Sheffield Hallam University

A Sheffield Hallam University thesis

Representing autism as a discourse within ableist economies of doubt

Hannah Ebben

A thesis submitted in partial fulfilment of the requirements of

Sheffield Hallam University

for the degree of Doctor of Philosophy

September 2019

Table of Contents

Abstract

This thesis explores the theme of epistemological uncertainty about autism in visual culture. It is based around the research question 'What is the epistemology of autism as a discourse in the film *Extremely Loud & Incredibly Close* (2011), the CBBC *Newsround* special "My Autism and Me" (2011), and the YouTube video *In My Language* (2006)? My study of the representation of autism is constructionist and solely focused on autism as a discourse, and not on autism as a clinical condition. My critical consideration of the autism category in society is informed by Fiona Kumari Campbell's definition of ableism: the normative power enforcement of abled-centric social standards. "My Autism and Me" and *In My Language* contain personal accounts of autistic people. In my thesis, I regard the personal account not as a static source on inside knowledge on life with autism, but as a relational process of acknowledgement of cultural texts as autistic voice.

Each case study conveys the state of 'not-knowing' autism. *Extremely Loud & Incredibly Close* portrays a character who is not definitively diagnosed with autism and whose characterisation invites audience speculation about the nature of his condition. "My Autism and Me" renders the abstract notion of autism concrete for a young audience and explains that the cause of autism is still unknown. *In My Language* problematises certainties about non-verbal autism by resisting the interpretation of non-verbal self-expression as meaningless. My thesis theorises these topics of speculating, rendering and resisting as important aspects of the cultural significance of epistemological doubt on autism. I propose the term 'political economy of doubt' to highlight that uncertainties on knowing autism are at the forefront of meaning exchange on the concept of autism. I argue that my case studies continue, rather than criticise, ableist normativity with their peculiar themes of knowing and not-knowing autism.

Acknowledgements

I wish to dedicate this PhD thesis to the Autistic and Disabled people who cannot cope with reading my thesis due to accessibility constraints. I found my personal academic homecoming in critical theory that would soon become a major delight in my life. However, I can imagine that dense abstract content distributed at universities is the site of survival for others, regardless of my claim to allegiance to the field of Disability Studies. I would like to state that this position of survival is valid and legitimate and should be a part of inclusive practice as much as I could get myself heard in academia in a way that relieved my own struggles and challenges.

1. Introduction

This academic study concerns the use and function of the clinical category of autism in visual culture and in uneven power relations within the distinction between 'ability' and 'disability' in society in general. This thesis exclusively focuses on the cultural significance of the autism category, and not on the clinically observed neurobiological condition, with deficits in social-emotional interaction, restrictive behaviour and hypersensitivity to sensory input as its list of symptoms (American Psychiatric Association, 2013). My focus constitutes and structures a specific and distinguished interest in one aspect of the cultural representation of autism: that of the exploration of epistemological uncertainty in visual culture. Epistemology is the philosophy of knowledge, and I propose that the experience of autism, ability and disability is notably shaped by the premise that not much is known about the condition (Frith, 1992). This particular premise is evident in public portrayal of the concept of autism in and outside research and clinical practice: for example, a 2011 special issue of scientific journal *Nature* introduces autism as an "enigma" that puzzles researchers (p. 21). Epistemological doubt is a topic of concern that has been tackled by different forms of media with different conceptions of the topic of autism, and that draws my interest from a Cultural Studies and Disability Studies perspective. My thesis thus answers the research question 'What is the epistemology of autism as a discourse in the film *Extremely Loud & Incredibly Close* (2011), the animated children's documentary "My Autism and Me" (2011), and the YouTube video *In My Language* (2006)?' I explore cultural conceptions of autism epistemology with one concept per respective case study that exemplifies a distinctive aspect of epistemological doubt: speculation on autism, rendering autism understandable to a young audience, and resisting normative ways of knowing autism.

During a four-year PhD project, I have executed discursive analyses and textual analyses of the aforementioned cultural objects in an inductive reading. The analyses have been informed by a set of theoretical frameworks that cover power, cultural representation, and the social and cultural dimensions of dis/ability (Goodley, 2014) and diagnostic categories. Crucial to these frameworks are my approaches to autism as

a discourse, representation, and the personal account, that will be outlined in chapters that are separate from the case studies. *Genealogy* is the key methodological framework with which I study the topic of epistemological uncertainty in relation to the representation of autism in my case studies. The term 'genealogy' does not refer to the study of lineage and ancestry here, but to the traces of knowledge, power and ideas from the past as they appear in present texts and parlance. My research object, question, and methodology correspond with the field of Cultural Studies, as it is concerned with the interpretive study of power relations through studies of signs and the way in which they constitute meaning within society, or signifying practices (Barker, 2003, p.7).

In order to capture the epistemological stance towards autism as a discourse per case study, I have formulated a metaphorical concept for each of them, that is, an overarching theme that can be verbalised as 'autism is…'. All three concepts are based on readings of the use of autism within narrative, script, and style. Autism in *Extremely Loud & Incredibly Close* is an option to *speculate* about in relation to the condition of the protagonist and is *rendered* to clear animations and explanations for educative purposes in "My Autism and Me". However, *In My Language* creates a translation of a non-verbal Autistic woman's expressions to *resist* the cultural expectation of a clearly rendered conception of autism, and of a strategically nuanced stance on deviance as a site of speculation.

In my case studies, autism is speculated, rendered, and resisted; my conclusion on these epistemological stances towards autism is the great importance, significance, and implications of not-knowing autism in *Extremely Loud*, "My Autism and Me" and *In My Language.* Although this topic of not-knowing takes on different forms in each case study, its recurrence is striking enough to pay close attention to it in my analysis of the cultural representation of autism. In *Extremely Loud*, the audience does not know for sure whether its protagonist, a young boy who lives with trauma and bereavement, has autism, because his recount of autism tests specifies that his results were not fully conclusive. Moreover, the children's documentary "My Autism and Me" mentions in its description of autism that scientists know about divergent workings of the brain in people with autism, but not about its cause. Finally, the YouTube video *In My*

Language confronts its audience with its own prejudiced preconceptions of people with non-verbal autism. Meanwhile, the video has provoked online controversy with allegations that its subject may not have autism, which is a claim that I neither wish to confirm nor deny as a researcher who works with Humanities methodology. In all three case studies, autism is defined as something that defies a decisive definition in one way or another, which sparks interest in possible deeper implications of the message that one might simply never know what autism fully entails.

Based on the theme of not-knowing autism and its importance for critical studies of autism, the thesis argument based on my research question is not a rounded answer but a theoretisation of a *political economy of doubt.* 'Doubt' is a key word in this PhD thesis that summarises the overarching theme of scientific and societal uncertainty surrounding knowledge on autism that is central to each of my case studies. In addition, 'political economy' refers to the meaning exchange in the production and consumption of culture that concretises the sentiment of epistemological uncertainty on autism in society, in and outside the clinical realm, towards a unifying hope for further understanding. The language used in the *Nature* special issue on the autism 'enigma' illustrates what I mean by epistemological doubt, and the way in which this abstract sentiment of uncertainty concretely gains shape as a constant exchange of knowledge and meaning. Its introductory statement formulates scientific unclarity regarding the heterogeneity, increases of diagnoses, and cause of autism and states that "[everything about autism spectrum disorder conspires to make it hard to understand". It then describes groups and individuals in science and society who negotiate and attempt to resolve these uncertainties regarding autism: unfounded theories "fill the void", researchers propose answers, and advocates fight for access to answers. As the introductory statement concludes: "The complexities that make autism hard to understand are a magnet for researchers – and this should lead to a future with less fiction and more much-needed fact" (Nature, 2011, p. 21). When reading this statement from *Nature,* I am solely interested in its word choices, instead of the topic of autism itself. What the language displays very effectively is the interrelationship between the premise that much is and is not known about autism on the one hand, and researchers and stakeholders who wish to eventually resolve this

epistemological uncertainty on the other. This interrelationship leads to resources, funding, and also a distinctive form of representation that I have outlined in this thesis, which I have specified as a study of the cultural representation of autism in visual media rather than scientific knowledge. I call this view on the representation of autism in each of my case studies a political economy of doubt: epistemological doubt is the valuable currency that is being exchanged and (re)produced and that determines attention being paid to autism. With my metaphorical concepts per case study, I aim to develop more knowledge *about* knowledge on autism, rather than the neurobiological notion of autism as a diagnosable condition in people. I would like to argue that doubt shapes and sustains knowledge-building surrounding the assumed material reality of autism. Each autism metaphorical concept that I have formulated touches upon a specific element of such meaning exchanges.

With all these diverse manifestations of epistemological doubt on autism and dis/ability, my thesis poses the argument that the occurrence of a sense of epistemological doubt in visual culture does not necessarily mean that a depiction of autism is notably subversive and non-conformist. Instead, my cultural analysis shows that epistemological uncertainty actualises autism in the public and cultural consciousness and strengthens the pre-existing flow of knowledge-building and the dis/ability binary in and outside the clinical setting. The introductory statement from *Nature* exemplifies how strong the bond between researchers and the topic of autism has become because of the very premise of understanding the enigma: epistemological uncertainty makes the concept of autism solid instead of porous. With their depiction of epistemological uncertainty, each of my case studies is complacent in keeping the notion of autism an enigma. My theme chapters all explore normativity, as my case studies reaffirm rather than undermine the non-disabled norm: each of them lacks open disability prejudice, yet still presumes life without a clinical condition as a presupposed standard. The political economy of doubt thus forms the basis of my interpretation of my case studies and adds more insight into the topic of *ableism*, or the cultural production of able-ness and the deviance from this perfected norm (Campbell, 2008; Goodley, 2014). This understanding of autism, as elaborated by Campbell (2008), lies at the core of my particular study of autism and dis/ability in a

social and cultural context. Within this research on autism and epistemology in visual culture, I position myself within the field of Disability Studies by means of a critical interrogation of able-ness as the central normal standard. In section 1.2, which is dedicated to my contribution to knowledge, I will elaborate on the fields of Disability Studies and Critical Autism Studies and explain that I practice a critical studies of ableism. Following the critical theoretical stance on (popular) culture as a site of hegemony and resistance (Hall, 1981), I localise my case studies, that is, three cultural objects that all employ autism as a discourse, into larger structures of ableist economies of doubt. Ultimately, I will call for vigilance in the face of apparent nuanced interpretations of autism. It is important to note that such interpretations may contain sly negotiations of knowing and not-knowing autism that unevenly distribute who can express what about human diversity and political voice.

In her conclusion on her studies of the cultural representation of autistic people and negotiations of space, Ebben (2015) asserted that it is important to acknowledge and affirm the comprehensive cultural constellation of autism. Throughout this whole thesis, I would like to take this further: the overall research aim is an attempt to take responsibility for the cultural significance of autism. This responsibility lies both in the research object, question, and method that are reported here, and in my ultimate incitement for further thinking and action on the myriad functions of the term 'autism' in society, without a wish for the elimination of this term. I make clear what this motivation for shared cultural responsibility entails in a comprehensive introduction that presents my engagement with discourse, Cultural Studies, and Disability Studies, and subsequently, my own theorisations that have grown out of my analysis and findings. First, I will present autism as a discourse, how this relates to a naturalised biomedical understanding of the diagnostic category, and its aim to focus on the intertwinement of knowledge and power. I will then expand upon the significance of culture for studying the triad of autism, knowledge and power. This is followed by a detailed explanation of my contribution to knowledge. The explanation consists of two parts: one that places me in relation to established critical analyses of autism and dis/ability, and one that unpicks how my thesis continues work that centres autism rights by decentring autism and autistic people. Subsequently, I will present my

formulations of autism epistemology per case study as 'metaphorical concepts', a term from Lakoff and Johnson (1980). I will summarise each of my three metaphorical concepts at the heart of my case studies and the theme of doubt that arises from them. Finally, I will provide a thesis structure outline.

1.1 Research object, area, and field: the discursive production of autism in cultural representation

The object of research in this study is autism as a discourse. Whenever I employ the word 'autism' in this thesis, I solely refer to the social and cultural significance of the word in society; I distinguish the signifier from the clinical intervention-based approach that the diagnostic category conventionally signifies. There is 'autism', the neurobiological condition with symptoms of socio-emotional withdrawal and aversion to overwhelming stimuli (American Psychiatric Association, 2013), and 'autism', the concept that appears in arts and culture; it is the second that this study specialises in. Throughout my research, I have consistently upheld a constructionist notion of autism, strictly as distinctive from the psychopathological disorder, in order to fully commit myself to studies of culture. 'Constructionism' means that the meaning of the word 'autism' does not lie in a phenomenon outside of texts and culture, but that I pay attention to the (re)production of meaning in case study texts themselves. This means that my interest in autism is not focused on the logic of a 'clinical condition' or a 'neurodevelopmental disorder' (American Psychiatric Association, 2013) that is presumed with the act of saying or writing the word, but on the very word 'autism' itself. I consistently employ the specified formulation 'autism as a discourse' throughout my thesis.

My understanding of discourse is Foucauldian, that is, as the site of knowledge production within culturally shared meaning (Hall, 1997, pp. 42-44). This implies a corpus, and not just one source, of statements, utterances and practices in which the term 'autism', autism spectrum disorder (American Psychiatric Association, 2013) or other diagnostic categories have been used in a certain way and not in another way at a given point in history (Foucault, 1972, 27). In *The Archeology of Knowledge* (1972), Foucault encouraged the identification of relation and regularity amongst such statements as a discursive formation, and the conditions that have actualised these

regularities as rules of formation (p. 38). Discourse is thus not identical to language itself, as Foucault expressed his interest in researching what discourse does beyond "designating things", even though it consists of signs (p. 49). By presenting my research object as the discursive formation of the autism category and the topic of representation as the research area, I am not saying that 'anything goes' and that the word 'autism' can be arbitrarily used in a cultural context. Discourse is a historically situated regime that also stakes out that which cannot be stated. Instead, I affirm the cultural construction of autism (Nadesan, 2005), which does not mean that I embrace its occurrence, but that I centralise cultural text and production of power/knowledge as the bearer of meaning, critically interpreted through cultural analysis. In section 1.3, I argue that my focus on discursive formation alone decentralises static scientific ideas on how to know autism in order to put autism rights central to my thesis. First, I discuss Foucault's intertwinement of discourse, truth and power in this section.

With my research object, I express my interest in discursive practice, or the production of meaning on the 'autism' signifier within institutions, groups, and the statements that they produce, regardless of a 'truth' to its normalised *claims* to the truth. My study of autism does not assume a pre-discursive "history of the referent" (Foucault, 1972, 47), or the question what autism 'is'. This assumption would neutralise the term 'autism' as neutral and reaffirm the scientific realism that I am attempting to undermine: the notion that the world is 'out there' outside of the mind and empirically describable as the 'truth' (Psillos, 1999, p. xix). Foucault rejected a focus on a 'truth' outside of discourse to "define these *objects* [e.g. autism] without reference to the *ground*, the *foundation of things*, but by relating them to the body of rules that enable them to form as objects of a discourse and thus constitute the conditions of their historical appearance" (Foucault, 1972, 47-48, original italics). For example, it is tempting to grant the *Diagnostical Manual of Mental Disorders* (DSM) epistemological authority as it seemingly definitively lists impairing 'characteristics'. However, appeals to absolute knowledge obscure assemblages behind agreements on definitions, like the use of the DSM within ritualised examination in clinical spaces (see Foucault, 1977, 182-1986) and historically specific conceptions of psychopathology (Foucault, 1972, 40). 'Autism spectrum disorder' as a DSM-listed category (American Psychiatric

Association, 2013) gains meaning as scientifically sensical knowledge (McGuire, 2011, 112), and because of this, the DSM not referenced in this thesis as a definition on what autism 'is'. My thesis does not consist of a systemic unpicking of 'rules of formation' but does approach autism as something that is meaningful strictly within discourse and collectively produced knowledge formation.

This approach marks a shift away from the logic of assumed neurodevelopmental disorder and towards a focus on the intertwinement of power and knowledge that is central to my research question on epistemology, or the philosophy of knowledge. For Foucault (1980a), power wielding cannot be seen separately from a "certain economy of discourses of truth", so that the production of 'truth' obeys power but power is also maintained through truth (pp. 93). It is pivotal to note that this is not just regressive power: in an interview with Fontana and Pasquino (Foucault, 1980b), Foucault laments the narrow and restricted understanding of power as regressive, repressive, and prohibiting. He states that it instead "needs to be considered as a productive network which runs through the whole social body" (119). Continuing the DSM example, its claim to the truth on the autism category is being presupposed and upheld by a multiform exercise of power. This includes the authority of the people who wrote it, the power relations within the clinical spaces where diagnosis takes place, but also the fact that many people employ the DSM definition of autism without questioning its normativity. Here, power is enacted from within people and the discourse they employ. The use of a historically specific manual and the use of its formulations regulates and sustains power/knowledge, both in and outside the realm of diagnosis and intervention within an enclosed repressive medical power structure. The expanding presence and complexity of autism as a discourse in everyday life (Lester, 2012) brings more relevance to productive power and the significance of the autism category *as* category. As McGuire and Michalko (2011) recognise, the wish for more knowledge on autism stands for power exercise (163); the normalised nature of the scientifically realist autism category sparks academic interest in the social implications of the triad of autism, knowledge, and power.

Within this thesis, the enactment of power/knowledge in everyday life is theorised according to an object-based Cultural Studies framework. This means that my study is

a consideration of epistemologies of autism as a discourse through the analyses of cultural texts as a site of signification. In these analyses, I am focused on the power in the constitution and circulation of meaning on autism as a set of discursive practices that delimit what can be stated on the diagnostic category and that ground and normalise the "common-sensical" (Barker, 2003, p. 7). My case studies containing autism as a discourse are cultural texts (Waltz, 2005); cultural texts are not only instances of language but also cover advertising, film, digital media, medical sources like the DSM, or any other generator of meaning (Barker, 2003, p. 5). More specifically, the case studies are instances of visual culture, which here stands for the practice of looking (Sturken & Cartwright, 2009) around produced and distributed Hollywood film, British children's documentary and YouTube video. With regards to autism as a discourse, my broad definition of text shifts my attention beyond medical and intervention-based sources, narratives and theories and towards the way in which people enact knowing autism in the realm of visual culture.

The process of meaning-making within texts is *representation* (Hall, 1997; Waltz, 2005), which I selected as my area of research within my study of autism, truth, and power. This selection continues academic literature on cultural depictions of autism (see Murray, 2008a; Osteen, 2008; Loftis, 2015) and on discursive practices of autism, the institution of developmental psychology, and power imbalance (McGuire, 2011; McGuire, 2016). With autism as a discourse as a research object, I do not appeal to an assumed reality outside of the statements embedded within texts, history, and contexts. Because of this, my approach to representation is *constructionist* (Hall, 1997, pp. 25-26): in my interpretation, I locate the meaning of the case studies in acts of signification. Within this constructionist approach, I understand autism epistemologies in my case studies is *performative* (Austin, 1962), which means that the act of signification and epistemology *produces* a reality rather than reflects a pre-discursive reality. Moreover, as my approach to autism challenges scientific claims to the truth, my inquiry will largely be philosophical and interpretive rather than strictly and empirically methodological (Morley, 2008, p. 268). Nevertheless, my research area of the cultural representation of autism as a discourse has informed methodology, that is, a discursive analysis of language and a textual analysis of the formal qualities of the

case studies. In a separate chapter on representation, I will outline a methodology of textual analysis that is informed by vocabulary from Metz (1982) with which I will bridge Film Studies with my constructionist approach to epistemology of autism as a discourse in representation.

In the next two sections, I will present how I *problematise* these constructions of autism, knowledge, and power in an extensive discussion of my contribution to knowledge on autism as a discourse. The first one of them positions my thesis in relation to previous critical literature on dis/ability and autism. It reflects on my stance on this literature and presents the vocabulary that I am adopting from it throughout my arguments.

1.2 Contribution to knowledge: Placing my study within critical academic engagement with dis/ability

My contribution to knowledge is constituted by a dual site of critical analysis, that is, the analysis of the cultural representation of autism as a discourse, and the critical consideration of previous conceptualisations and incitements to 'rethink' autism and taxonomies of human difference. This section will place my study of autism as a discourse within existing literature from the field of Disability Studies (Goodley, 2017a) and declarations of Critical Disability Studies (Goodley, 2017b) and Critical Autism Studies (Davidson and Orsini, 2013a; Runswick-Cole, Mallett & Timimi, 2016). It presents both an acknowledgement of previous intellectual and academic traditions of dis/ability and a caution to locate my thesis as part of a 'school' of academic thinking. Both functions intermingle: I cannot place myself outside the previous academic work that I refer to, as much as I cannot place myself outside discursive practices. With a short introduction to the field of Disability Studies, and its disputes on what exactly is grasped with the 'disability' category, I will present my thesis as a contestation of *ableism* (Campbell, 2009). I then outline my stance on the realm of criticality that surrounds the autism category in recent literature that declares criticality within Disability Studies and the context of autism. With my discussion of criticality, I will specifically talk about the *declaration* of criticality, or more specifically, the social practice of formulating criticality: the fact that networks of Disability Studies scholars are engaged in new non-normative conceptions of autism. I, too, have a specific site of

criticality, since I align myself with Campbell's critical study of ableism. As such, I employ the notion of ableism to declare my criticality in a way that suits my desire to make room for more diverse, new and individualised ways of depicting and talking about dis/ability. To elaborate on this underlying wish for more non-normative dis/ability depictions, I discuss why cultural texts are so important to my declaration of criticality with the help of Titchkosky's concept of the *textured life of embodiment* (Titchkosky, 2007). This section will thus explain how I position cultural representation of autism as a discourse within ableism and point out the importance of a 'criticality' that does not pretend to transcend the things it is contesting.

The autism category lies within the scope of Disability Studies as one of the DSM's "labels" (Goodley, 2017a, p. 2) that contribute to the ever-expanding presence and social significance of disability categories (pp. 1-3). Although the field of Disability Studies is too extensive to address in its full academic multiformity, scope, and international establishment, what unites it is its interdisciplinary and cross-disability (Hoppe, Schippers & Kool, 2011) study of the social and cultural dimensions of disability. Ferguson and Nusbaum (2012) list the rejection of a narrow focus on the medical and individualised impact of and intervention in disability, the consideration of disability alongside other categories of difference such as race, class and gender, and the emphasis on participation from disabled advocates and scholars as overarching concerns (pp. 72-74). Locating disability in the realm of the social has incited academic and activist practice that focuses on the social barriers that oppress   disabled people as a minority group and that has strengthened political engagement. The introduction of the 'social model' realisation that individualised 'cure' or overcoming is not the only 'way out' of suffering thus brought personal and political self-esteem (Shakespeare, 2010).

The social model of disability in contrast to personal and biomedical conditions of physical and/or mental impairment is not a consistent site of contestation within the field of Disability Studies (Goodley, 2017a). In challenges to the disability/impairment binary, scholars stress   the inevitable intertwinement of the two in their political significance (Tremain, 2005), the importance of embodied negotiations of the social world (Garland-Thompson, 2011) and the power within suggestions of the pre-

discursive in impairment as a discourse (Tremain, 2005, p. 11). Furthermore, the materialism of the shift towards tackling social barriers has been challenged as a distinctively British (Goodley, 2017a, p. 11) concern from a sociological and social policy perspective (Goodley, Hughes & Davis, 2012, p. 3). Other 'models' of disability have been defined and outlined, both as a compensation to the risk of totalisation that a social model alone could bring, and as networks of research on disability outside of Britain (Barnes, 2012). Notable examples are the more North American 'cultural model' that locates disability within the realm of cultural meaning and a site of conceptualisation (Goodley, 2017a, p. 19-20), and a Nordic 'relational model' that defines disability as a dialectic between impairment and environment (p. 16-17). Furthermore, a 'Critical Disability Studies' has taken form in the twenty-first century, that is interested in transdisciplinary social theory of disability inspired by intersectionality theory, or the conceptualisation of oppression through the lens of intersecting minority identities (Crenshaw, 1991; Goodley, 2017b). This declaration of the critical takes up "disability [as] *the* space from which to think through a host of political, theoretical and practical issues that are relevant to us all" (Goodley et al., 2012, p. 3).

The shift away from the pre-discursive domain of the naturalised medical condition of impairment has largely informed my interest in Disability Studies in relation to autism as a discourse (see also Corker & French, 1999). However, the room for contestation within the field implies academic practices of the 'critical', which first needs attention itself. My thesis on the representation of autism as a discourse is at first sight a Critical Disability Studies monograph according to a cultural model of disability. My interest in autism, knowledge and power within the broad realm of signifying practices, outlined in my reflection on Cultural Studies, fits within cultural Disability Studies literature that offers cultural analysis of minority politics (Goodley, 2017a, p. 14-15; Barker, 2003: p. 7). Moreover, both Critical Disability Studies and Cultural Studies are shaped by *poststructuralism* in social theory, which rejects theoretisation as excavation of historical-materialist social structures and instead regards meaning as situated within fickle networks of texts (Goodley, 2017b; Berressem, 2017). Although my analyses and findings in this thesis aim to contribute to these networks and critical traditions, I also

would like to respond with caution to a strict classification into a 'school' of thought on 'disability'. Goodley (2017a) warns against "pigeon-holing specific arguments in terms of distinct models" (p. 17), and Van Hove et al. (2016) applaud developments in Disability Studies that go beyond a 'battle of the models' (p. 8). Despite apparent academic proximity to Critical Disability Studies, I would like to situate my own criticality within the scope of Disability Studies as a whole (see Meekosha & Shuttleworth, 2009). Laments of a rooted British materialist social model erase the radicality of rejecting a pre-discursive medical realm from a Dutch perspective, as my native Dutch language lacks any distinction of 'disability' as a social condition (Bramsen & Cardol, 2016, p. 109). Additionally, narrow attentions to 'models' risk presuppositions of a 'medical model' (McGrath, 2012, p. 146), which would erroneously imply equality between the asymmetrical declaration of a 'social' model and the normalised 'medical' that the 'social' model is supposed to dismantle. With regard to these reservations, declaring 'Disability Studies' itself is and already should be critical.

My declaration of dis/ability criticality in my study on the cultural representation of autism as a discourse lies within ableism, a term that I will employ throughout my thesis. This means that I will consistently use ableism as my framework of the cultural system that I intend to problematise with my aim to take cultural responsibility for the cultural significance of the autism category. I follow Campbell's (2005) definition of a "network of beliefs and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (p. 127). The word 'ableism' should be distinguished from 'disablism', or prejudice against disabled people, and is not meant to be accusatory: instead, it is a descriptive tool that is meant to understand the unconscious enforcement of the able norm better. Pivotal here is the inversion of a traditional focus on "an able-bodied voice/lens towards disability" (Campbell, 2009, p. 4) that has unconsciously been maintained in studies of disablism that focus on the social oppression and lack of inclusion of people with disabilities (Goodley, 2014). This means that the condition of disablement, or producing and becoming the 'other', has extensively been interrogated, whilst assumed normativity remains unquestioned (see

also Michalko, 2002). The 'able' in ableism thus stands for an imagined community that upholds the utopian fantasy of homogeneous sociality amongst perfected bodies and minds. Resisting this performativity of able-ness as 'compulsory' (see also McRuer, 2006) means asking what disablement could reveal about 'normalcy', with a disability lens towards able-ness and "ableism's function in inaugurating the norm" (Campbell, 2009, p. 5). Within ableism, disability becomes a negative ontology as a less-than-human: a negation of the "thinkable" (p. 13), the "positive" (p. 12), the " recognisable" (11), and the "desirable"" (p. 194), which goes further than oppression and marginalisation. As Campbell argues, "[v]iewing the disabled body as simply *matter out of place* that needs to be dispensed with or at least cleaned up is erroneous. The disabled body *has* a place, a place in liminality to secure the performative enactment of the normal" (p. 12). This implies that declarations of positivity and inclusion reaffirm ableism in their very preconception of the negative that one wishes to counter. In the face of presence meant to compensate absence, disability is thus present, not in the sense of a pre-discursive reality, but in the very enactment of ableism (pp. 13-15).

In my thesis, I place my research area, or the cultural representation of autism as a discourse, within the enactment of ableism, and not within disablism. The topic of not-knowing autism, which comes to the fore in my case studies that each feature autism as a discourse ot-autism, exemplifies this critical interrogation of ableness. The state of not-knowing in science, society and culture calls the stable condition of the autism category into question as a marker of distinction between disability and ableness. Not-autism and autism are equally important in my critical studies of ableism. Going beyond an interest in 'labels' as disability categories within Disability Studies and literature on the oppressive nature of 'labelling' (Hodge, 2016), I touch upon discursive practices of categorisation within the normative able-ness rather than the construction of disabled subjects. This means that I am more interested in the practices that *precede* the act of diagnostic categorisation and intervention based on pathologized difference. What could autism as a discourse and its occurrence in signifying practices tell us about the norm and its sustainability? With my analyses of three case studies that employ autism as a discourse, I analyse and theorise the insidiousness of ableist signification that lays down the foundations for the exact use of the autism category.

This is an addition to and deviation from literature on cultural depictions of autism that theorises stereotypes (Draaisma, 2009; van de Beek, 2011), oppressive autism narratives (Osteen, 2013), and the reason why society may now favour media on autism (Murray, 2008). The study of stereotypes as negative ontologies favours disablism, while I am drawn to ableism because it broadens my interest in autism and power/knowledge towards the realm of epistemological dominion over 'ability' as well as disability oppression.

With my choice of ableism and the political economy of doubt as my contribution to (Cultural/Critical) Disability Studies work, I thus aim to enable a more comprehensive critical interrogation of normalcy beyond pathologisation and disability. I would like to contribute to demystifying the circulation of ability and of doubt about the fickle boundaries that determine what counts as disabled and what does not. At stake here is what Titchkosky (2007) calls the textured life of embodiment. With her question on the organisation of "current discursive action" of embodiment (p. 7), Titchkosky expresses interest in the way dis/ability is interwoven in everyday life through the occurrence and weight of text, as it gains its significance through enactment (p. 17). This strongly resembles my motivation to study the cultural representation of autism as a discourse in order to localise discursive practices within the everyday and appeal for cultural responsibility over it shared by 'everyone'. Titchkosky's overarching aim is to interrogate taken-for-granted conceptions of disability as a self-affirming cycle of problem and proposed solution, or to "notice, read, and write disability otherwise than the dominant modalities of daily life" (pp. 8-9). What is important here is that she regards her own work as a part of the same textured life as well when she positions herself in the field of Disability Studies just like I have done in this section (p. 37). I would like to declare this thesis as an addition to any other cultural text, including academic literature, that employs autism as a discourse. This declaration positions me as somebody whose writing may address the cultural construction and representation of autism, the structures of ableism, and previous Disability Studies traditions, but that I do not wish to claim to stand above their dynamics. Just because I am taking a stance on them in an academic context does not mean that I can transcend these systems:

this would only bring the overconfidence that I am 'outsmarting' others and forming alliances with other 'smart' people.

This brings me back to the role of the 'critical' in established literature: I would like to acknowledge that my Critical Autism Studies would be a Critical Ableism Studies (Campbell, 2009, p. 29). My focus of problematisation is not only ableism, but also 'criticality' itself. I draw inspiration from multiple declarations of Critical Autism Studies, like the books *Worlds of Autism* (2013) and *Rethinking Autism: Diagnosis, Identity and Equality* (2016). This does not mean that I dismantle them as 'autism/label outsmarters': it means that I do not declare myself to be a Critical Autism Studies authority figure who is an "expert manipulator" of this thinking tradition (Titchkosky, 2007, p. 36). Instead, my role is to consult declarations of 'critical autism studies' in order to negotiate their implications for autism as a discourse and my own work on this topic.

Within different sites of criticality that literature on autism locates itself, mine would be ableism. I am using the term 'sites of criticality' in order to grasp and distinguish the topics that these multiple declarations of 'criticality' attempt to deconstruct. Many of these are important themes throughout this thesis: the commodification of autism (Runswick-Cole & Mallett, 2012), biological essentialism in the 'myth' of autism (Timimi et al., 2010), claims to expertise (Milton, 2014), and the subordination of academics who identify as autistic (Arnold, 2013). The negotiation of each individual concept and their shared attempt towards the critical consists of attentiveness towards their critical potential. This attentiveness is necessary in order to avoid a narrow focus on the shift on a different autism epistemology ('rethinking') alone as the only act of criticality.

Whereas *Worlds of Autism* (2013) and *Rethinking Autism: Diagnosis, Identity and Equality* (2016) aspire to further commitment to new, more enabling ways of thinking on autism, both do so with a different set of argumentations and provocations, and my negotiations of them shape my own criticality. Davidson and Orsini (2013) coined the term 'critical autism studies' as the name of a University of Ottawa workshop and aim to interrogate "the ways in which power relations shape the field of autism" (pp. 11-12). This corresponds to my own triad of autism, knowledge, and power as one that sustains ableism. However, certain passages from Runswick-Cole et al. (2016) that

address the aims of 'rethinking' autism incite further unpicking by me. Runswick-Cole et al. locate their 'rethinking' process within the twofold question whether the autism diagnosis is "scientifically valid" and if it is helpful for people who identify as autistic and their social environment (p. 7). Their aim to "examine the pseudo-scientific claims upon which autism as biological disorder and different as premised" (p. 8) evokes my agreement with Hall's reflection on Blackness. He states that it would be unwise to reaffirm its status as a "biologically constituted racial category" as it would "valorize, by inversion, the very ground of the racism we are trying to deconstruct" (1992, p. 29-30). By declaring autism 'pseudo-scientific' within the context of Critical Autism Studies, one risks a revalorisation of the construct of biological essentialism in its attempt to debunk and negate it, and subsequently, a reaffirmation of the ableism of this normalised construct.

This revalorisation is a potential way in which criticality could claim power dominion rather than nuance over autism, while it is power that I would want to dismantle. As such, the conception of critique as something that might be considered to be "deeply challenging" and potentially upsetting (Runswick-Cole et al., 2016, p. 8) sparks concern. It could potentially re-establish the power imbalance of the innocence of the (enfant terrible) critical scholar versus the emotionally less stable opponent, like the 'expert/patient' asymmetry in diagnostics. Such points of approval and consideration engage me with the potential re-enforcement of ableism in claims of criticality, and I hope that my thesis will spark similar engagement as well. An important part of 'writing critically' is to leave open the opportunity to realise complicity when necessary in both one's own work and reactions to this work. Defensiveness would be futile here, as discomfort and fragilities are of academic interest and could enable us to ultimately think on and beyond undisrupted ableism – a radical step on its own. I will further explore such discomfort as 'crip killjoy' in my conclusion.

All in all, not only are my case studies part of a textured life of embodiment (or diagnostic categories), the whole corpus of Disability Studies is a part as well. This corpus includes declarations of the 'critical' that desire to 'rethink' disability models and the worth of the autism category, as well as my own analyses and theorisations. In my aim to problematise my research area of the cultural representation of autism as a

discourse, I located the textured life of embodiment within ableism. Campbell's notion of ableism outlines and motivates the vocabulary of my cultural critique. It also distinguishes me from literature that is more focused on disablism and the oppressive nature of labelling itself. My sense of cultural responsibility does not mean that I would like to 'undo' the oppression of categorisation or, by contrast, passively accept its impact. It means that I am affirmatively taking part in the very dynamics that I am addressing. In relation to my thinking on ableism, power/knowledge, and the production of autism through enacting signification, my specific research question focuses on formulating the epistemology of autism as a discourse in my case studies is the rejection of the desire to 'know' 'more' on autism. This rejection is an acknowledgement rather than a disregard of enablement, which will be further explained in the next section.

1.3 Centralising autism rights through decentralising the research object of autism

With my research object, area, and question, my contribution to this research would explicitly be to *decentralise* autism and autistic people as objects of scientific realist knowledge. While the last section was dedicated to my position within Disability Studies, ableism and criticality, this section elaborates its impact on this thesis, and more specifically, on my conceptualisations of autism, representation and the personal account. This impact can be summarised by a paradoxical statement on my stance towards my role as a researcher of autism as a discourse and signifying practices. My study contributes to academic (see Caruso, 2010; Bagatell, 2010) and activist (see Sinclair, 2012; Sequenzia, 2017) work that aims to affirm diversity and/or has studied such claims to affirmation, centralising autistic people and their wishes. In autism research, direct consultation of people who identify as autistic and their environment has resulted in reconsiderations of preferred research areas (Pellicano, Dismore & Charman, 2014) and terminology (Kenny et al., 2016), as well as participatory methods (Pellicano & Stears, 2011).

This thesis employs the term 'autistic community' in order to refer to autistic people as a collective at large. In research on autism that defies scientific realism, the existence of unity in a presumed group is contested. I would like to point out that my

25

terminology is not a signifier for people who are diagnosed with autism and who therefore 'have' it. Neither do I plead for an autism ontology for a clinically, demographically and/or politically homogeneous population of people who are labelled as autistic. Instead, the autistic community within this thesis is an *imagined community*, that is, a group of people who are bound together by a subjective conception of shared neurobiological difference (or 'neurodivergence') and not necessarily by close acquaintance or diagnostic categorisation. Adopted from Anderson (2006), 'imagined' means that persons who identify as autistic "will never know most of their fellow[s], meet them, or even hear of them, yet in the minds of each lives the image of their communion" (p. 6). It is this shift to *image* that exemplifies the importance of imagined autistic community in research on culture that employs critical theory and Humanities methodology. Cultural Studies research could acknowledge that audiences from these imagined communities may look at a cultural depiction of autism, like one of my three case studies, and think: "is this me, and does this film succeed in portraying people like me?" A mental conception of individual and presumed shared experience of autism can be depicted with words and images by an individual, artist or creative team, which brings forth more contributions to the textured life of embodiment. The chapter that details my critical and theoretical approach to autism includes a discussion on the notion of interpellation, which is closely related to the anticipation of audiences that may feel addressed and represented by cultural depictions ("is this me?"). Furthermore, in my chapter on personal accounts, I will present my way of distinguishing cultural texts that are authored by people who identify as autistic, without defying my goal to avoid autism ontology. Historiographic efforts to concretise the imagined community of people who identify as autistic, like Waltz (2013), have emphasised practices of advocacy and the critical texts that autism self-advocacy has brought forth.

My contribution to research on the autistic community aims to decentralise me as a researcher who claims to 'know' autism or people 'with' 'it' or who claims dominion over autism as a discourse through the act of declaring criticality. Titchkosky (2007) writes: "through critical attention to all the different permutations of the relation between the knower and the known, […] a kind of responsibility toward our embodied

existence [is inserted into the world]" (p. 37). With regard to autism as a discourse, relationships between the knower and the known are presupposed, like the autism category and its epistemology, or the sum of studies on how we know autism. As I explained in the section on my research object and area, my choice of discourse and a constructionist approach towards representation already decentralises a reading of cultural texts as pointers towards meaning within 'reality'. The textual and discourse analyses, as well as subsequent reflections on the place of my case studies within ableism, intend to understand culture better rather than autism or autistic people.

My problematisation of 'knowing autism' in my cultural analysis is a commitment to dismantle terminology, phrasings and methods that place the topic of autism as something that is displayed, traced, recognised, and intervened in. As this thesis is a text next to other texts from visual culture, academia, and activism, its analyses and theoretisations deconstruct power imbalances in everyday affirmations of the autism knower/known binary. The rights and interests of people who identify as autistic are thus centralised because their role as a research object to be understood and acknowledged is made obsolete in my focus on signifying practices within ableism.

By destabilising relationships between the researcher of people 'with' autism and the people who identify with the autism category, I thus attempt to further take 'autism studies' beyond the scope of the confined scientific gaze. Not only am I troubling scientific 'claims to the truth' and the source of meaning that lies within 'reality', people who 'have' and 'display' autism, I am also troubling autism as a central research topic in general. For me, the study of autism needs a scope that is concerned with discursive practices in ableist society, as I would call for shared cultural responsibility over it by 'everyone'.

1.4 Outlining autism as an ableist palimpsest of epistemologies in the conceptual chapters

My thinking shift on autism and autistic people will be concretised in multiple ways throughout my chapters on autism, representation, and the personal account that offers my conceptual products next to my metaphorical concepts that constitute my case studies. I will make the previously discussed notions of epistemology and

Foucauldian discursive formation more concrete in this section with a discussion of Foucault's method of genealogy, or the complex, rootless and layered historiography of knowledge formation in the seemingly neutral present. My fifth chapter on personal accounts delves even further into the topic of genealogy. My thesis decentralises my role as the knower of autism as a challenge to the positivist gaze in ableism, or the naturalised assumption that dis/abled embodiment can be objectively known through empirical examination. Positivism is closely related to my earlier definition of scientific realism from the section on discourse and extends insights on the topic from the fields of Critical Race Theory (Yancy, 2017) and Gender Studies (see Pritchard & Morgan, 2000). The conceptual chapters continue existing critical literature, but my contribution to such literature is watchfulness to potential pitfalls of recentring autistic people in research.

All three conceptual chapters offer key theoretisation on autism as a discourse within ableism. In my chapter on my approach to autism, I will challenge the ableist 'complex' subject and the valorisation of autism indices to unpick positivism. The chapter on representation will outline how I have continued my efforts to affirm self-expression in the form of textual analysis that works with the notion of 'metaphor' in my previous theoretical work on autism as a discourse and in vocabulary from Film Studies (Metz, 1982). Finally, the chapter on personal accounts will offer an approach to identification with autism and speaking for autistic people that introduces a sensibility for the ableist cultural acknowledgement of voice.

Together, the conceptual chapters exemplify my stance on the epistemology of autism as a discourse, as specified in my research question. Epistemology is not a matter of identifying divergences in autism research and practice paradigms (Kuhn, 1970), or a history of 'knowing' autism 'better', but a palimpsest of enactments of 'knowing'. A palimpsest is parchment on which documents can be erased and overwritten, and thus leave traces of previous text. In his revision of Nietzsche's term 'genealogy', Foucault (1971b) evokes the palimpsest as something that "operates on a field of [scratched over and recopied] entangled and confused parchments" (p. 139). His term outlines a kind of historiography of knowledge that comprehensively documents fickle and recurring events that apparently lack historical embeddedness or seem to be

unremarkable in the face of history (pp. 139-140). This historiography resists "meta-historical deployment of ideal significations" as well as a search for 'origins' within history (p. 140). Instead, it traces the inconsistency of 'incidents', rather than roots, that have shaped contemporary notions of the 'truth' (p. 146).

The term 'political economy of doubt', or rather 'ableist economies of doubt' in order to highlight my challenge to ableist normativity, presents my peculiar history of the present that is interwoven throughout my conceptual and case study chapters. As I have illustrated with the language of 'enigma' used in the *Nature* special issue, not-knowing autism has a lasting affirmative effect upon scientific research on autism and, subsequently, on public attention that is being paid to this research area. Epistemological doubt generates interest, funding, more hypotheses, study results, and so on. Simultaneously, I will discuss in my chapter on personal accounts that different sources and forms of knowledge on autism, like expertise versus life experiences, can clash with one another. The increasingly fickle boundaries between autistic and non-autistic people and, in general, the decreased strictness of clinical distinctions between ability and disability, cause discomfort and dispute. Science, culture and society are involved in a constant exchange of meaning on autism with the affirmative but also discontenting notion that knowledge on autism at large is incomplete, indecisive and contradictory. These sentiments of affirmation and discontent with not-knowing autism are scattered around throughout clinical and public discourse, which has inspired me to further theorise and conceptualise 'knowing' autism in this thesis. My interest in epistemological uncertainty about dis/ability is thus a historiography of present discourse: a Humanities methodology with which I have analysed my research area of cultural representation and my three case studies.

I will further focus on the genealogy of discontent surrounding not-knowing autism, and subjects who identify with the label, in the personal account chapter. My contribution to insights in the fickleness of the historical shift towards the 'speaking' categorised research object, and the implications of uneasiness from scientific circles about the 'possibility' of speech, are located there. McGuire (2016), Georgiou (2014), Vakirtzi and Bayliss (2013) and McDonagh (2008) have used the term 'genealogy' as a

'history of the present' in relation to autism and the formation of subjectivity. A major thematic backbone of publications within the recent trend of autism historiographies (Waltz, 2013; Feinstein, 2010; Silberman, 2015), next to the impact of shifts from psychoanalytic to neurobiological studies of autism, is the rise of autism self-advocacy and thus conscious political subject formation through a claim on voice. There, I will argue that identification with autism is performed amidst cultural fears of a 'scientific oxymoron' of autistic voice. These fears maintain power imbalances between the assumed 'knower' and the 'known' to the disadvantage of those who consciously build new creative endeavours to rewrite the palimpsest of the history of autism epistemologies.

Negotiating concerns about the reinforcement of essentialism by people who identify as autistic (Milton & Timimi, 2016), my conceptual chapters and focus on case studies informed by Cultural Studies affirm the right to creativity and self-expression within the textured life of embodiment. My specific focus on epistemologies here serves to map ableism as a potential for this right to become narrowed down and repressed in its creative range of expression. An inquiry into structures of signification around autism as a discourse that places the category into the realm of the production of able-ness could include themes that presume the perfected human and performances of able-ness. For example, the very premise of both sports and traffic is to let people 'move' in a desired way and showcase this ideal in the public sphere. Initiations of traffic accessibility and disabled sports might curb oppression of disabled people but still leave everyday showcasing of able-ness intact. A critique of ableism would thus be a way to enable rethinking and rewriting disability differently (Titchkosky, 2007) for broadened structures of signification, without claiming dominion over this process as a researcher. 'Epistemologies' in my critical ableism studies are themes around knowing autism that are encased in the realm of each of my case studies that I perform a textual analysis on with special attention to ableist modes of expression. In the next section, I will explain how I foreground and formulate these themes with the concept of the 'metaphorical concept'.

1.5 Formulating epistemological metaphorical concepts in the cultural analysis of autism as a discourse

Each of my case studies presents formulations of a *metaphorical concept* (Lakoff & Johnson, 1980) based on a textual analysis in order to encapsulate an epistemological mode within each of the selected cultural texts. This section will outline what this entails in terms of my critical ableism studies. In each case study, I flesh out overarching epistemological themes and their significance to ableist palimpsestic genealogies of epistemological doubt. Autism metaphors have been dissected before in academic literature, such as dehumanising metaphors of autistic people as beasts or subhuman machines (Waltz, 2003) and spatialised metaphors of autism as a covering shell (Broderick & Ne'eman, 2008) or alien displacement (Hacking, 2009b). These articles are often inspired by Sontag's essay *Illness as metaphor* (1977). As metaphors have a great persuading power (Charteris-Black, 2004), the general imagery of autism as less-than-human effectively conveys pathos in science (Duffy & Dorner, 2011). Because of this, metaphors have been pivotal to the medical history of autism: proponent of the psychoanalyst 'refrigerator mother theory', Bettelheim (1967) famously used the notion of the 'empty fortress' to convey a view on autism as an enclosed shell.

The importance of metaphors for the historiography of illness and autism epistemology prompts me to put metaphor, or rather metaphorical concepts, front and centre in cultural analyses of my case studies: metaphor aids my genealogy of autism research. A focus on my research object of autism as a discourse alone would narrow down my textual analysis to linguistic determinism in my readings and would still 'identify' the 'occurrence' of autism, whereas 'identification' and autism 'acknowledgement' are the very things that I decentralise. Instead, I will use the fact that a study of autism as a discourse beyond the evocation of 'real' subjects and knowledge only brings me to more discourse to my advantage. I specify the way autism gets 'known' in visual culture regardless of the diegetic (the depicted world) or extradiegetic (everything else that the spectator can perceive) nature of the cultural text. This realm of what exactly gets 'known' might be a theme that might seem distinct from autism and ableism but still highlights an aspect of the significance of

autism as a discourse in visual culture with which I could provide a reading of distinctive ways of signifying autism based on textual analysis.

To capture this realm for further insight in overarching autism themes, I need a theoretical 'split' in autism signification, which I invoke through Lakoff and Johnson's notion of the metaphorical concept. In *Metaphors We Live By* (1980), Lakoff and Johnson refer to the metaphor as one concept that is grasped in respect of another concept. They present an understanding of metaphor that is much broader than just a linguistic expression of resemblance: it is something that is 'lived' as it is intertwined with action. For example, a metaphorical concept such as 'argument is war' not only covers language that expresses argumentation with words that refer to warfare, as "*argument* is partially structured, understood, performed, and talked about" in terms of war" (p. 5; original emphasis). Statements are thus defended, and opponents attacked, in the way people enact arguments. Subsequently, 'war' is conceived through understanding and action. Such a regularity of conceiving one concept in terms of another could highlight one component of a concept and hide another, just like partnership and synergy can easily be forgotten within the 'argument is war' metaphorical concept (p. 10). As metaphors are 'lived', they produce social realities as they bring consistency to lived experience (p. 156), just like textured embodiment is 'lived' through signification. Metaphors can be grounded on taken-for-granted conventions but can alternatively provide creative and innovative meaning-making, like in prose or poetry (p. 139). A notion of a conventional metaphorical concept appears as 'truth' in understanding in case of mutually reinforcing coherence of speech and act, whilst nonconventional metaphors disrupt coherence (p. 174). In my explanation of the usefulness of this broad interpretation of metaphor, I first must acknowledge the ableism of the 'we' in *Metaphors We Live By*. As Vidali (2010) objects, Lakoff and Johnson rely on assumptions of universalised corporeal orientations towards physical environment and the world in their argument on metaphor "as essential to human understanding" (Lakoff & Johnson, 1980, 196). Although I will not adopt their cognitive linguistics and unproblematised ableist notions of the body in space, I still share their challenge to an objectivist view of metaphor in philosophy and linguistics. Within objectivism, or the localisation of meaning into objectivity,

metaphor is a mere subjective distraction to the 'truth' (p. 196-197). Lakoff and Johnson's dismissal of objectivism creates an opportunity to employ the metaphorical concept within my interest in autism as a discourse, because of my own subversion of scientific realism in the study of representation.

With Lakoff and Johnson's principle of the metaphorical concept as an understanding and enactment of one thing in terms of another, I concretise the possibilities of 'mapping' distinguishing significations of the autism category in terms of something else within representation. The induction of metaphor in my conceptual vocabulary itself already further subverts neutralised positivist talk on autism and its presumed 'characteristics', as metaphor is often evoked in scientific research on a lack of understanding of figurative language (Happé, 1995). With representation or meaning-making as my research area, the coherence in Lakoff and Johnson's metaphorical concepts helps me to interpret overarching themes regarding autism as a discourse that I perceive in compartmentalised analyses of case studies. The sum of my interpretations of juxtaposed qualities in visual culture or cinematic codes (Metz, 1974) gives rise to autism metaphor, or a deeper understanding of the significance of themes that are not the same but closely related to conceptions of autism.

It is in autism imagery such as the empty fortress' that my desired 'split' takes place: these understandings all cover the *source domain* of metaphor, or the 'outside' concept that is evoked in metaphorical expressions of autism. The autism concept is the target domain, or the concept that is signified and grasped (Kövecses, 2010, p. 9) could be understood as a metaphorical concept in itself. Lakoff and Johnson (1980) discuss ontological metaphors, in which abstract concepts are conceptualised as materialised entities (pp. 25-26); this corresponds to the critique of *reification* from the fields of psychiatry and philosophy of science (Nieweg, 2005; Hyman, 2010). Reification refers to the logical fallacy in which conceptual abstraction is mistaken for a material pre-discursive reality. An example of such a formulation can be found in the sentence from the Nature introductory statement, "[e]verything about autism spectrum disorder conspires to make it hard to understand" (p. 21). Here, the abstract phenomenon of a disorder is described as a concrete, conscious and active conspirator. The term 'reification' will be heavily featured in my thesis as it is of great

interest to the performative power of the autism category. Within my study of signifying practices, I will unpick both source and target domain with my own new formulations of metaphorical concepts, based around ways of 'knowing' autism and based on textual analysis of case studies that feature autism as a discourse.

My readings of my case studies consist of formulations of one metaphorical concept for each one of them; these formulations will be presented in the next section. In accordance with the position of my thesis within instead of outside and on the textured life of embodiment, these formulations are a creative act next to the creative act of the cultural texts that I analyse. The representation chapter will outline what it is that I 'do' methodologically with my formulations of autism metaphorical concepts in my discourse and textual analyses. Beyond this act of formulation per case studies, I also acknowledge potential metaphorical concepts that are situated beyond my case studies or any single cultural text, being located within ableism in general. For example, one specifically isolated metaphorical concept, that of autism as epidemic, forms the focal point of critical analysis in Ebben (2018). Transcending the realm of the scientifically valid, the notion of an autism epidemic touches upon cultural desires to recognise deviance; the cultural construction of recognition is a topic that will be discussed in the chapter on representation as well.

An important overarching issue in more culturally embedded metaphorical concepts that will be pivotal to my dissection of ableism throughout my thesis is cyclic self-affirmation. For example, the notion of autism as an enigma (Frith, 1992) confirms itself in its very evocation of mystery. If we 'know' 'more' on autism, we are closer to cracking the enigma, but if we do 'not' know more on autism, we are convinced that autism is indeed an enigma. Likewise, the autism epidemic metaphor could potentially self-affirm its own cautionary tales of contagion and excess, whether this excess is biomedical or discursive. Ebben (2018) interlinks fears of heightened autism epidemiology with the rhetoric of warnings against diagnostic inflation (Frances, 2012; Thoutenhoofd & Batstra, 2013). The rhetoric of autism epidemic and diagnostic inflation share themes of uncontrollability and estrangement from the 'normal'. While the diagnostic inflation debate acknowledges the reification of autism, it still relies on a narrative of contagion (Ebben, 2018, pp. 150-151). In general, evocations of

'increase', 'omnipresence' and 'disproportionate' attention to autism as a discourse have become common in (critical) literature on autism (see Runswick-Cole & Mallett, 2012). Within my own observation of increase narratives, the notion of excess becomes strongly buttressed: I start noticing a rhetoric of excess 'so often' that I, too, become motivated to note the excess of excess rhetoric. Excess and enigma are so strong as larger metaphorical concepts because of their double-edged sword nature. These are words that stimulate and engage people to care about both reified and dereified notions of autism and are affirmative because of this. Simultaneously, they also reaffirm the exact autism epistemologies that they are pretending to challenge: an enigma needs a state of not-knowing and the hope that 'we' will come to know 'one time', whilst excess stands for uncontrollability. As Campbell (2009) states that "[t]he disabled body induces a fear as being a body out of control" within ableism (p. 8), the latter induces concern on the role of control in ableism. The right to creative self-expression within the textured life of embodiment might also be curbed within ableism based on cultural fears around loss of control over signification.

Whichever way I further theorise autism as a discourse through the formation and/or conceptualisation of metaphorical concepts, wider implications of ableism arise, not despite but because of figurative double-edged swords. This is the theme of the next section, which will outline the main findings of my case studies and my proposal of a political economy of doubt as a new term for an ableist system.

1.6 Dismantling a political economy of doubt through autism metaphorical concepts in my case studies

My case study chapters will present the metaphorical concepts that I conceived in my discourse and textual analyses and that all touch upon a certain epistemology of autism. Each metaphorical concept that is central to each case study chapter, namely autism-is-speculated, autism-is-rendered and autism-is-resisted, highlights a different aspect of epistemological uncertainty in my meta-epistemological framework that I call ableist economies of doubt. The motivation for my selection of (in order of the thesis case study chapters) *Extremely Loud & Incredibly Close*, "My Autism and Me" and *In My Language* lies in their mutual balance and recent production history. First, all the subjects of my case studies have been made in the last eleven years; two of them were

released in the same year, 2011. *Extremely Loud* (the film title will be shortened like this from now on) and "My Autism and Me" postdate influential academic literature with an extensive focus on cultural depiction of autism, like Murray (2008) and Osteen (2008). Posted online in 2007, *In My Language* does feature in Murray (2008, p. 34-36). Nevertheless, it is significant as a case study because it precedes the production of multimedia storytelling by autistic people within academic acknowledgement and facilitation, like the Canadian *Enacting Autism Inclusion* project (iHuman, 2018). These production and distribution periods of the case studies are thus significant to me as I put the case studies into academic consideration in ways that have not yet been done before. My intention with this is to counter the constant presence of the film *Rain Man* in academic discourse on depictions of autism (Baker, 2008; Draaisma, 2009) and focus on recent structures of signification instead. Second, the case studies are diverse in terms of their genre, genre conventions, and complexity as cultural texts that are related to other cultural texts. They cover respectively a feature film that follows the narrative and stylistic conventions of classical Hollywood cinema, a documentary film from CBBC's *Newsround*, and an independently produced and distributed video on social media networking site YouTube. Lastly, the three case studies each portray a speaking person who is or can be identified as autistic in various ways. The narrator and protagonist of *Extremely Loud* is a boy who tells about past autism tests, "My Autism and Me" portrays personal stories of autistic children as personal accounts (Lawson, 2000), and *In My Language* is a personal account that is produced and distributed by autistic activist Amelia Baggs. I will outline my inductive reading and its underpinning through a special focus on production and distribution in the representation chapter. Each case study does not aim to stand for Hollywood film, documentaries with personal accounts, and autobiographical personal accounts, which means that I am not going to deduce anything on cultural depictions in general. Instead, my selection of case studies allows me to delve deeply into thematic structures that I have encountered in order to conceptualise metaphorical concepts.

All three metaphorical concepts cover epistemologies and are thus concerned with the enactment of knowing and, importantly, not-knowing autism, which exemplifies the thesis theme of autism representation within an able-centric political economy of

doubt. Ableist autism signification thus gets reified not only through autism epistemologies but also the seeming negation of knowing autism. I first present 'autism-is-speculated' in *Extremely Loud*, which encompasses epistemological doubt in the manifestation of uncertainty about the protagonist's condition, who is and yet is not explicitly identified as autistic since autism test results are mentioned to be 'not definitive'. *Extremely Loud* follows protagonist Oskar Schell, who struggles to cope with the death of his father during the attacks on the World Trade Centre on September 11, 2001. When he finds a mysterious key assigned to a 'Black' in his father's cupboard, he starts a visit to each household with the Black surname in New York City, hoping that the key lock might bring him closer to his father. The film does not provide an actual confirmation that Oskar is autistic yet does include a scene during which he recounts non-definitive test results for "Asperger's disease". Through its complex interrelationship between autism as a discourse and the cultural trauma of 9/11, and its narrative of the loss of an intervening father figure, the film presupposes speculating spectatorship amidst the high prevalence of cues of deviance. My formulation of an autism-is-speculated metaphorical concept will be central to the *Extremely Loud* case study. This chapter focuses on the enactment of 'warning signs' (McGuire, 2016) that the film stimulates rather than an assumed ontology of autism as 'speculative' on itself.

In the next case study, "My Autism and Me", I will present the autism-is-rendered metaphorical concept. I outline how a children's documentary depicts the notion of autism and several children who identify with it. In line with my central thesis theme of the importance of 'not-knowing' autism, I pay special attention to a claim that scientists do not know for sure what autism is. The CBBC *Newsround* special portrays an unequivocal notion of autism as a 'different' functioning of the 'brain' that 'expresses itself' in divergent ways in a variety of children. Presented by 13-year-old Rosie King, who has Asperger's Syndrome herself, the documentary guides the audience through interviews of a variety of British autistic children. It has a strong didactic quality, as its combination of animation and documentary creates representational strategies (Honess-Roe, 2013) that render the complex biomedical definition of autism into a concrete educative story for children.

Central to the third and final case study, *In My Language*, is the autism-is-resisted metaphorical concept, which details concrete expressions of defiance to the way autism is known and understood in depictions of a non-verbal person who identifies as autistic. Expectations of the autism category as something with clear cues to speculate about, and as something rendered into a bite-sized version for the sake of understanding, are subverted in *In My Language.* The video starts with Baggs's movements and sounds in a domestic environment, and then cuts to an intertitle that states "A Translation". Through assisting communicative technology, Baggs states that her movements are her language and should be interpreted as such, warning of the pitfalls of assuming insignificance and lack of voice behind non-verbal autistic and disabled people. Baggs's defence of her meaningful connection to the world through her own creative 'ability' forces the audience to rethink expectations of how to know autism. It thus forms resistance to such stabilised gazes, which means that this chapter will expound on the implications of autism-is-resisted for theorisations of activist products that declare autistic creativity as a conscious action of self-identification. In all case study chapters, I will offer close readings of the film, documentary, and YouTube video in order to interpret their overarching enactment of 'knowing' autism. The formulation of metaphorical concepts aid to concretise these enactments and further interpret their implications for ableism.

