

NATALIE KRUSE

Temple Grandin and the Mediation of Autism Debates at the Interface between Life Writing and the Life Sciences

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To my amazing parents for their unconditional love and support.
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Preface

Over the last decades it has become increasingly evident that the diagnostic label “autism spectrum disorder” comprises a heterogeneous group of people whose symptoms and (dis)abilities can manifest in sometimes strikingly different ways. Because researchers are still oblivious as to whether high-functioning autism and Asperger’s syndrome are one and the same (e.g., have the same etiology), speaking about autism as a general concept makes it an ethically complex endeavor. In light of the pronounced diversity, I consider it necessary to address some words regarding my choice of language and the autism terminology I have chosen to deploy. In this book, I will mainly focus on the higher-functioning forms of autism, while also including knowledge and research about other expressions of the condition where I see fit. When referring to the label of “autism,” I generally use it as a shorthand for the entire autism spectrum; it thus includes both so-called ‘high-functioning’ and ‘low-functioning’ autists. Although with the latest (5th) edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* of the American Psychiatric Association Asperger’s syndrome was officially dropped as a formal diagnosis, in a few cases I will still make reference to it as “the term continues to be used commonly to describe people with average or higher cognitive and language ability paired with challenges in the social realm as well as other challenges common in autism” (Prizant ix).

In the wake of several disability rights and autistic self-advocacy movements, there has been growing disagreement within the autistic community regarding the ways in which to address those diagnosed with autism. In the following chapters, I will predominantly use the term “autistic person” as it is preferred by many people on the spectrum (Sinclair 1993, Pellicano et al. 2014, 769). Another widely accepted term within the autism community is “on the (autism) spectrum,” which I will use as well. Besides these expressions, in some instances, I will also speak of “a person with autism,” commonly known as “person-first language.” It is

chiefly used by parents and professional associations searching for a cure for autism, while refusing “to acknowledge the very existence of an identity issue” (Ortega 433). While, for them, autism is simply a disease (433), others—predominantly those on the higher end of the autism spectrum, like scholar Michelle Dawson—maintain that using person-first language “would be as bizarre as using ‘person with femaleness’ to designate a woman” (qtd. in Harmon 2004). Many people on the higher end of the spectrum, therefore, favor the label “autistic,” feeling that the condition is an inherent part of their identity and not something bad (Sinclair 1993, 2013; Ortega 2009). They argue that “[a]utism is not an appendage, but an inseparable part of a person’s makeup” (Dekker 1-2).¹ I would like to stress that all these choices are individual preferences. In an attempt to do justice to the many possibilities in referring to a person diagnosed with autism spectrum disorder, in this book, I have therefore chosen to employ a variation of terms that I will use arbitrarily and interchangeably, not in an ill-informed way and in ignorance of the disputes and politics that surround this language, but only in the interest of sentence variation and writing aesthetic.

Historically, as sociologists Damian Milton and Mike Bracher remark, “Where autistic voices have been integrated into discussions by non-autistic academics, these tend to involve problematic interpretations of the source material” (65). In acknowledging the conflicted politics of speaking about a group of people that one is not a member of (see Alcoff 1991), I am aware of my role as a non-autistic literary scholar writing about autism. In this context, it would be appropriate to raise the fundamental question whether, in my role and position as an academic—and, therefore, geographically, socio-economically, and educationally advantaged person—I possess the legitimate authority to write about a group of people of whose life-worlds I know very little about. This privileged position clearly comes with a responsibility that I have attempted to assume to the best of my knowledge and belief.

¹ In recent years, this has even led to the adoption of a specific self-advocacy vocabulary for autistic people such as “Aspie,” “Cousin,” or “Curebie” (Bagatell 2007; Vidal and Ortega 174).

1 Introduction

With the proliferation of life writing accounts written by people on the autism spectrum, the ascendance of the cognitive neurosciences with their groundbreaking imaging techniques, the foundation of research centers, self-help organizations and advocacy groups, as well as the publication of numerous movies and TV series that feature autistic characters, the topic of autism has gained considerable prominence over time. Characteristically, autism—or more precisely autism spectrum disorders (ASD)—is described as a mystery condition, a great conundrum that “has attracted in the popular mind an amazed, fearful, or bewildered attention” (Sacks 2012, 181). According to Stuart Murray, “autism produces an often dizzying set of responses, from fascination and concern to sentimentality and fear, and those who seek to engage with this, or treat it, do so from multiple perspectives” (2012, 23–24). As journalist and editor Jon Sutton notes in an interview from 2014 with renowned neuroscientist Francesca Happé, autism has achieved an imposing public presence to a degree to which it seems to be “quite overrepresented” (763). In light of its increasing visibility, both in clinical and non-clinical contexts, one may even be enticed to conceptualize autism in terms of what Canadian philosopher of science, Ian Hacking—in reference to Susan Sontag’s *Illness as Metaphor* (1978)—has termed “pathology of our decade” (2010, 632–33). One of Sontag’s seminal book’s secondary themes was “that every era has its own illness, which shows as much about the age as about the disease” (632–33). While the infectious bacterial disease of tuberculosis was associated with the nineteenth century, the predominance of cancer has been ascribed to the twentieth century; today, autism seems to have supplanted these diseases, representing the condition of the twenty-first century. Hacking emphasizes that “the idea does not call into question the reality of autism, any more than Sontag doubted the reality of cancer. It suggests only that the heightened awareness of autism may reflect some more

general features of our time” (633).¹ One reason for the growing interest might be the, admittedly, impressive global rise in numbers of diagnoses during the preceding fifty to sixty years. While in the 1960s around 1 in 2,200 children were diagnosed with autism spectrum disorder (Lotter 1966; Treffert 1970), today, the prevalence has risen to nearly 1 in 54 in the United States (Maenner 2020) and continues to grow by 6-15 percent each year (CDC 2020). The skyrocketing of autism diagnoses underscores the overall relevance of the topic of autism and may serve to explain why discussions of autism have become more and more visible.

