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WHEN 'NO ONE' DOES ANSWER. A QUALITATIVE RESEARCH CRITICALLY EXAMINING AUTISM THROUGH INTERVIEWS WITH ADULT AUTISTS

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**Abstract**

Autism is often presented as a seriously disabling neurodevelopmental brain disease, and those who suffer from it are seen as individuals trapped in themselves, confused, and unable to communicate. Current research within the Clinical Model of Disability looks into the causes and seeks a possible cure for autism. However, some communities of Autists are articulating a discourse which challenges the assumption that autism is a disorder that needs to be treated or cured. Such discourse claims that autism is merely a natural variation of the configuration of the human mind, with its unique ways of socializing, communicating and sensing, all of which need to be recognized, respected and valued. Their main argument is that by excluding the neurodiverse from the discussion of what normalcy constitutes, they are being subjected to a certain epistemological violence, which deprives them of voice and agency to contest these discourses.

As a reaction to this, and to the notorious absence of an Autist perspective in special needs education courses, this thesis explores how Autists themselves see and experience their autism. The goal of the thesis is to broaden the perspective from which we look at normalcy and neurodiversity.

For the purpose of this thesis, 6 participants on the autism spectrum from Finland and the UK agreed to participate in private two-way exchanges to express their own views on autism. The data was collected through semi-structured interviews, email and other electronic exchanges. Using the principles of Qualitative Content Analysis, the data was processed into descriptive themes which showcase the different ways in which the participants see and experience their autism. Grounded on a subjectivist and poststructuralist epistemological stance, the theoretical framework of the thesis is defined within the Social Model of Disability, and the analysis and discussion of the data were carried out borrowing conceptual tools from Critical Disability Studies. The findings suggest that it is possible to experience autism in a variety of ways, including autism as an identity, as a normal human variation, as a disability because of others, as an impairment, or as a reason to feel proud.

These findings suggest that the experience of autism is open to many variations, hinting at the complexity and intersectionality of the issue. The variability in the stories of the participants suggests also that the experience of autism does not happen in isolation, but in a constant and interdependent interplay of many other factors such as cultural background, current context, socioeconomic background, gender, age, employment status, support structures or a lack of them. Although there were some common elements in the experiences that the participants shared, it can be said that the most defining feature of the data, as a whole, is the significant differences found in the way autism was experienced and described by the participants.

Autism can be experienced in a great variety of ways, depending on the specific circumstances of the individual, and the preconceptions and expectations that are present in a given sociocultural context. While Autists can be described in many different ways, in the end, being Autist is just an arbitrary label. Everyone has impairments. Everyone has cognitive capacities that enable them to do certain things, and not others. A diagnosis can offer a label for an individual, which may provide help and support for that individual. Labels tell us nothing about a person. The idea of treating autism should always be positive, if it facilitates in any way the reciprocal encounter between two people. Perhaps acknowledging the cultural aspects of the experience of disability, treatments addressing cultural preconceptions should be promoted. The best possible way to treat autism, in any circumstance, is to treat it with dignity and respect. Treating real people with dignity is always about seeing the person, and forgetting the labels. Genuinely understanding other human beings involves talking and listening to them, on their own terms, and finding out what makes them an individual, and not what makes them part of a group. This is something which speaks not about the specificities of Autists, but more about our own capacity and limitations for genuine empathy and meaningful communication.

**Keywords** Autism, Critical Disability Studies, disability, epistemology, neurodiversity, Social Model of Disability
Table of Contents

1 Acknowledgements .............................................................................................................................................. 1

2 Introduction .......................................................................................................................................................... 2

  2.1 Background and motivation for the study ........................................................................................................ 2

  2.2 Research Overview: problem; aims; methods; results .................................................................................... 4

  2.3 Autism Spectrum Disorders ............................................................................................................................ 7

3 Theoretical Framework ......................................................................................................................................... 12

  3.1 Theoretical considerations ............................................................................................................................... 12

  3.1.1 Epistemology ........................................................................................................................................... 12

  3.1.2 Philosophical stance .................................................................................................................................. 13

  3.1.3 Methodology ........................................................................................................................................... 14

  3.2 Disability Studies ............................................................................................................................................. 14

  3.3 The Social Model of Disability ....................................................................................................................... 16

  3.4 Critical Disability Studies ................................................................................................................................ 20

  3.5 The Neurodiversity Movement ......................................................................................................................... 21

4 Methodology ........................................................................................................................................................ 25

  4.1 Qualitative Content Analysis .......................................................................................................................... 25

  4.2 Research Question ........................................................................................................................................... 27

  4.3 Coding ............................................................................................................................................................. 27

  4.4 The research process ........................................................................................................................................ 29

  4.5 The participants ............................................................................................................................................... 30

  4.5.1 Participants from Southern Finland ........................................................................................................... 31

  4.5.2 Participants from Oulu ................................................................................................................................ 32

  4.5.3 Participants from the UK ................................................................................................................................ 34

  4.6 Data, research material ..................................................................................................................................... 34

5 Findings ................................................................................................................................................................. 37

  5.1 Autism as identity ............................................................................................................................................. 37

  5.2 Autism as a normal human variation ................................................................................................................ 39

  5.3 Autism as a disability because of others ........................................................................................................ 41

  5.4 Autist and proud .............................................................................................................................................. 43
1 Acknowledgements

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2 Introduction

The aim of this section is to introduce the reader to the topic of the research and to offer a point of reference through the text by outlining its starting points. In order to do so, I will first present a short account describing the background and main motivations behind the study, as well as my own initial position towards the topic. After that comes an introductory overview of the more formal aspects of the research in order to pin down my epistemological and ontological positions within the text. Finally, to engage those readers not familiar with the topic of autism, I will clarify a number of key concepts and issues, which will be used and referred to throughout the study.

2.1. Background and motivation for the study

To set the context of the study, all through my teacher education years, and also later during my work in schools, I felt that some fundamental questions were always left unanswered whenever I was exposed to topics of disability in general, and of autism in particular. The prevalent approach would include a clinical perspective, speculating about the potential causes of autism (genetic; environmental; dietary; exposure to toxins) and offering a symptomatic description of the condition, while a pedagogical perspective would advise on how to deal with Autists in schools. What was missing, I felt, was an explanation about the subjective experience of autism. How is autism experienced? What is it like to be Autist? How do Autists feel? For me, the appeal of these questions is based on the belief that only by engaging with these questions, can genuine foundations be laid in order to develop significant and empathetic relationships with Autists. For this reason, my impression more often than not was that Autists were being discussed as objects to be handled, rather than as individuals with their own subjectivity to interact with.

My natural curiosity was usually left itching by the fact that I was never able to understand what being an Autist means in terms of the experience of self; how it feels, or how the world looks like being an Autist. This gap in my teacher education, I felt, only contributed to the depersonification and the perceived strangeness that is generally associated with autism. Since the formal options to further educate myself in the topic were limited, I stored the unanswered questions in the back of my mind, and moved
Some time afterwards, at the turn of the millennium, I was exploring some internet-based virtual worlds, curious about their potential for language teaching. Very unexpectedly, I came across something truly fascinating: in these emerging 3D virtual worlds of text-based and emoticon-enhanced communication, I found active and thriving communities of people describing themselves as Autists. But could that really be true? I approached these communities with great curiosity, and as with all internet-based interactions, I proceeded with a large amount of cautiousness and scepticism. Instead of the picture that I had been given of the silent Autist unable to communicate (Attwood, 2007; Kanner, 1949; Jacobson, Mulick, and Schwartz, 1995; King & Bearman, 2009), I found very vocal and articulate individuals with fast fingers and sharp insights: “I cannot speak, but I can type lightning-fast”. Some of these persons were very receptive to my interest and questions, and indeed explained to me the well-researched fact that virtual worlds, these new kind of non-oral environments, were enabling them and other neurologically diverse persons to share with one another their personal experiences. This was facilitating the emergence of shared histories and identities, as well as a forbidden sense of belonging, of community (Biever, 2007; Mennecke 2008; Strickland, 1997). All this made a big impression on me. There are whole communities of Autists discussing identity, neuroscience and politics… could that be real? They even had produced an Autist manifesto (silentmiaow, 2007).

Slightly puzzled, but indeed very excited, I set out to learn more about all this, not only motivated by raw curiosity, but also because I felt that within their discussions and by listening to their opinions, I was finding sharp and refreshing questions which forced me to revisit my own assumptions about identity, personhood and life in general. They were basically questioning aspects and assumptions of modern societies such as those of ability, diversity and inclusion, which I was not even aware were defining the way I saw myself and others. As a result of these first contacts, I became familiar with some autism-related Internet communities, as well as some prominent Autist figures and texts of reference. Threading these together, I got a glimpse of a number of topics that some Autists identified as being at issue in discourses around special needs education and autism. It is perhaps relevant to the discussion that will take place later in this study, to point out that some of these topics included issues of agency, normalcy, ability, personhood, representation, dignity and epistemic violence, all issues which are shared
by the struggles of cultural and ethnic minorities (Spivak, 1988).

After studying at the University of Oulu issues in ethics, multiculturalism, inclusion and postmodernist theory, I realised that a study critically readdressing autism from new angles would be relevant and compatible with the general line of the study programme. My own motivations to choose this topic were, on the one hand, to satisfy the need to react to a discomforting gap in the curriculum of the programme in relation to critical disability studies, and on the other hand, to think and reflect about the topic in order to bridge this gap in my formal education. For these reasons, I decided to explore autism through the subjective experiences and impressions of Autists.

2.2 Research Overview: problem; aims; methods; results

The images which autism commonly invokes in the collective consciousness still resemble very closely some of the ideas and assumptions which were used over a century ago by the clinical model: autists are individuals unable to communicate, who have serious socialisation impairments, suffer cognitive retardation, and generally speaking, seem isolated, confused and trapped within themselves (Altman, 2001; Kanner, 1949; Farrugia, 2009). This particular way of conceptualising autism is often grounded on certain assumptions about the capacity of Autists to communicate or to process thoughts at all, a position which on its own carries strong implications regarding the subjectivity and personhood of Autists. It is fairly common to find examples of charities, media or health authorities referring to Autists using the “kidnapped person” metaphor, an idea which suggests that autism is a disease which, so to speak, kidnapsthe person leaving no one inside an Autist. As an illustrative example, let us consider the words of the director of the National Institute of Mental Health in the United States and head of an interagency federal panel on autism, Thomas Insel:

"We're talking about a [...] tremendously disabling brain disease, which really robs a child and a family of the personhood of this child," (Insel, 2005)

However, the past few decades have witnessed a gradual shift towards more positive discourses
in the way in which autism is represented and discussed, both in academia and in popular culture. Running parallel to this shift, we find that some of the assumptions mentioned above are also being challenged. This shift of paradigms can partially be traced back to deeper insights gained into autism thanks to studies in the aetiology (the study of causes) of autism disorders, especially in the fields of genetics and neuroscience, and partially thanks to the work of self-advocating individuals and groups campaigning energetically for the visibility, agency, interests and rights of Autists (Farrugia, 2009). On the one hand, we have a long clinical tradition portraying autism as an obscure and little understood brain disease. On the other hand, we have scores of people who in the past might have been described as "kidnap victims", who are now telling the world, "I was not kidnapped; I've been here all along — and I have been listening" (Seidel, 2005).

In view of the emergence of these new paradigms in the way we see autism, this thesis aims to serve as an introduction to some of the discussions taking place in self-advocacy circles, while at the same time highlighting the significance that these discussions have for the whole society, and not just for Autists or for special needs education professionals. To achieve this, for over two years, I was in contact with adult Autists and self-advocacy communities in Finland, the USA and the UK, and explored some of the ways in which they see, understand and discuss autism.

A guiding principle throughout the study has been to privilege the discussions taking place outside the mainstream by paying extra attention to dissenting and alternative ways to conceptualise autism. More specifically, the present study was designed as an effort to contribute to the visibility and resonance of these dissenting voices coming from Autist circles in order to challenge the discourses that question the subjectivity of Autists. Therefore, the overarching aim of the research has been to highlight those perspectives coming from Autists, which problematize some of the notions surrounding the concepts of ability and disability, and to critically readdress these notions attending to epistemological and ontological considerations. The position that I take in this approach is based on the belief that after challenging and critically discussing these issues, conditions are created for a better understanding of such complex phenomena such as those manifest in autism as a subjective ontological experience.

