

Autism as heredity, autism as heritage

The movement of autism back and forth through time

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Abstract

Kinship relations constitute the grooves through which autism travels temporally. On the one hand, the biological components of the condition are understood to journey from one generation to the next through the passing down of genetic information. Yet on the other hand, autism is often employed retrospectively as an explanatory model and a marker for a unique personhood; this can occur in retelling to oneself and to others the story of one's familial history, as well as, sometimes, the story of humanity as a whole. In this way, autistic people's construction of autism as a cross-generational familial keystone offers them new opportunities for self-expression and self-creation. Through this temporal reframing of autism, the heritability of the condition might instead be reconceptualised as heritage.

Keywords

autism, heredity, heritage, neurodiversity, temporality

There are potentially many avenues through which to discuss the temporal dynamics of autism. One could, for example, consider how autistic people commonly experience social interaction as unintuitive, which results in the need to constantly and consciously calculate one's

utterances and actions. Casual conversations, therefore, are often experienced by people on the spectrum as long and arduous intellectual endeavours, and thus arguably engender a unique experience of time in everyday social settings.¹ But this is not what this paper is about.

Alternatively, one might choose to focus on autistic people's diagnostic careers. The lives of many people on the spectrum are punctuated with recurring diagnostic events – that is, episodic encounters with psychiatric practitioners at various points in their childhood, adolescence, and adulthood, during which they are intermittently labelled as suffering from anxiety, depression, dyspraxia, alexithymia, etc., before finally arriving at the eventual diagnosis of autism. Each diagnostic label heavily alters the subject's sense of narrative, leading ultimately (and arguably) to a temporally disjointed biography. But this is not what this paper is about either.

Instead, I want to focus on another interesting dynamic associated with the autism spectrum: the developing tension between autism as a hereditary condition and autism as a social and cultural artefact. More specifically, I want to explore the temporal component of this tension, whereby autism can be seen to move simultaneously both forwards and backwards through time. As a genetically induced condition, autism can be said to move from one generation to the next (albeit typically not in any clear or predetermined fashion). However, as a social category and label, autism often tends to travel in quite the opposite direction, from current generations to previous ones. This process is ignited when parents seek and receive an autism diagnosis for themselves, following the autism-labelling of their children. Their own parents (the autistic child's grandparents) are subsequently understood anew as possibly being, or having been, autistic, and so are their parents before them, and so on.

Sometimes, in fact, autism is transported all the way back to the very early days of humanity. Such was the case when a recent article in the popular online platform *The Conversation* suggested that 'it is clearly time for a reappraisal of what autism has brought to human origins' (Spikins 2017). A similar sentiment was expressed by Michael Fitzgerald, a professor of psychiatry specialising in autism, who claims: 'All human evolution was driven by Asperger's and autistic people. The human race would still be sitting around in caves chattering to each other if it were not for them' (quoted in Griffin 2006).

In this Think Piece, I examine this bidirectional temporal movement of autism. In so doing, I discuss how ancestral histories are understood anew in light of present-day categories, and how present social relations are interpreted in light of assumed pasts. What does this tell us

1 See Belek (2018).

about how we understand our bodies, or more specifically our brains, as links in a chain which expands over large temporal frameworks?

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Most historical accounts of autism begin with a sporadic review of incidences that could arguably be regarded as cases of autism from past centuries, long before the category of autism even existed. Thus, tales of ‘holy fools’ from ancient Russia (Challis and Dewey 1974), ‘wild boys’ from early modern France (Feinstein 2010), or ‘feral children’ from early modern Germany (Grinker 2007) are casually suggested as potentially representing cases of autism from the past. Rab Houston and Uta Frith (2000) – the former a social historian, the latter a professor of cognitive neuroscience – have argued that an eighteenth-century Scottish landowner by the name of Hugh Blair, labelled a ‘natural idiot’ by his contemporaries, represents a classic case of autism. Various renowned historical figures – including scientists (e.g., Isaac Newton, Albert Einstein, and Alan Turing), authors (e.g., Herman Melville, Lewis Carroll, and James Joyce) and other prominent figures in their fields (e.g., Michelangelo, Wolfgang Amadeus Mozart, Ludwig Wittgenstein, and Stanley Kubrick) – have also been identified as exhibiting traits and behaviours which potentially indicate an autism spectrum condition (Brown 2000; Fitzgerald 2004).

