Jenny Bergenmar, »Translation and untellability. Autistic subjects in autobiographical discourse«

**ABSTRACT**

This article discusses the conditions for and reception of autobiographies by autistic persons from a critical disability perspective. Taking as a point of departure theories of narrativity where storytelling is seen as an essential human trait and narrative as a prerequisite for the construction of a self, the article discusses different modes of representing autistic subjectivity, in some cases contradicting these assumptions. In some of the »canonized« autistic autobiographies, the narrative script of overcoming autism is strongly present. The article shows how this is not merely an adaptation to the expectations of the audience, but also a method strategically employed as a means to avoid objectification and to gain agency. Although some autobiographical representations of autistic personhood resist having to translate their experience or language to fit the narrative script of disability, audiences tend to appropriate them into the expected narrative trajectory of overcoming, thus rendering alternative representations of autistic personhood unacknowledged.

Jenny Bergenmar, PhD, Associate Professor, Department of literature, history of ideas and religion, University of Gothenburg.

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TRANSLATION AND UNTELLABILITY. Autistic subjects in autobiographical discourse

John Elder Robison’s autobiography *Look Me in the Eye. My Life with Asperger’s* (2008) includes a preface by his brother, Augusten Burroughs. Burroughs writes about the curious fact that the chapter about John in his own memoirs received so much attention from readers, despite the frightening, comical and unlikely experiences of his own life. »At every event, people approached me and said, ‘I have Asperger’s syndrome, just like your brother. Thank you for writing about it.’« This was in 2002.

Since then the number of autobiographical narratives about autism has increased dramatically. In *Representing Autism* (2008) Stuart Murray counts some 55 texts by autistic writers, published in English between 1985 and 2004, and this development has continued even more rapidly in the last 10 years. The surge of autistic life writing can no doubt partly be explained by the growing public interest in what fiction, mass media and popular culture have presented as an enigmatic and threatening condition, possibly spreading like an epidemic. Many autistic persons perceive these popular narratives as misrepresentations. Autism tends to become the focus of a »politics of staring« in much the same way as physical disability has. Autism is the object of »fascination« in popular culture, as Murray puts it. However, Thomas Couser remarks that destigmatization is one factor behind the many contemporary illness narratives, and that »those illnesses that are especially threatening – either because they are common or because they are particularly fraught with cultural significance – tend to provoke relatively large numbers of narratives«.

As Couser’s statement indicates, the development of autistic life writing is also correlated with pathography as a prolific genre in the twenty-first century. In a society where people, due to medical and technological advances, have come to expect good health, disease and disability tend to be regarded as all the more troubling and abnormal. The pathographies account for a significant number of memoirs by people previously unknown to the public – »the nobody memoirs«, as opposed to the traditional »somebody memoirs« written by distinguished persons with existing audiences.

Indeed, the two most famous autistic autobiographical writers, Temple Grandin and Donna Williams, started out writing »nobody memoirs« about their experiences of living with autism, and have since then certainly become »somebod-
ies» in the public sphere. Williams even uses the same termino-
logy in the titles of her autobiographies: the first one entitled
Nobody Nowhere (1992) and the second Somebody Somewhere:
Breaking Free from the World of Autism (1994). As the titles
indicate, there is a narrative trajectory from the position of a
nobody in the nowhere land of autism to that of a subject with
agency in the world. In Donna Williams’s narrative, a subject is
emerging from nowhere, and this is also what Temple Grandin

Williams and Grandin are often discussed as the pioneers
of the »autiebiography«, a label used to distinguish autobiog-
raphies about autism written by people with autism from
those written by, for example, parents of autistic children.
They are both active as autism advisors and have written
several handbooks on autism besides the autobiographical
ones. Daniel Tammet is another autistic autobiographical
writer who has reached a large audience with Born on a Blue
Day (2007). Like Grandin and Williams he describes his child-
hood and adolescence. In the narrative of his adult life, he
focuses mainly on his mathematical and linguistic talents. The
UK publisher presents him as a prodigy: »He has Savant
syndrome, an extremely rare form of Asperger’s that gives him
almost unimaginable mental powers, much like the Rain Man
portrayed by Dustin Hoffman.« This similarity was also
alluded to in the title of a documentary about Tammet’s savant
abilities, Brainman, which also featured Simon Baron Cohen,
professor of psychopathology at Cambridge University, and
Kim Peek, the inspiration for the character of Raymond Babitt
in Rain Man.