During the present study, some adults from Finland and the UK identified as Autists agreed to participate in private two-way exchanges to express their own views on autism. The data was collected
using primarily semi-structured interviews where I asked the participants to tell me about what they think about and how they see autism. The data collected from the participants came in the form of email exchanges, chat logs and audio recorded from face-to-face interviews. In total, the data is comprised of slightly more than 7 hours of face-to-face interviews, 23 emails, and 5 pages of chat logs, resulting in a total of 308 pages of data in text format. The thesis was designed as a qualitative study, choosing content analysis as the preferred methodology to approach, organise and analyse the data collected. During the analysis, I seek to identify parts where the participants pondered about the experience of being Autists, its challenges and potential, and selected some of them to discuss them in relation to the theoretical framework. During the discussion part of the thesis, I elaborate on some of the issues raised by the participants, and reflect on their significance for the discussion on personhood, ability and diversity; in so doing, I problematize the mainstream clinical discourses portraying autism as merely a disabling developmental disease (see Rapin, 1997; Jacobson, Mulick, and Schwartz, 1995; Volkmar and Lord, 1998; and Carpentierei and Morgan, 1996).

The outcome of the analysis and of the discussion suggests a high degree of complexity on the subjective experience of autism, hinting at the existence of a great variety of ways to live and conceptualise it. Seeing the subjective experience of autism as a phenomena sitting on the intersection of several other factors (such as gender, socioeconomic status, schooling, support, sociocultural context, etc.), the findings of this thesis suggest cautiousness when extrapolating the experiences of one Autist onto others. The complex nature and impact of autism, which determines to a great degree how a given person is going to sense, communicate, think and definitively be, calls for the need to consider fundamental ontological and epistemological questions in the discussion of autism. My position in this thesis is that a discussion on autism (especially in relation to special needs education and inclusion) is always going to be meet a theoretical ceiling due to the resistance to accept Autists not as deficient versions of full human beings, but as a legitimate variations of the complex experience of human existence. Any initiative seeking the inclusion of the neurodiverse, no matter how well intended, is always going to be limiting the full potential of those for whom the initiative was devised if it fails to acknowledge the existence of different ways of sensing, thinking, communicating and being. While it is possible to accommodate the neurodiverse and to improve their general well-being, it is only by engaging in a profound ontological discussion that we can pave the way for the potential contributions that the
neurodiverse can make, surpassing the limitations of the neurotypical minds.

In summary, during this research I interviewed adult Autists and collected, organised and analysed some of the alternative ways to conceptualise autism beyond the imaginary of the clinical model. The data was discussed framing it within epistemological and ontological discussions on ability and diversity. As a reaction to the dominant discourses questioning and undermining the personhood of Autists, special emphasis was given to what Autists themselves have to say about the topic.

2.3 Autism Spectrum Disorders

In the following section, I will offer a brief introduction to the origin and current status of autism as a neurodevelopmental disorder. At the same time, I will clarify some of the different ways in which Autists are commonly classified, as well as the terminology associated with these categories. The section will end with a few words about my specific choice of terminology in the context of this study. The purpose of this introduction is to provide readers with basic background knowledge on Autism Spectrum Disorders (ASDs) and to familiarize them with some of the terminology used. To begin this section, I will introduce a few remarks on my choice of wording referring to autism and Autists throughout the present text. Very concretely, when referring to people identified as being on the Autism Spectrum, I will be using the term 'Autist'. In so doing, I will be subscribing to the convention in use in some communities associated with the autism right movement and neurodiversity culture. The general argument behind this idea is that an expression such as 'a person with autism' or 'an Autistic person' might suggest that autism is something external to the person, something that can be separated from that person, the notion that being Autistic is something that affects the process of being a normal person. People identifying strongly as Autists, might see autism as an inseparable part of who they are, and sometimes feel strongly about the idea of being 'cured of it' (Jaarsma & Wellin, 2011; Ortega, 2009). Since the aim of the thesis is to give exposure to these alternative ways to conceptualise autism, I see fit to subscribe to these conventions myself.

From the moment that the term 'autism' was first coined, its very definition and boundaries have been very difficult to pin down (King & Bearman, 2009; Yasmin & Neggers, 2014). The subjective nature of the diagnostic criteria used, as well as the intersection of clinical disciplines at which autism is located
(those of psychiatry, psychology, neurology and pediatrics), have rendered it problematic to reach a clear consensus on the boundaries of autism. What is autism? What are the traits associated to autism? How many and how clearly these traits need to be manifested in order to be able to define someone as 'Autist'? My interest in disability studies lies primarily in their capacity to problematize and deconstruct the concept of 'normalcy'. Drawing from standpoint theory, my position in this thesis supports the idea that significant and meaningful insights on 'normalcy' could be gained by including into the discussion the insights of those not considered 'normal'. In the following, I offer a brief historical account about the origin of the term 'autism' in clinical contexts.

Let us commence by reviewing the word 'autism' itself. Etymologically, 'autism' derives from the Greek word 'autós' (αὐτός) literally meaning self, and the suffix -ism, which the Merrian-Webster dictionary defines as "the act, practice, or process of doing something". Therefore, etymologically speaking, 'autism' comes to mean selfism, or the act, practice, or process of being in one's self. Clinically speaking, the term 'autism' was first introduced in the modern Western medical tradition in 1916 by the Swiss psychiatrist Eugen Bleuler. It is interesting to note that the context in which Bleuler used the term was to describe one of the symptoms of schizophrenia, specifically one characterized by an exaggerated self-centeredness (Attwood, 2007; Bleuler, 1916). It has been noted (Farrugia, 2009) that its origins in clinical psychiatry, and in the context of schizophrenia (another highly stigmatized mental disorder) might have had an emotional impact on the way autism was conceptualized later on. In spite of its origins and use in relation to schizophrenia, the first uses of the term 'autism' in the contexts in which we use it today took place nearly 30 years later, on the early 1940s, when, almost simultaneously, two different psychiatrists coincidentally adopted the term in separate and unconnected case-studies. Regarding the adoption of the term, it must be clarified that it was common practice in the field of psychiatry to borrow and adapt terms that were already in use and which were familiar to practitioners, rather than introducing completely new terms (Farrugia, 2009). The authors of these studies were two Austrian psychiatrists, Leo Kanner (based in the USA) and the pediatrician Hans Asperger (based in Austria). In the contexts of these studies, the term 'autism' was used to describe peculiar patterns of behavior (syndromes) in children. The first recorded case was the work of Leo Kanner, who used 'autism' to describe a syndrome that he observed in some children showing an obsession with routine and severe problems with communication. Almost contemporary to Kanner's work (Farrugia, 2009; Wing, 1997), Hans Asperger made allusion to Bleuler's term while describing a syndrome in children very similar to the one identified by Kanner.
Although indeed remarkably similar, these studies presented also some differences. One fundamental difference between the two studies was that while Kanner offered clear diagnosis criteria for the syndrome (obsession with routine and severe problems with communication), Hans Asperger, in his study, did not offer any such criteria for the diagnosis, limiting himself just to a very detailed description of the syndrome. But perhaps the most significant difference was that unlike those observed by Kanner, Asperger's children did not show evidence of intellectual deficiency or delay in language development (Asperger, 1944; Attwood, 2007; Farrugia, 2009). These differences contributed to the notion of two different kinds or primary levels of autism: one based on Kanner's study, associated to severe problems of communication and intellectual deficiency, often referred to as 'low-functioning autism' or 'classic autism', and another one based on the study by Hans Asperger, often referred to as 'high-functioning autism' or 'Asperger's Syndrome' (King & Bearman, 2009; Wing, 1997).

In spite of this distinction, the diagnostic criteria for each of the two conditions has been subjected to criticism and continuous revisions, being disputed even today. To illustrate how vague the diagnostic boundaries of these conditions are, it is perhaps significant to note that it took more than 30 years after the publication of the two studies until Lorna Wing (1981) saw and made the connection between the two. Although it has been argued that another possible explanation for this unusual delay might have been the fact that Asperger's work remained largely unknown in medical circles during his lifetime, possibly because of being published only in German and because of a post-war aversion to all things German (Farrugia, 2009). In any case, even in the case of Kanner's observations, which were published in English, the study of autism only enjoyed limited attention from the mainstream clinical circles, being considered over decades up until the early 70s, as a rather rare, little understood and obscure disorder (Corrigan, 2005; Thornicroft, 2006; Farrugia, 2009).

The attention that autism drew from medical circles began to increase dramatically during the late 1980s and early 1990s as the result of a number of different factors. On the one hand, the classification criteria for both disorders would start to converge in the early 1980s when, after reading Asperger's publications in its German original, Lorna Wing first introduced Asperger's syndrome to English audiences with her paper "Asperger's Syndrome: a clinical account" (Wing, 1981). With Wing's publication, a link with Kanner's autism would be drawn for the first time, introducing at the same time the notion of a continuum, the Autism Spectrum Disorder (ASD). Still, autism continued to gather limited
attention. Asperger's original work was translated into English a decade later, in 1993.

We have established that the clinical origins of autism were a bit obscure and that its definition and diagnosis criteria have been quite unclear (WHO, 1980). We have also seen how the Kanner’s and Asperger’s studies stayed separated for over 50 years. The current situation is an improvement in the sense that the study of autism study has gained significant attention, but even today, the etiology, diagnosis criteria and best practices for the treatment of autism remain highly debated. In modern psychiatry, diagnosis procedures are done based around a checklist assessment in which it is determined if a patient matches the selected criteria or not. This diagnostic criteria are collected, agreed and published in renowned medical manuals that are then used as reference by practitioners. Two of the most important of such manuals are the Diagnostic and Statistical Manual for Mental Disorders (DSM) published by the American Psychiatric Association, and the International Classification of Diseases (ICD) by the World Health Organization. Vague diagnostic criteria lead to vague diagnostic processes as well as to debatable practices, a situation which in some Autist circles is used as grounds to challenge the significance and validity of such diagnosis, or even the idea of defining and pinning down autism in deterministic terms (Ortega, 2009).

At present, and in spite of the advances made in genetic and neurological studies on autism, the causes of autism remain largely unknown. A review of research (e.g. Gerdts, Bernier, Dawson & Estes, 2013) on family and fraternal-twins suggests that there exists a high dependence on genetic factors, meaning, that when one twin presents Autists traits, it is many times more likely that the other twin will have them as well when compared to the control population. The same applies to families. If there is already a diagnosis in a family line, the recurrence rate of new cases is much higher, compared to other populations. In fact, autism is considered to be the neuropsychiatric disorder with the highest genetic incidence (Gerdts, Bernier, Dawson & Estes, 2013). In spite of this, when it comes to its causes, and unlike other neuropsychiatric disorders, the specific causing gene for autism has not been identified. The current consensus considers the idea to be very plausible that autism might be related to the combination of certain genes which, in themselves play no significant role on the occurrence of the disorder. Other factors are also considered, with varying degrees of support, as possible contributing factors causing autism, such as environment, air pollution, diet and exposure to substances such as mercury (Windham, Zhang, Gunier, Coren & Grether, 2006). While discussions continue to attempt to pin down the causes,
the clinical diagnosis guidelines and the best possible treatments of autism, a growing number of Autists and scholars have engaged in an entirely different conversation. As we will review in more detail in the next chapter, the Internet has witnessed the appearance and the exponential growth of Autist communities that, parallel to the clinical model discussions, have started to articulate discourses which question the definition of autism as a developmental disorder altogether. Their core argument is that once we factor out dominant ontological and epistemological assumptions about what constitutes a normal person, autism can be conceptualised as just another natural variation of human neurology, a mere variation in the way the human brain is integrated and connected, with its own unique features, strengths and weaknesses. These discourses are generally grouped as confirming the so-called autism right, the autism culture, or the neurodiversity movement, which will be discussed in more detail during the next chapter. To end this section, let us quote the known words of the American doctor in animal science and Autist activist Prof. Dr. Temple Grandin, which perhaps illustrates and summarises clearly this idea of the proud Autist identity:

“If I could snap my fingers and be non-autistic, I would not. Autism is part of what I am”
(Temple Grandin, in Jaarsma & Wellin, 2011)
3 Theoretical Framework

In this section, I will introduce the reader to the theoretical aspects considered during this study. The aim of the section is to clarify the epistemological and ontological angles, which inform the theoretical framework of the thesis. First, the theoretical position of the text will be discussed by answering three main fundamental questions. Later, I will talk about the theories and ideas that are used as lenses throughout the text; these include Disability Studies (Social Model of Disability, Critical Disability Studies and Neurodiversity discourses), Poststructuralism, Subjectivism and Critical Theory. At the end of the chapter, and once the theoretical foundations of the thesis are clarified, I will also position myself as a researcher in the context of this study, delineating while so doing the epistemological and ontological angles from which I engage with the topic.

3.1 Theoretical considerations

The first glimpse of the theoretical framework will be given by answering the following three questions: What is the theory of knowledge (epistemology) embedded in the theoretical perspective informing the research? What is the theoretical perspective (or philosophical stance) lying behind the methodology I choose? What specific methodology governs my choice and use of research methods?

