hacking, "Humans, Aliens & Autism."

disorder is connected to stigmatization. This label will adhere to a person for the rest of their life, with sometimes undesired effects, such as being rejected for a job based on a supposed mental instability or having troubles with forming relationships because others do not know how to cope with a person with such a label (or are afraid or put off before even entering a relationship). Autistic people whose autism is seen as their identity, might experience the opposite of what is described above. Having autism as one's identity and not as a disorder, might avoid stigmatization; a favorable aspect of this conceptualization. However, it may also result in a situation where someone with autism needs (medical) care, but this need is not recognized by society, because this person is not conceived of as 'ill'. Another possibility is that the lack of recognition is not on society, but on the person with autism. If he or she understands autism as an identity, there is no need to consult a psychiatrist or seek help in any form or shape.

A counter argument against the claim that autism understood as someone's identity is unfavorable because it may lead to undertreatment, is that this consequence cannot be attributed to the conceptualization of autism as an identity. Instead, it is due to the way our society, and care institutions in particular, are organized. In order to receive mental health care, often a psychiatric diagnosis is required. When autism is understood as an identity, the autistic person will not accept a diagnosis and will therefore not be eligible for a psychiatric consultation. This implies that a conceptualization of autism as an identity is not the problematic aspect, because the way society is organized is not intrinsic to the concept of autism.

This raises the question whether it is possible to understand autism as an identity only and not to have undertreatment. In our current society, with the way care institutions are organized, I do not think that this is feasible. For a conceptualization of autism I consider it to be necessary to always have a connection with mental health care.

### *Utilitarianism*

According to utilitarianism, the best choice in a moral dilemma would be the choice that leads to the greatest good for the largest number of people. Utilitarianism is a subcategory of consequentialism, one of the main approaches in normative ethics. The decision of whether an action is right or wrong, is based on its results. It does not matter how one feels about a situation, or what someone's motivations behind their behavior are.

The classic example of utilitarian decision-making is that of the ‘Trolley Case’ by Philippa Foot,<sup>50</sup> in which a bystander is forced to make a decision about a train carriage speeding towards five railway workers. By diverting the train to another track, the bystander can save the five railway workers, but one railway worker that is working on the other track, will be killed. Choosing to save the five railway workers at the expense of the one worker on the other track, is the utilitarian decision. This would lead to the best overall result; one victim as opposed to five victims in this case is the greatest good for the largest number of people. When faced with the dilemma of what the most desirable concept of autism is, a utilitarian is concerned with what the consequences of the use of the two concepts are. One’s motivations for choosing either the disorder-view or the identity-view are irrelevant, since only the result counts.

Let us assume that the greatest good is well-being. The best possible consequence would be that the overall level of well-being is increased. Will this be more likely the result of using the disorder-view or the identity-view? Looking at the paradigm cases in which the choice of concept has an effect on stigmatization and mental health care, the utilitarian will have to decide which consequences are the most desirable. The disorder-view of autism will lead to stigmatization, while the identity-view will lead to more difficulties in receiving the appropriate mental health care. Which of those views will have the most positive (or, in this case, the least negative) effect on well-being? Having read many testimonies by people with autism or parents with autistic children, I have come to know that this question is very difficult to answer. Both sides use convincing arguments, but more importantly, they have different ideas on what would constitute the highest level of well-being for autistic people. If this disagreement cannot be solved, it will not be possible to decide what would be the right decision from a utilitarian point of view. At this point, utilitarianism seems to be unable to resolve the disorder vs. identity dilemma.

### *Disability ethics*

Elizabeth Barnes developed a well-known theory of disability.<sup>51</sup> She explicitly states that the connection between disability and well-being is fundamental for the philosophical account of disability. Barnes supports the ‘mere-difference’ view on disability, which she describes as follows: “Having a disability is something that makes you different, but not something that by

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<sup>50</sup> Philippa Foot, “The Problem of Abortion and the Doctrine of Double Effect,” *Oxford Review* 5 (1967): 5–15.

<sup>51</sup> Elizabeth Barnes, *The Minority Body: A Theory of Disability* (Oxford University Press, 2016), <https://doi.org/10.1093/acprof:oso/9780198732587.001.0001>.

itself makes you worse off because of that difference. Being disabled is simply something that makes you a minority—it is a way of having a minority body.”<sup>52</sup> The same can be said about autism; it is a way of having a minority mind. However, this does not mean that being autistic is always easy. On the contrary, having autism or having a child, sibling or partner who is autistic can be very difficult. On this negative side of autism (or in other words, the ‘value-ladenness’ of the concept of autism), I will elaborate in Chapter 3, when discussing the concept of mental disorder.

The debate on disability is related to the debate on autism, because it revolves around the question what kind of effect being different has on one’s well-being and the protection of one’s interests. In this thesis, I refrain myself from addressing every interest people might have, and focus on well-being.

In the ‘mere-difference’ view, disability is something that makes one different from someone else, but it does not need to have any effect on a person’s well-being. It can affect someone’s well-being, but that might for instance be a result of how society treats people with a disability, not a characteristic of the disability itself. Barnes explains this with making a reference to homosexuality in a liberal society: “Most people hold a mere-difference view of gayness. And yet gay people tend to be at higher risk of depression, anxiety, self-harm, and suicide. It could well be the case that gay people have, on average, lower levels of well-being than straight people. But such discrepancy would not be remotely mysterious, nor would it in any way threaten a mere-difference view of gayness. It’s not easy to be gay in contemporary society. Straightness is the perceived norm, and gayness is discriminated against. Most of us, I’d wager, would attribute any discrepancy in well-being between gay people and straight people to the way society treats gay people, not to gayness itself. That is, we don’t think such a discrepancy (if there is one) tells us anything about the effect gayness itself has on well-being.”<sup>53</sup>

Barnes’ view on gayness can be applied to autism too. This view would unfold as follows. The discrepancy in well-being between autistic people and non-autistic people can (at least) partly be attributed to how society treats people with autism. How the norms are for social conduct and, for example, what kind of behavior is expected of children, can be the reason that autistic people feel as if they do not fit in, because they cannot conform to those norms and kinds of behavior. The lower levels of well-being are not inherently part of the

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<sup>52</sup> Barnes, 79.