Judging by these three examples, one could come to the
conclusion that autobiographies about autistic experience are
written by persons who on the one hand have their autism to
thank for certain gifts, or »mental powers«, to use the words of
Tammet’s publisher, and on the other hand have to struggle to
»emerge« from their disability as autonomous subjects. There
are of course many kinds of autistic autobiographies, but
Murray points out that the »overcoming« narrative of disability
is predominant. When it comes to autism this is specifically true
for autobiographies written by parents, often with titles such as
Let Me Hear Your Voice. A Family’s Triumph over Autism and A
Real Boy. How Autism Shattered Our Lives – and Made a Family
from the Pieces. However, many autobiographies by people
with autism spectrum diagnoses also follow this given script,
even though their authors make strong cases for autism as an
alternative identity rather than just a disability. Success in
adult life forms the backdrop of the autobiographical narratives
about the former disabled identities in Grandin’s, Williams’s
and Tammet’s autobiographies. Grandin’s wish to convince her
audience of autism as strength and a prerequisite for certain
abilities, for example her own ability to understand cattle, also functions as a legitimizing discourse for the neurotypical audience by underlining autistic ableness. A cynical view of Grandin, writes Murray, is that she acts fundamentally as an interpreter, a figure who is read and has become successful precisely because of her ability to allow the curious majority a window into her autism, through which they can practise their fascination with difference and muse on the nature of the human condition.\(^\text{15}\)

This raises the question of how responsive to neurotypical experience and cognition, style and language an autistic autobiography must be to gain the interest and acclaim of a broader audience.\(^\text{16}\) Moreover, the conditions for autistic life writing in a normate public sphere also call for an investigation into what is not translatable into the autobiographical genre conventions. In this article, I will discuss representations of autistic experience in relation to the powerful script of overcoming. Are there experiences or subject positions that are not tellable within this culturally expected narrative of autism? In what different ways can autistic experience be rendered comprehensible in autobiographical form? As suggested by Murray, these questions necessarily entail a consideration of Grandin, Williams and Tammet and other autistic autobiographers as writers, possibly functioning as translators or interpreters of autistic experience.\(^\text{17}\) Are narratives like these, in fact, creating a notion of the autistic self, appropriated to the neurotypical? Then how can a narrative of autistic experience written against or outside of that normativity be constructed?

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**LIFE WRITING AND ITS SUBJECTS**

Even though the concept of pathography is often used in describing life narratives about illness and disability, I would like to stress that autistic life writing differs from illness pathographies in two respects. Firstly, like disability life writing generally, it does not presuppose a search for a cure or the fight for survival or recovery, especially not when it comes to writers who themselves have been diagnosed with autism or identify as autistic. In these cases, autism or Asperger syndrome is more likely to be represented as a valuable or integrated part of the individual’s identity. Secondly, since autism spectrum diagnoses include what, from a medical perspective, are seen as impairments in communication, the conditions for writing autobiography are different from pathography in general. Illness can be a trauma in itself and thus an experience that is hard to represent. But besides the challenge of finding the language to express what it means to live with a disability, those who have another way of relating to and using verbal language also have to deal with other complications. For example, if you, like Temple Grandin, consider visual language
your primary language, life writing requires a much more radical translation of experience than it does for verbal thinkers.\textsuperscript{18} Even Paul John Eakin, who in \textit{Living Autobiographically} (2008) stresses the narrativity of identity very strongly, observes that `while we are interrogating the proposition that self-narration is the sine qua non of identity, we should pause to consider its exclusionary implications for those individuals – many autistics among others – who never master narrative in the first place'.\textsuperscript{19} Eakin thus acknowledges the normativity of the proposition, and revealingly also speaks of narrative as something to `master'. Sidonie Smith has also addressed the inherent normativity in the concept of narrative identity: `Persons diagnosed with severe autism often neither construct nor communicate accounts of their experiential histories. [...] They remain subjects for whom autobiographical narrating does not become an everyday practice.'\textsuperscript{20}