3.1.1 Epistemology

What is the theory of knowledge (epistemology) embedded in the theoretical perspective informing the research? Epistemologically speaking, the study is grounded on a stance, which is closer to the traditions of subjectivism and constructivism than it is to those of objectivism and positivism. That is, the epistemological premises of this study assume that different (personal, cultural, religious, political, historical...) subjectivities can indeed give birth to different ways to conceptualise, and indeed experience, autism; all of which would constitute different, yet genuine and legitimate epistemological (Demarrais, 1999) and ontological (Biesta, 2010) positions in their own right. Hence, the research process has involved giving up positivist expectations of an objective and universal truth concerning autism to be uncovered by the end of the study. Likewise, during the course of the study, I also made the exercise of temporarily suspending my own assumptions and experiences in order to better engage and 'be
touched' by those offered by the participants. This does not mean that, as a result, I am expecting my analysis to be neutral and unbiased. On the contrary, I assume and acknowledge that my interpretation of the data is unavoidably going to be greatly defined by my own views, experiences and expectations. Nevertheless, I considered that attempting to suspend my own judgement was a crucial step towards genuinely empathising with the participants' views and experiences. Therefore, embedded in subjectivist and constructivist traditions, the aim of the research is not to produce general and definite statements about the conceptualisation of autism, but rather to explore the participants’ own experiences, to take them in, and to examine through them less known takes on autism. Thus, the participants of the study and their views are not seen as representing those of the entire Autist population. They are looked upon as representing merely their own legitimate subjectivities and positions, as an illustration of the complex and diverse population that comprises the so called Autist community.

3.1.2. Philosophical stance

Now that my epistemological position in reference to this thesis has been stated, I will briefly discuss the theoretical perspective informing the study. The overarching aim of this study is to give exposure to the ideas and impressions that a number of Autists themselves have on autism. On the one hand, this approach is inspired by postulates found in standpoint theory, which, as Harding (1998) explains, is characterised by the assumption that "the activities of those who are exploited by [dominant] social hierarchies can provide starting points for thought — for everyone's research and scholarship — from which otherwise obscured relations that people have with each other and with the natural world can become visible". That is, informing the present thesis there is a certain assumption which supports the idea that by favouring the standpoint of Autists, new insights could be gained by everyone, Autists and non-Autists alike, contributing to a better understanding of the nuances and complexities surrounding personhood, disability, diversity and autism itself. On the other hand, the drive for the thesis is also grounded on aspects of Critical Theory (Benhabib, 1986; Mezirow, 1981), since the philosophical stance of the study implicitly suggests the intention to prompt societal change in the way autism is perceived and treated. More specifically, by favouring the views and perceptions of people identified as Autists, I am implicitly expressing a certain will to discuss and question those discourses, which reject and
undermine the personhood of Autists.

3.1.3. Methodology

Now that the epistemological and theoretical positions have been introduced, let us address the question of which methodology governs my choice and use of research methods, as well as the specific techniques and procedures which were used in the process. In order to introduce to the discussion on some of the alternative discourses coming from self-advocacy circles, a qualitative, and mostly descriptive methodology was needed. Ideally, the contributions of the participants could be synthesised and organised in order to give the reader a general idea of the kind of themes and issues which are articulated in self-advocacy communities. Therefore, the descriptive focus of Qualitative Content Analysis (QCA) seemed like a particularly suitable option (Fairbrother, 2014). The use of QCA methodology governs also the choice to use interviews as the primary source of data. Since the aim of the study is to explore alternative narratives on autism found in self-advocacy circles, and considering that I myself am an outsider in these communities, the possibility to encounter unexpected and unknown outcomes was considered likely, and therefore the design of the study favoured the use of semi-structured interviews rather than structured ones. Likewise, I judged the idea of allowing the contributions of the participants to define the main themes and issues to be important, reasoning why, instead of starting off with pre-established research themes and categories. I therefore adopted a data-driven approach. This means that the data coming from the participants were determinant while establishing the research themes on which the analysis and discussion will later focus (Denzin & Lincoln, 2011; Fairbrother, 2014).

3.2 Disability Studies

Being the case that autism is framed as a neurodevelopmental disorder, it is unavoidable to include in the thesis a review of some of the most relevant discussions taking place in disability studies. Notwithstanding, and in order to better situate myself and the reader within the text, I feel compelled to state that the aims of the study are only partially linked to discussions on disability itself or special needs education. It needs to be stressed that the focus of the present study is defined by a desire to explore how the discourses articulated by Autists problematize dominant notions of normalcy, disability and inclusion. Therefore, this section is going to be about selecting and discussing some of the models and theories in
Disability Studies which problematize the very notion of disability. Thus, the aim of this section is to present a brief overview of Disability Studies in order to delineate how, in the context of this thesis, autism is going to be conceptualised away from the definitions of disability and impairment as they are articulated in the clinical model.

To put things into perspective and to better understand the sensitivity of this issue, it is crucial to remember that merely 50 years ago, “the disabled” were a dehumanized category in the clinical model, objects of study, and a category of beings for which all kinds of treatments and procedures were extent of almost any ethical consideration. There exists abundant, well-documented and chilling evidence about this. Many authors have written about the very many horrible things that have been done to 'the disabled' in the name of science: imprisoned in institutions, sterilized, surgically mutilated, lobotomized, euthanized, eugenized, reduced to passivity through electrical shock therapies, placed in chemical and physical straitjackets, denied education, denied employment, and denied meaningful lives (see Braddock & Parrish, 2001; Linton, 1998; Morris, 1991; Sobsey, 1994). Of course, it also must be said that the best of intentions motivated most of these procedures. They simply followed the recommendations of the latest research into the cause and cure of disability. As objects of this research, “the disabled” became dehumanized conditions, categories, and examples to be cured, ameliorated, or cared for in institutions, rather than human beings to be loved, cherished, and nurtured in their families and communities.” (Mertens, Sullivan, & Stace, 2011). This is perhaps the main reason why a critical re-evaluation of disability which frames Autists not as objects of study but as active participants with their own subjectivities and unique contributions becomes such a needed and meaningful enterprise.

Theoretically speaking, this study shares common grounds with some of the critical theories within Disability Studies (Charlton, 2000; Oliver, 1991; UPIAS, 1975). The defining feature of these theories is that they readdress in various ways the notion of 'disability', mainly by abandoning the use of the statistical normal as a point of reference and by moving the focus away from the individual. Instead, they seek to problematize the concept of disability by relativizing and situating it always in relation to the historical and sociocultural contexts in which it appears. This critical examination of context, culture and societies is central in the discussion of disability. More specifically, the theoretical framework of this study is partially informed by ideas taken from the Social Model of Disability (SMD), Critical Disability Studies and the Disability Rights Movement (DRM). The following sections briefly introduce each of
The concepts.

### 3.3 The Social Model of Disability

In this section we will review the origins of the Social Model of Disability (SMD) and its theoretical underpinnings. We will see that the analysis that the SMD makes of disability is primarily characterised by the separation of the concepts of 'impairment' and 'disability'. We will later discuss how these two concepts are differentiated. But let us commence by saying that such separation results in the creation of theoretical stances which place the focus on culture, and thus frames disability as an issue of oppression and power relations. The theoretical framework of the present study is partially informed by some of these critical theories with which it shares common ontological and epistemological grounds (Barns, Oliver & Barton, 2002; Campbell & Oliver, 1996; Man Ling Lee, 2011).

The philosophical stance of the SMD is defined within the tradition of postmodernism, understood as a spectrum of intellectual perspectives that shared between them a general “incredulity toward metanarratives” and which started to question the philosophical foundation of the Enlightenment and its ideals of universality, rationality, objectivity, and progress (Lyotard, 1984). The SMD also borrowed from feminist traditions, for example, it drew from the original feminist insights that the politically marginalised is also epistemologically excluded. The introduction of epistemological considerations in the conceptualisation of disability reaffirms the postmodern elements of the SMD. Postmodernism facilitates a new equation between knowledge and power by asserting that "to be known as a cognitive subject in one's own terms is to be empowered" (Man Ling Lee, 2011).

As was said earlier, the SMD is a theoretical model used within Disability Studies. It is characterised by a change of paradigm in the study of disability, moving the focus away from the individual and conceptualising disability as a subproduct of the interactions between individual and environment. This approach critically examining the relationship between the individual and the environment makes it a socio-political approach with roots in the Civil Right Movements (Hahn, 1982; Lynk, 2002).

Theoretically speaking, the fundamental analysis of disability which is made by the SMD is based
on the separation of the concepts of 'impairment' and 'disability'. Indeed, this crucial distinction between these two concepts serves as the launching ground from which to articulate critical stances “viewing disabled citizens as an oppressed minority” (Hahn, 1988). It can be said that these theoretical approaches seeking to move beyond biomedical models of disability were mainstreamed when the United Nations adopted in 1982 the World Programme of Action Concerning Disabled Persons, a document which already put forward the idea of adopting a socio-political model of disability as an alternative to the biomedical one (McKenna, 1998). The articulating concept in that document was that of 'handicap', which was defined as “a disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal, depending on age, sex, social and cultural factors, for that individual” (UN WPACDP, 1982). This notion about the link between disability and socio-cultural factors was further established by the United Nations Convention on the Rights of People with Disabilities in 2002, which reaffirmed the relationship between individual and environment by defining 'people with disability' as: “those who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various attitudinal and environmental barriers, hinders their full and effective participation in society on an equal basis with others” (UN CRPD, 2002).

But what is this crucial distinction about? Proponents of the SMD argue that while people might indeed have mobility, sensory, psychological, intellectual, cognitive or other kinds of impairments, on the other hand, disability only manifests itself when in interaction with a sociocultural context. Disability is defined as the negative social response to those impairments which result in the exclusion of the impaired from the political, economical and social organizations of their communities (McKenna, 1998). Part of the significance of this crucial distinction might be seen more clearly when we acknowledge that, since we are not omnipotent nor omniscient beings, we all have different kinds of impairments -that is, our physical, intellectual, social or sensory capacities are always partial and limited. The question of whether or not our limitations and partial capabilities are going to constitute a disability can only be answered when they are considered and situated in a given sociocultural context.

Let us explore further the implications of the distinction between impairment and disability by considering two illustrative examples. First, we will compare two impairments which are similar in nature, but which are asymmetrical when considering the prevalence in which they result in a disability: one is a limited sensory capacity to distinguish different frequencies in light (colour), and the other one
a limited sensory capacity to distinguish different frequencies in sound (pitch). In both impairments, there is a sensory limitation to perceive light and sound frequency respectively. In the first of these impairments, a person with difficulties differentiating light-frequency might have problems distinguishing colours and associating an unequivocal name for the colour of a given object. Similarly, the latter impairment might make problematic to associate the pitch of a given sound to the name of a note (whether it is G, E, C#, etc.). If we follow the terminology of the SMD, we can say that both of these conditions constitute impairments, but that they result in a disability only when in interaction with specific socio-cultural environments (United Nations, 2002; UPIAS, 1976). For instance, since most of Western societies tend to rely more on colour cues than they do on pitch, the limited capacity of a person to see colour might result in a disability, for example, while using traffic lights or trying to specify an object to another person by describing its colour. On the other hand, since most Western societies do not tend to attribute much importance to the pitch of sounds, people with a limited capacity to hear pitch will be terrible singers, but nevertheless they will be able to fully participate in the political, social and economic life; this means that their impairment will rarely result in a disability… unless they decide to join jazz musicians’ jam sessions, in which subculture their limitation to perceive pitch will probably result in a disability. Thus, the core argument here is that disability is always dependant on the sociocultural context in which the individual is located and the degree to which these limitations are going to be accommodated and taken into account. Furthermore, since cultural contexts are formed by socially constructed ideas, likewise disability is neither a given nor an objective phenomenon, but a socially constructed idea within which we find ingrained issues of discourse and power relations (Foucault, 1982).

As the second example, let us consider briefly the fascinating case of Martha's Vineyard, a small community in the USA documented by the cultural and medical anthropologist Nora Groce (1985). She wrote that between the seventeenth and early twentieth century, in this remote community in Massachusetts there was an extremely high rate of a severe hereditary impairment: deafness. Groce noted that, although deafness usually constitutes a disability for deaf people in most societies, the inhabitants of Martha's Vineyard did not experience deafness as a disability (and nor were deaf persons seen as disabled) because the prevalence of the impairment was so high that the whole community was fully functional in Sign Language. Hearing and deaf people alike simply grew up bilingually speaking both English and in sign language (Groce, 1985). Put into the terms of the SMD, even if deafness remained
as a limitation, an impairment, it did not constitute a disability because it did not prevent deaf people from fully participating in all aspects of community life, including work, church affairs, politics and social life. This example is very significant because it clearly illustrates the interplay between the notions of normalcy, disability and agency, and their relation to the sociocultural contexts in which they occur.