At the same time, most social science researchers would agree that autism is a product of specific – and specifically modern – practices, cultural values, and systems of knowledge. As such, it cannot be said to have been present in any of these individuals, at least in any real sense. It can be argued that labelling historical figures who lived before the category of autism emerged as autistic is essentially an anachronism; akin, perhaps, to suggesting that Julius Caesar was Italian or that Joan of Arc was a feminist. And yet, such claims seem to capture people’s imaginations (much more than the somewhat more mundane medical history of the category of autism does, in any case). I therefore agree with Stuart Murray (2012, 40) when he asks: ‘Is it... possible to talk about autism before it had a medical formulation?... How would the linguistic and narrative conditions that pre-date [modern terminology] possibly suggest any idea of autistic presence?’.

It was only in the early 1940s that two articles were published, independently of one another, which proposed an entirely new category of childhood disorder. One was published in English by American psychiatrist Leo Kanner, while the other was published in German by Austrian paediatrician Hans Asperger. In both cases, the proposed condition was said to be marked by a lack of responsiveness to others and a tendency towards repetition.

It is perhaps relevant here that at least one detailed historical account of autism (Feinstein 2010) mentions, though only as a short aside, an interesting biographical detail concerning Kanner's own father. An Orthodox Jewish man from a small Austrian village, he was reported to have been eccentric, lacking in social skills, and having an obsessive fascination with the Talmud, which he had apparently memorised in its entirety. Now, to ask whether Kanner's father was in fact autistic is to be guilty of the same sort of anachronism as those historians who have applied the label to the likes of Newton or Mozart. Yet it is nevertheless significant, in light of the focus of this paper, to consider the possibly crucial role that kinship relations – marked by a certain social eccentricity – may have played in the very inception of the category of autism.

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In October 2013, only a month or so into my ethnographic fieldwork, I received a message in my Facebook inbox from an informant I call Linda. This was a response to an advert I had posted in a Facebook group, where I shared the details of my research project and asked if any members of the group – mostly autistic adults in the UK – would be interested in taking part. 'Dear Ben', this message read. 'I am a 39-year-old Aspie female and I would like to help with your study'. The conversation which ensued developed into a year-long dialogue, which involved hundreds upon hundreds of Facebook messages, many face-to-face meetings, and access to a whole new field site – a social group of about thirty autistic adults who would meet regularly at their local pub.

Linda had previously worked as a science teacher at a local secondary school, although she now spent most of her days raising her five children, who at the time of fieldwork ranged in age between two and twenty-one years old. She was only seventeen when she became pregnant with her first child.

'I was unmarried and undiagnosed', she once told me. 'And at that point in my life I felt very worthless'. It was unfortunately common for many of my interlocutors to recount their adolescent years as accompanied with such experiences of insignificance, so Linda was not unusual in that regard. Yet it is already interesting to note the implicit connection she makes here between her feelings of worthlessness and her experience of solitude and marginality – a marginality which she describes both in familial ('unmarried') and nosological ('undiagnosed') terms. Her autism diagnosis was, for Linda, as much a rite of passage into a new *social* position as any other; equivalent, in many ways, to the role of marriage. Indeed, such was the case with most, if not all, of my interlocutors.

No fewer than three of Linda's children have been diagnosed with autism. It was only when a child of hers was labelled autistic for the second time that Linda realised the label might also

apply to herself. This led her to seek, and subsequently receive, an autism diagnosis. ‘If I did not have autistic children’, she reflected, ‘I would not have learned about my own difference – although I always knew I *was* different’. While from a heredity perspective, then, it could be said that Linda (or rather, her DNA) is at least partly the source of her children’s autism, it is equally the case that, in a very real sense, her children’s autism *is the source of her own*.

Many of my conversations with Linda revolved around her children, and she would very often reflect on the challenges and rewards of her role as parent. Primarily, she conceived of this role as involving teaching her children various strategies for mitigating the difficulties associated with autism. These are strategies that she herself has developed over the years: strategies, for example, for identifying her emotions; for communicating her feelings in socially recognisable ways; for appreciating the impact her behaviour has on others; and for striving towards feeling safe, worthy, and confident.

