

Neurodiversity Studies

A New Critical Paradigm

Edited by Hanna Bertilsdotter Rosqvist,
Nick Chown and Anna Stenning

First published in 2020

ISBN: 978-0-367-33831-2 (hbk)

ISBN: 978-0-429-32229-7 (ebk)

Chapter 7

Understanding empathy through a study of autistic life writing

On the importance of neurodivergent morality

Anna Stenning

(CC BY-NC-ND 4.0)



Routledge
Taylor & Francis Group
LONDON AND NEW YORK

Understanding empathy through a study of autistic life writing

On the importance of neurodivergent morality

Anna Stenning

Introduction

The notion that autism is defined by empathy deficits (and the related ideas of an absent Theory of Mind (ToM), otherwise known as mindblindness), has been used to suggest that autistic people are not fully moral (Barnbaum, 2008). As scholars and activists have observed in connection to cognitive theories about autism in general, autistic people have been denied characteristics that are commonly considered part of what it is to be fully human, including empathy, morality, a sense of self, imagination, narrative identity, integrity; introspection, self-hood, personhood; rhetoricity, gender, meaning-making, sociality, or flourishing (McDonagh, 2013; Milton, 2012; Rodas, 2018; Yergeau, 2018). They show how, in each case, these limitations are based on foreshortened or even non-standard definitions of these qualities, to ensure that they only apply to a cultural ‘in-group’. This impoverishes the generalisability of any empirical or theoretical research that relies on it. These assertions become harder to sustain as more prominent autistics (e.g. Temple Grandin, Chris Packham, Greta Thunberg, Hannah Gadsby) enter the public arena and make valuable contributions to discussions about the nature of an ethical human life, and to what it means to be neurodivergent.

Within the academic realm, the ethical implications of human neurodivergence are far from well understood, and yet it is on this basis that funding and interventions are decided. While this may seem purely a ‘theoretical’ exercise within an academic essay, I believe that granting ethical value to neurodivergent people must happen both top down (challenging established theory and methodology) and bottom up (from experience), to have a chance to impact on society more widely. It is hoped that this chapter will be of some practical help to scholars who genuinely understand the value of including neurodivergent voices in both the methodological and ethical justifications for their work. While this kind of inclusion is often tokenistic and based on a shallow understanding of co-production or impact, much ‘ethical work’ needs to be done to question why it is happening

in such ways. Within the field of autism research, I offer the following initial exploration.

Simon Baron-Cohen is the theorist most responsible for the association of autism and empathy deficits in the popular imagination. His idea of empathy is a propensity to ‘naturally and spontaneously [tune] into someone else’s thoughts and feelings, whatever these might be’ (2003, p. 21). He believes that this is absent or impaired in autistic people. On the other hand, the literary critic Patrick McDonagh – as part of the first wave of critical autism studies within the humanities and social sciences that was willing to grant autistic voices some authority – observed that ‘many autistic people assert that they do experience empathy’ and this includes overwhelming empathy for other people and other species (2013, pp. 155–156). McDonagh considers that empathy, in Baron-Cohen’s ‘cognitive’ sense, has been taken as a necessary basis upon which economic and social transactions take place. However, he notes that despite being depicted as a quality that is essential to humanity, empathy has no single characterisation through history. He concludes, therefore, ‘empathy is an abstraction, a reification; any definition is bound to be the sum of a cluster of responses that someone (or some culture) defines *a priori* as “empathic”’ (p. 47). Indeed, as we will discuss in detail, the question of what empathy is even within autism is significantly more nuanced and complex than Baron-Cohen’s characterisation suggests. And it is interesting to note that, from McDonagh’s writing to the present, humanities scholarship has retained an interest in autistic empathy in connection to our supposed affinity with other species (see, e.g. Figueroa, 2017).

And yet within the humanities, the prevalence of deficits-based models of autism is perhaps most problematically demonstrated by Deborah R. Barnbaum’s *The Ethics of Autism: Among Them, But Not of Them* (2008). Basing her work on Baron-Cohen’s cognitive empathy deficits view of autism, Barnbaum saw autism as the limit case of full moral agency, where moral judgements are based on either automatically following rules or imitating other people’s responses without fully understanding why. Her arguments, if generalised, suggest that Greta Thunberg’s environmental activism is either a kind of parroting of genuine moral judgements made by others or that she is not autistic. While it might be unfair to attribute this anachronistic judgement to Barnbaum, Greta Thunberg has recently been accused of both kinds of ‘faking’ by contemporary critics. Thunberg has replied eloquently to these charges, as I explore below.

While this chapter focuses on autism–empathy–environmental discourses, the purported lack of autistic capacity for moral judgements contributes to the difficulty autistic people have in being believed when they report violence and abuse (see, for example, Dimensions 2019). This urgently needs to be addressed by all autism researchers, both neurodivergent and otherwise. To begin to understand and question the existing discourses on autism, empathy, and environmental experience, I offer a speed-tour of some of the psychological, philosophical, and literary contexts in which they have been addressed, at least in the West. Future work might also consider whether focusing on environmental experience is helpful or

if it plays to existing agendas where we are valued only in relation to a neurotypically defined end, such as providing expert knowledge on other species.

As discussed elsewhere in this volume, the philosophical stance of enactivism makes it unlikely that we will find a single neurological basis for autism, even if monotropism offers a helpful guide to a more universal aspect of autistic experience. If the human mind is enactive, it will depend on its social, biological cultural, and material contexts, as well as the life history of the individual. This means that is likely that only part of morality is ‘cognitive’; even cognitive psychologists, who arguably would have little to say about the non-cognitive realm of affect and emotions, have asserted that empathy has an affective component. There are intuitively (at least to this author) other ways to experience empathy – corporeal, sensual – which have yet to be investigated (da Silva 2015; Grandin & Richter 2014).