As a matter of fact, autism has not only gained a considerable amount of attention in popular discussions during the last decades but has also been the subject of major research projects conducted by committed scholars of varied disciplinary provenance from all over the world (see Autism Research Centre 2020; Autism Research Institute n.d.; Autism Research Trust n.d.; Autistica n.d.). And yet, as I will show in the course of this book, the condition persistently evades categories and definitions on several levels; it is precisely its *epistemic inaccessibility*, which turns autism into such a complex research subject. Autism’s elusiveness becomes visible if we attempt to classify it in terms of its status as either a biomedical or social category. People on the autism spectrum, clinicians, and scholars have long been occupied with the question whether autism is a disease, a disability, or rather a new form of identity and different way of being in this world (see Dekker 1999; Sinclair 1993; Ne’eman 2011; Yergeau 2017). While social constructivists argue that it is socially induced and should, therefore, be called a disability, biomedical professionals, geneticists, and neuroscientists would certainly contest this assertion claiming that the condition is a pathological phenomenon rooted in (neuro)biology and faulty genes (see Mundell 2019; Yang et al. 2018; Happé 2018). A thorough investigation of the life-worlds of people on the spectrum, however, reveals that autism seems to be both: a condition whose causes lie in a sophisticated interplay of neurobiological and epigenetic processes *and* which is subject to a series of social and environ-

¹ One certainly has to be careful with enqueuing autism along with clinically manifest diseases such as tuberculosis and cancer. As I will explain later, autism is neither an illness or a disease (nor can it clearly be defined as a disability). Placing autism with other pathologies would only reinforce the medical model, which the autistic community, as well as academic scholars, in their majority, spurn and want to move away from.

mental factors that can affect the degree of severity and different expressions of autism to a considerable extent (see Nadesan 2005; Grinker 2007).² In view of this immense complexity that autism poses and related polarized debates that has emerged over the last decades, a multi-perspective approach to the subject seems to me a matter of necessity and urgency. One particularly notable literary approach coming from the field of the humanities would certainly be Majia Holmer Nadesan's *Constructing Autism: Unravelling the "Truth" and Understanding the Social* (2005). In her book, the mother of an autistic child and Communication Studies scholar examines the historical and social events that enabled autism to be identified as a distinct disorder in the early twentieth century (Blurb). Moreover, she criticizes the life science's failed recognition of the cultural and social factors that, apart from (neuro)biological influences, play into the different manifestations of autism. Because of its multi-angle view on the spectrum condition, Nadesan's oeuvre presents a major source of reference for my book. Another noteworthy example I will refer to on several occasions is medical humanities and critical disability studies scholar Stuart Murray's *Autism* (2012). In his groundbreaking book, he skillfully combines medical, historical, and cultural approaches. He offers a well-rounded depiction of autism that does justice to the complexity immanent in the neurodevelopmental disorder and, in so doing, contributes to an improved understanding of the condition.

What these projects share is a vital discussion of autism at the nexus of biology and culture, nature and nurture. The tight interconnectedness between the biological and the social that characterizes autism increases its status as a fiercely contested condition. While "[t]he tricky crossing of biology and culture in medical practice is hardly unique to autism," "there is something about autism's range of interactions with 'the social' that make this a particularly vexed issue in autism research" (Silverman 2008 qtd. in Fitzgerald 50). The condition unremittingly triggers heated debates in disparate disciplinary fields with its researchers competing for their respective privilege of interpretation. Because it cannot be clearly assigned to either category, autism spectrum disorders represents a particularly attractive subject for a literary analysis within the genre of life writing; it

² Accordingly, the neurodevelopmental disorder should be located somewhere at the interface between illness and disability—depending on the respective vantage point from which one perceives autism.

therefore deserves my scholarly scrutiny. In screening recent publications, we find an increasing number of narratives by authors who discuss their personal experiences with illness and disability in the context of the cognitive neurosciences.³ Despite the epistemological chasms that still exist in our understanding of how the autistic brain operates, we can justifiably claim that the “new brain sciences” (Abi-Rached 2008) as they are also called, in the last decades of the late 20th and early 21st century, have developed into a leading discipline, if not even the *Leitdisziplin* for autism research (Banerjee 2019, 57). As largely uncharted territory, they hold the potential to offer illuminating insights into cerebral worlds and minds hitherto unknown to us, while, simultaneously, providing much scope for critical analysis, especially in view of the ongoing debates surrounding their scientific claims to objectivity. While it is true that there are many aspects that still elude medical research, what cannot be denied is that there has been a rapid dissemination of knowledge in the sciences, which, in large parts, also contributed to an overall improved understanding of the nature and different manifestations of autism. Because it has become almost impossible to discuss the neurodevelopmental condition without also considering it in the context of these, comparatively, recent developments, I will include this research approach into my literary investigation.