This conceptualisation of disability as the result of the interaction of the individual and the environment has given birth to more radical stands in Disability Studies, which articulate the issue of disability well away from the clinical model. In these discourses, the concept of disability is framed primarily as an issue of exclusion and power relations. A high profile and well-known example of this discourse can be found in a 2001 policy document of the Ministry of Health of New Zealand which in relation to the distinction of disability and impairment stated: “Disability is not something individuals have. What individuals have are impairments. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments [...] Disability is the process which happens when one group of people create barriers by designing a world only for their way of living, taking no account of the impairments other people have...” (New Zealand Ministry of Health, 2001). This transcended the association of disability and culture, and problematized it even further, by pointing out that culture is constructed through processes that involved people as major agents, and hinting at issues of inclusion, of voice, and of epistemic violence (Spivak, 1988).

In summary, Disability Studies have undergone a gradual shift in the focus of the study of disability. There has been a transition from favouring mostly the clinical model of disability, which conceptualised disability as a phenomenon exclusively connected with the individual, towards a more holistic approach which understood disability as the result of the interaction between the impairments that individuals have and the socio-cultural contexts within which they live. This approach to disability is what characterises the Social Model of Disability. We have also seen that from the Social Model of Disability, more critical theoretical positions were developed which not only framed disability in relation to socio-cultural contexts, but also saw in it issues of oppression and power relations. Who decides how our societies are going to be organised? Whose needs and capacities are going to be taken into account?
In the next section, we will take a closer look at some of these critical discourses and their positioning.

### 3.4 Critical Disability Studies

Indeed, the SMD marks a point of departure for disability studies. By problematizing the notion of disability in relation to socio-cultural aspects, new paradigms in the approach to disability emerged. Some of these new paradigms drew from standpoint theory, which enabled a move towards exploring disability not as a way to categorise people, but as a new standpoint from which to critically examine societies. As Harding (1998) explains, the core argument of standpoint theory is that "the activities of those who are exploited by [dominant] social hierarchies can provide starting points for thought — for everyone's research and scholarship — from which otherwise obscured relations that people have with each other and with the natural world can become visible" (p. 150). Indeed, the basic idea here is that disability studies, if turned around, can be used not only as a classifying category in reference to individuals, but perhaps more meaningfully, could be used as a lens to examine some less known angles of cultures, human relations and societies revealed from these unique viewpoints.

One of the more critical stances include for example Critical Disability Theory (CDT), which builds upon critical theory, adding to its analysis considerations of the intersectional dimension of the experience of disability, drawing specifically from critical feminist theories, critical race theories and postcolonial theories. Pothier and Devlin (2006) elaborated on critical disability theory putting forward that CDT holds that "disability is not fundamentally a question of medicine or health, nor is it just an issue of sensitivity and compassion; rather, it is a question of politics and power(lessness), power over, and power to" (p. 2). Like other branches of critical theory, CDT builds upon standpoint theory and the specific experiences of people with disabilities (or of people who are defined as disabled) in relation to dominant conceptions of 'normal'. The focus of CDT is thus to question the locus of the problems that people with disabilities encounter, putting emphasis on a critical analysis of society's response and the power issues embedded in the relationship between disability and society. In so doing, CDT offers a powerful tool to reconceptualise, reconstruct and empower the identity of the disabled (Sleeter, 2010).

Elaborating this discursive line further, and framing it within a pragmatic lens, disability activism emerged from the SMD as an approach to disability with a clear empowering and political focus. Central
to the claims of disability activism is the request for equal citizenship and civil rights (Canada, Europe, Australia, and New Zealand, Barnes, Oliver, & Barton, 2002; UK, Campbell & Oliver, 1996; USA, Anspach, 1979). In this context, it has been noted that equal citizenship is understood as a claim for the right to be economically and socially productive, instead of being forced into a life-dependency on welfare, charity and good will (Scotch, 2001). As they developed their strategies, disability activism drew heavily from the theory and praxis of other identity-based movements, such as the Civil Rights Movement and the women's movement (Shapiro, 1993). Similarly, their activism and struggle has also been compared to that of African-Americans (Barnartt and Scotch, 2001). Like empowered actors in these movements, disability rights activists engaged in direct action, challenging state power through demonstrations, sit-ins and marches. As Shakespeare (1993) argues, these activities were especially salient for disabled persons because they directly challenged a dominant stereotype of the disabled as passive and incapable (see also Scotch, 1988).

### 3.5 The Neurodiversity Movement

As we saw earlier, the Social Model of Disability problematized the concept of disability by moving the locus of the problem away from the individual and exposing the unequivocal link between disability and society. We also reviewed how Critical Disability Theory problematized this even further by critically examining issues of power and agency in the very processes by which societies accommodate or ignore the diverse needs and abilities of people. What is going to be accommodated? Who decides it? Can everyone participate in the processes where these things are decided? Spawning from the momentum gathered by these discourses, the Neurodiversity Movement (also called the Autism Rights Movement or Autistic Culture Movement) more specifically addresses these issues from an ontological and political angle in relation to the struggles, primarily of those on the autism spectrum and those neurologically diverse more generally (Jaarsma & Wellin, 2011; Ortega, 2009; Seidel, 2005).

It has been the norm, and still is fairly common, to portray autism in popular culture using very obscure and over-dramatic motifs. For example, in his piece in the New York Magazine, Andrew Solomon (2007) wrote that the New York University Child Study Center designed an ad campaign to raise awareness about autism in the form of ransom notes. The notes went: “We have your son. We will make sure he will not be able to care for himself or interact socially as long as he lives. This is only the
beginning.” It was signed “Autism”. In a similar vein, the earlier mentioned words of Thomas Insel, director of the National Institute of Mental Health and chair of the Interagency Autism Coordinating Committee in the USA, who referred to autism saying: "we're talking about […] a tremendously disabling brain disease which really robs a child and a family of the personhood of this child," (USA Today, 2005). In these two high profile and by no means isolated examples, we can identify one of the core assumptions of the medical model, namely, that autism is a terrible brain disease which needs urgent cure because it diminishes the personhood of those ‘suffering’ from it. And this is precisely where the Neurodiversity Movement takes issue. In response to this conceptualisation of autism, proponents of the neurodiversity movement problematize the assumptions underpinning it, discussing the subjacent issues of power, agency and representation in the processes by which personhood is unilaterally defined by the neurologically typical and arbitrarily selecting the attributes and abilities of the statistically normal as the universal reference for personhood. That is, if someone cannot communicate the way most of us do, we conclude that person is unable to communicate at all. If someone cannot interact with others like the rest of us, then we say that person is unable to socialise with others. If someone cannot be the way most of us are, then we question if there really is someone inside of that person (Savarese, 2010; Savarese & Savarese, 2012).

One of the first persons to articulate the positions of the neurodiversity movement was Jim Sinclair (1993). Sinclair himself is an Autist who only started speaking at the age of 12. Up until that age, doctors considered that he would never learn to speak. In 1993 he published an article entitled “Don’t Mourn for Us”. The following excerpt is taken from his demolishing open letter to parents:

“It is not possible to separate the autism from the person. Therefore, when parents say, ‘I wish my child did not have autism,’ what they’re really saying is, ‘I wish the Autistic child I have did not exist and I had a different (non-Autistic) child instead.’ Read that again. This is what we hear when you mourn over our existence. This is what we hear when you pray for a cure. This is what we know, when you tell us of your fondest hopes and dreams for us: that your greatest wish is that one day we will cease to be, and strangers you can love will move in behind our faces.” (Sinclair, 1993).

As delineated by Sinclair, the position of the neurodiversity movement is one, which aims to open
up the discussion on autism for ontological considerations. As Ortega (2007) writes “[t]he proponents of the neurodiversity movement claim that their condition is not something to be cured, but rather a human specificity or difference, with different ways of socializing, communicating and sensing, that may not necessarily be disadvantageous and that must be equally respected”. In fact, some proponents of the concept of neurodiversity are critical to the idea of 'curing autism' and claim that the clinical model and the treatment of autism undermines the dignity of Autists (Harmon, 2004; Saner 2007; Dawson et al., 2004).

Indeed, the neurodiversity movement defends the notion of the existence of diverse yet legitimate ways of being (fully) human. Kathleen Seidel, vocal activist in the portal neurodiversity.com, took issue with Insel words quoted above and wrote to him a public letter in 2005, in which she argued:

“All too many people feel free to characterize Autistic people as living a "fate worse than death," as "never really there," as "kidnap victims" and "hollow shells" [...] The last thing in the world that they need is reinforcement by a prominent government official of the all-too-prevalent public perception that they are somehow "less than human," either in childhood or adulthood. A person who has difficulty with communication, with being touched, or with making eye contact is no less of a person than one who does not have these difficulties” (Seidel, 2005).

The central question to be addressed is thus: can the neurodiverse participate in the discussions where it is decided what constitutes a full human being? Or is it that we tacitly impose as a condition to participate in this discussion that they think, communicate and interact like most of us do? Indeed, this dehumanisation of the neurologically diverse is not only an ontological and rhetorical discussion, but also a prominently political one. As noted by Judy Singer (1999) in her article “Why can’t you be normal for once in your life?” the neurological diverse constitute an addition to the more familiar political categories of race, class and gender (Singer, 1999).

Jaarsma & Wellin (2011) examine the appearance, articulation and evolution of the notion of 'neurodiversity'. They also make an assessment and recommendation about the validity of the neurodiversity claims. In their analysis of the validity of the neurodiversity proposal, the authors differentiate between high-functioning Autists and low-functioning Autists. They argue that the claims
made by the neurodiversity movement should be accepted only in cases in which autism does not interfere very severely with the 'normal' functions and behaviours of the person, and be rejected for cases of deep or non-verbal autism. Jaarsma & Wellin made a valid point in looking at the concept of neurodiversity from a purely pragmatic point of view. Indeed, accommodating the so-called high-functioning Autists is less complicated than accommodating non-verbal Autists. However, their analysis fails to engage with the deeply philosophical dimension of the discussion. The point is not to accept and accommodate Autists in the basis that they succeed at being more like 'us' neurotypicals. Perhaps more significantly, the valuable contribution that the neurodiversity claim makes falls precisely onto the neurotypicals. The neurodiversity claim highlights very clearly the difficulties, confusion and inability that those who are considered able and normal experience when they face the task of recognising as full equals and of empathising with those that they perceive of as being significantly different from themselves. The significance of the neurodiversity position lies primarily within the theoretical spaces and ethical issues which overlap many of the issues of ‘Otherness’ as discussed by postcolonial theory (Spivak, 1988).

The most valuable contribution of the neurodiversity discourse, which is perhaps too commonly overlooked, is not about bringing the neurodiverse closer to the statistical normal and thus facilitating their integration; ironically, it is that those deemed unable to communicate, socialise or feel empathy do, through their neurodiversity discourse, expose very lucidly the flaws, bias and limitations of the neurotypical themselves. The neurodiversity discourse thus both pushes for the recognition and dignity of the neurodiverse, while at the same time places a mirror in front of us, exposing the limitations and impairments in our own ways to sense, communicate, socialise and feel empathy (Savarese, 2010; Seidel, 2005, Shakespeare, 1996; Shakespeare 2006).
4 Methodology

In this section we will review the methodological choices and procedures that gave birth to the present study. A guiding principle in the process was to ensure that both the methodology chosen and the ontological and epistemological position of the text were coherent with the research question and with the declared goals of the study. For this reason, this section will go back to the overall view of the study in order to help the reader get a clearer picture of where I stand within the thesis. Finally, this section will also deal with the research process itself as well as with more formal empirical aspects of the thesis, such as: how did I approach the whole research? Where did I start? How did I get familiarized with the topic? With which criteria did I look for participants? Where and how did I find them? Who were they? What did they focus on? What kind of data did I collect? How did I collect it? How did I process it?

4.1 Qualitative Content Analysis

Since the main purpose of the research question is to provide a glimpse on some of the different ways in which autism can be conceptualised, the methodical and descriptive focus which is characteristic of Content Analysis seemed particularly relevant. More specifically, a qualitative approach was favoured over a quantitative one after considering that the research question does not seek to offer an objective, broad and general picture on the representation of autism, but rather to explore some more specific nuances of less familiar discourses around autism. The focus of this inquiry on the subjective experiences and views of the participants was considered to justify the use of qualitative analysis methods. Therefore, this thesis uses Qualitative Content Analysis as the preferred methodology to analyse and organise the data coming from the interviews (Fairbrother, 2014). A suitable code-frame was designed in order to better organise and describe the main themes which emerged from the participants' views regarding autism. The specific way in which the code frame was used will be discussed in the next chapter, dealing with the empirical.

Using the principles of qualitative content analysis to engage with the data is a coherent course of action when considering the epistemological position of the text. As we reviewed earlier, the present study is designed taking from the traditions of subjectivism and constructionism. That is,
epistemological premises of this study acknowledges that different (personal, cultural, religious, political, historical...) subjectivities can indeed give birth to different ways to conceptualise, and indeed experience, autism; all of which would constitute different, yet genuine and legitimate epistemological and ontological positions in themselves (Ortega, 2009; Savarese, 2010; Shakespeare, 2006; Sinclair, 1993; Singer, 1999). The unique ways in which the participants describe and discuss autism are entrenched in their own personal subjectivities. This subjective dimension in the data and discussion, far from depriving them of significance, adds value to the present study, offering the possibility to explore through an exercise of empathy some alternative ways in which autism can be perceived. Using standpoint theory as a theoretical referent, it is possible to take the discussion beyond the particular subjective experiences of the participants and to reflect on issues which perhaps tend to remain hidden and unexamined by those of us who are non-Autist.