Scholars – especially feminist and postcolonial critics – in the field of auto/biography studies have long challenged the normative view of autobiographical selfhood as centred, unified and sovereign. Eakin is of course aware of this; however, he sides not with a Foucauldian underlining of the social and cultural constraints in the construction of the self but rather with the normal development of the autonomous subject as described in developmental psychology.\textsuperscript{21} The ability to create a narrative identity is not only a social and cultural expectation but is connected to children’s development of individual identity, and perhaps, Eakin suggests with reference to Antonio Damasio, even connected to biological functions. In Damasio’s view, there is a pre-linguistic narrative of consciousness, but the link Eakin makes between these `non-verbal, biological manifestations' and the expression of self in autobiographical narrative remains unclear.\textsuperscript{22}

However, Damasio’s claim that the sense of self does not require verbal language is more useful for understanding autistic selfhood than the poststructuralist view that there is no subject outside of verbal language. Moreover, the limitations of the autobiographical genre as connected to a certain kind of subjectivity might be a problem in itself for those who cannot position themselves as the male, Western, autonomous `I' traditionally claiming the leading part of the narrative. `If feminism challenges the conflation of male subjectivity with `the human', postcolonialists question the equally common, if often only implicit, historical equation of the (theoretically ungendered) western Self with `the human'.'\textsuperscript{23} Bart Moore-Gilbert writes in his introduction to postcolonial life writing. Autistic life writing challenges the notion of `the human' as well, along with autobiographical genre conventions.

There are some intrinsic conditions of autobiographical writing connected to the subject’s cognition, body and position in
society that may be difficult for autistic subjects (among others) to appropriate. On the other hand, autistic persons writing autobiographically can be said to claim their humanity by narrativizing their personal experience. Amy Shuman neatly sums up the link between storytelling and humanity:

— Sometimes, especially in the popular literature, storytelling is asserted to be a representation of either the human soul or the human brain. Just as the prehensile thumb and tool making have been used to distinguish humans from other species, so also storytelling is invoked to delineate humanity. According to this claim, humans are the only beings who can report their experiences, and storytelling is the vehicle and repository for accumulating, sorting, and making meaning out of experience.24

The autobiographical genre has often been used for political purposes, indeed to claim human rights. Several of the 52 genres of life narrative Sidonie Smith and Julia Watson distinguish in Reading Autobiography (2001) have a political stance: the slave narrative and «testimonio», for example, designating autobiographical narratives involving a certain group’s oppression and struggle.25 While the autobiographies written by persons on the autistic spectrum and printed in book form might not always be strikingly political, the life writing in blogs, Internet forums and on YouTube often is. Autism activists use digital media to represent autistic personhood and citizenship. Nancy Bagatell has expressed this as move «from cure to community» – from the medicalized view of autism as an impairing condition to be cured, to a civil rights movement, where autistic individuals demand the privilege of self-definition.

This also entails a shift from an expert discourse to a subjective discourse of autism. One of the questions Bagatell poses is how it is possible that an autistic community has emerged, given the social and communication deficits that are so strongly stressed in the medical discourse of autism. Besides the opportunities provided by the development of the Internet, Bagatell links the emergence of an autistic community to the establishment of a disability rights movement, and also to the broadening of the autism spectrum to include high-functioning autism and Asperger syndrome.26 The persons writing about autistic subjectivity are usually (but not always) persons with Asperger syndrome or high-functioning autism, while the more impaired autistic persons (especially children) are more often the subjects of autobiographical accounts by parents and siblings.

Thus, for autistic biography, there seem to be two factors standing in the way – firstly, a cognitive difference affecting language, perception and social knowledge, and secondly,
experiences that do not have the necessary »storyability« and »tellability«. These two concepts initially come from social linguistics but have also been used in narrative theory.27 Here I follow Shuman, who describes »storyability« as »what gets told in a story« and »tellability« as »who has the right to tell a story«.28 Another way to explain the concepts is to say that they signify what stories are worth telling and who can make them worth telling in a certain social context. Thus, tellability, as Shuman stresses, relies on entitlement to experiences or ownership of experiences.29