In my explorations of autism epistemologies in my case studies through textual and discourse analysis, it initially may seem as if they offer nuanced views on autism as a discourse. *Extremely Loud* is a Hollywood feature film that does not definitively 'label' Oskar, so that the audience can decide for themselves without being told that the protagonist represents what autism 'is'. Similarly, "My Autism and Me" guides the audience through several personal accounts that all emphasise the diversity among autistic children and that affirm the chances that the children have in life as long as the right support is provided. It is a colourful documentary with an autistic teenager who provides the presentation herself. Amelia Baggs and her *In My Language* video were featured on CNN shortly after its release (Gajilan, 2007) and it has received recognition in autism literature as a complex and layered depiction of "autistic presence" (Murray, 2008). In *Neurotribes* (2015), Silberman asserts that "few clips on YouTube offer a

glimpse into a mind so profoundly humane" (p. 16), as Baggs affirms her communication as meaningful rather than impaired. As much academic literature on cultural depictions of autism counters the restriction in stereotypes (Murray, 2008; Loftis, 2015), my case studies appear to avoid restriction and enable speculation, educative and creative rendering, and resistance that nuances, deepens, and enriches autism representation. Affirming "rich diversity" (Davidson & Orsini, 2013, p. 24) and "individuality" beyond "labels" (Hodge, 2016, p. 200) is an important motivation within declarations of Critical Autism Studies as well.

However, with my case studies and metaphorical concepts, I interrogate these seeming claims to positive diversity, as my analyses and findings have brought me to the topic of doubt that is central to this thesis. Doubt transcends the metaphorical concept, as I would not like to assert that autism is conceived in terms of nuance or a determined lack of certainty about what it 'is' or how we come to 'know' it. I rather would call it an ableist strategy that negotiates the actualisation of the autism category and 'realisations' of the 'limited' capacity of such a category in a way that slyly (re)produces power over both disability and perfected ableness. Addressing doubt within my case studies and metaphorical concepts reveals complexities behind the affirmation of nuance that may not be that positive. In the chapter on *Extremely Loud*, I argue that the sensibility towards speculation is based on hyperawareness of 'warning signs' of perceived deviance, which is *strengthened*, rather than attenuated, by the backdrop of 9/11 cultural trauma. In my reading of ableist normativity, I emphasise persistent narratives of the 'good' intervening parent, rather than a negation of definitive autism diagnosis. Moreover, the creative, accessible, and educational rendering of life 'with' autism in "My Autism and Me" has political implications, juggling a semi-ambiguous reality by suggesting that we 'know but we don't know' autism. It presents the imagination behind creative expressions from Rosie, whose 'brain' allegedly 'works' "a bit differently" as she herself says, as a (potentially) personal success story that generates neoliberal value, profit, and labour, both despite and because of reified autism. In the case study on "My Autism and Me", I will deconstruct its claims to heterogeneity as discursive dominion over 'positive' messages on 'difference' that invests in the hope that autism is ultimately a resource

of social market value. Finally, despite the positive reception by mainstream media, journalism, and Cultural Disability Studies literature, Baggs evokes and has attracted direct forms of doubt. In *In My Language*, she says: "I would like to honestly know how many people, if you met me on the street, would believe I wrote this", arguing that doubt about her thoughtfulness arises out of conceptions of the full human as a thinking being. Indeed, blogs have arisen that doubt Baggs's identification with autism as expressed in the video (Amanda Baggs Autism Controversy, s.a.; Best, 2008). The *In My Language* case study will include reflections on the cultural significance of explicit accusations of insincerity of a person who produced and distributed a personal account.

In this thesis, what I defend are my theorisations of ableism based on my cultural analysis, which here means that I present and encourage further Disability Studies research on what I call a political economy of doubt. With 'political economy of doubt', I refer to an ableist structure of signification that shapes and spreads itself through suggestions of doubt, or more precisely, through subtle and sly negotiations of 'not being sure (yet)' on the topic of autism. The exact phrasing is derived from Novas (2006) and his "political economy of hope" (p. 289) as the politicised action among patients' groups of investment in hopes for scientific progress and cures. 'Economy' here does not refer to the exchange of money and goods: it lies closer to Ahmed's notion of 'economic' in her notion of 'affective' economies, or the circulation of love and hate within the social world (Ahmed, 2004, pp. 119-123). Doubt itself is the economy, as it is the thing that orchestrates power/knowledge. My three case studies partake in this economy as well, as all of them are cultural texts that employ a set of strategies that invoke a 'semi-ambiguous' way of 'knowing' autism. It is this semi-ambiguity that camouflages itself with its very appearance of moderation, which makes it a pivotal point of concern regarding the embeddedness and self-affirmation of ableism.

Within the spread and normalisation of the fantasy of able-ness, doubt and nuance on the condition of disablement are re-confirmed over and over because of their apparent open-mindedness. This deviates from critiques on 'labelling' and reification, since these deconstructions of categorisation assume a misleading sense of *certainty* in

society. By contrast, the political economy of doubt invites a deeper reading that does not rely on an assumed lack of awareness of oppressive labelling, but that is dedicated to the everyday enactment of dis/ability as carefully organised cultural desire and cultural fear. Within society, there are desires to learn the 'truth' about the reified notion of autism (McGuire, 2013), but also fears of discursive contagion in the form of 'diagnostic inflation', and of the 'fake' disabled person.

Cultural desires and fears highlight power imbalance, and dismantling power imbalance constitutes my critique of ableism. For example, doubt suggests freedom, but a selective kind, that assumes an aware diagnostic gaze (*Extremely Loud*), creative methods for 'explaining' autism ("My Autism and Me") and appreciation for the 'real' autistic voice (*In My Language*), from a restricted viewpoint. In the personal account, or a non-fictional portrayal of an autistic person, this asymmetry in restriction could result in divergent public reactions toward independent accounts made by persons who identify as autistic and have allowed themselves freedom of expression. For example, whereas CBBC's "My Autism and Me" contains the promise of market value in a stylistically eclectic depiction of a group of autistic children, Baggs has attracted easily findable online doubt based on the content of her polemical self-distributed video. Doubt thus suggests a power imbalance on the level of careful negotiations of open identification, or a disciplinary force onto autistic people above the pathologizing scientific gaze: not only is the 'autistic subject' pathological but potentially unfaithful as well. The fear for uncontrollable identification with autism amid strategic doubt implies further insights into existing 'sites of criticality' within autism in Disability Studies like the "unruly body" (Hodge, 2014) and "challenging behaviour" (Slater, 2013). Here, the unruliness would be a 'lack' of control over the enactment of autistic voice within internalised sly structures of doubt. Even though diagnostic inflation has been an influential site of criticality as well (Frances, 2012), this understanding of discursive excess of the autism category could fail to problematise what exactly is 'inflated' as a 'currency' (Runswick-Cole & Mallett, 2012). Ultimately, Frances's image of the "fashionable" autism category diagnosed at the "slightest sign" (Frances, 2012, p. 147) provokes imagery of 'polluters' in an opaque 'pool' of people who identify as autistic (Ebben, 2018, p. 151). This could reinforce rather than challenge ableist power

asymmetry that a political economy of doubt might bring, as 'anyone' could become 'suspicious' in their proximity to the polluted pool.

Because of these interests in the constellation of doubt within my metaphorical concepts of autism speculated, rendered, and resisted, and of concern for power im/balance, my placement of cultural representation of autism within ableist economies of doubt is my thesis finding. Key to my caution around ableist economies of doubt is the dominion over both ability (the skill to provide self-expression with negotiations of autism categorisation) and disability in a way that could hamper both in the realm of the right for self-expression and that could leave sly normativity uninterrogated. In terms of the cultural responsibility over autism categorisation, I would want to encourage separation of two layers of taken-for-grantedness. One is the medical underpinnings of the pathologized category of autism, and the other the desirability of supposed 'new' 'nuanced' principles on the 'truth' of autism, as the latter could normalise ableist economies of doubt.

1.7 Thesis structure

The theme of doubt within the analyses of my case studies and within the conceptualisations that arise from ableist epistemologies of autism as a discourse will be gradually implemented in each individual chapter. The middle piece forms the extension of the kind of argument summary that I have outlined in the previous section of this introduction. Next to the three case studies, the middle piece contains three separate chapters with conceptualisations of one specific area of interest. One is dedicated to my approach to autism in relation to existing critical literature, one is dedicated to representation, and one is dedicated to the personal account as a subtopic of representation and a declaration of autistic voice. These three topics fill extensive separate chapters that are equally as long as the case studies, because they present conceptual insights that are pivotal to my overall defence of the political economy of doubt. The conceptual chapters will provide essential conceptualisation behind the case studies and will all focus on the importance of avoiding the risk of re-centralising autism and autistic people within an academic context, critical or not. This provision of key concepts has shaped the chapter order: the approach to autism chapter precedes all chapters, and the subsequent representation chapter precedes all

case studies and particularly the *Extremely Loud* chapter as an independently produced Hollywood film. After *Extremely Loud*, two personal accounts follow, which is why the chapter on the personal account is located in between. All chapters are ordered in succession according to a pyramidal principle: the first one offers foundational information that is needed for the second one, the second one includes insights that are needed to understand the third one, and so on. My motivation for my overall thesis structure and its balance between case studies and conceptual chapters is to make clear that it is my response to my analyses that shapes my theorisation of autism, representation, ableism, and doubt.

The chapter on my approach to autism forms a theoretical basis and core consideration of previous cultural and critical academic literature on autism. This basis is grounded on three themes: biopolitics (Foucault, 1978), the commodification of autism (Runswick-Cole & Mallett, 2012), and indexicality (Peirce, 1955). This chapter will present specific vocabulary based on these three themes. These theorisations and vocabulary will be applied to practices of looking (Sturken & Cartwright, 2009) in the chapter on representation. This will contain a more detailed discussion of method: notes on method and techniques are smoothly integrated in the explanations of how I formulate metaphorical concepts based on discursive and textual analyses there. I will outline my motivation, as a declarator of criticality myself, to focus my concern for 'inclusive practice' on the right to rewrite the textured life of embodiment. I will then interlink my insights on the valorisation of the autism information-thing through expectations of autism contiguity with my focus on cinematic codes with a discussion of my creative take on Metz's notion of metaphor presented syntagmatically, categorised as a mode of meaning ensuing from interconnected signification in cinema (Metz, 1982, p. 189). The first case study, *Extremely Loud*, will cover a detailed analysis of the scene that features the recounting of an autism test result with a short comparison with Foer's novel. I will then outline the topic of hyperawareness for cues of deviance within the intersection of autism as a discourse and the cultural trauma of 9/11. This will then be followed by a reflection on the narrative of parental intervention in the feature film. The chapter on personal account will delineate how I come to conceive the personal account as a mutual act of acknowledgement of autistic

voice, rather than an autobiographical text. My thoughts on the genealogy of autistic voice as a disruptive scientific oxymoron will form my point of departure here; Erevelles's 2005 insights on historical denials of rational speech as interlinked with contemporary debates on facilitated communication and late capitalism will also be pivotal. The chapter on "My Autism and Me" will dissect the importance of 'me' and 'my autism' in claims of being "a bit differently", of the role of animation, of an artistic rendering of the brain, and of the construction of a 'neurobiological' citizen. *In My Language* will consist of a negotiation of Baggs's rhetoric of translation, claim to autistic online space, and presentation of her movement through space as language. I perform this with the help of my self-made term 'atopos' that I developed in my MA dissertation (2015). I will then reflect on the implications of direct doubt on ableist notions of the 'skilled' and 'able' subject, which will subvert the neoliberal neurobiological citizen in "My Autism and Me". The conclusion will present findings on my case study and the theme of doubt, the limitations to my choices, and further implications of a political economy of doubt on future research. I will end with a contemplation on what imagining the act of 'rethinking' autism could look like beyond the desire for 'positivity' alone through the concept of 'crip killjoy'.

Throughout my whole thesis, I will use first-person language (Titchkosky, 2001) in line with the wishes of Autistic people (Kenny et al., 2016) and the singular they in cases of gendered pronouns are not necessary. I will avoid deadnaming (see Wilkinson, 2017), which is why I will consistently refer to Baggs as 'Amelia Baggs'. I will paraphrase carefully and extensively, with context and page numbers outside of quotes. I intend to enable further reading, re-reading, and debate on the issues that I raise. This could enable transparency on how we consider, include, and employ someone else's intellectual work.

2. Approach to autism

This chapter offers a further explanation of my approach to autism in this thesis, as it forms an elaborate theoretical underpinning to the decentralisation of the will to 'know' autism that my thesis rests upon. The three theories that I will be engaging with are Foucauldian bio-power, the commodification of autism and the index as a type of signification. Overall, the chapter outlines what a contribution to knowledge in the form of an academic decentralisation of the autism category means in practice in relation to the conceptualisations and readings to come. As I separate autism as a discourse and autism as a clinical condition throughout this thesis, my selection of concepts from critical theory elaborates the scope and area of research that is on discourse and visual culture specifically. The notion of 'approach' offers room for further detail on the kind of contestation that my research on autism as a discourse is involved in with regard to my critical stance on ableism. Additional vocabulary beyond 'discourse' alone can make my decentralisation of a pre-discursive neurobiological reality within my research project more consistent.

My approach to autism, solely studied as discourse and not as a clinical condition, is thus part of my contribution to knowledge on autism from a Disability Studies perspective that interrogates the distinction between ability and disability with cultural analysis. It touches upon the delineation of my research object within my own enactment of dis/abled signification as my contribution to the textured life of embodiment. As I already stated in the introduction, Titchkosky (2007) writes about disability as something that is textually interwoven in everyday life, with Disability Studies writing being in itself a contribution to this discursive (re)production of dis/ability as a performative utterance. Performativity means that language shapes reality rather than reflects it, and that speech is thus an 'act' in itself (Searle, 1969). This applies Austin's notion of the performative utterance to discourse and culturally and socially enacted meaning-making in general. Austin (1962) calls expressions such as 'I hereby name this ship' or an 'I do' during wedding ceremonies performative utterances: they not only inform bystanders but are declaratory ('hereby') and contractual actions that change reality in the right circumstances (pp. 5-8). Wider

social and cultural applications of this idea of action rather than reflection through speech have been useful in social constructivist literature that has aimed to undermine biology as the source of knowledge. A famous example is Butler's problematisation of the sex/gender binary in her view that both are made meaningful through the sum of constant culturally embedded and unconscious acts (Butler, 1993). In my act of meaning-making, I make the unconscious mechanisms of performativity conscious with my position as the researcher who decentralises autism and autistic people and centralises the production of meaning.

The underlying theme of performativity in my research object of autism as a discourse is thus fleshed out in a tripartite structure of three core concepts that each touch upon important considerations regarding my area of representation. The three themes are covered in three individual sections. The first one covers the triad of autism, knowledge and power as presented in the introduction in more detail through its focus on the claims to neurobiological reality in the pre-discursive notion of autism. Bio-power is the central concept of this first section. There, I consider Foucault's often inconsistent use of the terms 'biopower' and 'biopolitics' (Foucault, 1976; Foucault, 1978) and Anglo-Foucauldian thinking on the contemporary 'politics of life itself' (Rose, 2007) that has further built upon these terms (Rabinow & Rose, 2006). With Tremain's use of biopower in her notion of the 'government of disability' (Tremain, 2005), I offer a reading of literature on autism that declares to be critical of social movements that supposedly re-establish neurological difference in people who identify and/or have been identified as autistic. This reading will result in caution about the 'complex' able subject rather than the restrictive pathologisation of the claim to autistic cerebral subjectivity.

The second section is focused on commodification, as it explains my consideration of meaning exchanges in culture and society, or 'economies' in the 'ableist economies of doubt' term. It deploys the vocabulary from one key academic concept: the commodification of autism, as developed by Runswick-Cole and Mallett (2012; 2016). With the help of Marxist theory, Runswick-Cole and Mallett conceptualise the autism category as a disembodied good to be bought and sold as a reaction to the large amount of academic attention to the delineated subject of autism. I explain the

significance of their choice of words such as 'information-thing' and 'promise' to my thesis and add the notion of *interpellation* as presented by Althusser (1970) in his writings on the workings of ideology. My motivation to highlight commodification as a theoretical concept for a section is to enable thought about self-confirming circulations of valorised information-things as a meaning exchange regarding autism as a discourse.

The third and last section combines my problematisation of normalised realism in the scientific and popular use of the autism category with semiotics, or the study of signs (de Saussure, 1959) and signifying practices (Barker, 2003). The notion of semiotics is of direct concern to visual culture, as my case studies are concerned with the study of film in particular, and the construction of in/visibility. In the introduction, I identified signifying practices as a central point of concern in the field of Cultural Studies. I employ Peirce's notion of the index as one of three ways in which a sign can refer to an object, as its description as an "association by contiguity" (Peirce, 1955, p. 108) helps me to deconstruct social expectations of in/visible 'warning signs' of pathologized deviance (McGuire, 2016).

Overall, the common themes that are raised in each of the three themes not only encapsulate my approach to autism but also shine light on my stance on ableist normativity. In the introduction, I presented my conceptual shift of regarding autism diagnostic categorisation as ableist rather than disablist. The dismantling of ableism is thus key to my declaration of autism criticality and my stance of caution with regard to what I present as the political economy of doubt. My interest in bio-power deviates from academic interest in the social production of the 'labelled' subject who forms a sense of self and community in negotiation with claims to neurobiological singularity, as I instead express my interest in the production of the 'complex' normative subject. In the case of Runswick-Cole and Mallett's notion of the commodification of autism, I highlight the hybridity of the phrase 'information-thing' that captures the intertwinement of reification and knowledge circulation. Finally, the section on indexicality captures the normative gaze in the normalised binary of visibility and invisibility in disability that I would like to undermine.

47

The formation of the 'complex' subject, the hybridity in the autism 'information-thing' and the normative gaze that 'trains' readiness for action and intervention all capture elements of ableist economies of doubt. Ableism encapsulates not only disabled subjects but idealised notions of 'complex' abled subjectivity as well;   it has simultaneous dominion over dualities like the assumed materiality of the autism 'thing' and the flow of 'information. The sum of my epistemological metaphorical concepts covers the theme of doubt as dominion over singularity and complexity at the same time, which will be discussed per case study. With the notion of indexicality, I offer room for thought about the power implications of the 'visibility' of dis/abled subjects. Whereas my study object of autism as a discourse is complemented with theory, it is the palimpsest of epistemologies in constant contestation (like declarations of criticality on diagnostic categorisation) within ableism that I ultimately problematise through cultural analysis.

2.1 Bio-power

This section on the Foucauldian terms 'bio-power' and 'biopolitics' contains further reflections on power/knowledge built around the cultural significance of life itself and claims to biomedical knowledge. Bio-power is the control and conduct of the sustained life of populations; I evoke this Foucauldian notion in this thesis in order to outline how I centralise autism rights by decentralising 'the self', as I pointed out in the introduction. The self is a product of the governed sustainability of life within populations, but is not a passive recipient of a diagnostic label: instead, the self is defined, concretised and actualised in active negotiations of categories of ability and disability. The cultural significance and valorisation of biological information and the government of the self will be concretised in the chapter on the case study "My Autism and Me". My analysis of this children's documentary features abstractions of biological material and a conception of the good living citizen with sufficient market value to serve an ableist society. My Foucauldian focus on biomedical knowledge in particular aims to denaturalise the notion of autism from unquestioned scientific realism. As such, bio-power is a part of my genealogy of not-knowing autism with which I learn more about ableism and knowledge-building.

Central to my interest in bio-power is the potential for critical analysis to decentralise the individual 'self' and gain greater insight in the significance of biomedical knowledge on the normative abled human and its deviations in culture and everyday life. The self here is not a passive actor who is subordinate to the diagnostic practice of 'labelling' on the basis of clinical insights, but an active self-governor of one's own vitality within a normative and disciplining system. I will present my engagement with Foucault's attempt to grasp a power that deviates from sovereignty and that is concerned with the 'politics of life itself' (Rose, 2007) in order to sketch the biomedical subject in the public realm as a phenomenon of enacted 'complexity' rather than pathologised deviance through 'labelling'. In this section, I will first discuss Foucault's work on biopower, Tremain's notion of the government of disability, and previous adaptions of Rose's vocabulary in declarations of criticality and the potential reaffirmations of academic ableist hegemony that I notice in it. I will then reflect on the cultural significance of neurobiological information and the role of the 'complex' 'variegated' individual within it, that some declarations of criticality have characterised as being in jeopardy. I will then argue that it is the deconstruction of exactly this appeal to 'complex' 'individuality' that forms the relevance of bio-power to my approach to autism in this thesis.

In Foucault's work, the concept of bio-power first appeared in a 1976 lecture as recorded in *Society Must Be Defended*, after which it was adopted again in the first book of the series *The History of Sexuality* (1978). In the latter, Foucault explains a new kind of power over life and death that arose in the seventeenth century, or the era that he lists as the classical age (pp. 135-139). Before, the task of sovereign authority was the privilege to "decide life and death" (p. 135): lives were either taken or spared (p. 136). However, the classical age brought a shift in the regulation, administration, and preservation of life and death in the anticipation and interest of *populations* in which their "biological existence" is now the point of concern (p. 137). Productive power now had the "function of administering life" while regulations such as the death penalty became more difficult to effectively manage, which heralded a shift towards "power to *foster* life or *disallow* it to the point of death" (p. 138). This "era of 'biopower'" (p. 140) brought vitality to the concern of the public sphere, which

resulted in new controlling administration that disciplined the body as a compartmentalised anatomical entity and a vessel for life, reproduction and life expectancy. This discipline consisted of a "series of interventions and *regulatory controls*" that construct individuality based on the investment in life, which he refers to as biopolitics (p. 139; original emphasis). This mode of power production over the sum of vital bodies was present at "every level of the social body" and was utilised and sustained by economic, educational and military institutions (p. 141). In bio-power, power/knowledge was concerned with generating "transformation of human life" (p. 143), as the Western subject had learned to understand itself as a "living species" amongst a vital population that could anticipate its own sustainability (p. 142). As such, juridical bio-power was not centred around law but around the regulatory techniques of measuring and hierarchising medical and administrative corrective mechanisms within a "normalizing society" (p. 144). The very subjects of this constant investment in life became aware of this goal of life as self-realisation in the nineteenth century with an increasing political demand and fight for the 'right' to live and attain one's full potential in life (pp. 144-145). Resistance to bio-power was thus also motivated by this very same need for life, which brings a circularity to the implementation of biopolitics.

Bio-power is a fruitful theoretical framework that could help to map the sum of 'compulsory' performances of vital species-centric 'fitness' aimed to invest in the sustainability of populations. As such, it is of interest to ableism as a site of criticality that aims to place categorisation within compulsory ableness. Tremain (2005) offers further insights on the importance of biopolitics for Disability Studies, as she foregrounds the formation of the disabled subject as deviant out of the medical administrative techniques in bio-power that secure the wellbeing of the population. These techniques of power have classified and controlled "social anomalies" as impaired or insane, as the social practice of human taxonomy has individualised people into 'cases'; for Foucault, the subject and its self-awareness consist of its very subjugation to control from outside assumed 'individuality' (p. 6). Of particular interest to ableism is Tremain's discussion of the government of disability, or any form of activity that constitutes the productive power that creates and conducts disabled subjects and un/consciously outlines what people can and cannot do and say (p. 8).

Tremain regards the realisation of government as opposed to repressive normalisation through law as pivotal to thorough disability theory that questions claims to the medical and apolitical in the definition of impairment as separated from the sociocultural condition of disability (pp. 9-11). This very depoliticization is part of biopolitical conduct itself.

Tremain's insistence on government helps me to switch my attention to diagnostic categories within governance of health throughout society as a whole rather than the oppressive force of categorisation itself that classifies and separates 'impairment' as independent of any political condition. As such, my evocation of bio-power in my thesis and ableism as its site of criticality aims to foreground productive power as well as the construction of the dis/abled subject in affirmation of life itself rather than oppression of 'unique' characteristics 'behind' the 'label'. The cultural significance of biological information herein lies in the appeal of depictions of human vitality and anatomy to complete populations and not just for people who are identified as autistic.

In the formation of populations that are politically sustained by life itself, it is especially relevant for my approach to autism and declarations on criticality around it to focus on the formation of the subject as a negotiator of segmented biological singularity. Aside from his book *The Archaeology of Knowledge* (1972), which covers his methodology in his earlier work on discursive formation, Foucault has never truly offered a toolbox on doing proper 'Foucauldian' research. This means that an application of his work is an interpretive rather than an instructive act and that cultural analysis does not need to 'obey' any directional force as 'prescribed' by a theoretical framework. Despite Foucault's inconsistent definitions of bio-power and biopolitics (Rabinow & Rose, 2006, p. 197), thinkers like Agamben (p. 198), McGuire (2016), Rose (2007) and Novas (2006) have employed the vocabulary in their work on human life, subjectivity and the politics of biomedical knowledge. Rabinow and Rose (2006) bring an abstracted minimum of unity to the "analytic utility" of bio-power and list this unity as a tripartite corpus of thought. The first condition of an academic text on biopower is that it includes considerations of life and discourses of biological and demographic vitality from sources that are widely considered to be authorities. The second shared

point of consideration is "[s]trategies for intervention" in life amongst categorised and uncategorised collectives of people. The last one is "[m]odes of subjectification, through which individuals are brought to work on themselves" (p. 197), intervention and the formation of individual and group subjectivity. To emphasise and clarify the latter, I would like to add further definitions of molecularization, optimisation and subjectification provided by Rose (2007). Molecularisation stands for vital entities that can be isolated, manipulated and regulated for the sake of optimisation, or warranting a desired future by governing (ill) health. Subjectification stands for mobilised and ever-changing self-understanding and organisations of subjects based on biological make-up (pp. 5-6). (A glossary of terms and definitions used in this chapter and thesis at large can be found in Appendix 1.)

Writings on modes of subjectification by theorists like Rose have found their way into the kind of writing that I have identified as 'sites of criticality' in my introduction, with the intention to contribute to criticality with caution. My attention to bio-power (cor)responds to the importance of Foucault, Rabinow and Rose's terminology for critical literature on autism (Goodley, 2016), autistic communities (Brownlow & O'Dell, 2013) and the concept of neurodiversity and the formation of the cerebral subject (Ortega, 2013). 'Neurodiversity' affirms assumed neurobiological difference as diversity rather than a pathology in need of a cure in favour of normalised and naturalised 'neurotypicality' (Jaarsma & Welin, 2012). These sources employ terms such as 'biosociality' (Goodley, 2016) and 'biological citizenship' (Hughes, 2009) that have respectively been developed by Rabinow (1996) and Rose and Novas (2005) to describe sociality and citizenship in contemporary and international bioscientific fields of knowledge like genetics. Declarations of criticality on autism have thus expressed interest in the political activity of autistic people in relation to language of neurobiological singularity as a "formation of kinds of human subject in terms of 'somatic individuality'" (Rabinow & Rose, 2006, p. 198).

I would like to take caution with the adoption of neurobiological subjectification as an accusation against people who identify with the autism category. Literature that is concerned with the critical study of autism and 'neurodiversity' expresses concern that people who identify as autistic, or the vocabulary that is often actively used by them,

affirm and further normalise claims to biomedical 'truths'. This concern consists of warnings about "identity politics" (Ortega, 2013, p. 85) and an understanding of biological citizenship as a singular activist act claimed by disabled activists (Hughes, 2009). The notion of a singular group of disabled activists 'with' 'their' biological citizenship seems to deviate from Rose, who does not conceptualise the term as a tool to 'identify' singularity that is being 'accused' of risking biological essentialism. Instead, biological citizenship is a recent transnational stage in the history of "citizenship projects" or the ways in which repressive power bodies have anticipated groups as citizens (Rose, 2007, p. 131). The warnings stress homogenisation: as Goodley (2016) states in the wake of the biopolitics of the autism "populist discourse", "autism is *the* way of capturing the variegated nature of humanity" (p. 156; original italics). Furthermore, Ortega (2013) challenges claims to a unique cerebral make-up that have come from autism and neurodiversity self-advocates, stating that such notions of someone's unique brain' "may serve to designate 'my mind' or, perhaps more precisely, just 'I' or 'me'" (p. 84). Assertions to speak for "all autistics" according to a shared cerebral difference could "embod[y] the typologizing of brain difference at the expense of autistic's own individual differences" (p. 85). The threat of cerebral subjectification is thus a threat of declaring Vertretung, or one isolated element of representation that encapsulates the act of speaking on behalf of someone or something (Spivak, 1988; Sanders, 2002), based on assumed shared neurobiology.

I emphasise such warnings of misplaced homogeneity because they could risk the re-establishment of the power distributions over populations, while vocabulary on bio-power could enable the conceptual decentralisation of exactly this hierarchisation. The papers from Goodley (2016, pp. 155-156) and Ortega (2013, pp. 74-75) do refer to academic literature that contains this corpus of thought. Nevertheless, I regard their use of this material as a means to conclude with concerns of a 'total eclipse' of a heterogeneous self behind biological reductionist presuppositions of shared neurobiological deviance as overly precipitous. Here, the academic act of theory application might risk overlooking the ableist hegemony between the researcher and the researched, like I have outlined with decentralisation in my contribution to knowledge. Terminology such as "biological citizenship" and "subjectification" aid

Goodley (2016) to voice his laments of essentialism in activism that is supposedly grounded on neurology (p. 152, 156). What is not fully made clear here are the exact epistemologies of subversion in the kind of activism that he approaches with the help of Hughes's notion of biological citizenship. Likewise, Ortega (2013) is committed to the "analysis of the cerebralization of autism within the neurodiversity movement" (p. 75), which recentralises people who identify with a diagnostic category as the research object. 'Neurodiversity' has not consistently been named as a 'movement'; Broderick and Ne'eman (2008) call it a "counter-narrative", for example (p. 467).

Positioning neurodiversity nevertheless as a site of criticality in a study of 'texts' or 'signs' that come from autistic people might re-emulate the exact hegemony of naturalising 'kinds' of people that it aims to undermine with the help of bio-power. Naming 'neurodiversity' in the wake of essentialism within the research object rather than the researcher shapes a 'movement' as a wilfully disruptive force that obscures the thing that is 'eclipsed': the 'variegated nature of humanity' or 'individual difference'. When reinforcements of ableist hegemony of knowledge formation on 'pseudo/scientific' autism in academic publications go unquestioned, declarations of criticality could ultimately impose *dominion* over the 'complex' 'individual' rather than deconstruct biological reductionism.

Such a powerful presupposition of complex individuality is the exact thing that an interpretative reading of Foucault and Tremain has helped me to unpick with regard to ableism as my site of criticality. It is here that I would like to mark a different kind of thinking that has been sparked by Foucault's discussion of vital power on the level of populations: the realisation that I can problematise presuppositions of 'individuality' itself. Ableism is closely related to presuppositions of the 'complex' individual as the image of complexity invites consideration of a dismantling of 'complexity' in individual life as a perfected ideal that is compulsorily enacted within populations. I would like to evoke my explanation of genealogy from the introduction here in order to explain my choice to employ Foucault's study of power relations in the 'classical age'. Foucault's historiographies are not empirical but offer a new, closer look at a time period that one tends to think about as more enlightened, rational and humane than preceding eras. The re-examination of supposed enlightenment has solidified a site of criticality

that consists of the apparently ahistorical within and beyond Foucault's work, such as in the adoption of vocabulary on the biopolitical in declarations of criticality on autism and disability. The apparent ahistorical as a site of criticality includes human rationality, individuality and, specific to the scope of this thesis, having a voice of one's own. The upcoming chapter on personal accounts zooms in on the rise of autistic voices as a more specific example of the genealogy of the knowledge that comes from people who identify with the concept of autism. There, I am not presupposing authenticity of knowledge that comes from within individuals who are part of this social group, rather than outside of it. Instead, I explore the historically situated concept of autistic personal accounts as a relational process of acknowledgement, in which autism is *being known* 'from the inside' by the 'outside' world.

For now, what Foucault's terms such as bio-power and the apparatus provide me is room for problematisation of productive notions of the free, unique, and 'complex' self in general, instead of 'labelling' as supposed repression of this self. My consideration of productive power is part of my research on ableism as my site of criticality. Ultimately, I localise categorisation in ableism with which I grasp comprehensive compulsory ableness in power/knowledge, which is what has sparked my interest in bio-power and biopolitics. By contrast, when Goodley (2016) states that "[a]utism is a biopolitical category that cannot help producing in excess of itself" (p. 156), he seems to envision and position the concept of biopolitics as a negative repressive force 'imposed' on pre-essentialism. For me, a rejection of autism as an assumed pre-discursive and a-transformative cerebral clinical category is fruitful, but not yet enough to fully recognise a critique of ableism in the study of culture of 'everywhere'. In my interpretation of bio-power and Tremain's use of the term in relation to disability, its fruitfulness arises by locating it in this realm of the 'everyone' and 'everything'. My challenge to scientific realism and essentialism mostly lies in my very selection of my research object and area within this thesis itself. Both have directed my attention to the complete scale of cultural significance, not only to undermine biological reductionism, but also to undermine the power relations that come with an aim to understand claims to autistic group identity better. Just like my use of Campbell's term

'ableism' in cultural analysis is not accusatory, I find the use of bio-power in the possibility of the non-accusatory.

Discussing Foucault's writing on bio-power, I would like to explain how his thinking has helped me to reflect on productive power in relation to biological information as a production of an *affirmation*, instead of an obscuration, of ableist rational individuality. This sense of individuality arises in negotiation with molecularised biovalue, or biological material that can be medically and economically invested in with the aim to improve health and networks of people who work on this (Rose, 2007, p. 32). Negotiating biovalue is not necessarily empowering but instead presupposes a great amount of personal responsibility (Rose, 2007, p. 134) which disciplines members of a population in everyday life, sustained by a shared belief in one's own individuality. This belief is what naturalises this form of discipline and what makes it so hard to decipher. In the chapters that cover conceptions and case studies of personal accounts, I will elaborate the notion of responsibility over the self in the context of neoliberalism in Disability Studies literature.

To concretise the affirmation of the 'complex' 'responsible' individual that negotiates biovalue, I would like to lay out a short reading of an everyday cultural artefact: a poster from beverage company Drench's marketing campaign *Don't Decide* (Kennedy, 2017). Its visuals contain the two large-print words "Water?" and "Juice?" and the accompanying smaller incitement "Free your brain, don't decide". The specific reference to the brain points to the cultural significance of cognitive neuroscience in and outside the realm of autism that is also noted by Ortega (2013). Nevertheless, the "your" in "your brain" here is of real concern to my thoughts on affirmation of individuality instead of reductionist and determinist understandings of the self as directed by the brain. The word "you" addresses a population and not any social group in particular: every person has a brain and everyone sometimes experiences indecisiveness. Now, that indecisiveness can be resolved by an act of 'freeing' the brain. The word thus presupposes and thus shapes a *population*, or virtually anyone who encounters the text and sold product: this population can be called on for further regulation on consumerism, health, fitness, and so on. Simultaneously, this regulation and appeal to cognitive fitness and liberation also seem to do justice to the

individuality and the free will of each individual person who encounters the poster. The brain as biological entity gains its significance for human vitality because it can be 'freed' according to the incitement: it is biovalue as a to-be-freed entity, which affirms the supposed personal agency of the freer. It is interesting to note that the act that 'initiates' this negotiation of the brain and affirmation of personal free will is a rejection of 'labels' for the promoted beverage, visualised on the poster as aestheticized words that together form a colourful palette. The 'rejection' of labels in this marketing artefact directs individuals to this sole drink as they 'do not decide' and thus take responsibility for their sense of cerebral self-fulfilment. This duality of the assumed population ('everyone' has a brain) and affirmation of the free responsible self (you can free your brain too) is what constitutes the kind of compulsorily-abled subjectification based on vital discourse on bodily organs that I am interested in.

My small textual analysis highlights the function of my thoughts on the normalised affirmation of personhood that negotiates biovalue on the levels of ableism, apparatuses, and my case studies. Bluntly stated, the biological subject regards itself as a 'free' subject in a taken-for-granted fashion, exactly because it 'has' a brain, genes, chromosomes and the like just like 'everyone else' within a population. This realm of the 'everyone' is an ableist conception of the universalised working 'vital' body, which implies objectification of disability as death (Waltz, 2008) or as a threat to the general health of the population. Simultaneously, it is the 'everyone' that is of interest to this thesis and its critique of ableism: for me, the biological subject is something that concerns and evokes the 'everyone' as a population to-be-governed, rather than a group of people who claims cerebral deviance through self-identification with autism. On the level of the personal account, I will provide a deeper discussion of my aim to study the personal account as a cultural construct of acknowledgement of voice in the chapter on this issue. On the level of visual culture, it is important to place aestheticized depictions of the brain, the 'place' of reified autism according to (cognitive) neurobiology, in a genealogy of visual empirical study of this organ. Nineteenth-century scientific disciplines such as phrenology and craniometry classified people according to intelligence and race based on observations of the head, often mediated through photography (Cartwright, 1995; Jacobs, 2001). The implications of

visualisations in contemporary means of mapping and comparative analysis of the cerebral like fMRI scans have also been studied. Van Dijck (2005) notes that the confidence in the scientific validity of such devices creates an impression of the clinical gaze as natural and apolitical. To grasp the politics of cerebral visualisation, it is important to look at the fickle history of the way biovalue has been visualised and to dare to make sensitive links to scientific paradigms that are now seen as 'obsolete'.

Continuing my shift towards the 'everyone' in an in-depth consideration of the meaning exchange, I would like to unpick one interpretation of the social and cultural function of the autism category: that of commodification in Runswick-Cole and Mallett (2012; 2016). Rabinow and Rose state that

> [i[n the new political economy of vitality, transnational flows of knowledge, cells, tissues and intellectual property are coupled with local intensifications and regulated by supranational institutions. Mobilizations of persons, tissues, organs, pathogens and therapeutics operate at different speeds and encounter local obstacles and incitements (p. 215).

I am interested in the flow of the autism category and the way in which it grants value to the term 'autism', as vocabulary like 'diagnostic inflation' forms sites of criticality but also may leave the presupposition that the autism term is a currency untouched. In the next section, I further explore this notion of currency in relation to the scientific realism in the reification of the autism thing in and outside the mobilisation of populations as negotiators of the 'brain'.

2.2 Commodification of autism

The word 'commodification' allows me to think in terms of circulation in line with my term 'ableist economies of doubt', aside from the articles written by Ahmed (2004) and Novas (2006) that prompted this particular phrasing. 'Commodification' will thus further exemplify my localisation of autism categorisation within compulsory ableness and expand upon my earlier interest in problematising complexity rather than the claim to cerebral group singularity. The vocabulary from Runswick-Cole and Mallett that is of interest to my thesis comes from their 2012 book chapter, with additional references to their 2016 book chapter. This is not a limited comprehensive report of Runswick-Cole and Mallett's development of their term. Instead, this section serves to

indicate that their terms "information-thing" (2012, p. 42) and the "promise" that the autism category brings (2016, pp. 119-121) are useful for my conception of ableism as a site of criticality.

Together, this new set of words offers a comprehensive and precise discussion of my academic endeavour to separate 'autism' the discourse from 'autism' the condition. I contribute to existing critical analysis of the autism category with the addition of the term 'interpellation' and a greater focus on cultural representation, expanding my previous definition of reification in this thesis as presented in the introduction. As I have outlined there, the notion of reification that problematises the makings of the autism concept into a thing is key to my conception of the target domain in my metaphorical concepts that denaturalise scientific realist epistemologies of autism as a discourse. Throughout the thesis, I will maintain the 'information-thing' formulation in order to signify my efforts to dereify the concept of autism and conduct analyses of epistemological uncertainty as a flow of information, or an ableist economy of doubt. I do not adopt Runswick-Cole and Mallett's arguments regarding 'commodification' as a site of criticality itself, as the concept will mostly function to emphasise circulation and meaning exchange. Whereas the previous two sections expressed caution regarding declarations of criticality on autism, this section consists of beholden acknowledgement of terminology related to writings on commodification as tools for my approach to autism. In this thesis, any use of the term 'commodification' solely covers my own engagement with Runswick-Cole and Mallett's vocabulary.

Runswick-Cole and Mallett (2012) react to the ever-growing attention that is paid to autism in academia with a Marxist reading of the academic framing of the concept of autism as a thing to be "branded, marketed and sold" (pp. 33-34). The concept of 'autism' in an abstracted form becomes marketable within the academic world, where it is exchanged and consumed in the shape of information, often detached from the people who are identified as autistic and who initially provided information and data (pp. 38-41). Theorising the production of knowledge on autism, they identify processes of abstraction of autism information into an assumed 'thing' and, as an extension of this, into a buyable and sellable good that meets an "unsatisfied desire" for resolutions and interventions (p. 36). Borrowing from Marxists' conceptualizations of labour,

Runswick-Cole and Mallett identify both professionals and people identified as autistic as both producers and consumers of autism as an externalized "information-thing", distanced from subjective experiences of human diversity (pp. 42-43). Autism thus becomes something that is perceived as "beyond human making or changing" and "as such the commodity is perceived as a fixed, static, and ahistorical 'thing'", which is the basic principle of the Marxist notion of *fetishism* (p. 44). The user-value of autism is defined by a strong *promise* of an explanation through medical knowledge, which renders the involvement of academics in the commodification of autism invisible (pp. 44-45). Overall, Runswick-Cole and Mallett position commodification as their site of criticality. They note their contribution to knowledge as attention to "the amount of discussion autism is generating" in declarations of critical studies of autism and argue that a "defetishisation" of the autism category could reveal harm to disability rights (p. 36).

The question is what Runswick-Cole and Mallett's vocabulary highlights and clarifies for me. Their conception of autism as something to be bought and sold serves to name the "trouble" that the authors felt with the reification of impairment (Runswick-Cole and Mallett, 2016, p. 111) as a "largely unproblematized entity within academia" (2012, p. 34). My reading of this 'vocabulary of trouble' has functioned as a prospect of further freedom and understanding to approach autism as a meaning exchange within academic and public institutions that 'buy' and 'sell' autism. I thus transcend realist claims to autism as a neurobiological promise of explanations for a more thorough understanding of the workings of normative institutional power, rather than warn of the threat of the dominance of "one brand of impairment over another" (p. 46). Runswick-Cole and Mallett have not only directed my attention to the abstracted category of autism as a pre-discursive 'thing' but have also made me think about autism as something that gains and generates form, value and significance through exchange. This thinking process has specified my aim to understand culture better. What I will ultimately understand better are the cultural texts and speech acts that (re)produce this process of commodification of the autism information-thing and that are both the purveyors and the results of it.

To clarify my insights gained with an understanding of the cultural significance of autism as a value exchange, I would like to specify my adoption of Runswick-Cole and Mallett's phrasings 'information-thing' and 'promise'. Runswick-Cole and Mallett (2012) employ the notion of the information-thing in their question of how to map the actors that contribute to the "marketplace of autism information" (p. 42). They reach beyond a simplified understanding of this marketplace as a division between professional experts who have access to knowledge production and people who identify as autistic and their personal network who lack this access. This reach considers the "instruments of labour" (Marx, cited in Runswick-Cole and Mallett, 2012, p. 43) of behaviour to-be-empirically-studied in addition to professional action and intervention, as Runswick-Cole and Mallett emphasise the mutual labour of medical experts and autistic people. Within this mutual labour, alienation takes place: although collectively constructed, the capital of autism information is faced as if it exists 'out there' without the involvement of labourers. With this Marxist terminology, Runswick-Cole and Mallett state that "[w]e are all labourers, and by virtue of being labourers, we are also all consumers" (p. 43), since autism provides information (consumption) that forms material for the production of further information.

I am foregrounding the word 'information-thing' in this analysis of labour and alienation because it suggests hybridity in reification. The production and consumption of information on autism dislocate an assumed product or thing from the labour of production itself, while the 'flesh' of the autism 'thing' consists of information and its exchange. This hybridity of 'information' and 'thing' highlights autism 'currency', or the presupposition of a widespread economy of meaning-making, more than the notion of reification does. Debates on reification follow the insight of alienation as they pinpoint the "fallacy of misplaced concreteness" (Nieweg, 2005, p. 10) in which a concept that is bound to human thought is mistaken for something natural and distant from human creation. I would like to employ the term 'autism information-thing' to signify reified autism as it moves my interest from 'mistaken belief' to a conception of the population as producers/consumers that form and sustain an economy of autism discourse.

Similar to the exemplification of hybridity in the reified autism 'information-thing', the notion of the promise grants words to the value of the autism currency in this

economy. While alienation deconstructed the invisibility of human meaning-making, this notion serves to conceive the satisfaction of a desire and need that is required for "labour to reappear as a commodity" according to the Marxist process of fetishism (Runswick-Cole and Mallett, 2012, p. 44). Runswick-Cole and Mallett refer to Haug's discussion of the need for an object that a consumer has, even if that object is not directly experienced during the instance of exchange. Here, the value of the object lies in its promise, which causes Runswick-Cole and Mallett to wonder what this promise could be in the case of commodified autism. They argue that it is "coherent explanations" (p. 44), but their question prompts more answers in me that aid me to further unpick the user-value of the autism 'information-thing'. Based on McGuire's concept of war on autism in advocacy (2016), the promise could be quick and timely recognition and intervention, which is one that reveals pursuance of hyperawareness that I will address in the indexicality section and the representation chapter. Furthermore, my reflections on bio-power spark conceptions of the promise of 'free' individual will of the 'complex', 'heterogeneous' subject characterised by conscious actions of negotiating a kind of isolated neurobiological difference that is 'detached' from this free self. What bundles my explorations of promise together and sustains theorisation is Runswick-Cole and Mallett's (2012) conclusion that "the circular logic of a self-sustaining commodity chain is established through the power of promise" (p. 44). In my example of the 'autism-is-enigmatic' metaphorical concept of the introduction, I referred to a similar self-confirming structure of signification that provoked further thought on the power of reified insecurity. It is here that the notion of commodification proves to be fruitful for my consideration of representations of autism within ableist economies of doubt. My thesis ultimately theorises circulations of the autism information-thing through a self-affirming and unquestioned process of actualisation through doubt. In both hybridity and circularity, I again find the kind of wide reach of compulsory abledness at the backdrop to my approach to autism.

Runswick-Cole and Mallett's engagement with Marxist terminology thus offers me a kind of vocabulary and terminology that aid to look closer at the function of reified autism within the ableist self-sustaining circular exchange of an information-thing hybridity. This exchange gains value, mobilisation, and significance for further study

through promise. Further reconciling the commodification of autism with my analyses of signs and cultural texts and formulation of epistemologies as encased in my case studies, I would like to add Althusser's notion of interpellation, a concept from Marxist theory that Runswick-Cole and Mallett do not cover. Althusser (1970) lists interpellation as a characteristic of ideology that "constitutes" individuals as subjects (p. 160). My reference to his interpretation of ideology only serves to elaborate on the formation of the subject and unique individuality as addressed before in the section on bio-power. It is this "recruiting" and "transformation" of individuals into subjects (p. 163) that I am interested in and that will form a closer understanding of the role of autism commodification in my research project. In his discussion on interpellation, Althusser dissects everyday instances in which people perform a sequence of instances in which one hails the other with the call "hey, you there" and the other "turns round" as a token of recognition that they are the person hailed (p. 163). Althusser calls sequences like these ideological since they exemplify that the individual is constructed as the "always-already-subject" who is constantly being hailed throughout one's whole life (p. 164). I would like to draw a parallel with my interpretation of the affirmation rather than obscuration of individuality in bio-power. In power over life within a population, people feel that their free personal will is being affirmed because they are encouraged to be in constant negotiation with 'their' brain, genes, and other biovalue. As parts of a regulated population, they are interpellated as subjects because of constant cues of biovalue to-be-negotiated that are supposedly 'inside' their living functioning bodies.

This is where autism as a discourse comes in: as a cue of neurobiological deviance, the detached autism information-thing is a hailing or a "hey, you there"' in itself. This interpretation of autism as a discourse mirrors analyses of psychiatric subjectification by China Mills (2014). She argues that psychiatric intervention functions as an Althusserian interpellation that recruits subjects, using a quote from an anti-psychotic medicine company representative that emphasises how the term 'bipolar depression' draws people to the ad (p. 72). Diagnostic categories thus hail people as subjects, which I further like to substantiate with an anecdote that Runswick-Cole and Mallett (2016) provide in their description of the beginnings of their theorisations on autism.

They sketch an airport setting in which an Italian check-in counter clerk "enthusiastically" affirms a mother's remark about her son's special needs related to autism and lets both pass (p. 110). I would like to argue that this affirmation means that the disclosure of autism as a discourse assigns this clerk an additional role as a person who clears the line for an autistic person. For me, the commodification of autism thus means that the information-thing orchestrates roles and functions of people and puts them into place towards the imperative of promised recognition and intervention. In relation to the use of autism as a discourse in everyday life, people are assigned roles of 'the parent', 'the layman', 'the teacher who has had several autistic children in their class', and so on. This does not mean that the autism information-thing 'lures in' people with its brand-like quality and its promise of identification initiation. Instead, naming interpellation is an incitement for wide acknowledgement of the sum of performative circulation of meaning, networks, information on the brain and scientific paradigms without the pretension to stand above it.

Interpellation, or the hailing quality of autism as a discourse, summarises the function of Runswick-Cole and Mallett's vocabulary on the commodification of autism in my thesis. Autism as a discourse recruits biological subjects and assigns them roles of labour in a self-sustaining circulation of production/consumption based on the promise of resolution and timely intervention. I will further explore the power of discourse and 'signs' of autism within such a self-sustaining economy of diagnostic categorisation by employing semiotics as a critical framework that suits my study of visual culture in the next section on autism indices.

2.3 Indexicality

The term 'indexicality' as presented in this section lies closest to my interest in visual culture that will be further explored in the chapter with my conceptualisation of representation within my thesis. The previous two sections established a thorough placement of my approach to autism into the realm of the cultural and the social production of information-thing value within a power dynamic of populations and apparatuses as 'marketplaces'. This section aims to concretise this shift in thinking into a closer look on how to problematise social expectations of the 'mark' of realist reified autism in everyday life through textual analysis. The alleged and expected visibility of

disability, or the lack thereof, is central to the section as a useful aspect of the study of ableism through analyses of (partly) visual media. Because not-knowing autism is such a pivotal recurring topic throughout the analyses of all three case studies, it is worthwhile to reconsider the distinction between visible characteristics of a (portrayed) disability, invisible disability and ableness in visual culture. In a clinical and cultural context, characteristics of dis/ability are often determined by the act of looking at potential indicators of impairment. However, this social expectation of visibility that is integral to the historically fickle dis/ability binary begs the question how to know autism if it is not visible, and what it means to not-know autism in a visual medium. In order to further explore epistemological uncertainty and the theme of not-knowing autism in visual culture, it is helpful to problematise fixed boundaries between visibility and invisibility as a normalised marker of distinction between ability and disability. In this section, I thus introduce new terminology that will be highly important for the chapters to come: the anticipation of contiguity will be more thoroughly explored and explained in the chapter on representation. In addition, the hyperaware gaze will be central to the *Extremely Loud & Incredibly Close* case study. Inspired by McGuire (2016), it refers to the striking prevalence of signs of deviation from the able-centric norm that accumulate into indicators that 'point' at the potential of diagnostic inflation.

My focus on cultural expectation and anticipation of autism signification in my research that looks at case studies from visual culture exemplifies my challenge to positivism and scientific realism. It comprehensively decentralises the diagnoser and the diagnosed and places autism within cultural production and circulation. Here, with 'indexicality' as a specific kind of vocabulary that comes from Peirce (1955), I will question the construction of 'proof'. My challenge to 'proof' deconstructs the structures of and actors in signification that sustain a constant reinforcement of the 'information-thing', similar to the valorising and self-fulfilling quality of the promise of resolution and its power in shaping exchanges of meaning-making. This theoretical framework is grounded on my suspicion that the categorisation of autism as an "invisible disability" (Broderick and Ne'eman, 2008, p. 473) might insufficiently subvert a naturalised understanding of 'proof' of disability as something to observe.

This categorisation creates a binary opposition that I will call in/visibility from now on, with which I undermine the taken-for-granted ontological duality and present it as one phenomenon. In/visibility is a significant point of concern in academic literature on cultural depictions of autism: Murray (2008) outlines how the public fascination for autism has resulted in representations of autistic people with pronounced visually apparent eccentricities. I would like to state that such reliance on the in/visibility binary fails to problematise scientific realism and enables unquestioned inclusion of phrasings like "difficulties associated with autism" (Honess-Roe, 2013, p. 126) in Humanities literature. It presupposes 'observable' people and conditions without considering the social production and shared labour that create this 'to-be-observed-ness' in the first place. This section aims to respond to this failure with discussions of insights from McGuire (2016) and a reflection on descriptions of the semiotic category of the index from Peirce (1995). The interpretation of indexicality as outlined in this section has been expounded before in Ebben (2015) and more prominently and decisively in her later article on autism as epidemic (Ebben, 2018).

Conforming my theoretical framework throughout this chapter, I would first like to situate the concept of in/visibility in cultural encounters and meaning exchange as well as in the power dynamics that blur out awareness of this naturalised social production. This relational understanding of the fluid concept of in/visibility, and the cultural critique of asymmetrical power relations that can come out of it, largely motivates my use of the term 'indexicality' in this section. The clinical category of autism presupposes the clinical encounter, which is in itself a power imbalance between a person that observes and diagnoses deviance and the person that is being observed (Kirmayer, 2005). This power imbalance here is constituted within the social enactment of visibility: Foucault (1977) interlinks the establishment of "economies of visibility" (p. 187) in his concept of the disciplining mechanism of examination (p. 184). Within the context of ritualised enforcement of normativity within eighteenth-century medical and educational institutions (pp. 185-187), discipline was constituted in a way that foregrounded a "normalising judgement" with an appeal to truth through the circular constancy of observation (p. 184). Here, the execution of power stayed invisible while "at the same time it imposes on those whom it subjects a principle of

compulsory visibility" (p. 187). The cultural insistence of normativity as 'compulsive' is a concept that I have highlighted before in Campbell's notion of ableism. Similar to my conception and establishment of the 'complex' individual who is interpellated as a subject, examination documents the assemblage of visual impressions in a way that constitutes the individual (p. 189). The individual as such becomes a case because it is this established individuality that is being described and 'corrected' (pp. 191-192).

Compulsory visibility as a continuous and ceremonial site of power evokes discourse of people 'displaying' a 'case' of autism that acts to further normalise normativity but that also highlights the strong role of internalised looking in everyday language surrounding autism. Foucault's notion of the normalising gaze sparks interest in the representation of autism in visual culture, since the topic of the gaze as the site of cultural criticism in the study of cinema has been pivotal to classic feminist film criticism (Mulvey, 1999). My loose adaptation of the gaze in film criticism to ableist normative spectatorship will be further explained and implemented in textual analysis of narrative film in the representation chapter and the *Extremely Loud & Incredibly Close* case study.

To introduce the theoretical language of the 'hyperaware gaze' that highlights power, dominion and negativity in in/visibility, I would like to turn to McGuire (2016) and her reading of "autism red flags" in her textual analyses of advocacy posters (p. 99). McGuire's reading is particularly useful for the analysis of autism signs in visual culture, which is the main focus of my case study chapters. Mirroring Foucault's historiography of highly ritualised institutionalised examination that constructs archives of individual cases compared against normativity, McGuire establishes the normative gaze as one that is continuously aware and watchful according to a disembodied all-seeing "medical imperative" (pp. 86-98). The normalised medical gaze is constituted as a convergence of cultural texts such as the posters, the medical field in the realm of scientific realism that implies constant disembodied looking for deviance, and the internalisation of 'normal' looking and hyperawareness of social non-normativity for the sake of early intervention (pp. 92-93). Normativity thus captures the cultural fear of pathology and the cultural desire to 'take action' and inaugurate the politics of quick-paced time management (p. 103). On the 'red flag' posters that list autism 'signs'

In child development, the interpellated subject is prompted to act upon "visual cues that belong to a visual culture where any *sign* of autism is implicitly narrated as a *warning sign*" (pp. 87).

I would like to continue McGuire's analysis of the (re)production of autism in/visibility and the site of compulsive visibility as problematisation of normativity in the discursive formation of autism. In such a continuation, I focus on expounding on this visual culture where the 'warning signs' allegedly belong. The posters appeal to the authority of early intervening professionals and interpellate implied teachable readers who must internalize their examining and normalizing gaze through the suggestion of danger and urgency (McGuire 2016, p. 87-88). This interpellation brings further internalisation of messages like these: one perceives signs, is faced with cultural texts that strategically steer such a way of looking, and continues looking for more signs. McGuire's reading thus offers insights in the cultural circular process of the hyperaware gaze, with the promise that identification of abnormality can occur more quickly and efficiently. This circular process is also highly relevant to my thesis topic of autism, epistemology and doubt at large. The opaque notion of autism gets concretised in accumulated visual cues on an autism advocacy poster that are more easily visible and thus knowable to the spectator. The listed signs in McGuire's reading 'point' to the potential of autism 'in' a child and thus the anticipation of desired early intervention (p. 83; Russell, 2016).

In order to situate 'pointers' as an evocation of scientific realism in in/visibility, I add Peircean semiotics of the "sign" to McGuire's insights. Peirce (1955) distinguished iconography, indexicality and symbolism as three ways in which a sign can refer to an object (pp. 99–101). All three relationships raise points of discussion about signs that refer to disability. An icon directly resembles and carries characteristics of the object it refers to (104–105). For example, the International Symbol of Access, or the stick puppet in the wheelchair, is an icon, and has raised academic concern about its implication that the declaration of disability access is equal to adjustments for wheelchairs (Fritsch, 2013). A symbol is only related to the object in terms of cultural conventions (p. 112). McGuire and Michalko (2011) have offered a critical reading of a famous autism symbol, the puzzle piece, and its imperative towards 'solving' the puzzle or 'wanting to know' autism 'better'. The index is of interest to me: it is not

necessarily related to an object through resemblance, but through an assumed causality that suggests that the sign is directly affected by the presence of the object (Peirce, 1955, pp. 107–108). Just like a clock can literally point out the time, a clouded sky could indicate humid weather because of the assumed natural forces that play out in front of subjects. As Peirce states, indicators such as the sky and barometers make people suppose a "probable connection" (p. 109).

What draws me to indexicality as a vocabulary for the problematisation of autism epistemology, everyday scientifically realism and practices of looking is that "[p]sychologically, the action of indices depends upon association by contiguity" (p. 108). It is not the psychological 'origin' that inspires me here, but the implied anticipation of contiguity in signification. Association by contiguity could add further consideration of the normativity in Foucault's examination and McGuire's autism 'warning signs' that encapsulate the everyday politics of looking, time and intervention. In a semiotic analysis of a cultural text, the principle of contiguity could be disrupted by a consideration of the assumed quick association that a sign supposedly evokes immediate reflexive direction to the object (p. 108). The appeal to automatic associative thinking might seem to further the realism of indices as 'natural phenomena', but it is exactly this automatism that I would like to dismantle in disability practices of looking.

In the case of cultural analysis through semiotics, Peirce's examples of social settings based around indexicality inspire me to envision the social expectation and demand of indexicality and static autism knowledge as a structural ableist issue in everyday dis/ability signification. He describes a setting in which two men talk about a fire in a chimney one of them just saw, while the other man asks questions about the exact details and location of the house. With his questions, the man "desires some *index* which shall connect his apprehension with the house meant" (p. 109; original emphasis). When it comes to indexicality in signification, I would like to expand such desire towards the anticipation of more indexical signs that point to a naturalised notion of autism 'in' children as evident in McGuire's reading. Indexicality could bring a vocabulary from semiotics that could capture instances of the everyday oppression of disabled people based on in/visibility and the provision of proof. In the cases of

expressions such as 'you do not look disabled' and 'why are you in a wheelchair', Peircian semiotics could offer a chance to put the social expectation of contiguity into words. As the image of the wheelchair is considered to be indexical, the evocation of disability indexicality occurs when people demand more indices: what is the condition that 'caused' the reliance on a wheelchair, and what are the 'signs' of this condition? The notion of epistemological doubt is also important here: if the anticipated social 'demand' for indexicality is not met in conversations, public administration or demographics, the stigma of disability as 'swindle' might come up. The 'spectator' here is thus the sum of anticipated ableist normativity rather than an actual or a hypothetical part of the public that desperately holds onto autism signifiers, so that the critical analysis revolves around anticipation in signification within the cultural object.

Challenging the in/visibility binary with McGuire's and Peirce's work and wordings, I have shifted attention away from sight and towards the fact that the words 'disability' and 'autism' strongly anticipate the occurrence of visibility as a token of evidence. I have problematised this social anticipation with the help of the term 'indexicality'. Following McGuire (2016), I have troubled in/visibility as a social construct of teaching assumed 'viewers' "that bodies are readable, and thus knowable, by attentive observation to the signs they emit" (p. 93). This visual literacy implies desire in Peirce's sense: the wish for smooth connections between one textual index, that of autism as a discourse, and expected verbal and nonverbal expressions of deviance. My exploration of indexicality thus undermines the realism of the information-thing and broadens my conception of the commodification of autism by further delving into imperatives to look for and know autism. These imperatives, and the role of looking, will be further explored with the help of film theory and an overview of my method of formulating metaphorical concepts based on my case studies.