Therefore, the research process involved an avoidance of positivist expectations, as well as the notion of an objective and universal truth concerning autism to be grasped as a phenomenological entity. Anchored on this premise, the researcher's own assumptions and subjectivities were suspended during the data collection phase, and the preliminary analysis, in order to better engage and 'be touched' by the accounts offered by the participants. This does not mean that as a result I am expecting my analysis to be completely neutral and unbiased. On the contrary, I assume that my interpretation of the data is unavoidably defined by my own views and experiences. I acknowledge my own bias and subjectivity hoping that they could act as launching pads from which others could further explore the topic. Nevertheless, I do consider that attempting to suspend my own judgement and remain open minded, was a crucial step to listen genuinely and to attempt to empathise with the participants' views. This is even more important in this case in particular because of the criticism found in neurodiversity discourses that highlight the tendency to over-impose the experiences, ideas and narratives of non-Autist over those on the spectrum.

Along this line of argumentation, it has to be stated that the aim of the research is not to produce general and definite statements about the conceptualisation of autism, nor to present what Autists, in general, say about autism. The participants of the study and their views are not seen as representing the entire Autistic population. Quite the contrary, they are looked upon as merely representing their own subjectivities and positions, as an illustration of the complex and diverse population that comprises the
Autistic community, and propelling to the front of the discussion the ontological importance of acknowledging and legitimizing the diversity which does indeed exists in the experience of human life in all its forms and variants, neurological or otherwise. The choice to use Qualitative Content Analysis has defined both the methodical and descriptive angle used to approach the data, as well as the lens through which the research question have been discussed. Following QCA principles, the primary aim was to organise the data coming from the interviews, producing a coding framework that could describe clearly the views of the participants, as well as the different nuances and issues which emerged when discussing autism. But the overall goal is to give an idea about the positions of the participants and to entice the reader to read further and to find out more. In chapter 5, the data is presented, organised by themes and the answers that the participants gave to the specific research questions. Later on, in chapter 6, I discuss these answers from my own point of view, and reflect upon them connecting back to the literature.

### 4.2 Research Question

This study was devised around the idea of engaging with Autists and to explore alternative discourses on autism. Special emphasis was given to those discourses that challenge the dominant discourses and narratives which depict Autists as silent, trapped or disabled. To open up the discussion, the following question was specifically addressed:

RQ. How do Autists see and experience their autism?

Even though the interviews were designed to be semi-structured, I tried with a varying degree of success to steer the conversations towards addressing this question. The analysis part of this study will take the contributions and insights of the participants as well as the current literature on the topic, and reflect on themes that emerge from the data.

### 4.3 Coding

The coding framework for the data was partly data-driven and went through several changes during the analysis. For example, the initial coding framework focused more specifically on the philosophical
aspects of the neurodiversity discourse, such as discussions on the legitimacy of the demands for the recognition of personhood and agency for the neurologically diverse, even when their specificities do not resemble very closely those of the statistical normal (Jaarsma & Wellin, 2011; Savarese, 2010). The original coding frame also included themes that addressed the ethical issues underlying the unequal relation between those deemed normal statistically and those who are considered atypical, or to put it in neurodiversity terms, the relation between the neurotypical and the neurodiverse. But, since QCA is concerned with describing the specifics of the data, it is not unusual that the code-frame changes and gets fine-tuned during the research process in order to better encompass the material. Indeed, after processing the data, the coding framework retained some of these philosophical angles, but it also morphed during the process to include a number of issues, which I had not anticipated, but that very clearly were of importance for the participants. For example, the participants brought up issues regarding parenting and education. The role of parents, how parent’s expectations, resources and attitudes toward autism can affect the life of Autists; the challenges, victories and pitfalls in education: What has changed forgood schools? What is still problematic? One of the participants discussed challenges surrounding employment for Autists, as well as issues of accommodation in the work place. Another one reflected on issues around diagnosis and the access to public support services and resources.

As it is logical, in accordance with the principles of QCA and honouring the declared intention of this thesis to favour the agency and voice of Autists, the coding framework and the analysis shifted in order to include and encompass these issues raised by the participants. So for example, when processing the data looking for answers to the research question, I looked for themes that could group together the very different ways in which the participants talked about autism. Once these themes were found and defined, I read once again the participants contributions organized by themes, and connecting what they were saying back to the literature and the theoretical framework. After presenting these themes in chapter 5, during chapter 6, the discussion part, I present and reflect on these links between data and literature, putting forward the insights and conclusions that I got as a result of this research project.

Allowing the contributions of the participants to determine the themes, and approaching the discussion part of this thesis through these data-driven themes, complicated somewhat the research process and made wrapping everything up more challenging. Specifically, the data suggested strongly that people do experience autism differently, and this complicated the process of finding a clear narrative with which to
answer the research question. Nevertheless, I also consider that letting the data define the themes helped me to better understand the deep complexities surrounding the experience of autism, alerting me about the risk of oversimplifying it and of painting it with a single brush. Overall, I wholeheartedly feel that letting the participants steer the focus of the research contributed greatly to the significance of the study and in making the research process a meaningful learning experience.

4.4 The research process

In order to fulfil the aim of this study, which is to explore alternative discourses on autism, I started by getting acquainted with the topic by reading introductory articles and approaching online Autist communities. Very quickly, it became clear that autism was being discussed in very different terms inside and outside of Autist communities. As Jaarsma & Wellin (2011) pointed out, the general tendency outside of Autist communities is to replicate the discourses and imaginary of the medical model of disability, while perhaps unsurprisingly, proponents of the Neurodiversity claims are disproportionally situated in autism communities and self-advocacy circles. Instead of just reviewing and analysing the neurodiversity discourse, I thought that it would be more interesting to directly get Autists to talk about it. As a consequence of this, and in principle, I was thus looking for participants that were diagnosed or that self-identified as being Autists.

There were two main motivations for me to do this. On the one hand, in most of the Autist communities that I visited (Wrong Planet, Aspies For Freedom, Autism Community of Second Life, Autistic Self Advocacy Network, Neurodiversity.com, among others) there was a very explicit demand for journalists, writers, researchers, film-makers or other people willing to discuss or represent autism, to include the Autistic community in the process. In Monaghan (1998) the author quotes Simi Linton (1998), co-director of the Disability Studies project at Hunter College, when he adopted the famous phrase “Nothing about us without us” in relation to self-advocacy work in disability studies. Indeed, this motto appeared verbatim not uncommonly in these online communities and was almost always present, at least implicitly. But of course, the whole controversy about how to conceptualise autism deals very much with issues of agency, authenticity and representation, so it just seemed to me that the coherent thing to do, albeit more complicated, would be to find Autists willing to contribute to this thesis and to create spaces for them to express their views in it. For this reason, one of the core assumptions of the
thesis quickly became that Autists themselves have things to say.

The other, more personal motivation for me to interview adult Autists was that I wanted to experience first-hand engaging with Autists in a dialogue about autism. Part obstinacy, part scepticism, it did not matter to me how Autists had been portrayed before; I simply wanted to see for myself how communication with Autists would go. I just wanted to shake off my prejudices and to go and meet Autists, and the thesis provided me with an ideal opportunity to do so. Originally, I envisioned the research process as being two-fold. In order to be able to offer a general introduction to the topic of autism, I first had to familiarise myself with academic literature dealing with autism to get an overview of the evolution of the discourses around autism, as well as the current state of the discussion, and the most current trends and issues. On the other hand, having no previous involvement with disability studies or special needs communities, I had to start looking for possible participants, reaching out trying to make contacts to see where I could find Autists willing to discuss autism with me.

One could say that the research process itself started by me going to academic databases and searching for articles dealing with autism. Some of the keywords that I used in the searches were 'autism', 'Asperger's syndrome' and 'neurodiversity'. To my surprise, these searches yielded overwhelmingly abundant results evidencing the exponential growth and attention that, especially during the last decade, autism has gathered both in academia and in popular culture. Much of the material that I found addressed autism from a clinical perspective, mostly looking at the causes of the occurrence of autism, offering grounds to pin down the aetiology of the condition to genetic factors, environmental conditions or components that have to do with neurochemistry and diet (Rapin, 1997; WHO, 1980; Yasmin & Neggers, 2014). Given the abundant material, and the fact that my principal concern was not so much to study the clinical aspects of autism, but to offer an introduction to how autism is conceptualised, I decided to narrow these results down by focusing specifically on literature that offered different narratives of autism and that contextualised it within social, cultural, cognitive or developmental terms.

4.5 The participants

During this time, I started to turn to different organisations, which I thought might be good starting points from which to find possible participants. For practical reasons, and to avoid issues of inconsistency, a
general criterion was defined when looking for participants. Firstly, I was looking for individuals who either had a diagnosis of autism or that self-identified as Autist without having a formal diagnosis. Secondly, I looked for individuals who could discuss comfortably in English in order to avoid translations or interpreters. Thirdly, considering the heavy emotional charge of some of the topics to be discussed, and the statistical correlation between autism, depression and anxiety, for merely pragmatic reasons I decided that it would be wise to avoid teenage participants and stick to adults. In the end, 6 participants took part in the study: 2 in Oulu, 2 in Southern Finland, and 2 in the UK. The average age of the participants was 37, the gender distribution being 3 females and 3 males. The level of education of the participants included 4 out of 5 in possession of a higher education degree, and the remaining participant with compulsory level studies only. In the following paragraphs, I will offer a brief account about how I approached and found the participants.

Table 1. General information about the participants

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age Range</th>
<th>Occupation</th>
<th>Location</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Female</td>
<td>41-45</td>
<td>Therapist</td>
<td>Southern Finland</td>
</tr>
<tr>
<td>2</td>
<td>Male</td>
<td>41-45</td>
<td>PhD. Psych., Unemployed</td>
<td>Southern Finland</td>
</tr>
<tr>
<td>3</td>
<td>Male</td>
<td>25-30</td>
<td>University Student</td>
<td>Oulu</td>
</tr>
<tr>
<td>4</td>
<td>Female</td>
<td>36-40</td>
<td>Special Needs Teacher</td>
<td>Oulu</td>
</tr>
<tr>
<td>5</td>
<td>Female</td>
<td>36-40</td>
<td>Counselor for Special Needs</td>
<td>UK</td>
</tr>
<tr>
<td>6</td>
<td>Male</td>
<td>31-35</td>
<td>Advocacy, Hacktivist</td>
<td>UK</td>
</tr>
</tbody>
</table>

4.5.1 Participants from Southern Finland

I started the process by sending emails attempting to contact one of the biggest platforms for support and advocacy work for autism in Finland, the Finnish Association for Autism and Asperger's Syndrome
(Autismi- ja AspergerLiitto ry). I contacted their offices in Oulu and asked them about people in Finland who might be willing to discuss neurodiversity and self-advocacy work with me in the context of a Master's thesis. While these requests were met with a generally receptive attitude, a significant limitation that I faced here was that my level of Finnish was not good enough to discuss these issues in depth, which in turn reduced dramatically the number of people with whom I could in principle talk. Although I was aware that there exists the possibility to use interpreters and translators in the research process, I considered that translating interviews and having an additional barrier between the participants and myself would have only complicated a process that already implied challenges in communication, making the idea of using interpreters or translators simply too cumbersome. Based on these grounds, and partly for methodological and pragmatic reasons, in the end I decided to limit the profile of the participants to people who might be able to discuss their views on autism comfortably in English.

While many in the Finnish Association for Autism and Asperger's Syndrome did speak English, finding willing participants turned out to be more challenging than I had anticipated initially. Retrospectively, I now consider that an added difficulty was that inside autism communities there is a prevalent reluctance to discuss autism with people who are themselves not on the spectrum (especially in relation to academia and charity organisations), due to a general feeling of being very often misrepresented, mistreated, and exploited to advance someone else's agenda. Luckily, after a few months of exchanging emails and meeting up with people from the organisation in order to clarify my motivation and position, I was finally directed towards two Autists in Southern Finland who were considered in the association to be vocal, rather radical in their views, fluent English speakers and very likely to be willing to discuss autism with me. This is how I found my first two participants, with whom I would exchange some preliminary emails before travelling to meet them in person. The meetings rather focused on issues of employment and access to support services. But they also were very critical both of current practices in treating autism and of some of the neurodiversity claims

**4.5.2 Participants from Oulu**

At the same time, I had turned to my contacts at the University of Oulu and to those involved in education to ask them if they knew adult Autists in Oulu or people who could point me towards them. From these sources I received several hints and heads ups about potential participants, some of whom were students
at the university believed to be on the spectrum, and some of whom were involved professionally in special education. I sent out numerous messages briefly explaining my research interest in an attempt to establish contact with these persons and to see if they would be willing to meet with me to discuss the topic in more detail. Unfortunately, the majority of them declined the invitation to participate citing various reasons (lack of time, availability, or interest). Receiving such responses (or lack of them) was quite discouraging, and it translated as a blow to my motivation since I had assumed that people would be rather positive to the idea of expressing their own views about autism. Finding adequate and willing participants turned out to be much more complicated than I thought, and it made me question the choice of topic. Retrospectively, I consider that perhaps back then I was not fully aware of the complex and intertwining issues surrounding the experience of autism, and that I was not sufficiently sensitive to the mixed feelings that the people I contacted might have had about autism or to the inappropriateness and intrusion of coming as an outsider to do research about autism. While some people might adhere to the neurodiversity movement and its ideas, other Autists might not feel that being Autist constitutes an important part of who they are, and thus might feel offended by someone like me approaching them to write about autism.