In fact, entitlement has been at the core of the discussion about representation of autistic experiences. In the article »Mark Haddon’s popularity and other curious incidents in my life as an autistic«, autism advocate Gyasi Burks-Abbott discusses entitlement in relation to fictional representations, and more specifically, Mark Haddon’s popular novel about an autistic boy, *The Curious Incident of the Dog in the Night-Time* (2003), though without using this particular concept. Burks-Abbott is critical of the impact fictional stories like Haddon’s have on the public’s understanding of autism. Haddon draws on a scientific and popular understanding of autism that is highly contested among autistic persons themselves. He uncritically subscribes to the theory of mind doctrine, depriving the autistic subject of an ability to understand how other people think and – as in *Rain Man* – provides the autistic character with an extraordinary mathematical ability that is used to add a bit of ableness to the otherwise disabled subject. Burks-Abbott remarks: »Haddon has relegated the autistic to otherworldliness while establishing a non-autistic author like himself as the necessary medium between autistic and non-autistic reality.«30

The question Burks-Abbott poses is why use a fictional account by a non-autistic person as a source for understanding autism when there are plenty of autobiographical accounts by autistic persons? It is basically the same critique as has been directed to the many autobiographies by parents of children with autism. They are of course entitled to their own experiences, but the fact is that their autobiographical narratives claim their relevance through their children’s disability. There is also a power relation present between the able adult parent and the disabled child, who may not have a chance to decline being the subject of narrative representation and may not agree with how autistic identity is represented.

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**TRANSLATING AUTISM**

For persons with autism who write about their own lives, entitlement is not contested in the same way as it is for parents and others writing about autism. Personal experience narratives are regarded as more authentic. Yet they may also be used
in an effort to ‘grant a voice’ to a group whose ideas, perspectives, or experiences have not been heard, and in that case, they too may be controversial. Shuman discusses Temple Grandin’s *Thinking in Pictures* as an example of a personal narrative that also makes claims to speak for others who have no voice. It contains plenty of general statements about autistic persons, often defending the value of autistic identity and refuting scientific truths: »People with autism are capable of forming very strong emotional bonds« or »For people with autism, rules are very important, because we concentrate intensely on how things are done.« In statements like these, Grandin leaves the position of the autobiographical narrator and enters the position of an expert or advisor. Similar to Murray, Shuman describes Grandin as an intermediary between the autistic and neurotypical cultures. She is an »anthropologist on Mars«, to use her own phrase picked up by Oliver Sacks in his book *An Anthropologist on Mars* (1995), which contains one chapter about Temple Grandin, representing one of the *Seven Paradoxical Tales* mentioned in the subtitle. For Grandin the expression signifies feeling like one is on an alien planet, trying hard to study and understand the aliens (neurotypicals).

I agree with Shuman that the role of the anthropologist suggests something more than writing one’s own personal experience narrative. It is a position that could be used to defamiliarize neurotypical behaviour from an autistic viewpoint, and to some extent Grandin uses it in this way. However, the narrative is more directed towards explaining the autistic behaviour to the neurotypical reader, who needs to learn, for example, that autistic »[i]ndividuals who scream and tantrum every time they go into a large supermarket have […] problems with sensory oversensitivity«. As a person who grew up with the impairments of classical or low-functioning autism (no speech, poor eye contact, tantrums, appearance of deafness, no interest in people, and constant staring off into space), Grandin can also claim to speak for other people with low-functioning autism, who, unlike people with Asperger syndrome or high-functioning autism, usually cannot report their experiences in written form.

Grandin’s narrating »I«, divided between the autobiographical and expert position, may not be representative of autistic autobiography generally, but as Murray points out, it has similarities with Donna Williams’s use of personal experience as a foundation for her instruction of autism, for example in the handbook *Autism. An Inside Out Approach* (1996). Daniel Tammet sticks to the autobiographical narrative and refrains from stating general »truths« about autistic identity in his autobiography *Born on a Blue Day*. But since the book’s publication, he has become »one of the world’s few well known autistic savants«, to use his own description in his following