<sup>53</sup> Barnes, 56.

concept of autism, but of the effect it has on how society treats autistic people. Autism could also be a ‘mere-difference’, which would be compatible with the ‘identity-view’ and not with the ‘disorder-view’. Autism as an identity would mean that the autism is a mere difference of a person compared to others, while other persons have other differences shaping their identities.

In the ‘bad-difference’ view, however, having a disability inherently means that, all things considered, one’s well-being is negatively affected. The ‘disorder-view’ can be seen as the equivalent of the ‘bad-difference’ view.

This same distinction between the ‘mere difference view’ and the ‘bad difference view’ lies beneath our question about autism. Whether we should adhere to ‘autism’ as a disorder or as an identity can be phrased in other words: does having autism mean that someone is inevitably worse off, or would it be possible that it has no effect on someone’s well-being? Unfortunately, disability activists still hold contrasting views and there is no consensus on what the best account of disability is. This means that on this specific topic, the disability debate of ‘mere-difference’ vs. ‘bad-difference’ cannot provide a solution for the debate about the conceptualization of autism. However, aiming for a solution might be too ambitious. Any illuminating insights would already be valuable. In the next chapter, I will elaborate on a specific variant of the mere-difference view by Barnes which could possibly be of help in the conceptualization of autism as simultaneously a disorder and an identity.

### *Virtue ethics*

Virtue ethics is one of the principal approaches in normative ethics, next to consequentialism and deontology. The rightness or wrongness of an action is determined by the motives and the moral character of the person that acts. This contrasts with the utilitarian theory as described before, where the consequences of an action determine whether that act is right or wrong. Since Aristotle, many different virtue ethics theories have been developed, but virtues and vices are always the fundamental aspects of virtue ethics. Many concepts used in later times also have roots in this ancient philosophy. “These are *arête* (excellence or virtue), *phronesis* (practical or moral wisdom) and *eudaimonia* (usually translated as happiness or flourishing) [emphasis added].”<sup>54</sup>

According to all virtue ethical theories, a good person possesses certain virtues and phronesis. This phronesis is an understanding of what is harmful and what is beneficial. It is a

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<sup>54</sup> Rosalind Hursthouse and Glen Pettigrove, “Virtue Ethics,” in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (Metaphysics Research Lab, Stanford University, 2018), <https://plato.stanford.edu/archives/win2018/entries/ethics-virtue/>.

trait that is developed through life. Children cannot have phronesis, simply because they haven't had the time to learn this practical wisdom. It is this wisdom that provides a good person with the capacity to do the right thing in any given situation. Examples of virtues are: "Plato emphasized four virtues in particular, which were later called cardinal virtues: wisdom, courage, temperance and justice. Other important virtues are fortitude, generosity, self-respect, good temper, and sincerity."<sup>55</sup>

A virtuous person would possess the four cardinal virtues described by Aristotle. How would such a person address the question of what autism is? How would a virtuous person understand autism; as a disorder or as an identity? It is imaginable that a wise person, possessing the virtue of wisdom, is aware of the controversy in the debate about autism. He or she would know that many people are hurt by calling autism a disorder, but that there are also people who strongly believe that autism should not be seen as an identity, because they believe it to be a disease that needs to be cured. This means that a virtuous person would be wise to not make a decision straight away, but inform him- or herself about the different sides. This would also be an act of temperance, since the virtuous person would be moderate in stating their opinion and try to find a decision that would be acceptable to the majority of the people.

A virtuous person might find it difficult to dispute the prominent view of autism in society, but if that is what he or she deems important it has to be done, and that would be an act of courage. The neurodiversity movement might be strongly voiced, but they are still a minority. Autism understood as a disorder is the main view in our current society. A courageous person will have to withstand our current social norms and speak up for the minority. Social justice will be achieved when people with autism are less stigmatized. This can be done by promoting the identity view instead of the disorder view. The wise and courageous person will do this, but will also keep in mind that some autistic people need health care. This will not be provided when autism is only understood as an identity. A virtuous person will have to find the perfect balance between these views. This process of introspective deliberation of what autism is, would also be a useful exercise for the virtuous person. Virtuous conceptualization requires the possession of many virtues and phronesis, which can be further developed during this process.

In this moral analysis, both understandings of autism appear to have a certain value. Utilitarianism, disability ethics and virtue ethics seem to be unable to decide which view would

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<sup>55</sup> James Fieser, "Ethics," in *The Internet Encyclopedia of Philosophy*, 2019, <https://www.iep.utm.edu/>.

be the most desirable. In the next chapter, I will go deeper into the subject of psychiatric disorder, in order to be able to decide whether autism belongs to this category.



## Chapter 3 – Psychiatric disorders

In the previous chapter, I have analyzed the moral consequences of using the concept of autism either as a disorder or as an identity. So far one of the suggestions seems to be that we cannot simply drop the understanding of autism either as an identity or as a disorder. In this chapter, I will further investigate what it means to say that something is a disorder. To claim that something is a disorder, or not, should imply that one has a clearly defined concept of what a disorder is, and it would mean that one also has an (implicit or explicit) idea about the opposite of having a disorder: health.

Firstly, I will explain a concept of health by Machteld Huber which I will argue to be very useful in the debate on autism. Secondly, I will investigate the concept of mental disorder; the conceptualization and the historical development that shaped this concept. Following this, I will address whether the concept of mental disorder can be value-free and make a comparison with Elizabeth Barnes' 'Value-Neutral Model of disability'.

Before reading this chapter, it is important to note two things. Firstly, the line between health and disease in psychiatry is always blurred.<sup>56</sup> When do we speak of a disorder? Where does the threshold lie? However, making an attempt at understanding and defining autism, will at the very least result in new insights and hopefully also in a better understanding of the lives autistic people are leading. Secondly, this chapter concerns psychiatric disorders in general. Autism is an example of a psychiatric disorder, but it differs from others, like depression or schizophrenia. The scope of this chapter does not allow me to elaborate on the question of why autism is different from (or similar to) other psychiatric disorders. Nevertheless, one overt difference is that certain psychiatric disorders, such as autism, are, as was said before, developmental disorders. Autism differs from many other mental disorders because it is a developmental disorder present in children from a very young age. This may have more implications for the development of someone's identity than for instance a depression that occurs later in one's life. This also brings up new questions about parental rights and duties; for example, parents have to decide whether they have their child tested for autism.<sup>57</sup>

### 3.1 Conceptualization of health

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<sup>56</sup> Keil, Keuck, and Hauswald, *Vagueness in Psychiatry*, 3.