Within the field of autistic life writing, several very high-profile memoirs by autistic authors have engaged with moral issues within environmental and interspecies ethics. The idea that autistics may experience greater environmental empathy may contribute to the ‘othering’ of neurodivergent people, through the assumption that we are somehow closer to nature than those who consider themselves to be neurotypical. However, this offers fruitful ground for thinking through popular representations of autism, as more people recognise that our times call for new ways of working (that ‘business as usual’ isn’t working). This offers scope for questioning not just what we do, but who does it (even if the eventual gain is for ‘normals’ rather than all of us). For instance, the young autistic climate activist, Greta Thunberg, states in her memoir *No One is Too Small to Make a Difference* (2019) that her moral clarity is not just possible in spite of, but it’s actually due to, her autism:

I have Asperger’s, and to me, almost everything is black or white. I think in many ways that we autistic are the normal ones and the rest of the people are pretty strange. They keep saying that climate change is an existential threat and the most important issue of all. And yet they just carry on as before.

(p. 7)

In line with other discourses that build upon the idea of autistic people having exceptional (if disturbing) skills, Thunberg suggests that autism allows for a kind of moral expertise, and that this is the ability to act upon moral judgements without anticipating recognition and esteem for doing so. As we’ll see, this turns the normalising forces of ‘recognition’ that are so often portrayed as key to *non-autistic* morality, on their head. Thunberg’s message works in two ways, according to her audience. If they share with her the assumption that it is possible to be autistic and moral without requiring just one sort of morality (as I believe she suggests) we simply take her claims at face value. If we believe that there has to be only one kind of morality, she may be playfully suggesting to neurotypicals that autistic people have a better claim to being moral, since we are the ones whose behaviour is consistent with our views rather than determined by social norms.

Thunberg's claims to experience moral and epistemic clarity would find very little support from existing medical literature on autism, unless it is accompanied by a kind of rhetorical 'disciplining' that implies there is something socially dangerous about us making moral judgements without external sanction (for more on the way that dominant medical narratives seek to discipline subjects, see Couser, 1997). Like Thunberg, the comedian Hannah Gadsby has described how her autism and reflective 'ability to see patterns' means 'not [having to look] out to the world to see how I should exist' (Valentish & Gadsby, 2018, n.p.).

In line with this, and writing in the *New Yorker* back in 1994, Oliver Sacks affirmed what Uta Frith had said of autistic social 'handicaps', that they have 'a reverse side to this "something," a sort of moral or intellectual intensity or purity, so far removed from the normal as to seem noble, ridiculous, or fearful to the rest of us' (1993/1994, n.p.). The idea of autism as a social handicap perhaps allows us to see some of the ways that the medical model of disability elides its normative model of what it counts to be social.

Yet, rather than appearing ridiculous, in her campaign work in the lead-up to the UN Climate Summit in 2019, Thunberg inspired many autistic and non-autistic activists to join the environmental movement (or to pay heed to her words), and this may even be more likely as a result of her non-normative social identity. Some of this might be down to ableist assumptions regarding the assumption that autistics are 'closer' to nature or moral purity or both, but no doubt it is also due to her intersectional position as a minority youth, neurodivergent, female activist. She exemplifies the possibility of moving from the margins to the centre of global discourse.

As the mock 'Greta Thunberg Helpline for adults angry at a child' shows, she provokes an intense response – hostility, as well as fear and ridicule – especially in 'middle-aged' men (Humphries & Williams, 2019). Yet the many negative responses towards her activism confirm the sinister cultural assumptions about autism, youth, and gender, with autism figuring as the opposite of rhetorically, emotionally functioning humanity, and a subsequent fear that might easily be disguised as righteous anger. For instance, Greta has also been subject to prejudice about autism that is normally saved for autistic adults and other youth who dare to challenge the notion that they might have knowledge that is worth sharing with the world.

While responses to Thunberg's public profile may be compounded by an upsurge in hostility towards minorities in general as a result of right-wing populism, psychologists who noted what they perceive as moral purity in autistic people have failed to explain this perception with any depth. While I do not believe this is a deliberate attempt to dehumanise or scapegoat autistics by psychologists, the suggestion that autistics lack empathy contributes to the othering that amplifies such fears.

Baron-Cohen's writings about autism and absent empathy remain the most influential account, and in its most recent form presents empathy as 'the ability to identify what someone else is thinking or feeling, and to respond to their

thoughts and feelings with an appropriate emotion' (Baron-Cohen, 2011, p. 12). While this was originally theorised in connection to a postulated defective ToM in autism, Baron-Cohen now focuses on empathy in relation to purported sex differences: that autistic tendencies towards systematising are a result of our 'extreme' manifestation of the male brain (2003). For Baron-Cohen, systemising and empathising are binary opposites, which are endowed according to gender and neurotype. His recent writing that autism is an 'empathy disorder' implies – as well as other problematic assumptions about gender – both that he believes he is right about what empathy is and that autism is best understood 'from the outside', because self-reports about empathy are misguided.

However, as Sue Fletcher-Watson and Geoff Bird have noted in a recent editorial for *Autism*, 'there is no standard, agreed-upon definition of empathy used in research' (2019, p. 1). Further, 'having the capacity for empathy is often seen as the defining characteristic of being human' (ibid.). The 'use of language that dehumanises [autistic people]' might be connected to 'tragically frequent' 'violations of the human rights of autistic people in residential care services' (p. 5). Fletcher-Watson and Geoff Bird also helpfully summarise the ways in which empathy has been defined in cognitivist debates. While sharing this approach, they are careful to note that autism does not exclude empathy in the ordinary sense. What may alter the emotional response described as affective empathy is a separate condition, called alexithymia but this condition does not preclude Theory of Mind (and, by implication, cognitive empathy) (p. 4).