Grandin’s, Williams’s and Tammet’s narratives bring into play the overcoming narrative, moving from the autistic nobody to the autistic savant/expert, from the subject position of the disabled and dependant to the subject position of the able and autonomous. Their translation of autism to a narrative understandable to a larger neurotypical audience provides precisely the window to the unknown required to induce fascination. Nevertheless, it is important to distinguish between what the autistic authors themselves say and do and what responses their stories elicit. It seems impossible to present a reflected, self-conscious narrative about autistic experience without being received as a strange and extraordinary phenomenon, since this narrative constitutes a clear break with what an autistic person is expected to be. Indeed, Sacks’s foreword to Temple Grandin’s *Emergence. Labeled Autistic* is a good example. It is an »extraordinary, unprecedented and, in a way, unthinkable book«, he writes, and he continues to describe autistic lives as »unimaginably different«, »bizarre« and mysterious. Notably, Tammet is very critical of Sacks’s representation of savants as »freakish and alien« and cites his account of two savant twins in *The Man Who Mistook His Wife for a Hat* (1985), where he sees them as

> a sort of grotesque Tweedledee and Tweedledum … they are undersized with disturbing proportions in head and hands, high-arched palates, high-arched feet, monotonous squeaky voices, a variety of peculiar tics and mannerisms … glasses so thick that their eyes seem distorted, giving them the appearance of absurd little professors, peering and pointing, with a misplaced, obsessed and absurd concentration … like pantomime puppets to start spontaneously on one of their ‘routines’«.

Tammet’s understated comment is that the description is »distinctly unsympathetic« and does not give an accurate picture of most people with savant syndrome. Another way of describing Sacks’s fascinated medical gaze is that it is dehumanizing, reducing persons to puppets or characters. It is also interesting that a neurologist is so concerned with physical appearance, enacting what Garland-Thomson would characterize as an exotic rhetoric of staring. The exotic rhetoric of staring constructs the object of staring as alien, sensationalized or entertaining, related to the ethnographic display of »savages«. This exoticizing gaze is also contrary to Tammet’s argument that the savant mind is not as strange, separate and
an anomalous as it is usually presented to be, but it is in keeping with how people in general think. Sacks’s statements are not written in a specialized scientific context, but represent a popular science discourse and can be regarded as two examples of a public understanding of autism. Being “unimaginably different” or “bizarre”, as he describes Grandin and her behaviours, or being an “absurd little professor” or “pantomime puppet” are of course not eligible subject positions for the autobiographical “I”. To avoid being exoticized or objectified, it is not surprising that many authors use the overcoming script. The narrative of the autobiographical “I” overcoming autism as a disabling condition, but still being autistic, means being able to explain autism, to promote a more nuanced understanding of it, and, above all, to gain agency. But the prize of gaining agency seems in this case to entail entering into the position as an almost normal subject.

**APPROPRIATING AUTISM**

As Stuart Murray has pointed out, the prevalence of the overcoming narrative in printed autobiographies can at least partly be explained by the demands of the publishing market. It’s simply easier to sell a story about succeeding despite disability to a non-disabled audience. Online narratives, in contrast, have no obligation to sell or to please the tastes of the public. Nor do they need to explain or translate autism, since the intended audience might be those who themselves identify as autistic. Murray discusses Amanda Baggs, a disability activist who has published several YouTube videos about autistic identity and ableism. She also runs the blog *ballastexistenz* where she writes about her own life experiences; the blog title echoes fascist eugenics and indicates the view of disabled people as burdens to society. In the video *In My Language*, Baggs dedicates the first part to a representation of nonverbal communication – a sensory interaction with the environment that, by neurotypical standards, does not qualify as intelligible. It consists of Baggs making humming noises, flapping, touching objects and making sounds with them – in short, behaving as a severely autistic person might be expected to. The other part of the video is a verbal translation of the first part, consisting of computer-assisted reading of a written text.

Murray’s point is that the juxtaposition of what from a normative viewpoint might be perceived as a “freak show”, as Baggs herself puts it, and the explanation/translation of it is in fact a justification of a different way of interacting with, responding to and perceiving the world. By establishing a clear difference between the performance in *In My Language* and the translation, Baggs is able to convey something more than the autistic experience adapted to neurotypical consciousness and narrative expectations. She explains her language
verbally to those who are unfamiliar with or unappreciative of it, but does not leave out her original non-verbal expression. The words can’t substitute her gestures, movements and sounds.