2.4 Conclusion: what is my approach to autism?
The selection of critical theory in this chapter bridged the gap between my question on epistemology and the topic of not-knowing in my case studies on the one hand, and the analyses of the cultural objects themselves on the other. I would like to summarise the selected vocabulary and theoretical layers behind my wider approach to autism

in my thesis, based on insights from this chapter and potentially also implications for film analysis. My approach to autism is one of sensibility towards cultural production of the term through the social enactment of valorisation within a network of interpellated actors that sustain a network of presupposed roles in which the autism information-thing is actualised. This actualisation consists of naturalised social expectation of contiguity in the wake of the scientifically realist presumption that in/visible autism 'signs' should indicate neurobiological difference, and thus a sort of difference that is negotiable by interpellated subjects within populations 'with' a 'diverse' neurobiological make-up. Within such a population of various designated roles toward the notion of autism, everyone contributes to the process of discursive formation and knowledge-building in order to help overcome epistemological uncertainty. The unconscious collective process of Interpellation is thus important to my notion of the political economy of doubt, which is also a social enactment of valorising abstracted and indecisively definable knowledge on autism and dis/ability. My interpretation of autism moves away from a pre-discursive scientifically realist 'thing' that 'resides' in the 'cerebral' and towards an understanding of the 'social' (Nadesan, 2008) that transcends 'individuality', 'uniqueness' and 'consciousness'. This interpretation has informed my own deliberative academic acts of selecting questions, objects of research, as the concepts of interest that I have presented in this chapter have sparked a peculiar kind of thinking. My research question, area selection and academic consideration presuppose a set of thoughts that broaden the cultural production of the significance of the autism category to the realm of cultural, commercial and political apparatuses within the naturalised government of populations. The discussion on bio-power has directed attention to the control over the self as a negotiator of neurobiological 'difference' in society and to the appeal of aestheticized biovalue in visual culture. Moreover, my discussions on commodification and indexicality have provided tools for the study of my case studies. My appeal to Peircian semiotics in the context of autism 'warning signs' 'awareness' helps to study signification in commercial and independently distributed films while avoiding the kind of subtle diagnostic language in textual analyses that I am undermining. The theorisations presented in this chapter do not form my site of criticality, because my

critical stance emanates from my case study readings and interpretations that highlight epistemologies of doubt that I find emblematic to the asymmetry of ableism.

In my next chapter on representation, I will further explore the political dimensions of the realm of 'visibility' as an asymmetrical power enactment and how it informs my interest in cultural texts. My approach to autism will be applied to the study of film and visual culture and will appeal to insights from the multiform field of Film Studies. It will further explore the normative gaze in my discussion of spectatorship with my own adaptation of insights from feminist film criticism. Furthermore, I will highlight how a textual analysis of my three case studies will be concluded by my theorisation of epistemological metaphorical concepts with the help of Christian Metz's notion of metaphor presented syntagmatically (Metz, 1977, p. 189). Here, I will clarify the relevance of my use of the semiotic term of indexicality as a marker of contiguity, which will aid me to make Metz's vocabulary mine. My take on the topic of metaphor in Film Studies clarifies my specific textual analyses with which I present my reading of epistemologies of autism as a discourse through outlining the source and target domain.

3. Representation

This chapter will outline my research area of representation. Now that my theoretical framework has been presented as my precise approach to autism, I turn to my very own approach to concrete cultural objects that have employed autism as a discourse. Representing autism, these cultural objects are examples of 'texts' that are interwoven, or "textured" as Titchkosky (2007) puts it, embodied and experienced in everyday life. I have decided upon my approach to autism in a way that is completely specific to answering my research question in this particular thesis. My research area is where my larger aim to centralise autism rights by decentralising   autism   and autistic people gains form. It is in representation that I can make the shift from research 'in' autism to research in meaning-making. Within the study of cultural texts that represent autism, abstract notions of performativity, autism commodification and in/visibility become concrete, as they help answer the question of what it means to know and not-know autism in the realm of culture and society. The interest in autism is completely discursive with room for enhanced constructionist insight through theory on subjectification and 'complex' citizenship, economies of information-things and in/visibility. My chapter on representation focuses on my application of my structural social critique within diagnostic categorisation as ableist rather than disablist to the study of visual culture. The 'answer' to the research question is theorisation, which I have already disclosed as the political economy of doubt. It is nevertheless important to unpick the research question 'What is the epistemology of autism as a discourse in the film *Extremely Loud & Incredibly Close* (2011), the animated children's documentary "My Autism and Me" (2011), and the YouTube video *In My Language* (2006)?'. This chapter will further explain the Humanities and Cultural Studies methodology behind this 'what'. The field of Cultural Studies does not necessarily have a predetermined set of methods (White & Schwoch, 2006). Nevertheless, I will outline how I have executed my readings of my three case studies and how my formulations of epistemological metaphorical concepts inaugurate my inductive study of juxtaposed filmic elements, a term that I borrow from Metz (1982). These readings ultimately led to the metaphorical concepts that each touch upon a different aspect of autism and epistemological uncertainty. My particular focus on representation, as outlined in this

separate chapter that precedes the case study chapters, is a key methodological component of the genealogical study of the historically fickle concepts of autism and dis/ability.

When it comes to my theoretical product of what I call the metaphorical concept, I will underpin my appeal to the metaphorical in the formulation of 'autism is…'. With the formulation, I capture a convergence of the autism information-thing (the target domain) with the theme selected by me that captures the overall way in which the information-thing makes 'itself' known (the source domain). The decision on the source domain is strongly motivated by a reading of ableist normativity, a theme that was outlined in the previous chapters. The metaphorical concept captures the 'epistemological' in the research question and the topic of not-knowing that I flagged up in my case studies. My aim to provide knowledge *on* knowledge in my cultural analysis means that I do not answer a question on a dominant paradigm on the medical and cultural history of autism. Instead, the 'epistemological' in each case study is the sum of the way in which getting-to-know-autism is enacted and constructed and how the autism information-thing' makes 'itself' knowable, recognisable and distinguishable. It is epistemology in relation to the research object of autism as a discourse that is captured in a conceptual system that conceives 'one' in terms of 'another' (Lakoff & Johnson, 1980). The target domain is concerned with the 'what' that we 'get to know' and the source domain is a thematic reflection on the 'getting-to-know' based on inductive analysis that prompts a consideration of ableist normativity. This chapter will explain this specific constructionist approach to representation that does not directly appeal to previous literature on the cultural representation of autism but that is unique to this particular research project. The notion of representation as presented in this chapter is thus not meant for direct replication in further study but instead acts as an elaboration on why and how I have implemented my approach to autism and the question of the epistemological in a study of cultural objects.

I will first discuss my motivation to focus on representation as a research area, with a discussion of deviation from previous literature on the topic and an overview of my choice to theorise autism and dis/ability through a reading of cultural objects based on

previous academic efforts. This will map my own history and position as a declarator of criticality, after I previously mainly assigned other sources the role of the declarator and I practise criticality myself as well. I will then defend my case study selection as listed in the research question itself. Although I have outlined a motivation in the introduction based on the common factors of the Hollywood film, children's documentary and YouTube video, their singularity needs to be outlined in more detail. I will give a brief statement on the importance of film production and distribution in the inductive reasoning that brought me to the theme of meaning circulation around doubt and ableist strategic complexity. I will then outline my textual analysis, which in this thesis means how I have executed each of my readings according to the duality in metaphorical language. I will appeal to metaphor in Film Studies with a loose adoption of Metz (1982) and metaphor, referential compatibility and discursive contiguity (189). Finally, I will link the act of formulating epistemological metaphorical concepts to the interpretation of normativity in film with a reflection on my notion of 'recognising' autism in film from my 2018 article on autism epidemic in film and everyday life. Overall, the last three sections cover case study selection, analysis and interpretation and will thus signal my Humanities methodology according to my Cultural Studies approach and informed by Film Studies.

3.1 Motivations for the representation research area

My motivation to select representation as my research area, with a case study selection of cultural objects from visual culture, is to inaugurate the affirmative qualities of the textured life of embodiment. Simply put, I regard representation of autism in and of itself as a good thing for everyday dis/abled life, as long as free artistic and cultural expression is warranted yet carefully cultivated and nurtured. I regard the textured life of embodiment as an affirmative place of free participation with shared ongoing signification in which the producers of cultural objects ideally have the affirmative right to enter this 'life'. Simultaneously, such localised signification is also a major point where the circular exchange of buying and selling the autism information-thing takes place. I would not want to avoid the possible tension between the right to self-expression and the further valorisation of scientific realism surrounding autism as a discourse. Instead, I would like to explore this exact tension as a way to understand ableist normativity better. Aside from my extensive theorisation, I would therefore like

to emphasise my object-based Cultural Studies angle with which I theorise ableist economies of doubt as presented in this thesis.

My aim to bridge in-depth conceptualisations of autism that actively dismantle scientific realism with readings of visual culture in separate case studies has not been attempted before, and as such needs careful consideration. For example, Vakirtzi (2010) has studied the formation of the autistic subject and has employed the same Foucauldian vocabulary as me, like bio-power (p. 98) and genealogy (pp. 18-21). My engagement with power/knowledge and decentralisations of the research object of autism more directly leads to considerations of representation, mediated 'voice' and cultural texts as case studies. Vakirtzi only briefly addresses cultural representation in an introductory statement on the prevalence of autism as a discourse in everyday life (p. 7) but does not accompany this with a full-fledged case study beyond narratives of autism subjectification in autobiographical accounts (pp. 99-106). Likewise, the discussion of the autism advocacy posters in McGuire (2016) does list a compartmentalisation of 'autism signs' (p. 84) but this only serves to establish her main theme of internalised alertness in the cultural construction of autism 'red flags'.

In research on cultural representation, key publications appeal to a mimetic approach to autism, while a constructionist understanding of the cultural construction of diagnostic categorisation is fundamental to my cultural analysis of the autism information-thing. The study of misrepresentations is prevalent: Murray recognises this as the defining paradigm of popular depictions of the clinical disorder (Murray, 2008b, p. 244-247). Osteen (2008) writes: "is it too much to expect simple accuracy? As it stands today, misleading stereotypes have shoved out virtually all other representations of autism from mainstream cinema" (p. 30). As I have outlined in the approach to autism chapter, I prioritise the study of valorisation and production of the autism information-thing beyond any claims on accurate 'ways' of representing autism and a 'right' way to know about 'it' through cultural texts. I strictly decentralise the topic of   autism   and people who identify with the term. Murray (2008a) speaks about "autistic presence" as something to foreground in academic concern on legitimising the "agency" of autistic people (xviii). By contrast, I employ decentralisation to centralise autism rights because academic writing that attempts to

affirm phenomenological existence based on an appeal to 'accurate' autism risks a practice of epistemological dominion over something as vague yet pervasive as 'being'.

In order to clarify my assertion of command in the use of separate case studies from cinema, documentary and YouTube video, I would like to turn to the specific history of my integration of the autism theme in my previous Cultural Studies practice. This process consists of an evolved sensibility for the cultural significance of the autism category that I have developed myself based on the study of popular culture. Ebben (2012) established the study of what I now call autism as a discourse in a reflective piece about the inadvertent moment of recognition when someone who identifies as autistic faces a piece of media that reflects one's personal experience. This moment is detected during the course of a research project on the public image of British electronic musician Gary Numan. The essay separates the domain of commitment to cultural analysis on the one hand, regardless of self-identification as autistic, and personal experience on the other, that should not interfere with the former. In a reflective article, I discussed my sentiment of rootlessness regarding the lack of any well-known theoretical conception of the cultural significance of autism. Ebben (2015) offers a self-invented theoretical 'root' intended to enable new, less pathologising vocabulary around dis/ability. Based on discursive analyses of various visual and literary representations of autistic people negotiating space, I developed theory in which I proposed attention to preoccupation to space as opposed to preoccupation with the self. The etymology of the word 'autism' highlights this withdrawal of the self, 'autos', which I changed into 'atopos' or out-of-placeness with its own possibilities for signification. I will further detail this 'atopos' term in the case study chapter of *In My Language*. I also worked with metaphor, as my creative play with etymology 'countered' the cynical outlook on various spatial metaphors of autism listed by Broderick and Ne'eman (2008) and I suggested enabling and depathologising creative potential instead.

My criticality has always been sparked by cultural analysis of case studies and has always resulted in the suggestion or proposal of a new theoretical underpinning to the cultural significance of autism. In this thesis, my analyses of case studies have also resulted in newly formulated concepts, like the metaphorical concepts and the notion

of political economy of doubt, that serve as my own theoretical framework. My academic positionality in the textured life of embodiment encapsulates this exact duality of a cultural object-based Humanities methodology that observes and the creative act of theorisation and conceptualisation. Even though my terminology for this duality has varied over the years, what has stayed consistent is the claim to enablement in my very act of theory creation and the motivation to extend this creation outside of academia so that others can experience this affirmation as well. All in all, my affirmative motivation of representation is multi-layered enablement: in research, and in the cultural object studied, in creative acts to come.

My thesis predominantly explores the 'critical' in 'critical autism studies' but not explicitly inclusive practice and the collection and presentation of autistic people's voices in it (see Beardon, Martin and Woolsey, 2009). For me, fulfilling the role of the researcher who focuses on autism as a discourse and creates theory is inclusive practice in itself, but this cannot be replicated in other qualitative studies. My aim for a consistent Cultural Studies project means that I avoid absolute claims about the generalisability of my research practice. Nevertheless, this choice limits knowledge on self-expression by people for whom dense theoretical writing is not accessible. I would therefore like to recommend future research that places the multi-layered enablement in my approach to representation in participatory action research projects (McIntyre, 2008). In such a project, a researcher could collaborate with disabled people outside of academia as equal co-workers on an article or filmed account for more diverse academic practice that is directly informed by dis/ability practice. In my next section, I will add more attention to the question why I am focusing on visual culture for now for the sake of Cultural Studies consistency

3.2 Singularity in the selection of case studies from visual culture

This section will outline my motivation to study visual culture in a thesis on autism as a discourse, and to compare three examples of visual media that are very different from one another beyond the recurring topic of not-knowing. Although I have described the textured life of embodiment as both a domain that I study and that I personally participate in, this does not specify why exactly I am focusing on one film, one children's documentary and one YouTube video. Visual culture is distinguishable from

potential case studies for discursive analysis like interviews, focus groups, advocacy posters, or academic writing.

The choice of film adds an interest in narrative and style to the study of depictions of autism and forms case studies that offer isolated cases of practices of looking (Sturken & Cartwright, 2009). The previous chapter described the realm of in/visibility, seeing autism 'signs' and discipline in examination as problematised naturalisation of autism as a discourse in the social expectation and condition to 'look'. It is in case studies that I concretise my problematisation in analyses of depictions. The English term 'representation' brings together two phenomena that are more specifically distinguished from each other in the German language. This chapter is concerned with cultural depiction, which is called Darstellung in German, as opposed to the act of speaking on behalf of someone or something, or Vertretung (Sanders, 2002). Both elements of representation are highly important in this thesis, as Vertretung is the domain of cultural criticism in the chapter with my constructionist definition of the personal account. The study of depictions brings compartmentalisation of scripted spoken text, the development of story (the chronological series of events in film) and plot (the order in which these events are presented in film itself) (Bordwell & Thompson, 2017, pp. 75-76), and the formal qualities of moving imagery or style to dis/ability in/visibility.

While my three case studies each feature one instance of such compartmentalisation, my inductive reasoning in my thesis focuses on a conceptualisation of autism as a discourse that gets 'known'. My comparative analysis thus lies in the discussion of epistemology and the reading of different normative and sly forms of epistemological doubt. Ebben (2015) isolated autistic characters negotiating space as a specified source of interest, incorporated into her research question. This focus on spatiality enabled the etymological shift from preoccupation with the self to space, just like my current question on epistemology enables a reading of my recurring theme of ableist dominion over epistemological doubt that brings rather than nuances normativity. However, epistemology is more conceptual in relation to autism as a discourse. It directs less attention to techniques of film style like mise-en-scene (the sum of details in film frames), cinematography (the way in which the way camera shots are filmed and

framed) and continuity editing (the creation of spatial unity and consistency through the succession of shots) (Bordwell & Thompson, 2017, pp. 113, 159, 230). Epistemology in the research question thus provides less room to justify the studies of the formal qualities of film that form the analytical backbone of case study chapters.

In order to still highlight the singularity of each case study from visual culture in a way that legitimises my conceptual comparative analysis, I will identify production and distribution for each case study. This serves to distinguish my case studies outside of the realm of autism as a discourse, personal accounts and the studies of ableism. In the chapter on *Extremely Loud & Incredibly Close*, I will address King's notion of Indiewood (2009) in order to link the significance of its use of autism as a discourse to the fact that the film is a Hollywood film from independent production company, Scott Rudin Productions. This is especially relevant since the film adaptation is based on a book that does not mention the condition. In the case of "My Autism and Me", I will pay attention to the production of the children's documentary based on accounts from director Victoria Bell. Lastly, I will pay special attention to the fact that the video *In My Language* was produced for and distributed on the social networking site YouTube.

I do not aspire to offer a historiography of autism in the film industry, with a full commitment to the wide distribution of popular culture on the topic. Instead, the special attention to production and distribution in my textual analyses aligns with my research as a contribution to the textured life of embodiment, as defined in the introduction. The films as cultural texts that depict autism and dis/ability are interwoven, or textured into society. As Turner (2006) states, "Film is a social practice for its makers and its audience: in its narratives and meanings we can locate evidence of the ways in which our culture makes sense of itself" (p. 4). While I am not concerned with 'locating evidence' of cultural signification, I would still like to emphasise the singularity of each of my case studies based on the notion that the three pieces of visual culture embody social practices of production and consumption of cultural capital. The next section will inaugurate the method of textual analysis in the formulation of epistemological concepts as my act of contribution to the textured life of embodiment. I justify my readings of my case studies based around the notion of metaphor in Film Studies.

3.3 Textual analyses in the formulation of epistemological metaphorical concepts

In this section, I describe the precise methodological process of the textual analyses of each of my case studies, with the study of metaphor in film, beyond language alone, as my point of departure. My formulation of epistemological concepts forms the chapter titles and backbone of each case study. Nevertheless, as each case study forms a reading of film, animated documentary and YouTube video, further focus on the field of Film Studies is needed in order to fully map how I have performed my textual analyses. The field of Film Studies involves a wide assemblage of different approaches towards film, from Russian formalist dissections on the visual characteristics of editing (Pudovkin, 1960) to disagreements on and differences in the precise use of terminology like mise-en-scene and framing for an adequate understanding of meaning in cinema (Gibbs, 2002; Bordwell and Thompson, 2017). For consistency, I employ the film analysis terminology of Bordwell and Thompson (2017). In order to do justice to the wide scope of film analysis as film, I would like to clarify how the formulation of a metaphorical concept on autism as a discourse resonates in the act of textual analysis. My textual analyses precede my theorisation and form the main content of the case study chapters. Simultaneously, they are still largely informed by my criticality on in/visibility of dis/ability and the cultural constellation of anticipated contiguity in the act of looking at the autism information-thing, as per the preceding chapter on my approach to autism.

In my clarification on what I 'do' in my case study chapters, Metz (1982) could aid my concern with associations by contiguity and formulating metaphorical concepts on autism epistemologies. In his cartography of cinematic signification, Metz distinguishes between the referent, or the semantic domain of a cinematic code or element in film, and the discursive, or the coded structure within such referents (pp. 186-188). The discursive should be regarded as separate from my research object of autism as a discourse. What is of interest to me here is that he distinguishes metaphor and metonymy in different ways in which imagery in film can link together. I will creatively employ his categorisations in order to map my approach to autism as a discourse in the act of inductive study of film.

In all my readings, I will describe my inductive reasoning based on the way in which I perceive a connection between a set of 'filmic elements', like a montage of different shots or the combination of mise-en-scene and scripted spoken text. These filmic elements strike me because they parallel or clash with one another, which makes them relevant to my readings of autism epistemology and ableist normativity. Metz maps four "types of textual concatenation" (p. 189). I would not want to look for or 'prove' them; I would like to adopt one of them as a clear explanation of the way in which I connect imagery that strikes me to meaning on autism epistemology. In a "metaphor presented syntagmatically", there is a kind of juxtaposition that Metz calls "[r]*eferential comparability and discursive contiguity*" (p. 189; original emphasis). On a semantic level, I indeed look for resemblances and contrasts in filmic elements that I highlight as significant for my reading. Beyond the statement of identifiable elements in the cultural object, I also highlight a thematic kind of presumed interlinkage that is the site of my deconstructive criticality: association by contiguity in anticipated autism indexicality. In metaphor presented syntagmatically, referential comparability is combined with discursive contiguity, and I would like to allow myself the freedom to impose my aim to deconstruct in/visibility and contiguity in Peirce onto this category.

What ultimately counts for me is that Metz allows me to connect the study of juxtapositions in my case studies from visual culture with the metaphorical. He clarifies that this category of juxtapositions within referential comparability and discursive contiguity have been extensively covered in film theory on topics such as editing. This recognition of previous classic film theory appeals to my desire to acknowledge the broad definition and history of the field of Film Studies in my justification for theorisation of autism and ableism with an object-based Cultural Studies approach. With my adoption of Metz's vocabulary, I have had the chance to work with metaphor beyond language and concepts, which I already outlined in the discussion on Lakoff and Johnson in the introduction. I could also include my observation of filmic elements in my understanding of metaphor, so that I could conduct a textual analysis of the use of autism as a discourse in visual culture without completely falling back on discourse alone. Based on my aim to undermine the cultural effects of contiguity that permeates the cultural demand for in/visibility in dis/ability, I also undermine the flow of semantic

imagery or 'co-occurrence' in juxtapositions that I point out and dissect in my reading. In such a focus on juxtapositions of filmic elements, I then further reflect on meaning with regards to autism epistemologies as encapsulated within a given case study, after which I pose a term that captures epistemology as a source metaphor. The target metaphor of autism   not only undermines reification, but also discursive contiguity in the context of film and the study of filmic elements that I interlink as significant to my reading.

Each case study thus focuses on different isolated filmic elements that are syntagmatically metaphorical. All three case studies heavily feature discourse: fragments from the film scenario, scripted documentary texts, or spoken language generated by assistive communicative technology. Besides this, each case study has different points of interest. *Extremely Loud & Incredibly Close* heavily features mise-en-scene: props, colour motifs, acting performances and the New York City setting. The importance of mise-en-scene draws interest to iconography in intersection with autism indexicality, as the film is set in New York City in the wake of the cultural trauma of 9/11. "My Autism and Me" discusses the use of animation in the context of children's documentary and compares differences in cinematography and animation style per personal account, since the documentary combines several accounts into one frame story of presenter Rosie's successes. Finally, *In My Language* pays specific attention to editing and its persuasive power. What I then 'do' with these striking details is processing them into the structure of an argument on ableist normativity and the topic of epistemological doubt. The metaphorical concepts introduce these arguments and form a thematic whole with regard to the epistemology of autism as a discourse and my overall presentation of the political economy of doubt in this thesis.

The topic of normativity is a challenging one, since a research question should not already include any reference to negative ontology. An overly ideologically instructive research question could already contain the very thing one hopes to find out in textual analyses. For example, if a research question is framed as 'what are the stereotypes of autism in film?', the researcher already partly knows in advance what they will ultimately find, namely, negative archetypes of autistic people and life with autism. Nevertheless, the cultural construction of in/visibility and the hyperaware gaze that is

trained to 'see' autism 'warning signs' as discussed in the approach to autism chapter already implies a normative a priori in my case study readings. A central topic of concern that has been important to the study of power imbalance in Film Studies is spectatorship. I will not deliver an extensive outline of the theme of spectatorship in Cultural Studies: I specify my discussion of the topic of the cultural desire to recognise in the next section.

3.4 Recognising autism and deviance in ableist visual culture spectatorship

This section continues my adoption of McGuire (2016) that I started in the chapter on my approach to autism, in order to reflect on the construction of indexicality in the social expectation of dis/ability in/visibility. In literature on the cultural representation of disability, I miss a critical consideration of the very in/visibility binary that 'makes' dis/ability 'knowable' within the politically laden act of looking. For example, Davis (2017) claims to look into "paradoxes of visibility and invisibility in cinema" (p. 39). In practice, his main critical concern goes out to the way in which disability is interwoven into film and television narratives as well as the casting of non-disabled people into disabled roles. As in/visibility is a major critical concern for me and the key to the discussion of normativity, I more explicitly link my dissection of in/visibility to the study of visual culture. I further explore the cultural anticipation of contiguity and the desire for autism indexicality in the cultural production and consumption of the autism information-thing that was my site of deconstruction before in my section on the commodification of autism.

In such an exploration of in/visibility and normativity, it is important to foreground spectatorship in a discussion of my notion of representation. In my textual analyses, I do not cover a study of audience responses to my case studies beyond remarks on the validity of claims to disability status from the video producer in the case of *In My Language.* Nevertheless, I am still invested in anticipated 'warning signs' to 'look' at within the range of my case studies. Regardless of its relevance for contemporary studies of film and the current ideological position of Film Studies (see Sturken and Cartwright, 2009), feminist film criticism has offered tools in the study of the gaze that centralises a dominant power position. The field of Film Studies has traditionally been heavily influenced by psychoanalysis. Mulvey (1999) and Metz (1982) both refer to the

Lacanian notion of the mirror stage in which the child first learns to distinguish themselves from their environment when looking in a mirror (Lacan, 1968). Cinema can also be a reflective mirror to distinguish the 'ego' in, since it appeals to the voyeuristic pleasure of looking and the narcissistic fixation on the self. Mulvey (1999) locates this pleasure of looking into her adoption of Freudian scopophilia that she argues to be pivotal to the male gaze in phallocentric narrative Hollywood cinema. I am focused on abled-centric normativity instead of phallocentric cinema, but nevertheless, the paradoxical pleasure of confrontation with the 'reveal' of diagnostic categorisation has been covered in this thesis as well. In the example of support that was instantly delivered upon reference to the autism information-thing from Runswick-Cole and Mallett (2016), it is striking that the affirmative response was 'enthusiastic'. Together with the anticipation of autism indexicality, it is fruitful to study the abled-centric gaze based on the pleasure of 'seeing' 'red flags' of deviance in my case studies.

Ebben (2018) has called this particular form of 'scopophilia' "the desire to recognize the undesirable" (p. 160). Under the promise of control over the medical and discursive 'spread' of pathology in society, visual culture could meet the cultural desire to examine and measure 'cases' in cultural objects that use autism as a discourse. The room for in/visibility within the spectacle of cinema can provide cues of deviance to look at in a display of attempted control over the 'spread' of autism. As 'warning signs' are worthy of early intervention and are thus not supposed to further spread, the focus of the scopophilia in the (anticipated) act of recognition is the undesirable (p. 159). What is the focus of the pleasure of looking is also the focus of possible elimination in the context of abled-centric normativity: the act of looking showcases ability to 'conquer' deviance. The enactment of 'recognising' disability through the ritualised act of looking is thus an intersection of my previous reflections on associations of contiguity in autism 'signs', the hyperaware trained gaze in McGuire (2016) and the notion of scopophilia. The latter could help to dismantle the normative gaze as a source of power in and outside the realm of visual culture. Just like the male gaze poses dominion over objectified women depicted within narrative Hollywood cinema despite the gender of the audience, an abled-centric gaze exemplifies the

power in constant visibility in the examination of dis/ability. Invisible disability or not, dis/ability here constitutes the 'always-already-visible' that is key to my reflection on McGuire's 'warning signs'.

The scopophilia in the ableist cultural desire to recognise is evident in my textual analyses that can be found in each case study chapter. The 9/11 iconography that I discuss in my *Extremely Loud & Incredibly Close* case study chapter adds more 'warning signs' to the speculation that protagonist Oskar might be autistic. The trauma of 9/11 that comes after the recount of autism 'tests' suggests that the intervening labour of his father, a victim of the terrorist attacks, might have been interrupted without a successor. In "My Autism and Me", the spectator is guided through several personal accounts of autistic children, throughout which creative and expressive animated sequences convey a sense of imagination. This evocation of creative imagination is missing in the case of 'severely autistic' Lenny, who is filmed from a different angle than the other kids who stay in the frame on eye-line level. De Lauretis (1984) states about film that it "re-members (fragments and makes whole again) the object of vision for the spectator; the spectator is continually moved along in the film's progress [...] and constantly held in place, in the place of the subject of vision" (p. 67). The YouTube video *In My Language* directly comments on the abled gaze that demands semiosis, as its subject offers a translation of her non-verbal non-normative communicative movement that she instructs to avoid regarding as symbolic.

In the case of *Extremely Loud & Incredibly Close* and "My Autism and Me", it is the reading of narrative structure that provides the most direct critique of ableist normativity. I will set out ableist normativity in this film in the next chapter, which is the first case study chapter in this thesis. I myself name the narrative and emotional resolution of the film as encapsulated in a moment of implied motherly mimicry of the child protagonist's actions. I call this resolution through mimicry the 'Son-Rise' narrative after an autism intervention, not as a direct emulation of the therapy, but as a narrative structure that presents normative 'good' parenthood in the context of protagonist Oskar's life story. The narrative structure of critical concern to me has already been named in "My Autism and Me". Child presenter Rosie is said to have a 'success story' in which her imagination, evident in the documentary style, has

conveyed itself into quantities of labour value. I deconstruct this promise of labour value both despite and because of autism with the notion of neoliberalism as an ableist ecosystem (Goodley, 2014). For De Lauretis (1984), narrative equals scopophilia in the study of desire and power in the study of film: "the operations of narrativity construct a full and unified visual space in which events take place as a drama of vision and a memory spectacle" (p. 6). I expound the Son-Rise intervention programme and the notion of neoliberalism as a way to exemplify the construction of such a 'full' visual space that is unified by the evocation of ableism. Spectatorship here is the a priori 'looker' that is assumed in the making of film narrative and style. In this thesis, I will exclusively refer to spectatorship in the benefit of the study of the construction of anticipated indexicality.

Concluding remarks

This chapter has justified my focus on representation and on visual culture in particular. It has showcased an approach to representation that I have formulated by myself in order to provide an answer to the research question of what the epistemology of autism as a discourse is in my three case studies. Since existing literature has not provided me with a conclusive approach to representation before, I have outlined my past attempts to theorise autism as a discourse through cultural analysis, which demonstrated my strictly constructionist approach to autism in visual culture. Furthermore, I included an overview of the way in which I bridge the production of a metaphorical concept per case study with a textual analysis and concern for normative spectatorship. In my textual analysis of my case studies, my own adoption of Metz has helped me to bridge my observations of filmic elements with my understanding of metaphor as concepts in my research on autism as a discourse. Without my textual analyses, autism as a discourse and metaphorical concepts would have solely been concerned with words, but I have broadened my scope to imagery. Ultimately, my textual analysis has been useful for theorising epistemological doubt and able-centric normativity on the basis of my case studies from visual culture, so that theoretical concepts such as indexicality and in/visibility can be concretely applied to cultural objects. Just like my approach to autism, representation is a conceptualisation from me, in the sense that it has been a domain

of theorisation based on insights on normative notions of looking. This chapter has provided room to expound how I defend my case study selection and analysis, as well as the theoretical reliance on textual analysis itself as a form of cultural analysis. My overall thesis structure is informed by my constructionist thought on autism as a discourse and (self-)identification, as well as my aim to learn more about the historically fickle boundaries of dis/ability, the diagnostic category and knowing and not-knowing autism. This chapter on representation will be followed by the first case study chapter, *Extremely Loud*. After this chapter, the final two case studies will be preceded by a theoretical chapter on my understanding of personal accounts as a relational process of acknowledging texts as autistic voices, in order to provide a comprehensive theoretical framework. The research project presentation is thus an ambitious task to prioritise ableism theorisation and present its results while also exemplifying film analysis. My future studies will experiment more thoroughly with the adequate structure for the studies of textured life of embodiment with inspiration from McGuire (2016) and Titchkosky (2007) and their discursive analyses. I will use this inspiration to rethink the form, function and meaning of the case study in my academic writing on ableism and the textured life of embodiment.

4. Extremely Loud & Incredibly Close (2011): Autism is speculated

"I think a lot of things are odd. People tell me I'm very odd all the time. I got tested once to see if I had Asperger's disease. Dad said it's for people who are smarter than everybody else but can't run straight. Tests weren't definitive."

- *Oskar Schell (Thomas Horn) in* Extremely Loud & Incredibly Close *(2011)*

This chapter presents my 'autism-is-speculated' metaphorical concept based on a reading of autism as a discourse, epistemology and ableist economies of doubt in the 2011 film *Extremely Loud & Incredibly Close*. *Extremely Loud* portrays the coping process of Oskar Schell after the death of his father during the attacks on the World Trade Centre. The film is an adaptation of the eponymous 2005 novel by Jonathan Safran Foer, in which autism is never mentioned. Directed by Stephen Daldry, the film constitutes a specific epistemology of autism based on a strategy of recognition in spectatorship that consists of speculation on the 'presence' of autism. The source domain of 'speculated' here refers to my interpretation of autism in a cultural object in the case of a character who is not-yet-diagnosed or not-quite-diagnosed. Such a character is of great interest for cultural analysis: it allows me to study the anticipation of contiguity in relation to the cultural significance of autism and epistemology. The word 'speculated' is a result of such research: the audience does not know for sure whether the protagonist has autism, but is provided with ample opportunity to speculate about his precise condition. Within my case study, the word 'speculated' is a concrete example of the hyperaware gaze that I discussed in the section on indexicality, in/visibility and contiguity in the chapter on my approach to autism. The gaze is not a sociological practice of looking here or an estimation of audience responses, but an occurrence of a high degree of saturation of signs of deviance in the case study, similar to the 'warning signs' and 'autism red flags'.

Central to this case study chapter is the portrayal of a protagonist, a boy named Oskar Shell, who is not formally diagnosed with autism but who does mention the condition, as shown in the quotation at the beginning. In several scenes throughout the film, including ones without speculation about Oskar's condition in the screenplay, Oskar's emotionally laden negotiations of public spaces and moments of social contact are

evident and prominent enough to identify his condition as at least ambiguous. This chapter lays out such moments of ambiguous characterisation, in scenes with and without explicitly speculative spoken text, in which the protagonist looks emotionally distressed and distinctively out of place in the social spaces around him. The film is set in New York City and follows Oskar's life after a traumatic event: the death of his father during the attacks on the World Trade Centre on 9/11. I pay close attention to the scene in which autism is discussed, additional scenes that evoke Oskar's trauma through 9/11 iconography, and the plot development and eventual resolution. Red flags are there to look out for: the saturation of signs in *Extremely Loud* as discussed in this chapter is emblematic of a desire to recognise, taxonomise and intervene in populations that lies at the basis of Foucauldian bio-power. I have elaborated upon bio-power in the chapter on my approach to autism. The importance of ambiguity about autism and Oskar's condition has motivated me to foreground 'speculation' in the metaphorical concept 'autism-is-speculated'. The audience might not know for certain if Oskar has autism, but it is precisely his ambiguous condition that drives the plot and visual cues in the film and that is of interest to me.

The story of *Extremely Loud* makes clear that Oskar has always had trouble connecting with people, and his father Thomas had already subtly helped him with this by taking Oskar on quests and adventures through New York City. Now that his father has passed away, Oskar finds a key with the surname 'Black' on it and decides to search for its owner. Throughout his series of visits to every person in New York City named 'Black', he actually gains more life experiences, makes more contact with his remaining family members, and comes to terms with what happened to him on 9/11. The search is a MacGuffin (Epstein, Wiesner and Duda, 2013), or an interchangeable object that sets the plot into motion but does not mean much in itself. As seen from the quote at the beginning of this section, Oskar only refers to the category of 'Asperger's Syndrome' in one scene, in which he recounts a past event of a 'test' that did not confirm or rule out the fact that he 'has' a 'form' of autism. My 'autism-is-speculated' metaphorical concept touches upon the circular self-confirmation of autism and epistemological doubt. The film creates a sense of doubt around the condition of the child protagonist and narrator exactly because it employs autism as a discourse: it is the autism

information-thing that is being used as a discourse. Simultaneously, the use of autism as a discourse is a speech act that changes the meaning of the film exactly because the lack of definitive diagnosis and self-identification encourages 'nuance', and thus epistemological doubt, around diagnostic categorisation.

In my reading of *Extremely Loud* as a case study, I would like to suggest that the notion of suggestion is the very thing that fleshes out the meaning of the film as a creative work that positions itself within the discursive practice of the category of autism. This means that I am careful and cautious with a reading of autism as a discourse in *Extremely Loud & Incredibly Close* as an addition of nuance that does not claim to offer an absolute truth on the condition of autism. Instead, Oskar's ambiguous condition is a rich palimpsest of intersecting themes and topics: 9/11, trauma and autism 'red flags'. Autism commodification in cinema produces an epistemology of speculation, not as a constant (re)affirmation of ambiguity and doubt, but rather as a reifying commodification of autism as examination with readiness for action and intervention. My notion of the cultural desire to recognise the undesirable will function as a tool in my textual analysis of *Extremely Loud & Incredibly Close*. This will be further explored in my close readings of specific scenes.

This case study starts with Oskar's appeal to autism as a discourse, which I then embed into a reading of his portrayal in the scene in question, which I then embed into a wider exploration of trauma and plot in *Extremely Loud*. I ask myself: when is autism as a discourse used, what happens in scenes in which autism is not mentioned, and how does the scene relate to different scenes with 'warning signs' of deviance, and the plot? Sequentially, autism gains shape beyond mentioning diagnostic testing in one scene, as my analysis visually and thematically interweaves with additional topics of importance regarding the film, like cultural memory and anything of pressing interest to my argument of epistemological doubt. As such, each section will delve into one thematic segment of my autism-is-speculated' metaphorical concept. Each epistemological metaphorical concept in this thesis explores a dynamic play between the acts of knowing and not-knowing. I will first discuss the adaptation of Foer's 2005 film into an independent Hollywood film that has been released as eligible for the Academy Awards. I will then isolate the use of autism as a discourse and do a reading

of the scene in which Oskar states that 'results were not definitive'. I will then outline how autism indexicality and the iconography of the collective trauma of 9/11 do not nuance one another but strengthen McGuire's notion of the hyperaware gaze. I will theorise hyperaware spectatorship strengthened by doubt rather than conviction on 'accurate' detection with a quote from Versluys (2009) with his comment on protagonist Oskar's condition in the 2005 novel. Finally, I will discuss the implications of Oskar's status as bereaved and 'not-yet-diagnosed' on a normative plot structure that involves resolution regarding parental intervention. I will compare the resolution of Oskar's MacGuffin quest to a Son-Rise intervention narrative that involves parental closeness through mimicry.

4.1 Producing *Extremely Loud & Incredibly Close* (2011) as a presentable 9/11 story: the role of Indiewood in the adaptation of the protagonist as possibly autistic

What sparks my interest in *Extremely Loud & Incredibly Close* as a case study on autism as a discourse is that the film mentions autism discourse, unlike the eponymous 2005 book by American writer Jonathan Safran Foer that the film is based on. Academic studies in comparative literature define adaptation as a process and product of interpretation. Hutcheon (2006) rejects the focus on the source work and on an academic demand for fidelity to this source work in previous research. This is very similar to my aim to create an alternative to the expectation of 'accuracy' in cultural representations of autism. In the previous chapters, I argued that a constructionist understanding of representation could undermine the culturally and historically specific positivist gaze. Hutcheon defines adaptation as an acknowledgement of transposition in its status as a cultural artefact, as a process of (re)creation and appropriation, and as an intertextual phenomenon that brings up memories of other cultural objects. Placing the addition of autism as a discourse in this definition, I would like to state that Oskar's comment on indecisive tests is located in a cultural object that is in any case intrinsically linked to Foer's novel and its interpretation of 9/11 as a collective wound.

The inclusion is significant as a choice in the appropriation process that tries to be 'faithful' to both the book and the characterisation of the protagonist Oskar Schell in a way that appeals to a wider audience. Apparently, this fidelity to Oskar includes an

emphasis on Asperger's Syndrome, even though the spectator is free to dismiss this reading based on his literal words in the film. By including an autism identifier that was absent in the novel, the film adaptation of *Extremely Loud & Incredibly Close* interprets its source material in a peculiar way: book protagonist Oskar's behaviour might be linked to Asperger's Syndrome. Simultaneously, the adaptation invites further interpretation of the main character through strategically placed cues of deviance that are left 'ambiguous' at the same time. The topic of film production is intrinsically linked to this commercialised production of different interpretations of Oskar's characterisation. As the film was produced by the independent company Scott Rudin Productions and the Hollywood-based Warner Bros. and was widely released in January 2012 (IMDb, 2019), *Extremely Loud & Incredibly Close* is an example of Indiewood cinema (King, 2009). This name for this particular intersection between Hollywood and 'niche' independent cinema has been employed since the mid-1990s to denote a segment of the film industry characterised by hybridity in production and consumption (pp. 2-3).

In the approach to autism chapter, I have touched upon the valorisation of the autism category within a system of commodification in which producer/consumers of the term exchange meaning and thus give form to the autism information-thing. The domain of Indiewood can be isolated as such a domain of commodification, as the film adaptation's choice to include autism as a discourse can be regarded within the context of this indie Hollywood sector. Producer Scott Rudin is the person who owns the homonymous independent company; he negotiates the intended prestige of a film based on a challenging novel that explores tough and sentimental themes such as the aftermath and grief of 9/11. King (2009) states that a major source of guaranteed cultural and financial prestige for Indiewood films lies "in the achievement of Academy Awards and nominations" (p. 7). Prizes thus form a tool for "exchanges between cultural and economic capital" (English, cited in King, p. 8). I would like to localise the commodification of autism within this production and consumption of cultural capital. To ensure revenue for a Hollywood film about a controversial topic, the film should not be too explicit without losing its emotional pathos and grativas. Several famous actors were cast for Oskar's family: Tom Hanks, Sandra Bullock and Max Von Sydow all deliver

emotional performances in a fictitious 9/11 account of one boy who lost his father during the attacks. The film was also released right within the annual film award season and was nominated for the Academy Award for Best Picture. Just like casting and film awards convey prestige and thus cultural capital   , the tragic story of one account of a cultural trauma is further solidified by the inclusion of the autism information-thing as pathos (Duffy & Dormer, 2011). The story of a boy who may have needed counselling even before he lost his father brings further tragedy to a depiction of 9/11. The autism information-thing serves as a layer of exchange that makes the recent tragedy of terrorist attacks more palatable for a wide American audience: it diverts direct attention away from politics surrounding terror.

This chapter will predominantly touch upon discourse and semiosis within the film itself. Nevertheless, the Indiewood production context of *Extremely Loud & Incredibly Close* does reveal more about the potential function of autism as a discourse as a part of cultural capital to be consumed by a broad audience. What is relevant here is that interviews as promotional material disclose the hope that the target audience will be interested and will invest time in this specific reading. Interviews on the film at the time of the world- premiere and limited release in the US (Gilchrist, 2011) invite the spectator to regard the inclusion of autism as a discourse as significant. Director Daldry outlines his attempts to make the depiction of autism 'accurate' and discusses the labour of consulting 'experts' in the pre-production stage. Daldry thus poses the question of 'knowing' autism 'correctly', while I am interested in the epistemological dynamics of ambiguity regarding the lack of a 'definitive' autism diagnosis in Oskar and how this is juxtaposed with narrative and style.

4.2 "Asperger's disease": pathologised language and the suggestion of autism in Oskar's recounting of test results

Extremely Loud & Incredibly Close starts with a brief scene at Thomas Schell's funeral and Oskar's complaints about the empty coffin, and a subsequent flashback to the close paternal bond that is characterised by quests through New York City. After the discovery of the Black key, a story arc is quickly put into motion in which we see Oskar planning his travels through New York City and his frightening walk to the first Black households that he visits. This is when the notion of autism is verbally referenced for

the first and only time during the entire film. Some of the preceding scenes are pivotal to a closer reading of this particular scene.   I will discuss them in more detail and place them into a broader perspective in the next section on autism indexicality and 9/11 iconography. For now, the next two sections will cover Oskar's use of autism as a discourse and the scene of Oskar's visit to Abby Black (Viola Davis) in which this textual fragment is located.

I will start off with a close reading of the line. The line is a recount of an unseen past event that took place in unspecified circumstances. It is not clear what Oskar means with 'all the time' in his remark that the notion of oddness, first brought up by Abby, is often applied to him as well. In addition, it is also left unknown when Oskar was 'tested', even though it is specified as a pre-9/11 past event as Oskar references a phrase from his father. This is significant in a film that is so much centred around the Twin Tower attack and its emotional aftermath on broken families: apparently, there has been a necessity to get Oskar tested before the effects of trauma. Finally, it is unclear where the Asperger's Syndrome test took place, what it involved, and who were the ones who got to 'see' 'if' he would 'have' 'it'. It could have been the unseen 'autism experts' who are implied in the phrasing 'test' (presumably a qualified counsellor or team), but it could also have been Oskar's parents, or anyone else with an interest in this information.

The presence of the term 'Asperger's' is striking because the plot never attempts to 'explain' the term outside Oskar's account of his father's specific interpretation. This shows a confidence that the target audience will have a basic understanding of autism spectrum disorders. It appeals to the clinical language that was in force at the time: 'Asperger's Disorder' was included in the DSM-IV(-TR) (American Psychiatric Association, 2000) that became obsolete in 2013 after the introduction of the DSM-5 and the umbrella category of Autism Spectrum Disorder (American Psychiatric Association, 2013).

Despite the significant recognisability of Asperger's Syndrome, Oskar does not use a clinically employed term like 'syndrome', 'disorder', or the more neutral 'condition', but instead talks about "Asperger's disease". 'Disease' has a more overtly pathological connotation and evokes physical suffering, immunology, and aetiology. Paired with

'Asperger's', the notion of 'Asperger's disease' sounds like sloppy phrasing, but does present Oskar as neither completely informed nor uninformed about autism as a discourse. The setting in which he uses the word and the recounting of his father's words point at a degree of naive oblivion towards the topic. Within this context, it is relevant to look at his father's explanation: "Dad said it's for people who are smarter than everybody else but can't run straight". It can be assumed that this was meant as a reassurance for Oskar that explained the abstract and emotionally charged notion of deviance in an accessible way. The 'smartness' affirms the idea of 'mild' autism as something that comes with higher intelligence. The 'impairment' that comes with 'being smarter than everybody else' is not being able to 'run straight', which is a spatial metaphor that could refer to one's life path or, more specifically, to the obstacles Oskar faces in his quests through New York before and after 9/11.

The combination of a recognised clinical category and the seemingly cruder word choice of 'disease' offers an interesting discursive take on pathology. This can be discussed in more detail with a brief consideration of pathologised language in the novel. Foer's novel covers Oskar's search for the Black key in roughly the same way as the film. Even though the meeting with Abby Black can be found in the novel as well, the notion of autism and the recounting of tests in the past is completely lacking. The story element in the book that comes closest to this recounting in the film is Oskar's meeting with a therapist who helps him and his mother with the 9/11 trauma. He makes remarks about the necessity of this help that are interesting within the context of pathologisation. He says that he attends his meeting because of access to a "raise in [his] allowance", and that he does not understand why he would need help. Addressing his feelings caused by trauma as "heavy boots", he states "it seemed to me that you *should* wear heavy boots when your dad dies, and if you *aren't* wearing heavy boots, *then* you need help" (p. 200; original emphasis). This statement reads as a critical consideration of the institutionalised act of 'helping' a person with emotional issues, in which Oskar depathologises his own issues according to a bureaucratically informed support set-up.

Just like Oskar contests the clinical realm in Foer's novel, I would like to state that the addition of a clinical term like 'Asperger's' 'disease' in the film is a specific reading of

Extremely Loud's diegesis as the story of a boy who struggles with everyday life and thus has been granted access to clinical tests. In the 2011 film, Oskar not only suggests autism with his use of pathologised language and recount of a diagnostic test. What ultimately matters in this reading is the fact that 'results were not definitive', which does not offer an absolute answer on Oskar's actual condition. This is the most concrete moment of speculation in the film, as the notion of doubt is literally pointed out by Oskar in his recount of his autism test. It is also worth stressing that Oskar is not and could never be a fleshed-out person with actual 'test results', and that both the use of a clinical term and the indefinite test results are discursive. The indefinite status is strategic, because the conscious choice of uncertainty about the 'actual' 'presence' of autism can never be 'right' or 'wrong' from a scientific, activist, or moral perspective. No matter how the film has 'invested' in its representation of autism, it can always be defended with the argument that it is not made absolutely clear that Oskar actually 'has' 'it'.

I explicitly refuse to suggest that Oskar's recounting of indefinite autism texts is a less absolute cultural representation of autism. The condition does not get explained as one homogeneous thing and is therefore more 'nuanced'. Nevertheless, doubt and nuance about diagnosis is not more or less 'accurate', as I undermine a mimetic reading of autism representation throughout this thesis and instead focus on the formation of epistemology encased in the case study itself. A profound in-depth representation does not necessarily resist an unambiguous reading, because speculation could be a commodified information-thing in and of itself. When it comes to the film itself, and the scene in which the line appears, there is the layer of identification with Oskar and Abby Black that adds more significance. I will discuss this in further detail in the next session.

4.3 Protagonist characterisation as 'odd' in the scene that features autism as a discourse

In this section, I will expound the fact that the very scene in which autism as a discourse is being employed is also one in which Oskar is characterised as someone who handles an emotionally laden situation 'oddly'. The spectator is introduced to Oskar in scenes that grant a coherent and comprehensive characterisation of his

personality; the first meeting with Abby Black has a specific role in this sense of coherence. In order to concretely work with the notion of spectatorship as an anticipated act of 'recognising' autism as presented in the representation chapter, I would like to employ the vocabulary of Smith (1994). Listing different ways in which an audience feels sympathy for a character as a cinematic construct, he offers a precise interpretation of the notion of identification through a distinction between 'imagining' (central) and 'imagining that' (acentral). The first form of imagination involves an imagined placement of the self 'in' someone else's 'shoes'. With 'imagining that', Smith means that we do not locate ourselves inside the imagined situation but sympathise with an imagined different person within a given setting (p. 36). It is this acentral "structure of sympathisation" that Smith is mapping (p. 39). His characterisation triad offers a language that is useful for my reading: he distinguishes recognition, alignment, and allegiance in his discussion of meaning-making within the relationship between the film and the spectator. Recognition is about the coherent and cohesive accumulation of information on a character that a spectator gets throughout the plot. This also includes the growth that a character goes through, but nevertheless, there is often an appeal to information on human agents that the spectator has from 'real' experiences. Although a character is a textual construct, Smith still invokes an idea of a "mimetic hypothesis" that aids to comprehend a character as a complete whole (p. 40). The notion of alignment means that the audience is 'located' in close proximity to the character, with easy access to their perception, expressions, and feelings. Perceptual alignment stands for the notion of point of view. The last category in the triad is allegiance, which is moral (dis)approval of a character (p. 41). If recognition, alignment, and allegiance all suggest proximity, a depicted character is usually good-natured and round and thus easy to identify and sympathise with.

During the first meeting with Abby Black, there is a striking use of alignment and allegiance that transcends Oskar's point of view and extends its scope towards Abby's emotional state, which leads to less allegiance with Oskar. Immediately after unlocking the door, Abby is tense, and her remark that she is "in the middle of something" suggests that the voice behind her has something to do with this. Oskar asks for clarity

about this matter, and then insists on being   let in, using the mailbox as the only opening into the house to talk through (picture 1). Apart from some brief conversations with the doorman of his apartment building, this is the first time that Oskar's behaviour and choices clash with someone else's and the first major instance of friction after the clash. Overall, the viewer is spatially aligned with him and gains more personal insights due to the voice-over. Nevertheless, the viewer may not be able to experience allegiance with Oskar, as it is made clear that he arrives at an inconvenient moment. Within such a situation, many people would affirm the tension that can be seen on Abby's face and would give her room to deal with her personal situation in her own house. If this scene were to have consisted of a full spatial and perceptual alignment with Oskar, the viewer would only have seen Oskar's face without Abby's reaction, so that they cannot form a smooth narrative that conveys Abby's discomfort. I would like to state that the viewer 'knows' more than Oskar, and that the film thus suggests an impaired expression of empathy in him.

Oskar enters the house nevertheless. In shots of the interior, the narrow corridor is striking as it suggests less freedom of movement for both characters (picture 2). When Abby's husband is drawing her attention, she walks straight ahead from her kitchen to the stairs, being followed by Oskar in very similar movements. Oskar's large blue eyes are steadily fixed onto Abby as he reflects on a picture of an elephant who appears to cry. The subject matter is interesting within this context, as it focuses on communication and the possibility of emotional expression; Oskar suggests that elephants are unable to cry. At this point, the editing and cinematography exploit the emotional reactions of Abby Black, whilst the men present are doing the action: her husband is leaving and frantically shouting at her, while Oskar initiates a talk on his interests and about the destination of the Black key. After looking at the picture of the elephant, Abby sits down on the staircase, which is a place that is not designed for sitting but is meant as a path to get from one to the other floor. She stares at the staircase and ground below her, which is a position of inactiveness that suggests emotional release. Abby unambiguously cries, unlike the elephant in the picture that could have been manipulated through Photoshop. Abby's husband is now the third person who uses the linear paths of the house: he hastily walks down while calling

someone on the phone, ignoring Abby. He is intentionally obscured; his identity must remain hidden for the resolution of the Black key plot point, as he ultimately turns out to be the 'Black' whom Oskar is looking for. After Oskar's request for clarification, Abby confirms that the man is her husband, taking away ambiguity on the identity of the third person and suggesting marital problems. Right after this, she states that "You must think this is very odd", which prompts him to tell about the 'Asperger's disease' tests (picture 3).

The suggestion of oddness in the script enhances the context of the simultaneous spatial and perceptual alignment with Oskar and the social-emotional problematisation of allegiance with the very same character. While Oskar's behaviour towards Abby and obliviousness to the emotional distress and implied marital problems could be perceived as a dissonance of allegiance with regard to social behaviour that is considered to be 'appropriate', Abby suggests that her own situation generates alienation and that Oskar is the person who must find this 'odd'. Subsequently, Oskar adopts the word 'odd' in relation to 'a lot of things' and then to himself. The references to 'Asperger's disease' are pronounced with the same pitch and intonation as the words spoken right before, while the camera goes to a reverse shot of Abby who slightly tilts her head and reveals more tears. Right before Abby's husband walks down the stairs, she is shown to be participating in a conversation with Oskar, after which a word relating to autism is used at the very moment when Abby turns her head downwards and displays her emotions. Because she is sitting on a staircase, the location of both characters in the domestic space is also peculiar: Oskar, wanting to talk to Abby, is standing in very close proximity to Abby but is still separated from her by banisters. As she is sitting on a heightened platform, Oskar's eye level is slightly higher than Abby's. Moreover, because they do not directly face each other, a traditional shot-reverse shot editing pattern is not possible in this setting.

Abby and Oskar make eye contact again when the latter addresses his quest when recounting his father in relation to 'Asperger's Disease' and asks about potential affiliations with Thomas Schell. Abby's passive position and sadness are subverted at the very moment Oskar mentions 9/11; Abby turns her head and looks at Oskar with a shocked expression. References to this personal and cultural trauma trigger such a

response, but the reaction does not occur when it comes to the concept of autism. Oskar now changes his position and moves towards the front of the staircase while mentioning his purpose: finding the destination of the key. Mentioning 9/11 triggers action and sets the plot development back into motion. A miscommunication between the characters, alienated and separated from each other throughout this scene, results in a delay of the ultimate resolution of the question to whom the key belonged, namely, to Abby's former father-in-law.

The scene that features autism as a discourse thus presents a sense of alienation, with apparent aloofness in Oskar and an emotional release from Abby. Not only does it present seemingly minor details that will turn out to be pivotal at the end of the film, it also positions the viewer in such a way that it informs about friction between two people. Even though this friction never culminates in a clash, the spectator may feel a closer allegiance with Abby here than with Oskar throughout the entire scene. Abby has a reason to be upset, and with her unconcealed tears, she compensates Oskar's less open expression of emotion. The distinctive use of continuity editing, with shot-reverse shots that do not always align their eyes and facial expressions, gives the expression that Oskar insistently initiates a conversation and questions at a 'wrong' moment. The editing and cinematography clearly show the close proximity between Abby and Oskar, which results in close spatial and perceptual alignment with both of them, as well as an impression of a coherent dialogue as a form of social contact that the wider audience will recognise.

What I would like to stress here with regard to the friction and the decreased allegiance with Oskar is the fact that the cinematography and editing frame Oskar as deviant at the moment that he employs autism as a discourse in a way that suggests that he was 'tested' for it without a clear subsequent diagnosis. The suggestion of deviance in characterisation, isolated within one scene, is immediately followed by a recounting of a clinical context in which 'deviance' was suggested too. The 'autism warning signs' might not be that clearly delineated as in autism advocacy posters like in McGuire's analysis, but the scene still isolates and facilitates awareness of deviance in a way that resonates in the entire film. I will further analyse and theorise such 'hyperawareness' as an indexical bind (autism and/or deviance always comes with

indices that can be observed and pointed out) through doubt on autism diagnosis in the next sections.

4.4 Visual motifs and the indexicality of deviance in *Extremely Loud & Incredibly Close*

In this section, I would like to create a transition between the Abby Black scene and the film as a whole through a discussion of recurring visual motifs and its place in the plot. A look at the way in which the film suggests unity through cinematic codes and narrative structure could help understand how it constructs a diegetic and extradiegetic unity. This unity could reveal the significance of the inclusion of autism as a discourse for the entire film and its sum of motifs as 'cues'. The Abby Black scene takes place one-third of the way through the film. It is positioned after a long flashback with a collection of scenes that depict Oskar's life with his father and the start of the quest for the destination of the Black key. Its use of colour mirrors visual motifs that were seen in these previous scenes. One of these lies close to spatiality and the story arc of the Black key search: the muted white and brown colours in home interiors as opposed to the colour blue in details related to Oskar and his quest. The moving boxes from Abby's husband and the staircase have brown wood colours, which are also very prevalent at Oskar's apartment, especially in scenes that feature interactions with his mother and his paternal grandmother who lives right across from him. Scenes that take place in the apartment and that focus on Oskar's family often have dimmed soft lighting, such as Thomas's intact room in which Oskar finds the key by accident. By contrast, Oskar's bedroom contains a lot of blue. This is the setting of his quest preparations and the location of props that are important to the plot. The colour blue can also be seen in Oskar's eyes, the cap that he wears when going outside on his quest, the sky during activities related to his quest, and the lighting on the streets of New York City at night. Finally, it is abundantly present in the interior of Abby's ex-husband William Black's office building, where Oskar ultimately learns about the destination of the key.

Together, the two visual motifs form a space of inner emotional conflict that Oskar negotiates throughout the plot, oscillating between his personal search for the destination of the Black key and his interpersonal relationships that he builds. Blue is

the colour of Oskar's 'world', in which he goes on quests to go out of his 'comfort zone' and into situations that make him, in his own words, "panicky". Blue was also the monochrome colour of the sky on September 11, 2001, when the nice weather formed a poignant contrast with the fire, smoke and ash from the burning towers. The sky is covering New York City to this day, just like Oskar continues his life after his loss. Brown colours and wooden textures show up in domestic spaces in which personal and highly emotional encounters with key characters take place. Abby is emotional about implied marital problems and sits down upon a wooden surface while Oskar is interrogating her. Similarly, in later scenes in his apartment building, Oskar's mother shows expressive emotions that make Oskar's interactions with her seem aloof and bends down or collapses on wooden floors. During scenes in which Oskar hides within tight wooden spaces, extreme close-ups of acts of self-harm are shown. Oskar plucks his skin, leaving wounds that he shows during the first meeting with his grandfather, then known as the 'renter'.

The juxtaposition of emotional conflict in the narrative and visual motifs forms an important platform for indices of deviance, but also as a structure of expectations of contiguity in Oskar's 'oddness' in the eyes of the anticipated spectator. By the time we reach this scene with the discursive speculation, the visual motifs that accompany Oskar's conflict have already been introduced and connected with the story of the loss of a loved parent during 9/11. Moreover, we have also heard instances of Oskar's extradiegetic voice-over in which he refers to supposed timeless difficulties in his life in the present simple and present perfect. He had a "hard time" approaching people during his father's lifetime, and he has always had trouble "doing certain things" before 9/11. Note the word 'certain' here, which brings a degree of indeterminacy to his claim, like his comment "Results weren't definitive". The loose definition of "Asperger's disease" already anticipates an audience that has a basic ability to recognise the words and think about their significance in the case of Oskar. The self-harm imagery is the only 'sign' of emotional distress that is forthcoming, but the depiction of self-harm is quickly shown after the Abby Black scene.