However, not only from a neuroscientific perspective but also from a literary one, an exploration of this, on many levels, complex condition that autism has proven to be, promises important insights. In the literary world there has lately been a veritable explosion of narratives in which

³ A comprehensive survey of contemporary literature’s engagement and interaction with the neurosciences can be found in Jason Tougaw’s *The Elusive Brain: Literary Experiments in the Neuroscience* (2018), featuring a foreword by acclaimed American neuroscientist Joseph E. LeDoux. In his fascinating book, Tougaw examines a number of what he calls “brain memoirs” and “neuronovels,” to which he counts the narratives of Temple Grandin, Oliver Sacks, Siri Hustvedt, and Tito Rajarshi Mukhopadhyay. As he states, these literary texts “work by telling stories about brain-related experiences that invite readers to consider a full range of philosophical and social implications of the relations between their brains, minds, bodies, and worlds” (5). With his balanced account, that can be recognized as a paradigm example of an interdisciplinary investigation, he makes a substantial contribution to the fields of the neurosciences and literary studies.

autism plays a central role (Hacking 2010, 632). These representations include a vast body of literature such as, for instance, biographies (Blastland 2007a; Fields-Meyer 2011; Iversen 2007; Park 1982), fictional accounts (Haddon 2004; Simsion 2014), movies (Levinson 1998; Evans 2006; Khan 2010; Næss 2005; see also Neilson 2015), theater plays (Stephens 2012), documentaries (Winslet et al. 2010; Suskind 2014), TV series (Gatiss and Moffat 2010; Lorre and Prady 2007; Rashid 2017; Shore 2017), as well as fantasy and graphic novels (Bargiela 2019; Schreiter 2014). The literary landscape has produced an impressive array of diverse accounts about the condition. The sudden ascent of autism in literature becomes all the more remarkable if we consider that stories about the neurodevelopmental disorder were virtually non-existent 40 years ago. Only from 2000 onwards, accounts by people on the spectrum have become increasingly popular (Hacking 2010, 632), and much has been written about autism since then. Even famous old novels or nonfiction accounts are read retroactively as narratives whose characters were autistic (632).

It hardly seems surprising then that, in their essay “The Pathos of ‘Mindblindness’: Autism, Science, and Sadness in ‘Theory of Mind’ Narratives” (2011), scholars of English John Duffy and Rebecca Dörner have identified autism’s “status as an essentially narrative condition” (201). Their argument encapsulates the seemingly dispersed arguments which seek to explain the allure that autism exudes in a variety of different areas. In my function as a literary scholar, Duffy and Dörner’s conceptualization of autism as a narrative condition strikes me as an especially promising approach, which is why I would like to incorporate their idea into my ensuing investigation. By framing autism spectrum disorders in the context of narrative, we get access to an enlarged scope of maneuver that enables us to explore the boundary condition beyond the, habitually, strictly separated disciplinary boundaries that discuss it. After all, as scholar of American studies and life writing Alfred Hornung remarks, both “life writing and life sciences share and depart from stories about life told by human subjects on different occasions in a number of different forms” (2013, x). Through this multi-pronged approach, I will place myself within recent debates about interactions of personal experiences and scientific research, which have culminated in promising cooperations of scholars from medicine and the humanities (Banerjee 2018; Banerjee et al. 2013; Charon and Montello 2002; Hornung 2015). What has emerged out of this newfound interest is the interdisciplinary field of *medical*

humanities. It is “an emerging field of inquiry in which humanities and social sciences perspectives are brought to bear upon an exploration of the human side of medicine” (Centre for Medical Humanities Blog). As a research domain that works at the intersections of the life sciences and life writing about experiences with illness and disability, the medical humanities present an ideal starting point from which to discuss autism spectrum disorders. It seems equally suitable as a framework in overcoming the division between the “hard” sciences and “soft” humanities (Hornung 2013, 2015). This becomes especially pertinent if we take into account that the opposed positions of the life sciences and the humanities with their seemingly different methodological approaches and accesses to knowledge—the division between the subjective and the objective—paired with their skepticism towards “foreign” narrative representations and practices, have long impeded or even prevented entirely a potentially fertile cooperation. The comparatively novel exchanges that take place between humanities’ scholars and researchers from the natural and life sciences, not only question “the conventional wisdom of life writing” but also challenge the genre’s disciplinary borders (Hornung 2013, x). Noteworthy to mention in this context, especially regarding its relevance to this book’s focal point, would be the emergence of first-person illness and disability narratives. Autobiography⁴, as “the most universal, most democratic form of literature” (Couser 2016, 3), can address crucial aspects of human embodiment and experience, which is why it represents also an ideal gateway from which to study autism spectrum disorders. Notable contributions investigating these boundary aspects of human life in the context of autobiography—in both a broader and narrower sense—have come from scholars like, *inter alia*, Michael Bérubé (2000, 2005), Rita Charon (2002, 2005), G. Thomas Couser (1997, 2004, 2009, 2011), Paul J. Eakin (1999, 2004, 2008, 2015), and Arthur Frank (2013). To varying degrees and from different disciplinary, as well as personal viewpoints, they explore illness and disability narratives in a shared “recognition of the need for a renewed focus on the patient’s story and its individual and collective function” (Conway 12). And yet, the actual significance of a directly affected person’s lived experience with autism and its potential

⁴ While the term “autobiography” usually covers the author’s full span of life, “memoir” is used for self-referential accounts that cover either the entirety *or* only parts of this life (see Yagoda 2009). In this book, however, I will use the words “autobiography” and “memoir” interchangeably.

value for the life sciences has received fairly scant attention in academic discussions. It is for this reason that, as an American studies scholar, I want to place myself within a literary debate of autism that also takes into the account the close interaction between the individual experience with the condition and the knowledge produced by the life sciences.