Fletcher-Watson and Bird suggest there are four main component stages to what is ordinarily considered empathy, rather than the two or three that Baron-Cohen has discussed. These include (A) noticing that someone is feeling something due to their behaviour; (B) correctly interpreting the feeling behind observed behaviour; (C) 'having noticed and correctly interpreted the emotional signals of another person, [the next step] is to feel those feelings – to have an affinity for, resonate with, or mirror – how that person feels' (p. 2). For Fletcher-Watson and Bird, this is what 'we most often refer to when we talk about empathy colloquially' and 'it is also the least easy to measure, potentially the most important, and the only component unique to empathy' (p. 2). Finally, (D) there is the need to decide upon and express a response, and this can lead to misunderstandings since it is possible autistic people are 'not following the same response-script as a neurotypical person' (p. 2).

Autism research can illuminate how a monotropic focus, with a subsequent, although possibly independent, inattention to social cues, and difficulty reading 'across' the autistic/non-autistic divide, may result in neurotypical underestimation of empathy in autistic people along the different stages of this process (pp. 1–2). This is supported by much of the existing autistic life writing. Fletcher-Watson and Bird even suggest that it might be helpful to 'understand the way that empathy might be felt and expressed between two autistic people' (p. 4).¹ I would add that it would be helpful to understand the way that monotropic focus might be felt and expressed between two people, rather than concentrate research exclusively in terms of autistic deviance from a hypothetical norm.

Baron-Cohen has accepted the possibility of intact affective empathy in autistics – defined variously as ‘an appropriate emotional response to another person’s emotional state’ (2003, p. 43) and ‘our emotional reactions to people’ (2011, p. xi). Yet Baron-Cohen’s ability to communicate his theory of autism with a wide audience depends on the elision of these nuances into a single term, without it being explicit that what he most often means by empathy is, in the case of autism, ‘cognitive empathy’, defined by him as ‘the ability to identify what other people are thinking or feeling’. If there is an impairment in autistic people being able to identify non-autistic mental states, this is parallel to the ways in which non-autistics try to understand autistic people, as Damian Milton and others have indicated (Milton, 2012; Chown, 2014). Further, following Fletcher-Watson and Bird, what we ordinarily mean when we talk about empathy is the ‘affinity feeling’ and this is what people are misled into believing is absent in autism if they are unaware of the wider discussion.

Like Fletcher-Watson and Bird, Baron-Cohen tells a more complex story about how empathy might be diminished in otherwise potentially empathic autistic people when other factors are present (see Baron-Cohen, 2011; Fletcher-Watson and Bird, 2019, p. 4). From this perspective, as well as the enactivist stance mentioned earlier, the idea that empathy defines neurodivergence in general seems particularly questionable.

And yet Baron Cohen and Sally Wheelwright have distinguished a further subtype of affective empathy that should be no more problematic for autistic people than anyone else. They call this sympathy – ‘where the observer’s emotional response to the distress of another leads the observer to feel a desire to take action to alleviate the other person’s suffering’ (2004). Empathy in popular discourse also suggests this ‘desire to alleviate suffering’, rather than the more specific sense of an ‘ability to identify what someone else is thinking or feeling’ (Baron-Cohen, 2011). While it may be true that autistics and non-autistics struggle to understand other neurotypes, intuitive position-taking is not required in many cases of what Baron-Cohen and Wheelwright call sympathy. It could turn out that sympathy is equally rare in all neurotypes.

The capacity to ‘tune in’ to other people as required by Baron-Cohen’s cognitive empathy, or for steps A and B in Fletcher-Watson and Bird’s pathway to empathy, might even hinder other kinds of moral behaviour. When it comes to moral concern for future generations or other species, it becomes clear that, even if we can describe ourselves as *feeling* something like this, we cannot know it. If this feeling depends on a general and non-specific ‘desire to alleviate suffering’, it might have underpinnings in the ‘overwhelming affectual empathy’ that some autistic people describe themselves as feeling, alongside a sense of powerlessness about being able to influence the social norms of the present generation.

The denigrated status of autistic people, and our supposed affinity with other species are perhaps factors that initially inspired neurotypical interest in autistic life writing. I believe that there have been, broadly speaking, three

‘generations’ of autistic life writing in English since 1980, which can loosely be described as:

- a Approximately 1987–1993: those that define or translate what autism is for a non-autistic audience, which were published after the publication of the DSM-III (the first version of the diagnostic manual to include autism in the form of Infantile Autism). These accounts are written chronologically and often build upon, and critique, existing medical representations by describing what it is to live an adult life with autism; and in doing so, lay the foundation for what is to live a good life with autism (even if they may represent the condition as precluding certain aspects of flourishing). These are mainly, if not exclusively, received as narratives of restitution (following Couser, 1997) or ‘chaos’ in Arthur Frank’s sense (1995).
- b 1994–2013: those that define a life retrospectively in the context of a later diagnosis of autism for the sake of what earlier experiences contributed to the possibilities of living an ethical life. This generation is influenced both by first-generation works and by the diagnostic criteria for autism in the DSM-IV, which includes Autistic Disorder and Asperger’s Disorder which no longer require the onset of ‘symptoms’ observable by a clinician before 30 months but require the external validation by a caregiver. Coinciding with the autism self-advocacy movement, these works are less inflected by the idea of autism as a pathology or something that precludes selfhood. Writing from the position of their adult life, authors question fundamental assumptions about the nature of autism and need to refer to other autistic people as a source of authority. These are more likely to be read as quest narratives.
- c After 2013: those that seek to intervene in the social world more widely than in cultural understandings of autism. While the DSM-5 continues to define autism in terms of childhood behaviours, these texts name autism as a key aspect of identity (shared by one or more individuals across different age groupings). While they may be received as autoethnography (see Rose, 2008), paratextual discussions of these texts may perpetuate pathological representations of the authors’ autism (see McGrath, 2017, pp. 174–176).