<sup>57</sup> Hens, Robeyns, and Schaubroeck, "The Ethics of Autism," 5.

When talking about the conceptualization of health, a good place to start is by consulting the definition of the World Health Organization (WHO). This definition describes health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.”<sup>58</sup> Given the increasing amount of the population that lives with chronic diseases, this definition does no longer fit the idea of being healthy.

Huber et al. propose a new dynamic concept, “health as the ability to adapt and self-manage.”<sup>59</sup> For the conceptualization of health, according to Huber et al., we need to look at the three important domains of health: physical, mental, and social. “In the physical domain a healthy organism is capable of “allostasis”—the maintenance of physiological homeostasis through changing circumstances.”<sup>60</sup> When threatened by harm, the ability to protect one’s physical body and restore the equilibrium (even though that might be an adapted equilibrium), is part of being a healthy organism. However, when this protective mechanism fails, an organism can suffer from a state of illness. In the mental domain, the concept of a “sense of coherence” is used to explain the new concept of health by Huber et al. This is a factor that contributes to mental health because it promotes “a successful capacity to cope, recover from strong psychological stress, and prevent post-traumatic stress disorders. The sense of coherence includes the subjective faculties enhancing the comprehensibility, manageability, and meaningfulness of a difficult situation.”<sup>61</sup> In the social domain, health is improved by independence despite suffering from an illness. “Health in this domain can be regarded as a dynamic balance between opportunities and limitations, shifting through life and affected by external conditions such as social and environmental challenges.”<sup>62</sup> The feeling of being in charge of your own life improves subjective well-being.

These explanations of the new concept of health in the three domains imply that a person can suffer from a certain disease, but if that person manages to cope with this situation and can still experience a sense of well-being, that person can be considered healthy. This new definition of health and disease is of use in the discussion about autism and psychiatric diagnoses in general. One can be diagnosed with an autism spectrum disorder, while being content with one’s way of living and experience high levels of well-being. I believe that such a person is healthy, while still having the diagnosis of autism. Coping, resilience, adaptation;

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<sup>58</sup> M. Huber et al., “How Should We Define Health?,” *BMJ* 343, no. jul26 2 (July 26, 2011): 1, <https://doi.org/10.1136/bmj.d4163>.

<sup>59</sup> Huber et al., 2.

<sup>60</sup> Huber et al., 2.

<sup>61</sup> Huber et al., 2.

<sup>62</sup> Huber et al., 2.

all terms that are especially important to psychiatric patients. The world around them is sometimes described as ‘alien’ to them.<sup>63</sup> Living and functioning in a society that is not adjusted to your ‘brain wiring’, requires resilience and adaptation. When autistic people learn to cope with their problems stemming from autism, they can be as happy and healthy as everyone without such a diagnosis.

This means that you can be considered healthy, while still coping with the issues related to the diagnosis of autism. It is a condition that influences one’s life, but it does not make a person not-healthy. However, this is not the same as claiming that autism is not a disorder. It means that autism can be a disorder, but a person with autism can still be healthy. This line of argumentation is similar to the view that autism can be both an identity and a disorder. Autism as a part of your identity does not mean that your entire identity is taken over by a disorder.

### 3.2 Conceptualization of mental disorder

Having explained the conceptualization of health by Huber et al., we can now also articulate a definition of disorder. I would like to suggest that the absence of the ability to adapt and self-manage up to a level where one would have a sufficiently high enough level of well-being, could be the concept of a disorder. However, is that a sufficient description of a mental disorder? To see whether this reversed definition of health by Huber et al. can be used for mental disorders, such as autism as described in the DSM-5, I will elaborate on different ideas about what psychiatric disorders are conceived of. First, I will give a concise account of the historical development of the concept. Subsequently, I will highlight three views on the concept of mental disorder.

#### Historical perspective on mental disorder

To understand how we came to our current concept of mental disorder, it is useful to look at the historical development of the concept. In the history of medicine, for a long time, illnesses have been identified with anatomical deviancies. For somatic diseases, science aimed to find a biological cause for the medical condition. However, for most of the psychiatric disorders there has not been identified an anatomical substrate yet. We simply do not know why they develop in some people and not in others. Despite the identification of many environmental and genetic factors that contribute to the development of autism, no specific gene or anatomical abnormality for autism has been found. The pro-cure movement supports the search for this

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<sup>63</sup> Hacking, “Humans, Aliens & Autism.”

gene, but the neurodiversity movement claims that this search is futile, since autism is not something that should be cured.

In the history of the conceptualization of mental disorder, different approaches can be distinguished. Derek Bolton described three of those.<sup>64</sup> In the beginning of the twentieth century, the first psychiatrists began to give an account of disorders by describing the abnormal states of their patients (phenomenology of symptoms) and from this, they made a classification into syndromes. They assumed the underlying pathology of the mental disorders would be similar to those of the somatic disorders. This medical approach sees the existence of mental disorders as self-evident. The next approach, the psychological paradigm, disputes this view. Psychologists claim that mental disorders can mimic the effect of neurological lesions, causing the abnormal behavior. The assumption that there must be an anatomical substrate was no longer present. The third approach, the sociological approach from the 1960s, contests that assumption radically. This approach is rooted in social constructivism and conflicts with the medical model of psychiatric disorders. Writers such as Foucault, Goffman and Szasz argued that a mental disorder is a deviance from the social norms of the dominant group in a society. These critiques on mainstream psychiatry remain relevant topics of discussion today.

#### A first definition

As a starting point, I will use the description of mental disorder provided by Jennifer Radden in the Stanford Encyclopedia of Philosophy: “The concepts of mental disorder, or illness, are ascribed to deviations from normal thoughts, reasoning, feelings, attitudes, and actions that are by their subjects, or by others, considered socially or personally dysfunctional and apt for treatment.”<sup>65</sup> Important terms are ‘normal’, ‘dysfunctional’, and ‘apt for treatment’. A mental disorder is apparently something that makes a person act in an abnormal way and it is something that could (or maybe even should) be treated. There are core concepts that are often ascribed to mental disorders, such as disunity, irrationality, the presence of suffering and disability.<sup>66</sup> These aspects distinguish normal mental states from abnormal mental states and hence indicate the presence of a mental disorder.