Temple Grandin in the Prism of General Autism Debates

For the purpose of illustration of more general autism debates, in this book, I will engage with the writings of American animal scientist and autistic Temple Grandin. Through my examination of her life story, I will follow Nadesan, Murray, and many other committed scholars in their efforts to provide, at least, partial answers to some of the most pressing issues that exist in contemporary discussions about autism located at the intersections of the humanities and life sciences. Entering the topic of autism spectrum disorders via the personal account of someone who possesses first-hand experience with the condition and, thus, has privileged access to the phenomenological world of autism, represents an ideal prerequisite for a close-to-life representation of autistic embodiment.

In the following, I would like to introduce the protagonist of my book. Mary Temple Grandin—that is her full name—was born on August 29, 1947, in Boston, MA, USA. At the age of two she received the diagnosis of “brain damage”; she did not speak until she was three and a half years old (*Brain 3*). Later in life, her diagnosis was corrected to autism, even more later to Asperger’s syndrome, which, today, is a high-functioning autism form of the condition on the broad autism continuum.⁵ While, as a child she was on the brink of being institutionalized, today, Grandin is an associate Professor of Animal Science at Colorado State University and has gained an international reputation as an expert in the livestock and meat-packing industry “for her groundbreaking designs of humane cattle-handling equipment, techniques, and setting standards of good practice in handling animals” (Baron-Cohen 2005, n.pag.). She has become particularly famous for her extraordinary visual skills and her ability to think in pictures that have “allowed her to connect with animals in

⁵ In fact, Grandin was never formally diagnosed with autism until she was in her forties.

ways most people never could” (Phifer). However, she is not only celebrated for her contributions to the livestock industry but has made a name for herself as a prolific author of several autobiographical works. While, these days, we find a plethora of life writing accounts written by people on the autism spectrum, few have been as successful as Grandin’s. In part, this may be owed to the fact that “[s]he was one of the first people with considerable professional qualifications...to go public about her diagnosis of autism” (Baron-Cohen 2005, n.pag.), when she released *Emergence: Labeled Autistic* in the year of 1986. Aside from her autobiographical narratives, she has published over one hundred peer-reviewed scientific papers on the topic of autism and animal behavior.⁶ She, furthermore, is the subject of the eponymous Emmy Award-winning HBO documentary film, *Temple Grandin* (2010), starring Claire Danes as Grandin in the leading role and has made it on *Time Magazine*’s list of the 100 most influential people of 2010 in the “Heroes” category (Hauser). The Wall Street Journal went even so far as to say that she is “easily the most famous autistic woman in the world” (Weiss).

In my book, her narratives function as a model for an intervention of life writing by a directly affected person that may possibly prove relevant for the knowledge production in the life sciences. I am aware of the fact that Grandin’s personal life story about autism is only one of many thousands. With an increasing visibility of autistic individuals in the public and professional sphere and an ever-growing rise in diagnoses, more and more accounts about how it is to live with autism have emerged. It has been particularly in the last two decades that a plurality of published first-hand accounts dealing with autism spectrum disorders have entered the literary landscape (e.g., Higashida 2013; Mukhopadhyay 2000, 2008, 2011; Prince-Hughes 2004; Robison 2008; Tammet 2007; Williams 1992, 1995). And yet, it has been a conscious decision of mine to select Grandin as a prime example for my ensuing exploration of autism that is embedded in a much broader debate for multiple reasons. First, it is the unique combination of private insights into autism and the scientific knowledge she has attained on the subject over the years which makes her accounts particularly interesting from a literary studies perspective with a marked interdisciplinary orientation. Grandin’s representation of autism, in general,

⁶ For a comprehensive list of Grandin’s livestock publications visit: <https://www.grandin.com/livestock.publications.html>.

and her personal history, in particular, can be considered as unparalleled in the ways she reconciles the level of subjectivity—her phenomenological insights of lived experience with autism—with the objectivity-seeking disciplines of the life sciences. Her self-reports can, thus, not only be acknowledged as notable additions to scientific debates about autism, but they can further be seen as a subversion of the static genre confines of life writing. Both her personal writing style and the co-construction between the “objective” life sciences, with which she is affiliated as an animal scientist, and the subjective experiences with autism, Grandin presents a challenge to narrative expectations and customary categories of life writing. This effective combination offers an ideal entrance point into more profound discussions of the subject of autism at the interface between life writing and the life sciences. As I will demonstrate, Grandin’s works serve as a paradigm of an interdisciplinary synergy that is of special epistemic significance.

While her life story is usually discussed under the lens of her significant contributions to the field of animal welfare (Dimas 2017; Johnston 2019) or her personal emergence from a severely troubled child to a world-renowned scientist, so far, surprisingly little light has been shed on the ways she acts as a mediator between the life sciences and the genre of (autistic) life writing. In the Merriam Webster Dictionary, the term ‘mediation’ is defined as an “intervention between conflicting parties to promote reconciliation, settlement, or compromise.” In my example of Grandin, this intervention takes place at the intersections between the life sciences and the humanities. However, I would like to go a step further in claiming that she functions not only as a simple mediator; given her autistic capabilities and narrative choices, I will argue that Grandin can be considered, what I wish to entitle, a *diplomautist*—a person on the autism spectrum who mediates and conducts negotiations between different (neuro)cultures. The term derives from the word diplomatist—a less common and dated word for diplomat. Grandin, as an autistic “native,” understands the subtleties of autistic language and behavior and acts as an intermediary between the autistic and non-autistic world; in the role of an autistic diplomat. She skillfully manages to translate and negotiate between these different (neuro)cultures and modes of thinking in a way that is legible to both neurotypical and autistic people. Grandin can be conceived of as a *diplomautist* in multiple respects: first, as a professor and expert on livestock, an animal scientist and consultant, she serves as an