These strategies have played an integral and crucial role in Linda’s active crafting of what autism means to her. They highlight the various ways in which autism is not a given state, but rather the result of constant deliberation, reasoning, and negotiation.² Teaching these strategies to her children represents an effort to convey this uniquely designed meaning of autism to her family. Thus, Linda is essentially creating an idiosyncratic ‘version’ of this condition: this, she is teaching her children, is what autism is in their family. It is significant to appreciate that Linda offers the same education to her autistic and non-autistic children alike – in effect, treating the category of autism not as an individual descriptor, and certainly not merely a medical fact, but rather as a space of moral reasoning and interpretation, which underlies her role as parent and matriarch.

Linda would very often tell me about her deep love and adoration for her children, thus pushing against the popular misconception that autism somehow involves an emotional deficit. This maternal affection was equal only to her love for her maternal grandparents. ‘The only other person able to understand me empathically was my grandad’, she once told me. She went on to reminisce about him at length:

My grandfather grew up in an orphanage, and joined the military, where he would play brass instruments, and served in the Sahara and Italy. He was extremely bright – but underachieved in life. He had lots of acquaintances but no real friends. He was very fussy about certain things – his trousers being the exact correct length, doing his army exercises twice a day, etc. ... He was not typical! He used a social script in public and

2 See Belek (2019).

had ‘phrases’ he always used. Sometimes people were obviously embarrassed or irritated by him, but he did not notice. He always tried to play the joker and make others laugh. He was desperate to be liked but could not seem to form deeper friendships. He loved routine and got very stressed if the unexpected happened. He was also highly sensitive to noise – as I am.

‘He had *such* a hard life!’. Linda repeated this statement several times during our first interview. ‘He was definitely an Aspie but I did not find out about myself and my children until after he passed away – so he never knew’.

The meaning of autism is seen here to be negotiated in retrospect. Linda’s claim that her grandfather was autistic satisfies much more than nostalgia. Nor is Linda making use of her grandfather’s post-mortem diagnosis as a model for understanding her own difficulties. Quite the opposite: hers and her children’s autism are employed by her as a framework for understanding her grandad’s uniqueness as a person, and as an explanation for the many difficulties *he* had experienced throughout his life.

When her grandfather died, years before we met, Linda had written a poem for him. ‘I thank you for showing me so much of yourself and all that love and compassion’, it starts. ‘No other soul in this world knows me as you have done, our minds were the same mind’. It is this notion of a presumed ‘sameness of minds’ that I am referring to when developing this idea of autism as heritage.

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At around the same time of our ongoing engagement, Linda was stepping up, as chair of her local autism social group, to protest a policy decision by her city council. The policy plan specifically targeted autistic adults, and while it did focus on the problem of unemployment among the city’s autistic population – an all-round pressing concern – it nevertheless fell short of satisfying group members.

Linda authored a response email to the city councillor in charge of the policy design. ‘By not seeking our views’, she wrote, ‘you have produced something that we are angered and offended by. ... We will not endorse the document’. Her appeals were acknowledged, and the committee members accepted her insistence that they rethink the suggested policy.

In September 2014, the council was celebrating the launch of its new autism strategy in a conference venue in the city centre. The event started with introductory remarks and pleasantries from the city councillor, followed by a self-congratulatory speech by the local Member of Parliament. Linda was then called up to the stage. She had been invited to offer

her own thoughts on the policy, yet she chose to use the stage for a slightly different purpose: to share her feelings of pride towards her second child. Her intention was to shift the audience's attention away from autism as a public health concern and towards autism as a valuable and desirable manifestation of human diversity. 'My eldest daughter', she started, 'is beautiful, vibrant, and intelligent. She is perfectly kind, considerate, and caring. She has infinite potential'. Nearing the end of her allotted time, Linda offered listeners a glimpse of her daughter's own familial horizons: 'Perhaps she too will have autistic children of her own', she said. 'Children I will be honoured to welcome into our family'.

Linda's conception of herself as part of an autistic lineage thus completes a full cycle; alongside using autism to rearticulate her ancestral past, she similarly employs it as a vehicle through which to envision her family's future. As Linda invokes the possibility of her unborn grandchildren being autistic, this invocation is placed along a two-way path that no longer draws its significance purely on heredity. That which she envisions as passing on from her grandfather to herself, from herself to her daughter, and from her daughter to her grandchildren, is not autism as a genetic reality. Rather, she envisions autism as the expected continuation of her family's autistic heritage.