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<sup>64</sup> Derek Bolton, “What Is Mental Disorder?,” *Psychiatry* 8, no. 12 (December 2009): 468–70, <https://doi.org/10.1016/j.mppsy.2009.09.002>.

<sup>65</sup> Jennifer Radden, “Mental Disorder (Illness),” in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (Metaphysics Research Lab, Stanford University, 2019), <https://plato.stanford.edu/archives/spr2019/entries/mental-disorder/>.

<sup>66</sup> Radden.

Radden's definition of mental disorder has shortcomings in that it turns 'mental disorder' into a label one would not like to receive. Are there different ways of conceptualizing mental disorder without those shortcomings? I could describe many other definitions of mental disorder, with either different or the same shortcomings as the one by Radden. To me, it is of more interest which kind or which type of thing a psychiatric disorder is. Kendler, Zachar and Craver suggest a model based on the philosophy of Richard Boyd for understanding psychiatric disorders.<sup>67</sup> They explain three ways of thinking about psychiatric disorders that they discern in the literature and in psychiatric practices, and instead propose a fourth one, which they think is the most useful: *the mechanistic property cluster (MPC) model*.

#### The Mechanistic Property Cluster (MPC) model

This MPC model brings the discussion on the conceptualization of mental disorder to another level. Instead of the practical requirements, Kendler, Zachar and Craver discuss which category the concept of mental disorder belongs to. Are mental disorders part of an essentialist category, social constructs or practical kinds? These two latter options correspond with the views on autism as described in Chapter 2. Practical kinds are the diagnoses used by psychiatrists, whilst socially constructed kinds obviously relate to the social constructivism view on autism.

First of all, essentialist categories are different from the views described in the second chapter. "Essentialist kinds have essences, and they exist whether or not we recognize them. They are indifferent to our psychiatric classifications."<sup>68</sup> In this essentialist view, a disorder such as autism should have one essential feature, from which all other signs and symptoms follow. Everyone with autism has this essential feature; non-autistic people do not have that feature. However, as Kendler, Zachar and Craver argue, since autism consists of a widely diverse spectrum, an essentialist view cannot hold. The heterogeneity and the influence of genetic and environmental factors on the development of autism make the essentialist category untenable.

Secondly, Kendler, Zachar and Craver dismiss the social constructionist view. They agree that societies influence and shape the concept of psychiatric disorder, but that does not mean that psychiatric disorders in general do not have common underlying mechanisms. "That

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<sup>67</sup> K. S. Kendler, P. Zachar, and C. Craver, "What Kinds of Things Are Psychiatric Disorders?," *Psychological Medicine* 41, no. 6 (June 2011): 1143–50, <https://doi.org/10.1017/S0033291710001844>.

<sup>68</sup> Kendler, Zachar, and Craver, 1144.

is, we deny that psychiatric kinds have as the basis of their existence only the fact that a particular culture finds them worth distinguishing.”<sup>69</sup>

Thirdly, the view of psychiatric disorders as practical kinds is based on pragmatism. Scientific constructs are created as instruments for achieving a particular goal. Whether these constructs are useful, is based on whether they succeed in achieving that goal. The question is not what is the ‘right’ construct, but which one is the most useful in reaching the goals set for that construct. This view can be considered as congruent with the description of disorders in the DSM-5. Kendler, Zachar and Craver agree that the practical kinds view is attractive, and certainly more useful than the other two, but they also note an issue: “The problem is that it also sacrifices any clear advice as to how classifications should be built. Pragmatism enjoins us to build useful theories, but it is agnostic about which kinds of theories are most likely to be useful.”<sup>70</sup>

With their MPC model, Kendler, Zachar and Craver claim to overcome these problems that are associated to the essentialist view, social construct view or the practical kinds account. Instead of searching for the essence of a psychiatric disorder either in biology or in social constructs, the focus should lie on finding “the complex and multi-level causal mechanisms that produce, underlie and sustain psychiatric syndromes.”<sup>71</sup> The mechanistic property clusters were originally developed by Richard Boyd: “The definition of a species, from a property cluster perspective, ‘depends upon the imperfectly shared and homeostatically related morphological, physiological and behavioral features which characterize its members’”<sup>72</sup> According to the MPC model, kinds do not have one singular feature that defines them, but they are made up by several different features that belong to the same cluster. The MPC view admits that there are certain explanatory structures underlying psychiatric disorders, but they are disorganized and not as clear as we might want them to be. “The ‘kind-ness’ of species is not, from an MPC perspective, produced by a defining essence but rather from more or less stable patterns of complex interaction between behavior, environment and physiology that have arisen through development, evolution and interaction with an environment.”<sup>73</sup>

This explanation of the different levels that play a role can account for the heterogeneity that is often part of the characteristics of psychiatric disorders. Different aspects of a psychiatric

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<sup>69</sup> Kendler, Zachar, and Craver, 1145.

<sup>70</sup> Kendler, Zachar, and Craver, 1146.

<sup>71</sup> Kendler, Zachar, and Craver, 1146.

<sup>72</sup> Kendler, Zachar, and Craver, 1146.

<sup>73</sup> Kendler, Zachar, and Craver, 1146–47.

disorder are combined in different ways in different patients; they interact with each other. Those different aspects can be caused by many different influences. This makes disorders seem like a relatively stable set of traits (which all belong to a certain cluster), while the individual patients all have their specific set of symptoms. This also means that, according to the MPC model, psychiatric disorders are not kinds that are forced upon the world by psychiatrists. They are natural kinds with a structure of different levels and causes that can be discovered. However, those different levels and overlapping mechanisms make it difficult to relate the causes of the disorder directly to a diagnosis. Categorization of psychiatric disorders remains a project with fuzzy boundaries, as was already noted in the introduction of this chapter. Yet, according to Kendler, Zachar and Craver, the MPC model provides us with as much structure as possible. Besides that, many of the (biological) causes of psychiatric disorders are nowadays still unknown, but the authors believe that in the future, many more will be discovered. This would make the categorization and the translation from mechanisms to diagnoses easier.