Since by then I was already aware of the general scepticism with which these requests to participate in research were likely to be met, I changed my approach when contacting people I did not know. I always proceeded very cautiously, having in mind that many Autists would take my approaching them as an unwelcomed move. I was aware that, frequently, Autists would prefer to avoid being identified primarily in relation to their autism. Acknowledging the sensitivity of the issue and the potential intrusion that such messages could be perceived as, in the end, I opted for giving up altogether further attempts to contact people so randomly. Luckily, not everything was in vain and in the end, one of the tips that I had received led me to a very positive response from someone working in special education, diagnosed as being on the spectrum, and a parent of a young person also with an autism-related diagnosis. This would be my third participant. Perhaps because of her work as a special education teacher, the conversation orbited towards issues of parenting and the need for education for parents and caretakers of children on the spectrum. The second participant from Oulu simply came to me. He had gotten very recently a diagnosis on the so-called high-functioning end of the spectrum, and knowing that I was writing on the topic through common friends, approached me to discuss his impressions on the diagnosis process and
the definition of autism as a disability

4.5.3 Participants from the UK

In this last section, I will relate how I found the two participants from UK for the study. During the spring of 2012, I had a 3-month placement as a research associate in a higher education institution in the UK. The research work that I carried out there was related to education, but unrelated to autism. Nevertheless, the connection to the higher education institution and being temporally relocated to an English speaking country constituted a fantastic chance to find more participants for my study. I contacted several advocacy and support organisations working with autism asking for an appointment with someone in order to discuss the topic. One of the persons who agreed to meet me identified himself as an online advocacy Autist and as a hacktivist. He has an official diagnosis and is a non-verbal Autist. We never met in person, but we communicated electronically on and off for over 6 months. We discussed very diverse topics, although the conversation tended to lean towards political, philosophical and ontological issues that pictured the discussion of autism as an issue of diversity and oppression. The second participant was a professional with many years of experience working in a higher education institution as counsellor for students with special needs. Both her teenage children and herself have a formal diagnosis on the spectrum. She problematized especially the definition of normalcy and discussed the neurodiversity movement pointing out the huge waste of human capital that results from understanding ability in a narrow sense, and not being able to recognised people’s diversity and possible contributions.

4.6 Data, research material

In this section, I will briefly describe the data collected, as well as how it was collected and processed. The data was collected from the participants in the form of email exchanges, chat logs and audio recorded from face-to-face interviews. In total, the data is comprised of slightly more than 7 hours of face-to-face interviews, 23 emails, and 5 pages of chat logs, resulting in a total of 308 pages of data in transcribed text format.

Initially, I had the intention to use data from the online forums of the Autist communities with which
I entered into contact. Unfortunately, I met difficulties in getting clearance from these communities to carry out my research within their platforms, and in the end I decided not to use this data. The grounds upon which permission to carry out the research was denied in these communities were mostly related to requests to adjust the study according to the principles of community research models. Just to be clear, while I do agree that a study of significance on autism should be designed together with the community, initial discussions on how the study should be done led me to think that such a level of involvement of the community, co-authoring the study and making them participants of the whole writing process, subjecting the text to the scrutiny and edition process of the participants, would simply require a scope of time, energy and depth that probably surpasses both the expectations of a research at the Master's level, as well as my own skills as a novice researcher. Nevertheless, I want to acknowledge that from the beginning I saw these requests as reasonable and justified.

Even if this thesis was not intended to be a community research project, I want to acknowledge this request and to take this opportunity to state explicitly, that I agree wholeheartedly that further research on autism not only could benefit greatly from involving Autists directly in the process, but also that advanced academic work failing to include them incurs a severe bias in the discussion of normalcy. Considering both the ever-growing body of literature on autism, as well as the emerging visibility and willingness of Autists to be vocal about their views, it is remarkable to note the minimal proportion of academic work that is done in collaboration with Autists. As a result, many valuable and very valid insights are being missed in academia when the discussion does not acknowledge explicitly the epistemological and ontological assumptions underpinning our views. Indeed, the neurodiverse do experience and perceive life differently; they think and communicate in ways, which are different to most. If only we could acknowledge the flaws of associating the statistical normal with the absolute representation of the human condition, and limitations of our own ways of sensing, communicating and being, then we could understand the truly significant lessons that we are missing; the huge potential to question and interrogate narrowing discourses of ability, considering the neurodiverse, normalcy, ability, inclusion, communication and personhood in ways which are not very familiar to the neurotypical. From a Standpoint Theory perspective, their valid insights could be incorporated into the discussion opening up new angles and theoretical spaces from which to expand and enrich our understanding on these issues. Needless to say, there is huge significance and relevance in letting the Autist community itself define
what the most pressing issues surrounding autism are.
5 Findings

During the interviews, the participants discussed how they see and experience autism, as well as reflected about the most pressing issues regarding the welfare of Autists. The data that was collected from these interviews suggests that the experience of autism is open to many variations, hinting at the complexity and intersectionality of the issue. The variability in the stories of the participants suggests also that the experience of autism does not happen in isolation, but in a constant and interdependent interplay of many other factors such as cultural background, current context, socioeconomic background, gender, age, employment status, support structures or lack of them. Although there were some common elements in the experiences that the participants shared, it can be said that the most defining feature of the data, as a whole, is the significant differences found in the way autism was experienced and described by the participants. In the following paragraphs, I introduce themes that I selected as answering the research question. The selected themes showcase the different ways in which the participants talked about autism during the discussions, and respond solely to my subjective decisions about which themes and narratives represent more vividly the most interesting trends that I encountered in the literature, online communities and current popular culture. To better differentiate what the data says, and what I say, I will leave the discussion elements of the analysis out of this section in order to present the findings with descriptive rather than reflective remarks.

The question of how do Autists see and experience their autism is answered by a number of themes: some Autists see autism as part of their identity; some question the idea that it is a disorder and frame it as a normal human variation; and some others acknowledge there are disabling features in autism, while partially linking these disabilities to other people’s lack of understanding of autism. In the following we review these themes more closely together with some illustrative quotes:

5.1 Autism as identity

The general trend was that the participants made a strong association between autism and who they were. They expressed in different ways the idea that being Autists had affected significantly how and who they are. Some framed this relationship between autism and self as a more negative one, while others meant
it more positively. Perhaps this association between themselves and autism is unsurprising if we consider that the participants belong to a subgroup of the whole Autist community: those with an interest in talking openly about it. Regardless of its significance, a clear theme that emerges from the data is the idea that being Autists, in a way, can explain why they are the way they are.

“I have Asperger’s. That means that if you do something like that, it will definitely freak me out”

“Sometimes I just find it is easier to tell people from the beginning: I am an Autist, if I offend you in any way, please let me know.”

“This is who I am. I cannot even imagine what life would be like without autism”

One of the participants also said that being diagnosed as an Autist brought a great deal of peace of mind to her life. This participant in particular narrated that prior to a formal diagnosis, she always felt like an “alien”, broken, inadequate, insecure and basically just “not the same” as others.

“Growing up in a small rural community, you know, this idea of diversity and acceptance that somehow is present nowadays, didn’t exist at all, and I remember those years as feeling very lonely and bad about myself. Growing up being different in a small community such as NameTown was a really hard thing to do. I didn’t really have friends, other kids bullied me and made fun of me… I always felt that there was something ‘wrong’ with myself, I just couldn’t tell what it was”.

In this case, the participant explained that getting a diagnosis as an adult actually brought an explanation to what these feelings were about and an understanding about the way she was. Being diagnosed as a high-functioning Autist meant for her being placed inside of a framework where her peculiarities and issues were perfectly defined, a framework within which she made perfect sense:

“It was such a relief to find out that there was an explanation, that there were others just like me. Somehow it set me free of this feeling of being wrong, inadequate. Suddenly I understood why I
was the way I was and knowing that there were others like me made me feel so relieved”.

In summary, although some participants related more positively than others, in general they related strongly to the idea of being defined as Autists. They felt that being Autists both explained how they were and gave them a feeling of identity.

5.2 Autism as a normal human variation

Another theme that emerges from the interviews is the rejection of autism as a disease or disorder. Quite in line with the neurodiversity discourses, the participants tended to portray autism rather as a variation of the human mind. Feeling strongly identified with autism as shown above, it is unsurprising that the participants also tended to feel strongly about the idea of seeing autism as a disease, or about curing it.

One participant in particular felt very strongly about being labelled as disabled. He had gone through a long process of assessment and diagnosis, and later on underwent counselling and diverse therapies with social workers to determine the support services that would best suit him. Being in possession of higher education degrees, Master’s degrees in psychology and education, and a PhD with honors in clinical psychology, this participant claimed that he felt condescension and irritated by the way the whole process was handled by professionals in Finland. His impression was that people associated being Autist with mental retardation, and that people made the assumption that he could not understand what was being discussed. As a disclaimer for the quotations to come, I have to say that in addition to the diagnosis of autism, he had been diagnosed also with coprolalia, the involuntary utterance of profanity or of socially inappropriate or derogatory remarks. The professionals were less educated than himself, which was the reason why he claimed to feel very offended by the fact that they talked to him as if he were a child. Having achieved a considerable degree of excellence in his studies, he had this feeling of self-assuredness, of confidence, which then conflicted with his difficulties to find and retain employment. His was a very interesting interview because he often turned the whole discourse on autism around, presenting as positive some things which are usually portrayed as negative features of Autists, and shedding light on neurotypical behaviors from angles which presented them as negative traits. Most illustratively, this example comparing Autists peer support meetings with department meetings at a
“Have you ever been in a department meeting? God, how I hate those fucking morons. You know, there we are, listening to someone talking some nonsense about some shitty study without group control, no triangulation of data (...) fucked up, absolute crap. And what do you think? Everyone is fucking nodding or staring at the floor and not saying shit (...) Can you believe it?! We all bloody know that you fucking need a bloody control group, but those fucking morons won’t say anything and just keep nodding until their heads fall off! That’s not science! There has to be scientific rigor or there is no science!”

“Then we are in the Asperger’s peer support meetings, you know, where we Aspies meet once in a while and complain and talk about things (...) and you have to see those meetings, haha. Everyone is speaking their minds out, shouting, giving their opinion, and people get so involved, so emotional, so offended (...) but we speak about it. No one holds anything back. The conversation is there in the open. No whispering here and there. No backstabbing. If I got a problem with you, I tell you. We just speak it as it is and at the end of the day, we all know what happened and who thought what. And then I have to compare both meetings and… fuck, and accept that some twat out there is going to call me ‘disabled’. Fuck that, you fucking morons! You are the ones who can’t discuss shit! You are the retarded ones!”

Less dramatically, but along the same lines, a participant who had just gotten his diagnosis around the time of the interviews, pondered also about the significance of the diagnosis criteria. In this case, the participant experiences had to do with a difficulty to understand the implications of the diagnosis or the significance of diagnosis criteria such as the difficulty to face a day without a clear schedule, or the ability to read social cues.

“I just don’t understand why it is a disorder. I don’t think I have a mental problem. I have peculiar daily rituals and fixed schedules, and maybe I misunderstand sometimes facial expressions, but I don’t see why this is considered a disorder. I study theoretical physics, that’s what interests me. I don’t go around telling those who simply don’t get quantum physics that they have a disorder. I think that putting more importance on reading facial expressions than in theoretical physics is just a matter
of subjectivity, it is just a choice without justification. I don’t feel disabled, I feel I am just different”

“I don’t think it is better or worse. We are just fucking different, full stop”

“I heard the doctor said that he thought that there was a very high probability that my diagnosis was Asperger’s, but it didn’t make me feel very different because I didn’t understand what that meant. For me Asperger’s syndrome only means that people are different, but so what? I knew that already”.

Along the same lines, another participant reflected about the definition of autism as a disorder:

“I don’t know… when I hear people talking about finding a cure for autism, I do not know what to think. Yes, I would like to handle stressful situations better and maybe to be more independent, but talking about curing me… I don’t know, it is not right. It feels like an intrusion.”

