Autism

BEN BELEK The Hebrew University of Jerusalem

The concept of autism is historically contingent. It did not exist, in any proper sense, before it was invoked by medical and mental health professionals in the twentieth century. This entry aims to shed light on this relatively recent concept. First, it contextualises autism within the broader social, epistemological, and political circumstances of its emergence and ongoing negotiation, showing autism to be a dynamic concept, whose meaning is constantly in flux. Second, it revisits some of the more insightful or influential analyses that autism has received over the years in anthropology and adjacent disciplines. And third, it illustrates that anthropologists have been particularly attuned to everyday experiences of autism, comparing it to other forms of human difference while occupying an ambivalent stance towards biomedical approaches to it. A discussion on how autism might matter for the discipline of anthropology features very briefly in the conclusion.

Disciplinary landscapes

Research into autism tends to cluster around two main analytic poles (see Solomon 2010). The epistemic gap between these analytic poles is considerable, and is sometimes discussed as a barrier to the advantageous progression of autism research at large (e.g. Orsini & Smith 2010, Raz et al. 2017, Yergeau 2010). On one end of the spectrum of autism research are the biomedical disciplines, which typically construe the condition as a neurodevelopmental disorder, and focus on those aspects of autism which they perceive as cognitive and social deficits. Research in these areas tends to address questions relating to the causality of autism, its underlying mechanisms, its symptoms, and its prevalence. Consequently, it promotes interventions of different kinds, working towards the development of better standardised diagnostic procedures for autism, technologies for early detection, methods of behaviour therapy, and in some instances, pharmacological treatment.

On the other analytic pole, there are those disciplines which include anthropology, sociology, history, rhetoric, geography, communication, gender studies, and disability studies. Scholars working in this tradition tend to view autism as a socio-political category, and a central component of individual experience and of social interaction. Studies produced within these disciplines thus focus on such spheres as language and sociality, identity and subjectivity, care work and expertise, knowledge-making and meaning-making, while others go about challenging literature in the biomedically-inclined disciplines. Moreover, within this analytic pole, autism self-advocacy occupies a crucial position, whereby autistic authors employ their
experiential expertise, as well as social and literary theory and an oftentimes keen sense of social and cultural critique, to produce valuable scholarship.

The anthropological study of autism can be grounded in the broader field of the anthropology of disability (see Devlieger 2018 for a review). The anthropology of disability has been slow to include cognitive disabilities within its purview (with the notable exception of Edgerton 1967). This may be the case because attempting to theorise cognitive difference anthropologically requires challenging one of the discipline's rarely disputed assumptions: that human beings all share similar cognitive capacities (Mc Kearney & Zoanni 2018). Nevertheless, a body of literature has emerged over the past decades that focuses on such topics as dementia, intellectual disability, and mental illness, thereby accepting the challenge of envisioning collective life without assuming psychic unity. Anthropological studies of autism, in particular, can be said to constitute a cornerstone in this emerging anthropology of cognitive disability (Mc Kearney & Zoanni 2018). They have also contributed to broader conversations in such subfields as psychological anthropology (e.g. Mattingly 2017), medical anthropology (e.g. Kaufman 2010), linguistic anthropology (e.g. Ochs & Solomon 2008), as well as social and cultural anthropology more broadly (e.g. Grinker 2007).

In what follows, anthropological insights on autism will be joined with important insights from other disciplines. While anthropological engagements with autism are not necessarily unique in their underlying assumptions or styles of argumentation, they do share some distinct analytical and epistemological commitments. First among those is a systematic engagement with the narratives, experiences, and everyday actions of autistic people, as well as with the distinct social worlds they inhabit. Anthropology's insistence on ethnography carves an important analytical space that acknowledges the role of agency, controversy, and creativity in the category's enactment and negotiation. Also typical in the anthropology of autism are frequent reflections over the type of difference that the category of autism represents, and its comparability to other forms of difference – mainly, culture – with which the discipline has traditionally engaged. Thirdly, anthropologists working on autism have usually remained ambivalent towards the claims of the biomedical disciplines. Their general reluctance to either wholly reject these disciplines' expertise or to uncritically accept it has afforded anthropologists a privileged position from which to attend to the epistemological dynamics surrounding autism.