arbitrator between the life sciences and the phenomenological world of autistic people. Grandin straddles the polarities of professional biomedical discourse about autism and the inner lifeworld that is immanent in her experience with autism. If we closely follow her descriptions, we can see how she shuttles between her personal experiences—her embodied knowledge—and the scientific explanations, which are employed to provide an epistemological base for her lived experience. Second, she reconciles the medical and the social framing of autism through the exploration of her first-hand experiences. Given that autism is tightly embedded in a network of multi-disciplinary conceptualizations, her personal experience of autism is influenced and mediated by the theories and practices of several disciplinary fields that, ever since its first mentioning by Leo Kanner and Hans Asperger in the 1940s, have competed for their respective power of interpretation. In her first-person accounts she neatly interweaves objective neuroscientific findings obtained by the numerous studies and examinations she participated in, with the more subjective, phenomenological insights she has been able to attain through her personal experiences with autism; she shows that her physiology and her phenomenology are inextricably linked with and mutually dependent on one other and, therefore, cannot be separated. As Tougaw notes, like most neurological narratives, Grandin's accounts "take the form of a quest—for new knowledge, understanding, healing, adaptation, and for reconciliation between scientific theory, medical practice, and the lived experience of patients (and writers)" (77). My exploration of her works will demonstrate that it is through her life writing that Grandin is able to move from being an external medical object to a self-competent subject of knowledge who is claiming her agency and advocating for not only herself but also other autists, while, at the same time, clearing up misconceptions and prejudices about the condition. In her function as a *diplomaautist*, Grandin represents and protects the interests of the autistic world by challenging normative assumptions and breaking up stereotypes about autism that have been upheld persistently by biomedical discourse and popular beliefs.

As the following chapters and my analysis of Grandin's life writing works, in particular, will reveal, autism functions as a magnifying glass that complicates "normal" debates on many different levels. In my book, I employ the neurodevelopmental condition of autism as a showcase example that stands in for other forms of human diversity that fail to comply with society's narrow, standardized vision of human embodiment and

behavior. While I will not be able to discuss other neuro-conditions in more depth, showing that autism is embedded in a much larger debate within the realm of medical humanities, will increase the relevance and scope of my narrative investigation of Grandin's autie-biographies. A broadening of the debate and the extension to other neuro-conditions could further signal a new paradigm shift in understanding human otherness in general.

In this book, a critical juxtaposition of the social and medical model of autism will help uncover the conflicting views that exist in the theorizations of autism spectrum disorders and the implications these very models have on how the condition is perceived and treated on both a private, scientific as well as a much broader political level. More importantly, however, it will expose the highly insecure and unresolved status that the neurodevelopmental disorder holds within professional debates, which underscores one of my central claims, namely that the life sciences and humanities have to come together and join forces in order to ensure an improved understanding of autism. My examination will reveal that it is precisely through the mediation between her neurology and the phenomenological level of autism that Grandin manages the balancing act of equally doing justice to both sides, instead of lapsing into a polarized debate of which perspective on autism is "truer" or "the right one." Notably, with the introduction of the *diplomaautist* term, I want to turn preconceived notions about autism on its head. It is often assumed that people on the autism spectrum fail to put themselves in another person's position as they are said to lack the ability to empathize with others and act in a diplomatic way. As my analysis will show, Grandin's example serves as a counter-argument to these claims. Importantly, the *diplomaautist* term turns the autistic subject into a shapeshifter and authority figure that actively participates in the process of fostering mutual understanding between different neuro-cultures. At the same time—being fully in line with disability studies claims—it can be employed against the rhetoric of misery that has long persisted and continues to be deployed in discussions about autism. Based on the previous propositions, in the following chapters, I will provide ample textual evidence for why she qualifies for this term and what makes her particularly special in comparison to other autists—who, of course, have also had their fair share in promoting a growing autism awareness by sharing their phenomenological insights with a broader audience.

In anticipation of criticism regarding my coinage, I would briefly like to address the term's ethical boundaries. I want to make clear from the outset that this neologism is, in no way, meant to be understood as a devaluation or belittlement of autistic people. Neither is it my intention to imply that autists are, generally, unable to function as "full" diplomats. What I do intend to stress with this compound word, however, is the central role of the autist—with his or her unique expertise deriving from the lived experience with autism—in mediating between the autistic and neurotypical world. It places the autistic person's—in this book's case, Grandin's—lived experience and subjective feelings in the center and foreground of all actions and highlights the increased level of personhood and agency that comes with that special positioning. I would like to remark here that the term is, self-evidently, not only limited to Grandin but can be applied to many other people on the autism spectrum who put their time, efforts, and passion in liaising between the autistic and neurotypical world; she serves as only one, albeit powerful, example among others. Throughout the next chapters, I want to take a closer look at Grandin's autobiographical accounts *Emergence: Labeled Autistic* (1986), *Thinking in Pictures* (1995), *Animals in Translation* (2005), and *The Autistic Brain* (2013) in order to examine the specific modes of narration and the hybrid, interdisciplinary nature that characterize her narratives. I would further like to add here as a side note that I will exploit Grandin's narratives as both primary and secondary sources. Given the density and richness of information that her works provide on the topic of autism spectrum disorders, her accounts have turned out to be invaluable sources for my theoretical framework in this book. What becomes obvious in sighting the numerous narratives that Grandin has published over the years is a shift in topical foci. While her fledgling work *Emergence* has a strong emphasis on her medical history, the process of coming to a diagnosis of autism, and the challenges and hardships she and her family had to endure during her childhood and adolescence, *Thinking in Pictures* focuses more on her remarkable visual skills and the positive attributes of autism. *The Autistic Brain*, on the other hand, reflects the transition from the biomedical and psychological model of autism to recent neuroscientific and epigenetic approaches that have affected a shift away from a deficit-oriented to a strength-based perspective on the condition. With *Animals in Translation* Grandin has created a book that differs from her published predecessors for it focuses on domestic and agricultural animal's behavior instead of

her own life story. In great detail, she explains why animals behave the way they do and gives practical advice on how to manage difficult animals. Because her narratives, in large parts, overlap in their thematic scope and content—sometimes even entire verbatim passages—I will not discuss them separately and in strict chronological order, neither will I perform a “one book per chapter” close reading. Instead, I will refer to them whenever I see fit to support my argument.