As an autobiographical performance, *In My Language* shares an element of translation of autistic experience with the authors of the bestselling autistic autobiographies previously mentioned. One difference, though, is that the narrative of overcoming is absent. *In My Language* is not told from the vantage point of success or overcoming disability. Baggs can’t boast any specific achievements, as can Grandin or Tammet, apart from her disability rights activism. The storyability is thus different: Baggs presents a story about personhood, rights and citizenship, which is to some extent present in many autistic autobiographies but often subordinated to the overcoming script. Although Baggs does not make claims for any specific group of people, she uses her own experience to criticize the regulation of normalcy, in this case concerning language and cognition, which renders some ways of thinking, perceiving and interacting invalid.

In doing so, Murray remarks, »Baggs knowingly extends her commentary to a more generalized idea of life with autism.« Her statement could be expressed as a demand to be seen and acknowledged without having to earn it through achievements. Personhood is also central in another of her YouTube videos, *Being an Unperson*. In this video she describes the experience of not being treated like an adult individual with equal rights, but rather like a child, pet or a non-human creature filling other people with disgust. Being an unperson thus means being dehumanized by others, »considered non-communicative« and »having your behaviour, or words if you have them, moulded to fit what other people want or expect of you«. This has not only ethical and existential consequences, but also legal ones, because »an unperson can’t tell about beatings, rape, torture, and murder«. »Being an unperson« is more like an act of testifying to oppression than a narrative of life experiences.

Both *In My Language* and *Being an Unperson* discuss what stories of personhood are tellable and what languages are accepted – and not accepted – for telling them. Baggs addresses the experience of having to tell about oneself in a way that fits other people’s expectations. Her videos seem to be deliberately performed in a way that does not fit the expectations or meet the fascination of the audience. Garland-Thomson writes that »[s]taring at disability choreographs a visual relation between a spectator and a spectacle«. In *In My Language*, Baggs takes care to block this staring by stating that the video has »not been intended as a voyeuristic freak show where you get to look at the bizarre workings of the autistic mind«. Instead, she declares that »it is meant as a strong statement of the existence and value of many different kinds of thinking and interaction«.
Her rhetoric is as much accusing as explaining, and in this she differs from Grandin, Williams and Tammet, who all describe a gradual adjustment to the world of the normal, and explore differences rather than power relations. Despite her intentions, Baggs’s reception as a non-speaking autistic making claims about personhood, cognitive abilities and civil rights has resulted in her too becoming an autism celebrity, featured in Wired Magazine and on CNN. This could indicate a more open-minded public perception of autistics, but clearly Baggs is also used to fulfilling different needs of the audience. As an example of a non-speaking autistic still able to communicate, she hopes to parents with autistic children. Despite Baggs’s intentions, there is also a tendency towards fascination, since she is presented as an exceptional case causing scientists to “reconsider what they know about autism” as it is presented in the title of the Wired article.

The impact of Baggs’s view of autism, which can be placed within the neurodiversity movement, has also led to a questioning of her entitlement to speak about autism. That she gives the impression of being a low-functioning autistic person, yet able to think and communicate abstractly or even philosophically, has raised doubts about her diagnosis and led to worries about what consequences the focus on persons like her might have for people with severe disabilities and cognitive impairments. Do they really benefit from the neurodiversity movement’s insistence that we should talk about difference rather than disability? One way of interpreting these questions is to say that they are about whose story it is. If Amanda Baggs is understood as a person expressing her own language and personhood, she is entitled to her narrative (or in this case, her performance). If, on the other hand, she makes claims about, for example, low-functioning, nonverbal autistic persons in general, her entitlement might be questioned.

Interestingly, Baggs stays close to personal experience both in her videos and in her blog posts, but when she became a focus of media interest, she was called upon to become a representative for a group, for example, answering questions about autism in general. In a blog post from 2013, Baggs writes that her intention with In My Language was misunderstood. It is not a video about autism, “it’s a video about communication and understanding and personhood that happens to be made by an autistic person.” She also claims to have tried to explain this to CNN, but “they left out that part of the interview, in favour of putting their own words in my mouth.”