For Linda, autism serves as a link in a chain that spans across generations, between grandfather, herself, and her children. Autism is the stuff, it could be said, of which Linda conceives her family as being made. Indeed, such was the case for many of my autistic interlocutors, who would often invoke memories of parents, grandparents, uncles and aunts, reinterpreting their personalities and relationships in light of the autism label. Autism can thus be understood as the temporal axis along which one imagines not only one's own life, but also one's familial origins, on the one hand, and familial horizons, on the other. It is the thread, in other words, that connects past, present, and future. It is the basis on which a sense of family continuity can be constructed.

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To say that autism has a genetic component is to make a claim about the location of the condition; namely, that it is organic, biological, grounded in the body. In addition, it is to make a claim about the channel through which autism moves in the world; namely, that it (whatever 'it' may be) sustains through time by the passing down of genetic information from one generation to the next.

The wide acceptance of the heredity of autism is, of course, consistent with its popular view in the biomedical discourse as a biological, neurological disorder. However, as I hope to have shown, to view autism as merely a biological phenomenon, and to attribute its persistence

purely to questions of heredity, is to ignore the plethora of social, cultural, and historical circumstances that shape its meaning today.

As we track the travels of autism – and indeed any other condition, mental, developmental, or physiological – along temporal trajectories, we would do well to consider their continuity as assemblages of not only biological or molecular bonds, but of social ones as well. And thus, we would be wise to consider their temporality not merely as chronological and sequential, but as bidirectional, moving backwards as well as forwards in time.

About the author

Ben Belek is a postdoctoral research fellow in social and medical anthropology at the Martin Buber Society of Fellows at the Hebrew University. He received his PhD in 2016 from the Division of Social Anthropology at the University of Cambridge. His previous project focused on questions concerning subjectivity, embodiment, advocacy, and activism among autistic adults in the UK. Articles from this project have been published in *Ethos*, *Medical Anthropology*, and *Philosophy, Psychiatry & Psychology*. His current project engages with the value economies underpinning the global blood plasma industry.

References

- Belek, Ben. 2018. ‘Autism and the Proficiency of Social Ineptitude: Probing the Rules of “Appropriate” Behavior’. *Ethos* 46 (2): 161–179. <https://doi.org/10.1111/etho.12202>.
- Belek, Ben. 2019. ‘Articulating Sensory Sensitivity: From Bodies with Autism to Autistic Bodies’. *Medical Anthropology* 38 (1): 30–43. <https://doi.org/10.1080/01459740.2018.1460750>.
- Brown, Julie. 2000. *Writers on the Spectrum: How Autism and Asperger Syndrome Have Influenced Literary Writing*. London: Jessica Kingsley.
- Challis, Natalia, and Horace W. Dewey. 1974. ‘The Blessed Fools of Old Russia’. *Jahrbücher für Geschichte Osteuropas* 22 (1): 1–11.
- Feinstein, Adam. 2010. *A History of Autism: Conversations with the Pioneers*. Oxford: Wiley-Blackwell.
- Fitzgerald, Michael. 2004. *Autism and Creativity: Is There a Link between Autism in Men and Exceptional Ability?* New York: Routledge.
- Griffin, Joe. 2006. ‘Autistic Tendencies: The Consequences for our Culture. Joe Griffin Interviews Prof Michael Fitzgerald’. *Human Givens Blog*, 23 July. <http://blog.humangivens.com/2012/07/hg-library-autistic-tendencies.html>.

- Grinker, Roy Richard. 2007. *Unstrange Minds: Remapping the World of Autism*. New York: Basic Books.
- Houston, Rab, and Uta Frith. 2000. *Autism in History: The Case of Hugh Blair of Borgue*. Oxford: Blackwell.
- Murray, Stuart. 2012. *Autism*. New York: Routledge.
- Spikins, Penny. 2017. 'How Our Autistic Ancestors Played an Important Role in Human Evolution'. *The Conversation*, 28 March. <https://theconversation.com/how-our-autistic-ancestors-played-an-important-role-in-human-evolution-73477>.
- Ullman, Doris. *Aunt Cord Ritchie and Family, Hindman, Kentucky*. Circa 1932–1934. Platinum print. 20 x 15.3 cm. The J. Paul Getty Museum, Los Angeles. <http://www.getty.edu/art/collection/objects/62500/doris-ulmann-aunt-cord-ritchie-and-family-hindman-kentucky-american-about-1932-1934/>.