As already indicated, over the last eight decades, autism has proven to be a popular object of investigation of numerous disciplinary fields that have sought to understand and explain the condition from multiple lenses. In order to provide a solid foundational basis for my ensuing discussion of Grandin’s life narratives and more general autism debates, I consider it essential to, first, prepare the ground with a historiographical tracing of autism. *Chapter 2* will offer important background knowledge on the phenomenon of autism spectrum disorders by putting a special focus on historical and present theorizations produced by psychology and the life sciences. With my overview of autism’s convoluted medical history, the reader will attain sufficient understanding of the current state of autism research and will, furthermore, get initial insights into the complexities that the condition poses on multiple levels. As the chapter will also put forth, the life sciences with their numerous scientific accounts have been the main actors in discussing and defining autism (Feinstein 2010; Silberman 2016); their theories have shaped the way autistic individuals were perceived and medically treated at different points in time of history, which, as the subsequent chapters will show, has also implications on the ways autistic life writing accounts have been historically received.⁷ Because we cannot ignore the social aspects and environmental influences that significantly determine how autism manifests, I will present an alternative approach to the pathology paradigm of autism: the social-constructionist model of disability studies. It is an “interdisciplinary field of

⁷ One prominent example of a leading theory in neuroscientific autism research would be Professor of Developmental Psychopathology and Director of the Autism Research Centre at the University of Cambridge, UK, Simon Baron-Cohen’s famous Theory of Mind, which will be discussed in a later section of this book. He is the author of numerous scientific papers and monographs, e.g., *Mindblindness: An Essay on Autism and Theory of Mind* (1995), *The Essential Difference: Men, Women and the Extreme Male Brain* (2003), and *Zero Degrees of Empathy: A New Theory of Human Cruelty* (2011).

inquiry that expands the understanding of disability from a health science perspective to consider it as a civil and human rights issue, a minority identity, a sociological formation, an [sic] historic community, a diversity group, and a category of critical analysis in culture and the arts” (Emory University 2019). Disability studies scholars have positioned themselves in opposition to the medical model with its pathology paradigm that perceives digressions from standards of normality in need of correction, cure, or even elimination (see Garland-Thomson 1997, 2002; Linton 1998, 2005; Davis 1995, 2001; Siebers 2008; Snyder et al. 2002; Snyder and Mitchell 2001). Similar to feminist Judith Butler’s revision of the sex-gender-system (1990), a reexamination of the impairment-disability binary can contribute to a more open and less discriminating handling of bodies and minds that seem to fail to comply with society’s narrow vision of human embodiment (Donaldson 2002, 112). According to Nadesan,

Although the field of disability studies might, on the surface, appear to have a more narrow scope than the sociology of medicine, it holds direct relevance for understanding how bodies are pathologized and/or normalized because disability functions as an umbrella term that embraces all people who are seen as ‘disabled,’ whether from disease, psychiatric condition, or physical limitation. (181)

An examination of autobiographical works about autism through a disability studies lens will offer fresh insights into autism and its often associated status of “deviance” from society’s constructed standards of normativity. Chiefly in alignment with the field of disability studies is what has come to be known by the term of “neurodiversity movement.” Neurodiversity rights advocates fight for a recognition of people with different kinds of cognitive and neurological issues such as autism. They bring a new perspective to human diversity by reframing “the symptoms and behaviors of the people who would ordinarily be classified as non-neurotypical” as “simply normal expressions of human function rather than disorders to be diagnosed and treated” (*Applied Behavior Analysis Edu*), thereby, promoting a greater involvement of people in autism debates. In my discussion of both the disability studies approach and the neurodiversity movement I will highlight autism’s status as a versatile and controversially debated condition that is not only open to but *requires* a multi-perspective approach.

Chapter 3 starts off with a short introduction into the life writing genre and auto/biography studies, followed by a contextualization of the emergence of autistic life writing, which has not only found a relatively late entrance in the literary sphere but has also experienced kind of a rough start. Until the mid to late 1980s, first-hand accounts about autism were still considered an impossibility as previous psychological and biomedical assumptions in which most knowledge about the condition was deeply mired held the view that people with autism are incapable of self-narration.⁸ Today, an abundance of stories about autism corroborate that life writing narratives by people diagnosed with autism—individuals with more severe forms included—obviously *do* exist. More than merely existing, throughout the last decades, many people on the spectrum have proven that they possess rich inner lives, astuteness, humor and, in many cases, immense talents that challenge our understanding of dis/abilities. My analysis of Grandin’s works, in particular, will demonstrate the significance of the emergence of her, hitherto unprecedented, self-representational accounts about autism, which have served as encouraging examples and a motivative force for other autistic people to narrate and publish their own life stories.