Temple Grandin’s *Emergence: Labelled Autistic* (with Margaret Scariano, 1986) is an example of the first generation. Dawn Prince-Hughes’s (1994) *Songs of the Gorilla Nation: My Journey Through Autism* is a helpful example of the second and Gunilla Gerland’s (1997) *A Real Person: Life on the Outside* is ambiguously located between the first and second generations, as both an intervention in broader understandings of autism and as an attempt at ‘talking back’ from the position of the author’s own lived experience/the emerging autism community. It is within this third generation that I locate Greta Thunberg’s manifesto/memoir. One of the unique aspects of her work is Thunberg’s insight into how the social context of common assumptions about autistics and adolescents will inform her reader’s responses to her work.

The general movement in these texts away from medical models of autism, and towards a more socially situated understanding of autism, has happened since autistic life writing was able to reach a wide audience in the 1990s. And yet, each text exceeds this simple classification as it works to construct the narrator who is both recognisably ‘a person’ and an expert on autism in their own right, in one way or another. While the contradictions and issues involved in this are beyond the scope of this chapter, the emerging autistic discourses about personhood involve discussions of moral agency that are relevant. It is worth a brief digression into the context in which the texts were received to enable a broader discussion about some of the themes raised.

A brief history of responses to autistic life writing

Early autistic memoirists were criticised in terms of the authenticity of their representations on the basis of their supposed inability to introspect or communicate with an imagined audience (see Sacks, 1993/1994), or if they were granted the ability to introspect and describe authentic experiences, they lacked sufficient ToM to select the sorts of incidents their audience would want to hear about (see Happé, 1991). One prominent idea within literary criticism was that these memoirs could tell us about limits of narrativity and subjectivity, based on assumed medical deficits’ in meta-representation and ToM (Jurecic, 2006; Smith, 1996; Zunshine, 2003). Others saw cases like Grandin’s as evidence of triumph over a condition that made such writing impossible, or as an exceptional rarity.

Oliver Sacks – a neurologist and writer of a memoir about his own recovery from a mysterious illness – subsequently raised the profile of several autistic life writers, including Grandin, in his essay ‘An anthropologist on Mars’ (1993/1994). He challenged both humanists and psychologists to reconsider the social and communicative potential development of autistics. Bearing in mind that autism was, at this time, only diagnosed according to supposed developmental differences observed during the first 30 months of a child’s life, he lent his professional credibility to the idea that nonverbal infant autism might become highly articulate adult autism. What lay in between remained *terra incognita*.

Second-generation memoirs by autistic writers, which were published after the advent of the DSM-IV in 1994, endorsed a much broader characterisation of autism and Asperger’s. Because they no longer required such an early onset of symptoms, these works unsurprisingly present much broader representations of lives and experiences under the label ‘autism’. At the same time, the autism self-advocacy and neurodiversity movements were gaining momentum as a result of the work of autistic individuals who understood, and powerfully articulated, how autistic differences in communication and sensory profiles did not preclude *relating* to others as a human being (Sinclair, 1993). The Autism Self-Advocacy Network lent support to first-person accounts of autism through its mantra ‘Nothing about us without us’. Self-advocacy and the idea

of neurodiversity as a naturally occurring difference supported recognition of autistic moral agency.

Autistic life writing in both print and online forms has experienced huge growth in the past two decades. Many recent works, such as Chris Packham's *Fingers in the Sparkle Jar* (2017) and Greta Thunberg's *No One Is Too Small to Make a Difference* (2019), include descriptions of their authors' ethical beliefs in the widest sense. And yet within literary and rhetorical studies the idea that autistics lack a narrative capacity persists (as Yergeau, 2013, explains). Packham and Thunberg demonstrate that whatever autism is, it is not *defined* by an absence of moral sentiment or narrative and rhetorical skills.

While the neurodiversity movement continues to challenge stigma about autism and other neurodevelopmental conditions, Baron-Cohen continues to describe autism as an 'empathy disorder'. Originally basing his claims about autism and empathy on supposed ToM deficits, from 2003, Baron-Cohen persuaded readers of *The Essential Difference* that autism was an extreme manifestation of a binary 'cognitive' opposition between men and women, with the male and autistic brain capable of systematising only at the expense of the ability to empathise (2003). Inspired by this and debates about the ethics of finding a cure or diagnostic test for autism, Deborah Barnbaum subsequently published *The Ethics of Autism* in 2008. Barnbaum extended Baron-Cohen's argument about empathy deficits to conclude that autistic people are only able to count as moral agents based on rule-following rather than as a result of acting from a (more important) moral feeling or perception. She implied that this afforded some value to autistic lives, but placed fewer obligations on conventional moral agents than the harm that would arise from disregarding autistic subjects from the moral realm. This is because people 'compromise their own moral standing, their own claim to membership in the moral community, when they disqualify others' (p. 102). Once again, autistic morality is represented as 'other' and less important than neurotypical ethical behaviour, and the subjectivity that informs this isn't called into question. Barnbaum's methodological preference for a single moral theory, and unverified supposition of an undeniable non-autistic moral capacity, are called into question below.