The emergence of autism

The shifting meanings of autism – as a concept with which to make sense of certain atypical tendencies, a label with which to characterise those who hold such tendencies, and a category into which those so labelled are typically classified – derive from the historical processes of its emergence and subsequent negotiations. The history of autism therefore illustrates its fluid and dynamic nature and highlights the centrality of socio-cultural processes to the category's emergence.
Though a detailed social-historical account of autism remains outside the scope of this entry (but see Evans 2017, Eyal et al. 2010, Feinstein 2010, Nadesan 2005, Silberman 2015, Silverman 2012, Waltz 2013), a brief outline seems warranted. The concept of ‘autism’ had made its first appearance in medical literature in 1911 in the work of the Swiss psychiatrist Eugen Bleuler, when it was construed as a symptom of childhood schizophrenia. The concept had mostly retained this meaning until 1943, when the Austrian-born American psychiatrist Leo Kanner published his article ‘Autistic disturbances of affective contact’. This was the very first publication in which autism (then ‘infantile autism’) was described as a distinct disorder, preceding by a single year a publication by Hans Asperger, a German psychiatrist, in which he described a quite similar condition which he termed ‘autistic psychopathy’.

In the 1960s and 1970s, studies into the ‘new’ syndrome were becoming increasingly common, yet there was still much confusion. Many researchers and clinicians still interpreted it as a type of schizophrenia, while diagnosticians often associated autistic traits with brain dysfunction, mental retardation, or child psychosis. The 1980s saw an increase in systematic research into autism, as researchers began to demonstrate a clear biological factor to the condition, refuting previous assertions about its supposed psychogenesis. By the 1990s, more rigorous evaluation criteria were being devised, and it became increasingly recognised that autism may be a life-long condition. Subsequently, the condition re-emerged as a neurological developmental disorder - the framing that governs much of the academic discourse today.

An often-told fact about autism is the steep rise of its prevalence rates over the past three decades. It is this rise which has helped fuel false claims about the cause of the condition, including those concerning an alleged link between autism and vaccines (for critical accounts of such claims see Kaufman 2010, Offit 2008, Orsini & Smith 2010, Sobo 2015). Gil Eyal et al. (2010), however, convincingly attribute this rise to the widening of the diagnostic criteria for autism, as well as to improved access to diagnostic services. The authors provide a focused review of the entries for autism in the Diagnostic and statistical manual of mental disorders (DSM), published by the American Psychiatric Association, demonstrating that its diagnostic criteria were becoming more inclusive with every new edition (see also Eyal 2013). It is through these broadening criteria that autism was increasingly being stretched into a ‘spectrum’, an idea originally coined by Lorna Wing & Judith Gould (1979) that has since become almost synonymous with the condition itself.

**Autism’s ontological status**

Currently, the term ‘autism spectrum conditions’ has indeed come to represent a broad range of cognitive and behavioural atypicalities. Though it is generally accepted that the traits associated with the category of autism are shaped by genetic factors (e.g. Geschwind 2009), a focus on biological processes is fundamentally unsatisfactory in fully accounting for the phenomenon. The understanding, representation,
and framing of autism significantly depend on variations in any society’s hegemonic values, conceptions of normality, dominant norms of social interaction, and organising structures of knowledge and classification. Autism, therefore, is an emergent product of interrelated social as well as biological processes (e.g. Eyal et al. 2010, Grinker 2007, Nadesan 2005, Silverman 2012).

A popular way of making sense of the interplay between the natural and the socially constructed nature of autism is Ian Hacking’s (1999) ‘looping effect’. Hacking conceives of people as ‘interactive kinds’ in the sense that they react to the categories, concepts or ideas which relate to them, and change as a result. Consequently, these categories and concepts need to be adjusted to these changes, in a continuous circle. Elsewhere, Hacking (2009a) has demonstrated a mechanism through which autism is thusly constantly reconstituted. This occurs as autobiographies by autistic authors affect the ways their autistic readers come to understand their own experiences as autistic. Eyal et al. (2014) further acknowledge that the looping effect of autism goes beyond shaping its meaning formalistically through classification and description. Rather, the practical meaning of the label is constantly negotiated as shifting understandings of autism shape – and are then in turn shaped by – autistic people’s experiences of their bodies, for example, their styles of interactions, and their daily habits.