Given the existing continuity between a phenomenological approach and the subjective experience on which practically all autobiographical life writing narratives are based on, phenomenology as a theoretical framework fits with the objective of this book and will prove to be an indispensable investigative tool for my analysis of Grandin’s first-hand accounts about autism. As my investigation will show, first-hand phenomenological insights—as they are portrayed in experience-based accounts—are paramount in getting a more comprehensive picture of the

⁸ One recent and seminal work on the topic of autistic authorship and its troubled status comes from autistic academic and Associate Professor of English, Melanie Yergeau. With *Authoring Autism: On Rhetoric and Neurological Queerness* (2017), Yergeau has created narrative, in which she passes, betimes, scathing criticism on the ways that scientists and clinicians have called into question autistic rhetoricity. She not only defines neurodivergence⁸ as a form of identity but also argues that autistics are the “best-equipped people to define their experiences,” which is why they should be acknowledged and appreciated in the process of knowledge production about autism. Because of its content’s accuracy of fit for my book I will frequently refer to her work, especially in the chapter on the limits of autistic narration.

condition. *Chapter 3* will therefore stress the significance of anecdotal evidence in debunking common stereotypes about autistic behavior and creating an improved understanding of their life-worlds that may even turn out relevant for life sciences research. By using the concept of phenomenology as a theoretical foundation, we will be able to gain access to different individual worlds and explore in detail how autistic people are making sense of their personal and social environments. The incorporation of first-person phenomenological accounts of autism will prove essential in uncovering the inherent co-construction of life writing and life sciences accounts about autism and the constant interaction that exists between the different modes and styles of narration in which the condition is commonly represented. Importantly, self-representational narratives provide explanations for and accurate interpretations of specific behavioral patterns of autistic people's lived realities and their sometimes strikingly different ways of being in the world.

As already mentioned, the status of autistic authorship has been a markedly troubled one, as the self-reports by people on the spectrum have been subject to the rigorous scrutiny, if not even discreditation, by medical authorities. Autism has been commonly viewed as a "rhetorical problem" (Yergeau 2017). People on the autism spectrum, by nature of their assumed disability and mentally inscribed otherness, were constitutionally held to be incapable of self-narration; their lives were deemed as un-storyable. If there were stories at all, they were (and betimes continue to be) read under the lens of their alleged pathology. In spite of or, rather, *because* of her fame and unique skills, which seem to be closely intertwined with her condition, throughout her career, Grandin has been subject to the external gaze of medical professionals, with her behaviors and narrative choices being meticulously deconstructed and analyzed. As *the* leading figure in the sub-genre of autie-biographies, Grandin has been repeatedly exposed to critics—both within and beyond professional realms—who have questioned her authority as a capable and sole author of her works as well as the accuracy of her autism diagnosis. The mere existence of her life writing accounts has led medical experts to believe that she could not but be recovered from autism, otherwise she would not have been able to exhibit the very abilities to narrate her own life.

In the first part of *Chapter 3*, I will explore the factors that have led to this skepticism towards autie-biographies and will further identify the repercussions that this kind of reading entails. What does it say about the

habitual practices involved in reading and discussing autobiographical works by people who do not comply with normative expectations both with respect to the stories they tell and the specific strategies they employ to narrativize their lives? Rather than being acknowledged as authorial subjects who have found their voice to share their lived experience with an audience, autistic life writers have been viewed as medical objects. My examination will reveal that the search for autistic symptomatology in autie-biographies⁹ is only symptomatic of the unequal power relations that exist between the knowledge held by scientific experts and those who are directly affected and, thus, possess an embodied experience with the condition. In order to highlight this, I will refer to medical humanities scholars Felice Aull and Bradley Lewis's concept of "medical orientalism" (2004), which can be employed as a useful framework to illustrate how not only autism but also other neuro-conditions such as schizophrenia have been scrutinized and queried under the gaze of clinicians.

In the second part of *Chapter 3*, I will turn towards the topic of autistic communication, which represents one of the key factors in the somewhat tarnished status of life writing by people on the spectrum and the still limited knowledge about the condition in the life sciences. Particularly noteworthy to mention in this context would be Grandin's discussion of sensory issues and the crucial role they play in causing a series of symptoms which, sometimes, lead to paradoxical reactions in autistic people. Both in her autobiographical narratives, scientific papers, and public lectures, Grandin repeatedly sheds light on the importance of acknowledging sensory issues as a key impairment in autism. Because of the centrality of the topic for autistic people that deserves closer attention, and in view of its usefulness by way of illustration, I will take it up as a key example for my literary investigation. I will also refer to the narratives of non-verbal autists and autie-biographers Tito Rajarshi Mukhopadhyay and Carly Fleischmann, whose competencies have been repeatedly called into question on the basis of their lack of (verbal) communication skills that stand in direct opposition to the astounding insights they display in their autobiographical accounts. The incorporation of Grandin's, Mukhopadhyay's, and Fleischmann's personal testimonies in my analysis will underline the systematic blackguarding of autistic life writing accounts. Furthermore, it will broaden the discursive scope by taking into consideration not only

⁹ Autobiographies written by people on the autism spectrum.

the epistemological level of autism provided by the life sciences but also the lived experience portrayed in life writing narratives by those diagnosed with autism.