While the first generation of autistic life writing written before 1993 broke new ground by positioning autistic writers as authorities on autistic experience once they had 'overcome' the condition through the efforts of others and become 'a person', these texts did not directly address empathy. However, Dawn Prince-Hughes's 2004 memoir *Songs of the Gorilla Nation* described the author's affective empathy and compassion for other species (which built, in some ways, on Grandin's interest in farm animals). This provided the authority that allowed her own claims to be both a moral agent with full personhood, and therefore able to make assertions about her autism. Due to prevailing stereotypes about autism, Prince-Hughes's narrative could still be read as one of 'overcoming' autism.

In her 1996 memoir *A Real Person*, Gunilla Gerland described her desire to lead an ethical life despite being (in her view) both disabled by her autism and by her family circumstances. While Gerland did not seem to consider that autism

is compatible with moral behaviour – in fact, her memoir represents a quest to overcome autism for the sake of having the sort of human relationships that are conventionally seen as normal and therefore moral – she also demonstrated how non-autistics fail to achieve meaningful inter-personal relationships.

While first-generation critical autism studies have focused on these ‘from the inside’ accounts and tried to translate them into recognisable experiences for neurotypical audiences (Davidson & Smith, 2009; Solomon, 2010 and 2015), there has been limited attention paid to descriptions of ethical sentiments in autistic life writing, let alone willingness to assume that they might tell us anything worth knowing about individual lives. Those who are exploring ‘autistic’ forms of rhetoric and language helpfully identified how first-generation writers such as Grandin and Prince-Hughes are subject to the pressure to translate their writing into work that meets the expectations of non-autistic readers, for instance in the use of language and in the requirement for disclosure (see Rodas, 2018, pp. 21–23; Murray, 2008, p. 33). These texts employed, to various extents, recognised ‘discourse conventions’ (Yergeau, 2018, p. 21), and succumbed to ‘market demands’ since they were ‘[g]rounded in the heroic tradition of the *Bildungsroman*, or the traditional overcoming narrative, confession or apologia’ (Rodas, 2018, p. 21). Yet to focus on this exclusively fails to do justice to the ways in which *any writer* is confined by their knowledge of existing literary conventions. The life narratives of Prince-Hughes, Gerland, and Thunberg may indeed be read as *autistic testimonio*, since, as Irene Rose has observed, they offer a ‘recounting of group oppression’ and demand ‘an active reader response’ (Rose, 2008, p. 48). As a manifesto for an audience that is assumed to share the same response, Thunberg’s work may be read as both autistic and youth-environmentalist *testimonio*, and as an attempt to name autistic moral agency outside of the *Bildungsroman* tradition.

Empathy across neurotype and species

As noted above, *Songs of the Gorilla Nation* (2004) is Dawn Prince-Hughes’s memoir of her early life and her adults diagnosis of Asperger’s at a time when she also discovers her vocation (and as such is a *Bildungsroman*); but it is also a work that situates her autism as both ‘like and unlike’ other people’s autism, and she refers readers to works by Grandin and David Miedzianik (Rose, 2008, p. 48). Gunilla Gerland, in *A Real Person: Life on the Outside* (1997), is similarly concerned with her own spiritual growth, but she also challenges conventional ideas about autism in Sweden at the time of writing. Greta Thunberg’s memoir/manifesto *No One Is Too Small to Make a Difference*, a generation later, witnesses the author’s struggles to gain recognition as a moral agent in the context of both her autism and the climate crisis, and her work arguably speaks to anyone who is struggling to influence anthropocentric behaviour, regardless of neurotype.

Prince-Hughes’s narrative encompasses her turbulent childhood and adolescence. She described her own social struggles, her affinities with the natural environment and early experiences of her sexuality. The ‘coming of age’ aspect of her

account did not involve normalisation or overcoming any of her ‘queer’ tendencies, but she linked her own traumatic experiences to oppression faced by others. However, her authority as a witness to events may be constructed either on the basis of later expertise as a scientist or in relation to her role as an autoethnographer creating a ‘collective record’ of the ways autistic voices have been oppressed (Rose, 2008, p. 47).

Like all the authors considered here, Prince-Hughes described her lifelong desire for moral purpose, for meaning defined as connection with human others, and for ‘companionship that validates one’s experiences from afar’ (Prince-Hughes, 1994, p. 33). While understanding that both these latter were at odds with popular understandings of autism at the time (which were based on ToM deficiencies), she urged an understanding of ‘direct sources of experience’ of autism, since this helps to overcome over-generalisations based on ‘known patterns of autism’ (p. 7) and a limited number of examples.

Prince-Hughes’s narrative climax centres on her reconfigured understanding of the social world. After a period in which she began to observe a family of gorillas at a Seattle zoo, she started to see her own life differently. As a result of her supposed social difference, she began to compare herself to both the captive gorillas and humans ‘who are not bright on the stage of common action’ (p. 4). She found in the literal glass that separated the observers from the gorillas a symbol for the boundary between the neurotypical gaze on the human or animal other. While earlier authors had described themselves as other, Prince-Hughes posited her own, and the gorillas’, difference as produced by the mechanisms that were designed to facilitate their interaction – the zoo. And like the glass barrier that separated the gorillas from their human observers, the gaze can be both metaphorically and literally interrupted or broken.