When Baggs’s autobiographical representation moves from user-generated media to commercially controlled media, it is appropriated into the overcoming script. If we trust Baggs’s claim that her intention was to perform another kind of communication, directed towards the environment rather than
other subjects, the translation of this behaviour becomes the proof of a low-functioning autistic being able to overcome the inability to communicate. It is possible to see In My Language as an attempt to represent an inappropriate/d other, to use Trinh T. Min-ha's concept. »To be an inappropriate/d other«, Haraway explains, »is not to fit in the taxon, to be dislocated from the available maps specifying kinds of actors and kinds of narratives.« If autistic subjectivity has the potential to locate itself as inappropriate/d otherness, as persons not fitting into the taxonomies, not belonging to already established subjectivities or narratives, this position seems to constantly risk being appropriated by the discourse of normalization or overcoming.

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**Untelling Autism**

In The Wounded Storyteller, Arthur W. Frank distinguishes between three different kinds of illness stories: restitution, quest, and chaos narrative. While many parents' narratives about their children's autism (at least many American ones) are stories of restitution, beginning with the wish for and expectation of a healthy, normal child, realizing the child’s impairments and fighting them successfully, the two other story scripts are more common in autobiographies written by people with autism. The autobiographies of Grandin, Williams and Tammet can be characterized as quest stories. They tell the story of a subject without agency, and in some cases even without a sense of a separate self, surviving in an environment which punishes individuals who do not conform to normalcy. The motivation for telling this narrative is that – at least to some extent – it saves the subject from being objectified and allows for the promotion of a better understanding of autistic experiences. The downside of this narrative is that it is what might be called an ableist narrative of autism, requiring an overcoming of disability and often compensating for it with extraordinary gifts of mathematical or visual thinking.

This translation of autism into a discourse of ability is a publicly tellable story of autism. In contrast, Amanda Baggs’s resistance to normalizing the performance of her own language might be seen as a personal emancipatory counter-narrative. But even if it was intended as such, it was quickly appropriated as another ableist narrative of autism, by a person with her intellect intact, despite her behaviour and body signalling severe disability. That Baggs’s In My Language might be seen as an untellable story of autism is confirmed by the responses to it – a questioning of her diagnosis and thus her entitlement on the one hand (»she can’t be that autistic«), and on the other hand an appropriation of autism into normalcy (»autistic persons might seem strange but they are actually smart«). Both of these reactions function as a means to make her narrative tellable.
The third category of illness narratives distinguished by Frank is the »chaos narrative«. Joseph N. Straus claims that more recent autistic memoirs are directed towards self-discovery rather than overcoming and conversion, and are more similar to chaos stories, lacking causal order and not driven by the hope of recovery. The chaos stories, however, according to Frank, refer to instances where the subject has no distance from experience and is unable to reflect on it: »Lived chaos makes reflection and consequently storytelling, impossible.« Here Frank is voicing the same view of the relation between experience and narrative as that dominating trauma theory. People who have suffered traumatic experiences have difficulty organizing these into a coherent narrative. The memories come in repeated fragments, and there is no proceeding of events, development or even a language adequate to convey them.

An existence interrupted or disrupted by disease, disability or trauma may be conveyed narratively by an aesthetic structure that reflects the fragmentation and patching together of a broken life, or through a story which presents an enigma rather than a »remedy« or solution, the editors of *Unfitting Stories. Narrative Approaches to Disease, Disability and Trauma* state. It is unclear which »chaos narratives« of autism Straus refers to, but he clearly sees them as a narrative script offering an opportunity to resist normalizing demands for recovery or ability. The problem with this is that autobiographical narratives of autism in many cases have nothing to do with trauma. Most autistic writers would indeed resist the thought of their lives being »broken«. The untellability of trauma is different from the untellability of autism. Autistic autobiography might include trauma but is usually not primarily directed towards the narrativization and overcoming of traumatic memories (for example through scriptotherapy).

The untellability is not primarily connected to experience but to perception and language. Tammet and Grandin are not very explicit about emotions, but they put a lot of effort into the narrative of cognitive and perceptual difference. Baggs’s »narrative« is a vocal, sensory but nonverbal interaction with her environment. What she in fact is conveying is that there is a subject even without a narrative. Grandin would perhaps agree with her, experiencing the visual as preceding the verbal. It’s possible to see this as an answer to and a critique of Frank’s statement that »stories do not simply describe the self; they are the self’s medium of being«. Evidently, there are other »mediums of being« than the »story«.