And here a written excerpt framing the same opposition to defining autism as a disorder worded in rather ontological terms:

“I think there is a type of violence implicit in the idea of ‘curing’ autism. Just in the same way that it is violent to talk about curing homosexuality. It seems like some people mix the normal, in its statistical sense, with some sort of moral normal. Normal is good and pure. All deviations must be cured! That IS violence”

In summary, participants felt strongly about the idea of framing autism as a disorder and mostly rejected the notion of autism as a disease to be cured. Underneath their positions, we can find parallelism with the neurodiversity claims, such as a certain ontological assertion that defends the particular features of Autists, framing them not as deficits, but as legitimate ways of being.

5.3 **Autism as a disability because of others**

Another theme that emerges from the interviews is the idea that, at least partially, the experience of autism as a disabling condition is related strongly to others. For example, the participants talked about how
Autists do experience disability because of the little sensibility and empathy that people usually have towards diversity, and specifically, neurodiversity. The conversation at times went also towards issues of education and parenting. Central to this theme is the notion of expectations. What are our expectations when encountering others? Are we open minded about people transgressing etiquette and other subtle and tacit social rules? Do we make assumptions about the capacity and intelligence of someone, governed by conscious or unconscious expectations about behavior and communication? The underlying idea is that the attitudes that others have about autism affect greatly the way autism is going to be experienced by that person, for both better and worse.

"The first thing I tell parents is not to lower the expectations for their child, just because he has a diagnosis. If you expect less of a person, he will somehow get the message that he is less than others and behave accordingly"

The core argument here is that if people had a realistic picture of the traits of autism, many of the disabling situations which Autists encounter could be easily avoided. It is possible to see commonalities of this theme with the Social Model of Disability, since it moves the locus of the problem of disability away from the individual, and empathizes the social and relational aspects of it.

Two of the participants shared the idea that a big part of the problems associated with the experience of autism as a disorder has to do more with other people’s assumptions and misconceptions, than with the specific features of the autism spectrum disorders. According to them, very often it is people’s ignorance and their inability to understand what autism is that causes many conflicts and stressful situations for Autists. Much distress could be avoided if people simply tried to understand Autists. As an example, let us consider this extract from one interview, where the participant is talking about a process through which she gave counselling to an employer interested in taking one of her Autist students as trainee:

“I told them that he was reliable, methodical, hard-working and perfectly capable of taking any responsibility position in the restaurant (...) I also told them that the only thing they should avoid was to put him in customer service (...) It went well for a couple of weeks, but then there was a situation in the cafeteria and someone had to be temporarily at the counter, and they asked him to
do it. It was a disaster. He got nervous, customers got offended, which made him confused, and in the end it all exploded (...) They just didn’t understand that at the desk, smiling at customers and asking if they wanted something else was not the best place for him to be”.

Her position here was that the employer did not understand that a task as ordinary and as simple as being at the counter for a short while, dealing with customers, meant a significant challenge and a source of great stress for someone on the spectrum; someone who might have difficulties to blend in a given social role and automatically know how to behave in a way appropriate to that role. Let us consider also this other quote, where the participant is explained that something as trivial as a change in the planned schedule in school can create a lot of stress for some Autists. This, in her view, could be easily avoided if more teachers understood how distressful changes like this can be for Autists:

“My son was struggling in school, but I think it was partially because his teachers didn’t understand what having autism is like (…) For example, sometimes the teacher would decide spontaneously to change the schedule of the day and to change a Maths class for an English class. The teacher didn’t understand why such a thing would put my son in complete disarray, and often interpreted his reactions as unjustified tantrums”

Below the same idea, but framed in relation to social situations:

“Sometimes people are too intransigent, too impatient. I think most people are not even aware of how limited are the acceptable ways of behaving socially. Behave a little differently, avoiding eye contact for example, and all eyes will be on you. Everyone will instantly think that there is something wrong with you if you flinch when someone touches you (…) But then everyone understands if you say that, for example, you simply can’t stand the sound of nails scratching a blackboard”

5.4 **Autist and proud**

Another theme that appears intermittently throughout the data is a certain feeling of pride at being Autist. Sometimes this pride is framed as pride in being Autist, while other times it is expressed in association
with the idea of having a special talent or skill. In a number of instances during the interviews the participants mentioned, hinted or otherwise suggested some sort of savant ability:

“I started reading and writing at a very early stage”

“I had trouble in school, except in mathematics. In mathematics I was always well ahead of the class”

“… so I started playing a lot the piano to relax. I could be doing something at the computer or something, and then I’d stop to have a break and sit for a 3-hour streak on the piano. I actually became quite good at it. I could play very complex and demanding pieces”

“Memorizing all that stuff was never a problem for me, while some of my classmates really struggled memorizing all those medical terms”

“… it is always a trade-off. Being an Autist of course has its down side as well, but I really like being able to do things that others cannot. I kind of feel proud to say that I am an Autist”

At the same time, the very same theme was lucidly problematized by one of the participants who looked at it from the other angle, pointing out the enormous pressure that there exists on Autists to develop savant skills, as if being savant was a redeeming resource that Autists could resort to.

“And this is something that bothers me a lot because, because not everyone on the spectrum has these special talents (…) I want myself and others to be celebrated for who we are, regardless of the fantastic things that we can or cannot do”

5.5  Autism as an impairment

In contrast with this rather positive portrayal of Autists as individuals with exceptional talents, the participants also put forward on a number of occasions what they considered the dangers of over-romanticizing autism. In a climate of growing public debt and a constant push to reduce the public sector
expenditure, there is always this fear that support services and facilities for the neurodiverse could be reduced. For this reason, one of the participants explained that the struggle for the dignity of Autists has to be carried out very carefully, because the idea is not that Autists are all fine and need no support. The idea which, sometimes is difficult to balance is that Autists are no less than others, in spite of needing support. In other words, that dependency on institutions or on others is not a reason to decimate the dignity and worth of anyone. Autists can be both worthy individuals and members of society, and in need of support:

“Other people might take them for granted, but there are actually many things which, are a challenge for me”

“There is always a tension between seeking to be recognized and accepted as we are, and the struggle to... secure access to support services for people on the spectrum”

“Since I am high-functioning and have a higher degree and so on, sometimes it is hard to explain to [social services] why I do need a support allowance, especially to people who have no experience and no idea about autism”

“I am not saying that I don’t need help, sometimes I do. There are situations which I cannot handle and I need help to deal with them”

In summary, even if the participants defended autism as a normal variation of the human brain configuration and adhered to the discourse of Autists as an underprivileged minority, they also acknowledged the existence of impairments associated with autism. The importance of acknowledging these impairments was justified primarily in relation to issues of access to support services.
6 Discussion

In the previous chapter we reviewed the themes that appeared from the data and the finding which suggested that the experience of autism is open to many variations. The data also hinted at the complexity and intersectionality of the subjective experience of autism as a possible explanation for its variability. In this section, I will reflect upon the different themes by discussing them in relation to the literature and the theoretical framework of this thesis.

Firstly, we saw that Autists can see their autism as a strong component of their identity. We also reviewed a case in which, a participant said that being diagnosed as an Autist gave her comfort and a feeling of identity. Seen from the perspective of the neurodiversity discourse, which criticizes strongly the clinical model and highlights issues in the diagnostic procedure, this might seem like an interesting paradox. On the one hand, we have people claiming that a diagnosis might undermine the dignity of Autists, and on the other hand, we have that some Autists might actually find comfort in being diagnosed with autism. However, I think this apparent paradox can be better understood if we consider that, sometimes, a diagnosis can offer a narrative with which to explain a personal history of continued exposure to disabling situations. Feelings of inadequacy are common in Autists who are unable to find an explanation about why certain situations are disabling for them and not for others. I find plausible that a diagnosis providing such explanation can be experienced as a relief and a comforting experience. Being diagnosed as an Autist can provide two very useful things; firstly, a narrative to contextualize otherwise unexplained feelings of inadequacy, and secondly, comfort from knowing that there are many people with the same impairments. However, the aspects of the diagnosis with which the neurodiversity discourse takes issue are not necessarily related to these two elements. The neurodiversity claim problematizes aspects of the discourse of diagnosis, which are embedded within a specific narrative on the clinical model. I am referring to a narrative which is based on a model that places the statistical normal as point of reference, and conceptualizes as deficits all differences and deviations from this ideal. As we saw in the review of the literature, this specific discourse of diagnosis conceptualizes autism as a neurodevelopmental brain disease, which certainly undermines the dignity of Autists by portraying them mostly in reference to impairments and deficits, and rejecting any claim suggesting that being Autist is a different, yet a legitimate way of being fully human. In this sense, it is possible to talk about diagnosis both as a problematic and undermining procedure as well as a source of relief and identity. However, I
also want to point out that if societies were organized in such a way that the specific impairments associated with autism were accommodated (in a similar fashion as deafness was normalized in the case of Martha’s Vineyard), there would be no need for a narrative to explain feelings of inadequacy, because these would not exist specifically in reference to autism in the first place. It is certainly essential to look at issues of disability always keeping in sight the interplay between the biological and the sociocultural. Focusing on the individual exceedingly oversimplifies the complex realities surrounding the subjective experience of autism.

We can link this to the polemic words of Thomas Insel defining autism as a “tremendously disabling brain disease”. Of course, these words partially reflect a reality that, as described by the participants of this thesis, many Autists do experience. Autists do encounter challenges and might struggle in doing certain tasks. However, as postulated by the proponents of the Social Model of Disability, we need to differentiate between impairments, which occur in the individual, and disabilities, which appear from the resulting interaction between these impairments and specific sociocultural contexts. The disabling aspects of autism do not occur in the individual in isolation, but always as the result of the interaction with a given sociocultural context. For this reason, I find very problematic framing autism as a terribly disabling disease, placing the locus of the condition solely on the individual without analysing critically the sociocultural conditions that facilitate the experience of disability by Autists. Looking at mainstream discourses on autism, which tend to ignore this cultural component and, indeed, the political undertones of the discussion of autism, I consider that it is crucial to examine critically the cultural assumptions underpinning our understanding of disability, and to bring forward the voice of Autists themselves, as a way to disrupt and challenge those discourses undermining their agency.

We can problematize this even further by highlighting how failing to critically examine the sociocultural conditions that facilitate the experience of disability has implications for our conceptualization of both the neurodiverse and the neurotypical. This can be framed in poststructural terms, and as an issue of power relations and epistemic violence (see Spivak, 1988; Foucault, 1982). Indeed, those with the power to unilaterally articulate and define the normal, both in ontological and epistemological terms, inflict a certain violence upon those who are not allowed the means to contest these discourses. Very interestingly, this unequal balance of power relations, where there is a unilateral capacity to conceptualize the normal, has been highlighted from studies which have been done not only
in philosophy or anthropology, but, surprisingly, also in economics. In Cowen (2011), many classical economic experiments were reproduced with an Autists population, and the results were compared with those obtained from a non-Autists population. The study suggests that Autists might be able to make more rational choices in contexts of peer pressure and framing effects, due to the lack of empathy, which is usually presented as a deficit, but which in this case might constitute an advantage. In short, these studies in neuroeconomics expose a certain cognitive bias in our conceptualisation of the dichotomy normalcy-disorder. This bias makes us blind to our own impairments, while at the same time they prevent us from seeing shortcomings in models of autism which present it purely as a disorders.

Notwithstanding, I consider that the same cognitive bias that is exposed by these studies is at the same time being reproduced through some of its analyses. The same epistemological violence that is highlighted by these arguments is being reproduced when we base our defence of the value of the neurodiverse merely upon their performative potential. By conditioning the value of the neurodiverse to their capacity to perform, produce or satisfy any other condition that we choose, we are again conditioning the ontological and cognitive agency of the neurodiverse to our own terms and expectations. The crucial issue that is revealed here, and which constitutes in my view the core argument in the neurodiversity claim, is that we are dealing fundamentally with an issue of power, representation and politics. To be empowered involves being acknowledged as a complete human being, as a subject with ontological and cognitive agency, in one’s own terms, and not exclusively in others’. It is this idea, which inspired me to think the hardest while engaging with this topic. The unequal grounds upon which these ontological discussions takes place, reveal a number of implications and insights. We assume that it is the neurodiverse the ones who need to learn how to communicate in neurotypical ways so that communication can take place. But at the same time, the failure of neurotypicals to learn ways to communicate and relate to the neurodiverse, are simply ignored and discarded from any discussion. There is a powerful paradox when the neurodiverse find ways to communicate with us, and what they tell the neurotypical world is: ‘So, now you see? I was not kidnapped, I was here all the time’. This paradox highlights questions regarding how we attribute or negate personhood to others, question which, certainly need to be addressed. But it also exposes unequivocally a serious limitation in the capacity for empathy in current ways to see the world. Because, does this same lack of empathy not apply also in cases where we deal with neurodiverse individuals who, in fact, do not answer back in ways in which, we can recognize and understand? Is this same lack of empathy, what governs the ultimately cruel and unethical
ways in which, we treat other animals and the environment? Was this same lack of empathy not in the center of the encounters of the Western Enlightenment men with those ‘Others’ found in the periphery? Is it not that what the neurodiverse really are saying, is that it is us, neurotypicals, the ones self-centered, trapped in ourselves and unable to communicate with others? Is our definition of autism, a mere psychological projection of our own impairments and limitations for empathy with the superdiverse? I do not have an answer for these questions, but here they are.