Prince-Hughes described her interactions with a male gorilla called Congo. She retrospectively narrates the experience of feeding him strawberries as the first time ‘she connected to a living person’ as she ‘never had before’. Laying fruit at the edge of the enclosure, between the bars and the glass, Prince-Hughes is ‘compelled to put the berries in the same repeating order’, which results in Congo and Prince-Hughes putting their ‘fingers down at the same time’. Congo’s

gigantic finger, black and leathery, soft and warm, rested on my own digit. We stared at our fingers, neither of us moved. Finally, I looked up into his soft brown eyes. They were dancing with surprise.

(p. 6)

The significance of this encounter, for Prince-Hughes, is that she finds a reflection of her own urges for repetition and ritual and a sense of ‘what it is to not be alone’ (p. 6). She imaginatively placed herself in the position of Congo and attempted to reverse the direction of the gaze. Reflecting on the ritualistic aspects of such play in the gorillas, Prince-Hughes noted that it may have another function in both humans and gorillas:

I began to understand ritual and its power a bit more. I had the advantage of watching my gorilla family in ritual activity, sometimes as a reaction to their confinement but often born of a spiritual, an aesthetic, even an educational need. At this time, I learned the value and beauty of ritual.

(p. 19)

While admitting that the gorillas' repetitive behaviours may be a response to the restrictive conditions of the zoo, Prince-Hughes suggested that rituals, repetitions, or 'perseverances' for autistic people, may provide sources of pleasure. Through this and other examples of her own sense of affinity with – and other people's dis-affinity with – the gorillas, Prince-Hughes is motivated to pursue a career in gorilla conservation. While Temple Grandin described herself as an anthropologist on Mars, Prince-Hughes presented herself as a xenobiologist presenting the 'normal human' as other.

Morally ambivalent empathy: the pain caused by assumed cognitive empathy

Gunilla Gerland described her early life, prior to diagnosis, in her 1997 memoir, *A Real Person*. While unhappy with the 'high functioning' classification of her autism diagnosis, since it 'sounded like something you might say about an object that was slightly defective' (1997, p. 239), it allowed her to think of her difference having a biological basis rather than a moral origin, and it allowed her to understand herself as a 'real person' rather than one who was deliberately difficult, defective, or lazy (p. 238). While she generally reiterated a pathological view of autism as a handicap, she did not seem to think that this prevented her from being morally concerned for other people (particularly her sister, Kerstin).

Gerland's spiritual journey was, like Prince-Hughes's and Grandin's, one that depended on 'overcoming' of social limitations. However, like Prince-Hughes and Hannah Gadsby, she did not consider herself to need social recognition to authorise her own version of events or to form judgements about others, even as a child. Although Gerland's childhood and adolescence were marked by both emotional and physical abuse at the hands of her father, and later by her mother's alcohol and drug use, her memoir was chosen by both Barnbaum and Baron-Cohen as an example of autistic empathic failings. Discussing the possibility of autistic ethics based on rule-following in 2009, Baron-Cohen, who presumably had not read Gerland's memoir, repeated Deborah Barnbaum's comments about Gerland in *The Ethics of Autism: Among Us, But Not of Us*.

Gunilla Gerland, who has autism and describes how she was unperturbed by the death of her father, comparing his loss to a bowl of fruit that was on the table one day and gone the next.

(Baron-Cohen, 2008)

While he concludes that removing autistic people from the ‘moral community’ would be immoral, Baron-Cohen considers Gerland’s writing an example of the solipsism that precludes the ‘visceral’ response that ordinarily produces moral action. However, the suggestion that Gerland’s father had died is a misunderstanding: he had simply moved out. Gerland’s responses throughout *A Real Person* are extremely visceral, and this is why it stands out as an exceptional piece of writing. Like Barnbaum, he omitted from mentioning that Gerland was only an infant at the time and that her father had also been abusive (Gerland, 1997, pp. 42–43).

While Barnbaum refers to the fact that Gerland’s father had only moved out and had not died, she does not connect this to Gerland’s early difficulties making predictions about the future, nor does she mention Gerland’s early concern for her sister’s wellbeing. This suggests that Barnbaum had read *A Real Person* with the intention of finding instances of empathic deficiencies in accordance with her earlier reading of Baron-Cohen. Barnbaum’s account exemplifies the self-fulfilling prophecy of the neurotypical gaze on an autistic subject.

Gerland became an autism advocate after publishing this memoir, working to educate professionals on how to engage more compassionately with verbal and non-verbal autistic people. She also became one of the pioneers of autistic participation in research on autism (see, e.g. Gerland, 1997). As her work, like Grandin’s, came with recommendations from the prominent clinical psychologist, Christopher Gillberg, we may assume that the neurotypical gaze may have shaped the kinds of stories Gerland told about both her own and collective autism. And yet, neurotypical intervention may have provided an opportunity for Gerland’s individual self-, and self–other-, reflection. Gerland contrasted her own biological understanding of her autism with what was then the conventional psychoanalytical view that autism resulted from deficient parenting – in fact, she turned this view on its head. She stated that her autism helped her avoid becoming too ‘neurotic’ as a result of that same bad parenting (1997, p. 250). The resulting story is indeed one of triumph over the adverse conditions of a ‘biological handicap’ and a ‘dysfunctional family’ (p. 250). Yet in Gerland’s description, neither handicap nor dysfunctional family preclude her from having experiences which, according to Fletcher-Watson and Bird, are what is ordinarily meant when we talk about empathy.