By the time the film reaches the moment Oskar starts his visit to Abby Black, a scene starts that is pivotal to my notion of autism-is-speculated. On his way to Abby, who

resides in Brooklyn and thus a different borough, he decides to walk through a crowded city street. He states: "Because public transportation makes me panicky, I walk. I have always had a hard time doing certain things, but the worst day made the list a lot longer." A frightened Oskar is being shown running in the direction of the camera, filmed in selective focus (picture 4). On an extradiegetic level, Oskar lists details in the street that invoke fear, in a voice that becomes louder and louder as he increasingly becomes frightened. The details he lists include running people, airplanes, and "children with no parents" (picture 5). This scene combines several elements from the novel, like its frequent use of descriptive enumerations, its scrapbook design with photographs next to text, and Oskar's list of fears that he has after 9/11.

Because the audience has already seen Oskar's motivations and emotional struggles and is now being bombarded with details that we see alongside him, it is tempting to think of this moment as sensory overload. 'Recognising' sensory overload is an appeal to its genealogy as a term that has increasingly been used in the clinical world (American Psychiatric Association, 2013). It goes back to Simmel (1903) and his work on the human mind in the metropolis. He identified a key feature of the psychological layout of the metropolitan man: the experience of an "*intensification of nervous simulation* which results from the swift and uninterrupted change of inner and outer stimuli" (p. 175; original emphasis). The issue of sensory processing difficulties has been introduced to the clinical world by the field of occupational therapy (Schaaf & Miller, 2005). By 2011, it was commonly used within the context of autism, even though the DSM-5 was the first diagnostic manual to include it as a 'characteristic' of 'autism spectrum disorder' two years later (American Psychiatric Association, 2013).

I would like to argue that the hyperaware gaze becomes a relevant term in the unusually fast editing and loud narrator voice, not despite but because of the fact that autism is only pondered and left indistinct in the film. In the section on indexicality in the chapter on my approach to autism, I used the phrase 'hyperaware gaze' for a sense of vigilance of 'warning signs' for deviant behaviour in visual culture that invites speculation and the anticipation of intervention. Determined to go on his quest, Oskar throws himself into the wild blue world of the New York cityscape at broad daylight, a space that still contains its hectic everyday accumulation of stimuli with or without the

disruption on 9/11. I would want to avoid the statement that Oskar 'has' sensory overload here, but the film's use of the clinical category of 'Asperger's' (prevalent in 2011) points out that speculators are 'getting close' but that 'they themselves' could 'decide' whether or not Oskar 'has autism'. This illusion of choice affirms an active engagement with the cinematic construct of Oskar as 'odd' and hints at his status as the 'not-yet-labelled'. Protagonist Oskar is thus constructed as the 'to-be-diagnosed' and presents an ongoing paradoxical pleasure of deciding a clinical category onto his image. I wrote about scopophilia, or the pleasure of looking, in the chapter on representation, and it is this paradoxical sense of affirmation that I wish to point out with the help of this term. It is this specific signification of the 'to-be-diagnosed' object of the gaze that brings forth the cultural desire in recognition in the sense of the social production of indices of deviance and in the disciplinary act of looking in examination.

The combination of confirmation and doubt in examination brings the allowance to assume a 'reason' behind perceived deviance or, inverted, signs of 'proof' that can verify the presence of a clinical category. 'Signs' of autism are notions of the cultural production of promise within a social desire to speculate and recognize, sparked by a scene that depicts sensory overload. I would like to defend a reading of 'sensory overload' in *Extremely Loud & Incredibly Close* as a social and artistic process of index creation rather than an indexical sign in and of itself. When it comes to spectatorship as a cultural production of speculation on deviance and potential pathology, it is important that the exact term is 'Asperger's' within a film that depicts the aftermath of the World Trade Centre attacks. After all, the list of overwhelming sights that Oskar recites includes references to the crash of the hijacked airplanes in the Twin Towers. I would like to state that the construction of autism indices cannot be regarded separately from its intersecting theme of trauma. This will be the focus of the next section.

4.5 The intersection of autism and trauma

The novel and the film adaptation of *Extremely Loud & Incredibly Close* both depict the aftermath of the attacks on the World Trade Centre on September 11, 2001; the ritualised use and repetition of that day's imagery is an important feature of the status of 9/11 as a *cultural memory.* The theme of cultural memory is a sub-field within

literary studies and distinguishes personal memories and collective memories that people experience together in a group setting. Cultural memories often transcend the minds and actions of people that have 'actually' been part of the historical event. The management of such memories is heavily ritualised. They gain significance out of a cultural choice to commemorate a delineated piece of the past, and often involve monuments as objects of memory and specific selections in the things we do and do not publicly remember (Green, 2004). In short, the field of cultural memory studies commemoration as a performative act, while I also study the social categorisation and recognition of autism as performative. This similarity gains extra depth considering that the theme of trauma is also frequently covered within the context of cultural memory. Foer's 2005 novel has been a frequent case study in literature on cultural memory and trauma theory. This inclusion motivates a more detailed consideration of the theme of trauma in the film. I would like to discuss these details here nevertheless, because they help to interpret autism as an added discourse that was not there in the novel. The implication of an extra 'wound' of trauma adds more distinctive 'warning signs' to this additional use of autism as a discourse, and the increased quantity of signs could enhance rather than nuance the hyperaware gaze.

The focus on trauma adds the question how individuals, societies, and fictional characters cope with 'wounds' from the past. Within the context of fiction, trauma is theorised as a failure to master the signification of harmful experiences and the resulting compulsive reliving of them. Caruth (1996) calls this kind of confused and distressed signification the unclaimed experience that defies narrative structure. A distinctive feature of the academic study of trauma in literary theory is its emphasis on insights from psychoanalysis as vocabulary in the theoretisation of psychological trauma and its effect of inaccessibility to the harmful event. Such insights come without a direct application of his psychoanalytic method as an actual clinical intervention. I have admitted my own indebtedness to the use of psychoanalytic language in film studies in my section on recognition in spectatorship in the representation chapter. This was meant to highlight previous film theorists who have developed interrogating ways of looking at normalised gazes. Trauma, as well as the current taxonomy of Post-Traumatic Stress Disorder as currently described in the *DSM-*

5, has a broader genealogy than just psychoanalytic concepts of the human mind. According to Howell (2012), the conceptual wound of trauma becomes increasingly physical again in mainstream science. The 'wound' in Humanities-based trauma theory has been based on the psychological wound as established in psychoanalysis. Nevertheless, there has been a strong turn towards the neurobiological in the Western clinical world, with research on neurons and brain imaging. Moreover, Howell warns that trauma is gradually ceasing to be a question of memory and is now often defined within the context of 'resilience training'. Whereas the current clinical notion of PTSD originates from insights on shell shock among soldiers and the advocacy of Vietnam veterans, contemporary military training involves exercises for psychological and emotional 'fitness' for war. Regardless of wider conceptual frameworks of trauma in the future, both Caruth and Howell offer the insight that 'trauma' is a historically and culturally specific phenomenon. The historically relative and performative nature of memory and trauma in culture and literature (Plate & Smelik, 2012) could enable a consideration of trauma next to autism in *Extremely Loud & Incredibly Close* and its 9/11 backdrop.

In the wake of the 'indefiniteness' of autism that appeals to the desire to speculate in the film, it is interesting that literature on trauma in *Extremely Loud* specifies the exact source of Oskar's stress regarding 9/11. In the film, there is a story arc in addition to the quest for the destination of the Black key. Oskar hides an answer machine with a recording of his father's voice. Its content directly relates to 9/11, or the "worst day" as Oskar repeatedly calls it. The film shows his acts of self-harm right after very short clips of the recordings are heard in a scene not long after his visit to Abby, that takes place in Oskar's room. When he works together on his quest with a mysterious 'renter' in his grandmother's house, who turns out to be his paternal grandfather, he reveals the audio except for one missed call. Oskar recounts the content of this missed call to William Black, the man who knows the destination of the Black key: it turns out that his father called him when he was in one of the Twin Towers, but that Oskar did not dare to pick up the phone. The last call consists of Thomas's reiterated question "Are you there?", which breaks off at the exact moment the tower collapsed.

Analyses of the theme of trauma in the novel name Oskar's inability to pick up the phone when he receives the calls, and his guilt about this, as the source of his trauma (Codde, 2009). The focus on one specific and easily recognisable traumatic event nuances and evens out the possibility that the cues of deviance as analysed in this chapter are a part of autism. However, the specific parallelism of autism and trauma in the film brings up *more* potential readings of the protagonist with additional complexity and opportunity for speculation, rather than a more limited reading of Oskar as 'just' traumatised. In order to explain this, I would like to return to the 'sensory overload' scene that I discussed in the previous section. The scene conveys a cinematic spectacle through its use of shallow focus and quick editing that physically overwhelms the viewer and that, according to Cappelli (2016) conveys a state of human vulnerability. Many things Oskar notices and mentions also bear a similarity to well-known 9/11 imagery, which implies the recollection of trauma, or individual and collective vulnerability in the face of terrorism. The ambiguity of autism and trauma becomes clear through textual and visual elements. I would like to repeat the text that is spoken by Oskar in a voice-over: "I have always had a hard time doing certain things, but the worst day made the list a lot longer". Oskar's remark, induced by the sight of sensory triggers, invokes both the clinically accepted paradigm of autism as a lifelong condition (American Psychiatric Association, 2013) and the notion of the traumatic event and its aftermath. Walking down a busy street is presented as something Oskar has trouble doing, as he points out in an explanatory and didactic style and a formulation in the present perfect. The temporal dimensions of these remarks consist of a juxtaposition of two markers of time: some things "have always" been difficult, and other things have been difficult ever since "the worst day". When listing the stress triggers, his voice-over becomes partly diegetic as his tone of voice mirrors the panicked emotional state that is evident in Oskar's on-screen facial expression and the quick succession of point-of-view shots.

When it comes to the visual parallelism, I would like to return to the Peircian semiotics that I have outlined in the chapter with my approach to autism. If one would like to read the moment of sensory overload as an 'index' for autism, then the details of the airplane, the high buildings, and the running children could alternatively be read as

9/11 iconography. As I already explained in my presentation of Peirce's triad of signification, the icon resembles the object it refers to. There is an element of metonymy here. For example, the proximity of a low-flying airplane and a skyscraper does not stand for the day itself or historical event as a whole but represents a small visual part of the day. The object of reference in 9/11 iconography is thus small details that point at a documentable terrorist event. On their own, voice recordings, photographs, and filmed footage are indices or 'proofs' to the truths of what happened on the 11th of September 2011 (Gunning, 2004). The burning towers invite an indexical reading: the architectural damage and subsequent collapse were caused by airplanes that were hijacked and repurposed as destructive missiles. However, now that the '9/11' day has become a part of our cultural memory, their ritualized use in the media makes these details icons. They still resemble the historical events on '9/11', but they have become part of a wider enactment of commemoration. Their strategic familiarity transcends Oskar's specific story of the loss of his father: it is a reminder of tragedy for the Western world in general. I therefore would like to connect the reminders of 9/11 with iconography rather than with indexicality: they are more than cues of a potential trauma re-enactment in Oskar but also appeal to imagery that has been continuously referenced and broadcast since 2001.

Moreover, my choice of 'iconography' in relation to trauma mirrors the reading of the novel *Extremely Loud & Incredibly Close* in Codde (2007). He discusses the fascination for the visual in Foer's work, as well as the emphasis on pictures and visual images between pages of text in the material book. He links this to the inability to linguistically grasp a harmful event, which means that the traumatic experience is eventually memorised in the form of iconic visual imagery. He argues that this inevitability of iconography in the wake of a loss of words and texts has also shaped the emphasis on visuals in Foer's novel.

The principle of iconography that fills up a void consisting of inconceivability can easily be applied to visual cues in the 2011 film adaptation as well. A reading of the 'sensory overload' scene that prioritises trauma could stress the visuals above the textual cue that "the worst day made the list [of things that Oskar has trouble doing] a lot longer". Oskar exclaims that the death of his father "does not make sense" throughout the film.

It could be stated that he can only grasp the death of his father through icons, which is conveyed to the audience through interruptions of narrative by specific visuals. Besides the 'sensory overload' scene, images of the unidentified people who jumped out of the burning Twin Towers are frequently seen, even though they often do not contribute to the plot development. In the previous section, I expounded the way in which the film enables a reading of the 'sensory overload scene' as indexical cues of autism in the previous section. In addition to this or, indeed, parallel to this, the cultural and academic engagement with the theme of trauma reveals a different reading of Oskar's condition based on the same filmic material.

Aside from the potentiality of visual and textual cues of Oskar's trauma in the film, the role of trauma should be nuanced on the level of its entire plot. Academic literature on trauma in Foer's novel discusses the frequent interruptions of Oskar's story in first-person perspective by letters from Oskar's grandfather to his unborn, and later deceased, son (Oskar's father), and his grandmother's messages to him. These letters form a separate story that is largely abridged in the film: Oskar's grandfather lost his lover during the 1945 Allied bombing of Dresden and then married her sister, Oskar's grandmother, after which they settled in the United States. The emotional impact of the bombing left the grandfather (whom Oskar refers to as the 'renter', initially oblivious to his true identity) unable to speak. This mirrors Codde's argument about the loss of linguistic signification of trauma; he discusses the motif of failures to communicate amongst the Schell family members throughout the book as illustrative of this loss. Even though the silent character of the 'renter' still appears in the film as Oskar's assistant through part of his visits to the Black households (in the book, this is a separate character whom Oskar meets halfway), this secondary literary plot is gone. This implies less importance of (cultural) trauma to the 2011 film *Extremely Loud & Incredibly Close*'s depiction of the Schell family.

The removal of the grandparents' sub-plot also downplays cultural trauma and offers room for a deeper comprehension of Oskar as 'potentially autistic'. This motivates me to focus on Oskar's search for the destination of the Black key, and its role within the entire film. Codde locates this within the theme of failures to communicate and the "inaccessibility of one's own traumatic past". I would like to state that the film allows a

110

different reading of Oskar's quest according to my 'autism-is-speculated' principle: the plot line of the quest ultimately reaffirms able-centric norms surrounding the search for a correct parental intervention for Oskar. The next section delves into the dis/ability threshold and how Oskar's transgression of this border between autism and not-autism has been evoked in a pejorative way in past literary analyses. After that section, I dedicate the final section of my reading of *Extremely Loud* to the quest narrative.

4.6 Normative hyperaware spectatorship and the ableist pejorative status of the discursive 'border'

Ultimately, I would not like to arrive at a resolution to a reading of Oskar as autistic or traumatised based on the 'sensory overload' scene: I would not want to decide a definitive diagnosis for Oskar. The lack of resolution in the film is the exact thing that I would like to theorise as an ableist power imbalance through speculative looking. I would like to argue that the potential index of "Asperger's" implies autism 'warning signs' as dissected by McGuire (2016) and that the additional 9/11 iconography enhances that implication. In the addition of more cues for disciplined hyperawareness of the not-yet-diagnosed, spectatorship is formed based on a power imbalance between the spectator and the diegetic point of view of the protagonist. Even though Oskar does not have enough words to express his trauma, the scenario does give him lines that specifically recount an autism test from before 9/11. Furthermore, the 9/11 iconography has been repeated over and over in the media, so that its emotional resonance has been desensitised compared to Oskar's fresh memory of his father's death and inability to respond to his father's calls. It is in this power imbalance that speculative spectatorship thrives, as there are only 'more' cues to be aware of and more ways to secure the time-transcending quality of the examining gaze that measures, assesses, and intervenes.

The tambourine is another cue that establishes the autism-trauma intersection in a way that brings the kind of apparent 'nuance' that I regard as hyperaware spectatorship. Oskar frequently carries a tambourine, and in the novel, Oskar and other characters sometimes comment on it. With the references to the Dresden bombing during the Second World War in the novel, it is tempting to interpret the

tambourine as a reference to Gunther Grass's book *The Tin Drum* (1964). This is set during and after the Second World War and also features a boy who carries a musical instrument, even though this is a boy who does not grow up. This implausible element could highlight Oskar's rather magical realist status as an adult in a nine-year-old's body. As the film adaptation downplays the intersection of 9/11 and war-torn Germany, the tambourine seems to have gotten a different purpose: Oskar now states that it "helps to keep him calm". In the context of the anticipation of autism indexicality that I have discussed before, this means that the tambourine is a 'stim toy' (see Weststeyn et al., 2005). Despite the calming effect for Oskar within the diegetic realm, the prop conveniently adds an extradiegetic layer of tension to suspenseful scenes for the audience due to its continuously rattling noise. The intersection of intertextuality related to trauma, the implication of self-stimulatory behaviour and the extradiegetic effect of enhanced emotional immersion is emblematic to the spectatorship that is strengthened rather than   weakened by the fact that Oskar 'might' or 'might not' 'have' autism.

In order to further theorise the kind of spectatorship that I identify in this chapter as being actualised through instead of despite doubt, I would like to evoke a reading of Oskar in Versluys (2009). He has included the novel in an extensive case study in his book *Out of the Blue* on trauma in literary depictions of 9/11. In his consideration of the personal and psychological dimensions to the character of Oskar Schell in Foer's novel, he discusses his deviant behaviour as evident in passages like his talk about the Hiroshima bombing at school. Versluys argues that Oskar often seems "desensitised and emotionally numb to the point of autism" (p. 107). The decided yet crude use of the word 'autism' denotes a certain *degree* of something: Oskar's emotional engagement with his surroundings almost crosses a line as it is believed to be so bad that it 'borders' on the 'pathological'. It shows that a suggestion of autism as something that is 'almost' there can be more pejorative and bring in more negative rhetorical pathos than a straightforward confirmation of autism as something that unambiguously 'is' there. I would like to argue that the rough recognition of autism in an academic reading of Foer's 2005 book quite precisely reflects spectatorship in "Asperger's disease" in the film. This is not because Versluys reflects or represents the

anticipated spectator that is central to this section. The issue of speculating spectatorship instead lies in his discursive enhancement of cues of deviance as something that 'borders' on, rather than 'is', a pathologised category. Doubt, or a category 'bordering' on the autism information-thing, is the thing that 'makes' autism 'known', which brings me to my 'autism-is-speculated' epistemological metaphorical concept. Doubt helps in constituting diagnostic categorisation as something that actualises the dis/abled subject in cinema, and is thus intrinsic to normativity. The next section will explore normativity in the formation of the 'good' autism parent through narrative structure, or more specifically, the story of Oskar's quest through New York City.

4.7 "I wanted to understand": The rise of a Son-Rise narrative in the representation of Oskar's parents and Oskar's MacGuffin quest

While the previous section was dedicated to themes and motifs that add to normative hyperaware spectatorship that finds actualisation through doubt, this section is concerned with the way in which the film plot reaches a resolution. This resolution forms a distinctive interpretation of Oskar's parents that may remind us of clinical, historical, and cultural narratives of 'autism parents'.

Even though Oskar's quest centred around the destination of Oskar's key seems to be the main plot-driving device, the ultimate solution does not truly lead to a resolution of the plot. After the scene of Thomas Schell's funeral and the flashbacks to Oskar's family life with him, Oskar enters his father's bedroom and accidentally pushes and breaks a blue vase (note the recurring colour motif), which reveals an envelope with the key inside that initiates Oskar's search. His quest through New York City brings him to all the households with citizens with the 'Black' surname, because he wants to find the one person named 'Black' who is referenced in the writings on the key envelope. This person might grant access to the lock that the key fits in, which might be a door, a safe-deposit box, or a vault. Oskar believes that the content that is revealed after unlocking could bring him 'closer' to his father. When Oskar finally finds out about the original owner of the vase, Abby's ex-husband William, it turns out that the key belonged to William's deceased father instead of Oskar's. The true 'Black' of interest was 'incredibly close' all this time. If William had known about Oskar's search, he could

have responded much earlier, but he was distracted during the scene that featured autism as a discourse. The content of the vault is unknown: even though William offers Oskar the opportunity to find it out together, Oskar declines out of disappointment that the content does not relate to his own father.

Even though a wish for proximity to his deceased father is what motivates Oskar to visit all Black households, I would like to say that the content of the unlocked door or vault is a MacGuffin. The term, popularised by director Alfred Hitchcock, refers to a search for a desirable object that sets the plot in motion, with the implication that the reveal forms a major part of the plot resolution (Epstein, Wiesner and Duda, 2013). Nevertheless, the film or series ultimately focuses on the quest for the object itself and the life lessons of the people involved in it, so that the object and its exact nature lose their relevance. In *Extremely Loud & Incredibly Close*, the door or vault is a mere vessel, and the key functions to get access to the content of this vessel. The key is a visible material thing that drives the plot, and Oskar is shown while frantically attempting to open doors and safe-deposit boxes. However, the thing that drives the plot and ultimately becomes unimportant is the unknown content that Oskar hopes to retrieve, and on which his desire to come closer to his father is projected. The MacGuffin here is thus an unknown object that is only evident in its presumed vessel. What is interesting in terms of autism as a discourse is that 'diagnosis' has been identified as a MacGuffin itself. Epstein, Wiesner and Duda criticise diagnostic categorisation in the DSM-5 as discursive psychotherapeutic vessels that direct attention away from cultural criticism within therapeutic settings.

Moving away from the 'MacGuffin' of both the Black key and the film's recounting of diagnostic tests, I would like to state that the true resolution comes from reconciliation between Oskar and his family after his 'good' dad has fallen away. Oskar's parents are pivotal when it comes to the significance of Oskar's quest as a learning process in and of itself, the role of his parents, the loss of his father, and his reconciliation process with his mother. Throughout the film, scenes of Oskar's quest are alternated with scenes that show friction and emotional clashes with his mother. This friction is reconciled after the true 'Black' was discovered. What is key to the narrative structure

and a formation of a true resolution of the 'quest' plot is that normative 'good' parenthood is being sustained after the 'good' autism father has passed away.

In the film plot, Oskar's father Thomas is presented as the main source of action upon the 'warning signs' that are cultivated in hyperaware spectatorship. In Oskar's recounting of the 'autism tests', he only mentions his father as a person who was aware of its implications and who attempted to explain this to Oskar. The fact that Oskar quotes his father brings in a sense of obliviousness in him regarding the term 'Asperger's', emphasised by 'disease'. Thomas Schell 'knew more' about the condition that is the central focus of the recounting. Earlier in this chapter, I emphasised the significance of the position of the Abby Black visit scene within the entire plot. Similarly, it is important to localise this implication of Thomas's involvement in a diagnostic process as something that is brought up after the flashback that introduces him to the audience. The introductory flashback shows Thomas's invention of a 'quest' for Oskar, in which they together search for a mythical 'sixth borough' in New York City. A key scene involving the role of Oskar's father as the 'intervening parent' is included here. In this scene, Oskar spies on a prop that is presumably self-made: a mirror that is assembled on a shovel that Oskar uses to secretly spy on his parents in a separate room. Because of the spatial and perceptual alignment with Oskar when he spies on his parents (apparently at night, as the lights are on), it becomes clear that the audience learns something alongside Oskar that it is not 'supposed' to know. Apparently unaware of Oskar's surveillance, Thomas and Linda Schell discuss Oskar's activities regarding the sixth borough quest. Thomas points out that he invents and plans specific tasks for Oskar in order to motivate him to talk to other people, which he supposedly does not do often outside of the quest setting. Indeed, an earlier flashback depicted Oskar talking with strangers at Central Park while finding a prop that is relevant to his quest. In an extra-diegetic retrospect, Oskar states in a voice-over that his father knew about his troubles with interpersonal connection.

The film thus suggests that Thomas helped Oskar with his socio-emotional skills and his ability to negotiate New York City, and that the help had a great influence on Oskar. Significantly, right after the 'sensory overload scene' during his walk to Abby Black's house, he finds himself on Manhattan Bridge, initially unable to cross over. He then

experiences a flashback to his father and his persuasion to try to swing high at one of the swings at Central Park, after which he summons up enough courage to run over the bridge. Ultimately, at the very last moment of the film, the swing is where both the chronological story and the presentation of the plot end: Oskar finds a note that his father left there, and then tries the swing yet again. Giving the illusion that he is defying his own death by contacting Oskar, Thomas congratulates his son with completing the search for the 'sixth borough'.

All scenes that I have discussed here are not present in the novel. They are nevertheless concerned with a consistent narrative: before his death, Thomas helped his son to try new things and cope with his socio-emotional difficulties, and his legacy can still be felt. When an unseen 'autism test' occurred, he made sure Oskar was reassured with a personal interpretation of the notion of 'mild' autism that still left his intelligence intact. I would like to state that this background story of Thomas's relationship with his son evokes coherence with Oskar's recounting of his test for "Asperger's disease", and that this evocation is an interpretive adaptational choice for the portrayal of the Schell family. The interpretation of Thomas Schell in the film adaptation adds instances of successful communication and assistance. This brings a new potential reading to Oskar's new, more recent quest. It continues Thomas's efforts to let him speak to strangers more and give him confidence to develop his social skills, even if Thomas is not physically there anymore. With the letter in the Central Park swing, his presence as a guide briefly returns, or the audience is at least briefly reminded of his efforts to help Oskar.

Ultimately, the help contributes to Oskar's socio-emotional development, which makes the bereavement of Thomas Schell even more bitter. In the film adaptation, Oskar's father not only represents the broken families after the 9/11 attack. The coherent narrative of a 'good' father helping a 'potentially' autistic character also addresses the fears of parents who are insecure about the future of their autistic children when they die. In his reflections on autism parents' accounts and male responsibility, Murray (2008a) notes that many biographies of mothers feature themselves as the guardian. The role of fathers in the narrative is conversely more passive, or "either absent or peripheral" (p. 161). In *Extremely Loud & Incredibly Close*, Oskar's father is not just

passive or absent but is actually prominent, exactly because of his sudden absence. The father is continuously shown as a caring parent who shows responsibility towards the socio-emotionally divergent protagonist throughout the story. It is he who negotiates Oskar's challenges, but disappears, leaving a broken family with a mother who is not the hero of the story but is instead often too overcome by emotions to act. Even though his father made the necessary 'progress', Oskar is left undiagnosed (or potentially not-yet-diagnosed), leaving his legacy and the diagnosing gaze of the audience to the task to 'aid' him. Just like the intersection of trauma, this narrative of continuing paternal legacy only further appeals to hyperaware spectatorship in its 'readiness-for-intervention' as one character is strongly implied to act upon this readiness in the diegetic sphere.

The resolution to the seemingly incomplete embedded 'mission' to offer parental intervention to Oskar comes at the end, right after Oskar's meeting with William Black in which he learns about the true destination of the key. Upset by his seemingly failed quest and aim to get closer to his father, he has a tantrum in his bedroom. His mother finds him there and calms him down while lowering herself by kneeling on the floor of the bedroom, which mirrors previous scenes that featured her. She reassures Oskar that he does not need to be normal. Again, the legacy of Thomas Schell can be heard in a moment of commemoration, as she says that he would have been proud. Right afterwards, a revelation follows that I consider to be of great importance to the representation of the 'good' parent in the film. Linda Schell tells Oskar that she knew all along about his quest to contact all the people in New York City called 'Black'. She starts to recount the events that led to her discovery. Flashback shots follow, in which the doorkeeper tells her that Oskar borrowed several telephone books, making her suspicious that he was 'up to something'. This led her to repeat Oskar's investigation with Oskar's own objects (crafted props of schemes and maps), and to contact the people named Black whom Oskar was about to visit in order to prepare them for his arrival. She sees through Oskar's sense of reasoning, and Oskar comments on it. A montage sequence follows, with the diegetic sounds of their conversation in the background: shots of Linda's visits are alternated with Oskar's visits to the same people in the same places. The extradiegetic score gets louder and louder, signifying

increasing emotional depth and inviting emotional engagement with this revelation, which comes as a great surprise to both Oskar and the spectator.

Linda's actions and the way Oskar and the audience learn about them are not only significant to the narrative structure, but also important to my reading of the film's plot on the sudden disappearance to Oskar of the 'good' dad. I would like to write out Linda and Oskar's exact words during their conversation about Linda's actions. After she tells about her suspicions that Oskar is executing a secret plan, she states: "So I went into your room and tried to think like you did. I wanted to understand". Oskar asks: "You were snooping on me?", after which she answers: "I was searching for you". At first glance, it becomes clear that this moment reassures some potential worries from the audience about the apparent lack of supervision that Oskar gets during his lone walks through New York City. Linda states that she would never let Oskar "out of sight", implying that she kept a responsible 'motherly' eye on him all along. Any worries about an opposite extreme, that is, 'snooping' in Oskar's personal possessions in his private space without consent, are also negated with the words "I was searching for you".

What draws my attention is Linda's desire to 'understand' and 'find' her son, repeating his quest in this process. The exact focus of the mother-son reconciliation and the emotional catharsis that follows in the reveal of her involvement is an act of mimicry in Linda. She tried to figure out what her son was up to, by thinking 'just like' her son. She reconstructs his unique thinking process that we have extensively been introduced to throughout the film and acts according to this recreation. This is a double reproduction: she not only mimics her son's occupations, but also her late husband's strategic use of a quest narrative in order to steer Oskar into socio-emotional skill 'training'. The choices of the sentences "I wanted to understand" and "I was searching for you" are particularly significant. They express a desire that is parallel to Oskar's desire that drives his quest throughout the film: his mission to come "closer" to his father. Linda voices her wish for greater proximity to her son, but she frames this within knowing and understanding.

I would like to state that the emotional reveal of mimicry as a method for greater proximity to a boy who lost his father, and thus his anchor through his socio-emotional

negotiation of the world, mirrors the 'narrative' of intervention in the Son-Rise programme (Kaufman, 1994). Developed by Barry and Samahria Kaufman, this intervention puts emphasis on parent-child play in a domestic context. The method in question consists of a study of a child's stimming (repetitive motor movements) as 'behaviour', and a subsequent systematic imitation of this behaviour by a parent during play. The intended effect is that the child will eventually start to make more social contact. Linda's choice to mimic her child's quest activities does not directly resemble a play-based intervention with the aim to make Oskar more sociable. Nevertheless, the theme of mimicry within narrative resolution and emotional catharsis is still featured in a dramatic form of storytelling on-screen. A television film that was based on the Kaufmans, *Son-Rise: A Miracle of Love* (1979), can clarify intervention as narrative structure. The film follows the road to 'recovery' of Raun Kaufman and his parent   s' involvement in this. Pondering what their seemingly aloof child's condition might be, they realise that he could be autistic, which is continuously addressed with spatial metaphors throughout the movie. Raun is supposedly not 'present' in close proximity to his parents: the audience look at his hand-flapping through his father Barry's point of view as he wonders "where" his child is. He then suggests the possibility of autism, which would "literally" mean that he is living in "his own world". Resisting 1970s practices of institutionalisation, Raun's parents decide to create their own intervention: they start to mimic their child's fixation on flapping and spinning. Ultimately, this 'gives' their child 'back' at their sides, as his process of alleged 'recovery' is referenced in terms of 'closer proximity'.

In *Extremely Loud & Incredibly Close*, even though Oskar does not recover and his condition is strategically left 'ambiguous', there is an 'overcoming' narrative (Osteen, 2013) that consists of a restored relationship with a member of a broken family. Oskar makes a transition from reliance on his father to reliance on his mother. I would like to argue that this happens through the evocation of an autism intervention in the narrative of emotional proximity through mimicry. The cathartic sense of resolution that this television film brings is directly evoked by this story of a family that 'finds' a 'missing child' back through a non-conforming approach to the autistic son. In the case of the *Extremely Loud* film adaptation, Linda invokes the same sentiment through

words such as 'understand' and 'closer', which is included in the film as an emotional moment of 'resolution'. Her desire to understand Oskar that   is evident in her first acts of mimicry mirrors the study of a child's 'fixations' with the intention to imitate them. Furthermore, her 'search' for Oskar brings to   mind the role of spatial autism metaphors in the plot development of the *Son-Rise* film.

What thus interests me about my declaration of a Son-Rise intervention narrative in *Exremely Loud & Incredibly Close* is the fact that Linda's mimicry itself is the emotional climax and the most satisfying and wrapped-up reveal of this film adaptation. Her mimicry presents her as a worthy successor to Thomas's efforts to engage Oskar more with the 'outside world' of New York City. If one accepts a reading of Oskar as autistic, which is an option that I have dissected in previous sections, then Thomas and Linda Schell are 'good' 'autism parents' who consciously negotiate the relationship with their son in order to create moments of intervention. Oskar is motivated to seek his limits and 'push' them, under the explicit or hidden guidance of his parents. Such limits consist of Thomas's encouragement to try the swings at Central Park, Oskar's search for the sixth borough, and, in retrospect, his series of visits to persons called Black in general. Next to its employment of autism as a discourse, the film adaptation has a distinctive motif of discovery and trickery, first initiated by Thomas Schell and then adopted by Linda Schell after his death, that exemplifies communication deemed successful. On a thematic level, the source of resolution in the film covers another instance of autism parent guidance, which makes the seemingly meaningless 'Black' search through New York City meaningful again, yet also appeals to a larger theme of recovery not unlike the Son-Rise programme. My evocation of the Son-Rise programme here is meant to raise debate on its role in the genealogy of autism, deviance, and overcoming. I would like to state that a further study of the theme of mimicry in the context of autism as a discourse is of particular value for future research. The article "Autistic Expertise" from Milton (2014) could be useful here. Milton employs Turing's 'imitation game' artificial intelligence test in his critical study of knowledge production and autism 'expertise', which also carries a strong theme of discursive praxis as mimicry.

4.8 Concluding remarks

My first declaration of an epistemological metaphorical concept, 'autism-is-speculated', has offered a comprehensive analysis of how uncertainty about autism in a not-yet-diagnosed character shapes my interpretation of the meaning and ableist implications of a film scenario, story, editing and mise-en-scene. It aided the mapping of a kind of normative spectatorship as anticipated in the adaptation of a book without autism as a discourse into an Indiewood production that does mention the diagnosis. While autism was not featured in *Extremely Loud* as a novel, the added suggestion that Oskar might have autism in the film adaptation offers a fruitful source for analysis of the cultural significance of not-knowing if a character has autism. 'Anticipation' here is a juxtaposition of indexicality, iconography and narrative syntaxis as analysed in different filmic elements per subject that is relevant to my interpretive theme of speculation about Oskar's precise condition. I have mapped how the hyperaware gaze on 'warning signs', as evident in McGuire (2016), could be manifested in cinema, with room for further theorisation on speculative spectatorship. Overall, *Extremely Loud* as a film adaptation has a storyline of the bereavement of a 'good' father who is sensible to the potentiality of autism and acts accordingly, and the remaining mother who continues his efforts in secret. It is a specific interpretation of Oskar and his parents that the film has chosen. When it comes to autism-is-speculated, the 'Son-Rise resolution' has the same kind of seemingly ambiguous sensibility as the inclusion of the term "Asperger's disease" in Oskar's recount of psychological tests. On the one hand, the film clearly states that the results were not definitive, but on the other, it still made the choice to include the very specific term "Asperger's" in favour of anything else.

I would like to state that *Extremely Loud & Incredibly Close* actualises autism as a culturally significant phenomenon through, and not despite, epistemological doubt. I would not want to regard the film as a plot on coping with autism. Instead, my formulation of a metaphorical concept points out the mechanism of such a reading of the plot, that is, the mechanism that fleshes out a sense of 'uncertainty' about autism. Even though Oskar's 'condition' is presented as 'uncertain', Thomas's attempts to help him cope with socio-emotional difficulties and the efforts of his mother to guide him through his 'Black' key quest are still there and together further normalise a narrative

of 'good' autism parenting. I would like to employ the word 'strategy' yet again here in order to point out the importance of the unity of the autism-but-not-quite narrative that is hidden in the film's scenes that I have dissected in this section. Its unique use of 'doubt' about Oskar's condition is still a conscious choice of 'autism' portrayal. Doubt reproduces the hyperaware gaze as expounded in my reading of McGuire's work and my employment of Peircian semiotics as my critical vocabulary. Even though the majority of the film shows perceptual and spatial alignment with Oskar, the viewer can also identify with his parents through allegiance with Thomas Schell as the attentive and intervening parent, and subsequently, with the efforts of the mother who has to 'continue' Thomas's work. Here, the film produces an alert attitude that is as preoccupied with 'lifelong challenges' as Oskar himself is and as ready for action as Oskar's parents are.

This reading of *Extremely Loud* is a reading of protagonist Oskar's 'condition', and ultimately about the implied overarching story of two parents who aid their son and the confusion that ensues after one of them suddenly falls away. It does not function to give a resolution on this matter. This reading has produced a more profound understanding of the hyperaware gaze of the assumed audience that comes from a society that is paranoid about uncontrolled deviance and that lives with autism as a commodified 'information-thing' that gives the promise of an ultimate resolution. If a resolution is not already there, the condition of 'autism' itself is left as 'not definitive', yet intriguing for audiences. This strong myth of autism that is definitively 'there' yet is supposedly 'surrounded' by 'mysteries' will be the focus of the next case study, "My Autism and Me". This brings the presence of a voice of a (potentially) autistic person to a renewed focus, as this will be my first personal account, as opposed to a feature film like *Extremely Loud & Incredibly Close.*

5. Studying the personal account as acknowledged autistic voice

This chapter is dedicated to the presentation of my specific notions of the *personal account* and *autistic voice*, that are crucial to my study of autism and epistemology in the cultural objects "My Autism and Me" and *In My Language*. Throughout my thesis, I do not rely upon a static understanding of autistic people, distinctive from non-autistic people, who are talking about themselves within the confines of a particular cultural text – the personal account – so that knowledge on autism is conveyed. Instead, I regard autistic voice as a highly relational form of autism epistemology that is based on *acknowledgement* rather than knowledge. Within cultural texts, a voice can be an 'autistic voice' insofar as these texts are being acknowledged in society as belonging to the imagined community of autistic people: they *become*, rather than *are*, accounts of people who identify as autistic. In my thesis, the term 'personal account' refers to a cultural text that has this differentiating property of featured voice being acknowledged as autistic voice. Autism epistemology is highly relational in this chapter, as 'knowing' here is contingent upon fluid and mutable connectivity between people who do and don't identify as autistic, as well as between time periods with variable public visibility of autistic people.

It is this mutability of time and self-identification inherent to my theme of acknowledgement that makes the personal account and autistic voice so important for my Humanities method of genealogy. The third section in this chapter will be completely dedicated to genealogy. I follow a historical trace in my understanding of autism personal account in the present in order to track and demonstrate how fickle this knowledge is within our contemporary textured life of embodiment, especially in the light of historical scientific realism. Throughout this chapter, I use the phrase 'scientific oxymoron' to illustrate this fickle cultural process of acknowledgement. The scientific oxymoron refers to presumed impossibility of autism personal accounts and

fears of inflated psychiatric diagnoses once people who were historically regarded as not being able to voice themselves do start voicing themselves. An example of such bewilderment about the possibility of autobiographical accounts from autistic people can be found in Sacks (1995). Sacks recounts his scepticism during his first encounter with the works of autistic ethologist Temple Grandin, because he believed that autistic persons lack the introspective capabilities that are needed to write an autobiographical account. Moreover, the release of the DSM-5 in 2013 sparked public debates in the field of psychiatry about the so-called inflation of diagnoses. Thoutenhoofd and Batstra (2013) have expressed their concerns that a sharp increase in diagnoses such as autism could possibly devalue the field of psychiatry. The response of scepticism and concern from Sacks, Thouthenhoofd and Batstra inspires my own cultural analysis on autistic voices. Autism and voice are the two things that are explicitly or implicitly presupposed to contradict one another like an oxymoron. The notion of autistic voice that I present in my thesis is useful more widely for studies of ableism, since it aims to dismantle the static and uninterrogated mundanity of abledness to enable the academic exploration of knowledge and being acknowledged.

In my upcoming case study chapters within the thesis, I focus on the cultural process of acknowledgement of autistic voice, rather than a corpus of texts authored by autistic people. Whilst *Extremely Loud & Incredibly Close* is a feature film that only depicts a narrator and protagonist who might have autism both case studies that follow are declarations of life reflection from people who identify as autistic. "My Autism and Me" contains interviews of autistic children that together render the autism category to a concrete educational subject; *In My Language* is a YouTube video that was produced and distributed by a woman who discloses self-identification and a specific interpretation of her outward expression. I isolate cultural texts that feature expressions from autistic people as a special topic on representation that needs separate attention from my representation chapter, because it converges with the question of agreement and affirmation of autistic people who 'voice' themselves. This convergence is relevant for my aim to put autism rights central with my focus on representation, or a decentralisation of the academic study of autism that wants to 'understand' autistic people 'better'. It dissects the cultural production of autism

epistemology first to enable an excavation of power relations within the declarations of and agreements on autistic voice.

In my upcoming readings of documentaries, biographies, and online 'user-generated content' such as YouTube videos, I will consider how the cultural object convinces its audience of its validity as a personal account. This question lies within my aim to understand the discourse of autism and cultural representations that employ it, rather than the concept of autism itself and the people identifying with it. The interactive process of acknowledgement does not make intention and source absolute, in accordance with Cultural Studies and its poststructuralist declaration of the 'death of the author' (Barthes, 1968) that locates meaning-making in the convergence of different texts and readings (Barker, 2003, p. 95). Throughout this chapter, I thus stress mutual meaning-making in society to enable further study of the valorisation and interpellative quality of autism as a discourse in the context of the study of cultural texts rather than autistic people   .

After the first section, which delineates the terms 'personal account' and 'voice', the second section presents my motivation to select the word 'acknowledgement' to mark what I am problematising with references to academic literature on autism autobiographies. The third section is dedicated to my reading of the genealogy of autistic voice: the construction and production of autism self-identification in texts that occurs in the shadow of the perceived impossibility that autistic people could produce a personal account. With my emphasis on cultural agreements about autistic voice and the autism information-thing, the focus on 'acknowledgement' deconstructs the fragility of declarations of voice since it enables me to place autistic voice in a historical context. Autism as a discourse has only been featured in texts since the beginning of the twentieth century; first as a pathologically withdrawn state of being by psychoanalyst Eugen Bleuler (1910) and later as an independent diagnostic category in the 1940s (Feinstein, 2010). Even though I am cautious to state that texts before these points in time cannot be read as accounts of autistic people, I would not want to classify them as acknowledged accounts. In terms of autism epistemology, 'we' cannot 'know' for sure whether texts before the 1940s captured life 'with' autism, as the autism information-thing is not directly negotiated; it is exactly this social practice of

'(not-)knowing' that lies at the basis of my genealogy of autism. It is here that the Foucauldian notion of genealogy, first used in the introduction, further comes to the fore. With the shift from a scientific disbelief in the possibility of introspection in autistic people (Sacks, 1995, p. 282) to the initiation of autistic communities and self-advocacy (Dekker, 1999; Waltz, 2013), the very suggestion of an autistic 'personal account' implies a limitation of 'disproven' scientifically realist claims on autism 'characteristics'. I provide a response to Erevelles's 2005 book chapter on the problematisation of the humanist subject in the facilitated communication validity debate. With a discussion of Rimland (2005) and Sacks (1995), I sketch the importance of the personal account as a 'scientific oxymoron'. I also discuss the implications for cultural criticism of declarations of autistic authorship.

With my understanding of the echoes of the 'scientific oxymoron', I localise a power imbalance that is pivotal to my next two case study readings, in which epistemological uncertainty is an important point of concern. In the final section, I outline the theme of power imbalance, captured by the theme of epistemological doubt, throughout the two upcoming case studies. Epistemological doubt in the children's television production "My Autism and Me" leads to a normative imperative of biovalue that benefits the labour market. The self-produced *In My Language* lies at the negative end of this normativity as it delivers a specific reading of filmed non-normative communication that lacks such a strategic employment of epistemological doubt and has attracted dispute despite its empowering message. As my thesis sketches an overarching political economy of doubt that spans my case studies, I avoid an absolute delineation of 'what counts' and what 'does not count' as a personal account. The very question of 'inclusion' and 'counting as' are the exact things that require problematisation, and my notion of the acknowledgement is tailored to such possible problematisations. Countering the emphasis on misleading conceptions of security and certainty in the declarations of criticality that I discussed in earlier chapters, my theme of different epistemologies and doubt is of interest to me because of its implications that uncertainty has already been a significant part and compartment of ableism. This fits my aim to consider categorisation as part of ableism rather than disablism.

5.1 Dissecting the 'personal' and the 'account'

I borrow the phrase   'personal account' from Lawson (2000), as its two-piece phrasing encapsulates the field of criticism that I cover in the cultural critique on in/visibility and the formation of the subject as negotiator of biovalue and the autism information-thing. In the section on bio-power in the chapter on my approach to autism, I defined biovalue as a specific biological entity, such as organs in the human body, that gains societal value because its health and lifespan can be controlled towards an optimalised condition. A person is an active subject in this process of government over one's own biological life, for whom the concept of autism is a clinically significant diagnostic term for examination and intervention of populations of people who are considered to have autism. The notion of an 'account' evokes a document, or an artefact, that contains reports of testimonies from a certain point of view (Corner, 1996). The word thus implies the presence of a medium with information that conforms to social expectations of indexicality in signification, which is something that I dissected in the approach to autism and representation chapters. An example of such anticipated indexicality would be 'accounts' of an event or phenomenon from a person being interviewed in a 'talking-heads' style documentary. Contiguity has long been a major source of academic interest in the study of documentary film (Honess-Roe, 2013, p. 29), which is important in the consideration of "My Autism and Me" as a televised children's documentary that is partly animated.

Within the social expectation of indexicality in the autism 'account' in general, the adjective 'personal' highlights an expected specification of the source: from a 'self', that is, the assumed individual who negotiates biovalue and self-identifies as living 'with' the autism information-thing. In this chapter, this appeal to the 'personal' is not an affirmation of this 'self' but a reference to the genealogy of voice. 'Voice' here stands for the function of textured life of embodiment to affirm and bring value to human beings, mirroring Couldry's (2010) argument that a negation of voice in accounts is a negation of humanisation (p. 1). This valorisation of expressions of voice furthers rather than denies certain human resources that make expressions 'matter' (p. 2); here, these expressions transcend speech alone and encompass the full potential of the medium at hand. The *In My Language* case study chapter revolves

around this reliance on YouTube video to convey the significance of language without speech. The term 'voice' implies "interdependency" of the speaker and the listener (Couldry, 2009, p. 579). This implication of interdependency is key to my aim to develop a more relational, rather than solitary, understanding of the personal account and its meaning and function in an ableist society. Despite the ableist unquestioned realism of the ability to hear, this interdependency is key to my formulation of 'acknowledgement' as something that arises out of an interactive process of cultural agreement on autism indexicality. Here, the 'account' mirrors Bordwell and Thompson's (2017) distinction of documentary from fictive feature films: the circular and mutually affirming process of promotion and expectation of a film as a documentary that "present[s] factual information about the world" (p. 351).

Both the 'personal', in the sense of declaring and facilitating voice, and the 'account' as a medium that carries this declaration are thus performative, enacted, and subject to mutual expectation of agreeable autistic voice. While *Extremely Loud & Incredibly Close* is not an account of autistic voice despite the narration and focalisation of the possibly autistic child protagonist, "My Autism and Me" and *In My Language* do hold the anticipation of conveying and facilitating perspectives of autistic people, respectively children and the video producer. It is in the performative mutual agreement of the personal account where I locate acknowledgement as my point of concern and departure in my study of cultural representation of autism self-identification.

This localisation comes with themes that I would like to explore further in the next section, in which I aim to outline my stance on the study of the 'personal' 'account'. An exploration of knowledge, epistemology, and power in the realm of the personal account within ableism seeks to affirm the creative potential of people who identify as autistic in line of centralising autism rights. However, studying or claiming proximity to this 'potential' lies outside my scope of a researcher interested in autism as a discourse, as it is ultimately the producers of cultural texts themselves who further constitute the textured life of embodiment with personal accounts as creative endeavours. The two themes that do lie within my reach of consideration in order to dissect the constitution and sustainability of ableism are positivism and autism self-

advocacy. With positivism, I touch upon the scientifically realist promise of a more 'direct' observation than the source of information as 'found' in personal accounts. With autism self-advocacy, I address literature that points out concerns of essentialism within social justice praxis of academics and thinkers who identify as autistic and base their work on affirming neurological divergence (Nadesan, 2005; Woods et al, 2018). The latter continues my thoughts on appealing to the 'complex' individual 'behind' the 'label' from the section on bio-power in my chapter on my approach to autism.

5.2 My stance and academic role towards the study of personal account as acknowledged autistic voice

This section will clarify my theoretical and conceptual stance in decentralising autism and autistic experience in my study of the shared performative phenomenon of acknowledgement in two of my three case studies as personal accounts. It aims to pinpoint the area of problematisation of my definition of the personal account as acknowledged autistic voice rather than autobiographical text. Central here is a consideration of my own role as an intervening researcher who writes a thesis and creates metaphorical concepts in it as additions to the cultural use of autism as a discourse as a textured life of embodiment. I am aware that the academic will to 'know' and 'gain insight' into experiences expressed in autobiographical accounts is a position of hegemonic dominion over creative endeavours that present self-identification with the concept of autism (McGuire & Michalko, 2011). Mirroring insights on bio-power from the chapter on my approach to autism, I include emphases on complexity and heterogeneity here, as my understanding of the neurobiological 'self' is one of construction of the 'autonomous' complex individual. Furthermore, I avoid claims to proximity to Murray's notion of 'autistic presence' (2008). This is because autism and autistic people as research objects could only obscure the power imbalance in the academic will to capture autism through 'understanding', while my focus on acknowledged autistic voice could centralise this very power imbalance itself. Simply put, I would not want to affirm the experiences and statements of people who self-identify as autistic because autism personal accounts already make themselves 'present'.

For me as a researcher, this leaves open the possibility to explore why mediated self-identification attracts academic concern anyway and to reflect on existing declarations of criticality in order to state how I contribute to the study of the cultural significance of autism. Such a dissection is an important feature of 'letting go' of 'wanting to know' and wanting to 'recognise' autistic people for who they 'are'. No matter how enabling this recognition might seem, it still presupposes academic intervention that implies that autistic voice needs a 'knower' and 'recogniser' first. Throughout this section, I will thus aim to problematise the power imbalance in 'nuanced' and 'inclusive' critical academic acts. I will seize the possibility to denaturalise the role of the 'empathic' capturer of autistic voice (Osteen, 2008), and thus the acknowledger of cultural texts as personal accounts.

With the precise choice of the term 'personal account' as detailed in the previous section, I consciously avoid the term 'autobiography'. My category of the personal account, acknowledged through mutual performativity within ableism, does not necessarily include autobiographies, or self-reflective life narratives that come from an author (Smith & Watson, 2010). At first sight, the personal account as autobiographic seems to be of importance for my thesis because it does not conform to the reinforcement of distance or an a priori gaze 'from outside' that neutralises the autism information-thing. However, with my role as a researcher who does not claim proximity to the kind of affirmation in the creative endeavour of mediated autism self-identification, I contest the notion of 'subjectivity' in and of itself. The 'personal' in the personal account suggests a degree of self-presentation, as the subject is a certain constellation of life 'with' autism; self-presentation is a corresponding characteristic of so-called "life writing" (p. 4). Nevertheless, I direct attention away from authorship and individualised author intention and towards the cultural and genealogical constellation of the notion of autistic voice as affirmed by the personal account (Foucault, 1969; Barthes, 1968).

In my two case studies that I have marked as personal accounts, I am more interested in analyses of production, style and discourse than in the understanding of the people portrayed or the message that persons who self-identify as autistic have wanted to convey. Although "My Autism and Me" contains portraits of children, with reports on

retrospective reflections on life 'with' this information-thing, the *Newsround* special was scripted by director Victoria Bell and produced for a children's broadcasting company. Moreover, *In My Language* is not only a video made by a non-verbal autistic woman, but also an online spatialised platform for further ongoing signification because it is posted and widely accessible on the video-sharing social networking site YouTube.

I include considerations of these dynamics of meaning-making in my readings in my aim to understand representation of autistic voice better and facilitate their empowering potential exactly by not wanting to grasp it academically. Previous studies (van der Palen, 2014; Van Goidsenhoven, 2017) have localised the inclusive potential of autism (auto)biographies within the discursive analyses of their case studies themselves. What could be overlooked in such academic acts is the concern in whose interest this promise of 'potential' in the more-than-currently-empowered manifests. With my focus on the more culturally grounded mutual act of acknowledgement, I facilitate thinking on autistic self-identification and self-presentation that poses the question to whom and to what people who identify as autistic 'owe' their life narratives. By addressing 'owing' information, I attempt to denaturalise personal accounts as sources of information that are passively 'waiting' to be discovered, included and interpreted, both with and without attention to autism rights and ableism, by a researcher. Instead, by asking the question to whom autistic people owe their knowledge gained from life experiences, I aim to think about autism knowledge and acknowledgement of voice as a relational cultural process of mutual meaning exchange. All in all, I would like to avoid explicit references to the autobiographical within this thesis to enable myself to denaturalise appeals to the self, shifting attention to the cultural significance of instances of identification with the notion of autism in cultural texts and their production.

Besides my vigilance on the question of who benefits from the 'potential' of affirming the 'self' in readings of the '(auto)biographical', I would also like to extend this vigilance on claims to nuance regarding Vertretung in autism personal accounts. The previous two chapters fully focused on cultural texts with attention to Film Studies as parts of the textured life of embodiment. I am now touching upon the ethics of a

consideration of personal accounts, academic, creative and/or educational, according to the same status of a 'case study' rather than an academic source. The category of the personal account adds the dimension of identification with autism, expertise (Milton, 2014) and academic merit to this. Do the academic efforts of people who identified as autistic (Woods et al., 2018) and their platforms, such as the journal *Autonomy* (Georgiou, 2014) count as personal accounts, and is it ethical to particularly feature them in this chapter? Would an imbalanced inclusion devalue academic writing because it is the fact that the authors identify as autistic themselves that is granted more priority? I pose such questions for further ongoing engagement with a system of ableism rather than the pretension that I am countering or overcoming the difficult questions that I am asking.

When it comes to different "claims to knowledge production and expertise within the field of autism studies" (Milton, 2014, p. 794), the question is how to affirmatively valorise knowledge production that comes from people who identify as autistic in general. This group of people who identify with the concept of autism might deliver insights that defy established ideas from any kind of scientific consensus at any given time, which could sow doubt, uncertainty and ultimately scepticism in experts, as I illustrated in the chapter introduction. Returning to Runswick-Cole and Mallett's notion of labour as outlined in the approach to autism chapter, it is important to theorise both 'experts' and 'non-experts' as labourers that produce and consume the autism information-thing together. Such a theorisation carefully examines the persistent and self-fulfilling cycle of meaning-making throughout society. However, it might be insufficient in grasping some of the complexities that go with this principle of autism commodification: whose autism information-thing production share has more chance of getting naturalised? What kinds of significance that are attached to the autism information-thing are seen as 'valid' and 'just' in which kind of contexts? The 'personal account' might express an affirmative point of departure for answering the question "what does all this mean for a person labelled with a commodified impairment?" (Runswick-Cole & Mallett, 2012, p. 47; Runswick-Cole et al, 2016). In the context of academic inquiry and concern, the question appeals to the issue of the practical impact of autism research on the producers/consumers of the autism

information-thing. Nevertheless, the act of asking might risk dominion over these 'labelled persons', as it implies a desire for relevance and significance for a presupposed population who have succumbed to 'labelling'. As such, even though direct academic concern with the 'personal account' seems to affirm them, it also could mean dominion over them and their signification: academic inquiry might restore the diagnostic gaze all over again.

The identification of dominion over the 'personal account' category brings me to the topic of personal accounts that have organised and strategized into acknowledged autistic communities (Dekker, 1999; Silberman, 2015) and self-advocacy (Waltz, 2013). I would like to avoid a reading of such communities as a re-establishment of the kind of historical neurobiological essentialism, as this could assign a kind of power to personal accounts that is boldly equalised with clinical literature. Instead, I hope to open up the chance to regard them as potential platforms for challenge in development instead. First documented in the early 1990s, autism self-advocacy has employed oppositional discourse directed to dominant narratives from parents, charities and interventions (Waltz, 2013: 134-143). Such defiant practices are based around the autism information-thing as a common affirmative identity rather than a negative ontology to be 'cured' (Bagatell, 2010). They offer transformative polemics on this affirmation aimed at discursive and social change (Sinclair, 2012). An important concept within these organised expressions of self-identification is neurodiversity, or the statement that assessments of divergent biovalue, molecularised as the 'neurological' here, are affirmative tokens of diversity next to and in harmony with non-pathologised 'typicality' (Jaarsma & Welin, 2012). Called a "movement" in academic literature (p. 21; Runswick-Cole, 2014), 'neurodiversity' in this thesis refers to a concept that may or may not have been mobilised in self-advocacy. Similarly, 'autism advocacy' has been specified by Nadesan (2005) as not 'quite' a "fully formed social movement" in its collective act of subversion of the negative ontology of the pathologised autism category (p. 204). In her reading of personal accounts from autistic advocates and activists, she notes that their claims of autistic people who share a "unique" and "ontologically different" neurobiological make-up is "simultaneously divisive and affirmative" (p. 208). She mirrors this with accounts of the autism category from the

1940s, an early descriptive act of taxonomy of pathologised qualities, to highlight perceived reinforcement of the autism information-thing as divergent despite the "ethos of tolerance" (p. 209). The caution for divisive attitudes in self-advocacy that could re-establish the biomedical categorising gaze can also be found in Runswick-Cole (2014). She argues against the positioning of an 'us' versus a 'them' within her identification of a neurodiversity movement within the commodification of autism as her site of criticality.

As a response to such argumentation, I would like to point out that the discursive power of accounts that disclose identification with the notion of autism might not be as far-reaching as historical clinical accounts. The critique on group formation amongst autistic people risks that this very group is conceived as homogeneous in academic literature once again, but not because of neurobiological make-up but because of discursive practices of allegiances. Such practices could also have creative output that could challenge ableism. In my aim to avoid the question of 'valid' claims to pan-Disability and autistic identity 'politics' in advocacy, I share the awareness of the transformative 'looping' qualities of the autism category as generated by personal accounts voiced in Hacking (1986; 2009a). In such a looping effect, self-identification with diagnostic classification transforms the self-characterisation, self-identification, language and behaviour of the persons who are labelled with a diagnosis. Nevertheless, I would like to avoid my use of constructionist theory against neurobiological essentialism as accusatory towards any kind of ongoing self-expression since it is the conscious act of creative meaning-making that I aim to enable. I would not want to interpret the transformative effect of this meaning-making upon society and its systems of diagnostic classifications as something that bastardises the very notion of psychopathology and human diversity. Instead, conscious efforts to bring in more flexible identity markers, through self-expression and creative freedom from the societal diagnostic gaze, could ensure that able-centric norms are being contested and knowledge from the margins can be preserved that would otherwise get lost.

Academic literature could bring worthwhile reminders of the flexibility of identity and the 'self'. In line of my criticality on the 'complex' self that is constructed within ableism, further effort is needed to prevent the possibility that personal accounts and

expressions of self-identification could be accused of causing autistic people's own oppression. For me, the avoidance of scientific realism is not the same as dropping the 'generalised' next to the 'preferred' 'whole' of the supposed realm outside 'scientific realism'. The ultimate point of concern would be how to theorise oppression, or how to think of power imbalance that make declarations of self-identification meaningful representations without making autism fixed and absolute. In the next section on genealogy, the notion of acknowledgement serves to sketch a palimpsest of epistemological doubt to disentangle accounts with the autism category. This 'doubt' lies in the shadow of the 'despite' in the conditionality that I evoke in the term 'acknowledgement'. In the realm of academic advocacy done by persons who identify as autistic I will offer a brief example of Milton's double empathy problem (2012), in which I regard 'ontology' through the lens of this genealogy of the scientific oxymoron. My genealogy of autistic voice could thus aid a kind of thinking on power dynamics in which doubt plays a pivotal role.