In rebutting long-standing, yet often inaccurate conceptions of autistic life-worlds, autie-biographies—the first-hand accounts by people on the autism spectrum—add an indispensable dimension to prevailing medical and biological interpretations of the condition and, in so doing, fulfill an important epistemic role in serving as counternarratives to biomedical autism paradigms. This becomes especially pertinent if we call to mind that, throughout its history, autism has been predominantly narrated by medical authorities from professional fields like psychiatry, psychology, and the life sciences (e.g., biomedicine, epigenetics, and the neurosciences). Notwithstanding their efforts to fully understand autism spectrum disorders, to this day, they have remained unable to obtain satisfying answers to the most pressing questions about the condition. Despite the controversial status of subjectivity in public and professional debates about autism, first-hand, phenomenological self-descriptions of autism, I suggest, can convey an improved understanding of how autism works and, more than that, offer a vantage point from which to perceive “the co-implication of impairment, disability and subjectivity or *Leib* and *Körper*” (van der Palen 51). At the same time, they bear the potential to profoundly change the ways we read, discuss, and understand the condition. In so doing, they present an important challenge to our conceptualizations of the fields of the life sciences and life writing with their rather strict genre confines. It is for this reason, I propose, autistic life writing should be rightfully acknowledged in the process of knowledge production about autism in both domains.

Following the theoretical contextualization in the first section of *Chapter 4*, the second half will be concerned with an examination of Grandin’s autobiographical narratives. My close reading will reveal how she thwarts attempts to diminish autistic competencies and, instead, promotes strengths, by stressing that autism is not a mere weakness that necessarily has to be overcome. I will show that it is through the discussion of her abilities to think in pictures that she reverses the notion of normalcy by turning her immense talent into a super-ability rather than a disability. She thereby reminds us that—similar to the process of arriving at a diagnosis of autism—the status of normalcy is a highly unstable and permeable category that very much depends on the vantage point—or rather the

neurological wiring—from which one sees and experiences the world; the supposedly sharp distinction between the normal and the pathological turns out to be much more blurred and less clear-cut than one may first anticipate. Equally complex are notions of cure and the appreciation of autistic capabilities that have long been neglected by autism scholars, which is why I will dedicate parts of my discussion to these crucial aspects of contemporary autism debates. I will not only engage with the emphasis on cure that is inextricably linked with the medical concept of illness and disability but will also look into the construction of normalcy from a disability studies perspective and how a reconsideration of disability might dissolve the boundaries between the “normal” and the “abnormal” mind.

In spite of the significant contributions the academic field of disability studies has made in understanding disability as a key human experience that is not exclusively rooted in biology but is subject to external factors in the social environment, there seems to be a blank spot on the map of academic investigations with regard to mental disabilities. While scholars in the field have put great emphasis on physical disabilities and the visible body (see Garland-Thomson 1997; Oliver 1990, 1996), they have, to a large part, systematically neglected invisible disabilities, such as neuro-logical and brain-related conditions like autism spectrum disorders. “Most major scholarship on disability—aside, perhaps, from research on deafness and Deaf culture,” literary scholar Mark Osteen confirms, “has also concentrated almost exclusively on visible physical disabilities,” while “unusual minds” and “conditions the naked eye cannot detect,” because they take place in the human brain, have remained mostly unseen (2008, 4). While, as Osteen has already mentioned, there is literature available on few invisible disabilities such as deafness (Davis 1995; Brueggemann 2009), the neurodevelopmental condition of autism has long been ignored by disability studies scholars.¹⁰ With my examination of autism from a disability studies lens, exemplified by Grandin’s narratives about autism, I intend to make a contribution to this debate.

¹⁰ While today we are, in fact, able to find publications in journals and monographies on the subject of invisible disability (see A. Davis 2005), mental illness, and psychiatric disability (see Donaldson 2018) by scholars from the fields of medical humanities and disability studies, this is a rather new phenomenon as it has only been in recent years that these contributions have sprouted from the academic (under)ground (Brewer 2018).

In the penultimate section of *Chapter 4*, I will address the issue of speaking for others and will fathom whether Grandin's narratives can, justifiably, be considered as being representative of other people's experiences with autism, and if she has the right to speak for other people on the spectrum. In spite of Grandin's popularity and success, time and again, she sees herself confronted with major criticism. Part of this critique is directed towards the question whether her life story stands in for a more collective experience with autism that is of political relevance, for it uncovers the underlying discursive practices, explanatory models, and narratives of the life sciences which used to define and still seek to explain the condition. My analysis will be based on Latin-American philosopher Linda Alcoff's seminal essay "The Problem of Speaking for Others" (1991); it will add an additional layer of complexity to the already intricate debate of autobiographical narratives in general, and the autie-biographies of Grandin, in particular.

I will close *Chapter 4* with a rather theoretical section that deals with the significance of new technologies in the context of autism and autistic life writing. As the title "Moving from Offline to Online Spaces: Imagining a Future of Autism and Autistic Life Writing" already indicates, the sub-chapter will engage with future possibilities for autistic life writing in virtual space. The Internet, in particular, has already proven its usefulness in terms of serving as an ideal platform and medium for autistic people to share their personal life stories in a relatively sensory-free and safe environment (Davidson 2008a; Dekker 2006). However, more than that, it uncovers the situationality of autistic "inadequacies," which—while, potentially, becoming visible in face-to-face communication—often vanish with a change of communication medium, as some of the symptoms of autism are dependent on the environment and can, therefore, be controlled with appropriate measures. In this context, Davis's comment would be most fitting, which is that "Many disabilities are constructed through the sense of sight and can be deconstructed in virtually real locations that do not rely on sight" (1995, 14). The Internet, simultaneously, uncovers the questionable division between dis/ability and helps dispel long-standing stereotypes about autistic people, i.e., their presumed (lack of) competencies. The continually growing shift from book manuscripts published offline to the dissemination of self-representational accounts via online blogs, autism forums, and chats will, furthermore, affect an increase of participatory opportunities and inclusion for those who cannot