Talking back: autism as moral motivation

While Gerland and Prince-Hughes describe their moral feelings, Greta Thunberg’s manifesto *No One Is Too Small to Make a Difference* requires us to take the possibility of her ability to make moral judgements as a given, so we are then able to critique the mere suggestion that autism can be defined as lack or deficiency. While Gerland and Prince-Hughes talk back to standard depictions of autistic empathy deficits and cast cognitive empathy as either problematic or unnecessary, Greta Thunberg (playfully) suggests that to lack cognitive empathy may actually, in some cases be a moral virtue. Gerland’s (presumably neurotypical) mother is

represented as lacking enough empathy to know that her daughter hates birthday parties (1997, p. 41). Prince-Hughes emphasises her own affective empathy for those whose mental states she cannot fully access, including those belonging to other species. Each author tells us something different about the impossibility of identifying any individual ‘faculty’ that will produce morally optimal outcomes in all cases. The possibility of autistic concern for other species offers a chance to ‘reverse’ the assumption that cognitive empathy is essential to moral behaviour, and to turn the gaze towards what might be missing in ‘neurotypical’ morality. Thunberg confronts us with the possibility that an unnamed group of cognitive others – future humans – depend on those who are motivated to act without typical social recognition, because they have had to find other ways to exist in a world that sees them as having less value.

Yet her demand for radical changes to society to prevent climate change has been met with criticism that echoes the denial of autistic empathy on the basis that it does not conform to neurotypical empathy. Andrew Bolt, who is a broadcaster on Australia’s Sky News, linked her claims to an alleged underlying pathology:

She suffered years of depression and anxiety attacks and was finally diagnosed with Asperger’s syndrome, high-functioning autism, and Obsessive-Compulsive Disorder. Her intense fear of the climate is not surprising from someone with disorders which intensify fears.

(Bolt, 2019)

If Bolt had taken the trouble to register what Thunberg had actually said about her autism, he’d need to respond differently. She states that it was not anxiety or compulsions that drove her actions to raise awareness about the threat of climate change, but her autism itself. In *No One Is Too Small to Make A Difference*, she says of her autism:

Some people mock me for my diagnosis. But Asperger is not a disease, it is a gift. People also say that since I have Asperger I couldn’t possibly put myself in this position. But that’s exactly why I did this. Because if I would have been ‘normal’ and social I would have organized myself in an organization or started an organization by myself [...]. But since I am not that good at socializing I did this instead. I was so frustrated that nothing was being done about the climate crisis, and I felt like I had to do something, anything.

(2019, p. 30)

Thunberg, here, casts standard rhetoric about autism defined by social deficits on its head. She implies that if she had placed a greater value on conformity with her peers – if she had a tendency to pick up on social cues or found herself ‘naturally and spontaneously tuning into someone else’s thoughts and feelings, whatever these might be’ (p. 21) – she would have found another (and possibly less effective) way to campaign to reduce global carbon emissions. Perhaps being relatively

more tuned in to those who share similar assumptions, or relatively more tuned in to the environment, through a monotropic focus, might have helped her get the message across.

However, I also believe Thunberg is also here knowingly performing, and thus parodying, the idea of autistic moral ‘purity’ that Frith (2014) describes: the work, as a whole, resists the idea that the narrator is superior to her assumed audience. Rather than saying that her autism limits her or gives her superpowers, she suggests that it has simply become a condition that has produced this particular outcome. And in this way Thunberg gestures towards a new understanding of autism – as simply difficulties that occur in some situations, rather than as a condition defined by moral limitations. Unlike Grandin or Prince-Hughes, her authority does not depend on any assumed ability to ‘speak for nature’, but it perhaps depends on the emergence of the voice of autistic adolescence – one that had been assumed not to exist.

The idea that autistic people are unable to make moral judgements, or are only able to blindly follow rules, speaks mainly to a normative urge to find a single story about what makes a good life. Meanwhile, the same story deprives us of the essential agency that is necessary for us – and possibly all of humanity – to flourish. The story of autism as defined by empathy deficits also plays to totalitarian conceptions of the good, since the world in which we live is dependent on multiple visions of what is right. Since even when recognised, autistic moral agency risks being co-opted into utilitarian enframings, it needs to be rearticulated.

In fact, to cast any neurotype as inherently pathological or valuable creates a situation in which groups who are perceived to share that trait are at risk of being sacrificed for the greater good. When we seek to locate a single feature such as empathy as a unique sign of our supposed individual worth, we are also at risk, not of debasing ourselves, but of not recognising our ongoing need to refine our own judgements according to the new circumstances in which we find ourselves.

This work was supported by the Wellcome Trust [218124/Z/19/Z]

Acknowledgements: with thanks to Nick Chown, Hanna Bertilsdotter Rosqvist, Robert Chapman, and David Perkins for their invaluable suggestions on this chapter.

Note

- 1 However, it seems to me that there may be a contradiction between the idea that empathy is misunderstood and the quest to address the ‘paucity of cognitive models of empathy’ (Fletcher-Watson & Bird, p. 4) given that empathy is in their own definition *affectual* as well as cognitive.

References

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC. American Psychiatric Association.