Another way to think about autism while considering both its biological and social-structural components is proposed by Elizabeth Fein (2015a). Fein holds that the condition we refer to as autism is at least in part shaped at the interface between a person’s natural tendencies and their social environments. She suggests that in many of today’s Western societies, where social relationships are based on choice rather than obligation, social difficulties at an early age might lead to exclusion and loneliness, as a child’s peers deny her their friendship. This social isolation leads to the exacerbation of the sometimes-subtle tendencies people may have already experienced, and so they are ultimately more likely to fall within the autism category. Damian Milton (2012) similarly focuses on the role of relationality in determining what constitutes autism. He reflects on the fact that both autistic and non-autistic people lack insight into the perceptions of the other, a disjuncture in reciprocity to which he refers as the ‘double empathy problem’. Yet despite this being a problem of reciprocity, the power imbalance between the groups enables one group to deem themselves normal, while the other group is reframed as indicating a social deficit.

**Self-advocacy and the neurodiversity movement**

Contrary to the view of autism common in the biomedical and psychological disciplines, which considers it a deficit or impairment, approaches based on neurodiversity consider autism to be a natural expression of human diversity (see Bagatell 2007, Chamak 2008, Grinker 2007, Lawson 2008, Savarese 2013, Waltz et al. 2015). This view partly stems from the social model of disability (Ginsburg & Rapp 2013, Oliver 1996, Shakespeare 2006), which acknowledges the crucial role of society and culture in shaping, if not
constructing, the category and experience of disability. Neurodiversity advocates further suggest that much as there exists a diversity of gender or ethnicity, so there exists a diversity of cognitive structures; that is, of ways of being (see Arnold 2017, Baggs 2010, Limburg 2016, Milton 2012, Ne’eman 2010, Prince 2010, Yergeau 2010, 2013, 2017). Autism, therefore, according to such claims, should be accepted, even celebrated.\(^5\)

While the neurodiversity paradigm and its accompanying discourses are varied and nuanced, several of its generally-accepted principles bear mentioning. First, neurodiversity proponents maintain that autism is an inseparable and integral part of the autistic person. It is in light of this view that many autistic authors express their explicit preference for identity-first language (i.e., autistic person), over person-first language (i.e., person with autism) (e.g. Lawson 2008, Milton & Lyte 2012). Moreover, imaginaries of a potential cure for autism, or of technologies of its prevention, are seen to constitute a form of intolerance and oppression. Another common attitude in neurodiversity discourse is a rejection of functioning labels with regards to autism. Advocates maintain that the binary distinction between high-functioning and low-functioning autism is not only simplistic, but that it may be wholly misleading (e.g. Milton & Lyte 2012, Murray 2009, Savarese & Savarese 2010, Yergeau 2010). ‘Functioning’, in the end, is contingent on societal expectation, access to support services, available assistive technology, and changing levels of comfort. Functioning may therefore not be a property of an individual, but a relational category (e.g. Williams 2006). Importantly, neurodiversity advocates further assert that autistic people ought to be included in all public discussions about the condition, from scientific inquiry, through media representation, to legislation and policy making: as per the central idiom in many disability rights movements, ‘nothing about us without us’.