5.3 Understanding acknowledgement of cultural texts as personal account through the genealogy of autistic voice and its conceived impossibility

Foucault's method of genealogy is the most concrete manifestation of my addition of the personal account as acknowledgement to literature on autistic (auto)biographies, Vertretung and declarations of self-identification and self-advocacy. It does not focus on the 'dawn' of autistic voice, that is, significant moments of 'beginnings' like the first categorised case studies in the 1940s or the first documentation of self-advocacy in the 1990s (Waltz, 2013). Considering the narrative of development and the "pervasive developmental disorder" (American Psychiatric Association, 2000), I reject the 'dawn' of the adult voice who has the discursive tools to subvert power relations, next to the autistic child who can break down objectifying dynamics less easily (Vakirtzi & Bayliss, 2013, p. 375). It also does not 'trace back' or 'excavate' any underlying core qualities of the discursive formation and the systemic roots from which it has sprouted. Instead, my genealogy of autistic voice here functions as a palette of inconsistent signification to dissect what it could mean if one poses the notion of an autistic people speaking, studied within the boundaries of this thesis as a recorded document within the confines of a cultural text.

What will not be excavated but formulated as an ongoing interrelation of discursive and historical elements, without a clear end point or estimated turn of events, is the shadow of impossibility and implosion. I am interested in the denial of autistic voice, which is a process of mutual agreement that is also implied in the word 'acknowledgement' yet is not quite 'negation' of validity of self-expression 'coming' from an autistic person. Indeed, the purpose of this interest is to let go this 'coming from' in terms of intention, authorship and reified autism 'within' the person. I instead theorise ableist economies of doubt, which here covers the cultural expectation and recognition of a consistent and representative 'voice', which could give more insight in how to study declarations of autism self-identification that are seemingly essentialist and divisive. This section will specify genealogy in the study of autism as a discourse with a short consideration of Vakirtzi and Bayliss (2013). Insights on the shift to genealogy will then be enriched by the study of the crisis of voice and humanist rational personhood in Erevelles's article and the controversy surrounding facilitated communication for non-verbal autistic people (2005). With these notions of the crisis of voice, I will sketch a palimpsest of paradigm shifts together with remarks on doubt on the validity of claims to self-identification, coming from Sacks (2005) and Rimland (2005) in response to Temple Grandin's autobiographical work (2005). The thinking on a 'scientific oxymoron' that will arise from this consideration of this palimpsestic assemblage will then be deployed in a short discussion of Milton's double empathy problem (2012) to revise claims to autism ontology in the light of insights on the importance of stressing im/possibility.

In order to clarify the usefulness of Foucault's method to my research object of autism as a discourse and definition of the personal account, I will turn to Vakirtzi and Bayliss's (2013) shift from an 'archaeology' of autism to the notion of genealogy. They position the act of genealogy as a reaction to the limitations of the Foucauldian method of archaeology, or the excavation of structure and discontinuity 'underneath' seemingly stable, universal, and naturalised signification (p. 371; Foucault, 1980a). They point out that this mode of critical analyses of discourse and power/knowledge could restrict comprehensive attention to the "causes of the transition from one way of thinking to another" (p. 371). Without temptation for continuity and an illusion of

an end point, a Foucauldian genealogy is concerned with a breakdown of conditions to causality through a fickle study of texts, knowledge and power (p. 371-2). While being cautious to adopt a possibly reductionist view of the act of genealogy, it is exactly such discontinuous modes of transition that are of interest to me to capture. Here, it is important to unsettle the notion that 'we' have begun to 'know' autism and autistic voice 'better' throughout the years. Instead of epistemological concern here is attention to the fickle discrepancies that the concept of autism carries.

The kind of unsettlement that I would like to approximate here is that of Erevelles's (2005) analysis of a "crisis of the humanist subject", which refers to controversies surrounding self-representation that comes from people who have been identified as "cognitively disabled" (p. 47). Erevelles's modern-day case study is specified with the formation of non-verbal autism as the cognitive disability 'in crisis'. This crisis lies in backlash against the use of facilitated communication, or verbal communication with the help of instructive and supportive human assistive support. Mirroring my own attention to poststructuralism in my thesis and my decentralisation of authorship and intention, Erevelles places this 'crisis' within wider poststructuralist problematisations of the essentialist Enlightenment notion of the 'self' through new understandings of these phenomena as produced within signification. She defends a further problematisation of the rational self out of the kind of crisis that she identifies. This problematisation is not because the cases now 'include' them into the realm of rationality that they were 'previously excluded' from, but because they allow further problematisation of this same rationality. Most importantly for my definition of the personal account, she evokes his question 'what is the author?' from Foucault's 1969 essay. The notion of the 'author' and the cultural expectation of its rational incidence comes forth out of the construction of unity that smooths out contradictions, giving the illusion of a mimetic viewpoint onto individual expression (Foucault, cited in Erevelles, 2005, p. 54). Such contradictions are much rougher within the facilitated communication controversy, as the notion of the autistic author "has already been assigned to the space of unreason (disability)" and thus reclaims "the role of rational subject" (p. 55). Erevelles interlinks contradiction and crisis with transitions in the

division of labour and commodity, like in movements towards late capitalism with its self-sustaining ableist belief in the free individual as a producer/consumer of goods.

In my reading of Erevelles, I am interested in the particular kind of disruption that is foregrounded as a 'crisis' and that comes up with the moment of problematisation of the unambiguous rational abled subject. I will not adopt the word 'crisis' myself because of its obstructive connotation of emergent calamity. Instead, my interest goes out to paradigm shifts that have very often been foregrounded as a main theme or 'narrative' throughout autism historiographies. A key shift is the change from the localisation of autism in childhood trauma caused by cold and aloof 'refrigerator' parenting to a biomedical reification of autism as a condition in neurocognitive science (Feinstein, 2010; Waltz, 2013; Nadesan, 2005). Kuhn (1970) poses paradigms and the possibility of shifts in them in science in order to dismantle the practice of science as a field of progress through ever-accumulating knowledge and findings. The term instead presupposes a comprehension of the field of science as a community held together by agreements, as paradigms are the ultimate scientific achievements that stem from these historically bound set of beliefs. In case "anomalies" to these paradigms (p. 5) counter agreements and the flow of new insights too much to subdue, new investigations form a "scientific revolution" (p. 6) with new scientific perceptions to its objects of study.

In my understanding of acknowledgement and the genealogy of autistic voice, I regard personal accounts as palimpsests of 'anomalies', or as disruptions of agreements on ableist exclusions from human subjectivity, articulation and self-expression. For me, Erevelles touches upon one of such disruptions with her discussion on autism, expression through non-normative interdependent means of communication, and the controversy that sparked it. To make the palimpsest imagery concrete, in my own academic endeavour of studying autism as a discourse in cultural texts, mediated declarations of autistic voice on 'erasable parchment' still have 'traces' of agreements of impossibility on it.

Without historiographies of an 'upcoming' movement of acknowledged autistic voice, I localise my study of the fickle and conditional process of 'acknowledgement' within

anomaly and the threat of a possible 'revolution' in conceptualisation from outside the scientifically realist positivist gaze. It is here that the formulation 'scientific oxymoron' concretely comes up, since it highlights the legacy of acknowledgement as something that occurs in the context of transgression of scientific agreements and paradigms. Indeed, the first published personal account written by American ethologist Temple Grandin, *Emergence: Labelled Autistic* (2005 [1986]) contained a self-representation of the author as a "recovered autistic" (p. 1). 'Recovery/recovering' suggests that mediated voice is only possible if the autism condition has been overcome in this 'unique' case. The book contains a foreword by Rimland (2005), who spearheaded the shift towards biomedical autism research as initiated by parents of autistic children. His foreword confirms the publication to be an account by stressing that it is a "true" story "so breathtakingly unusual that it will be taken by many as mere fiction" (p. 1). Similarly, Sack's expresses his initial surprise and disbelief in response to Grandin's autobiography in his own neurologist's account *An Anthropologist on Mars* (1995). In his response, I see a persistent historically situated belief that people with the diagnosis of autism lack the introspective skills that are required for expressions of 'voice' as outlined in this very chapter (p. 282). This report of initial scepticism exposes a small-scale instance of the bigger theme of problematised scientific agreement that deserves further attention from declarations of criticality on the concept of autism.

Using my insights from Foucauldian genealogical method and Erevelles's case studies of articulative expression outside of the ableist unified subject, I define my point of interest in autistic voice as a reminder that such scientific agreements were 'negated' or at least brought realisations of insufficient consistency and unity. Articulation poses a threat to scientific realism and its exertion of control over autism as a discourse and thus incites a will to restrain it. Simply put, the autism personal account was thought to be impossible and implausible. I resist an academic incorporation of this fact as something that has been overcome now that books and documentaries are produced, distributed, and promoted as (auto)biographical. Instead, the fickle nature of voice and its acknowledgement motivate me to regard personal accounts and claims to autistic voice and self-advocacy as texts that are still in non-chronological and non-causal

interrelation to scientific agreements that exclude the possibility of the autism personal account.

While claims to voice from people who identify as autistic seem to add to existing ableist notions of the autonomous speaking self, I would like to propose a different reading that enables a genealogy of a 'despite', in the sense that personal accounts occur and are performed in the shadow of realisation that paradigms within autism research and thinking have failed to incorporate the option of introspective articulation. I employ 'despite' to think about ableist cultural stances towards personal accounts as uncomfortable and excessive, as the question of 'excess' mirrors the theme of diagnostic inflation that I have rejected as a site of criticality. It is important to note here that 'inflation' not only contains valorisation, as unpicked in the chapter on my approach to autism, but also history. 'Inflation' also implies that the value of the autism information-thing has inflated and imploded through time and has shifted to a state of 'problematic' surplus, partly practised by people who identify as autistic. Indeed, in Rimland's foreword to Grandin's book, his description of Grandin's condition and alleged 'recovery' contains the remark that "[i]n recent years […] the term [autism] is vastly overused" (p. 1). With this remark, Rimland 'acknowledges' Grandin's voice as a fresh perspective of a possibly recovered autistic person that succeeds initial scepticism about an autistic population who generally does have an academic background unlike Grandin (p. 2) but precedes diagnostic inflation. The 'oxymoron' in my notion of the genealogy of autistic voice as a scientific oxymoron thus not only stands for the legacy of perceived impossibility, but also for the cultural fear of discursive implosion and confusion about the autism category.

My genealogy of voice thus allows thinking on acknowledgement as a confirmation of the occurrence of autistic voice in a cultural text according to the genealogy of the imploding scientific oxymoron of exactly this occurrence. Acknowledgement is a cultural construct of conditional affirmation that is subject to social and scientific agreements on whose 'voice' on autism counts as 'valid'. The personal account can be studied as a constellation of texts that together form acknowledgement of voice. Grandin has not only published *Emergence: Labelled Autistic* at a major non-fiction publishing company, it also contains introductions and co-authorship that further

'confirm' that her book is indeed an autism personal account and guarantee its 'uniqueness' despite the 'threat' of evaporating commodity value. Naming 'acknowledgement' foregrounds such cultural dynamics rather than claims about the status of certain texts as authored by autistic people, as such claims would actualise the kind of doubt that I am dissecting in this thesis.

My academic research object of autism as a discourse in cultural texts means that I will not identify anything that does not contain autism as a discourse as an autism personal account. I also would like to avoid retrospective diagnosing (Snyder, 2004) for the same reasons why I avoid a mimetic approach towards autism. Any form of retrospective interpretation of a cultural text as a 'personal account' or an example of autism life writing is inevitably an acknowledgement itself. My own practice of acknowledgement would also be bound to my own specific space and time in which the autism information-thing gets its value as a cerebral 'thing' detached from human making and interpretation. By contrast, I dissect the social process of acknowledgement to enable declarations of autism self-identification outside of the scientifically realist gaze, whilst being aware of the legacy of exactly this gaze and the power imbalances that they have brought to discursive formations of self-identification with a clinical category.

5.4 De/constructing claims to ontology in academic personal accounts of autism

This section covers the way in which the genealogy of autistic voice as a scientific oxymoron could help to study self-identification in writing in and outside academia, especially texts that might be regarded as reinforcement rather than problematisation of realism. It is key to point out that it would be problematic to conclude that people who identify with the concept of autism in accounts now claim their right to return to a realist understanding of autism or in/tolerated neurobiological 'difference' in general. Such histories of taxonomy, categorisation, and realist claims to the truth are exactly the ones that have denied people identified as autistic their acknowledgement of voice in the first place. This realisation is key to my genealogy and asks for a specific kind of (re)consideration of academic thinking in personal accounts that might easily be considered as essentialist. A rather straightforward example that I would like to raise here is Milton's double empathy problem. This term encapsulates his reflection

on the ontology on autism that reacts to the 'lack' of empathy that has been assigned to autistic people in scientific studies on the ability to imagine the mind of other individuals (Milton, 2012). Milton appeals to the "myth" of "Theory of Mind" (p. 884) that is a central point of isolation of lack and deficit in the current neurocognitive scientific paradigm (Nadesan, 2005) and which hypothesises that autistic people have lowered skills to imagine, 'theorise' and cognitively grasp other people's thoughts and feelings (Fuchs & De Jaegher, 2009).

As a challenge to its disabling effects, Milton (2012) poses a more mutual and intercorporeal play on the denial of empathy with his term "double empathy problem". Referring to a shared "disjuncture" between the lived experiences of autistic people and the social conventions of people who do not identify as autistic (p. 884), the formulation of the term aims to decentralise disruption of social interaction outside of the autistic person. This aim stems from a discussion of the "ontological status" of autism (p. 883), which might seem to reinforce the kind of scientific realism that Milton attempts to deconstruct. However, I would like to state that this kind of engagement with 'ontology' is an engagement with the genealogy of clinical taxonomy in scientific realism, its limitations, and societal revolt against its claim to absolute truth, next to my exploration of the genealogy of autistic voice. By foregrounding and subverting the isolationist scientific theory of Theory of Mind, Milton evokes and plays with the realism of the legacy of denial of empathy. This occurs in a subversion of 'empathy' as a topic of concern to ableism and ableist social interaction in general rather than personal 'impaired' socio-emotional skills.

To frame Milton as disruptive to declarations of criticality on autism would thus be ironic in the light of this play with the ableist notions of 'lack of empathy' that have already heavily discredited autistic voice to begin with. He maps the legacy of the exact realism that is at the core of declarations of criticality through subverting it from the inside. By claiming legacy, Milton does not necessarily make his life 'with' an ontological autism information-thing absolute but instead enacts and facilitates a temporalisation of autism self-identification. I have focused on Milton as an example of declarations of autistic voice; it is through such acknowledgement of claims to ableist paradigm, time, and legacy that I would like to affirm personal accounts in

academia. My affirmation contributes to my centralisation of autism rights in my thesis through intellectual harmony rather than research object dominion.

All in all, a potential result of my genealogical reflections could be the opportunity to start thinking from the point of imbalance: not in the sense of binary parallelism, but of the privileging and prioritising of one particular structure of signification over another. I add the concept of the political economy of doubt to existing literature that reflects on the importance of proximity towards personal accounts in favour of autism epistemology that does not come from people who declare self-identification. This includes the genealogy of autistic voice as writings that highlight the shadow of doubt in the very declarations that acknowledged personal accounts are 'different' from anything that came 'before', implying anomalies in a population that is hard to reach outside of the scientifically realist gaze. The focus of the next section, which introduces the study of acknowledgement in my next two case study chapters, is differences between respectable doubt as 'nuance' and doubt that disputes and silences, enabling and respectable doubt that also facilitates dispute.

5.5 My reading of power imbalance in my two analyses of personal accounts as acknowledgement

This section serves as a prelude and an introduction to the next two case study chapters, in which I explore acknowledgement of autistic voice in different modes of production, distribution, style and discourse. Both case studies revolve around portraits of one or several people who disclose self-identification with the notion of autism and convey meaning on autism epistemology. Central to these chapters is the exploration of uncertainty about the question of what 'autism' is and how one gets to know and recognise it, marked by me as key to my presentation of a political economy of doubt in the full thesis. Epistemological doubt is the theme that transcends and overarches the autism metaphorical concepts that I formulate for each case study. In the case of "My Autism and Me", this metaphorical concept is 'autism-is-rendered', and in *In My Language*, it is 'autism-is-resisted'. I will first outline the power imbalance in question, after which I will specify overarching themes like epistemology, normativity, and the production of voice in the case studies.

My presentation of the scientific oxymoron in social processes of acknowledgement contains and discloses the historical fact and perceived threat of uncertainty about changing boundaries between who does and does not count as autistic. Autism used to be diagnosed less often, which has sparked concerns about diagnostic inflation, and many autistic people have now proven themselves capable of sharing their life experiences, regardless of clinical consensus. Cultural texts with personal accounts are palimpsests of surprise, scepticism and awe for the 'miraculous' occurrence of voice, which presupposes that claims to self-presentation and self-identification might or might not be 'valid'. When it comes to my two personal account case studies "My Autism and Me" and *In My Language*, I would like to argue that the former constructs and manoeuvres epistemological 'doubt' as something that inaugurates actualisation of normativity through doubt, mirroring spectatorship in my reading of *Extremely Loud & Incredibly Close*. The latter contains more direct anticipations and expressions of doubt and dispute directed at the autistic producer and distributor of the cultural text. Whilst "My Autism and Me" is a frame story documentary of several shorter accounts presented by an autistic girl with scripted lines (V. Bell, 2018), *In My Language* contains the creative endeavour of a non-verbal autistic woman in a small-scale distribution on a personal YouTube channel. I would like to state that this difference of presentation of voice and self-identification in production and distribution is significant in relation to the imbalance between the contrasting forms of doubt that I sketch in the case study chapters.

For "My Autism and Me", a CBBC *Newsround* production that contains pre-scripted content, doubt is formative, normative and aids its specific biomedical reification of autism as an enabler of 'success stories'. *In My Language* might miss out on such seemingly affirmative and productive perceptions of 'nuance' and faces the oppressive shadow of the scientific oxymoron more directly. The video contains remarks that the spectator may not believe that the video is 'truly' made by the non-verbal autistic person depicted and a clear instructive reading of tactile and corporeal interactions with space as language. Furthermore, producer Baggs has gone through online backlash directed at the 'validity' of her claims to dis/ability. This contrast between sly negotiation of 'nuance' in "My Autism and Me" and the negative ableist force of doubt

and dispute in *In My Language* will form the basis of further conceptualisation of the political economy of doubt in the conclusion.

Both chapters will unpick autism epistemologies in a way that fleshes out my reflections on doubt in the case studies: how is autism 'known', how is its peculiarity conveyed, and for whose and what kind of interest does this occur? The chapter on "My Autism and Me" will present its epistemologies of doubt as 'semi-ambiguous'. With this formulation, I aim to capture its hybridity between the self-fulfilling certainty of biomedical reification and the creative freedom that comes with its emphasis on heterogeneity, imagination, and life opportunities. My academic engagement with *In My Language* will be slightly different as I will not actively engage in a study of epistemology of its message on non-normative tactile communication as language and voice. This specific message is conveyed in speech and subtitles after a play with social expectations of disability indexicality, or the will to know 'signs' of the 'non-person' that 'appear' in the document. I continue the kind of resistance towards dominion over personal account and the sensibility towards genealogies of presupposed impossibility that I have discussed in this chapter, by means of a harmonious contribution to the dis/ability conceptualisation in the video. This act of 'singing along' expands rather than interprets autism epistemology.

Another topic that binds the two case study readings together is the framework of performance and enactment of autistic voice. I do not regard the personal accounts as reflections of personal experience, but socially and historically bound platforms of active signification. In the case of "My Autism and Me", I will explain how its representational strategies of the use of animation and presentation in a documentary produce dominion over the specific 'semi-ambiguous' reification of autism as neurobiological human 'resource' with which one can achieve success both despite and because of it. In the *In My Language* case study chapter, I will focus on its status as a YouTube video in terms of a facilitation of online space for potential new meaning exchanges for people who identify as autistic.

Finally, my overall interest lies in a sketch of normativity as a way to outline and lay bare ableism. The "My Autism and Me" case study pays special attention to the promise of labour and proximity to the labour market because of its implications for

neoliberal naturalisations of the 'responsible' self who is 'freed' by the market, with reified autism as a 'unique selling point' in the laissez-faire politics of neoliberalism (Goodley, 2014). By contrast, the *In My Language* chapter is concerned with ableist normativity as a demand for consistent dis/ability distinction. This kind of pressure is imposed upon Baggs's creative endeavour to film and edit a persuasive message on voice within something that might seem like an index of voiceless disability. Its creator, Amelia Baggs, employs familiar discourse, style and emphasis on tactility. My reading of this highlights the normativity of dis/ability that comes forth in the ontological doubt, that is, preoccupied with the question 'is this truly autism?', about an articulate autistic person who is non-verbal 'yet able' to make a persuasive creative endeavour.

5.6 Concluding thoughts: undermining fatalism in the face of power imbalance

This chapter has been a specification of my approach to autism and representation that was the focus of the previous two conceptual chapters. I argue that a text that is produced by a subject who identifies as autistic is not necessarily a static artefact that holds a unilateral and deeper truth on lived experience. Instead, the personal account transcends static self-narration and is much better understood as a set of relations between texts and people in which autistic voice is or is not acknowledged. I have presented this particular understanding of the personal account right before the two case study chapters that are themselves personal accounts. Personal accounts are 'textured' within society, just like epistemological doubt surrounding the diagnostic concept of autism has generated a fervent and ableist meaning exchange. My chapter and its central argument acts as an elaboration and specification of my method of genealogy that I have presented in the thesis introduction: my definition of the personal account helps to uncover the conceived impossibility of autistic voice throughout history. The phrasing 'scientific oxymoron' has exemplified this sense of implosion in autism self-identification and signification that I have conveyed with a method of genealogy. Overall, my notion of the personal account is one of a palimpsest of autistic voice on which perceived conditionality prevails in the notion of an autistic person speaking in a mediated account. By declaring my next two case studies as personal accounts and focusing on the cultural process of acknowledgement in both chapters, I enable the study of power imbalance that could befall autistic persons who create their own cultural texts and declare self-identification. This grants

room to flesh out the meaning and implications of a political economy of doubt and further academic interest in ableist economies of doubt.

Although I greatly appreciate the theoretical room that I have provided myself with in terms of carefully considering the personal account and the constructionist notion of acknowledgement, I also understand its density. I might also risk impressions that my focus on acknowledgement might be an overly cynical reflection on self-expression by autistic people or that it might not lead to practical recommendations for the improvement of enabling autism representation. In future dissections of the genealogy of autistic voice and ableist power imbalance, I hope to deliver more concrete reflections on 'autism (auto)biographies' as well as potential room to interrogate power imbalance with a more practical outlook on creative 'free play'.

6. CBBC's *Newsround* special "My Autism and Me" (2011): Autism is rendered

This theme chapter presents the metaphorical concept of 'autism-is-rendered', which captures the issue of autism and ableist epistemological uncertainty in the 2011 British children's documentary short "My Autism and Me". Within this case study, I mean by 'rendering' autism 'representing in a certain form' or, more specifically to this particular theme chapter, 'making an abstraction comprehensible and concrete for an audience that is new to the issue at hand'. In a series of short portrayals of children who are identified as autistic, the documentary presents the abstract notion of autism with creative means such as animated sequences, brief explanations of autism, and reports on challenges faced by children. Key to my reading of "My Autism and Me" is its parallelised combination of 'knowing' and 'not-knowing' autism, which I call semi-ambiguity about the condition of autism. An audience of young children is a blank slate, since they need explanatory and creative concretisation of the concept of autism in order to get to 'know' 'it'. "My Autism and Me" is full of visual, textual, stylistic and thematic juxtapositions that are central to this case study chapter. First, the documentary juxtaposes six different idiosyncratic voices of children identified as autistic that are clearly stylistically distinguished from one another, predominantly with the use of animation juxtaposed with live-action scenes, often superimposed next to the children. Located in and in-between scenes of individual stories, animation renders the concept of autism concrete and tangible for a young audience and creates a positive atmosphere. Within the confines of the case study chapter, the 'autism-is-rendered metaphorical concept allows me to delve into the creative didactic means

with which children's stories are acknowledged as autistic voice. With this focus, I centre the topic of epistemological uncertainty as strongly present throughout the documentary, as well as its depiction of the presumed heterogeneous nature of autism itself and the children who live with the diagnostic label.

The word 'rendered' is meant to signify that a world of children with autism that was previously not well-known is now being acknowledged as a personal account, albeit with the explicit commentary that scientists "do not know what causes [autism]". As an epistemologically uncertain topic, the personal account has here been made 'representable' according to a set of creative strategies and the premise that not much is known on autism. My metaphorical concept mirrors Didi-Huberman's (2016) term 'to render sensible' from his cultural analysis of the works of author James Agee and photographer Walker Evans, who each portrayed societally oppressed people whose lives often slip away from the public consciousness. Didi-Huberman defines "to render sensible" as a process of "render[ing] accessible to the senses, even to render accessible what our senses […] do not always know how to perceive as 'making sense' ": a forgotten history suddenly becomes "sensible" (p. 85). "My Autism and Me" makes children's stories accessible, visible and representable in a way that they were not made visible before, by means of imagery that appeals to children, like rainbows and drawings that come to life. Even though such imagery makes the accounts of life with autism tangible, its connection with knowledge on autism is heavily abstracted. As such, the documentary shows another manifestation of epistemological ambiguity on how to know autism, similar to the case study *Extremely Loud* in which I formulate its particular manifestation of ableist epistemological uncertainty as 'speculated'. The source domain of 'rendered' is based on my interpretation of textual and visual cues sequentially to autism as a discourse.

"My Autism and Me" is a 16-minute television special that was aired by CBBC's children's current affairs programme *Newsround. The Newsround* specials are short documentaries of irregular length that aim to let children themselves speak about serious life issues (Bell, 2018). This aim makes the episode "My Autism and Me" a relevant case study of the cultural acknowledgement of personal accounts and the way in which they make 'autism' 'known'. In order to emphasise that I am looking at one

episode, 'My Autism and Me' is not written in italics but between double apostrophes. The documentary contains short features of children who tell about their lives and a frame story by 13-year-old child presenter Rosie King. Aimed at a young audience with its strong didactic purpose, it juxtaposes live-action reports with animation and animated sequences made by studio Black North. Its information on autism extends to the internet, with an online guide that includes more information on autism characteristics and further resources to consult on the topic and potential support. Not only is the audience addressed and informed, it is also incited to take appropriate action if necessary. Throughout this multimedia project, the only clearly recognisable information resources are seemingly children themselves: the children who are identified as having a 'form' of autism, including Rosie, and their family and friends. Rosie King narrates the documentary and interrupts short biographical sections with her commentary and explanations, while several children are interviewed about their lives with accompanying animations. Rosie's mother is the only adult speaking in front of the camera, as she talks about the only silent autistic child portrayed: Rosie's younger brother Lenny. Taking into account every scene that features a child who is identified as autistic, the number of personal accounts is seven: presenter Rosie, three separate short features (called "stories") of autistic children, and one scene with interview segments of three others. It is the construction of these personal accounts through cinematic codes within the documentary short that forms the focus of my reading.

In line with the aim of "My Autism and Me" to create more awareness and understanding of autism amongst a general young audience, the term 'autism' forms a documentable yet tangible thing that can be shaped into creative iconographic forms in order to convey life 'with' it. Not only do the accounts of the seven children reify autism as a thing that 'affects' them in 'different' ways, the animation sequences also bring in schematic abstractions and expressive fantasy worlds that give meaning, clarification, and illustration to their stories. Even though the presumed indexicality of documentary and creative representational strategies of animation seem to preclude one another, animation and documentary have been combined before. Honess-Roe (2013) argues that animation affirms instead of problematises the expressive depiction

of non-fictional events that are common in documentaries. The animation/documentary hybrid thus smoothly renders the condition of autism in a way that easily conveys a clear message about human difference to a young audience, giving the illusion of a 'mirror' onto the reality of imagination and expression.

Within "My Autism and Me", this also means that autism itself is reified and thus rendered into something outside of the boundaries of a clinical category. In my metaphorical concept, it is autism   and not documentary accounts that are being rendered. The documentary contains the message that "it does not have to hold you back" and that a rich life 'on the spectrum' can be attained once misunderstandings are gone and forms of support are found. Rainbow colours, funny sound effects, and light music add an uplifting tone to this message. Regardless of its infectious positivity, this introduces a specific neoliberal interpretation of life 'with autism' that consists of individual resilience and responsibility. Rosie not only talks about autism as a difference in her 'brain' and in her 'life'. She also presents the way in which she managed to adapt this 'typicality' to taken-for-granted notions of capital and value and achieved "success" through her illustrations – clearly mirroring the use of animation in the documentary. The metaphorical concept of 'autism is rendered' does not just show the explanation style of this autism report. It shows a very distinct take on the very notion of autism itself, in a way that strongly steers autistic and non-autistic people but simultaneously is hard to detect because of its subtly embedded message of productivity.

Thematically, with regard to my interest in 'knowing' autism and the personal account as an acknowledgement of autistic voice, the question of autism and epistemology is characteristically two-faced in "My Autism and Me". I name this observation 'Janusheads' in this chapter. Each child has their challenges, but also their particular ways of overcoming them; they have a disability but still have a chance to develop their strengths. The children are presented as people who can make a positive, recognisable contribution to society. In isolation, these focal points are unequivocally positive, which is underlined by the recurring visual motif of colourful rainbows that refer to the autism spectrum and its diversity. However, with the 'autism-is-rendered' metaphorical concept, I wish to point out the pervasive abled normativity in "My

Autism and Me": its two-faced portrayal of autism, knowledge and personal accounts leads to an underlying neoliberal message of imperative market value. The affirmative acknowledgement of autistic voice is prevalent, yet conditional and bound to the provision of market value; the implication of such a depiction might be that a life without a job is a life without intrinsic value and potential. Future research that builds further upon the 'autism-is-rendered' metaphorical concept should be conducted with awareness of the fact that a seemingly positive and well-layered depiction can still direct towards narrow abled ideas of societal worth.

My argument on "My Autism and Me" will be outlined in different sections. The structure here is roughly the same as in the *Extremely Loud & Incredibly Close* case study chapter: I start out with autism as a discourse and then widen my scope towards a discussion of normative epistemologies of negotiated doubt. The first two sections will describe the way in which the documentary distinguishes different personal accounts on autism and how the use of autism categorisation brings validity to these accounts as acknowledged autistic voice. Central here is the clever negotiation of epistemological dualisms or the aforementioned Janusheads, which is also a key theme in my defence of the political economy of doubt. My subsequent section on the use of animation outlines the theme of imagination, after which I discuss the formation of the autism-information thing as a negotiation of biovalue in the next section on the documentary's artistic rendering of the brain. My final section will outline the ableist normativity towards which the dualities and autism as valorised biovalue negotiate: the assurance of the neoliberal 'success story' both despite and because of autism.

6.1 "Me" and "my autism": dissecting speaking subjects

The presentation and narrating style of "My Autism and Me" already becomes apparent in its very title. The word 'autism' has been squeezed between two pronouns: "autism" is accompanied by a first-person possessive pronoun, while a first-person object pronoun is positioned after the "and". Even though the "and" suggests an entity that is separate from "autism" as the thing that the "my" points to, the words "me" and "my" suggest that they all refer to the same person. Because of the first-person pronouns, this person must be capable of speaking and must have the introspective skills to identify a sense of self. As the documentary portrays different

perspectives from autistic children, it is ambiguous who the "me" in the title is, although Rosie might qualify the most as the presenter that guides the audience through the different stories. The middle-ground position of the word "autism" in the title downplays its effect as a pathologised label that determines the content of the documentary. It is even stronger than 'person-first' language on autism that asserts that the person and their label are not mutually comparable and the 'person' should be put 'first' in order to 'prevent' dehumanisation. The "and me" adds yet another emphasis on the 'person'. The three-partite structure of the title thus creates two entities: one that reifies autism as a thing to possess by an individual, and one that expresses the agency of this individual, creating a somehow different entity from the reified autism. The title "My Autism and Me" shows that reification of autism often results in a reification of the self; the documentary does accept autistic personhood, but one that possesses and takes on agency in the wake of this 'thing' called autism.

The introduction of the documentary itself might seem to slightly complicate the title. Rosie King stands in a park, waves with her arms, and introduces herself as "Rosie", after which a superimposed animation of her name adorned with flowers appears as if she has 'made' this juxtaposed reality into 'being'. The very short time between the movement and the animation suggests indexicality. She then briefly expounds her living situation and her future plans as an "actress". Brief superimposed animations of abstract colours and a theatre curtain create divisions between these statements. A medium close-up without animation shows Rosie explaining that she "also has autism, which means that my brain works a bit differently". The audience is introduced to the autism information-thing at the same time: the word "also" suggests that this thing is somehow separate from Rosie's families and dream job, which are things that many children are asked about by adults. A further explanation of the word immediately follows: autism is assumed to 'mean' something 'to Rosie' and it is quickly presented as significant in and of itself. A very brief montage, or a 'teaser', follows of the animation sequences and live-action shots that will soon follow (the significance of autism triggers an overview of everything that is to come), and Rosie is now heard in a voice-over.

Her presence as a placeless extradiegetic voice establishes her dominant presence in the entire documentary, as she is the only person portrayed who transcends her position as a girl in her everyday living environment and is aware of all interviewees. This contrasts with Oskar's role as the narrator in *Extremely Loud & Incredibly Close*, who only comments on his personal thoughts and impressions. In her account of the production of "My Autism and Me", director Victoria Bell (2018) has confirmed that the voice-overs and sections with Rosie as a presenter were scripted by her along with a layout of each personal account 'story'. Rosie acted as a consultant who could check if she agreed and was comfortable with the content that she would present on-camera, although her account of her life and her brother that were separate from her presenter role were not scripted. Bell, coming from special education, is also the person who interviewed the children, during which she asked what autism meant for them and what they would want other people to know about it. The confirmation that Rosie does not speak her own text in her presenter role and that the interviews originated from predetermined questions does not change my reading of "My Autism and Me" as a personal account. What is central to my definition of the term and subsequent readings of cultural objects is the way in which 'acknowledgement' of accounts as autistic voice gains shape. Nevertheless, it is important to not just dismiss author intention while erasing the process of documentary production. In the *Extremely Loud & Incredibly Close* case study, the role of the potentially autistic protagonist becomes clearer with a consideration of cultural capital exchange in Indiewood cinema. Here, the insights on scripted texts from Rosie enhance my notion of the personal account as a cultural process of acknowledgement instead of a presentation of autism being 'present'.

In my reading of autism epistemologies and the common theme of doubt, it is discourse that counts for me, rather than the source of the acknowledged personal account. In her presenter role, Rosie states: "I'm going to take you into my world". Although the documentary makes clear that Rosie indeed is a girl (me) with autism (my autism), it also presents itself as a spatial movement through a 'world' that Rosie is living 'in'. This evocation of a 'world' mirrors language on autism that is based on spatial withdrawal. Broderick and Ne'eman (2008) assert that such persistent

metaphors come from psychoanalytic notions of the child that is 'locked' within itself and is in need of rescue (p. 466). Rosie's world, conversely, consists of colours, happy soft guitar music heard in the background, and "imagination". She will show "how autism affects children in all sorts of different ways", which again seems a bit inconsistent: even though Rosie's world seems to be unique and singular to her and her imagination, her 'world' also consists of autism 'affecting' children 'differently'.

The viewer will dive into a new spatial entity other than its own, but simultaneously, it will also be introduced to a collection of stories that all reflect on the autism thing that children can 'possess', and those children are all located in the 'real' 'world' like schools. This Janushead of seemingly contradictory information is the most important feature of the documentary when it comes to its use of autism as a discourse and will be an important theme in this case study overall. Right after the teaser and right before the title screen, Rosie appears in a medium long shot in the park again, and now directly addresses the audience, which   is asked to "stick with me and find out what it really means to be autistic". Within the story world that the documentary conveys, Rosie will be a guide who steers the viewers through this new autism 'world' (stick with me), a truth bringer or myth debunker (what it really means), and, most concretely, our presenter.

This 50-second introduction establishes and initiates a clear structure of narration and narrators. Right after its ending, Rosie now sits in a colourful bedroom on a couch/bed hybrid and is one of the autistic children who reflects on "the kind of autism" she has, rather than our presenter. Barely looking at the camera, she now reflects on moments of confusion with peers, as well as her word/sensation synaesthesia and personification of inanimate objects, with very brief information on characteristics of Asperger's Syndrome in general. This is followed by an animated sequence with its own title card and background music, in which Rosie is heard as a voice-over in her role of presenter again.

Right afterwards, we see alternating short personal accounts of three different boys from different ages, whom we see only in a black-and-white medium close-up on the side of the screen with juxtaposed illustrative animation. The children talk about their personal experiences with anxiety, challenges with executive functioning, and

concentration issues. What is striking is the consistency of their use of the present simple tense: "I have anxiety issues", "I need to try and think very hard about it". The present simple is mostly used in cases of general facts and customs, and within the context of autism, it helps to express autism characteristics and the way in which 'autism' affects each of these three children. As such, 'autism' gets reified into a consistent general whole that is very personal at the same time. It also effectively prevents ambiguity and the expectation of indexicality. If the present continuous or the past tense had been used, like in 'I am having anxiety issues' or 'I had anxiety issues' respectively, the indexical gaze could 'demand' contiguity all over again. Questions why the anxiety is not immediately apparent during filming, or why the child expressing the anxiety issues is still identifying as autistic, touch upon this cultural desire for indexicality. Just like Rosie, the children also talk in terms of possibilities and occasions: "I am sometimes easily distracted", "If someone does touch me...". They seem to be located in a white room on their own, yet interviewer Bell is heavily implied to be present. One child says "I'm sorry, I can't really describe it" when he is talking about his personal sense of deviance.

While introducing the section on Tony, after a wipe away from the three short interviews that contain rainbow animation, Rosie combines her personal account of autism and her presentation role while being in the park again. Her account of autism 'giving' her unusual memory and imagination skills and its potential impression on others forms a prelude to the new report on Tony. Unlike the section with the three short succeeding spoken accounts, Tony is not only interviewed but is also filmed in his own house. He also has his own animated title screen. The report largely focuses on his great interest in the strategy board game Warhammer. Rosie's voice-over is still heard in the beginning, and still gives accounts of reified autism 'expressing itself': she mentions the pathologised term 'obsession' in relation to Tony's interest in Warhammer. Tony's younger sister is also a person who is shown speaking, reflecting on autistic people in general, Tony's interest, and his difficulty in finding friends. Overall, the report focuses on the positive effect of the board game on Tony's wellbeing and his negotiation of friendships, as he makes friends through the game as

well. Tony himself reflects on his perceived differences with "normal" people's interests and questions what is normal anyway.

In contrast to this first short report that focuses on one particular autistic child, the second one differs from this constructed personal account. In another presentation interlude that introduces the next report, Rosie tells about more severe "types" of autism compared to her own. This is followed by a hard cut to a medium close-up of Rosie's brother Lenny, who does not get an intertitle, but is instead introduced by Rosie, who states that Lenny cannot talk. Lenny is the only child identified as autistic in the documentary who does not speak for himself, despite the fact that the short report is focused on him. Instead of the clear division between shots with interviews and 'fly-on-the-wall' shots during Tony's report, most of the shots featuring Lenny in this report show him in close proximity to Rosie, who delivers commentary. He is seemingly oblivious to the fact that he is being filmed and followed, unlike all other autistic children in the documentary. In separate shots, Rosie and, in one instance, her mother reflect on Lenny, his interests, and the visibility of his disability in what appear to be separate rooms due to the camera angle.

The third report does feature an autistic person speaking again and is the only one that is not situated in a domestic space but in a clearly recognisable school. Rosie introduces Ben's story through the lens of the lack of visibility and understanding that autism gets, as well as the problems that this might bring. This is the first time that the notion of autism and its challenges is confirmed as something that comes into being within an interaction between the child and their environment. Ben is also introduced with a separate intertitle, just like Tony, but this third and last report is the first one with a distinctive narrative structure. Filmed within a school environment, together with and separate from other pupils, Ben is presented as a boy with difficulty managing his emotions, who used to be alienated and alone in his school environment because of bullying, but then received help and a separate room from a Learning Support Unit. Ben tells this story through interviews in a classroom, with animations superimposed on a whiteboard next to him. Ben is also the only autistic child besides Rosie who is heard in a voice-over, which is implied to be the diegetic sound of his classroom interview that is mixed onto shots of Ben in his everyday school

environment. He presents a clear-cut story of his life from being bullied out of misunderstandings to being "fairly OK" after school-based intervention. Short reflections of small groups of Ben's fellow pupils in the schoolyard confirm this more positive account. Ben's report closes on a positive note, with guitar music that continues to Rosie on Sheaf Square in Sheffield, telling more about the challenges that autistic people face through their lifespan. Together with a short superimposed visual on a shot of Ben that states that half of autistic children in schools are bullied, this is the first time that the information presented transcends the realm of personal accounts and generalised information on characteristics. Rosie lists information such as employment grades, after which she introduces her own "success story" with a separate intertitle, wrapping up the reports with personal accounts, her role as the documentary presenter, and her message of hope.

Overall, six autistic children are seen being introspective and speaking about their own lives: Rosie, Tony, Ben, and the three children from the short interview sequence. Besides Rosie, these are all white British boys. The people who are visibly speaking about autism and the children portrayed are Tony's sister, Rosie's mother, and Ben's classmates. Rosie smoothly transitions from an autistic girl who reflects on her personality and life to a presenter who gives a broader context to the information shown. Her brother Lenny is the only person who does not speak and only is spoken about. More quantitative information on the documentary like this (that is, details that can be counted) will not reveal what makes the accounts of all these narrators acknowledgeable and prompts people to accept the information shown as coming from autistic people. In the wake of the ontological and epistemological doubt that the notion of autistic people speaking for themselves brings, the discourse used in the documentary could tell a lot about the construction of valid words on autism. Ultimately, not only is autism 'rendered' for children, but also for the sake of a larger establishment of validity and respectability.

6.2 Acknowledgment of the personal account in the construction of validity of autistic voice

This section will discuss the topic of acknowledgement of autistic voice through the concept of validity and how the accounts of the children speaking are constructed as

'valid' through a negotiation of epistemological dualisms. Looking back at Rosie's introduction of herself and her life, it is important to note that she states that autism means for her that her "brain works a bit differently". The notion of autism as something related to the brain will be highlighted in a separate section on brain imagining, so for now, I will only focus on the phrase "a bit differently". I have noted before that Rosie's evocation of the term 'autism' as an axis of identification is immediately followed by a confirmation that this means something, while the remark that she also has autism simultaneously reassures that this does not represent her 'full' personality. Autism is linked to the notion of 'functioning': the brain is stated to 'work' in a certain 'way', and Rosie's brain works "differently". Significantly, the word 'differently' not only establishes Rosie's deviance, it is also preceded by a phrase that specifies this deviance: a bit. Rosie is different, but at least not quite significantly so. A diminutive word like this aims to diminish the material effects of autism: it 'causes' something, which is a difference worth contemplating and considering, but it is not something that causes much concern for Rosie. The presence of the wording "a bit"' has a disarming effect: we have just seen her talking about her family and about her hopes of becoming a "world-famous actress", so we could easily accept her as one of us, who we could talk to and who could be our guide through the 'world' of autism. Rosie is an everyday girl but with a twist.

This notion of the 'middle ground' is a clever negotiation of seemingly contradictory epistemological cues that is highly important throughout "My Autism and Me" as a whole. The reason why this could easily go unnoticed is its resemblance to nuance alone: that the documentary allegedly moves away from generalisations on autism that present one story as the absolute truth on life with the condition. However, specific paradoxical moments like the fact that the documentary presents a variety of perspectives yet is framed as a trip through Rosie's world could dismantle nuance on the condition of autism and initiate readings of complex Janusheads of contradictory information. Such Janusheads grant freedom of creativity within the realm of "My Autism and Me" as culturally acknowledged autistic voice. The construction of cultural acknowledgement of voice lies within clever negotiations of autism, such as the phrase "a bit differently", as such terms construct and guide our acceptance of Rosie as an

autistic voice. In this case, she is positioned as someone with a difference but with a respectable difference: one that does not threaten her right to speak about and on behalf of autism.

The reifying language on autism that Rosie employs about her 'difference' is strategically inconsistent in a way that makes the autism information-thing malleable and adaptable. When she talks about her memory and imaginative skills while introducing Tony, she states that she would not want to exchange 'her' autism for anything else as she would not be the same without it. At the end of the documentary, while standing at Sheaf Square, she ponders her dreams of becoming an actress, or a Dalek, an otherworldly robot-like creature from the Doctor Who franchise. She then says: "I don't see why my autism should stop me". Phrases like these bring uncertainty about the 'thing' that is autism. On the one hand, it is reified as something that Rosie gains her imagination from, which fits within the aim of "My Autism and Me" to represent autism through creative means. On the other hand, it also apparently could defy her ability to dream of her future – she just does not 'let' this 'happen'. Whenever the link between autism and imagination suits the narrative of the documentary in general, that is, Rosie taking responsibility over her life 'with' autism, autism becomes more positively reified. If it does not 'grant' her anything, then there is at least a 'me', like in the "My Autism and Me" title, that can intervene. When it comes to reification, it is thus not enough to just conclude that the documentary presents an abstract concept as a stable materialised thing that 'affects' children in 'different' ways, even though this is very apparent on the surface. Here, reification, the conception of an abstract concept as a concrete material entity, is a rhetorical tool that, either consciously or unconsciously, flexibly adapts itself to the story of independence, or at least the way towards it, that should be conveyed.

Rosie, who describes herself as having Asperger's Syndrome, does represent this adaptability, whereas her younger brother is not eligible for it as he is described as having a "severe type". Rosie introduces her brother by making the distinction between 'types' of autism apparent to the viewer, referring to "lots of different kinds" of autism. In 2011, the DSM-IV-TR was still in active use and featured clear distinctions between autism severity in two separate "pervasive developmental disorders".

Classical autism is the more 'severe' type of autism that comes with speech 'impediments' in early childhood, unlike Asperger's Syndrome (American Psychiatric Association, 2000). Within the documentary, Rosie's brother Lenny is referred to as having "classic autism". Lenny's information on his life is less ambiguous and less suited for a positive story of achievement, whereas Tony and Ben report success based on friendships with peers and anger management, respectively. Lenny's segment contains the only moment in which developmental milestones are discussed: Rosie tells the audience that he cannot speak, "even though he is nine years old".

At this point the documentary employs cinematic codes that bring associations with the feral child, or the child that has grown up in the wild at a large spatial and mental distance from human 'civilisation' (Waltz, 2008, p. 15). Lenny is filmed from a lower angle in the shots that he climbs behind the television in his home, in contrast to the other children who are filmed on eye-line level and face the camera (picture 6). In addition, in the shot in which Rosie talks about her brother and is seemingly located in a separate space from him, the walls and cushions have a distinctive leopard skin pattern (picture 7). Throughout the entire Lenny section, Rosie stands close to her younger brother, and gives commentary about the things he likes and tends to do. Lenny frequently uses the physical space of his house in different ways than intended. He flips over a couch that is intended to sit on and instead uses it as a drum, he climbs behind the television screen, and he closes doors for no apparent reason. Rosie offers some more explanation on this, and states that her brother is "nesting" on the television. The presence of Lenny in a domestic space that prompts commentary, as well as the animal metaphor of "nesting", give an overall sense of a nature documentary, in which it is not made clear if Lenny has given his consent to his contribution. This becomes particularly inconvenient if one considers the fact that Lenny is located in the private space of the family bathroom, being half-naked and surrounded with soap. The feral child imagery renders Lenny, as a child with 'severe' autism, passive, in contrast to his 'high-functioning' sister.

It is this contrast that adds validity to the heterogeneity of autism as portrayed in this documentary. On herself, Rosie negotiates her difference as an autistic girl: she is different, but a bit different, adding a crucial bit of unthreatening negation of her

status as other. On a secondary level, she is also contrasted with her brother and his 'classic' autism, which dismisses any potential doubts from the public about the all-too positive sides of carrying a psychopathological label. Rosie is "a bit differently", but luckily, she does not have the "more severe type". She is 'autistic enough' to be believed as a resource on the subject, but she is also 'not too autistic', so that her credibility stands – there are always people out there whose autism causes more issues when it comes to speaking skills.

This negotiation of extremes and combinations of apparent contradictions is the construction of autism being rendered in "My Autism and Me". Autism is a concrete material thing and is thus homogeneous – while it expresses itself in a heterogeneous way that leads to a plethora of personal accounts. Autism makes people who they are – but it should not stop anyone from attaining their goals in life and as such become completely defined by it. When it comes to my 'autism is rendered' metaphorical concept in "My Autism and Me", one could think of this as the foundational form of rendering autism, that is concerned with the basic conceptualisation of the condition, with which a message on the nature of autism and life 'with' it is conveyed to the audience. In order to have a clearer view of this message and of the creative measures that have been undertaken to 'render' autism and its message of positivity to a young audience, I would like to have a closer look at its use of animation.

6.3 The use of animation as an evocation of autism, heterogeneity and imagination

"My Autism and Me" heavily features animation, both in separate sequences and superimposed onto shots (picture 8). Rosie introduces herself and the topic of autism through such superimposed imagery, she does the voice-over on an animated sequence that gives a general explanation of the term and discloses that she has made illustrations for a book herself. The embeddedness of animation within Rosie's presentation of the documentary as a journey through 'her world' conveys a reality that is alternate yet exists parallel to the live-action sequences that are framed as 'everyday life'. The metaphor of the parallel reality fits closely to the spatial metaphor of autism as withdrawal that I mentioned in my introduction. The superposition also fits within the message of stimuli that are perceived and approached 'differently',

162

which is similar to Rosie's accounts of personification and synaesthesia, and her mother's commentary that Lenny possibly acts differently because of certain stimuli. The animation here creates an augmented reality from a particular and exceptional point of view: 'we' see the world neutrally but seen through the 'eyes' or the 'world' of autism, it is different, and the meaning of the images is changed. The augmented reality effect positions live-action sequences as a 'neutral' look onto the world, and animation as the singular viewpoint that gives another meaning to this supposed neutrality. In the case of "My Autism and Me", specifically, the   superimposed animated sequences are located next to, or edited between, shots of autistic people speaking, in order to add a layer of depth and expression to their words. This also has a clarifying effect: the scene with general explanation of autism renders abstract information on deviance comprehensible for a younger public with no background knowledge of the condition.

Within its educational aims to provide clarification and a sense of a 'world on its own', "My Autism and Me" features various forms of animation in order to add more emphasis on the heterogeneity of the different personal accounts in the documentary. Rosie's presentation sequences have superimposed animation, whereas the moments during which she talks about her own perceptions and memory skills are   interrupted with short moving sequences and are thus edited in as separate shots. Rosie can still be heard in the background, as the sound from the live-action shots is still mixed in as a background sound during the animated shots. This alternation of superimposed imagery and separate shots that interrupt live-action personal accounts continues through the other sections that cover the stories of the other children.

The animations that express Tony's interest in Warhammer are notably different from anything else during the documentary. Separate shots that accompany Tony's words are seen for the first time when he explains his playing strategies, right after his sister told us that his interest in the game is more profound than an average person's hobby. The miniature figures are depicted as polygons in a 3D computer-generated animation, with superimposed white outlines of algebraic formulas (picture 9). Interestingly, Tony is talking about Warhammer here, but various sound clips of his voice and bleeping computer sound effects are mixed together in such a way that makes his exact words

incomprehensible. The style prioritises the general fact that he is engaged with the game above the content of his strategies. Even though his voice is heard, his words are blurred out in order to invoke the message that Tony might know what he is talking about, but the general audience might not. The abstract mathematical signs enhance this effect, as it is unclear whether they directly refer to Tony's words. The figurative 'white noise' that is generated through sound and animation thus convey Tony's 'otherness' because it is impossible for the audience to comprehend his words and thoughts, whether or not someone might know Warhammer. The animation thus defies clarity here, whereas the other uses of animation in *My Autism and Me* attempt to render autism more comprehensible and concrete. The concreteness returns later on, with an animation of the polygon soldiers and tanks that are colour-coded and grouped together, showing Tony's desire for order. An animated shot that accompanies his game as a source of company and comfort depicts the soldiers surrounding a large robot figure. The robot is personified as Tony himself, thus having an 'avatar' in the parallel universe of the Warhammer-themed CGI.

Ben's animations move away from 3D polygons and return to plainness, with thick black-and-white outlines and a few colour accents. The animations can be seen on a whiteboard in shots that feature Ben talking about himself in a classroom, and have soft sound effects, which again parallels illustration with a new superimposed reality (picture 10). They form a storyline out of Ben's words: misunderstandings about his autism made his anger issues worse and caused blackouts and moments in which he is robbed of his agency. After a period of depression, a new separate room at his school offered him a chance to let go of his emotions in a safe space. Whereas some of its imagery directly mirrors Ben's words, such as the floating stars that Ben sees when he is uncontrollably angry, some of it is fantasy as well, most notably the growling bear with the drawn boy that represents Ben in its belly. This combination of literal depictions of personal accounts and more fantastical elements is a common one throughout the entire documentary.

 Whereas the animated sequences illustrate the notion of autism as presented in "My Autism and Me", some of the ones that accompany the personal accounts add a second diegesis to the stories of life with autism. Whereas Tony's is based on the order

and symmetry of *Warhammer*, Ben's show a short narrative of a boy who is captivated by his emotions. This second diegesis is important to the metaphor of autism-is-rendered and add to the notion that the audience is taken into 'another' 'world', presented by Rosie during the introduction. It also adds an expressive layer of comprehension, so that children who might not be able to grasp the verbal personal accounts could still look at the little animated stories and be captivated by their emotional depth.

In a further consideration of this secondary diegesis, it is important to note that a lot of the animated sequences feature anthropomorphism. Even though Ben is represented by a small boy turned 'feral' and locked away within the belly of a wild bear (picture 11), the animation that accompanies Tony's experience of companionship presents him as a large robot, surrounded by his Warhammer soldier miniatures (picture 12). The short scene of the three following children consists of footage of the boys with an animated background covered in a light blue, that show small rectangular blocks that interact with each other. Each time interaction fails, the autistic block turns red or blue and falls forward (picture 13). Such sudden additions of colour hues in an otherwise monochrome animation are a recurring motif and probably represent an ascendance into emotional deviance, heightened stress levels, pathology, and otherness. The use of animation thus shifts borders on the human and the non-human, affirming personhood in non-humans "in all shapes and sizes", as the documentary reifies autism – while Lenny was depicted in a way that evoked subhuman notions of the feral child. Significantly, his section was the only one that does not contain any animation, not even a title screen.

Overall, the most common visual theme consists of rainbow-coloured surfaces and geometrical shapes. These shapes are also featured in title screens, the end credits, the intertitles, and the wipes that indicate transitions between various subjects and personal accounts (picture 14). They thus act as a visual guide to the viewer that brings clarity to the diversity of stories addressed, in addition to Rosie's spoken commentary. Her exposition of her family members and of figures related to the wellbeing of autistic people is accompanied by human figures that are drawn in a distinctive style, with large skin-coloured faces, two dots for eyes, and a small line for a mouth. When Rosie

is sitting on her bed and talks about her personification of inanimate objects and word-touch synaesthesia, her words are accompanied by shots of two anthropomorphic types of shoes, round shapes that show body parts that represent senses and subsequently the term 'words', and handwritten terms adorned with visual cues of the tactile sensation they represent (picture 15). Even though the shot with the shoes has smooth animation, the handwriting is displayed in what appears to be a lower frame rate with shaky lines that constantly jump around. The jumpy lines suggest hand-drawn imperfect animation, as if Rosie has made it all by herself, or is drawing out her perception of the world for the viewer. The childlike sketched-out illustration that is edited into Rosie's personal account gives the impression of closeness to Rosie's own talents and crafts; the last shot of the documentary indeed shows a picture drawn by Rosie flying away by itself.

Both the rainbow colours as a 'palette' and the childlike tactile animation style represent the motif of imagination as a characterisation for Rosie. She states that she has a lot of imagination, that she believes that 'her' autism has 'granted' her this, and that she would like to share her gift with the viewer. It is important to highlight this within a discussion of personal accounts, as autistic children were not believed to have imagination in the first place. In order to be sensible to the genealogy of autism as something that was believed to take away the possibility to be introspective, one could ask the question how the use of animation and the theme of imagination makes Rosie's contribution 'acknowledgeable'.

It is important to link imagination closely to the narrative of success and the defiance of the restrictions of the 'real' life-action world as opposed to the 'freedom' of animated signs. Rosie presents her sense of imagination, and the frequent use of animation inevitably culminates in the reveal that she did her own work as an illustrator. She presents different 'types' of autism, and children who are 'affected' with autism 'differently', but the illustrations that make these stories more engaging are also interrelated with her 'imagination' and authorship of published drawings that are shown at the end. The rainbow motif evokes the diversity of the stories shown, related to the notion of the autism/colour 'spectrum'. When Rosie herself lists the things that she wants to become, which are a hairdresser, an actress, and a Dalek, she

fuses endless opportunity with the category that she inevitably shares with the other children: autism. This enumeration of 'opportunities', both plausible ones and children's fantasies, follows information on autism and employability, which squares possibility with duty: one can be anything one wants, as long as one contributes to society through labour. The thing that potentially could hamper her in dreaming up her labour opportunities is 'her' autism – but she does not 'let' it stop her, and she does "not see why" it "should" let her. Indeed, we have already seen some of her labour at an early age already: her animations. At the very end, her animation of a winged girl even comes to life and flies away, defying natural laws of arts and physics. The animated girl is able to overcome its own nature, just like Rosie cannot be 'stopped' by 'her' autism and she can succeed because autism does not have to lead to failure. In order to better understand how the autism information-thing is called into 'being' via animation in "My Autism and Me", and how it contributes to the message of success, I would like to turn to its short introduction to autism and the biopolitical notion of the complex able self.

6.4 Negotiating biovalue: the 'we know but we don't know'

This section will argue for a state of 'we know but we don't know' in relation to the epistemology of autism as something that is known to be 'located' in the brain and thus of autistic identification as cerebral subjectification. In "My Autism and Me" the brain is being valorised as the biological mass that 'contains' the autism information-thing. Because of this depiction of the brain, it is here that I concretely apply the notions of bio-power and biovalue (here the functioning of the brain), presented in the chapter on my approach to autism, to a case study analysis. The discussion of animation underlines my reading of getting to 'know' autism in "My Autism and Me" as intrinsically linked to imagination as an imperative. Imagination helps to envision new things and new worlds, including things beyond our nature, like ambitious human tasks that would make reified autism less threatening. The story of "My Autism and Me" is a story of a girl who overcomes her 'nature' and thinks in terms of opportunities. The central focus of this section is the short educational sequence titled "What is autism?", narrated by Rosie in a voice-over. I will give a brief analysis of the sequence and its depiction of the brain. I will then invoke my discussion on bio-power from the approach to autism chapter and my stance that it can help to map the

complex 'abled' human rather than the autistic subject that can be 'accused' of being essentialist. Negotiating biovalue and hope, the path to abled-centric subjectification is marked by the remark that we know yet do not know much about autism, so that the epistemology of doubt is key to the bio-politics in "My Autism and Me".

The 30-second explanation titled "What is autism?" has a very consistent animation style, with small humanoid puppets in different colours in the same shade against an orange background. The consistent style and the fast pace make clear that this sequence is exclusively educational beyond the realm of the personal account. Spatial indicators like a house are seen very briefly, but generally, the sequence presents a space-less unrecognisable space in order to convey a sense of universality and disembodied reality. The puppets do not really act but instead are mostly there for schematic purposes, but they do fit into the overall theme of heterogeneity because of their colours and their shapes that represent autism "com[ing] in all shapes and sizes". Another visual motif is the square comic balloon, signifying people talking about autism. This could potentially be read as a mark of performativity as talking is such an important visual cue in a sequence on natural 'facts'.

This status of autism as something innate within nature is highlighted in one shot. This is also the first and only instance in which recognisable expert figures appear as a general signifier of "scientists", as stated by Rosie. The puppets are shown in the typical animation style of this section at the right side of the screen, but with white moustaches, glasses, and a white overcoat (picture 16). The puppets are thus not neutral like in the shots before but are implied to be old men who are practising their occupation. A shelf with pots can be seen right above them, which is a spatial marker of a laboratory or any other place in which chemicals are used and stored. Next to this shelf, a large orange comic balloon appears, and the silhouette of a bald human head pops up en profile, with the outline of the brain and several differently coloured and shaped cogs within it. Some of the cogs are round, and some are toothed and slightly overlap, as if they keep themselves turning around. Together, they seem to be parts of a machine, which is further confirmed by a soft sound of turning wheels. This is all perfectly timed with Rosie's words: "Scientists know it affects the brain works, but they don't know what causes it" (picture 17). Reaching the part about the unknown

168

cause, we zoom in on the content of the comic balloon, and question marks in an archaic-looking font pop up around the human head silhouette.

