Review article

Within a single lifetime: Recent writings on autism

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John Donvan and Caren Zucker, In a Different Key: The Story of Autism. London: Allen Lane, 2017. 688 pp. ISBN: 978-0-2419-5817-9

Bonnie Evans, The Metamorphosis of Autism: A History of Child Development in Britain. Manchester: The University of Manchester Press, 2017. 500 pp. ISBN: 978-0-7190-9592-4

Des Fitzgerald, Tracing Autism: Uncertainty, Ambiguity, and the Affective Labour of Neuroscience. Seattle: The University of Washington Press, 2017. 214 pp. ISBN: 978-0-295-74191-8

Edith Sheffer, Asperger’s Children: The Origins of Autism in Nazi Vienna. New York & London: W.W. Norton & Company, 2018. 317 pp. ISBN: 978-0-393-60964-6

Melanie Yergeau, Authoring Autism: On Rhetoric and Neurological Queerness. Durham, NC: Duke University Press, 2018. 302 pp. ISBN: 978-0-8223-7020-8
In response to a recent funding application, an anonymous reviewer said of my profile that: ‘Given the number of fine books about autism that have emerged in recent years, it is a little unfortunate that he hasn’t produced one himself’. While the continuing absence of a fine book – indeed, any book – on autism continues to haunt me, the reviewer was and is absolutely correct. When I began writing a proposal for a PhD on autism more-or-less exactly ten years ago, Majia Nadesan’s Constructing Autism (2005) was one of very few texts published which considered autism in a manner informed by either the social sciences or humanities. That situation has since changed radically. Eyal et al. published The Autism Matrix (2010), perhaps still the best known entry into the canon. Next came Chloe Silverman’s Understanding Autism (2012). Then, in the last two of three years, there has been a veritable deluge. In addition to Jennifer Singh’s Multiple Autisms (2016) and Steve Silberman’s NeuroTribes (2015), I here find myself here reviewing 5 - five! - monographs. Many fine books indeed.

The longest and perhaps most ambitious of the texts covered here is In a Different Key (IDK) by John Donvan and Caren Zucker and its most obvious point of comparison is Silberman’s NeuroTribes. Extra-textually: Both books are written by esteemed American journalists; are incredibly lengthy (IDK is 688 pages, NeuroTribes 592); were published under the Penguin publishing umbrella (Penguin itself in the case of the former, imprint Avery in the case of the latter); have received or been nominated for prestigious awards (IDK was nominated for the Pulitzer Prize for General Nonfiction in 2016; NeuroTribes won the Samuel Johnson prize for best non-fiction in the English language); and are evidently targeted at a popular audience. There are also significant similarities in terms of content: both books trace the story of autism from pre-history (that is, many decades or even centuries before the naming of autism in the 1940s) to the present day, and use the needle of individual stories to stitch together a grander historical fabric.
It is also telling that both Neurotribes and IDK have received a degree of academic cachet, winning a significant number of plaudits amongst a general audience whilst simultaneously racking up citations at a rate which would probably please the four academics whose work is also reviewed here. This academic success should in a sense be unsurprising: one of the primary lessons of these two books (as with those by Silverman and Singh) is that the line between expertise and ignorance, scientific and lay, has been redrawn, breached, and traversed so often that, when it comes to autism, the distinctions increasingly lack meaning. The ability of self-activists, parents, and charitable bodies to shape the condition and understandings of it – to both write and make history, as I’ve phrased it elsewhere (Hollin, 2017a) – and to do so from both inside and outside of the academy, is one of the defining features of autism in the contemporary moment. It’s fitting, therefore, that this review covers books written by social scientists, historians, rhetoricians, journalists, parents, and autistic individuals because it is in these entanglements and intersections that the story of autism is currently being told.

The central story of IDK is that ‘when something changed for the better, it was because parents had stepped up’ (IDK, p. 112). Parents are the ‘constant presence,’ the cogs of history that are driven ‘sometimes by desperation, sometimes by anger, and always by love’ (ibid.: xiii). This is a story which has been told before – by the aforementioned Chloe Silverman for example, who is disappointingly left uncited – but there is something different here: IDK has a parental gaze.

It isn’t just that the stories told are those of parents, it is that we are placed resolutely in the parents’ shoes and see things entirely from their perspective. There are times when the parental gaze works incredibly well. The book’s first section on Donald Triplett – Case 1 in Kanner’s first ever study on autism and therefore the first person, we might have it, ever to be diagnosed with autism – and his mother Mary’s attempt to procure a diagnosis is strong.
Section 3, ‘the end of institutions’, interweaves facts and emotions in a way which lifts the whole history. At other times, the alignment with the parent rather than, say, the autistic child is likely to prove more controversial. The chapter ‘home on a Monday afternoon’ details the murder of Dougie Gibson, an autistic adolescent, by his father Alec. Donvan and Zucker don’t excuse Alec Gibson but they do render his decision not only comprehensible but, in some sense, reasonable. For an academic audience, the centralization of parents is also likely to frustrate at times: characters sometimes have internal monologues akin to those in a Hilary Mantel novel; some claims seem generalized in the extreme (I’m not a historian, but the statement that ‘medical notation and archiving were rudimentary before the twentieth century’ (IDK, p. 38) strikes me as suspect); and the treatment of key figures is occasionally offensive: the first page devoted to Bruno Bettelheim (ibid.: 81) makes it clear that a) he wasn’t an ‘actual’ (i.e. medical) doctor; b) spent his career faking any expertise in the human psyche; c) was unbelievably, irredeemably ugly. Later we find that, under criticism, ‘Bettelheim’s ace card was his history inside the Nazi camps’ (ibid.: 84). This pantomime villainy, dismissal of personal suffering, and insistence that Bettelheim was not only wrong but wicked (and don’t forget ugly) really does little for the book.