#### Why the MPC model is limited

Not everyone concurs with Kendler, Zachar and Craver about mental disorders. Berend Verhoeff, a prominent Dutch author in the field of the philosophy of psychiatry in general and autism in particular, disagrees with them.

Besides its many advantages, the MPC model applied to autism is not the solution we need, according to Verhoeff.<sup>74</sup> Using autism as a concrete case, he tries to understand the nature of psychiatric disorders in a different way. Verhoeff disputes the assumption made by Kendler, Zachar and Craver that psychiatric disorders are natural kinds with a structure of different levels and causes that can be discovered. This naturalistic approach is limited, because it neglects the social and historical aspects that are inextricably linked to the concept of autism. This limitation is ascribed to the unnatural division of two types of demarcations in psychiatry. A naturalistic model is only concerned with the categorization of distinct psychiatric disorders (demarcation of disorders within psychiatry), while the distinction between normality and abnormality (demarcation of disorders to distinguish them from normality) is just as relevant when describing the concept of autism.

According to Verhoeff, social and historical influences shape the concept of autism to such a degree that the concept is obligated to account for these influences. “This issue of setting the boundaries of autism is not just a matter of demarcating a coherent cluster of signs and

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<sup>74</sup> Verhoeff, “The Autism Puzzle.”

symptoms, it is also a matter of demarcating normality from pathology.”<sup>75</sup> Especially for autism, social norms and historical development shape the concept itself. If autistic people display unusual behavior, this is perceived as unusual because the social norms require different behavior of a person. Furthermore, these requirements may shift, resulting in a different concept in a different period of time. On these conceptual and historical grounds, Verhoeff argues against the use of the MPC model as a way to understand psychiatric disorders. Verhoeff’s claim about the importance of the social and historical influences on the concept of autism sheds light on the importance of the normal-abnormal distinction. In the closing paragraph of this chapter, I will address the topic of abnormality in further detail.

#### **Mental disorder: a value-laden concept**

Earlier, I mentioned the difference between the descriptive definition of autism in the DSM-5 and the normative, value-laden understanding of autism of the pro-cure movement. The descriptive definition is intended to be value-neutral. There are proponents of the view that there can be a value-neutral, naturalist description of mental disorder. The MPC model by Kendler, Zachar and Craver as described above is an example of such a naturalist description. However, evaluativists claim that even though the biological approach to diseases aims to be value-neutral, society stigmatizes having a mental illness anyway.<sup>76</sup> The concept may be intended as not being value-laden, but it is normatively loaded by how society reacts to it. For example, the term ‘cure’ is a value-laden term, as it implies a change for the better. When this is used in the context of mental disorder, that concept is immediately value-laden. These values are therefore always attached to the concept of mental illness. One may question whether a concept can be seen separately from those values. According to Kathleen Stock, mentioned earlier in the section on self-identification, merely describing a concept is not the same as expressing normative value about it.<sup>77</sup> However, as Stock notes, this distinction between facts and values is rejected by her critics, for instance by those inspired by the philosophy of Foucault. I, too, doubt whether it is possible to make this distinction concerning the concept of autism. Nowadays, it seems almost impossible to mention autism, or psychiatric disorders in general, without the connotation of, for example, abnormality.

It is possible to make an analogy with the disability debate, in which much is said on the value-ladenness of the concept. Elizabeth Barnes, mentioned earlier in the section on

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<sup>75</sup> Verhoeff, 7.

<sup>76</sup> Radden, “Mental Disorder (Illness).”

<sup>77</sup> Stock, “Doing Better in Arguments about Sex, Gender, and Trans Rights.”



disability ethics, developed the ‘Value-Neutral Model’ of disability.<sup>78</sup> This ‘Value-Neutral Model’ is a particular form of the ‘mere-difference’ view of disability. According to the ‘Value-Neutral Model’ of disability, Barnes explains, social attitudes and prejudices make up for many of the difficulties experienced by disabled people, but not (necessarily) for all of them. Some aspects of disability make a person worse-off, even in an ideal society. This seems paradoxical when combined with the ‘mere-difference’ view. However, as stated by Barnes, it is not mutually exclusive.

According to Barnes, it is possible to create an account of disability where both the ‘mere-difference’ view and the idea that having a disability comes with elements that make one worse-off, are combined. It is even consistent to hold the view that disability in itself does not make you worse off, but that, at the same time, a disability can be bad for some people or in specific situations. Some aspects of being disabled can be bad for you, while other aspects have a positive effect on your life. In that case, the overall value of the disability as a whole is neutral, while it consists of both good and bad aspects. The overall value-neutral-ness does not make those specific aspects any less good or bad. Barnes elaborates on this claim by stating how she uses the phrases ‘good for’ and ‘bad for’. Something is good for a person when it has a positive effect on that person’s well-being and something is bad when it has a negative effect on well-being.

Following this, Barnes explains the difference between ‘global bads’ and ‘local bads’. ‘Global bads’ are things that are bad for you ‘all things considered’. ‘Local bads’ are things that are bad for certain aspects of your life or things that are bad at a particular time in your life. The same reasoning goes for ‘global goods’ and ‘local goods’. Barnes explains how something can be a local bad and a global good at the same time by making an analogy of going for an early morning run. Getting up at 6:00 a.m. can have a negative effect on a person’s well-being at that specific moment because that person does not like getting up that early, making it a ‘local bad’. However, simultaneously, getting up early every day for a morning run is a ‘global good’ because overall it has a positive effect on a person’s well-being, by enhancing this person’s overall fitness and happiness and because it reduces stress. In this case, the person might consider those ‘bad’ early mornings of minor importance, because he or she prefers to be fit and happy in general. Similarly, something that is a ‘global bad’, can also be a ‘local good’.

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<sup>78</sup> Barnes, *The Minority Body*.

Before proceeding with Barnes' argumentation, a few points should be mentioned. It seems that Barnes assumes that there are many disabled people who consider their disability to be a 'global good'. However, one can question whether this group is an exception to the rule. It is imaginable that many people consider their disability to be a 'global bad', with significantly more experiences of 'local bads'. For those, it might be difficult to accept disability as a neutral feature.