Identity, community, and subjectivity

The idea of autism as a form of alterity lends itself to questions of identity, subjectivity, citizenship, activism, and community, which have indeed stood as the basis of numerous anthropological studies. A major paradigm from which autistic people draw their self-definition is the neuroscientific discourse; for example, in adopting the view that autism implies an atypical wiring of the brain. According to Francisco Ortega (2009: 426), this preference reflects a diffusion of neuroscientific claims that extends beyond the laboratory and into various social domains. This cerebralised self-definition of autistic people may constitute the very basis of popular claims for ‘neurodiversity’ (see also Ortega 2013, Ortega & Choudhury 2011). Yet alongside the neurodiversity discourse, which values taking pride in one’s difference, there also exists the biomedical discourse, which values sameness, normalcy, and efforts to conform. Nancy Bagatell (2007) has thus pointed out that what best characterises the process of identity construction among autistic people is the active and difficult orchestrating of these mostly opposing voices. In other words, assuming an autistic identity is ultimately an active process driven by personal agency and choice.
Such biology-based discourses on autism might also serve as a powerful source of resistance. In assuming an identity constructed around neuroscience, members of the neurodiversity movement question the notion that impairment is objective or absolute (Brownlow & O’Dell 2013). Activists thus appropriate whatever biological basis autism may have – precisely that which according to a deficit model would be considered the cause of disability – and negotiate its meaning, turning it into a positive. Biological essentialism here serves to claim a natural difference between themselves and the hegemonic majority. Citizenship, the authors claim – neurobiological citizenship, in this case – is reflected by people asserting the freedom to negotiate a governing regime, and alternately reject it, accept it or withdraw from it entirely.

The distinctive possibilities for sociality supported by digital media have offered people with disabilities new opportunities for self-expression and self-determination. Such collective creations play a role in producing social spaces that are inclusive of the fact of disability, thereby expanding our understanding of what it means for people with disabilities to be human (Ginsburg 2012). Autistic people’s shared experiential backgrounds, along with a shared identity as autistic, are thus conductive of a collective voice (Davidson 2008). It is significant that these processes occur online; a social landscape where the communication difficulties associated with autism become less emphasised. Online media, moreover, has allowed autistic people to communicate freely without ‘betraying their autism’ (Antze 2010: 317) by obliging themselves to make eye-contact, for example, or suppressing their atypical body language; without, that is, pretending to be ‘normal’. Under the mostly discursive, predictable, and asimultaneous conditions of online communication, autism need not be an obstacle to communicating successfully, nor to forming relationships or establishing communities.

Yet while the role of the internet in affording the emergence of autistic communities should not be downplayed, such community building is not restricted to online spaces. Notable examples of actual spaces designed by autistic adults in order to accommodate the preferences and tendencies of those on the autism spectrum – conducive of what might be called an autistic culture (Dekker 1999, Sinclair 2010) – include Autreat (see Sinclair 2005), and its British counterpart, Autscape. A fascinating example of one such social spaces is a summer camp for autistic youth dedicated to live-action roleplaying games, which was explored ethnographically by Fein (2015b). A ‘folk healing system’, as she deems it, the camp, with its games and accompanying mythologies, offers a rich assemblage of cultural resources: characters, themes, and narratives. Players draw from these sources to metaphorically conceptualise and express their turbulent experiences. Fein further notes that this sociocultural ecology of the camp – with its predictable structures and relational commitments – allows campers to reformulate the challenges associated with autism, transforming them from sources of estrangement into opportunities for mutual recognition and shared enjoyment.
More insight on subjectivity and citizenship in the context of autism comes from authors who engage with the autism rights movement from a gender perspective. Kristin Bumiller (2008) considers the implications of the attempted normalization of autistic people – which among other things includes attempts to eliminate supposedly ‘wrong’ gender behaviour – and analyses autistic activists’ rejection thereof. She argues that the neurodiversity movement offers a unique contribution to the democratic political system, in illustrating that notions of citizenship need not be based on sameness (as it is sometimes imagined) nor on difference (as notions of diversity in other contexts often imply). This is because both sameness and difference imply a ‘norm’ against which people’s individual value is measured. Instead, autistic people’s ‘quirky’ citizenship is to be based on inclusion, acceptance, and individual roles and contributions to civic life.¹

**Language and sociality**

Autism is characterised by an equivocal relationship with typical, i.e. symbolic and conventionalised, language. For both Dawn Prince (2010), an autistic anthropologist and Amanda Baggs (2010), an autistic self-advocate, conventional language is neither natural nor intuitive but partial and constraining. In their respective works, the authors articulate their preference for unconventional linguistic structures: modes of non-symbolic connection to the world that nevertheless capture its beauty and the richness of worldly experience. In light of these different linguistic styles commonly found among autistic people, they often experience difficulties in their attempts to make sense of social etiquette. And although many autistic people work continuously to uncover the underlying principles of social rules, they frequently remain unsuccessful in putting this knowledge into practice. As a result, they turn to shaping their social environments in an attempt to redefine the terms under which the appropriateness of their actions is evaluated. Failure to abide by etiquette should therefore be taken not as mere lack of success, but at least in part as deliberate action and contemplative craft (Belek 2018).