With this artistic rendering of the brain, which was already very briefly teased during the introduction sequence, "My Autism and Me" firmly localises the reified notion of autism as something related to a specific human organ. To repeat Rosie's words in the documentary, it shows the brain "work[ing] a bit differently". This mirrors our current scientific paradigm of neurobiological research within which autism is currently most dominantly studied. The head silhouette is not clearly recognisable as a specific human being, and thus gives the impression that these 'workings' of the 'brain' transcend the heterogeneity of origins, cultures, customs, and institutions amongst the human population. Even though the documentary conveys heterogeneity as much as it possibly can through animation and the succession of children interviewed, this is a shot that attempts to homogenise both the human condition as creatures with a head with a brain in it, and autistic people with brains that 'work' 'differently'.

Brains themselves, and supposed 'differences' amongst them, are commonly visualised through scans in order to deliver scientific proof and thus a visual index of mappable pathological deviance in an individual 'case'. What is striking is that the organ in "My Autism and Me" is made clearly recognisable by a white outline, but that the animation does not show a mass of tissue but instead a collection of cogs. Throughout the history of science, the brain has often been visualised as an assemblage of different parts with different functions. The en profile silhouette and the fragmented brain 'structure' in "My Autism and Me" resemble depictions of the human mind within the practice of phrenology, which aimed to measure the skull in order to retrieve information about human minds and personalities through localisations of different parts of the brain (Tomlinson, 2005). Even though phrenology is now considered to be outdated, the field has resonated in education, the arts and the history of enslavement to such an extent that it is highly relevant for social justice because of its implications for race, scientific racism and oppression (Broeckman, 2000; Hamilton, 2008). In phrenology, indices of personality differences are studied as part of differences in a mapped skull and brain. "My Autism and Me" primarily focuses on children's lives and behaviours, while using brain imagery to suggest that these

have an origin in neurobiology. All in all, the current dominance of neurobiology in science that reifies autism has a big impact on the formation of the cerebral subject in visual culture, a theme that was outlined in the approach to autism chapter.

The outline of the brain is pivotal to autism and bio-power: the visual evocation of the 'complex' neurobiological self who is 'able' to spread a message of imagination, validity, and chances in life, both 'despite' and 'because of' autism. Clearly, autism as one's reified biological differences can be negotiated in such a way that this 'shouldn't stop' anyone from reaching their 'full potential'. This implies abled subjectification as a form of agency that could 'prevail' in the wake of potential differences that are 'caused' by a neurobiological difference. I would like to return here to Rose's *The Politics of Life Itself* (2007) and its vocabulary of molecularisation, optimalisation and subjectification (pp. 5-6) that I have discussed in the section on bio-power in the approach to autism chapter. As a refresher, brief descriptions and definitions of these words can be found in the glossary in the appendix. Rose first sets out a conceptualisation of molecular life to become identified and regulated. Indeed, the documentary talks about 'the brain' that is working 'differently', and not about any other part or element of the human body. 'The brain' becomes the thing that is centralised into the reification of autism, which also makes it the thing that is studied by "scientists" and overcome by the autistic children. This focus on an optimal socio-political future to be striven for by technologies is called 'optimization' by Rose. The next one is the most important when it comes to the study of identification with autism and the personal account: subjectification, or the construction of human agency in the wake of molecularization and optimization. The autistic subject contributes to society in normative ways, and the emphasis on 'the brain' situates human biological life as the identifiable and mobilisable 'biological information-thing' in a process of molecularisation. Every part of the population has a brain (one cannot survive without it) and 'every' autistic person has a brain 'working differently', which makes it suitable for intervention by the state apparatus and, on a more horizontal level, by our new sense of 'citizenship'. The subjectivity that one can form out of this notion of 'the brain' as something to negotiate in order to achieve success in life is not necessarily formed on 'sociality', at least not within the boundaries of the personal

accounts in "My Autism and Me". Instead, 'subjectification' here means that one's presumed 'biological make-up' prompts notions of the self as active subjects that decide on their own individual fates.

The picture of the 'cogged brain' in the documentary not only signifies a reified account of autistic identification, but also streamlines its message of imagination and empowerment in a way that foregrounds the abled-centric 'good life'. When it comes to declaration of autism self-identification as cerebral subjectification, Rosie does imply a sense of a shared identity. She is the one who guides us through the different personal accounts and who talks about "my world" in relation to autism. Nevertheless, what strongly suggests a biopolitics of abled subjectification through shared cerebral divergence is not the way in which the different personal accounts are interrelated in a network established by the concept of autism, but by the brain imagery and the overall message of imagination and future prospects because of/despite the category of autism.

The focus on brain imagery in "My Autism and Me" is thus significant within the formation of an abled subject that negotiates the brain in an ongoing travel through imagination and success. The outline of the segmented brain establishes biovalue. Novas (2006) talks about Catherine Waldby's understanding of biovalue as biological information or bodily material could become valuable as things that could improve public health or could increase fields of economic capital (p. 291). The focus on the brain, the brain as a machine, and the brain as something that 'functions' as the sum of its parts is a very carefully chosen visual image that sets its centrality to autism subjectification in motion.

I think the cerebral subjectification is enhanced, rather than hampered, by Rosie's specific phrasing: "Scientists know it affects the way the brain works, but we don't know what causes it". The reification of autism in "My Autism and Me" acknowledges the neurobiological paradigm in contemporary scientific research on autism, but also alleges that there is still a long way to go before 'we' truly 'know' the aetiology of autism. Even though this might look like a nuanced take on the biological origins of autism, it still makes some strong assertions on the production and distribution of knowledge of the subject. It combines and strongly interrelates the fact that there is

knowledge and scientific work out there on neuroscience that somehow confirms a presence of autism, but also that it is well-known that 'we' are not there yet. We know, and we also know that we don't know. Novas uses the concept of biovalue in his reflection on what he calls the political economy of hope, in which activism and patients' organisations contribute to biomedical fields based on the hopes of new scientific findings that people have. Such hopes are very important motivations to become active, politically orientated, and motivated to transform bioscientific practice (pp. 294-296). The fact that Rosie here evokes aetiology ("what causes it") draws attention to the origins of our reified understandings of autism, and that we can strive for the ultimate retrieval of this information. Just like the documentary carefully negotiates the reification of autism and the combination of homogeneity with heterogeneity, the phrase gains its significance through two seemingly contradictory elements. Here, these elements convey a strong sense of hope: we are not there yet, but we might be someday. This semi-ambiguity mirrors the self-confirming circularity from the 'autism is enigmatic' metaphorical concept from the introduction. Both cases retrieve information, hope, and the confidence that we could continue our engagement with the reified concept of autism. This is what I would like to call a political economy of doubt: autism commodification happens here because of doubt as symbolic capital that valorises the juxtaposition of the image of the brain as biovalue and the question marks that surrounds it.

I would like to conceptualise this specific economy of the autism information-thing and epistemological doubt in "My Autism and Me" as 'we know but we don't know'. This quality of 'we know but we don't know' in the animated documentary stands for an autism information-thing that is homogeneous yet heterogeneous, and that brings imagination yet has the capacities to hamper it. The reification of autism as an area of epistemological doubt solidifies something that brings social, emotional, and economical capital through the political economy of hope and the state of being 'half-way there' in 'knowing autism'. This capital appears in "My Autism and Me" in more autism personal accounts: illustrations, television appearances (we also see Rosie in footage of *The One Show*), a social network based on Warhammer, and anger management. Rosie, hosting a wide arrange of accounts, does not express any

potential epistemological doubt on her hopes for productivity in the future ("I don't see why my autism should stop me") and expresses such productivity as a personal active choice ("However it affects you, it does not have *to* hold you back"). In my next section, I will assert that this message is fundamentally neoliberal, delivering a reading of the framing of the personal account as a "success story".

6.5 "I'm on the right track, baby, I was born this way": autistic personal account acknowledged as an abled-centric neoliberal success story

In the last few sections of this case study, I dissected a motif of semi-ambiguous epistemological doubt that covers its discourse, visual vocabulary, and use of animation as a whole. I now would like to give suggestions on its ultimate destination and political implications, based around the theme of the success story. Similar to the intervention-like Son-Rise narrative in my reading of *Extremely Loud & Incredibly Close*, I would like to link ableist normativity to a narrative that forms a resolution of the autism epistemology that I have mapped as 'autism-is-rendered'. Rosie's account is called a "success story" in the documentary's last intertitle.

As 'biovalue' renders autism as a commodity that 'resides' in the brain, the valorisation of autism extends beyond neurobiological subjectification and towards value in abled-centric society. This society produces labour, and perceived social 'integration' that is declared as 'success'. After all, the animated documentary moves to a monologue of Rosie in a voice-over, who declares that she is successful as an animator and that she feels motivated to spread more understanding of autism to the wider public. This does not directly presume that "My Autism and Me" is entirely Rosie's project, but it still centres her 'success story' as the conclusion of all personal accounts shown as a whole. The category of autism ultimately 'grants' Rosie imagination and skills that can be employed in a way that provides something material and useful: her illustrations in her mother's book. The behind-the-scenes shots of the making of the documentary and additional studio footage of *The One Show* further build on this notion of provision: she now has access to British television, and "My Autism and Me" is visual proof of this. This definitively establishes a sense of Rosie 'succeeding' in her young life, and as she tells the audience, the fact that she has autism "does not mean" that she "can't".

Serving the role of a good example and potential role model for others, this is the message that children are left with when they finish watching "My Autism and Me".

I would like to state that this particular message, as well as the specific ways in which autism and normative notions of 'success' are reified, is part of a system of neoliberalism. I here adopt the ableist notion of neoliberalism from Goodley (2014), who states that the socio-political context for ableism to thrive in can be found in the latest "economic and ideological conditions" of late capitalism (p. 26). For Goodley, the neoliberal focus on privatised market value creates seemingly individual 'free' citizenship that helps itself into contributing to this market outside of the state. This particular production of the 'idealised' self as deregulated by constantly transformative state policy upholds a system in which the labour market is being served. I emphasise the idealised self here in order to stress the parallel with Campbell's notion of compulsory ableness as a social norm based on a mythical perfect healthy self. The neoliberal citizen is productive and ready for labour because of their entrepreneurial mindset and temporal and mental adaptability. Neoliberalism is thus an "ecosystem" (p. 26) in which epistemologies of the self are based around this allegiance to the market: "[w]e become a knowing subject but a subject knowing of and known by the market" (p. 27). It is therefore valuable to localise my focus on the formation of autism epistemologies and asymmetrical power in the examining gaze in this context of ableist neoliberalism as expounded by Goodley. The normative power of spectatorship and anticipated 'recognition' of autism indexicality might seem like a sincere interest in individual success stories from autistic children. However, when one localises acknowledgement of personal accounts in neoliberalism, spectatorship comes with anticipation and hope for an 'equal' role in the labour market, with or without a 'brain' that works "a bit differently".

The egalitarianism behind a neoliberal political and social structure can easily be mistaken for individual empowerment. As Goodley states: "Behind the ostensibly liberatory discourses of fulfilment, freedom development and personal growth lurk technologies of governance", which can be found in "self-monitoring, aggrandisement and entrepreneurial spirit" (p. 27). The neoliberal imperative of individual initiative and contributions to economic growths works best if diversity based on race, ethnicity,

gender identity, and disability is seen as something obsolete which does not 'have to' affect us anymore. Especially in relation to the ideal of the allegedly depoliticised historical 'end point', this could mask indifference to structural injustice based on identity as 'enlightened' 'tolerance' of 'diversity'. It might seem that autism self-identification does not 'matter' anymore if we all strive for individual 'potential' and thus for 'empowerment'. However, this assumption could only make asymmetrical power relations of normative neoliberal spectatorship even more subtle and sly than they already are with the notion of 'we know but we don't know'.

I would like to regard Rosie's phrases "I don't see why my autism should stop me" and "however it affects you, it does not have to hold you back" in "My Autism and Me" within the context of the sly naturalisation of labour value. Because of the cheerful tone of the overall documentary and the hopeful end message of potential at the end, it is easy to overlook their great significance in terms of power and autism as a discourse. Regarding neoliberal notions of self-empowerment as a form of biopolitics (a form of control upon populations based on the politics of life itself), I would like to state that the imperative of self-realisation projects teachings on living a life with responsibility onto populations. It teaches these citizens how to learn to live responsibly, negotiate challenges around this learning process, and think about health as a choice to personally intervene in so that social services and other individuals do not have to be 'charged' with this. In practice, this means that citizens are encouraged and encourage each other to track how their health progresses in life. This form of power is so pervasive, because it is practised in a way that makes people think that they are affirming our own personal integrity and autonomy through 'self-empowerment'.

In terms of the autism information-thing, the biovalue of a 'diverging brain' can be negotiated so that it can contain the promise of future labour-market value. Rosie is not stopped by 'her' autism and convinces the audience that they also do not have to be held back by that thing called autism as well. Autism is not necessarily overcome here. Instead, I have read autism as a discourse in "My Autism and Me" as something that is carefully negotiated in order to let it serve homogeneity, heterogeneity, impairments, and gifts. The autism information-thing thus leads to an overarching

175

message of a neoliberal responsible sense of self. The didactic purposes of the documentary not only address a reified notion of autism, but also a certain form of ableist neoliberal citizenship as well. The 'empowered' (or to-be-empowered) subject shapes their sense of responsibility and subjectivity through a conception of an 'autistic brain' as something that can be understood (we know but we don't know) and acted upon.

The material result of this act of and call for responsibilisation is not value, labour, and profit despite autism but because of it. So far, we have considered the 'rendering' of autism in this case study as a visual and discursive process of reification, as a construction of the 'credibility' of the personal accounts as 'real and valid autistic children speaking', as something that must be didactically communicated in creative ways to a young audience, and as something that cleverly conveys both the freedom of imagination and the restriction of categorisation in its animated sequences. When it comes to the neoliberal valorisation of autism, it is important to briefly consider some of Rosie's remarks on her perceptions of her label of 'mild' autism. Commenting on her mnemonic skills that autism supposedly 'brings' her, she says: "Some people might call my obsession with facts a little bit boring. I call it focus". The viewer has just seen some of the petty facts that Rosie remembers in animated form and heard Rosie state that she "wouldn't want to swap [her] autism for anything".

Here, both animation and spoken descriptions of life with autism render autism on a secondary level, because we are invited to interpret them in a certain way. Rosie affirms the 'existence' of 'her' autism, or 'little difference' in the way her brain 'works', because she offers her own word for something that others might dismiss as insignificant and uninteresting: her 'focus'. This evokes autonomy: whatever people out there may say about me, I regard my autistic trait as something positive. By extension, she also claims to speak for Tony in reference to his interest in Warhammer, which is the section that immediately follows afterwards: "And I am not the only autistic person who thinks like this". The word 'focus' itself is subject to pathologisation in both its perceived 'lack' (attention deficit) and 'surplus' (hyperfocus). 'Focus' is still needed in order to deliver academic results and an overall

determined life attitude, and the assumption is that it brings Rosie one step closer to access to normalised indicators of success.

All these categories of rendering, and the more subtle form that affirms neoliberal notions of autonomy, prompt a reading of reified autism in "My Autism and Me" as a 'unique selling point'. The documentary does cover more negative experiences, such as school bullying, difficulties with making friends, anger control problems, and a child with a "more severe" form of autism. However, all of these issues are 'resolved' or at least 'appropriately assessed'. Tony's love for Warhammer does help to make a few friends through the gameplay and to feel comfortable while being surrounded by the miniature soldiers. Ben opens up to his school environment and classmates after help that is based at a learning support unit, where he can also release his anger. Lenny "can't really talk" and he will probably not have "much independence" and "will be looked after all his life", but nevertheless, Rosie declares that he is "brilliant". The short sequence with the alternating personal accounts of the three boys functions more as a general overview of autism symptoms and life with them, because of their consistent use of the present simple tense. But even here, the children talk about possibilities and action: one of them is "sometimes" easily annoyed and distracted and explains what he says whenever "someone does touch" him. Finally, the educational aims of "My Autism and Me" in its entirety fit into a general need for more understanding that is expressed throughout the documentary.

The heterogeneous settings and experiences together offer a sense of adequate negotiation by autistic people themselves. Again, this seems like personal empowerment on the surface. The general motif of appropriate assessment fits into the concept of resilience that is frequently discussed in literature on neoliberal politics and social structures. Howell (2015) argues that this term is used in political theory to deconstruct disguised notions of laissez-faire austerity within the discourse of political policy, but that a broader scope on discursive practice could help theorising social resilience as enhancement. This enhancement consists of a belief in the beneficial elements of targets of biopolitics that are 'bouncing forward' towards a hopeful future through adaptability.

Inspired by this notion of resilience, I would like to stress the importance of the construction of an adaptable autistic child as something that produces neoliberal value and enhanced socio-economic life, and that reified autism is something that a society could benefit from. Rosie states that 'her' autism 'gives' her "imagination", and it is her imagination that makes her stand out as a focused creative child who can facilitate 'better' understandings of autism and produce a contribution in a published book. She is the person who most apparently 'bounces forward'. Autism 'makes' her who she is, and within the scope of resilience as enhancement, her 'autistic brain' establishes her as a subject who does something new and generates efficient change in the way individual citizens understand autism.

Her concrete delivery and presentation of provided labour, in the form of illustrations, is accompanied by one of the instances in which she alludes to figures. She specifies the number of illustrations to "nearly twenty", which forms an inevitable call-back to her reference to statistics on unemployment in her shots at Sheaf Square. Here, she tells us that "only one in every six people with autism end up with a full-time job", juxtaposed by the animated heads and shoulders of six persons (picture 18). Five of them bend their heads and look sad, and one smiles, surrounded by short lined beams. The difference between the sad few and the 'lucky' one is a full-time job, not counting part-time jobs, volunteer work, carer duties, and potentially also a legal status as a self-employed worker. Rosie herself is still a child and cites information on autistic adults for the sake of her presentation role, but her number of twenty published illustrations suggests that she is on her way of becoming one of the 'shiny' people. The message of reified autism that comes with difficulties and yet provides imagination comes full circle here. Her role in the presentation and the personal account parts grants her 'validation' to speak and self-identify with autism as a responsible neoliberal subject who is not 'there' yet but is working hard on 'getting there'. As such, she 'delivers' both imagination, twenty illustrations, and ultimately "My Autism and Me" itself as forms of labour and potential beginnings of market value.

She has a "success story", called as such in the last intertitle, and the use of the word 'story' invites an interpretation of the representation of Rosie as a 'success story'. She may face some difficulties on her way, but at the end, her individual 'difference' of the

way her 'brain' works and her 'imagination' prevail. Ultimately, one of her own creations is animated in such a way that it transcends the boundaries of the flat blank two-dimensional surface of a piece of paper, breaks loose, and flies away, attaining a superhuman status (picture 19). Pounding music can be heard: the 2011 single "Born This Way" from Lady Gaga. Its audible chorus lyrics are: "I'm beautiful in my way / Cause God makes no mistakes" and "Don't hide yourself in regret / Just love yourself and you're set", culminating in the sentence "I'm on the right track, baby, I was born this way". The text calls for self-love and self-confidence: someone must be beautiful, because they exist in the world. Self-love is enough and eases regrets, just like Rosie embraces her opportunities in life 'despite' or 'because of' that thing called autism. She is a resilient productive hero figure because she stands for and creates biovalue: she was 'born this way'. This here means that she is able to negotiate her own presumed neurobiological difference, present to an extent ('a bit') that is respectable to neoliberal society. "It is worth getting to know us", she says, and 'worth' she brings forth indeed.

The hyperaware spectator comes into relevance here once again, similar to the prevalence of visual cues in *Extremely Loud & Incredibly Close* that are significant to the film's ambiguity around the topic of autism diagnosis. Growing up in a world saturated with images and videos, children will watch "My Autism and Me" as part of their larger engagement with visual culture. Within its short timeframe, the documentary convinces the viewer to accept a variety of autistic children despite their 'little differences', which is a message that is intended for an easy and convenient adoption in everyday life. Overall, "My Autism and Me" puts the normative 'good' life forward in its advocacy of more 'resilience' in children's lives.

6.6 Concluding remarks

In "My Autism and Me", autism is rendered accessible in different ways that each point to key themes in ableist normativity and the political economy of doubt. Autism is rendered in the sense that it gets 'known' to children by creative means with a strong evocation of positivity and heterogeneity. The aesthetic rendering of the brain reifies autism as neurobiological deviance (but not 'too' much, as Rosie is "a bit differently"), even though the documentary does tell that the aetiology is not clear 'yet'. As such,

the target metaphor of autism is being known through strategic epistemological dualisms of 'knowing' and 'not-knowing' what it 'is' that I have called 'Janusheads'. The clever negotiation of such Janusheads and the ableist power imbalance that this generates will be central to the further discussion of ableist economies of doubt in my conclusion. In this case study, I captured the political economy of doubt as 'semi-ambiguous epistemologies of doubt', which I will actively employ in my next case study *In My Language* as well. Semi-ambiguous epistemologies of doubt lead to more themes that are rendered towards a specific normative ableist goal that I have identified as neoliberalist in line with Goodley. The documentary presents success stories that form 'despite' and 'because' of autism or cerebral biovalue because they produce or promise the production of labour market value. Semi-ambiguous epistemologies of doubt valorise autism in a way that renders neoliberal citizenship to children through personal accounts. The personal accounts are 'acknowledged' because of the intention to depict   autism   during the productive stage and because of the way in which heterogeneity is being reified and 'validated'. In "My Autism and Me", acknowledgement of autistic voice is acknowledgement of ableist neoliberal normativity, which further renders challenges in children's lives into a path towards contribution to the labour market. 'Rendering' as such is highly normative and steeped in the clever negotiation of doubt that is at the core of my notion of ableist economies of doubt. My next and final case study, *In My Language*, focuses on autism epistemology and the 'ability' to produce and distribute a creative 'stance' on autism and communicative normativity without the filter of semi-ambiguous epistemologies of doubt. The video is another personal account of autism, and just like "My Autism and Me", the interplay with not-knowing autism that I explore in this case study is affirmative *and* has profound implications in terms of sustaining ableist normativity. "My Autism and Me" acknowledges and affirms children with autism yet poses the condition of neoliberal market value. Meanwhile, the YouTube video *In My Language* offers an insight into the possibility and persuasive quality of resisting the unconscious able-centric gaze through confronting assumptions on language, self-expression and non-verbal autism. Unfortunately, this resistance against the unquestioned flow of ableist economies of doubt has been impeded and hampered by reactions of doubt about the validity of the person with non-verbal autism who produced the video.

7. *In My Language* (2006): Autism is Resisted

This chapter presents the final epistemological metaphorical concept that overarches my case-study reading of the 2007 YouTube video *In My Language*: 'autism-is-resisted'. The video was posted on 14 January 2007 by the YouTube channel "silentmiaow", owned by Mel Baggs, who identifies herself as non-verbal autistic. It received media attention in 2007 and 2008 from sources such as CNN (Gupta, 2007; Cooper, 2007) and the New York Times website (Parker-Pope, 2008). Mel, an abbreviation of Amelia, is the name that she prefers to employ as her first name in favour of Amanda (Baggs, sine anno), which is the first name that was used in the aforementioned sources. To avoid deadnaming (Wilkinson, 2017), or the use of a name that has been rejected and changed by the holder, Baggs will be referred to as 'Mel'.

In My Language shows a woman who makes repetitive self-stimulatory movements inside a house, after which the text 'A Translation' appears and a computer-generated voice explains that the footage should be interpreted as expressive language in and of itself. With her depiction of constant non-verbal negotiation of space   equally as rich in signification as verbal speech, and her interrogation of preconceived notions of meaningful autism self-identification, Baggs resists autism knowledge as a paradigm that denies her fully acknowledged personhood. 'Resistance' here is first and foremost a cultural practice: Baggs produced and distributed the video as a statement in explicit defiance of anticipated audience expectations and judgement. I use 'resistance' as a highly situational and relational performance in which partakers in criticality declare themselves to be critical or resisting. In section 7.1, I will fully elaborate in which ways *In My Language* can be conceived as a cultural object that resists. I argue there that resistance in the video and by Baggs gets shaped by boldness, as it does not necessarily have to refer to reactive resistance against something other than ableist denial of non-verbal communication as speech.

It is this boldness that has informed the scope and subthemes of this case study chapter and its dedication to autistic voice as un/acknowledged. Similar to my focus on visual and textual cues as sequential to the 'not-quite-autistic' protagonist Oskar Shell in the *Extremely Loud* chapter, I analyse the cinematography and editing in *In My Language* to capture the persuasive power of Baggs's video manifesto. This particular specification is prompted by my understanding of Baggs's resistance as effectiveness of speech in its own right, regardless of positions within critical debates on autism and ableism. It is particularly telling that she employs language in order to problematise the presence of language as an all-determining index of intelligence, self-expression and capacity.

I also advocate for a more affirmative responses to *In My Language.* In this chapter, I outline negative reception of Baggs, consisting of suspicions that Baggs is allegedly feigning disability. I regard such accusations as a call to keep the ableist border between disability and ableness intact. This ontological doubt of autism and self-identification (does that person have autism?) must be distinguished from epistemological doubt that is a key theme in this thesis (how can we 'know' autism?). I pose my own affirmative addition to Baggs's affirmation of her 'untranslated' non-verbal speech next to *In My Language*, and next to this direct expression of doubt online. This personal act of resistance is one in which I myself drop the distance between my researcher role and the cultural object and add my own self-made concepts. I formulate concepts like the 'political economy of doubt' and each of my metaphorical concepts in order to give myself room to intellectually exist and nurture myself in, and to develop new structures of signification beyond the restrictive dis/ability binary. In my work at large, I aim to continue resisting able-centric normativity.

Overall, *In My Language* is crucial as a case study regarding my interest in the genealogy of autistic voice as acknowledgement, because it is a practical example of the scientific oxymoron term that I introduced in the personal account chapter. The scientific oxymoron is the experience and assessment of autism signification as vacuous once people who are thought of as unable to speak do start to express themselves. This case study chapter is an assemblage of points of interest surrounding

the question how the concept of the scientific oxymoron could play out in practice in the case of *In My Language*. As such, the 'autism-is-resisted' metaphorical concept that I present in this chapter is relevant to further study into acknowledged autistic voice. From Baggs, we could learn how to interpret cultural texts that challenge anticipated preconceived notions of autism in an ableist society, how to 'resist' as researchers ourselves, and how to consider forms of harassment that public figures who identify as disabled could receive.

Baggs identifies herself as a "disabled writer and artist" with multiple disabilities and expresses most affinity for and allegiance with the "developmental disability self-advocacy community", phrased as such to specify shared cultural history and experience rather than shared diagnosis (Baggs, sine anno). She is active on multiple social media accounts with different names that all include confirmations of her name and content authorship. silentmiaow is Baggs's public YouTube channel; in its description, she mentions that its videos are "about autistic liberation and disability rights" and notes the existence of a private account named "amandabaggs" (silentmiaow, 2006). At the time of writing, silentmiaow has 7237 subscribers and has posted 24 videos from 22 August 2006 to 27 September 2007 that all exclusively contain user-generated content rather than content from other media (Burgess & Green, 2009). This activity took place during the early history of the video-sharing website YouTube, which was founded in 2005 and has played a major role in the media industry ever since. Baggs's number of subscribers is now regarded as small in comparison with YouTube celebrities who each attract millions of subscribers and views and financially benefit from their content (Kenyon, 2016). Besides YouTube, she edits the blog Ballastexistenz (Baggs, sine anno) which has had frequent updates and new posts in 2018. It is named after the German word for 'ballast life' that was used to refer to people with psychical disabilities during the Third Reich and that was emblematic of its mentality of mass death for those considered to be 'weak' (Quensel, 2018).

Even though her online activities are spread over multiple social networking sites, her video *In My Language* has attracted the highest amount of interest from news organisations, blogs, artists, and academics. This interest focuses on the spoken and

subtitled commentary to several shots of Baggs and the message on the significance of this imagery that they convey. The video plays with expectations of the assumed viewer and presents a specific form of communication, agency, and the social and political notion of voice. Initially, Baggs is located in a domestic place, with a clearly identifiable living room. She rocks her body and flaps with her arms and hands, touching objects that she encounters. The intertitle "A Translation" then appears on the screen. The images of Baggs continue, but now a computer-generated voice can be heard saying: "The previous part of this video was in my native language". These words, along with the word "translation", establish and confirm the presence of language in the previous section, spoken by Baggs. The status of Baggs's negotiations of space as a language is confirmed and further explained with this statement, pronounced by the computer voice:

> Many people have assumed that when I talk about this being my language, that means that each part of the video must have a particular symbolic message within it, designed for the human mind to interpret. But my language is not about designing words or even visual symbols for people to interpret. It is about being in a constant conversation with every aspect of my environment, reacting physically to all parts of my surroundings.

With this presentation of her filmed movements and interaction with objects as her language, she subverts common notions of autism as a life of "being in a world of my own". This specific phrase has been countered by academic literature from before and after that focus on personal accounts and inclusion (Biklen, 2005; Davidson, 2007; Ebben, 2015). Via her computer voice, Baggs subsequently offers an excavation and a critique of ableism in assumptions of the lack of normative verbal language amongst an assumed audience that is referred to as 'you'. She points out general attitudes of dehumanization surrounding her negotiations of space, as they do not conform to normative verbal forms of communication. The images and spoken words list her use of the five senses with accompanying shots of things that she is in interaction with, after which she states that these interactions are "not enough" to be regarded as a rational individual unless she "directs" these acts to the "right" things. Her affirmation of the value of different forms of being and communicating eventually comes with a defence of those who have been considered non-humans throughout history. In

February 2007, CNN invited Baggs as an "Internet sensation" to the television programme *Anderson Cooper 360°* and hosted a Q&A with viewers, affirming her videos as personal accounts that show "how someone with autism experiences reality" (Cooper, 2007). Media attention like this, as well as reports on Baggs from other media sources, have formed an important source of criticism directed at her integrity as a non-verbal autistic woman. Several blogs argue that Baggs could indeed talk and have relationships during her high school years (Best, 2008b; Amanda Baggs Autism Controversy, sine anno). This direct expression of doubt is unique to the *In My Language* case study; here, 'doubt' predominantly refers to external presumptions, judgement and suspicion within this case study. The word 'doubt' in my theoretical concept of the 'political economy of doubt' refers to ongoing epistemological uncertainty as a property of the autism information-thing. Nevertheless, different definitions of the word 'doubt' apply to each of my case studies and their peculiar manifestation of epistemological doubt (speculation, rendering, resistance). With autism-is-speculated in *Extremely Loud*, 'doubt' is indecisiveness and curiosity on proper diagnosis, and with autism-is-rendered in "My Autism and Me", 'doubt' is the semi-ambiguous statement that 'we know but we don't know'.

Like the previous "My Autism and Me" chapter, this case study is an exploration of acknowledgement of autistic voice, or the lack thereof in the case of doubt about Baggs's dis/abilities. Whereas "My Autism and Me" was a documentary on autistic children that was written and produced by a non-autistic crew for a major broadcasting company, *In My Language* was independently produced and distributed by a person who identifies as autistic. Despite its free worldwide availability online, *In My Language* has had a small-scale reach compared to *Extremely Loud* and "My Autism and Me", with its small number of views (1.4 million) and channel subscribers. The implications of independent distribution on a social networking site are why this chapter is not only concerned with the video alone, but also with its place on a YouTube channel, above room for comments and alongside other videos that a YouTube visitor can navigate through. I include references to video and channel descriptions, to other posts on silentmiaow and to data such as numbers of views, comments and subscriptions as paratexts alongside a reading of Baggs's video .

Paratexts are elements besides the 'bare' cultural object of *In My Language* with which it presents itself as filmed user-generated content on a social networking site with room for annotation, continuity, and social interaction (Genette, 1991, p. 261; Guerney, 2011).

Central to this chapter is the emergence of voice within interconnection between cultural object, paratexts and responses to Baggs that together form the cultural distribution of acknowledgement of autistic voice. I do not cover the question of authorship and autobiography. Instead, I dissect Baggs's visual and textual conception of 'translation', the spatial outwardness of her 'language', her evocation and production of an online autistic community, and her anticipation of doubt about her authorship within the video. It is in these four themes that the (re)production and contestation of autistic voice in *In My Language* come to the fore; each of them forms the focus of one individual section. Right before, the first section lists different levels of 'resistance' that I find in Baggs's video and that have prompted me to name an 'autism-is-resisted' epistemological metaphorical concept.

7.1 Layers of resistance in my 'autism-is-resisted' metaphorical concept

I formulate the 'autism-is-resisted' metaphorical concept as a constellation of style, spoken and subtitled text, and my own theoretical input that is pivotal to this case study and the duality of an affirmative message on non-normative communication evoking dispute. On the level of the employment of autism as a discourse of *In My Language*, the spoken argument resists the 'autism-as-enigma' metaphorical concept when Baggs denies that "autistic people and other cognitively disabled people" are "inherently confusing" when lacking language. On the level of cultural critique, Baggs resists ableism when her presentation of her movement as language evolves into an argument against assumptions that a lack of normative verbal communication and coordinated negotiations of space equals a lack of personhood and humanity.

On the level of style combined with the use of computerized speech and subtitles, *In My Language* is uncompromising. Baggs's message of affirmative divergent meaning-making through 'spontaneous' interactions with her environment is framed by directive and interpretive editing and spoken and subtitled 'translation', steering the spectator towards a specific reading of continuous movement through space in the

video. I call this 'uncompromising' in order to name a kind of duality that resists the comfort of 'nuance' and clarity on dis/ability. Such nuance is evident in actuality yet possibility in autism-is-speculated and knowing yet not knowing in autism-is-rendered. The uncompromising style and message form the focus of the section on translation in *In My Language*. Here, I provide a reading of the editing and cinematography of the video in combination with the interpretation of movement as language that is evident in the spoken words and subtitles.

On the level of my role as an autistic researcher, I resist boundaries between my reading of the film and the reading that Baggs offers of assumptions on the worth of non-verbal and autistic life and self-expression in her presentation of movement as language. My own conceptualisation forms the basis of the second section: here, I participate in Baggs's language with an update to my term 'atopos' that I developed as an alternative to the 'self' in autism etymology. With this participation, the section follows Ebben (2015) and my method of creatively posing a new discursive tool next to my case studies. My method aimed to bring more discursive freedom to my study of representations of autism and spatiality, since the word 'autism' alone limited my cultural analysis.

On the level of Vertretung, *In My Language* resists presenting heterogeneity amongst autistic people within a careful establishment of validity that I wrote about in the "My Autism and Me" case study chapter. With its clear references to fellow autistic and cognitive disabled people as 'we' in combination with an assumed ableist audience that is addressed as 'you', Baggs seems to create an essentialist division between people who identify as disabled and those who do not. I counter this with insights from my 2016 article on formations of identity and voice on YouTube that emphasise conscious performance of identity and the creation of shared and inclusive geographies. With her YouTube film, her insistence on a 'we' and the constant negotiation of space and materiality that constitutes her claim to language, Baggs inaugurates and creates space that simultaneously creates what and whom the space is for and that thus holds the opportunity for more creative endeavours like hers.

Overall, the source domain of resistance does not refer to the concept or definition of autism itself, although Baggs disclosed her preference for 'disabled' above the sole

category of autism in her blog (Baggs, sine anno). The word 'resistance' captures subversion and protest, but not necessarily protest 'against' something (that is, what is resisted). By naming subversion, I show how *In My Language* is shaped by the boldness of the claim to autistic voice in the context of ableism. The last section contrasts this boldness to the oppressive qualities of the direct dispute and doubt that is directed to Baggs. It argues that her uncompromising presentation of dis/ability (disability in the sense of the performance of autistic spatiality; ability in her persuasive qualities that effectively present a message on disability/autism rights) touches upon the cultural fear of an imploding autism category. I interpret this subversion of compulsory ableness in the responses to *In My Language* with my commentary on the insistence on diagnostic inflation as a site of criticality in the study of the autism information-thing. With her persuasive skills, Baggs brings ability in a way that supposedly 'fails' to conform to semi-ambiguous epistemological doubt. I declare fears of dis/ability implosion to be oppressive. Such fears could bring back traces of past scientific belief in the impossibility of the autism personal account and curb the bold mobilisation of anti-ableist action that I am affirming with my reading of resistance in *In My Language.*

In terms of epistemological doubt in 'autism-is-resisted' and the oppressive notion of imploding dis/ability, this case study is the only one that will cover doubt that is directly present in the cultural object itself and its reception. In my previous two case studies, I highlighted doubt myself as part of my reading and formulation of metaphorical concepts: actualization through doubt in 'autism-is-speculated'; semi-ambiguous epistemological doubt in 'autism-is-rendered'. These highlights revealed my stance on the normativity that I found in the two case studies, like on the neoliberal conception of the heterogeneous population 'with' a reified kind of difference that is negotiable for the sake of market value in "My Autism and Me". By contrast, the doubt in this case study negates normativity in a way that tarnishes personal account as acknowledgement and most directly exemplifies the shadow of the scientific oxymoron that I explored in the personal account chapter. In this negation, this case study highlights the oppressive qualities of acknowledgement of autistic voice and thus the possible 'other side' of the power imbalance that I warn against in my discussions of ableist normativity in my previous two case studies.

7.2 The uncompromising persuasive power of 'translation' in the style, spoken word, and subtitles of *In My Language*

This section is concerned with the persuasive power of *In My Language*. The video covers the articulation and the affirmation of different forms of 'language' outside of the realm of verbal communication. It reveals meaning-making in exactly the kind of non-verbal rhythmic rocking movements presented in its portrayal of Baggs that her assumed viewer might perceive as indices of disability, or at least a divergence from the perfected able-centric human body. It thus points out and aims to confront social expectations of indexicality as ableist, offering her own expression, or her interaction with her environment, as a chance to express acceptance for 'other' languages outside of verbal speech. The message of the video is conveyed by the combination of a short video of Baggs and her computerized voice that offers a 'translation' of the images shown and confirms that her movements constitute language and self-expression just as much as the computer-generated voice does.

For a case study of the personal account, here a video produced by an autistic person, persuasion is an important point of interest because it can grasp how a cultural object can convey an accessible and convincing message about autistic voice. Baggs has not only rendered the abstract and heterogeneous notion of autism comprehensible, like "My Autism and Me" has done; she has also created a manifesto-like statement that argues for the integrity and understanding of autistic people and non-verbal expression. Persuasion by cinematic means shows skill, or the 'ability' to make a filmed plea – but this plea is for the acceptance of non-normative disabled communication. This brings me back to Erevelles's problematisation of the humanist rational subject in the facilitated communication debate, that I presented in my chapter on the personal account. Baggs puts lack of autonomy and rationality in 'crisis' through an autobiographical account, not only because of her message, but also because of the coherence of the video itself that she is proposing. The video is more than an attempt to unsettle social expectation of non-verbal communication as a possible indicator of incapacity. *In My Language* also offers unity and continuity in the creation of an argument that aims to unsettle and that contributes to a clear persuasive argument. With her 'translation', Baggs also brings the humanist subject into crisis because of her creative skills that benefit the strength of her argument. This section will mostly focus

on the place of the video on Youtube, the editing, the cinematography, and the use of written text.

In My Language is very similar to other videos posted on the silentmiaow channel, that also revolve around an essay spoken aloud by a computerised voice and accompanied by Baggs located in a domestic space. Their 4:3 aspect ratio and availability solely in low resolution show their age as YouTube videos, as options for widescreen and high definition videos only came after 2007 (Hopkins, 2008; YouTube Spotlight, 2008). The video starts with a medium long shot of Baggs in blacklight, framed slightly off-centre and facing a large window (picture 20). This shot abruptly cuts to a close-up, with a hand that shakes a thin bent metal object at the left side of the screen. This forms a harsh and discontinuous juxtaposition with the previous shot; there is no clear temporal or spatial continuity but a sudden ongoing single act: the movement of an object that makes a scraping sound. The camera is also shaking in a way that suggests the use of a handheld camera. Ultimately, all fourteen shots that precede the 'A Translation' intertitle are juxtaposed with abrupt changes in framing and in visible props that Baggs interacts with, like a slinky, a keyboard, and an open book (picture 21). The abrupt editing creates a sense of discontinuity that is enhanced by non-diegetic vocal sounds of Baggs. The vocals are accompanied by scratching noises that come from Baggs's interaction with the objects and that are as loud as the vocals.

After the intertitles, the editing, cinematography, and sound change in the subsequent eleven shots, starting with the first one, whicht features fingers moving to a jet of water at a sink (picture 22). The computer voice states: "The previous part of the video was in my native language", directly posing a reading of the content that came before. These previous shots are grouped together as a 'part' that is now 'over', as they constitute the language that Baggs considers as her 'first' language. The yellow subtitles, not annotated but ingrained in the video itself, assigns authorship to Baggs. Yellow is solely used for her computer voice, as another silentmiaow video, *A Way of Describing Autism*, quotes another person and uses blue subtitles instead. *In My Language* now superimposes subtitles and the sound of a computer voice to a close-up in order to convey a message: to confirm and affirm language. The shot with the jet of water now takes longer than the shots that came before and now accompanies an

explanation of Baggs's "ongoing response to what is around" her as language. The computer voice comments on the hand touching the jet of water as "this part of the video", showing non-diegetic awareness of the status of the video as a video. The commentary negates semiosis, as it states that the shot should not be regarded as symbolic and that it does not 'stand for' anything else but her interaction with the water.

The spoken text constitutes a moment of 'translation' as a superposition of shots that each portrays one section and the spoken words that convey a reading of them. The length of the jet of water close-up is now equally long as the spoken and subtitled reading of the video as a language, making room for the spoken and written explanation. The translating text is continued with more general remarks on misconceptions of Baggs's modes of expression as meaningless, with a new shot of Baggs in front of her window but now from a different angle. She is now seen from her right side, with different, softer lighting that comes from a natural light source (the window) and accentuates her face. The subsequent shot is also closely interconnected with the spoken words. Baggs now types on a computer, using assistive communicative software, while the computer voice and subtitles state "As you heard, I can sing along with what is around me. It is only when I type something in your language that you refer to me as having communication." In the visual cue of the source of the computer voice, the appeal to sound is interesting here. Aside from ambience, the pouring jet of water and the typing, the harsh sounds and vocals around her are gone after the intertitles. They are now referred to as 'singing' by a reference to earlier aural impressions from the spectator.

A wipe leads to five shots that show Baggs's interaction with objects and each focuses on one of the main five senses. The succession of shots depicting ongoing action in a steady rhythm mirrors the cinematic convention of the montage sequence, or a temporal ellipsis that covers a longer time period in a few shots (Bordwell & Thompson, 2017, pp. 251-252). Three shots follow, in which the computer voice says that it is "not enough" to express through sensing and that this sensing needs to have a purpose to be seen as meaningful. The last shot is a direct continuation of the very first shot in the video, which ends with Baggs who stops flapping her hands and turns

to her side once her translation has ended. With her carefully edited video, *In My Language* constructs a notion of a 'native tongue', 'her' language, to convey that her expressions do not mean that she is 'speaking in tongues'.

Baggs bridges meaning to disabled life and makes it significant, but also 'displays' ability through the very fact that she has produced a video. She is not fully spontaneously expressing herself in the shots listed above: she portrays her interactions with her surroundings in the specific spot of someone's home. More importantly for my reading here, the influence of (post-)production on the construction of the translation is very important: at least a camera and editing software were used to produce and distribute the video. The video reluctantly participates in assistive communicative technology as a limited normative form of communication, whilst its very production and distribution also further mark a set of specific acts for the benefit of communication via video. As such, the topic of the 'translation', put in the added title and intertitle screens, is not just a way to convey experience, but also a pivotal addition to add structure and unity.

This display of 'ability' involves employment of the normative language, that is, speech and writing, that the declaration of the translation is aiming to problematise. The computer voice and the subtitles are added after filming, just like the editing that changes after the 'A Translation' intertitle. The 'previous part' of the video alone appeared to be more dissonant and tactile. It had irregular jumps in locations and framing and a clear use of handheld camera that give the illusion of movement alongside Baggs as the bouncy suggestion of proximity imitates bodily presence and natural eye movements . Interestingly, a video that only contained the previous part was posted a day before the *In My Language* post. Called *In My Language (Untranslated Version),* it announces the addition of the 'translated' section in its description. A visitor of the silentmiaow YouTube channel could watch the video and interpret her movements through space without the context of the 'translation'. Nevertheless, the complete *In My Language* video has more views and is more likely to show up in recommendation lists of people interested in videos on related topics according to YouTube's algorithm (Airoldi, Beraldo & Gandini, 2016).

The 'translation' with the normative language and the plea for different communication comes after one-third of the full *In My Language* video. This part offers more symmetry and continuity in its editing: three shots precede and follow a short montage sequence that represent five senses in a tripartite structure separated by wipes. The lengths of each shot are longer and fit specific statements from the computerised voice so that a quick succession of images does not 'distract' from the message. The lack of distraction and the symmetry is striking, as this seems to approach Baggs' deconstruction of apparent 'lack' of coherent movements and self-expression with coherence in a stylistic sense. The identical content of the first and last shots of the complete *In My Language* video establishes symmetry and a mirror image with the start of the video and its 'untranslated' part. Starting and ending with two apparently continuous shots of Baggs flapping her hands while facing a window suggests a horseshoe-like syntaxis that allows a retrospective view on the 'untranslated' footage right at the beginning of the video. The untranslated part comes before the verbal confirmation that this 'flapping' is a conscious mode of expression.

While one would expect a parallel and analogous syntaxis of a bilingual message that contains the 'same' content in two different languages, the style of *In My Language* is one of a translation that is a mirror image of its 'untranslated' part instead. The complete 'bilingual' video thus looks more like a visual palindrome. Overall, this palindrome offers an 'antithesis', the translation, to a 'thesis' so that a 'synthesis' is formed: one that affirms tactility and materiality based on 'spontaneous' movement, anticipating yet 'solving' confusion. This kind of affirmation of tactility is known from arts and culture outside of the realm of Baggs's *In My Language* personal account, like video art as a display of video inside a physical space like a gallery or museum. Indeed, video artist Mark Leckey did include *In My Language* in his work *Prop4aShw* (2010–13) and has expressed his affinity for Baggs's negotiation of space and materiality in the art magazine *frieze* (Griffin, 2014). The synthesis in *In My Language* is thus persuasive in its presentation of movement as language according to conventions that have been employed in video art before.

In My Language is a creative endeavour with a clear persuasive style. In my exploration of the personal account, I regard it as a cultural text, produced and distributed by a

person who identifies herself as autistic, that not only presents an underacknowledged kind of voice but also forms an act of creative agency in itself. I would like to approach this declaration of autistic voice with the notion of resistance because I am interested in this uncompromising style of persuasion, that is, the creative 'ability' with which Baggs has underlined her message of language and has offered a specific reading of her video featuring seemingly ongoing negotiations of space. The portrayed person identified as autistic does not only 'show' coherence in non-normative self-expression but also in the skills and thus 'ability' to coherently convey this in a video through a familiar kind of spoken rhetoric and cinematic style. The 'translation' not only confirms her self-expression as language but is also a discursive persuasive tool in itself. My reading of "My Autism and Me" also addressed style, like the combination of animated and live-action footage, in order to dissect its educational aim to 'render' autism knowable to a young audience.

In terms of autism epistemology in "My Autism and Me", I talked about the semi-ambiguous epistemological doubt with which the documentary sketches a normative 'success story' of neoliberal market value. Here, autism epistemology comes to the fore in the suggestion of autistic voice in an unsettling kind of way exactly because of the coherent persuasion of *In My Language*. The persuasion echoes the genealogy of discomfort after challenges to clinical assumptions about abled-centric autonomy, as discussed in the personal account chapter. The cultural demand for Indexicality is undermined through an interplay of disability and ability: if this autistic person presents 'disabled' non-verbal communication as meaningful, then why does she show so much ability in making a convincing video? In the next sections, I would like to explore this echo of doubt and its oppressing implications for autistic creators more, with further discussions of Baggs's engagement with voice and her declarations of an autistic population.

7.3 Singing along with what is around: 'atopos' as a structure of signification for *In My Language*'s production of voice

This section is concerned with my own resisting act of conceptualisations beyond the boundaries of psychopathologisation, and how these concepts have helped my interpretation of Baggs's video. This personal addition to *In My Language* is my

response to Baggs's invitation to regard her negotiations of space and interaction with her environment as a meaningful personal account. I do not aim to 'understand' how Baggs presents her 'voice', but instead affirm her declaration of voice by engaging with my own creative endeavour next to *In My Language* as a cultural text. This creative endeavour is a reintroduction of the term 'atopos' that originates from Ebben (2015).

With this term, I will 'sing along' with Baggs "singing along" with what is around her, without the pretension to 'read' and interpret these words and their role in the video. This mirrors the reflection on translating non-verbal expression in Chew (2013), who poses the question how to translate her autistic son who is "bursting with communicative intent" but speaks in short phrases and verbal utterances (p. 309). I first elaborate on Chew's ideas on translations before I return to my notion and definition of 'atopos'. Using cultural theorist Walter Benjamin's work on translation to "ensure [her son's] centrality as a maker of meaning", she emphasises the process of affinity in the act of translation and of (re)assembling bits and pieces of the source text (p. 311). She then describes Benjamin's notion of the translation as a harmonic rather than facsimile expression of the intention of the source text and adapts it to the fragments of signification of her son's speech. For Chew, the translation of her son would require a product that is positioned in support and harmony with his speech and that does not repeat but extends meaning. Like Baggs, she uses the phrase "singing along" with him (p. 312). Baggs's reference to her vocals, accompanying her interactions with objects and their diegetic sound, and Chew's understanding of translating her son are both a 'song alongside' a source, respectively space and materiality for Baggs and the son's speech for Chew. This striking parallel motivates me to affirm Baggs's term 'translation' with a discussion of 'atopos' as a creative endeavour that harmonises with both her negotiations of the tactile and aural sensations around her and her reading of this as her language that she translates in the video. This effect of harmony is not meant to essentialise the reading of the depiction of Baggs, her movements and her sounds that is offered by my case study itself as 'true'. Instead, this section intends to provide an academic engagement with the kind of resistance to non-normative practices of looking that Baggs offers with her notions

of voice and translation in a video produced and distributed by a person who identifies as autistic.

While the previous section discussed the syntaxis of Baggs's translation to foreground the uncompromising 'able' persuasion in the video, this section is concerned with Baggs's social choreography in several fragments and shots of *In My Language*. St. Pierre (2015) reflects on non-normative disabled speech with communication theories that use the word 'choreography' to stress the interconnectedness of the body with its surroundings and the tempo and movement that evolve during this connection. He notes the importance of social choreography for disability theory. It allows thought about the privileging of culturally preferred "structuring of bodily and interbodily communicative practices" in ableism and the perception of 'failures' to act out such normalised 'dances' as 'incorrect' communication (p. 50).

Looking at each singular shot that depicts Baggs's body and hands in *In My Language*, 'translated' with the subtitles and computer voice or not, what I perceive is a set of different choreographies with a variety of expansions through space. For example, watching the earlier-discussed very first and last shot of *In My Language*, what strikes me are the oscillating back-and-forth rocking bodily movements and the quickly moving straight thin shapes of the fingers on the flapping hands that mirror the window frame in front of her. The motif of movement as coping was discussed before in the case of Oskar's tambourine in *Extremely Loud & Incredibly Close* and in Lenny's 'nesting' on a television in "My Autism and Me". Albeit filmed with the anticipation of including it in an online video, the shots of Baggs depict a continuous rhythm of fast manual movement in which the silhouette of Baggs's body in backlight stretches through the depicted room. She becomes one with it but not quite, as the silhouette matches the shapes of the objects in the room around her in backlight.

In addition to these shots, I would like to call the shot with the finger that moves through a jet of water an instance of interbodily choreography, despite the fact that the water is not a 'person' to 'speak' to. Visible at the left side of the frame, the falling water is a thick translucent line and is thus actual in its fluidity, like Baggs's continuous 'interaction' with the water by moving in and outside the stream. The movements in front of the window and the manual flapping through the jet of water all explore

boundaries and the 'reach' of the corporeal and material. The fluid translucent water is a separate unity to interact with yet allows movement through it. Furthermore, the backlight in the shots with Baggs as well as the harmony of her vocals with the scraping sounds of objects creates an impression of mimicry. I here do not mean the kind of mimicry as parental intervention that I discussed in *Extremely Loud & Incredibly Close*, but an absorption in space through mutual response (Caillois, 1935).

Aiming to create a harmony with Baggs's expression, or her claim to voice in the video, I propose 'atopos' as a discursive tool to facilitate signification outside of the boundaries of the semantics of autism. Ebben (2015; 2016b) proposed the term after the implication of autism as a 'preoccupation with the self' in everyday discourse proved to be limiting for the study of cultural representations of autistic people and negotiations of space. For new words that could grasp what was limiting, I situated my subversion of this implication in the etymology of the word 'autism'. Coined by Bleuler in relation to a symptom of schizophrenia (1910) and used as a separate category in the 1940s (Kanner, 1943; Asperger, 1944), it contains the Old Greek 'autos', which means 'self'. This interest in autism etymology, just like the choice to address Foucauldian genealogy, did not come from a wish to capture origin. The evocation etymology is instead meant to direct attention to the implications of spatiality in the preoccupation with the self that is embedded in the very word 'autism' and in the autism metaphor of withdrawal from social space (Broderick & Ne'eman, 2008).

Baggs highlights this focus on the right to self-expression beyond ableist restriction in her presentation of her negotiations of space as her underacknowledged non-normative language. In the computerised vocals and subtitles, she puts forward deep-seated imagery of withdrawal: "the way that I move when responding to everything around me is described as 'being in a world of my own'". She subsequently refers to normative interpersonal communication, recognised as "opening up" to the "world", as a "limited" selection of responses to surrounding environments. Based on my reading in this section, I would like to add fluctuations and corporeal expansions to stress that *In My Language* is a personal account of someone who is already 'in the world'. More specifically, this world is the textured life of embodiment: Baggs poses a

cultural object that presents her intense preoccupation with space and resists preoccupation with the self in the 'autos' association.

I would like to grasp this resistance in the 'translation' of *In My Language* with Ebben's (2015) shift from 'autos' to 'atopos' (ἄτοπος), which consists of negation (a) and spatiality (topos) and is Old Greek for 'out of place'. On its own, the association with spatialised strangeness is not necessarily positive, since Baggs's resistance to being considered a non-person evokes dehumanising spatial metaphors, or the autistic person as someone who is not from this world (Broderick & Ne'eman, 2008). However, by posing 'atopos' as a resistance to 'autos' in 'autism', Ebben (2015) aimed to create a "new structure of signification" (p. 44) that could enable new vocabulary and theory that stresses and affirms outwardness to space. When it comes to 'atopos' in etymology, the Old Greek word is processed into words like 'atopy' in immunology, or a hypersensitivity to outer stimuli and a strong bodily reaction onto the encounter of these stimuli (Coca & Cooke, 1923). This involves sensory overload, in which the harmful stimuli 'touching' the body cause swelling and thus expansion of the body. Another word from geography with the theme of spatial and material transgression is 'atopia': a world without territorial borders (Willke, 2001, p. 13). With the procession of a word meaning 'out of place' in words referring to the transgression of immunological and geological borders, my interest returns to expansions through space and the exploration and negotiation of the materiality of objects and substances shown within frames in *In My Language*.

With a focus on preoccupations with space, I would like to 'translate' Baggs's 'translation' as an assemblage of constant corporeal and spatial intertwinement. Focusing on signification based on preoccupations of space rather than 'indices' of 'withdrawal' from space and being 'trapped' into a 'self', I would like to read the shots as expression through different means of expansion through space. In each shot, Baggs passes through materiality, harmonises with it and mimics it: she is orienting towards it in different interactions. With this distinctive form of expression, *In My Language* is in itself an extension to my thinking on etymology, my resistance to it and my thinking on border transgression that was opened up by the shift to 'atopos'. Naming this extension in my reading of the case study is how I would like to affirm the video as a

personal account – or acknowledge its expression of voice from a person who is identified with the autism category. My shift from 'autos' to 'atopos' is my discursive and academic act of singing along with it, refusing to 'understand' it.

With my act of harmonious acknowledgement of voice, I acknowledge Baggs's non-normative social choreography as 'intelligible' and expressive because of its very preoccupation with space. In Ebben (2015), 'atopos' was meant to offer a depathologised alternative to analyses of autism as a pathologised kind of discourse in cultural objects. As I have selected ableism as my site of criticality in this PhD thesis, this aim for depathologisation in the face of pathologisation has been abandoned. Such an aim would centralise my own academic role as the bringer of the kind of creative 'intervention' that cultural representations of autism supposedly 'need'. As such, the proposal of the 'atopos' term is not an act of inclusion in and of itself within the confines of this case study chapter. My overall presentations of autism metaphorical concepts and a political economy of doubt first serve to grasp culture within ableism better, before prescribing 'alternatives'. What I want to put central instead is the construction and preservation of the perfected able body in society itself, with a focus on the role of autism as a discourse in this construction.

Baggs's 'outwardness' needs further exploration. With the structure of signification that could be put into motion with atopos, I have so far stumbled upon Baggs's constant exploration of corporeal, material and spatial borders within the frame of the shots. In the next section, I would like to expand my focus through her additional outwardness to other people who identify as disabled in *In My Language* and the way in which the video takes in space for ongoing signification. Whereas this section was concerned with the way in which Baggs's negotiations of space are framed in separate shots in the video, the next section details the spatial orientation presented in these shots in superposition with the computer voice and subtitles. These identify a 'you' as the viewer and an 'us', consisting of people that experience the negative oppressive effects of ableism as society fails to recognise them as speaking persons. This section presented my shift from 'autos' to 'atopos' and thus to spatialisation of my reading of this case study that features autism as a discourse. The next one accompanies this spatialisation with my shift of my understanding of the personal account from claims

to realism to claims to a situatedness in a specific ableist time and space, as developed in the personal account chapter.

7.4 Declaring dis/ableism and enacting spatiotemporal personhood in the facilitation of autistic online space and the use of pronouns

This section looks at pronouns and other suggestions of an 'outside' community that Baggs expands herself towards with the *In My Language* video. With her persuasive translation in *In My Language*, Baggs not only establishes a transgressive interaction with the space around her, without the hierarchies of a social choreography that is supposedly 'right' within ableism. She also reaches beyond the boundaries of her own self-identification with the autism category (as well as 'cognitive disability' as a more generalised term) and her own reading of her tactile self-expression as her language. With its distinct use of the words 'you', 'we' and 'they', *In My Language* moves towards implied audiences to be persuaded, to be addressed about their prejudices, and to be represented in the sense of Vertretung.

The "My Autism and Me" case study chapter consisted of my reading of the representational strategies used to suggest heterogeneity amongst the personal account and to suggest the validity of the 'mildly autistic' child presenter. Here, the persistent use of 'us' seems to evoke homogeneity and thus show less 'nuance'. However, as I explained in the previous case study chapter, epistemological dualities of certainty and complexity can be deployed in strategic ways that normalise a normative neoliberal model of 'personal' fulfillment. This case study centralizes the resistance to the taken-for-granted affirmation of nuance and to undermine a reading that stresses the illusion of a homogeneous group of people who practice non-normative communication. In the case of *In My Language*, the complexity of Vertretung to unpick for me is instead the proximity and harmony with anticipated dis/abled visitors.

This proposed harmony is of central concern here: the anticipation of the 'you' as the prejudiced YouTube video spectator and the 'we' as those who share the history of dispute of personhood that is a result of this prejudice. The 'we' is a conscious enactment of personhood within the possibilities bound to time and space. *In My Language* mobilises the dismissal of non-normative communication as a shared genealogy of disabled (non-)personhood, which is a creation of autistic kinship based

on shared time. The video is distributed online on the small-scaled and low-revenue YouTube channel silentmiaow and can thus be found and accessed on a platform that is open to comments, participation and community-building.

YouTube facilitates shared space. I already briefly explored the implications of appealing to history in personal accounts that seem like autism ontologies in my discussion of Milton's 'double empathy problem' in the personal account chapter. The understanding of personal accounts on autism on YouTube as a facilitation of space comes from insights from Ebben (2016a) on empowering online identity construction surrounding the autism category. In this article, I explored the importance of geography in literature on online autistic communities and further pursued thinking on the performance of autistic group 'identity' as a creation of space for new discourse and signification. All in all, rather than a critique of an 'us-versus-them', I understand *In My Language* as an outward preoccupation with community as a consciously enacted spatiotemporalisation of 'being' dis/abled 'together' (see Rosqvist, Brownlow and O'Dell, 2013).