Following the distinction of 'global goods' and 'local goods', Barnes highlights another important difference. Things can have an instrumental and a non-instrumental value. An example Barnes gives of this is a life-threatening disease such as cancer, which is according to her 'bad *simpliciter*', but it might be overall good for a cancer survivor to have had this experience because it gave someone new insights about what is important in life. This does not mean that having a life-threatening disease is in any way enjoyable, on the contrary, but it shows how something that seems to have only a negative effect on someone's life, can be good for a person in general. Something can be good for a person 'all things considered', despite also being something 'bad *simpliciter*'. Barnes understands '*simpliciter*' as follows: something, such as cancer, is 'bad *simpliciter*' in the way that someone who has cancer has a lower level of well-being than one would have if one did not have cancer. However, this does not mean that having cancer results in an overall decrease in well-being. Sometimes, something that is 'bad *simpliciter*', can have a positive effect on one's well-being. "The thought here is that if something is bad *simpliciter*, your life goes worse in virtue of it specifically, even if its overall causal effects on your well-being ultimately make you better off."<sup>79</sup>

The example of the life-threatening disease is an illustration of an experience with an instrumental value. It is only of value for the person because it gave new insights. An activity such as running early in the morning is an example of something that has non-instrumental value; a person can value the activity of running, which also has an instrumental value, by keeping someone fit and healthy. "Things that seem paradigmatically negative (like cancer) can sometimes have an overall positive effect on well-being [...]. That doesn't mean the experiences are themselves good or valuable. It just means that sometimes bad things can have good consequences, such that overall the good effects outweigh the bad."<sup>80</sup>

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<sup>79</sup> Barnes, 87.

<sup>80</sup> Barnes, 85.

The next step in Barnes' argumentation is the claim that there are only a few things 'good *simpliciter*' or 'bad *simpliciter*' with respect to a person's well-being. Most things are 'neutral *simpliciter*'; its presence does not make a person any better or worse off than other people. But regardless of the fact that something is 'good-, bad- or neutral *simpliciter*', the overall effect on someone's well-being can be different, depending on the circumstances. For instance, homosexuality in itself is not something that has a negative effect on a person's well-being, but it can be bad for a person's well-being to live in a society where homosexuality is not accepted. Not the characteristics of the homosexuality itself, but the external circumstances might make the overall effect of being homosexual a bad thing.

These distinctions between 'good for' and 'bad for', 'global good/bad' and 'local good/bad', instrumental value and non-instrumental value and 'good-, bad- or neutral *simpliciter*' are the basis of Barnes' 'Value-Neutral Model' of disability. She claims that disability is 'neutral *simpliciter*' with respect to well-being. It can be either good or bad for you, depending on the circumstances. At the same time, a disability can sometimes (or always) be a 'local bad'. Going back to one of the first claims about the 'Value-Neutral Model' of disability, social attitudes and prejudices make up for many of the bad things connected to having a disability, but not all. Nevertheless, there are inherent aspects of having a disability that are a 'local bad', so not every problematic aspect is due to social attitudes and prejudices.

This conclusion is very similar to my hypothesis that having autism can both be an identity (as in the 'mere-difference' view) and a disorder (as in the idea that having a disability can make you worse-off) at the same time. It seems that Barnes' argumentation about disability might solve the issue for autism as well. However, is it possible to make this analogy? What are the differences between being physically disabled and being autistic? Hens et al. argue that autism can be categorized as a disability, since there are more than enough examples of the suffering of people with autism. A difference between autism and physical disabilities is that the causes of autism remain unknown, while many physical disabilities have a known origin, and that the nature of autism is still unclear.<sup>81</sup> Since we have not (yet) reached a consensus on what autism is, familiar ethical debates about autism run the risk of being futuristic, according to Hens et al.. If you do not argue with the same conceptualization in mind, there is no point in discussing the topic.

However, I do think that the debate on the nature of autism itself, the exact topic of this thesis, can be compared to the discussion about the nature of disability. As stated earlier, autism

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<sup>81</sup> Hens, Robeyns, and Schaubroeck, "The Ethics of Autism," 5.

can be seen as having a minority mind, in the same way that physical disability can be seen as having a minority body. This would mean that one can argue that autism can be considered as value-neutral. Even though I find parts of Barnes' argumentation convincing, I do not think that one does justice to all the different views in the field of autism when arguing that autism can be seen as a neutral feature. To me, it seems more fitting not to search for the answer halfway between the two views, but to combine the disorder view and the identity view in one concept.

### 3.3 Abnormality

One of the main aspects of the concept of a psychiatric disorder, seems to be abnormality. Normality, or normal variation, can be understood in at least two different ways. The first option is in a statistical sense, when we ask ourselves: how common is a certain trait or kind of behavior? The other option is to think of normality in an evaluative sense: how accepted is a certain trait or kind of behavior? Jaarsma & Welin give the example of a gene pool, where certain genes that account for certain traits are often found, while others are exceptions. The survival of a gene in the human gene pool depends on its evolutionary value. If a certain trait is beneficial, the gene connected to that trait will be found in more people. Jaarsma & Welin suggest that if autism should be seen as a variant of the normal in the statistical sense, like the neurodiversity movement claims, there should be an evolutionary reason for the survival of the genes that are related to it.<sup>82</sup> This is not an opinion shared by everyone, especially since there are people who do not think that autism is in any way beneficial, but it presents a way to look at autism understood as a variant of the normal.

Either way, there are reasons to believe that autism is an abnormality, based on statistical data or social norms of what is seen as accepted behavior. According to Verhoeff, the social and historical influences shape the concept of autism to such a degree that the concept is obligated to account for these influences. Abnormality is thus, in our current society, an inherent aspect of autism. Whether this results in claiming that autism is a psychiatric disorder, is a separate question.

Related to these social norms that influence the concept of mental disorder, I described Elizabeth Barnes' Value-Neutral Model of disability. She claims that disability is 'neutral *simpliciter*' with respect to well-being. It can be either good or bad for you, depending on the circumstances. At the same time, a disability can sometimes (or always) be a 'local bad'. Social

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<sup>82</sup> Jaarsma and Welin, "Autism as a Natural Human Variation," 24.

attitudes and prejudices make up for many of the bad things connected to having a disability, but not all. Even though I considered parts of Barnes' argumentation to be convincing, I do not think that one does justice to all the different views in the field of autism when arguing that autism, similar to disability, can be seen as a neutral feature.