Elinor Ochs et al. (2004) have also discussed their autistic interlocutors’ difficulties pertaining to ‘social function’. They note that the skills required to converse successfully with each other exceed knowledge of interpersonal communication, to also involve the ‘socio-cultural knowledge’ necessary for appropriately inferring indexical signs. Autistic people’s reduced ability to make sense of some utterances or events, and to react in a conventionally appropriate manner, is to a large extent due to their difficulty in drawing upon knowledge of social context. Such social misconduct, and how autistic children account for it, is the focus of a study by Karen Sirota (2004), who demonstrates the ways in which parents use various expressions of accountability (such as justifications, apologies, or excuses) when instructing their children on how to navigate breaches of etiquette. Yet seeing as accountability is a highly context-specific practice, its effectiveness as a remedy depends on understanding the particular conditions of its use. In the context of autism and the frequent unpredictability that accompanies it, the success of this strategy is limited (see
also Ochs & Solomon 2008).

Some autistic authors articulate their arguably unique connection with animals (e.g. Grandin & Johnson 2009, Prince-Hughes 2004). Interactions with horses, for example, are said to enable various types of social behaviours and “open-up” autistic children to interactions they would otherwise typically avoid (Malcolm et al. 2018). Equine therapy thus facilitates a form of multi-species intersubjectivity, leading the way to novel possibilities for dynamic attunements between autistic and non-autistic people. Recently, the increasingly popular imaginaries of social robots as appropriate companions for autistic children has also been attended to. This notion is grounded in the persistent view of human sociality – especially where autistic people are concerned – as somehow mechanistic (see also Milton 2014). Yet others (e.g. Richardson 2018) contend that human to human attachment is in fact crucial to happiness and wellbeing. A successful therapeutic relationship depends on mutual trust, compassion, and empathy, and is therefore not replaceable by the ontologically divergent interactions between human and machine.

**Body and senses**

Various bodily attributions are common in autism: sensory sensitivity; a tendency towards repetitive movement, sometimes referred to as self-stimulating behaviours or ‘stimming’; and an atypical gait or posture, to name just a few examples. Autistic children have been shown in some cases to assume a laborious role when attempting to coordinate their (often atypical) bodily actions with societal expectations (Solomon 2011). Analysing video footage of a 9-year-old autistic girl interacting with classmates in the playground, Ochs (2015) has noted this minimally verbal child’s continually alternating bodily responses to the social situations developing around and towards her. This constant awareness of one’s own body – as an experiencing subject as well as an object exposed to the gaze of others – is what Ochs refers to as a form of corporeal reflexivity. In a similar engagement with corporal reflexivity in autism, it has been shown that autistic adults work to produce distinctions between bodily experiences of distress that they previously experienced as undistinguishable (Belek 2019a). Through a process of bodily cultivation, autistic adults come to design a specialised vocabulary – which includes such terms as trigger, overload, meltdown and shutdown – through which to attune more precisely and concretely to their atypical somatic sensations.

**Autism around the world**

Until quite recently, the anthropology of autism has focused primarily on the sociocultural conditions and implications of the category in Anglophone settings. This regional bias can be said to have set the tone for the discipline’s engagement with the topic at large, further evidenced by scholars’ frequent lack of acknowledgement that such a regional bias does in fact exist. Majia Nadesan (2005), among others, accentuates the crucial role that specific sociocultural, political, and epistemological developments in twentieth century Europe and North America had played in the emergence of autism. These include major
shifts in psychiatric paradigms, as well as changing formulations of the category of childhood and the resulting alterations of the perceived goals of early education. ‘Autism’, she thus argues, ‘could not have emerged in the nineteenth century ... because within the diagnostic categories of nineteenth century (and earlier) thought, autism was unthinkable’ (2005: 3). Although Nadesan does not press this point, her historical narratives indicate that the statement holds equally true concerning not only the temporal, but also the geographical and geopolitical locations of the category’s emergence. However, over the past two generations, autism diagnoses have become increasingly common throughout the world (e.g. Elsabbagh et al. 2012).