I would like to emphasise the production of space and time dedicated to the legacy of autism as a discourse, instead of appealing to a preconceived group of people who 'have' autism or a 'divergent' cognition. I again turn to my own academic efforts and insights. Ebben (2016a) aimed to capture "the social and spatial conditions in which the flow of meaning on autism thrives" with a special focus on online declarations of community (p. 51). I presented a literary review of ethnographies and qualitative research based on interviews that had a shared focus on geography. These studies reported autistic communities as certain negotiations of online and offline spaces, shared with or separate from people who do not identify as autistic, in which digital communication could remove the obstacles of face-to-face communication that some face. I employed this emphasis on spatiality and the creation and negotiation of space to imagine the facilitation and production of self-expression on YouTube as a platform on which video-uploading, sharing and commenting is a main vehicle of signification (Burgess & Green, 2008). Based on a reading of *In My Language* and another YouTube video that simulated negotiations of space by an autistic person, I argued that

the very fact that [the video producers] use YouTube as a platform to creatively present autism, perception, and voice already means that they are part of a wider online autistic community. They actively shape and contribute to the online flow of new signs on the autistic condition through web pages. This already signifies a particular geography based on a creative structure of signification (Ebben, 2016a, pp. 60-61).

Regardless of her exact addressees, which might be both disabled and non-disabled people, Baggs poses a political voice by the very deed of posting a YouTube video and thus facilitating space in the form of a web page (van Zoonen, Vis and Mihelj, 2010). This voice is spatialised as she has enabled interaction and signification with her channel. The silentmiaow channel features videos that form a direct response to other videos that pose a topic of discussion related to disability. Moreover, *In My Language* itself is open to written responses as well; many of the comments that have been posted so far reveal self-identification with a disability themselves. Finally, the video employs autism as a discourse within a proposed reading of her movements as language, enabling further moments of conscious meaning-making in and outside other YouTube videos with a discursive consistency. With her self-identification with autism and creative act of translation on a video-sharing website, Baggs participates in a discourse community, which is how Belek (2013) identifies the autistic YouTube community in his ethnography. Spatialisation covers past, present and future, that is, an appeal to existing discourse on autism, the presentation of a new creative object with its own style and message, and the facilitation of more texts that this message could spark.

For my reading of *In My Language*, I would like to employ my shift to 'atopos' again by extending Baggs's preoccupations with space beyond the interactions with her environment alone: she is also in constant interaction and signification with dis/abled readership itself. The persuasive quality of her video is spatiotemporal, as it anticipates readings to come and facilitates community-building based on this anticipation. For example, not only is the speech presented in the computer voice and subtitles a means to 'translate' Baggs's negotiation of space, the ingrained and thus standard subtitles also form close captions for Deaf people and others who need them. Accessibility here is an act of expressing affinity with both disabled people and the anticipation of a

viewer who might wish for the kind of clarification and persuasion that Baggs has called a 'translation'.

When it comes to my reading of pronouns in *In My Language*, I will not regard them as indicative of Baggs's addressees, but as a spatiotemporal orientation that dismantles ableism. The first pronoun used in the spoken and subtitled words is 'me'. The start of the video after 'A Translation' confirms that Baggs's movements and sound together form the language to be translated, but not interpreted as being a 'symbol' 'for' something, not based on resemblance but on cultural convention. It is here that the text refers to a group of people: "many people" have assumed semiosis, which *In My Language* wants to negate with the example of the jet of water shot. The reference to cultural expectations evolves into a description of oppression from a 'them': "they judge my existence, awareness, and personhood on which of a tiny and limited part of the world I appear to be reacting to". Mostly, 'they' react to Baggs, but nevertheless, after the category "autistic people or other cognitive disabled people" is mentioned in relation to the 'autism-is-enigmatic' metaphor, the 'I' becomes 'we' and Baggs's non-normative language becomes Vertretung for shared experiences of non-normative language. The 'they' becomes 'you' when the text refers to normative language throughout *In My Language*, like in failures to "read your language" and the need to speak "your" language to be regarded as communicative. The 'you' is also the addressee in cases of concrete messages that *In My Language* wants its viewers to adopt: "I want you to know that this has not been intended as a voyeuristic freak show where you get to look at the bizarre workings of the autistic mind". Overall, 'I' refers to the translated subject, or the producer and distributor of the video, who addresses a 'you' for whom the translation was made; 'translating', thus reaching out and participating in the normative communication of this assumed audience, leads to an interrogation of 'you'. Moreover, 'we' stands for a shared taxonomy and history of the kind of oppression based on communication from the 'them'.

The pronouns exemplify positionality: they put a mirror in front of the spectator and resist a neutralising disappearance of the anticipated examining ableist gaze. Here, the anticipated addressee and the appeal to a community of cognitively disabled people give form to the presentation of the ableism that *In My Language* deconstructs. As a

spectator, 'you' might see a montage of one person's gestures and sounds that are devoid of meaning. However, the act of translation not only points out that the shots are filled with meaning, it also directs attention to 'you' being filled with bias. The belief in both a devoid meaning and the position of the 'neutral' normalised gaze that anticipates indexicality is expandable to the denial of personhood based on a limited and hierarchised social choreography. Power imbalance is upheld by 'people', a category that can be generalised beyond the act of looking at this YouTube video.

In My Language strategically elicits a 'you' as an act of "staring back", which is Garland-Thompson's term for confident disability self-representation "[r]efusing to wilt under another's stare" (2009, p. 86). Importantly, Baggs stares herself: in the senses montage sequence, she turns and looks directly into the camera during a single close-up in the shot dedicated to sight. In her message of affirming constant and open social choreography, this is a strikingly strategic moment of performance. It underlines the dismantling of the supposedly neutral act of looking, similar to my own readings of the gaze, speculation and rendering in my discussions of representation and case studies in this thesis: Baggs is aware of 'you'. She reaches out to this 'you' through anticipating an ableist response and subsequently dismantling it with non-normative communication generated with assistive technology. I would like to state that the 'you' and 'they' in *In My Language* do not necessarily 'stand for' a group. The use of the pronouns is a creative act from Baggs herself that de/constructs the ableist recognising gaze that I have conceptualised and theorised in this thesis.

I would like to adopt this principle of creation to the 'we' in *In My Language* as well. The spoken and subtitled text contains sentences like: "We are even viewed as non-communicative if we don't speak the standard language, but other people are not considered non-communicative if they are so oblivious to our own languages as to believe they don't exist." The 'we' here encapsulates a pan-disability group defined by cognitive disability, evoking the field of cognitive psychology that has had a considerable impact on the clinical construction of autism as a discourse (Nadesan, 2005). Posing this pronoun and alluding to a seeming binary with 'you' and 'they' (Runswick-Cole, 2014) is bold as a 'risk' for 'accusations' of essentialism and doubt. In my reading, I undermine the question that I deconstructed as re-centralising autistic

people as the site of research and non-clinical intervention in the personal account chapter: is Baggs's claim to Vertretung of such a pan-disability group valid?

To further sketch this claim to pan-disability Vertretung, it should be noted that the pronoun 'we' often comes up in considerations of denial of personhood. Baggs sets out how the 'we' is regarded as "non-communicative", "confusing" and "non-persons" and ultimately specifies the violence and death faced by those whose "kind of thought is so unusual as to not be considered thought at all." Furthermore, *In My Language* ends with intertitles with scrolling end credits that mostly consist of dedications, one being "Dedicated to all other people who are considered non-persons or non-thinking". The dedication extends the plea for affirming non-normative communication in the video and is another way of expansion towards others in the form of written affinity. Overall, what joins the 'we' together is the reminder of the denial of the very conditions for community building, that is, the cultural acknowledgement of personhood.

My reading has affirmed *In My Language* as an act of facilitation of a specific time and place suited for shared signification and community-building. I do not problematise Baggs's use of pronouns as a reaffirmation of absolutist scientific realism, but instead I build further upon its steps towards a pan-disability union that can hopefully eventually result in pan-disability social action and praxis. Solely within the confines of this particular case study chapter and the room that I grant myself according to the 'autism-is-resisted' metaphorical concept, I and Baggs can be a 'we' in our wish for non-normative dis/abled self-expression. My resistance to the study of assumed homogeneous group-building means that I have shifted towards an exploration of orientation and proximity towards actors in ableism. The consideration of the 'we' has brought up acknowledgement despite the history of denial again, which formed the main theme of the personal account chapter. This 'despite' is significant, because Baggs's conception of denial of personhood also contains an expectation of doubt about her personhood and authorship. Unfortunately, Baggs's epistemology of resistance in the face of ableism has attracted the kind of contestation of her integrity that she had already predicted in *In My Language.* The implications of expected and actual ontological doubt (is this autism?) in the context of resistance are explored in the next section.

7.5 Ontological doubt and dispute of valid voice and the oppressive quality of acknowledged 'ability'

In this section, I provide a detailed analysis of controversy surrounding Baggs and her video *In My Language*, and take a stance against online doubts about Baggs and her self-identification as autistic. My discussion of ontological doubts regarding her exact dis/ability status, that is, questions about the validity of this self-identification, contains the phrasing 'disablist' instead of ableist that more closely fits my cultural analysis in my thesis as a whole. 'Disablism', or the prejudiced treatment of disabled people, is a stronger word that denounces invasive ontological doubt more directly and strongly. This section sketches the broader context of Baggs's unfortunate susceptibility to judgements about the reality of her disabilities, the precise nature of such responses of dispute, and my reflective thoughts on this situation with regards to societal acknowledgement of autistic voice and the forceful perpetuation of ableist normativity.

In My Language is a self-produced and self-distributed personal account that resonates, and I have located the theorisation of and participation in the 'autism-is-resisted' metaphorical concept in this resonation. The video itself is uncompromising in its message of unbound non-normative non-hierarchical negotiations of space on the one hand and its means of production and post-production that bring persuasion to this reader on the other. It also does not shy away from a use of pronouns that highlight positionality within an oppressive and judgemental system of ableism that prioritises limited prescribed social choreographies. As such, *In My Language* resists speculative spectatorship that is actualised through uncertainty of diagnosis and the condition of the 'not-yet-diagnosed' in need of adequate 'good' intervention, which I discussed in my *Extremely Loud & Incredibly Close* case study. Furthermore, the video resists the semi-ambiguity of the strategic heterogeneity of autism and its possible benefit of imagination, normalising a neoliberal narrative of orientation towards labour market value, that I unpicked in the "My Autism and Me" case study chapter. As the researcher of both, I resisted a sole role of the cultural analyst and partook in a facilitation of meaning-making myself, next to the facilitation of non-normative communication in the 'translation' construct of my case study. This action, the formulation of 'atopos', led to an emphasis on preoccupations with space and

expansion towards elements outside the corporeal to communicate to, mirroring Baggs's refusal to be seen as someone who lives in a world of her own. With thinking in terms of preoccupations of space rather than a 'self', I resisted an understanding of autistic 'community' as a fixed declaration of group identity by stressing the declaration of voice as a facilitation of online space dedicated to the possibility to interact and negotiate autism and ableism. This possibility may hold the promise of more enabling structures of signification, which is something that I have attempted to engage in as well with the discussion of a discursive emancipative tool. Overall, this chapter is not just a reading but also a harmonious partaking in the message of self-expression.

In the light of the promise of enabling kinds of resistance and ongoing affirmative meaning-making, it is striking that it is exactly this independently produced and distributed platform of possible meaning-making that anticipates and has attracted dispute and doubt. Without an inexhaustible dissection of the doubt that Baggs has received as an independent producer who has attracted media coverage in 2007 and 2008, I will explore what dispute could imply for *In My Language* and ableist economies of doubt. I will then provide my stance on these implications with an expression of caution with an overly positive outlook on Baggs's message of consideration for non-normative means of communication. This is not meant to further pursue dismissal of Baggs's personal account. Instead, I will direct attention to the oppressive qualities of ableism as apparent in the direct doubt   that has been aimed   at Baggs and the video that brought her internet publicity.

In *In My Language*, the translated written and spoken text appeals to the notion of doubt in the presentation of denial of personhood on the basis of perceived non-communication. The 'denial' is specified as the risk for and anticipation of doubt. The text considers normative social choreography as an imperative to direct senses to the "right things", while a failure could mean that "people doubt that I am a thinking being". Bridging perceptions of thought with perception of personhood, this doubt would subsequently lead to "doubt that I am a real person as well" (silentmiaow, 2007). This suggests that the concrete manifestation of denial of personhood within ableism manifests in concrete expressions of doubt. The text anticipates one instance of such

concrete doubt outside of the confinements of both the private space that she is negotiating and the facilitated online space of the YouTube web page: "I would like to honestly know how many people if you met me on the street would believe I wrote this."

Baggs, as the producer of the personal account and the person who has publicly self-identified as autistic, has indeed received a quantity of dispute online, which was directed against her claim to self-identification with autism and reliance on assistive communication technology. Blogs, including posts from a blogger called 'John Best' who has shown aversion to resistance of autism cure (Savarese & Savarese, 2010), deliver 'proof' related to reports of Baggs's high school life, including references to pictures as indices of ability (Amanda Baggs Autism Controversy, sine anno). They also denounce media outlets for validating the personal account of an autistic person whose claim to non-normative communication cannot be deduced (Best, 2007; Best, 2009) and lament what they consider to be misleading information (Best, 2008b). References to accusations of doubt based on supposedly 'contrasting' interpersonal experiences predating the silentmiaow YouTube channel have been reported on popular websites such as *Slate* (Lutz, 2013), which has brought more distribution to views otherwise shared on small blogs.

The doubt from outside the *In My Language* case study brings in claims or declarations of 'proof' that some have 'really met' Baggs on the 'streets' once. Such claims come with 'testimonies' from outside the space and time of the production, post-production and distribution of the video. This input 'counters' a 'deduction' that Baggs's claim to self-identification as disabled and a user of non-normative communication is 'invalid'. Overall, *In My Language* as a case study is one that has received both acknowledgement and a lack of acknowledgement. As a personal account, it is haunted by the manifestation of doubt that extends the disclosure of systemic and anticipated dispute of non-normative communication within ableism within the video itself.

To reflect on the cultural and political implications of limited acknowledgement of personal accounts through the circulation of doubt, I would like to conceptualise dispute and controversy in and outside the video as a problematization of dis/ability. In "My Autism and Me" as a personal account, the rendering of autism into a

'teachable' reified construct that 'does not have to hold children back' came with a careful negotiation of dis/ability in presenter Rosie. She self-identified as autistic but was still 'a bit' differently and preoccupied towards imagination and talent to an extent that she was 'able' to present scripted content. By contrast, Baggs in *In My Language* is more uncompromising in her account of dis/ability: she creates a space of alignment with disabled people in a persuasive video that showcases 'ability'. Her translation facilitates room for social interaction and the stimulation of the production of further non-normative social choreographies through a continuous flow of preoccupations with space. *In My Language* is not directed towards a promise of overcoming challenges in parenting or of ultimate neoliberal market value. The positive media coverage on Baggs only suggested that negotiations of space on their own could constitute consciousness in non-verbal disabled people as well.

'Overcoming' hardships in autism parenting and the promise of future participation in the labour market anticipate ability within a personal account of disability. Here, the evocation of 'ability' does not aid to further normalise ableist normativity but instead fuels the suggestion that Baggs might not be disabled after all. Abledness here stands for treason and negation of her affirmative message. Baggs performs ability in a way that does not compromise with the neoliberal myth of 'nuance', turning the careful negotiation of compulsory abledness upside down.

I would like to argue that the ableist economy of doubt, that is, meaning-exchange around epistemological uncertainty, in the case of the response to *In My Language* consists of backlash to autism self-identification out of the cultural fear of implosion of dis/ability. These dismissive suspicions against Baggs, casting a disablist shadow over the persuasive potential of *In My Language*, exemplify a failure of acknowledgement of autistic voice, as Baggs is being 'too disabled' and 'not disabled enough' at the same time. On the surface, *In My Language* offers a call for acceptance of non-normative forms of communication from disabled people in its declaration of space for more expression and interaction. However, it also provocatively addresses the cultural rejection of disabled self-expression as 'meaningless' ('too' disabled) while 'risking' the danger of accusations of being 'too able' in the production of the video and its disclosure of self-identification with the autism category ('not disabled enough').

In My Language exemplifies the other, less empowering side of the ableist actualisation of autism through doubt that I explored in my previous two case studies. With its declaration of and space for (potential) voice, the uncompromising YouTube video offers an autism epistemology that is not strategically semi-ambiguous but that implodes this 'safe' footing of compulsory abledness in its approach to autism, self-expression and autistic community. I would like to situate Baggs's vulnerability for speculative suspicion that she does not have autism within the subverted 'opportunity' to 'know' about Baggs's self-identification with autism and disability. This epistemology of implosion and the vulnerability of being the target of doubt coincides with the affirmative qualities of 'autism-is-resisted' that I myself have shown off in this case study chapter with the inclusion of my own dis/ability conceptualisation. *In My Language* inaugurates the right to free self-expression as it sparks more signification with its place on a video-sharing social networking site, including my own participation in its expansion through space with the 'atopos' term.

Whereas *Extremely Loud & Incredibly Close* and the CBBC documentary "My Autism and Me" benefit from ableist economies of doubt, Baggs unfairly risks dismissal of her autism personal account. I would like to link this disablist dismissal of acknowledgement of autistic voice with 'diagnostic inflation' as a site of criticality. While the academic declaration of diagnostics and autism identification as inflated is mostly concerned with autism rates (Thoutenhooft & Batstra, 2013), it could be interesting to think about the value exchange of the autism information-thing with regards to this epistemology of implosion. If the autism category 'dilutes' and the 'weight' of autism 'drops' because of the quantity of its identification in people, would doubt surrounding Baggs with her status of abledness as a source of accusatory dismissal instead of free self-expression signify 'dilution'? For me, the suggestion of the diluting value of psychopathological and clinical diagnoses reveals the problematic side of diagnostic inflation as a site of criticality, since such contestation of someone's self-identification with autism could potentially foster disablist public responses. Next to the denial of personhood, a non-verbal autistic video producer could also risk being regarded as a diluter of the autism category. Here, the observation of 'abledness' does not safeguard normativity in actualisations through doubt but weaponises this same

doubt so that creators and facilitators of enacted self-identification with disability are further excluded from the ableist norm. This exemplifies an area of power imbalance that could negatively affect and oppress content creators like Baggs.

7.6 Concluding remarks

All in all, I would like to state that the sentiment of resistance in *In My Language* consists of manifold forms of transgression. What is scientifically and clinically known about autism might be uncertain, but in her personal account, Baggs has transformed the principle of epistemological uncertainty and indecisiveness into a mirror, with which she reflects back societal assumptions on meaningful autistic and non-verbal self-expression. With its central message that Baggs's movements are not meaningless but constitute her language and interaction with the world around her, Baggs transgresses perceptions of non-normative language and expression, what non-verbal autism looks like, and what a meaningful life with autism is. Baggs has not just been filmed while singing along with the space and stimuli around her: after her YouTube video received a degree of exposure, popularity and ultimately also contestation, researchers like me are now 'singing along' to Baggs as well. Baggs's epistemology of transgression and resistance to audience expectations has inspired me to join in with my own theoretical concepts. These concepts like 'atopos' were originally formulated to capture lived experiences that cannot be captured with psychopathologising notions of human diversity. As a researcher, I would not want to 'understand' or 'admire' Baggs's affirmative language. Whilst video artist Leckey has expressed "envy" for Baggs's 'unique' negotiation of space and interaction with her environment (Griffin, 2014), I think that such an expression of preference for non-normative creativity would overlook the oppressive implications of ableist economies of doubt.

I would like to end this chapter with a reminder of the risk of disablist forms of doubt that a 'translative' YouTube video declaring autism self-identification could bring. Contrasting "My Autism and Me", this chapter is the other side of the same coin that constitutes my cultural analysis of the personal account as acknowledged autistic voice with its emphasis on the epistemology of implosion in 'autism-is-resisted' in *In My Language*. Doubt in "My Autism and Me" stood for a reinforcement of the seemingly positive affirmation of the neoliberal autonomous individual. In this case study, doubt

is a negation of self-identification with autism and the facilitation of shared self-expression. Both "My Autism and Me" and *In My Language* foreground the potential of the autistic people portrayed, but this particular (promise of) potential strictly falls within a neoliberal-ableist framework. In future critical studies of ableism and sentiments of epistemological uncertainty surrounding diagnostic categorisation, I hope to further explore the two-faced phenomenon of conditional affirmation of life with autism and disabilities in arts and culture.

8. Conclusion

In the introduction, I presented my research question as 'What is the epistemology of autism as a discourse in the film *Extremely Loud & Incredibly Close* (2011), the animated children's documentary "My Autism and Me" (2011), and the YouTube video *In My Language* (2006)?' With my discussions on my research object of autism as a discourse within structures of signification, my research area of representation, and my reflections on ableist normativity and its power imbalance, I can provide an answer. With my conceptions of autism itself as a performative utterance, the topic of representation and my specific focus on voice in personal account, I understand the epistemology of the autism category in my case studies as an enactment of certain forms of 'knowing' and 'not-knowing' autism. I have isolated speculating, rendering, and resisting autism as themes in my case studies that highlight autism discourse as government over the way in which difference (both pathological and the supposed 'positive') is not just disabling or enabling. Instead, the governance of difference through the specific use of the autism category consists of the dominion over both knowing and not-knowing autism. This dominion has come to the fore in my reflections of the question if a child is 'truly' autistic or 'just' traumatised in *Extremely Loud*, the construct of 'we know but we don't know' in "My Autism and Me", and the doubt about claims to autistic voice that Baggs alludes to in *In My Language*. The triad of autism, knowledge, and power in the careful negotiation of knowing and not-knowing implies a deeper structure of actualisation of the autism category through, and not despite, epistemological uncertainty surrounding the concept of autism.

In my thesis, my readings and subsequent interest in doubt have produced an answer to my research question that is twofold. On a micro level, the three case studies employ autism as a discourse according to a semi-ambiguous epistemology that slyly incorporates normative values on diversity, voice, and enablement, both strengthened and camouflaged by apparent non-universalised and reductionist interpretations of the condition of 'autism'. With my conceptual framework, I have practised a kind of Cultural Studies and Disability Studies research that solely focuses on autism,

discursive practices and a constructionist view of cultural representation, and not on the condition that the term signifies. My case study chapters all exemplified different manifestations of not-knowing autism, and I saw a fruitful source for further cultural analysis of autism and the cultural representation of it in this manifold phenomenon of not-knowing. *Extremely Loud* was speculative about the precise condition of its protagonist. "My Autism and Me" has rendered the abstract concept of autism and unknown lives of autistic children comprehensible and accessible for a young audience. *In My Language* subverts the clinical gaze and resists notions of non-verbal expression as meaningless.

On a macro level, these readings have led to a specific vocabulary that I formulated for this specific thesis based on a finding that has sparked the overarching theme of doubt: the fact that the case studies cannot be fully understood as 'nuanced' and 'non-absolute' depictions of autism. My exploration of epistemological uncertainty in multiple examples of cultural representation of autism from the late 2000's and early 2010's, and in particular the construction of acknowledged autistic voice, is a 'history of the present'. In my introduction and chapter on my notion of the personal account, I have called such a Humanities methodology genealogy. In need of a specific terminology that grasps the complexity of autism epistemologies in the case studies, I employed the term 'political economy of doubt' for the overarching theme of knowing and not-knowing throughout my case studies. The formulation of the term 'political economy of doubt', which refers to the exchange of meaning about autism, what is known and not (yet) known about 'it', has had multiple uses. It constitutes my active negotiation of my research question, my Humanities method of genealogy, my textual and discourse analyses based around formulating metaphorical concepts, and my thinking based on these analyses. Specifically, it has granted a vocabulary that helped to name meaning exchanges and practices of signification. For example, I interpreted autism in/visibility and 'red flags' as a social expectation of and desire for autism indexicality enacted by the knower and the known. Furthermore, the personal account was conceptualised as an acknowledgement of voice in which signification is a similarly mutual construction of identification and validation. My analyses of my case studies foregrounded processes of cultural legitimacy in which cultural discourse is

influenced by shared normative ideals of alert parenthood and the neoliberal productive protagonist, as well as differences in media, production, and distribution. During my interpretations of this cultural discourse, I created a term that reflected overarching themes in my case studies (doubt), did justice to meaning exchange (economy), and could prompt thinking beyond my research question on the politicised framework of 'ableism'.

Not only has terminology such as the 'political economy of doubt' been an overarching academic framework, it was also one that I have developed on my own. My presentation of the term is thus my active textual contribution to Titchkosky's notion of the textured life of embodiment, as it is a creative endeavour that responds to the cultural objects containing autism as a discourse in my research question. This approach to my research question mirrors and continues Ebben (2015) in which I coined the term 'atopos' to counter the failure of the 'autism' etymology to capture representations of autistic people who negotiate space. Whilst that critical action was explicitly a depathologising widening of autism vocabulary, the role of 'political economy of doubt' in this thesis is to call for shared commitment to the profound and undeniable cultural significance of diagnostic categories. Following this call for responsibility, I hope that my focus on doubt could sprout new ramifications within the textured life of embodiment and that epistemological uncertainty will become a more important theme in critical theory in the field of Disability Studies. With ramifications, I mean further thinking on autism as a discourse that shows an overall awareness and sensibility to my site of criticality, which has been Campbell's notion of ableism. My hope is why I have also used the term 'ableist economies of doubt' in my thesis, including its title, as it highlights the scope of economies of doubt beyond my research question alone. Ultimately, the cultural critique that formed the basis of my engagement with autism as a discourse and the case studies is what counts, as this provides relevance to the answer to my research question and the formulation of unique vocabulary. My project was focused on a fixed set of cultural objects with a research question that highlights epistemology and signification within cultural practices. Nevertheless, my conceptual chapters, readings and choices of words are

meaningful because of their wider critical implications that may or may not have been addressed within my methodology and case studies.

The last four sections of my thesis further outline and theorise ableist economies of doubt and their implications for further research. The first section summarises ableist normativity for each case study, after which the second section discusses normative power imbalance as evident in my theme of ableist economies of doubt. The third section is dedicated to the contributions of my argument and thesis to critical theory as well as the limitations of the scope of my project. The notion of the crip killjoy is central to the final section, with implications on resisting the seemingly rebellious stance of ableist 'nuance' for further study.

8.1 Unveiling abled-centric normativity in the case study chapters

My case studies analysed and problematised the way in which the texts convey normativity and the power imbalance that is implied within it, which places them within a system of ableism that centralises able-ness as more valid. Campbell's notion of ableism, or the societal pursuit of a perfected and archetypical norm of the healthy human being in favour of different and diverging ways of living, was the pivotal concept to this analysis of normativity. I analysed *Extremely Loud & Incredibly Close* with a particular sensibility of a constructionist view of practices of looking that consist of a normative gaze that trains hyperawareness of deviant 'cues'. This desire to recognise is apparent in the intersection and mutual reinforcement of autism indexicality and 9/11 iconography that evokes the personal impact of a highly televised cultural trauma, together with carefully framed and edited shots and scenes of a distressed Oskar. This intersection importantly comes from an Academy Award-nominated feature film from an independent studio in the Hollywood system that has conveyed the sensitive American story of 9/11. It did so through the more palpable smaller scale of a child who lost his father, conveying the pathos of clinical assessments with lack of clarity on socio-emotional developments without the delicate politics of terrorism, race, and the war on terror. The element of normativity in *Extremely Loud & Incredibly Close* lies within the narrative of Oskar's quest towards closer proximity to his father in the wake of personal and cultural traumatic event and the eventual resolution of the emotional distance with his mother. This resolution is

216

based on the reveal of Oskar's mother's involvement in Oskar's quest and its peculiar narrative of overcoming that I linked to the Son-Rise intervention programme. The mimicry of the child by the mother continues previous efforts from Oskar's father to guide the not-yet-diagnosed towards normatively 'good' child development and coming-of-age.

"My Autism and Me" also guides the spectator towards a path of challenges, creative expression and colourful animated 'imagination' as neoliberal self-realisation, and the promise of future labour. I addressed the normativity of its representational strategies that renders autism understandable and that constructed a narrative of an imagination-filled success story by highlighting the semi-ambiguity of its reified neurobiological visualisation of autism. I then uncovered its neoliberal affirmation of market value through the suggestion that a 'bit differently working' brain can be both the obstacle and the imaginative solution towards supposed unproblematised 'self-fulfilment'.

Produced and distributed independently by a disabled blogger, the *In My Language* YouTube video is an example of a personal account that does not follow a normative message of self-fulfilment. The video instead subverts the hyperaware gaze with its message that negotiations of space itself might be regarded as meaningless yet constitute her voice as a non-verbal autistic person. In a creative sense, the form of a translation and the persuasive qualities of the message of countering disability oppression brings resistance as 'potential' beyond the normative story 'towards' any promise of abled-centric subjectivity and 'success'. I further affirmed resistance of autism epistemology with a conceptualisation of my own depathologising term 'atopos', but also interpreted the detrimental effect of fears of doubt on integrity that were voiced in the video. These fears were evident in direct forms of dispute of the integrity of persons who identify as autistic, as they evoked the cultural fear of a discursive vacuum between the 'too disabled' and 'not disabled enough'. The two personal accounts in my list of case studies, one consisting of interviews within a scripted children's documentary and the other consisting of a self-produced and self-distributed video, revealed a social process of acknowledgement of autistic voice that is enabled but also clouded by their premise of self-expression. Rosie's 'imagination'

and the colourful and aesthetically pleasing frame story of children's life stories in "My Autism and Me" are embedded in a story that parallels creative potential with labour market potential, with autism employment demographics as a key motivator.

My case studies together form a platform for the production and consumption of normalcy, implied in the enactment of adding 'nuance' from a self-declarative 'fringe'. Doubt 'sells' and is desirable because it claims to bring a sanctuary of contestation to a presupposed insufficiently challenged disablist worldview in which objects of critical concern are 'labelled' by a disablist construction. Claiming a state of doubt regulates the hope for an alternative to the restrictive and homogenising diagnostic category of autism. The case studies could together form a glimpse of what a popular understanding and awareness of the 'nuances' of the diagnosis, its epistemology, and empowerment look like, but a certain kind of awareness that sustains the power imbalances of ableism. I have pointed out doubt as a recurring theme in my case studies that reveals such tensions yet evens them out to the extent that they become part of everyday life and 'sharpness' and thus become less noticeable. What sustains ableism is that this assumed 'sharpness' is applauded and thus left unproblematised. In the next section, I will outline my theoretisation of ableist economies of doubt as nuances that normalise rather than problematise abled-centric normativity.

8.2 Significance and implications of naming a 'political economy of doubt'

In the introduction of this thesis, I presented the phrase 'political economy of doubt' with which I referred to the key role of epistemological uncertainty, and the wish to resolve that uncertainty, in the (re)production and distribution of knowledge and meaning-making in science, society and culture. The term 'ableist economies of doubt' specifies that this relational process of meaning-making and the role of epistemological uncertainty therein adheres to able-centric social norms. By naming ableist economies of doubt, I am suggesting a promise of nuance, openness, and 'positivity' in the wake of profitable, unthreatening diversity, next to the interpellation of the autism category as a promise of a solution. Both have a strong imperative of sustaining labour and 'normalcy', or depathologisation in the case of autism intervention and the non-pathological in the case of doubt to diagnostic categorisation.

The promise of unthreatening difference that ultimately guarantees material and immaterial profit and prosperity is closely related to compulsory ableness as a performance of mythically perfect and enhanced human experience. My focus on ableism aids to map a world in which ableness is performed and constantly (re)produced as a perfected state of being. This state is therefore also a futile one, directed towards the idealised 'real' that covers both the everyday (the unquestioned) and the taken-for-granted hope for more closeness towards this 'real'. Instead of a picture of scientific realism as a belief in the 'out there', I deconstruct it as fundamentally mythical in the face of compulsory able-bodiedness that is omnipresent yet futile.

Scientific realism is profoundly ableist, as a deconstruction of ableism not only captures disablement but the dominion over 'complexity' as well. By naming ableist economies of doubt, implied within the autism epistemologies in my case studies, I have highlighted this dominion over the 'complex' human. 'Human complexity' is supposedly desired but also fails to problematise the power in the claim to the comprehensive understanding of the Foucauldian 'individual case' in examination: wanting to know 'every nuance' means that one w   ields power over this extensive 'everything'.

To clarify this farther-reaching power with the help of my research question and thesis, I would like to point out an overarching theme of hybridity in my overall defence of a political economy of doubt. In my discussion of Runswick-Cole and Mallett's notion of the commodification of autism, I already touched upon the appeal of the hybridity of the phrasing 'information-thing' as a term for reification. In *Extremely Loud & Incredibly Close*, the hyperaware gaze is constituted by the hybrid of autism indexicality and 9/11 iconography: it makes the spectator wonder if the chance that Oskar is autistic could be nuanced by his traumatic experience and vice versa. My reading of "My Autism and Me" stressed the negotiation of profit both because and despite reified autism, made absolute by the rhetoric of both 'knowing' and 'not-knowing' this 'difference' in the 'brain'. As Baggs resists scientific realist conventions of knowing and not-knowing, her translation forms a two-sided plea for acceptance, the

'untranslated' and the 'translated' to 'more regular language that plays with expectations of creativity and verbal eloquence.

When it comes to the apparent nuance of my case studies, what makes this theme of hybridity so important is that one can easily be employed as a 'nuance' of a statement that involves the other. Oskar might have autism, but his sensory overload may also be related to trauma, or vice versa in the sense that 'it might not be just trauma'. Here, the nuance to knowing could lie in the hope that we might once get to know what we do not know 'now'. The children portrayed in "My Autism and Me" are disabled but also have chances in life to turn their 'disabilities' into something more profitable. In *In My Language*, Baggs articulates herself, but might not be 'sincere' in her claims to autistic identity. Hybridities thus open the potential of strategic nuance and doubt, because of the evocation of two options that mutually reinforce each other so that one of them can be brought in when the other is suggested.

For me, autism as a discourse within ableist economies of doubt is a collection of hidden Janusheads that could reveal power imbalances. *Extremely Loud & Incredibly Close* and *In My Language* exemplify the privileged creative freedom to play with dualities as if they were two strings on a marionette, whilst Baggs faces and negotiates more direct forms of doubt about her integrity. I would like to state that this consistent hybridity overarching my case studies and these insights on power imbalance is why I have singled out a political economy of doubt as something that I do not grasp through Lakoff and Johnson's notion of the metaphorical concept. When unchallenged, nuance could be far-reaching and insidious as it covers both certainty and uncertainty, which has strongly motivated me to highlight economies of doubt as the main theme of this thesis. In terms of 'criticality', I thus warn for a fetishisation of the 'objection', as well as the belief in 'outsmarting' 'fallacies' in everyday life. Both risk becoming expressions of the belief that one stays 'above' the commodified autism information-thing. Instead, my thesis places 'nuance' and wariness of 'labelling' as part of ableism itself, rather than part of academic attempts to be critical about this.

I have named 'political economy of doubt' based on my research project in order to conceive compulsory able-ness as a constant unconscious need and pressure to be sharp in the wake of the 'potential fake', the 'potentially productive' and the 'good'

parent to the kid with the 'complex' and 'multi-layered' needs. Doubt distributes a sense of being 'halfway' towards 'definitive' knowledge, as well as suspicion and dispute of validity and sincerity of the autism category 'whenever' it is allegedly 'needed', no matter how much disabled people could suffer from this. All in all, my stance on doubt in this thesis is one of caution in which I ask for a specific kind of cultural awareness of the power asymmetry of dis/ability.

However, this is still within the confines of this specific study, whereas the main reason why I am so eager to present my terminology is its huge potential for further exploration outside of my research question alone. I hope to motivate new texts in the 'textured life of embodiment' that specify doubt as government, that is, the site of social control that populations unconsciously perform in order to keep autism rates 'in line'. My case studies come from film according to conventions of the field of Cultural Studies. This is helpful for academic work on the cultural depiction of autism, as my political economy of doubt is a new additional field of concern next to studies of stereotypes (Loftis, 2015), fascination (Murray, 2008) and staring (Garland-Thompson, 2009).

Nevertheless, I would like to call for additional cultural analysis on ableist notions of excess, control and moderation without the study of signs. I support wider discourse analyses of the things that can and cannot be said about diagnostic categorisation and the subtle theme of doubt that is interwoven in such productions of meaning. My use of Peirce's index in the approach to autism chapter could help with this, as I creatively adopted a term from semiotics as a tool to deconstruct social expectations of 'proof' of disability and in/visibility. Further research on this social contract could focus on the implied trust relationship between the spectator and the dis/abled person who is being looked at. Social expectations of contiguity imply a 'risk' of vulnerability to this relationship in case of a supposed 'lack' of proof, as well as hyperawareness of people who potentially 'show signs' of pathologized deviance.

Moreover, the culturally enforced fear of 'lacking' proof and dis/ability credibility brings me to the role of doubt in research on disablism. Disability oppression addresses the sensitive topic of cultural fear of 'feigning' disability and its impact on disabled people's lives in the form of distrust and additional bureaucratic labour

(Hannam-Swain, 2017). In the chapter on In My Language, I addressed the topic of disablism in relation to backlash and dispute about the validity of autism self-identification that Baggs received. I would be interested to see qualitative studies on literal and direct forms of doubt in the form of *microaggressions* as experienced by disabled, mad, and/or (self-)diagnosed people. Microaggressions are everyday subtle instances of oppression that are small yet impactful because of their high frequency and are often unnoticed and unrecognised by the perpetrator (Sue, 2010, p. xv). Disabled people might experience microaggressions that consist of implicit or explicit doubt concerning their disability or overall integrity and voice. This includes apparent affirmations of one's individuality and self-reliance. This inclusion would continue my reflections on governmentality and the genealogy of denied autistic voice that have led to an understanding of discourse on the neoliberal independent self in unproblematised ableism as dominion over the 'whole' person 'next' to the 'disability'. On the level of internalised ableism, or disability self-hatred (Campbell, 2009, p. 121), the theme of self-doubt among disabled people, possibly generated by microaggressions camouflaged as affirmation, is also an important topic of concern.

To conclude, my isolation of doubt as one way of conceiving the enactment and normalisation of ableism has not been meant as "another explanatory 'grand narrative', [or] a universalised and systematised conception of disability oppression" (p. 19). Instead, following Campbell, it aims to "highlight a convergence of networks of association that produce exclusionary categories and ontologies" (p. 19-20). I do not pretend to explain how to 'reveal' ableism as the overarching narrative of oppressive lives and cultural texts; the term 'ableism' functions to study the cultural production of pathologisation and the futile ideal of able-ness. This function motivates my choice to talk of a 'political economy', since it refers to my academic act of identifying unity and normativity in autism epistemologies that have come up in my answer to my research question. Since 'economy' puts forward the circulation of meaning, the theme of doubt highlights the cultural production and enactment of actualisation and normative notions of the self through 'nuance'. My presentation of a political economy of doubt suggests opportunities for new "sites of study" on previously unspoken regimes of

truth (p. 20) in future research. My contributions to knowledge on autism and ableism are outlined in the next section.

8.3 Contributions and limitations of my research project

This thesis established its contribution to knowledge as adding to both knowledge on the cultural depiction of autism and the practices of criticality that aim to 'rethink' the category. Such additions have been concretised by centralising disability rights by decentralising autism and autistic people. This decentralisation has been realised in my execution of the research question and definitions of its terminology, which has established my sensibility for production of meaning rather than a 'true' or 'false' resemblance to signs compared to an assumed pre-discursive reality.

The theoretical framework in my chapter on the approach to autism has made room for system critique that decentralises the communities and vocabulary of people who identify as autistic. This critique is concerned with the social production of the subject as a negotiator of molecularised biovalue within the circulation of the autism information-thing in society. I have discussed these concepts in my chapter on the approach to autism; short definitions for clarification can be found in the glossary. The chapter on representation particularised a constructionist view on representation that studies creative endeavours and presents a creative act itself, based on a continuation of my previous academic work that also tried to accomplish this goal. Recent continuations to create a framework of research on ableist normativity in cultural representation summarise an interest in autism in film as recognising spectatorship. Recognition stands for the cultural desire to recognise (pathologized) deviance in order to unite textual analysis of the gaze in film style and narrative with my challenge to categorisation within ableism. The chapter on personal accounts combined a focus on autism representation in autobiographical texts with further effort to challenge recentralising people who identify as autistic in 'critical' research. The personal account was conceptualised as a palimpsestic social process of acknowledgement of autistic voice, rather than a fixed cultural artefact that features an interviewed autistic person and/or definitive and absolute declarations of autistic authorship. My discussion of the genealogy of the articulate autistic added the theme of dispute of claims to voice, embedded in the personal account as a social process of

acknowledging autistic voice, which is important to my overarching theme of epistemological uncertainty. Overall, these conceptual explorations touched upon the construction and circulation of meaning and ableist ideology that informed my analysis of cultural objects, each with different production contexts, levels of ascribed cultural legitimacy, and different depictions of an autistic person speaking.

The theme of autism within ableist economies of doubt became evident in my case study readings, in which I unpick different ways of representing 'autism' that seem to be 'different' in a more subversive sense but instead affirm the norm exactly *through* this apparent subversive nature. My readings of three case studies addressed the normativity of recent cultural texts with different production contexts and representation of speaking autistic persons. I formulated autism metaphorical concepts based on textual and discourse analysis.

Concerned with the social production of meaning rather than the reveal of meaning within assumed pre-discursive reality, my thesis carefully negotiates claims to academic criticality that problematise biomedical claims to the truth on autism. I share concerns on the political implications of biomedical pre-discursive reified 'autism' and put forward Campbell's notion of ableism as my site of criticality. My research question, case study readings and conceptual engagements with the topic of autism have thus resulted in more insights on semi-ambiguous autism epistemologies per case study. They did so through a new vocabulary on doubt that can be further inquired in future studies. I hope to continue my assembly of autism, ableism, and epistemological doubt in future work.

Simultaneously, the feasible scope of a 'critical ableism studies' is also where the limitations and vulnerabilities of my thesis are located. In my commitment to cultural analysis and the political economy of doubt, I have largely directed this exact scope all by myself. This self-direction is intrinsic to my thesis structure and argument but might have resulted in an overambitious cultural theorisation project. With my thesis argument, I could base my cultural criticism of the autism diagnostic category around demystifying compulsory enactment of perfected ableness in society. My site of criticality has brought me enough theoretical freedom to situate abled-centric normativity in autism as a discourse, which then brought conceptual weight to bio-

power and indexicality, which then highly influenced my case study readings. Despite my conviction in my argument on ableist economies of doubt, my overall exploration of a critical ableism studies is so self-sustainable that I might risk creating an overly comprehensive critical theory as a response to existing Disability Studies debates. The term 'ableism' is not necessarily this comprehensive; Campbell's 2009 book title *Contours of Ableism* already implies sketches of ableism theory as a portfolio of fragmented ever-evolving ideas on dis/ability normativity. Because my insistence on diagnostic categorisation as ableist is permeated into my entire set of conceptualisations and epistemological metaphorical concepts, I am also fully responsible for their execution because it is entirely my own creative endeavour. Research projects on PhD level do not necessarily ask for such enormous responsibility.

My (bold) project aim has been to develop theory through cultural analysis. However, my self-imposed 'critical autism studies' here might have inadvertently established an entire strand of thinking beyond the origin of this presumed 'field', which is too much of a burden to carry in a PhD thesis. This potentially overambitious weight in the thesis could negatively influence thesis structure and argumentation, no matter how I try to make my site of criticality consistent. Furthermore, my strand of thinking has sprouted a fetishisation of interrogating declarations of criticality in order to present my own divergent and unique stance on dis/ability in cultural theory. Ultimately, my constant intellectual interrogations may not attain much more than an exploitation of vulnerabilities in academic debates with the implication that I bear sole responsibility over their 'correction'. My future academic work will be more mindful of proportion and scale in cultural criticism and the role of 'ableism' therein in favour of a personal portfolio of smaller studies.

8.4 Conceptualising crip killjoys beyond my thesis

Concluding this thesis, I would like to imagine how one might undermine criticality and the strategic Janushead of claiming 'nuance' from within in cultural theory, with concluding reflections on doubt and the crip killjoy (Ahmed, 2010; Johnson and McRuer, 2014). In this final section, I will first position my own criticality as a concern for the right to self-expression, after which I will introduce the topic of the crip killjoy with a dissection of its meaning to me. I will then consider the opportunities for a

critical reading of the 'crip killjoy' through Runswick-Cole's 'challenge' to 'challenging behaviour'. At the end of this thesis, I will pose the crip killjoy as a potential problematisation to the restorative normative power of 'nuance' in ableist economies of doubt.

I touch upon criticality based on the "cautionary tale" (Ebben, 2018, p. 160) of ableist power asymmetry in dominion over both 'certainty' and supposed 'nuance' to the certainty of the reified diagnostic category. When it comes to the theorisation that has been produced within the boundaries of this thesis, my warnings about the political economy of doubt might be considered as unsatisfactory and fatalistic. I would like to imagine further enablement of self-expression that is transformative from within. The notion of 'from within' means I would not want to undo the 'presence' of autism and the prevalence of diagnostic categories, as well as to pretend that 'ableism' can be 'resolved'. Instead, I would like to state that the imagination of a world 'without' ableism might be incomprehensible and an undesirable promise that risks a fetishisation of 'thinking differently' once again. A realistic starting point for academic thinking would be to be concerned with more than only the realisation of the limitations of a biomedical model or overall negative ontology of human difference.

Within the scope of this thesis, this 'more' could be continued as sensibility and cultural facilitation of free self-expression and participation within the textured life of embodiment. The metaphorical concepts of each case study all involved the circulation and implementation of the act of 'knowing'. Formulating metaphorical concepts allowed me to study abled-centric normativity and power imbalance, but simultaneously, I am also thinking about the things that free acts of 'knowing' could entail and what they imply for the affirmation and ethics of criticality.

Imagining such affirmative new forms of knowledge and the ways in which they could be undermined all along, I will reflect on the notion of the 'crip killjoy'. As my cautionary tale on ableist economics of doubt asks for vigilance, I find this term particularly relevant as a topic of concern on criticality. 'Killjoys' can come from alternative forms of knowledge that might be emotionally and intellectually considered as 'difficult', which makes them prone to reactions of discomfort and dismissal. Within Cultural and Critical Disability Studies, the crip killjoy is the adoption

of Ahmed's notion of the killjoy, put into the context of crip theory that problematises compulsory ableness (McRuer, 2006). Ahmed offers a feminist deconstruction of the gendered socially expected pursuit of happiness that creates archetypical roles of invasive and disruptive negativity such as the 'angry black woman' and the 'feminist killjoy' (Ahmed, 2010, p. 17). Johnson and McRuer (2014) adopt Ahmed's reclamation of the disruptive potential that is implied in the 'killjoy' reproach to the critique of compulsory abled   ness. They evoke a 'crip killjoy' who "refuses to play along" with the social imperative to be optimistic and hide discontent about disability (p. 136). For me, the crip killjoy is not localised in people but in meaning exchanges: crip narratives and networks that 'risk' discomfort. While my vocabulary on autism categorisation in ableism like indexicality, the 'promise' in commodification and recognition were built upon anticipation, the crip killjoy refuses to anticipate backlash and the policing of supposedly unfriendly and negative tone of political voice.

In order to outline the usefulness and scope of the crip killjoy, I would like to dissect the term. 'Crip' itself is a pejorative slur that has been appropriated for activist purposes. I would like to locate the 'crip' in circulations and networks of meaning exchange that are devoted to undermining able-centred signification. As the entire potentially limitless scope of 'ableism' cannot easily be pretended to be undermined, naming 'small' creative endeavours 'crip' could help to envision 'humble beginnings'. 'Humble' does not mean prudence out of servitude, but instead considers criticality in a strategically small scale that does not pretend to capture the full scope of ableist normativity but still allows involvement in rewriting and rethinking dis/ability signification. What interests me about the 'killjoy' and its inclusion within the context of Disability Studies is the room that it provides to convey the unease that the right to self-expression and self-identification with autism as a discourse could affirmatively bring. Within the power imbalance of distributed cultural legitimacy of the speaking person who identifies as autistic, disabled people may risk unsettlement and unease out of perceived negativity, and it is in this risk that the 'killjoy' is useful. It is affirmative as it helps to reflect on the possibility to accept that crip actions that try to unsettle ableism can be wry, as they confront ableist society with the genealogy of diagnostic taxonomies that it has created itself.

For criticality that aims to enable and affirmatively transform lives, the killjoy can counter a narrow focus on presumed positivity. Although literature within declarations of a critical autism studies often defend positive statements on individuality (Hodge, 2016) and complexity (Davidson & Orsini, 2013), positivity on diversity alone might not adequately push challenges to the ableist power imbalance of doubt and nuance. My reading of "My Autism and Me" made clear that an uplifting visual style does not have to be neutral and could actually enhance a neoliberal depiction of a 'success story'. Understandings of new 'enabling' autism epistemologies could become limited if they overly presuppose that people who identify as autistic want to be proud of and happy about individualised human difference. Personal accounts could face subtle or explicit accusations of unreasonable aggression and thus further pathologisation (ironically in the context of attempted depathologisation of 'negative' 'labelling') if they 'fail' to meet these presuppositions and instead address more culturally sensitive manifestations of power imbalance. This is especially relevant in terms of the display of the creative freedom that has historically been dismissed as a scientific oxymoron and that might dare to 'crip' disabled people as a 'we' to counter social expectations of the 'complex' 'individual' subject.

Overall, the right for self-expression in the form of crip killjoys could give a new spin to the notion of 'challenging behaviour' (Runswick-Cole, 2014), which is a site of criticality in the area of autism intervention. The nature of this 'challenge' to reclaim can be twofold: 'challenging behaviour' as in the 'ever-growing' 'pathologisation' of everyday life, and the intellectual 'challenge' of intellectual labour that could cause dismissal within society. When it comes to the 'inflation' of the prevalence of autism as a discourse in society as well as increases of acknowledged autistic personal accounts, I would like to evoke the provocative image of the discursive dis/abled pool 'pollutor'. My thesis has taken a cautious stance towards diagnostic inflation as a site of criticality, as its rhetoric of 'out-of-control rates' could normalise rather than counter an 'autism epidemic' metaphorical concept (Ebben, 2018, pp. 150-151). In my work, I have evoked fears of being a burden as internalised ableism and not as personal delusions, which resulted in the provocative use of the term "polluted pool" (p. 151). To 'crip' the killjoy is to declare myself to be a 'polluter' as it faces the theme of doubt

head-on through provocation: I am an articulate autistic person, and therefore, I, too, live in the shadow of potential doubt. Such a declaration has caused me to move away from the motivation to depathologise, as it might suggest that ableism is merely something 'faulty' in 'bigoted' thinking that we could easily step away from as long as we 'embrace diversity'. Even though excess is a painful subject from which people would like to distance themselves, discomfort is academically meaningful as it can help to grasp how radical a 'critical ableism studies' might be as a structure of thought that interrogates everyday life. If discomfort is interpreted as inherently undesirable for enabling conceptions of autism, established thinkers and scholars might be centralised as the ones under jeopardy in the aftermath of the 'opaque polluted pool' of autism rates. Discomfort could be the start of new kinds of knowledge, with less self-sustaining shared sense of outsmarting the catalyst of criticality, that is, the information-thing of autism. With the notion of the crip killjoy, freely creative representations could affirm new structures of signification as full unsettling 'polluting' presence in cultural debates.

The second way in which self-expression on dis/ability and 'humble beginnings' of radical epistemologies can be challenging is in terms of intellectual 'difficulty', which also risks permeating Disability Studies practice out of concerns for accessibility. I would like to argue that the criticality in Disability Studies should never put artificial restraint on intellectual depth, labour, and property, because the denial of depth will eventually harm everyone's right to self-expression. For example, the right for depth touches upon general ethical questions like the warranty of the integrity of intellectual property. Who owns what kind of knowledge, who has access to academia, and whose knowledge is recognised and prioritised? For example, a lot of creative input that comes from unpaid labour posted on social media might have academic theoretical relevance but will never become full-fledged references. It is important to express awareness of the amounts of unacknowledged work beyond academic publishing.

A conscious lack of intellectual depth could become coercion of control over budding networks of thought based on fears for recentralisations of negative ontologies that could harm rather than help the polyphony of knowledge outside of a White abled norm. Topics of disability and race bring discomfort because they invoke the genealogy

of categorisation in a way that people would rather 'not see' anymore as an act of tolerance, while these very topics serve to disseminate the cultural constellation of power imbalance. The denial of intellectual depth can be a way to deny people complex types of knowledge that could bring more insights on justice. Opinion pieces from Dutch anti-racist activists and writers have covered the issue that the persistent reinforcement of the issue of Dutch racism as a point of contentious debate (Nourhussen, 2017) keeps the level of thinking on the topic artificially low (Philipse, 2017). Concerns about mainstream debate in largely White Dutch public spaces within an already tense atmosphere regarding race issues suggest that unsatisfactory engagement with the intellectual labour of Dutch people of colour could safeguard White "self-congratulatory" self-conceptions of innocence and hierarchised objectivity (Wekker, 2016, pp. 166-170). Asymmetrical power is thus sustained over debate on the exact power imbalances that counter this hegemony when it comes to dis/ability, race, and their intersections (Crenshaw, 1991).

I would like to wind up this thesis with a final declaration on the usefulness for the crip killjoy as a humble beginning for undermining the ableist dominion over both concreteness and nuance in the political economy of doubt. Self-declarations of positionality in the fringes or the 'Devil's advocate' within ableist and arguably racist economies of doubt can be self-congratulatory because of the 'love' for criticality itself. Cultural texts that counter this regressive and reactionary dis/ability knowledge and dismantling the disguise of the doubter who claims dominion over radicality might come in unsettling forms that might 'look' like 'challenging behaviours' in common intellectual spaces. I expect a crip reversal of the Janushead of doubt: seemingly 'difficult' forms of knowledge that undermine the way we tend to think about criticality but that will reform dis/ability from the inside exactly because of this.

List of references

Ahmed, S. (2004). Affective economies. *Social text*, *22*(2), 117-139.

Ahmed, S. (2010). *The Promise of Happiness*. Durham/London: Duke University Press.

Airoldi, M., Beraldo, D. & Gandini, A. (2016). Follow the algorithm: An exploratory investigation of music on YouTube. *Poetics*, *57*, 10-13.

Althusser, L. (1970). Ideology and Ideological State Apparatuses (Notes towards an Investigation). In B. Brewster (transl.). (1971) *Lenin and Philosophy and other essays* (pp. 121-173)*.* London: NLB.

Amanda Baggs Autism Controversy. (sine anno). Several former 1994-1995 Simon's Rock College friends and classmates of Amanda Baggs have come forward in light of what they saw and read in the widespread 2007-2008 national media coverage of Baggs, to provide their observations of Baggs in 1994-1995 at Simon's Rock College; some witnesses continued their friendships with Baggs from 1995-1998. *Amanda Baggs Autism Controversy*. Retrieved from http://abaggs.blogspot.co.uk

American Psychiatric Association. (2000) DSM-IV-TR® Diagnostic and Statistical Manual of Mental Disorders: Chapter 1: Disorders Usually First Diagnosed in Infancy, Childhood, or Adolescence. *PsychiatryOnline.* Retrieved from
http://dsm.psychiatryonline.org/content.aspx?bookid=22&sectionid=1888402

American Psychiatric Association. (2013). Diagnostic and Statistical Manual of Mental Disorders, 5th Edition: Neurodevelopmental Disorders. *PsychiatryOnline.* Retrieved from
http://dsm.psychiatryonline.org//content.aspx?bookid=556&sectionid=41101757

Anderson, B. (2006). *Imagined Communities.* New Edition. London: Verso.

Arnold, L. (2013). Review: Autism A Social and Medical History. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, *1*(2). Retrieved from http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/RE2/html

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

Austin, J. L. (1962). *How to do Things with Words. The William James Lectures delivered at Harvard University in 1955*. Oxford: Clarendon Press.

Bagatell, N. (2007). Orchestrating voices: autism, identity and the power of discourse. *Disability & Society, 22*(4), pp. 413-426.

Bagatell, N. (2010). From Cure to Community: Transforming Notions of Autism. *Ethos: Journal of the Society for Psychological Anthropology*, *38*(1), 33-55.

Baggs, M. (2012). About. *Ballastexistenz.* Retrieved from https://ballastexistenz.wordpress.com/about-2/

Baker, A. D. (2008). Recognizing Jake: Contending with Formulaic and Spectacularized Representations of Autism in Film. In M. Osteen (Ed.), *Autism and Representation* (229-243). New York/London: Routledge.

Barnes, C. (2012). The social model of disability: Valuable or irrelevant? In N. Watson, A. Roulstone & C. Thomas (Eds.), *The Routledge handbook of disability studies* (pp. 12-29). Abingdon: Routledge.

Barker, C. (2003). *Cultural Studies: Theory and Practice.* Second edition. London: SAGE.

Barthes, R. (1968) The Death of the Author. In S. Heath (Ed.). *Image, Music, Text.* London: Fontana: 142-148.

BBC. (2011). Watch My Autism and Me – a Newsround special. *CBBC Newsround*. Retrieved from http://www.bbc.co.uk/newsround/15655232.

Beardon, L., Martin, N. & Woolsey, I. (2009). What do students with Asperger syndrome or highfunctioning autism want at colleges and university? (in their own words). *Good Autism Practice (GAP, 10*(2), 35-43.

Beek, A. van de. (2011) *Representatie en stereotypering van autism in films van 1988 tot 2010.* MA thesis supervised by E. Masson and E. Müller, Utrecht University.

Belek, B. (2013). *"I Believe It Can Change the Way Things Are". Identity Constructions Among Video-Bloggers with Asperger's Syndrome on Youtube.* Diemen: AMB.

Bell, C. (2010). Is Disability Studies Actually White Disability Studies? In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 374-382). New York: Routledge.

Bell, V. (2018, March 8-15). Private conversation with Victoria Bell [e-mail]. Referenced with written permission.

Best, J. (2007, November 19). Amanda Baggs on CCN Tonight at 10:00PM EST. *Hating Autism.* Retrieved from http://hatingautism.blogspot.com/2007/11/amanda-baggs-on-cnn-tonight-at-1000pm.html

Best, J. (2008a, February 11). A Letter About Amanda Baggs's Fraud. *Autism Fraud.* Retrieved from http://autismfraud.blogspot.co.uk/2008/02/letter-about-amanda-baggs-fraud.html

Best, J. (2008b, March 1) NY Times Falls for Hoax, Amanda Baggs. *Autism Fraud.* Retrieved from http://autismfraud.blogspot.com/2008/03/ny-times-falls-for-hoax-amanda-baggs.html

Best, J. (2009, August 22). Reporting Fraud, Amanda Baggs. *Hating Autism*. Retrieved from http://hatingautism.blogspot.com/2009/08/reporting-fraud-amanda-baggs.html

Bettelheim, B. (1967). *The Empty Fortress: Infantile Autism and the Birth of the Self.* New York City: The Free Press.

Biklen, D., Attfield, R., Bissonnette, L., Blackman, L., Burke, J., Frugone, A., Mukhopadhyay, T. R., and Rubin, S. (2005). *Autism and the Myth of the Person Alone.* New York City: New York University Press.

Bleuler, E. (1910). *Demenia Praecox oder Gruppe der Schizophrenien.* Leipzig: Franz Deuticke.

Bordwell, D. and Thompson, K. (2017). *Film Art: An Introduction.* Eleventh edition. New York City: McGraw-Hill.

Bramsen, I. & Cardol, M. (2016). Implicaties voor het onderwijs. Hbo-studenten gezondheidszorg ontmoeten mensen met een verstandelijke beperking. In G. Van Hove, A. Schippers, M. Cardol & E. De Schauwer (Eds.), *Disability Studies in de Lage Landen* (pp. 100-110). Antwerpen/Apeldoorn: Garant.

Broderick, A. A. & Ne'eman, A. (2008). Autism as metaphor: narrative and counter-narrative. *International Journal of Inclusive Education*, *12*(5-6), 459-476.

Broeckman, C. (2000). *A question of character: Scientific racism and the genres of American fiction, 1892-1912*. Tuscaloosa: The University of Alabama Press.

Brownlee, J. (2007, January 30). The Natural Language of Autism? *Wired.* Retrieved from https://www.wired.com/2007/01/the_natural_lan/

Brownlow, C. & O'Dell, L. (2013). Autism as a Form of Biological Citizenship. In: J. Davidson and M. Orsini (Eds.), *Worlds of Autism. Across the Spectrum of Neurological Difference* (pp. 97-114). Minneapolis: The University of Minnesota Press.

Burgess, J. & Green, J. (2008, October 15-18). Agency and Controversy in the YouTube Community. *Internet Research 9.0: Rethinking Community, Rethinking Place*, Copenhagen.

Burgess, J. & Green, J. (2009). *YouTube: Online Video and Participatory Culture.* Cambridge: Polity Press.

Burks-Abbott, G. (2008). Mark Haddon's Popularity and Other Curious Incidents in My Life as an Autistic. In M. Osteen (Ed.), *Autism and Representation* (pp. 289-296)*.* New York/London: Routledge.