Leaving these ontological considerations aside, this idea of being able to negotiate the terms upon which agency and normalcy are going to be defined, can be related to the theme from the data, which portrayed autism as a disability because of others. Indeed, if we acknowledge that disability has as much to do with biological factors as it has with cultural constructs, very clear power issues can be identified if there is an asymmetrical capacity to establish the cultural expectations which, are going to govern an encounter. If the recognition of personhood is conditioned to behaving, sensing, communicating or thinking in specific ways, we are automatically depriving the superdiverse of discursive tools and of legitimacy to contest this idea and to challenge the neurotypical cognitive biases. This is a highly crucial notion, because, how else are we going to start a deep self-reflective analysis of our own cognitive limitations and biases, if by principle, we exclude from the discussion precisely those who are beyond the ontologically and epistemologically familiar? How can we discuss the aspects of our culture that result in disabling experiences for the neurodiverse, if do not even consider a possibility to negotiate first the terms upon which this discussion can take place? Who can tell us about our biases and limitations, if we refuse to discuss them with those who inhabit ontological spaces beyond them?

In summary, autism can be experienced in a great variety of ways, depending on the specific circumstances of the individual, and the preconceptions and expectations that are present in a given sociocultural context. While Autists can be described in many different ways, in the end, being Autist is just an arbitrary label. Everyone has impairments. Everyone has cognitive capacities that enable them to do certain things, and not others. A diagnosis can offer a label for an individual, which may provide help and support for that individual. But labels tell us nothing about a person. The idea of treating autism should always be positive, if it facilitates in any way the reciprocal encounter between two people. But perhaps acknowledging the cultural aspects of the experience of disability, treatments addressing cultural preconceptions should be promoted. The best possible way to treat autism, in any circumstance, is to
treat it with dignity and respect. Treating real people with dignity is always about seeing the person, and forgetting the labels. Genuinely understanding another human being involves talking and listening to them, in their own terms, and finding out what makes them an individual, and not what makes them part of a group. This is something which perhaps speaks not about the specificities of Autists, but about our own capacity and limitations, for genuine empathy and meaningful communication.
7  Self-reflection on the study

In this chapter, I will reflect on a number of issues pertaining the thesis itself and considering issues of validity, reliability, significance, ethical issues, as well as flaws and contributions in my research, and possibilities for further study. The important aspect of this chapter is to force myself to step back from the text and to examine it from a distance. Reflecting on the process on a meta-level can help me identify more clearly the good and the bad, and help me to be more aware of my role in the thesis and the evolution of the whole process. Let us commence with issues of validity and reliability.

7.1 Validity, Reliability

The aim of the thesis is to explore what the participants feel and experience autism as a way to understand a little better the variability, intersectionality and complexity of the experience of autism. As stated earlier, the contributions of the participants are not seen as representative of the whole Autist community, which indeed is diverse and heterogeneous in its nature, but merely representing their own views and ideas. For this reason, the data collected and the analysis of it secure an acceptable degree of validity in achieving the declared goal by not aspiring to make general and universal statements about autism or the Autist community. On the other hand, there is an additional layer to be considered, which is that my analysis and interpretation of the participants’ contributions are undoubtedly affected by my own biases and predisposition, and therefore somewhat distorted versions of what the participants wished to convey themselves. This additional barrier is part of the research process and I consider that its impact can be minimized by being aware of it and by critically reflecting on it. Finally, an advanced draft of the thesis was sent back to the participants to make sure that they had a chance to make further comments or to point out parts that they considered did not reflect what their own views were.

7.2 Ethical issues

During the course of this thesis, I faced a number of ethical issues, which I tried to resolve to the best of my capacities. Hopefully discussing them during this section can serve both as an explanation for my
decisions and as a warning for people planning to do research in similar settings.

The first ethical dilemma, which I encountered was that of being an outsider. I realized that it was difficult for me to justify my interest in the topic right from the moment when I entered in contact with Autist online communities and they started inquiring why I wanted to write about autism. As it has been mentioned here, similar to what happens in other under- and misrepresented groups, many of the communities I contacted were fierce defenders of the motto “Nothing about us, without us”. Certainly, the impression of being far too commonly used and misrepresented in order to advance someone else’s agenda is a pervasive and justified feeling in these communities. It has been argued that the treatment and representation of Autist by others consistently undermines their dignity (see for example, Harmon, 2004; Saner 2007; Dawson, 2004), which just increases the reluctance with which outsiders are met. Considering that I am not myself on the spectrum and that neither have I a direct link to autism (none of my close relatives have a diagnosis), I indeed was just another neurotypical person wanting to write about autism. Understandably, as I stood there introducing myself as a non-Autist wanting to write about autism, I was met with reluctance and skepticism.

This did pose for me a dilemma in terms of legitimacy and agency and it made me question my choice of topic. After pondering about it, I do find that there is a certain contradiction in writing as a non-Autist while advocating for the inclusion of the voice of Autists. Do they actually need me to do this for them? While I do so, do I not undermine the very claim for agency that self-advocacy groups defend? Do I perpetuate the image of the unable and passive Autist by articulating their claims? I could certainly see that, as an outsider, it is somehow contradictory to talk about the Autists subjectivity and their capacity to discuss autism in their own terms. However, my intention is far from wanting to dominate the whole discussion and to speak in the name of Autists. In this thesis, I just point out to some very valid questions raised by the neurodiversity movement and I stress the need to discuss them openly and together with self-advocacy groups. Furthermore, and after carrying out the literature review, I also think that this thesis is partly justified by the marginal proportion of academic papers dealing with autism that include Autists authors or that consider in their discussion the positions defended by the proponents of the neurodiversity movement. Certainly, as I have already stated in this paper, I do feel strongly that further research could benefit from including Autists in research projects in more meaningful ways, for example giving them a more central and visible role, creating platforms where to engage with the insights
coming from their subjectivities, or for instance through community research projects, or honest and inclusive theoretical analysis of the proposals of the neurodiversity movement.

At the end of the day, I am still an outsider, but I hope that my intrusion can be forgiven if we consider that my position in the topic is no other than to point out the biases and flaws in academia resulting from excluding Autists from the discussion of ability and autism. My position is thus to highlight the very current need for academia to include the ontologically and epistemologically diverse (the neurodiverse being a fraction of these) in these fundamental discussions. Not only because they affect their lives to a great degree, but also because considering more varied standpoints during these discussions could help us all reflect critically on the way we see ourselves, and on the ways in which we engage with difference.

7.3 Flaws and contributions

As a novice researcher with limited research experience I faced many limitations when carrying out this study. Some of these limitations are related to the intersection of disciplines at which the study of autism stands as well as my own limited knowledge about them. To mention just a few, the discussion of autism can be taken on from psychiatry, psychology, neurology and pediatrics, but also from disability studies, cultural anthropology, politics, civil law, philosophy and education. I was worried that without knowing enough from many of these disciplines, it was difficult for me to get a more or less reasonably big picture of the topic. After reading about autism for months on end, much to my regret, I had to admit that the scope of the topic that I chose probably surpassed the capacities and certainly the expectations of a Master’s thesis. Much is being written about autism in neuroscience, in education, even in politics. That said, I must but acknowledge that the final thesis most likely lacks rigor and depth when considering the perspective of the clinical model, which is based on disciplines about which I indeed know very little. On the other hand, humble as it is, here remains my contribution introducing the unlikely reader to the complexities of the subjective experience of autism and to the discourses of the neurodiversity movement. Imperfect and incomplete as it stands, hopefully this thesis could nevertheless contribute its part to gather further interest in an all-inclusive discussion of autism and a more critical and self-reflective approach to special and inclusive education, the flaws of which can only be revealed with the help of
those who look at it from a perspective seldom explored.

Another regret that I have about the way the research was carried out was not to already have a more focused angle when I carried out the interviews. Perhaps I was not completely honest to myself about the real motivations behind the study. I confess that my expectations when I started writing about the topic was to find vocal Autists who could position themselves as advocates of the neurodiversity claims. Instead, I found myself struggling to handle and react to the mixed positions from which the participants exposed their views on autism, some of which embraced the Autist identity, while some others problematized its glorifying discourses. I was not sure what to make out of the fact that the participants, without exception, both supported the neurodiversity position and were very critical of some of its aspects at the same time. Initially I felt disoriented and at a loss about this. I felt frustrated about not being able to steer the interviews towards a discussion of autism on the terms that I wanted. My initial reaction after reviewing the transcript of the interviews was to question how relevant they were for the thesis since they did not serve to unconditionally support my intention of advocating in favor of the neurodiversity movement. As a researcher, I think the thesis has been a meaningful learning experience for me because it has taught me to really understand what data-driven research implies. I struggled with the result of the interviews simply because I was not ready to let the data (meaning, the participants) decide what the discussion was going to focus on and what the outcome would be. I had to let go of a certain sense of entitlement to say what I wanted to say about autism, which I admit I was holding onto. The process of writing this thesis has taught me to let go of fixed starting points and expectations in order to engage in the study of the topic in a much more meaningful and significant way. I believe that the same idea that I clumsily try to convey here, in relation to data-driven qualitative research, the researcher's preconceptions and wishes meeting the hard data, can be seen as an analogy of the interaction between a neurotypical person with a neurodiverse one: if we approach such an encounter with fixed expectations about what a meaningful interaction should include, it is likely that we end up feeling that indeed there were impairments to socialize. However, if we give up the idea that those impairments belong solely to the neurodiverse, and thus we acknowledge our own lack of flexibility to interact with others in terms different from our own, I think we could easily recognize two fundamental things. The first one, that when equipped with an honest willingness to connect, a meaningful interaction can certainly occur between two individuals, even when we cannot unilaterally decide the terms upon which it must take place. The second thing which we can recognize by approaching an encounter acknowledging
our own limitations and impairments to socialize with the neurologically diverse is to experience how frightening the feeling of confusion and loss can be when one does not know how exactly the interaction is expected to take place; this can only help us empathize with those who struggle daily with social cues or reading facial expressions.

However, the importance and relevance of these epistemological and ontological questions go beyond the rights of Autists and the need to address the cognitive biases of the neurotypical. They highlight other questions, which have to do with the potential and the inherent dignity of all human beings. They highlight a need to readdress critically our understanding of normalcy, a need to move beyond a deficit-oriented paradigm towards one of superdiversity, in order to unleash an untapped human potential for empathy. We already have software and telecommunication companies, such as Specialisterne or SAP AG, which have already repositioned themselves in their understanding of the neurodiverse by recognizing the contribution that they can do in economic terms. These companies specifically look for neurodiverse candidates in order to hire them to do certain tasks for which, due to their capacity to focus and long attention span, they are considered to be better suited than neurotypicals. We also see that this change of paradigm through which, we look at neurodiversity away from a deficit model has permeated popular culture, having as a result very popular TV series where the protagonist certainly exhibits autistic traits presented from positive angles. For example, the BBC re-enactment of the Sherlock Holmes stories, where the characteristic attention to detail and logical thinking of the detective is portrayed as an Autist trait. Another example is CBS series ‘The Big Bang Theory’, where one of the most popular and loved characters, Sheldon, is characterised by his narrow and deep interests, his ‘different’ social skills and a lack of sense for conventional humour. The point that I want to make here is that it is possible to see deviations from the statistical normal as positive, and indeed legitimate positions in themselves, something which Autists, have been saying for over a decade. A pertaining question perhaps is if educators, special needs specialists and otherwise, are participating in this change of paradigm and if the insights of the neurodiversity movement permeate educational discourses and praxis on inclusion and diversity. Are we acknowledging other ways of sensing, of communicating and of being? Are we addressing the unequal power relations issues embedded in the discussions? Do we address the ethical problems of discussing ‘personhood’ exclusively among the ‘normal’ and ‘abled’? Perhaps these insights could inspired us to re-evaluate the access of the neurodiverse to the discussion of
special needs education and inclusion ("Nothing about us, without us"). They certainly highlight a need to move the focus away from the individual and towards critically examining 'normalcy' as a sociocultural issue. Not only to discuss issues of diversity and inclusion, but also as a way to open up theoretical spaces from which to engage with the neurodiverse in an ontological discussion, where we learn to listen while they tell us, in a way we can understand, what it is to be a fully human, empathetic person.
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