Consequently, several anthropological studies have set about to explore the particular enactments of autism in more diverse geographic, cultural, and political contexts. — Ariel Cascio (2015a) is one example, as she analyses the use of the concept of rigidity by Italian professionals involved in providing therapy for autistic children. These practitioners frequently describe their clients as rigid, and consider rigidity a potential pitfall in their own work in autism service provision. By creating this semantic overlap between the experiences of people on the autism spectrum and their own, professionals open up a space of similarity between neurotypicals and autistic people, a rhetorical strategy which allows them to reflect more closely upon their work, while working to bridge the gap between the two groups.

In South Korea, local connotations and interpretations of autism lead mothers to resist thinking about their children as autistic (Grinker & Cho 2013). These South Korean mothers frequently attempt to battle exclusion and mitigate stigma in a society that values conformity, while also having to excuse their children’s difficulties in school in an environment that reveres academic excellence. Owing to their understandable reluctance, under such circumstances, to accept the label of autism, a local lay diagnostic concept has emerged; that of ‘border children’. Inconsistent with Western diagnostic classification, this emerging label has proven powerful in allowing mothers to reconcile their ambivalence to the label of autism with its implications of permanence and certainty, framing the condition instead as uncertain, contingent, and temporary.

This rejection of the label of ‘autism’ has also been described in an American context. Challenging the ethnic bias in the anthropology of autism, Cheryl Mattingly (2017) focuses on a family forced to deal with both race and disability: an African-American mother and her autistic child. Here, racial stereotyping, joined with a narrow view of autism, confines the child’s conceivable future possibilities; thus teaching the child, in his mother’s view, to internalise the fearful potentiality of his ‘becoming nothing’. Structurally visible threats associated with race and class are thus shown by Mattingly to play a central role in the opportunities presented to an autistic child as they enter adulthood. In light of this, it is claimed that refusing to accept an autism diagnosis might be the most logical means of protection from the pernicious threat posed by the entwinement of race and disability in certain social settings.
Conclusion

Anthropologists studying autism approach their object of study as they do other forms of human difference. They have employed such common heuristic frameworks as phenomenology, ethnomethodology, interpretivism, and critical theory to explore autistic subjectivities, experiences, bodies, and narratives, as well as the motivations and significations of other actors involved in shaping the condition. Yet one aspect of the phenomenon we call autism seems to call for a specialised interpretive framework: namely, its existence as both a historically contingent social construct, and as a name and category for underlying biological, neurological, and genetic conditions. It is predominantly this tension, never quite resolvable, that has led scholars to characterise autism as an uncertain entity (Hollin 2017b), a disability of context (Prince 2010), a disease and an epidemic of signification (Kaufman 2010, David & Orsini 2013) and an epidemic of discovery (Grinker 2007). Indeed, Ian Hacking may not have exaggerated when proposing, in reference to autism, that ‘we are participating in a living experiment in concept formation of a sort that does not come more than once in a dozen lifetimes’ (2009b: 506).

The anthropological literature recounted above constitutes a crucial step towards our better understanding of autism and of the people to whom this concept is said to apply. Yet the notion of neurodiversity might suggest that anthropologists should go further. They may want to incorporate their emerging understanding of autism into a broader analytical perspective in which the category of autism is no longer thematically and theoretically isolated. What may be needed is not only an anthropology of autism, but an anthropology with autism. As it was put by Richard Grinker,

> We need to focus attention on the anthropological study of a form of difference that has previously been conceived of as lying outside the realm of the social. The concept of "diversity," with all its positive connotations of acceptance and celebration of difference, need not only apply to gender, race, ethnicity, and religion. We can also begin to celebrate a diversity of minds (2010: 177).

Acknowledgements

I thank the entry's editor and reviewers for improving greatly on this text. Especially, I am grateful for their pointing out to me the discipline's bias to studying autism predominantly in Western English-speaking settings.