Butler, J. (1993). *Bodies that Matter. On the Discursive Limits of Sex*. London/New York: Routledge.

Caillois, R. (1935). Mimicry and Legendary Psychastenia. In C. Frank (Ed.). *The Edge of Surrealism: A Roger Caillois Reader* (pp. 91-103)*.* Durham/London: Duke University Press.

Campbell, F.K. (2005). Legislating Disability: Negative Ontologies and the Government of Legal Identities. In S. Tremain (Ed.), *Foucault and the Government of Disability* (pp. 108-130)*.* Ann Arbor: University of Michigan Press.

Campbell, F.A.K. (2008). Exploring internalized ableism using critical race theory. *Disability & Society*, *23*(2), 151-162.

Campbell, F.A.K. (2009). *Contours of Ableism: The Production of Disability and Abledness.* Basingstoke: Palgrave MacMillan.

Cappelli, M.L. (2016). Manufacturing consent in Extremely Loud and Incredibly Close: The visual aesthetics of tragedy, vulnerability, and triumph. *Cogent Social Sciences, 2*.

Cartwright, L. (1995). *Screening the Body: Tracing Medicine's Visual Culture.* Minneapolis: University of Minnesota Press.

Caruso, D. (2010). Autism in the U.S.: Social Movement and Legal Change. *American Journal of Law & Medicine, 36*, 483-539.

Caruth, C. (1996). *Unclaimed Experience: Trauma, Narrative, and History.* Baltimore: The Johns Hopkins University Press.

Charteris-Black, J. (2004). *Corpus approaches to critical metaphor analysis*. Basingstoke: Palgrave-MacMillan.

Chew, K. (2013). Autism and the Task of the Translator", In J. Davidson & M. Orsini (Eds.), *Worlds of Autism: Across the Spectrum of Neurological Difference* (pp. 305-317). Minneapolis: The University of Minnesota Press.

Coca, A.F. & Cooke, R.A. (1923). "On the classification of the phenomena of hypersensitiveness", in: *Journal of Immunology*, *8*, 163-182.

Codde, P. (2007). Philomena Revisited: Traumatic Iconocity in Jonathan Safran Foer's *Extremely Loud & Incredibly Close*. *Studies of American Fiction*, 35(2), 241-254.

Cooper, A. (2007, February 21). Why we should listen to 'unusual' voices. *CNN Anderson Cooper blog.* Retrieved from
http://www.cnn.com/HEALTH/blogs/paging.dr.gupta/2007/02/behind-veil-of-autism.html

Corker, M. & French, S. (1999). Reclaiming discourse in disability studies. In M. Corker & S. French (Eds.), *Disability Discourse* (pp. 1-11). Buckingham: Open University Press.

Corner, J. (1996). *The Art of Record: A Critical Introduction to Documentary.* Manchester: Manchester University Press.

Couldry, N. (2010). *Why Voice Matters: Culture and Politics After Neoliberalism*. London: SAGE.

Crenshaw, K. (1991). Mapping the margins: Intersectionality, identity politics, and violence against women of color. *Stanford Law Review*, *43*(6), 1241-1299.

Davidson, J. (2007) 'In a World of her Own…': Re-presenting alienation and emotion in the lives and writings of women with autism. *Gender, Place & Culture: A Journal of Feminist Geography*, 14(6), 659-677.

Davidson, J. (2008.) Autistic culture online: virtual communication and cultural expression on the spectrum. *Social & Cultural Geography*, 9(7), 791-806.

Davidson, J. & Henderson, V. L. (2010). 'Coming out' on the spectrum: autism, identity and disclosure. *Social & Cultural Geography*, 11(2), 155-170.

Davidson, J. & M. Orsini. (2013a). Introduction. Critical Autism Studies. Notes on an Emerging Field. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism: Across the Spectrum of Neurological Difference* (pp. 1-28). Minneapolis: The University of Minnesota Press.

Davidson, J. and M. Orsini. (2013b). The Shifting Horizons of Autism Online. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism: Across the Spectrum of Neurological Difference* (pp. 285-304). Minneapolis: The University of Minnesota Press.

Davidson, J. & Smith, M. (2009). Autistic autobiographies and more-than-human emotional geographies. *Environment and Planning D: Society and Space*, 27, 898-916.

Davis, L. J. (2017). The Ghettoization of Disability: Paradoxes of Visibility and Invisibility in Cinema. In A. Waldschmidt, H. Berressem & M. Ingwersen (Eds.), *Culture - Theory - Disability: Encounters between Disability Studies and Cultural Studies* (pp. 39-49). Bielefeld: transcript Verlag.

De Lauretis, T. (1984). *Alice Doesn't. Feminism, Semiotics, Cinema.* Bloomington: Indiana University Press.

Didi-Huberman, G. (2016). To Render Sensible. In A. Badiou, P. Bourdieu, J. Butler, G. Didi-Huberman, S. Khiari & J. Rancière, *What is a people?* (pp. 65-86). English translation. New York: Columbia University Press.

Dijck, J. van. (2005) *The Transparent Body. A Cultural Analysis of Medical Imagining.* Seattle: University of Washington Press.

Draaisma, D. (2009). Stereotypes of autism: On media representations of autism. *Philosophical Transactions of the Royal Society B*, 264(1522): 1475-1480.

Duffy, J., & Dorner, R. (2011). The pathos of "mindblindness": autism, science, and sadness in "Theory of Mind" narratives. *Journal of Literary & Cultural Disability Studies*, *5*(2), 201-215.

Ebben, H. (2012, April 5). Defining the rootless label: a romantically ironic appeal. *Notes on Metamodernism*. Retrieved from http://www.metamodernism.com/2012/04/05/defining-the-rootless-label-a-romantically-ironic-appeal/

Ebben, H. (2015). *In constant encounter with one's environment: Presenting counter-metaphors in the study of the discourse of autism and negotiations of space in literature and visual culture*. MA thesis supervised by L. Munteán and M. Waltz, Department of Literary and Cultural Studies, Radboud University Nijmegen.

Ebben, H. (2016a). Movement as language, signification as identity: Understanding and empowering the autistic community in online spaces. *TransMissions: The Journal of Film and Media Studies, 1*(1), 50-67.

Ebben, H. (2016b). Voorbij de lege burcht. De mogelijkheid van contra-metaforen in representaties van ruimte in gefilmde persoonlijke documenten over autisme. In G. Van Hove, A. Schippers, M. Cardol & E. De Schauwer (Eds.), *Disability Studies in de Lage Landen* (pp. 296-303). Antwerpen/Apeldoorn: Garant.

Ebben, H. (2018). The Desire to Recognise the Undesirable: De/Constructing the Autism Epidemic Metaphor and Contagion in Autism as a Discourse. *Feminist Formations*, *30*(1), 141-163.

Epstein, E., Wiesner, M., & Duda, L. (2013). DSM and the Diagnosis-MacGuffin: Implications for the Self and Society. *Australian and New Zealand Journal of Family Therapy*, *34*(2), 156-167.

Erevelles, N. (2005). Rivière, Facilitated Communication, and the Crisis of the Subject. In S. Tremain (Ed.), *Foucault and the Government of Disability* (pp. 45-64)*.* Ann Arbor: University of Michigan Press.

Feinstein, A. (2010). *A History of Autism: Conversations with the Pioneers.* London: John Wiley and Sons.

Ferguson, P. M. & Nusbaum, E. (2012). Disability Studies: What Is It and What Difference Does It Make? *Research & Practice for Persons with Severe Disabilities*, *37*(2), 70-80.

Foer, J. S. (2005). *Extremely Loud and Incredibly Close.* Boston: Houghton Mifflin.

Foucault, M. (1967). Different Spaces. In James Faubion (Ed.). (2000) *Michel Foucault. Aesthetics, Method, and Epistemology. Volume Two* (pp. 175-185)*.* Translated by Robert Hurley; first published in French in 1984. London: Penguin Books.

Foucault, M. (1969). What Is an Author? In D. Bouchard (Ed.). (1977). *Language, Counter-Memory, Practice: Selected Essays and Interviews* (pp. 113-138)*.* Translated by D. Bouchard and S. Simon. Oxford: Basil Blackwell.

Foucault, M. (1971a) "The Discourse on Language", in: Michel Foucault. (1972 [1969]) *The archeology of knowledge and The discourse on language* (pp. 215-237)*.* Translated by A. M. Sheridan Smith. New York City: Pantheon Books.

Foucault, M. (1971b). Nietzsche, Genealogy, History. In D. Bouchard (Ed.). (1977) *Language, Counter-Memory, Practice: Selected Essays and Interviews* (pp. 139-164)*.* Translated by D. Bouchard and S. Simon. Oxford: Basil Blackwell.

Foucault, M. (1972 [1969])*. The archeology of knowledge and The discourse on language.* Translated by A. M. Sheridan Smith. New York City: Pantheon Books.

Foucault, M. (1976). 17 March 1976. In M. Bertani & A. Fontana (Eds.). (2003). *"Society Must Be Defended": Lectures at the Collège de France, 1975-76* (pp. 239-272)*.* Translated by David Macey. New York: Picador.

Foucault, M. (1977 [1975]). *Discipline and Punish. The Birth of the Prison.* Translated by Alan Sheridan. London: Allen Lane.

Foucault, M. (1978). *The History of Sexuality. Volume 1: An Introduction.* Translated by Robert Hurley. New York: Pantheon Books.

Foucault, M. (1980a). Two Lectures. In C. Gordon (Ed.), *Power/Knowledge. Selected Interviews and Other Writings 1972-1977* (pp. 78-108)*.* New York City: Pantheon Books.

Foucault, M. (1980b). Truth and Power. In C. Gordon (Ed.), *Power/Knowledge. Selected Interviews and Other Writings 1972-1977* (pp. 109-133)*.* New York City: Pantheon Books.

Frances, A. (2012). *Saving Normal. An Insider's Revolt Against Out-of-Control Psychiatric Diagnosis, DSM-5, Big Pharma, and the Medicalization of Ordinary Life.* New York City: HarperCollins.

Fraser, N. (2003). Social Justice in the Age of Identity Politics: Redistribution, Recognition, and Participation. In N. Fraser and A. Honneth (Eds.), *Redistribution or Recognition? A Political-Philosophical Exchange* (pp. 7-109)*.* Translated by J. Golb, J. Ingram & C. Wilke. London/New York: Verso.

Frith, U. (1992). *Autism: Explaining the Enigma.* Oxford: Blackwell.

Fritsch, K. (2013). The neoliberal circulation of affects: Happiness, accessibility and the capacitation of disability as wheelchair. *Health, Culture and Society*, *5*(1), 135.

Fuchs, T. & De Jaegher, H. (2009). Enactive intersubjectivity: Participatory sense-making and mutual incorporation. *Phenomenology and the Cognitive Sciences*, 8, 465-486.

Gajilan, A. C. (2007, February 22). Living with autism in a world made for others. *CNN.* Retrieved from http://edition.cnn.com/2007/HEALTH/02/21/autism.amanda/index.html

Garland-Thompson, R. (2009). *Staring: How We Look.* Oxford: Oxford University Press.

Garland-Thompson, R. (2011). Misfits: A Feminist Materialist Disability Concept. *Hypatia*, 26(3), 591-609.

Genette, G. (1991). Introduction to the Paratext. *New Literary History*, 22(2), 261-272. Translated by M. Maclean.

Georgiou, K. (2014). Performing Autistic Subjectivities. What autism is, what autism isn't and the subjects in between. A genealogical exploration of the autistic subject in the psychoanalytic

literature. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(3). Retrieved from http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR12/html

Gergen, K. J. (1989). Warranting Voice and the Elaboration of the Self. In J. Shotter and K. J. Gergen (Eds.), *Texts of Identity* (pp. 70-81)*.* London: SAGE.

Ghai, A. (2012). Engaging with Disability with Postcolonial Theory. In D. Goodley, B. Hughes & L. Davis (Eds.), *Disability and Social Theory. New Developments and Directions* (pp. 270-286). Basingstoke: Palgrave Macmillan.

Gibbs, J. (2002). *Mise-en-Scène: Film Style and Interpretation.* Columbia: Wallflower Press.

Gilchrist, T. (2011). Stephen Daldry Talks Asperger's, Depicting 9/11 In 'Extremely Loud and Incredibly Close,' And The Oscars. *IndieWire.* Retrieved from http://blogs.indiewire.com/theplaylist/stephen-daldry-talks-aspergers-depicting-9-11-in-extremely-loud-and-incredibly-close-and-the-oscars.

Goodley, D. (2014). *Dis/ability studies. Theorising Disablism and Ableism*. London/New York: Routledge.

Goodley, D. (2016). Autism and the Human. In K. Runswick-Cole, R. Mallett and S. Timimi (Eds.), *Rethinking Autism: Diagnosis, Identity and Equality* (pp. 146-158). London/Philadelphia: Jessica Kingsley Publishers.

Goodley, D. (2017a) *Disability Studies. An Interdisciplinary Introduction.* Second edition. London: SAGE.

Goodley, D. (2017b). Dis/entangling Critical Disability Studies. In A. Waldschmidt, H. Berressem, and M. Ingwersen (Eds.), *Culture - Theory - Disability: Encounters between Disability Studies and Cultural Studies* (pp. 81-97). Bielefeld: transcript Verlag.

Goodley, D., Hughes, B. & Davis, L. (2012). Introducing Disability and Social Theory. In D. Goodley, B. Hughes & L. Davis (Eds.), *Disability and Social Theory. New Developments and Directions* (pp. 1-14). Basingstoke: Palgrave Macmillan.

Goodley, D. & Runswick-Cole, K. (2012). Reading Rosie: The postmodern disabled child. *Educational and child psychology*, *29*(2), 51-64.

Grandin, T. & Scariano, M. M. (1996 [1986]). *Emergence: Labeled Autistic. A True Story.* Revised edition. New York City: Grand Central Publishing.

Grass, G. (1964). *The Tin Drum.* Translated by R. Mannheim. New York: Vintage Books.

Green, A. (2004). Individual Remembering and 'Collective Memory': Theoretical Presuppositions and Contemporary Debates. *Oral History Society, 32*(2), Memory and Society, 35-44.

Griffin, J. (2014). A Thing for Things. *frieze*, *160*. Retrieved from https://web.archive.org/web/20150614025042/http://www.frieze.com/issue/article/a-thing-for-things/

Gubrium, A. & Harper, K. (2013). *Participatory Visual and Digital Methods.* London/New York: Routledge.

Guernsey, D. (2011). "It's just like a mini-mall": textuality and participatory culture on YouTube. In M. Kackman, M. Binfield, M. T. Payne, A. Perlman & B. Sebok (Eds.), *Flow TV: Television in the age of media convergence* (pp. 30-45)*.* New York: Routledge.

Gunning, T. (2004). What's the Point of an Index? or, Faking Photographs. *Nordicom Review*, *5*(½), 39-49.

Gupta, S. (2007, February 20). Behind the veil of autism. *CNN.* Retrieved from http://www.cnn.com/HEALTH/blogs/paging.dr.gupta/2007/02/behind-veil-of-autism.html

Hacking, I. (1986). Making Up People. In M. Biagioli (ed.). (1999). *The Science Studies Reader* (pp. 161-171). London: Routledge.

Hacking, I. (2009a). How we have been learning to talk about autism: a role for stories. *Metaphilosophy, 40*(3-4), 499-516.

Hacking, I. (2009b). Humans, aliens & autism. *Daedalus*, Summer 2009, 44-59.

Hall, S. (1981). The 'discovery' of popular culture. In R. Samuel (Ed.), *People's History and Social Theory* (pp. 227-240). London: Routledge & Kegan Paul Ltd.

Hall, S. (1992). "What Is This 'Black' in Black Popular Culture?" In G. C. Dent (Ed.), *Black Popular Culture: A Project by Michele Wallace* (pp. 21–33). Seattle: Bay Press.

Hall, S. (1997). The Work of Representation. In S. Hall (Ed.), *Representation: Cultural Representations and Signifying Practices* (pp. 13-74)*.* London: SAGE.

Hamilton, C.S. (2008). 'Am I Not a Man and a Brother?' Phrenology and Anti-Slavery. *Slavery and Abolition, 29*(2), 173-187.

Hannam-Swain, S. (2018). The additional labour of a disabled PhD student. *Disability & Society*, *33*(1), 138-142.

Happé, F. G. (1995). Understanding minds and metaphors: Insights from the study of figurative language in autism. *Metaphor and symbol*, *10*(4), 275-295.

Harris, M.P. (2005). Thought, Object and Experience in Film/Video Installation Art. In Tymieniecka AT. (Eds.), *Human Creation between Reality and Illusion* (pp. 185-197). Analecta Husserliana, The Yearbook of Phenomenological Research, 87. Dordrecht: Springer.

Hodge, N. (2014). Unruly bodies at conference. *Disability & Society*, *29*(4), 655-658.

Hodge, N. (2016). Schools without Labels. In K. Runswick-Cole, R. Mallett and S. Timimi (Eds.), *Rethinking Autism: Diagnosis, Identity and Equality* (pp. 203-). London/Philadelphia: Jessica Kingsley Publishers.

Honess-Roe, A. (2013). *Animated Documentary.* Basingstoke: Palgrave Macmillan.

Hopkins, M. (2008, November 24). YouTube Widescreen! *Mashable.* Retrieved from https://mashable.com/2008/11/24/youtube-widescreen/

Hoppe, S., A. Schippers, A. & Kool, J. (2011). *Disability Studies in Nederland. Verbinding in de context.* Amersfoort: Stichting Disability Studies in Nederland.

Howell, A. (2012). The Demise of PTSD: From Governing through Trauma to Governing Resilience. *Alternatives: Global, Local, Political, 37*(3), 214-226.

Howell, A. (2015). Resilience, war, and austerity: The ethics of military human enhancement and the politics of data. *Security Dialogue, 46*(1), 15– 31.

Hughes, B. (2009). Disability activisms: social model stalwarts and biological citizens. *Disability & Society*, *24*(6), 677-688.

Hutcheon, L. (2006). *A Theory of Adaptation.* New York: Routledge.

Hyman, S. (2010). The Diagnosis of Mental Disorders: The Problem of Reification. *The Annual Review of Clinical Psychology*, *6*, 155-179.

IMDb. (2019). Extremey Loud & Incredibly Close (2011). Retrieved from https://www.imdb.com/title/tt0477302/?ref_=nv_sr_1?ref_=nv_sr_1

iHuman. (2018, January 3). iHuman in Amsterdam: The Art of Belonging. *iHuman.* Retrieved from http://ihuman.group.shef.ac.uk/ihuman-amsterdam-art-belonging/

Jaarsma, P. & Welin, S. (2012). Autism as a Natural Human Variation: Reflections on the Claims of the Neurodiversity Movement. *Health Care Analysis*, *20*, 20-30.

Jacobs, K. (2001). *The Eye's Mind: Literary Modernism and Visual Culture.* Ithaca: Cornell University Press.

Johnson, M., & McRuer, R. (2014). Cripistemologies: introduction. *Journal of Literary & Cultural Disability Studies*, *8*(2), 127-148.

Jordan, C. J. (2010). Evolution of Autism Support and Understanding Via the World Wide Web. *Intellectual and Developmental Disabilities*, 48(3), 220-227.

Kanner, L. (1943). Autistic Disturbances of Affective Contact. *The Nervous Child*, 2, 217-250.

Kaufman, B.M. (1994). *Son-rise: The Miracle Continues.* Tiburon: H J Kramer Inc.

Kennedy, A. (2017, March 17) New bottle format for Drench. *Talking Retail.* Retrieved from https://www.talkingretail.com/products-news/soft-drinks/new-bottle-format-drench-17-03-2017/

Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, *20*(4), 442-462.

Kenyon, C. (2016, March 3). How YouTube Has Changed the Entertainment Industry. *Huffington Post.* Retrieved from https://www.huffingtonpost.co.uk/chloe-kenyon/youtube-entertainment-industry_b_9360434.html

King, G. (2009). *Indiewood, USA: Where Hollywood meets Independent Cinema.* London: I.B. Tauris & Co Ltd.

Kirmayer, L. J. (2005). Culture, Context and Experience in Psychiatric Diagnosis. *Psychopathology*, 38, 192-196.

Kövecses, Z. (2010). *Metaphor: A Practical Introduction*. Oxford: Oxford University Press.

Kuhn, T. S. (1970). *The Structure of Scientific Revolutions.* Second Edition, Enlarged. Chicago: The University of Chicago Press.

Lacan, J. (1968). "The Mirror-Phase as Formative of the Function of the I". *New Left Review*, *51*.

Lakoff, G, & Johnson, M. (1980). *Metaphors We Live By*. Chicago: The University of Chicago Press.

Lawson, W. (2000). *Life behind glass: A personal account of autism spectrum disorder*. London: Jessica Kingsley Publishers.

Lester, J. N. (2012). A discourse analysis of parent's talk around their children's autism labels. *Disability Studies Quarterly*, *32*(4). Retrieved from http://dsq-sds.org/article/view/1744/3176

Loftis, S. F. (2015). *Imagining Autism: Fiction and Stereotypes on the Spectrum.* Bloomington: Indiana University Press.

Lutz, A. S. F. (2013, January 16). Is the Neurodiversity Movement Misrepresenting Autism? *Slate.* Retrieved from http://www.slate.com/articles/health_and_science/medical_examiner/2013/01/autism_neurodiversity_does_facilitated_communication_work_and_who_speaks.html

McDonagh, P. (2008). Autism and Modernism. A Genealogical Exploration. In M. Osteen (Ed.), *Autism and Representation* (pp. 99-116)*.* New York/London: Routledge.

McGrath, E. (2012). Dancing with Disability: An Intersubjective Approach. In D. Goodley, B. Hughes & L. Davis (Eds.), *Disability and Social Theory. New Developments and Directions* (pp. 143-158). Basingstoke: Palgrave Macmillan.

McGuire, A. (2011). *The War on Autism: On Normative Violence and the Cultural Production of Autism Advocacy*. PhD Thesis supervised by T. Titchkosky, Department of Sociology and Equity Studies in Education, University of Toronto.

McGuire, A. (2013). Buying Time: The S/pace of Advocacy and the Cultural Production of Autism. *Canadian Journal of Disability Studies* 2(3), 98–124.

McGuire, A. (2016). *War on Autism: On the Cultural Logic of Normative Violence.* Ann Arbor: University of Michigan Press.

McGuire, A. & Michalko, R. (2011). Minds between Us: Autism, Mindblindness and the Uncertainty of Communication. *Educational Philosophy and Theory* 43(2), 162–77.

McRuer, R. (2006). *Crip Theory: Cultural Signs of Queerness and Disability.* New York: New York University Press.

McIntyre, A. (2008). *Participatory Action Research.* Thousand Oaks: SAGE Publications.

Meekosha, H. & Shuttleworth, R. (2009). What's so 'critical' about critical disability studies? *Australian Journal of Human Rights*, *15*(1), 47-75.

Melancon, T. (2017, March 18). Ramp Your Voice: An Interview with Vilissa Thompson. *Black Perspectives.* Retrieved from https://www.aaihs.org/ramp-your-voice-an-interview-with-vilissa-thompson/

Metz, C. (1974). *Language and cinema.* The Hague: Walter de Gruyter.

Metz, C. (1982). *The Imaginary Signifier: Psychoanalysis and the Cinema.* Translated by C. Britton, A. Williams, B. Brewster & A. Guzzetti. Bloomington and Indianapolis: Indiana University Press.

Michalko, R. (2002). *The Difference that Disability Makes.* Philadelphia: Temple University Press.

Mills, B. (2008). Autism and the Imagination. In M. Osteen (Ed.), *Autism and Representation* (pp. 117-132). New York: Routledge.

Mills, C. (2014). *Decolonizing Global Mental Health: The Psychiatrization of the Majority World*. London: Routledge.

Mills, C. (2015). The Psychiatrisation of Poverty: Rethinking the Mental Health-Poverty Nexus. *Social and Personality Psychology Compass*, 9(5), 213–222.

Milton, D.E.M. (2012). On the ontological status of autism: the 'double empathy problem'. *Disability & Society*, 27(6): 883-887.

Milton, D.E.M. (2014). Autistic expertise: a critical reflection on the production of knowledge in autism studies. *Autism* 18(7), 794-802.

Milton, D.E.M. & Bracher, M. (2013). Autistics speak but are they heard? *Medical Sociology online*, 7(2): 61-69.

Milton, D. & Timimi, S. (2016). Debate 1. Does autism have an essential nature? *Autism and Neurodiversity: Exploring Diagnosis.* Retrieved from
https://blogs.exeter.ac.uk/exploringdiagnosis/debates/debate-1/

Mitchell, D. & Snyder, S. (2010). Narrative Prosthesis. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 274-287). New York: Routledge.

Morley, C. (2008). Critical Reflection as a Research Methodology. In P. Liamputtong & J. Runbold (Eds.), *Knowing Differently: Arts-Based and Collaborative Research* (pp. 265-280). Nova Science Publishers. Hauppauge: Nova Science Publishers.

Mulvey, L. (1999). Visual Pleasure and Narrative Cinema. In L. Braudy and M. Cohen (Ed.), *Film Theory and Criticism: Introductory Readings* (pp. 833-844). New York: Oxford University Press.

Murray, S. (2006). Autism and the Contemporary Sentimental: Fiction and the Narrative Fascination of the Present. *Literature and Medicine*, 25(1), 24-45.

Murray, S. (2008a). *Representing Autism: Culture, Narrative, Fascination.* Liverpool University Press.

Murray, S. (2008b). Hollywood and the Fascination of Autism. In M. Osteen (Ed.), *Autism and Representation* (pp. 244-255). New York/London: Routledge.

Murray, S. (2013). Autism and the Posthuman. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism. Across the Spectrum of Neurological Difference* (pp. 53-72). Minneapolis: The University of Minnesota Press.

Nadesan, M.H. (2005). *Constructing Autism. Unravelling the 'truth' and understanding the social.* Abingdon: Routledge.

Nature. (2011). The Autism Enigma. *Nature 479*, special issue on neuroscience, 21.

Nieweg, E.H. (2005). Wat wij van Jip en Janneke kunnen leren. Over reïficatie (verdinglijking) in de psychiatrie. *Tijdschrift voor Psychiatrie*, 47(10), 687-696.

Nourhussen, S. (2017, November 16). Diversiteitsbeleid is een hol modewoord om subsidiepotten open te breken. *Trouw.* Retrieved from https://www.trouw.nl/opinie/diversiteitsbeleid-is-een-hol-modewoord-om-subsidiepotten-open-te-breken~a37cdb60/

Novas, C. (2006). The Political Economy of Hope: Patients' Organizations, Science and Biovalue. *BioSocieties*, *1*, 289-305.

Osteen, M. (2008). Autism and Representation: A Comprehensive Introduction. In M. Osteen (Ed.), *Autism and Representation* (1-47). New York/London: Routledge.

Osteen, M. (2013). Narrating Autism. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism. Across the Spectrum of Neurological Difference* (pp. 261-284). Minneapolis: The University of Minnesota Press.

Ortega, F. (2013). Cerebralizing Autism within the Neurodiversity Movement. In J. Davidson & M. Orsini (Eds.), *Worlds of Autism. Across the Spectrum of Neurological Difference* (pp. 73-95). Minneapolis: The University of Minnesota Press.

Palen, T. van der. (2014). *A Cyborg Autobiography: Autism & the Posthuman.* MA thesis supervised by dr. Susanne Knittel, Utrecht University.

Parker-Pope, T. (2008, February 28). The Language of Autism. *Well.* Retrieved from https://well.blogs.nytimes.com/2010/04/01/the-voices-of-autism/

Parnas, J. & Bovet, P. (1991). Autism in schizophrenia revisited. *Comprehensive Psychiatry,* 32(1), 7-21.

Peirce, C. S. (1955). Logic as Semiotic: The Theory of Signs. In J. Buchler (Ed.), *Philosophical Writings of Peirce* (pp. 98-119). New York City: Dover Publications.

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, *18*(7), 756-770.

Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: moving toward an ethically informed approach to autism research. *Autism Research*, *4*(4), 271-282.

Philipse, S. (2017, September 25). De intellectuele armoede van het racismedebat. *One World.* Retrieved from https://www.oneworld.nl/mensenrechten/intellectuele-armoede-racismedebat/

Plate, L., and Smelik, A. (2012). Performing Memory in Art and Popular Culture: An Introduction. In L. Plate & A. Smelik (Eds.), *Performing Memory in Art and Popular Culture* (pp. 1-22). Abingdon: Routledge.

Pritchard, A., & Morgan, N. J. (2000). Privileging the male gaze: Gendered tourism landscapes. *Annals of Tourism Research*, *27*(4), 884-905.

Psillos, S. (1999). *Scientific Realism: How science tracks truth.* London/New York: Routledge.

Pudovkin, V.I. (1960). *Film Technique and Film Acting.* New York: Grove Press Inc.

Quensel S. (2018). Die Apotheose: ‚Der Krieg gegen die psychisch Kranken'. In: S. Quensel (Ed.), *Irre, Anstalt, Therapie* (pp. 233-249). Wiesbaden: Springer VS.

Rabinow, P. (1996). Artificiality and enlightenment: From sociobiology to biosociality. In P. Rabinow (Ed.), *Essays on the anthropology of reason* (pp. 91–112). Princeton, NJ: Princeton University Press.

Rabinow, P. & Rose, N. (2006). Biopower Today. *BioSocieties*, *1*, 195-217.

Ridout, S. (2014). More Than Picture-Making: Reflecting on Collage as a Narrative Tool for Opening Discourse on the Involvement of Autistics in Autism Research. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, 1(2).

Rose, N. (2007). *The Politics of Life Itself. Biomedicine, Power, and Subjectivity in the Twenty-First Century.* Princeton: Princeton University Press.

Rose, N. & Novas, C. (2005). Biological citizenship. In A. Ong, & S. Collier (Eds.)*, Global assemblages: Technology, politics and ethics as anthropological problems* (pp. 439–463). Malden, MA: Blackwell Publishing.

Rosenbloom, R.M. (producer) & Jordan, G. (director). (1979). *Son-Rise: A Miracle of Love.* [DVD]. Sonoma Country: Filmways Television.

Rosqvist, H. B., Brownlow, C. & O'Dell, L. (2013). Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces. *Disability & Society*, 28(3), 367-379.

Rudin, S. (producer) & Daldry, S. (director). (2011). *Extremely Loud & Incredibly Close.* [DVD]. New York: Scott Rudin Productions.

Runswick-Cole, K. (2014). 'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times. *Disability & Society*, *29*(7), 1117-1129.

Runswick-Cole, K. (2016). Understanding This *Thing* Called Autism. In K. Runswick-Cole, R. Mallett and S. Timimi (Eds.), *Rethinking Autism: Diagnosis, Identity and Equality* (pp. 19-29). London/Philadelphia: Jessica Kingsley Publishers.

Runswick-Cole, K. & Mallett, R. (2012). Commodifying Autism: The Cultural Contexts of 'Disability' in the Academy. In D. Goodley, B. Hughes & L. Davis (Eds.), *Disability and Social Theory. New Developments and Directions* (pp. 33-51). Basingstoke: Palgrave Macmillan.

Runswick-Cole, K. and Mallett, R. (2016). The Commodification of Autism: What's at Stake? In K. Runswick-Cole, R. Mallett and S. Timimi (Eds.), *Rethinking Autism: Diagnosis, Identity and Equality* (pp. 110-132). London/Philadelphia: Jessica Kingsley Publishers.

Runswick-Cole, K., Mallett, R. & Timimi, S. (2016). Introduction. In K. Runswick-Cole, R. Mallett and S. Timimi (Eds.), *Rethinking Autism: Diagnosis, Identity and Equality* (pp. 7-15). London/Philadelphia: Jessica Kingsley Publishers.

Russell, G. (2016). Early Diagnosis of Autism: Is Earlier Always Better? In K. Runswick-Cole, R. Mallett and S. Timimi (Eds.), *Rethinking Autism: Diagnosis, Identity and Equality* (pp. 252-268). London/Philadelphia: Jessica Kingsley Publishers.

Sacks, O. (1995). *An Anthropologist on Mars: Seven Paradoxical Tales*. New York: Alfred A. Knopf.

Sanders, M. (2002). Representation: reading-otherwise. *Interventions. International Journal of Postcolonial Studies 4*(2): 198-204.

Sarrett, J. C. (2011). Trapped Children: Popular Images of Children with Autism in the 1960s and 2000s. *Journal of Medical Humanities*, *32*(2), 141-153.

Saussure, F. de. (1959 [2011]). *Course in General Linguistics*. P. Meisel and H. Saussy (Eds.). Translated by W. Baskin. New York: Columbia University Press.

Savarese, E. T. & Savarese, R. J. (2010). "The Superior Half of Speaking": An Introduction. *Disability Studies Quarterly*, *30*(1).

Schaaf, R.C. & L.J. Miller. (2005). Occupational therapy using a sensory integrative approach for children with developmental disabilities. *Mental retardation and developmental disabilities research reviews, 11*(2), 143-148.

Searle, J. R. (1969). *Speech acts. An Essay in the Philosophy of Language.* Cambridge University Press.

Sequenzia, A. (2017, October 5). Proudly Autistic by Amy Sequenzia. *Ollibean.* Retrieved from https://ollibean.com/proudly-autistic/

Shakespeare, T. (1997). Cultural Representation of Disabled People: Dustbins for disavowal? In L. Barton and M. Oliver (Eds.), *Disability Studies: Past, Present and Future* (pp. 217-233). Leeds: The Disability Press.

Shakespeare, T. (2010). The Social Model of Disability. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 266-273). New York: Routledge.

Sherry, M. (2007). (Post)colonizing Disability. *Wagadu*, *4*, 10-22.

Silberman, S. (2015). *Neurotribes. The Legacy of Autism and How to Think Smarter about People Who Think Differently.* London: Allen & Unwin.

silentmiaow. (sine anno). About*. Youtube.* Retrieved from https://www.youtube.com/user/silentmiaow/about

silentmiaow. (2006, November 3). *Being an Unperson.* [YouTube]. Retrieved from https://www.youtube.com/watch?v=4c5_3wqZ3Lk

silentimiaow. (2007, January 13). *In My Language (Untranslated Version).* [YouTube]. Retrieved from https://www.youtube.com/watch?v=4SF1csRLyxo

silentmiaow. (2007, January 14). *In My Language*. [YouTube]*.* Retrieved from https://www.youtube.com/watch?v=JnylM1hl2jc

silentmiaow. (2007, January 15). *Re: Re: Disability Characteristics and Political Correctness.* {YouTube]. Retrieved from https://www.youtube.com/watch?v=_-hW-ZLcejk

silentmiaow. (2007, March 26). *Jen Brings Her Dog to Work.* [YouTube]. Retrieved from https://www.youtube.com/watch?v=pDoY_Wq29eo

silentmiaow. (2007, April 1). *A Way of Describing Autism*. [YouTube]. Retrieved from https://www.youtube.com/watch?v=ic-zA4YfW-U

silentmiaow. (2007, September 27). *Happy Dance Meme (post your own!)*. [YouTube]. Retrieved from https://www.youtube.com/watch?v=KdTQSAmkBp0

Simmel, G. (1903). "The Metropolis and Mental Life", in: David Patrick Frisby and Mike Featherstone (Eds.). (2007). *Simmel on Culture: Selected Writings*. London: SAGE.

Sinclair, J. (2012). Don't Mourn for Us. *Autonomy, the Critical Journal of Interdisciplinary Autism Studies*, *1*(1). Retrieved from http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR1/html

Slater, J. (2013). Research with Dis/abled Youth: Taking a Critical Disability, 'Critically Young' Positionality. In T. Curran & K. Runswick-Cole (Eds.), *Disabled Children's Childhood Studies: Critical Approaches in a Global Context* (pp. 180-195). London: Palgrave Macmillan.

Solomon, O. (2010). What a Dog Can Do: Children with Autism and Therapy Dogs in Social Interaction. *ETHOS*, 38(1), 143-166.

Sontag, S. (1977). *Illness as Metaphor.* New York City: Farrar, Strauss and Giroux.

Smith, M. (1994). Altered states: character and emotional response in the cinema. *Cinema Journal*, *33*(4), 34-56.

Smith, S. & Watson, J. (2010). *Reading Autobiography: A Guide for Interpreting Life Narratives.* Second edition. Minneapolis: The University of Minnesota Press.

Snyder, A. (2004). Autistic genius? *Nature*, *428*(6982), 470.

Spivak, G. C. (1988). Can the Subaltern Speak? In C. Nelson & L. Grossberg (Eds.), *Marxism and the Interpretation of Culture* (pp. 271-313). Urbana/Chicago: University of Illinois Press.

St. Pierre, J. (2015). Distending Straight-Masculine Time: A Phenomenology of the Disabled Speaking Body. *Hypathia, 30*(1), 49-65.

Strauss, J. N. (2010). Autism as Culture. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 535-559.). New York: Routledge.

Sturken, M. & L. Cartwright, L. (2009). *Practices of Looking. An Introduction to Visual Culture.* Second Edition. Oxford: Oxford University Press.

Sue, D. W. (2010). *Microaggressions in Everyday Life: Race, Gender and Sexual Orientation*. Hoboken: John Wiley & Sons.

Thibault, R. (2014). Can Autistics Redefine Autism? The Cultural Politics of Autistic Activism. *Trans-Scripts*, *4*, 57-88.

Thoutenhoofd, E. & Batstra, L. (2013, March). Overleeft de psychiatrie de DSM-5? Diagnostische inflatie trivialiseert term stoornis. *De Psycholoog*, pp. 10-17.

Timimi, S., Gardner, N. & McCabe, B. (2010). *The Myth of Autism: Medicalising Men's and Boy's Social and Emotional Competence.* London: MacMillan Education UK.

Timmer, J. (2011, May 4). Autism epidemic? More likely we're just better at diagnosis. *Ars Technica*. Retrieved from http://arstechnica.com/science/2011/05/autism-epidemic-more-likely-were-just-better-at-diagnosis/

Titchkosky, T. (2001). Disability: A Rose by Any Other Name? "People-First" Language in Canadian Society. *Canadian Review of Sociology* 38(2), pp. 125-140.

Titchkosky, T. (2007). *Thinking and Writing Disability Differently: The Textured Life of Embodiment.* Toronto: University of Toronto Press.

Tomlinson, S. (2005). *Head Masters. Phrenology, Secular Education, and Nineteenth-Century Social Thought.* Tuscaloosa: The University of Alabama Press.

Tremain, S. (2005). Foucault, Governmentality, and Critical Disability Theory: An Introduction. In S. Tremain (Ed.), *Foucault and the Government of Disability* (pp. 1-24). Ann Arbor: University of Michigan Press.

Turner, G. (2006). *Film as Social Practice*. Fourth edition. London: Routledge.

Vakirtzi, E. (2010). *The Archaeology of Autism and the Emergence of the Autistic Subject.* PhD thesis supervised by P. Bayliss, Graduate School of Education, University of Exeter.

Vakirtzi, E., & Bayliss, P. (2013). Towards a Foucauldian methodology in the study of autism: Issues of archaeology, genealogy, and subjectification. *Journal of Philosophy of Education*, *47*(3), 364-378.

Van Goidsenhoven, L. (2017). *Autisme in Veelvoud. Het Potentieel van Life Writing voor Alternatieve Vormen van Subjectiviteit.* PhD thesis supervised by A. Masschelein, Faculteit Letterkunde, KU Leuven.

Van Hove, G., Cardol, M., Schippers, A. & De Schauwer, E. (2016). Situering. In G. Van Hove, A. Schippers, M. Cardol & E. De Schauwer (Eds.), *Disability Studies in de Lage Landen* (pp. 7-11). Antwerpen/Apeldoorn: Garant.

Venhuizen, G. (2017, October 20). Hoe vrouwen hun autisme camoufleren, en daar onder lijden. *Nrc.nl.* Retrieved from https://www.nrc.nl/nieuws/2017/10/20/verhuld-autisme-13592176-a1578058

Versluys, K. (2009). *Out of the Blue: September 11 and the Novel.* New York: Columbia University Press.

Vidali, A. (2010). Seeing What We Know: Disability and Theories of Metaphor. *Journal of Literary & Cultural Disability Studies*, *4*(1), 33-54.

Waltz, M. (2003). Metaphors of Autism, and Autism as Metaphor: An Exploration of Representation, in: *Second Global Conference. Inter-Disciplinary.Net.*

Waltz, M. (2005). Reading case studies of people with autistic spectrum disorders: a cultural studies approach to issues of disability representation. *Disability & Society*, *20*(4), 421-435.

Waltz, M. (2008). Autism = death. The social and medical impact of a catastrophic medical model of autistic spectrum disorders. *Popular Narrative Media, 1*(1), 13-24.

Waltz, M. (2013). *Autism. A Social and Medical History.* Basingstoke: Palgrave Macmillan.

Wekker, G. (2016). *White Innocence: Paradoxes of Colonialism and Race.* Durham: Duke University Press.

Weststeyn, T. et al. (2005). Recognizing Mimicked Autistic Self-Stimulatory Behaviors Using HMMs. *Ninth IEEE International Symposium on Wearable Computers, 2005*, 164-167.

Wilkinson, C. (2017). 'You're too much!': experiencing the straightness of security. *Critical Studies on Security*, *5*(1), 113-116.

Willke, H. (2001). *Atopia: Studiem zur atopischen Gesellschaft.* Frankfurt am Main: Suhrkamp.

White, M. & Schwoch, J. (2006). Introduction: The Questions of Method in Cultural Studies. In M. White & J. Schwoch (Eds.), *Questions of Method in Cultural Studies* (pp. 1-16). Oxford: Blackwell Publishing.

Woods, R., Milton, D., Arnold, L. & Graby, S. (2018). Redefining Critical Autism Studies: a more inclusive interpretation. *Disability & Society, 33*(6), 974-979.

Yancy, G. (2017). *Black Bodies, White Gazes: The Continuing Significance of Race in America.* Second edition. London: Rowman & Littlefield.

YouTube Spotlight. (2008, March 14). YouTube Videos in High Quality. *YouTube Official Blog.* Retrieved from https://youtube.googleblog.com/2008/03/youtube-videos-in-high-quality.html

Zoonen L. van, Vis, F. & Mihelj, S. (2010). Performing citizenship on YouTube: activism, satire and online debate around the anti-Islam video Fitna. *Critical Discourse Studies*, *7*(4), pp.

Appendix 1: Glossary

Ableism: this thesis employs Campbell's definition of ableism (2009) that refers to the construction and emulation of the perfected abled norm of the fit and healthy human in society. A critical analysis of ableism denaturalises the supposedly default abled condition as an archetype that enforces normativity, instead of an absence of disability in humans.

Ableist economies of doubt: a more specific term for the 'political economy of doubt' that captures the way in which each of my case studies exemplify ableist normativity, which means that they centre the abled societal norm in different ways. My thesis shows that epistemological uncertainty, or the mobilisation of doubt on the things we know about autism and autistic people, is an important point of concern for a broader critical consideration of ableism in Cultural Disability Studies research.

Atopos: Ebben's (2015) wordplay on the etymology of autism that substitutes the preoccupation with the self as suggested by the Old Greek word for 'self', 'autos', with a preoccupation with space, or 'topos'. The evocation of the Old Greek 'atopos', which means 'out-of-place', aims to move away from the autism signifier in favour of a more affirmative conception of dis/ability in cultural objects that contain characters who are identified as autistic and negotiate public spaces.

Autism-is-rendered: the metaphorical concept that is central to "My Autism and Me" (2011). It captures the creative representational strategies with which the children's documentary evokes an understanding of autism as something that we know yet don't know much about. The word 'render' serves to clarify a disclosure of an abstract concept and world to the general public that was previously unknown and unknowable by the senses. "My Autism and Me" has 'rendered' accessible the concept of autism by means of creative representational strategies.

Autism-is-resisted: the metaphorical concept that is central to *In My Language* (2006) and that refers to the way in which the YouTube video defies and directly challenges expectations of autism knowledge and acknowledged personal account.

Autism-is-speculated: the metaphorical concept that is central to *Extremely Loud & Incredibly Close* (2011) that features a protagonist whose condition is left uncertain and might or might not be autism or Asperger's Syndrome. The protagonist is a distinctive kind of character whose peculiar characterisation invites audience speculates on autism as a discours. As such, this film that uses autism as a discourse opens up a unique area of research on autism, cultural representation and epistemological uncertainty.

Autism information-thing: a phrasing used by Runswick-Cole and Mallett (2012) in order to specify their discussion of autism as a commodity. I employ the phrasing to foreground the fact that constant flows of information-exchange can turn autism into a 'thing'. See also reification.

Biopolitics: a concept from Foucault (1976; 1978) for the corpus of regulatory and normalising measures, techniques and institutions that discipline populations by investing in the stimulation of their health and biological life.

Bio-power: a key concept in the works of Foucault (1976; 1978) that refers to the regulation, administration and preservation of the biological existence of populations, as well as the power to "foster life" (Foucault, 1978, p. 138) and control vitality.

Biovalue: entities of biological information, separate to the 'self', that a subject negotiates in their everyday life. For example, in the case of a neurobiological condition, individuals build up a conception of 'the brain' as a valuable resource that needs to be understood and managed well in life. Biological information from the medical sciences, that is, the workings of the brain, gain value for meaning exchange in a social and cultural context.

Cinematography: the way in which camera shots are filmed and framed. The notion of cinematography covers everything in cinema that is governed by the operation of the camera. It includes camera angle, movements, choice of lens, depth of field, et ceetera.

Commodification of autism: Runswick Cole and Mallett's (2012; 2016) Marxist reading of the increasing valorisation and prominence of the autism category in academia and society. They argue that autism is being bought and sold as a commodity and gains

shape and meaning through this commodity fetishism, in anticipation of the clinical and scientific promise of interventions and solutions.

Compulsory abledness: a social norm of ablement and ability as the sole way of being healthy, fit and normal that represses non-normative embodiment and restricts dis/ability self-expression and epistemology in society.

Constructionism: in the context of representation, the study of cultural objects as social realities in their own right and with their own structure of signification beyond the reality that it is resembling. I adopt a constructionist view of autism and representation in order to avoid the study of the referent, or the clinical condition.

Cultural Studies: a field in the Humanities that studies the meaning, reception and/or context of cultural objects.

Disability Studies: an interdisciplinary and international field that studies disability from a social and cultural perspective and that advocates for disability justice and inclusion.

Dis/ability: a phrasing that specifies the fickle boundary between ability and disability that is of particular interest to my studies of ableism.

Disablism: prejudice against disabled people.

Discourse: the corpus of culturally shared meaning in statements and practices, studied in the Humanities and Social Sciences in order to get to know more about the impact of knowledge production beyond language and signs per se. The study of discourse is the study of anything that can be said about any topic of interest at any given time in history. In this thesis, my research object is specified as autism as a discourse, because I aim to strictly avoid a study of the referent of the word 'autism', namely, a neurobiological condition.

Discursive formation: the social production of discourse through speech and communicative practices.

Discursive practice: the production of meaning within interactions, social settings and institutions.

Editing: the succession of film shots. In a movie, documentary or video, film takes have been cut and reorganized into a new juxtaposition that warrants easy understanding of the filmic space, as well as events and dialogue within this space. Continuity editing is a form of editing that suggests and warrants spatial unity and consistency.

Epistemology: the philosophy of knowledge.

Gaze: a concept from film theory concerning the way in which visual media portrayals of certain subjects or social groups anticipate a certain conformist or non-conformist practice of looking, such as disciplining surveillance or heterosexual male desire.

Genealogy: a method of critical Humanities analysis and research that maps a 'history of the present' through considerations of layers and traces of meaning from the past and the present. It is used to critically dismantle seemingly everyday concepts with special emphasis on the fluidity of meaning. This definition comes from Foucault (1971b) who borrows the word from Nietzsche.

Hyperaware gaze: my term within this thesis that I borrow from McGuire's (2016) in arguments that so-called 'autism red flags' in autism awareness campaigns provide visual cues of warning signs that the spectator should be urgently aware of. In my study, the hyperaware gaze is a term for a disciplining practice of looking, anticipating vigilance with strong medical imperative of early recognition and intervention of non-normative behaviour.

Imagined community: a community of people who might not know one another personally but who are nevertheless connected by shared signifiers of and feelings of kinship for nation states and similar conceptions of communion. First introduced in the eponymous book by Anderson (2006). In my thesis, I regard the category of 'autistic people' as an imagined community rather than a population of people with a (diagnosis of a) clinical condition.

Index: a relationship between a sign and a referent in which the sign points to a natural phenomenon that is occurring in close causality and contiguity to the sign. For example, smoke is an indexical sign that could point to a fire that may be occurring at the same point in time and that may cause the smoke to appear.

Indiewood cinema: a concept from King (2009) that refers to independent films that are made outside of Hollywood mainstream but that are produced, distributed and/or exhibited by major Hollywood studios.

Interpellation: a characteristic of ideology in Marxist theory in which individuals in a society are constituted as subjects and are as such recruited into a role within the state apparatus. Ideology presumes subjects and their roles, which would be 'parent', 'practitioner' and 'psychologist' in the case of autism as a discourse, by hailing them according to these roles. In my thesis, I argue that autism as a discourse has a strong interpellative quality as it hails people as subjects who are negotiating the clinical category throughout life.

In/visibility: phrasing with which I emphasise the fickle boundary between visible and invisible disabilities in visual culture and with which I state that the distinction between the two gets established through representational strategies rather than the intrinsic nature of different impairments.

Janushead: a metaphor that I employ to refer to epistemological dualisms and invoked ambiguities that I have encountered in my case studies, like the statement that scientists know a lot but also don't know a lot about autism. Janus is a two-faced Roman god.

Metaphorical concept: concepts that constitute the heart of my argument in each of my case studies. Lakoff and Johnson (1980) define metaphorical concepts as a concept that is being conceived and grasped in respect to another concept beyond resemblance between the two alone. In the metaphor concept of 'autism is a journey', the concept of autism may be concretely experienced as a journey in someone's life, to the point that this conception of autism influences social realities.

Mimesis: the way in which a cultural object resembles reality; the presumption that visual culture shows or should show a clear 'mirror' onto the world.

Mise-en-scene: the sum of details within the film frame, including a film set, costumes, make-up and props.

Molecularisation: vital entities that can be isolated, manipulated and regulated, like the brain or the liver. See also biovalue.

Neurodiversity: an affirmative interpretation of life with a neurobiological condition that counters pathologisation and medicalization, and states that autism is neurodivergence, or a difference within the full range of neurobiological diversity of populations that is not inherently a disorder.

Ontology: the philosophy of being.

Optimisation: warranting a desired future by governing (ill) health.

Palimpsest: a metaphor for texts with different layers and earlier traces of meaning that are of interest to Humanities scholars and cultural analysis. A palimpsest is a manuscript on parchment with erased and overwritten fragments of handwriting.

Paratexts: a term from Genette (1991) that refers to texts and details that accompany my case studies and that are important to consider in cultural analysis next to the cultural objects themselves.

Performativity: the notion in critical theory that discourse can change the reality of the referent once a statement is being uttered or, on a societal scale, once a cultural practice is being naturally yet unconsciously repeated on a day-to-day basis. Autism as a discourse can be regarded as performative in the sense that the term is continuously being employed and evoked in clinical practice, scientific research, special education, and so on. Such continuous everyday practices have significant impact on the classification and perception of those identified and diagnosed as autistic, and therefore transforms the realities of people.

Political economy of doubt: a term that I have coined to analyse autism and epistemology in my case studies, inspired by the phrase 'political economy of hope' from Novas (2006). Characteristic to my case studies and central to my analyses is a meaning exchange (the 'political economy') between visual media and the spectator in which epistemological uncertainty is being negotiated: the fact that we do not know much about autism. In each of my three case studies, the complexity of 'knowing'

autism is a common theme, which has prompted me to use this phrasing in order to study epistemological uncertainty on autism in visual culture.

Positivism: the idea in scientific practice that knowledge can always be regarded as factually true if it has been empirically observed, studied and measured.

Power/knowledge: the key argument in Foucault's work that power is not just repressive but also productive, as power is constantly being yielded and limited through acceptable discourse and truth formations, and vice versa, that is, knowledge (re)produces power. Power and knowledge are very closely interlinked here.

Reification: the practice of describing abstract concepts as if they were concrete and tangible objects; the 'thingification' of diagnostic categories as entities that are presumed to reside in people's minds or bodies.

Representation: the thesis research area of (cultural) depiction of autism, studied with the goal to focus on signification alone. The word 'representation' can refer to two separate phenomena: Vertretung, which means the inclusion of a representative that stands in for a social group, and Darstellung, which stands for the portrayal of said social group.

Scientific oxymoron: my own phrasing in this thesis for a sentiment of discomfort and contestation in public responses to personal accounts of people who identify as autistic. I state that this sentiment can be understood as a culturally embedded presupposition of historical discrepancy between autistic people who are speaking for themselves and the past scientific consensus that autistic people lack the introspective ability to produce autobiographical statements.

Scientific realism: the presumption in the natural sciences that scientific theories and practices based on empirical observations and methods constitute real knowledge, regardless of human or societal influence.

Source domain of metaphor: the concept outside of the realm of the thing that is being signified and grasped in a metaphorical concept. In 'autism is a journey', the source domain is 'a journey'.

Scopophilia: the pleasure of looking, which is a key psychoanalytical term from feminist film criticism. In this thesis, I use the concept to evoke the notion that looking for and recognising signs of autism can be put forward as one of the pleasures of a film.

Speech act: the occurrence of speech that does not only verbally express meaning but that also creates or generates concrete action. For example, the declaration 'I hereby pronounce you man and wife' establishes a marriage between two people.

Subjectification: mobilised and ever-changing self-understanding and organisations of subjects based on one's biological make-up.

Target domain of metaphor: the concept that is being signified and grasped in a metaphorical concept. In 'autism is a journey', the target domain is 'autism'.

Textured life of embodiment: a concept of dis/ability that originates from Titchkosky (2007). She argues that disability is not only embodied and lived in flesh and blood, but that it is also interwoven in the fabric (texture) of everyday discursive practices.

Appendix 2: List of pictures

Screenshots are made by the author of the thesis for the sole purpose of criticism.

Picture 1

Picture 2

Picture 3

Picture 4

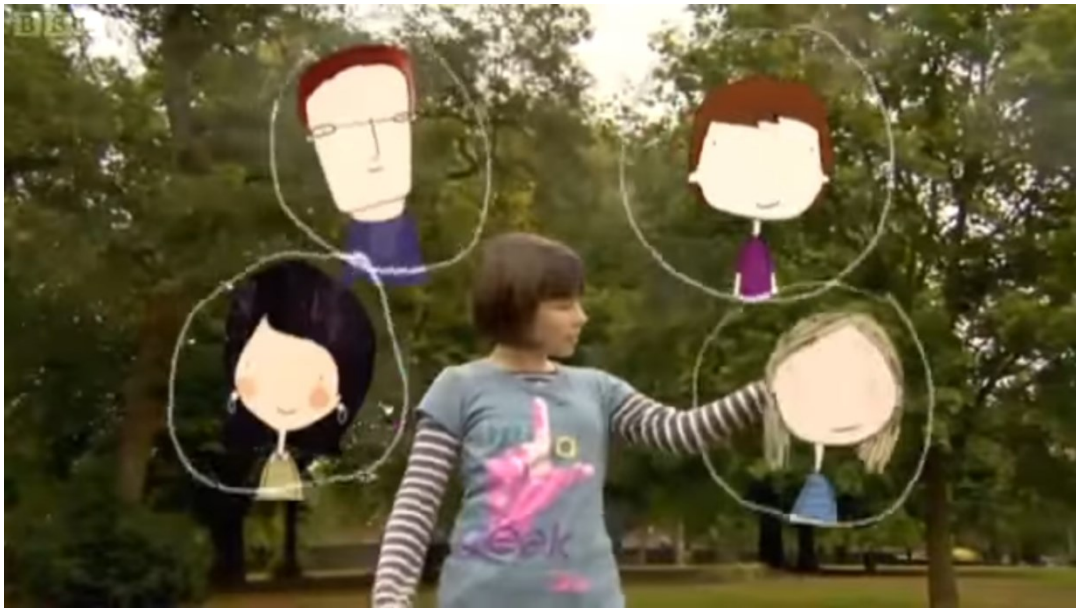Picture 5

Picture 6

Picture 7
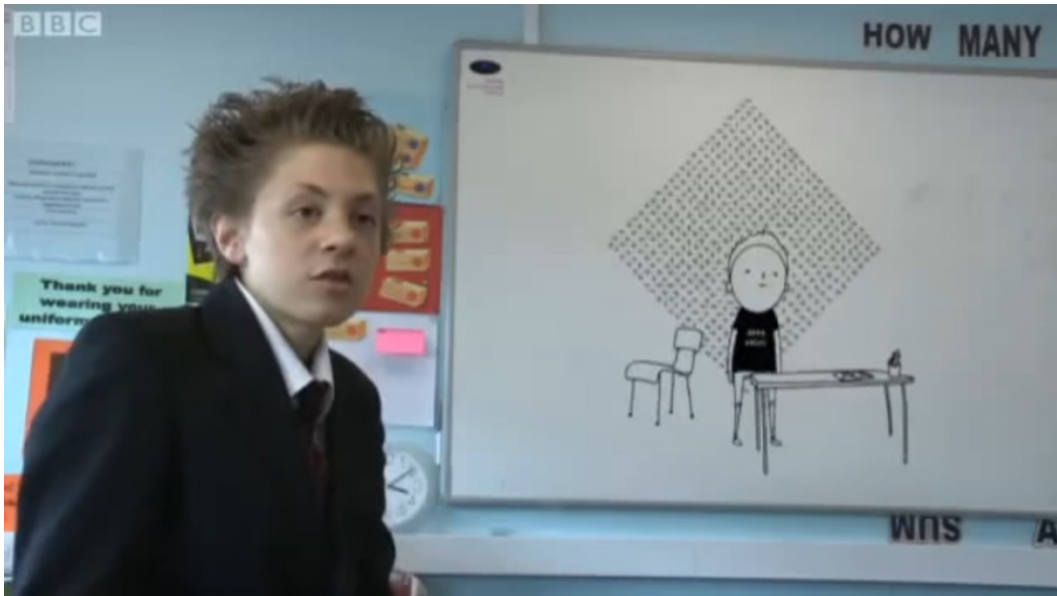

Picture 8

Picture 9

Picture 10

Picture 11

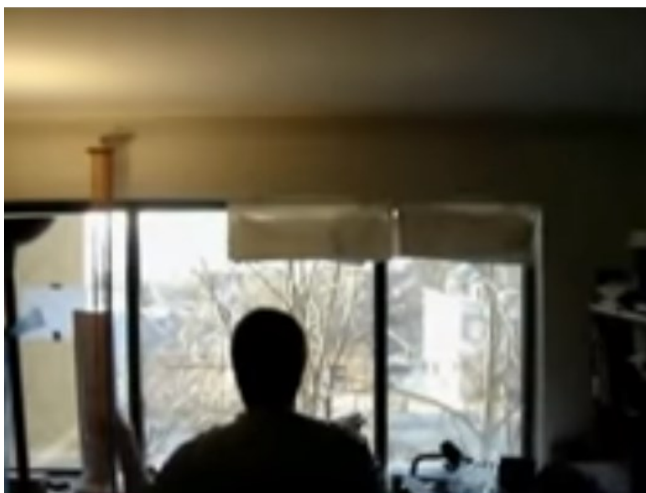Picture 12

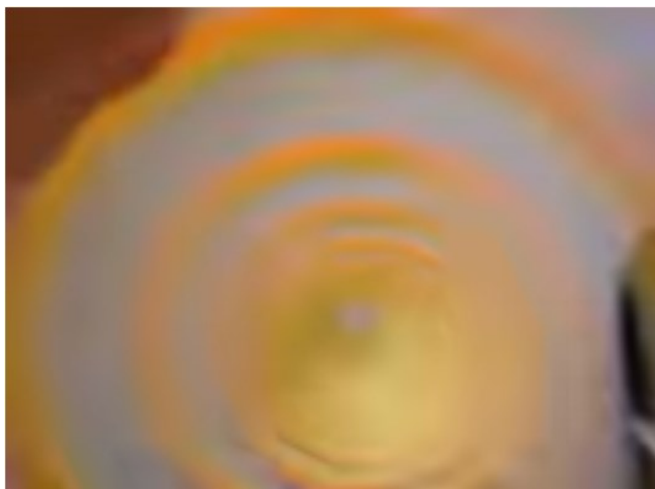Picture 13

Picture 14

Picture 15

Picture 16

Picture 17

Picture 18

Picture 19

Picture 20

Picture 21

Picture 22

It is about being in a constant conversation