Describing what a mental disorder exactly is, appeared to be at least as difficult as asking that question about autism. In the beginning of this chapter, Huber's definition of health led to the possible definition of disorder: the absence of the ability to adapt and self-manage up to a level where one would have a sufficiently high enough level of well-being. Using this concept might be helpful when trying to distinguish severe and mild cases of a psychiatric disorder, but it seems that this general definition of disorder does not cover the entire complexity of mental disorders. The distinction between normality and abnormality is not made clear enough. Besides that, what well-being is for people with a psychiatric disorder, is difficult to assess. I would like to suggest that it is practical to use the descriptive definition of mental disorder by Radden, without forgetting Verhoeff's claim about the importance of the social and historical influences on the concept of autism. Autism, in other words, can be understood as a disorder, but the definition can change as a result of changing social norms.

## Chapter 4 – Autism: disorder and identity

In the previous chapters, it has become clear that conceptualizing autism is a complicated undertaking. The six different understandings of autism that are described in Chapter 2 have not been able to satisfy all the parties involved. The ameliorative approach as explained in Chapter 1 requires a target concept of autism for which we can aim. Describing a target concept, means that you have to choose a certain understanding as being the most desirable one. In the forgoing chapter, I focused on the concept of psychiatric disorders. In this chapter, autism understood as an identity will be investigated. Finally, I will bring the conceptualizations of autism as a disorder and identity together, in an attempt to describe the target concept for the ameliorative approach.

### 4.1 Autism as an identity

Personal identity is generally used to refer to a specific set of properties and characteristics of a person that make that person ‘who he is’.<sup>83</sup> This personal identity can change over time, because a person may start to look at him- or herself differently. Some properties will become less defining, others will be of more importance. Personal identity is what we are searching for when we ask: ‘Who am I?’

“In his classic work *Stigma*, Edward Goffman argues that identity is formed when people assert pride in the thing that made them marginal, enabling them to achieve personal authenticity and political credibility.”<sup>84</sup> Autism could be such a thing that made someone marginal. This could, according to Goffman, have helped forming that person’s identity (if that person asserted pride in having autism). Being autistic could be seen as something valuable, something that makes someone special. The more a society tries to assimilate every minority group, the more strongly that minority group becomes pronounced in its singularity.

Elizabeth Barnes also connects being disabled to one’s (social) identity. “Being disabled is—at least for many disabled people—something that profoundly affects social identity and sense of self in much the same way. One’s overall experience of being disabled is much more than the experience of specific physical symptoms. Rather, it’s the complex, multi-faceted experience of inhabiting a body that doesn’t meet the social norms for what bodies

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<sup>83</sup> Eric T. Olson, “Personal Identity,” in *The Stanford Encyclopedia of Philosophy*, ed. Edward N. Zalta (Metaphysics Research Lab, Stanford University, 2017), <https://plato.stanford.edu/archives/sum2017/entries/i-identity-personal/#AccOurIdeThrTim>.

<sup>84</sup> Andrew Solomon, *Far from the Tree: Parents, Children and the Search for Identity*, 1st Scribner hardcover ed (New York: Scribner, 2012), 28.

should be like. When people value disability, they value this unique, complex experience.”<sup>85</sup> Many autistic people who advocate the identity view of autism express similar views. According to them, autism should be considered as something that provides one with a unique experience.

Earlier, I quoted one of the many blogs on autism and the autistic community. Another blog, the *Mighty*, is concerned with all different kinds of health challenges and disabilities. Autism is one of the topics too. One of the writers is Alex Lowery, who is on the autism spectrum and wants to raise awareness of autism. In one of his blogs he writes: “There are many people (mainly neurotypicals) who say you shouldn’t describe someone as “autistic.” It’s better to say they “have autism.” Some say the term “autistic” is offensive, that it defines a person and that it means they’re nothing more than their autism. Personally, I don’t see anything offensive about the term “autistic.” I use it quite frequently to describe others and myself on the spectrum. (...) I’ve also heard of a few people with autism who find the term “having autism” offensive because they feel that autism is a part of them and they want to be referred to as “autistic.” Even parents feel this way because they feel like autism is what makes their child who he or she is.”<sup>86</sup>

This problem with terminology does not, as explained in the introduction, fall under the scope of this thesis. However, it is closely related to the question of whether autism is an identity and it shows the problematic sides of (not) seeing autism as an identity.

The other problematic aspect of understanding autism as an identity has been described often in this thesis. The risk of not receiving the mental health care that is needed for people with severe cases of autism, is connected to the identity view.

## 4.2 Autism: disorder and identity in one

Understanding autism as a disorder or as an identity both comes with benefits and disadvantages. The target concept as described in Chapter 1, requires that the understanding of autism should lead to increased levels of well-being for people with autism, that it relates the concept of autism to mental health care and that it should be an accepted understanding by the majority of the people with autism. When this is achieved, gradually, the majority of the people in general will also take over this view on autism, thereby diminishing the stigma on autism.

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<sup>85</sup> Barnes, 107.

<sup>86</sup> Alex Lowery, “Am I Autistic or Do I Have Autism?,” *The Mighty* (blog), August 3, 2015, <https://themighty.com/2015/08/am-i-autistic-or-do-i-have-autism/>.

According to utilitarianism, disability ethics and virtue ethics, not one of the views on autism is better than the other. Each time, the solution lies somewhere in the middle. This implies that the new understanding of autism should consist of both the disorder view and the identity view.

To illustrate this, different narratives of autistic people are placed in a scatter plot (see Figure 1). This shows how diverse the spectrum of people with autism is, and how differently they think about their own life with autism. Some are entirely on the end of the identity view, while others strongly believe that autism is a disorder. However, most of them will be somewhere in between, partly supporting the identity view, partly understanding autism as a disorder. The conceptualization is not a dichotomous dilemma. Disorder and identity are, in other words, not mutually exclusive.