References

Angell, A.M. & O. Solomon 2017. ‘If I was a different ethnicity, would she treat me the same?’: Latino parents’ experiences obtaining autism services. *Disability & Society* **32**(8), 1142-64.


Belek, B. 2013. *I believe it can change the way things are. Identity constructions among video-bloggers with Asperger’s syndrome on YouTube*. Diemen: AMB Publishers.


Brezis, R.S., T.S. Weisner, T.C. Daley, N. Singhal, M. Barua & S.P. Chollera 2015. Parenting a child with autism in India: narratives before and after a parent-child intervention program. *Culture, Medicine, and*


Davidson, J. 2007. ‘In a world of her own...’: re-presenting alienation and emotion in the lives and writings of women with autism. Gender, Place and Culture 14(6), 659-77.


—— 2015a. 'No one has to be your friend': Asperger's syndrome and the vicious cycle of social disorder in late modern identity markets. *Ethos* 43(1), 82-107.


Giles, D.C. 2014. ‘DSM-V is taking away our identity’: the reaction of the online community to the proposed changes in the diagnosis of Asperger’s disorder. *Health* 18(2), 179-95.


——— 2009b. How we have been learning to talk about autism: a role for stories. Metaphilosophy 40, 499-516.


——— & Lyte 2012. The normalisation agenda and the psycho-emotional disablement of autistic people. *Autonomy* **1**(1), online (available at: [https://kar.kent.ac.uk/62638/](https://kar.kent.ac.uk/62638/)).


Ben Belek. Autism. CEA 17


Orsini, M. & M. Smith 2010. Social movements, knowledge and public policy: the case of autism activism in
Canada and the US. *Critical Policy Studies* 4, 38-57.


**Note on contributor**

Ben Belek is a research fellow in social and medical anthropology at the Martin Buber Society of Fellows at the Hebrew University in Jerusalem. His previous project focused on the ontological status of neurological diversity among autistic adults in the UK. In his current project, he explores the shifting values of blood constituents in the Israeli blood economy.

Grinker (2010: 173) has discussed the benefits of imagining autism as a spectrum, whereby the old image of the nonverbal, mentally underdeveloped, and unaffectionate male child has given way to the understanding that autism constitutes a broad range of strengths and weaknesses, tendencies and sensitivities. However, the use of the spectrum metaphor does have several disadvantages, as noted by Hacking: ‘To the mind of a physicist or a logician … spectra are linear and autism is not. Autism is a many-dimensional manifold of abilities and limitations.’ (2009b: 503)

Other studies focusing on the representation of autism in various media and its impact on understandings of the condition include Davidson (2007), Davidson & Smith (2009), Draaisma (2009), Hacking (2009b, 2009c), Murray (2008), and Waltz (2005, 2012); as well as the studies featured in an edited volume by Osteen (2008).

The relationality inherent in the notion and category of autism, and its opposition to socially contingent understandings of that which is ‘normal’ has been similarly addressed by Belek (2019b), Bagatell (2007), Eyal et al. (2010), Grinker (2013), Lawson (2008), Milton & Lyte (2012), Molloy & Vasil (2002) and Nadesan (2005), among others.

Studies which explicitly take this stance on autism as their starting point, are occasionally grouped together under the umbrella of “critical autism studies” (CAS) (O’Dell et al. 2016, Davidson & Orsini 2013, Runswick-Cole, Mallett & Timimi 2016, Woods et al. 2018).

For a comparable analysis of autistic subjectivities as representing a ‘neurostructural self’, see Fein (2011). For autism as neuroqueerness, see Yergeau (2017).

Other studies emphasising the active and often creative nature of constructing positive identities in autism include Badone et al. (2016), Bagatell (2010), Brownlow (2010), Davidson & Henderson (2010), and Fein (2015b).


See www.autscape.org


Solomon (2010, 2012, 2015) has similarly explored the ways sociality in some autistic children is facilitated and realised through social interactions with animals.


The intertwinenment of parenting, autism and ethnicity from a phenomenological perspective has also been addressed by Angell & Solomon (2017), Lawlor & Solomon (2017), and Solomon & Lawlor (2015).

The latter two drawing on Treichler (1987).