- Barnbaum, Deborah (2008). *'Among us, but not of us': The ethics of autism*. Bloomington, IN: Indiana University Press.
- Baron-Cohen, Simon (2003). *The essential difference: Men, women and the extreme male brain*. London: Allen Lane.
- Baron-Cohen, S. (2009). Does autism need a cure? *The Lancet*, 373(9675), 1595–1596.
- Baron-Cohen, Simon (2011). *Zero Degrees of Empathy*. London: Penguin.
- Baron-Cohen, Simon, & Sally Wheelwright (2004). The empathy quotient: An investigation of adults with Asperger syndrome or high functioning autism, and normal sex differences. *Journal of Autism and Developmental Disorders*, 34:163–175.
- Bolt, A. (2019). The disturbing secret to the cult of Greta Thunberg. *Herald Sun*, 1 August.
- Chown, N. (2014). More on the ontological status of autism and double empathy. *Disability and Society*, 29(10): 1672–1676.
- Couser, G. Thomas. (1997). *Recovering bodies: Illness, disability, and life writing*. Madison, WI: University of Wisconsin Press.
- da Silva, A. A. (2015). Researching empathy through staged performance. (Unpublished dissertation). Design School Kolding.
- Davidson, J., & Smith, M. (2009). Autistic autobiographies and more-than-human emotional geographies. *Environment and Planning D: Society and Space*, 27(5), 898–916.
- Dimensions (2019). Why don't people understand? Online at www.dimensions-uk.org/get-involved/campaigns/say-no-autism-learning-disability-hate-crime-imwithsam/know-more/dont-people-understand/ (accessed 24 January 2020).
- Figueroa, Robert Melchior Figueroa (2017). Autism and environmental identity: Environmental justice and the chains of empathy. In Sarah Jaquette Ray & Ray Sibara (Eds.), *Disability studies and the environmental humanities*. Lincoln, NE: University of Nebraska Press.
- Fletcher-Watson, S., & Bird, G. (2019). Autism and empathy: What are the real links? *Autism*, 24(1).
- Frank, Arthur (1995). *The wounded storyteller*. Chicago, IL: The University of Chicago Press.
- Frith, Uta (2014). Autism: Are we any closer to explaining the enigma? *The Psychologist*, 27(10):744–745.
- Gerland, Gunilla (1997). *A real person: Life on the outside* (translated by Joan Tate). London: Souvenir Press.
- Grandin, Temple & Margaret Scariano (1986). *Emergence: Labelled autistic*. Ann Arbor, MI: Ann Arbor Publishers.
- Grandin, Temple & Richter, Ruthann (2014). 5 Questions: Temple Grandin discusses autism, animal communication. Online at <https://med.stanford.edu/news/all-news/2014/11/5-questions-temple-grandin-discusses-autism-animal-communicati.html> (accessed 24 January 2020).
- Happé, Francesca (1991). Autism and Asperger syndrome: The autobiographical writings of three Asperger syndrome adults: problems of interpretation and implications for theory. In Uta Frith (ed.), *Autism and Asperger Syndrome* (pp. 207–242). Cambridge: Cambridge University Press.
- Humphries, Mark & Evan Williams (2019). Mark Humphries presents the Greta Thunberg helpline. www.abc.net.au/7.30/mark-humphries-presents-the-greta-thunberg-helpline/11561522 (accessed 14 November 2019).
- Jurecic, Ann (2006). Mindblindness: Autism, writing, and the problem of empathy. *Literature and Medicine*, 25(1), 1–23.

- McDonagh, Patrick (2013). Autism in an age of empathy: a cautionary critique. In Joyce Davidson and Michael Orsini (Eds.), *Worlds of autism: Across the spectrum of neurological difference*. Minneapolis, MI: University of Minnesota Press.
- McGrath, James (2017). *Naming adult autism*. London: Rowman & Littlefield.
- Milton, D. E. (2012). On the ontological status of autism: The 'double empathy problem'. *Disability & Society*, 27(6):883–887.
- Murray, Simon (2008). *Representing autism: Culture, nature, fascination*. Liverpool: Liverpool University Press.
- Packham, Chris (2017). *Fingers in the sparkle jar*, London: Ebury Press.
- Prince-Hughes, Dawn (1994). *Songs of the gorilla nation: My journey through autism*. New York: Harmony.
- Rodas, Julia Miele (2018). *Autistic disturbances: Theorizing autism poetics from the DSM to Robinson Crusoe*. Ann Arbor, MI: University of Michigan Press.
- Rose, Irene (2008). Autistic autobiography or autistic life narrative? *Journal of Literary Disability*, 2(1), 44–54.
- Sacks, Oliver (1993–1994). An anthropologist on Mars. *The New Yorker*, 27 December 1993 and 3 January 1994. www.newyorker.com/magazine/1993/12/27/anthropologist-mars (accessed 13 September 2019).
- Sinclair, J. (1993). Don't mourn for us. *Our Voice*, 1(3). URL: (Retrieved December 2019) www.autreat.com/dont_mourn.html
- Smith, Sidonie (1996). Taking it to the limit one more time. In Sidonie Smith & Julia Watson (Eds.), *Getting a life: Everyday uses of autobiography*. Minneapolis, MI: University of Minnesota Press.
- Solomon, O. (2010). What a dog can do: Children with autism and therapy dogs in social interaction. *Ethos*, 38(1), 143–166.
- Solomon, O. (2015). 'But-he'll fall!': Children with autism, interspecies intersubjectivity, and the problem of 'being social'. *Culture, Medicine and Psychiatry*, 39(2), 323–344. doi: 10.1007/s11013-015-9446-7.
- Thunberg, Greta (2019). *No One is Too Small to Make a Difference*. London: Penguin.
- Valentish, Jenny & Hannah Gadsby (2018). 'I broke the contract': how Hannah Gadsby's trauma transformed comedy. *Guardian*, 16 July 2018.
- Yergeau, Melanie (2013). 'Clinically significant disturbance: On theorists who theorize theory of mind. *Disability Studies Quarterly*, 33(4). <http://dsq-sds.org/article/view/3876/3405> (accessed 26 September 2019).
- Yergeau, Melanie (2018). *Authoring autism: On rhetoric and neurological queerness*. Durham, NC: Duke University Press.
- Zunshine, Lisa (2003). Theory of mind and experimental representations of fictional consciousness. *Narrative*, 11(3): 270–91.