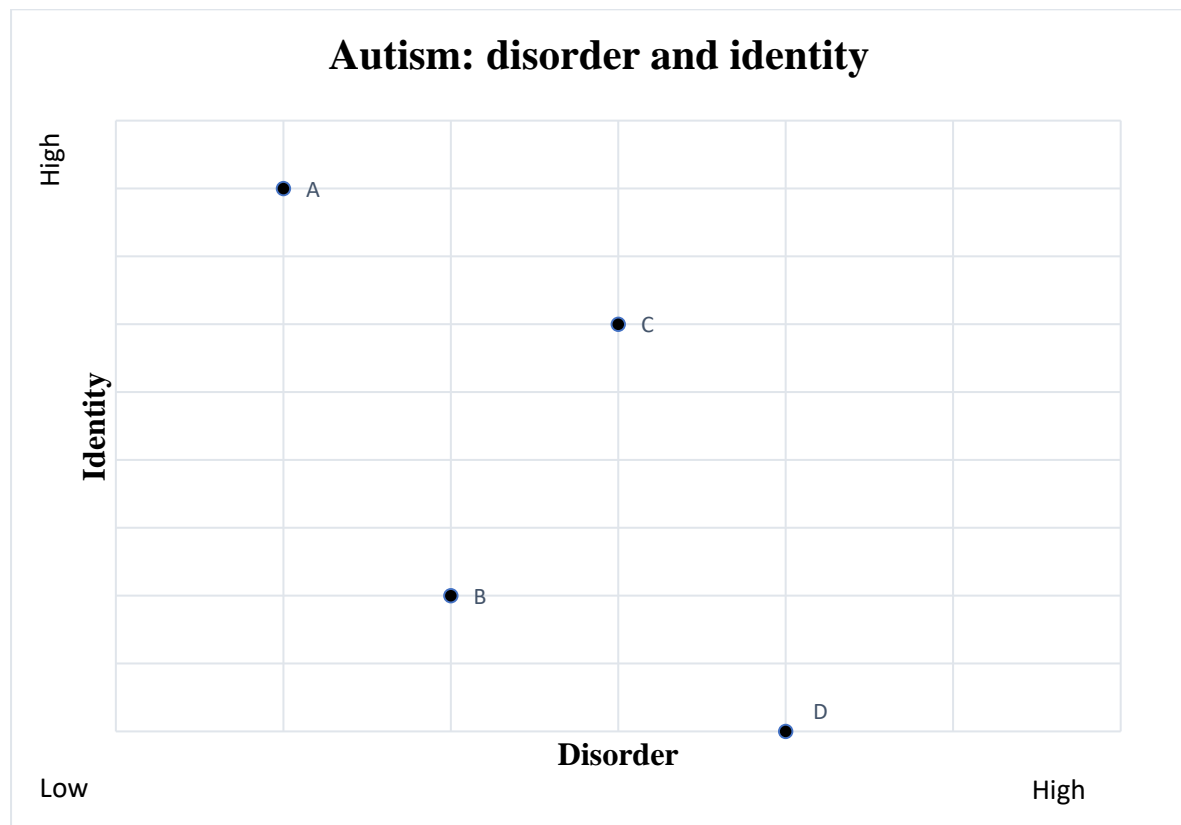


Fig. 1: Scatter plot Autism: disorder and identity

*Person A* understands autism primarily as an identity. He or she probably prefers the Identity First Language and wants to be called ‘an autistic person’ as opposed to ‘a person with autism’. There is minimal room for the disorder view of autism. Hence, *person A* could possibly be a supporter of the neurodiversity movement. *Person B* takes a less outspoken stance. He or she considers autism as equally an identity and a disorder. The difference with *Person C* is that the



latter feels more strongly about this topic. However, they would both agree that autism should be understood as simultaneously a disorder and an identity. Which one of the two views prevails at a certain moment, might be dependent on the circumstances. *Person D* understands autism primarily as a disorder. He or she probably suffers from having autism and does not identify with it. *Person D* could possibly be someone supporting the views of the ‘Autism Speaks’ organization.

These examples of different understandings of autism are indications of possible stances. Obviously, many more positions can be taken and everyone can understand autism in their own, personal way, based on their experiences. Only when all these different views are accounted for, the new concept of autism will be accepted by the majority of the people.

## Conclusion

Through writing this thesis, it has become clear that the debate on the concept of autism is very complex and multifaceted. By aiming to answer my research question – *is it possible to conceptualize autism as simultaneously a disorder and an identity* – I hoped to be able to give an account of autism that would be a helpful conceptualization for the people that are affected by it. For this conceptual analysis, I used Sally Haslanger’s ameliorative approach. For this ameliorative approach, we must raise normative questions about how we should understand autism. Why do we need a concept of autism and what concept would serve those purposes best? This ‘target concept’ is formed by the list of requirements, focusing on what would be a good life for people with autism. My hypothesis was that there must be an acceptable way in which autism can be seen both as an identity and as a disorder.

In the first chapter, it became clear that the purpose for a new understanding of autism is to promote well-being for autistic people. To recapitulate the requirements of the target concept: firstly, the understanding of autism should lead to a decrease of the stigmatization of autistic people. Secondly, it should consist of certain aspects that relate the concept of autism to mental health care. Thirdly, it should be a concept accepted by at least the majority of people with autism.

The six views on autism that were described in the second chapter, were narrowed down to the two main conceptualizations for further investigation. Following this description of the different views on the nature of autism, I analyzed the moral consequences of holding the two main views: autism as a disorder and autism as an identity. This moral analysis resulted in concluding that both understandings of autism appear to have a value that cannot be disregarded. Utilitarianism, disability ethics and virtue ethics seem to be unable to decide which view would be the most desirable.

In Chapter 3, the concept of psychiatric disorder was investigated in more detail. Describing what a mental disorder exactly is, appeared to be at least as difficult as asking that question about autism. Huber’s definition of health led to the possible definition of disorder which appeared to be not sufficient for the definition of mental disorder. I suggested that it is practical to use the descriptive definition of mental disorder by Radden, but to keep in mind Verhoeff’s claim about the importance of the social and historical influences on the concept of autism. Concerning the value-ladenness of the concept of mental disorder, Elizabeth Barnes’ Value-Neutral Model of disability proved to be at least partly convincing, but I do not think that autism can be seen as a neutral feature. It seems more fitting not to search for the answer

halfway between the two views, but to combine the disorder view and the identity view in one concept.

Understanding autism as a disorder or as an identity both comes with benefits and disadvantages. Only when using both understandings, the requirements of the target concept can be met. This is why autism should be understood as simultaneously a disorder and an identity.

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