Autistic autobiography can in many cases be said to contra-
dict the »proposition that self-narration is the sine qua non of identity«, to return to the quotation from Eakin at the beginning of this article. It is clear that in the reception of the autobiographical narratives by autistic persons, neurotypical readers tend to focus on what is relevant and important for them, such as ableness, autonomy, and verbal and social (including emotional) interaction. In short, these narratives are read within the paradigm of narrative identity, which constructs verbal language as a prerequisite for normal, adult humanity. The untellability of autism seems to lie in the orientation towards the sensory and perceptual engagement with the world. »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,« Amanda Baggs says in In My Language.

For all our fascinated interest in the autobiographical narratives of being an autistic subject, perhaps we should turn our attention to how these are received and interpreted in the public sphere. In this way, the wondrous, sentimental or exotic construction of disability Garland-Thomson discerns might be replaced by a critical analysis of why we need to see disability in this way. If the appropriation of autistic subjectivity into recognizable and normalizing scripts can be avoided, we might be able to develop concepts that are less excluding than that of narrative identity, or of communication and thinking as necessarily verbal. As long as disability must be compensated for by overcoming or exceptionality in order for the subject to avoid being medicalized or pitied, as long as autistic language and perception must be translated in order to be accepted as valid expressions of a self, autistic experience remains to some extent untellable.

ENDNOTES

2 Stuart Murray: Representing Autism. Culture, Narrative, Fascination (Liverpool, 2008), 45.
3 The widespread notion of autism as a medical epidemic is critically discussed in Gil Eyal et al. (eds.): The Autism Matrix. The Social Origins of the Autism Epidemic (Cambridge/Malden, 2010).
5 Murray: Representing Autism, 13.
6 G. Thomas Couser: Recovering Bodies. Illness, Disability, and Life Writing (Madison, 1997), 8.
8 G. Thomas Couser: Signifying Bodies. Disability in Contemporary Life Writing (Ann Arbor, 2009), 1.
13 Martin Weitz (producer/director): Brainman, [TV documentary] (United Kingdom, 2005).
15 Murray: Representing Autism, 39.
16 Neurotypical is a term intially used by the autism community to describe a person who is neurologically typical, that is, without neuropsychiatric conditions.
17 Murray: Representing Autism, 42.
22 Eakin: Living Autobiographically, 60–86, for quotation, see 71.
24 Amy Shuman: Other People’s Stories. Entitlement Claims and the Critique of Empathy (Urbana/Chicago, 2005), 9.


28 Shuman: Other People’s Stories, 8.

29 Shuman: Other People’s Stories, 51.


31 Shuman: Other People’s Stories, 153.

32 Grandin: Thinking in Pictures, 94, 108.

33 Grandin: Thinking in Pictures, 83.

34 Grandin: Thinking in Pictures, 33.

35 Murray: Representing Autism, 42.


38 Cited from Tammet, Embracing the Wide Skye, 25

39 Tammet: Embracing the Wide Sky, 25.


41 Murray: Representing Autism, 34.

42 »Central to a system of ableism are two elements, namely, the notion of the normative (and normal individual) and the enforcement of a divide between a so-called perfected or developed humanity (how humans are supposedly meant to be) and the aberrant, the unthinkable, the underdeveloped and therefore not really human.« (Fiona Kumari Campbell: »Stalking ableism. Using disability to expose ‘abled’ narcissisms« in Dan Goodley, Bill Hughes & Lennard Davies (eds.): Disability and Social Theory. New Development and Directions (Basingstoke, 2012), 215.


45 Murray, Representing Autism, 34.
Murray: Representing Autism, 35. Murray also discusses the various reactions to Baggs’s videos and blog posts, including those who question her condition, and thus also her entitlement to represent autism.


Garland-Thomson: »The politics of staring«, 56.


See Shuman: Other People’s Stories, 19, where she discusses untellability as involving the lack of recognition of a category – for example, date rape as a narrative untellable to those who believe that rape only occurs between strangers.

Joseph N. Straus: »Autism as culture« in Lennard J. Davis (ed.): The Disability Studies Reader (New York/Abingdon, 2010), 545.

Frank: The Wounded Storyteller, 97–98.

Valerie Raoul et al. (eds.): Unfitting Stories. Narrative Approaches to Disease, Disability and Trauma (Ontario, 2007), 28.

Smith & Watson: Reading Autobiography, 22.

Frank: The Wounded Storyteller, 53.