Perhaps the most significant academic contribution of IDK is its detailing of the life of Hans Asperger, although that matter is taken up more fully still in Edith Sheffer’s book Asperger’s Children (AC). Understandably, most of the literature devoted to the character of Asperger – and IDK is a primary example of this – has focused upon the most obvious question of his complicity with the Nazi regime. Asperger and his interlocutors have long articulated his as a story of resistance: Asperger was a ‘devout Catholic who never joined the Nazi party’ (AC, p. 16) and who may, indeed, have actively opposed it. As Sheffer phrases it, this version of Asperger ‘was using the autism diagnosis as a psychiatric Schindler’s list’ (ibid.) and his contribution should be similarly recognized. This was very much the view of Steve Silberman
in Neurotribes as recently as 2015. Since then, first through IDK and then through AC, the tide has turned somewhat.

Sheffer paints a suitably nuanced picture of Asperger. True, he was not a member of the Nazi party and it appears to have been widely known that Asperger was ‘not a Nazi enthusiast’ (AC, p. 91). Still, Asperger had ‘solid far-right-wing credentials, holding memberships in several antiliberal, antisocialist, antimodern, and anti-Semitic organizations’ (ibid.: 46). These were memberships which went beyond simple appeasement. Similarly, Asperger did not take part in the child ‘euthanasia’ programme operating out of the infamous Spiegelgrund institution in Vienna where at least 789 children were murdered during the Third Reich (ibid.: 103) and whose director, Erwin Jekelius, was dubbed ‘the overlord with the syringe’ in leaflets dropped by the British Airforce (ibid.: 130). Nonetheless:

Asperger appears to have been involved in the transfer of at least forty-four children to Spiegelgrund – at least nine youths from his clinic, two of whom died, and thirty-five youths that his city commission marked for ‘Jekelius Action’ and died. Given that he served as a consultant to numerous offices, and that the records are incomplete, the total number of children Asperger recommended for Spiegelgrund is likely higher. (ibid.: 147)

Sheffer thus argues that Asperger was directly implicated in the deaths of at least 37 children and, potentially, many more.

Ultimately, Sheffer concludes that ‘Asperger was a minor figure in the Nazi child euthanasia program, nowhere near as active as some of his associates’ but that he also made ‘decisions in a proactive, individual way, making conscious choices to resist some aspects of the regime, and conscious choices to participate in others’ (AC, p. 236). Ultimately, ‘One can
not escape the fact that Asperger worked within a system of mass killing as a conscious participant, very much tied to his world and to its horrors’ (ibid.: 237). It would be a shame, however, for Sheffer’s book to be reduced to an empirical investigation of Asperger’s character and culpability. As with the likes of Jakob von Uexküll and Martin Heidegger, it seems a crucial question as to whether Nazi ideology has seeped into Asperger’s body of work.

To put that differently: is the concept of autism itself shaped by its emergence under the Third Reich? Key to this question, Sheffer suggests, is the concept of ‘Gemüt’. Sheffer largely leaves Gemüt untranslated (not least because its labyrinthine existence appears to require a book length genealogy) but it translates loosely as ‘social feeling’ (AC, p. 69). Gemüt was key to the Nazi project:

The Nazi state aimed, above all, to create a spiritually united, strong, and racially pure German volk, which meant rearing children to be devoted to the regime, steadfast, and physically superior. These qualities required more than simple conformity. They required children’s capacity to feel a sense of belonging, which the regime sought to instil through collective organizations. (ibid.: 63)

Given therefore, that ‘having Gemüt is what it meant to be German’ (ibid.: 218) a child deemed to lack of Gemüt could easily find themselves within the Nazi euthanasia programme.

Given the above, it is instantly worrying to see that by the time of his famed work in 1944\(^1\) Asperger was defining ‘autistic psychopathy’ with reference to ‘anomalous Gemüt’ (AC, p. 219):
He was, essentially, defining autism and Nazism as inverse states of being.

While the root of facism (fascio) was the bundle, the group, the root of autism was autos, the condition of self. (ibid.: 220)

In the immediate context of the Second World War, this finding seems to instantly undercut any notion of autism as ‘a psychiatric Schindler’s list’ (AC, p. 16); Asperger’s framing surely placed these children at greater, not lesser, risk. In conceptual terms, it is hard to shake the feeling that this is important, although exactly why is harder to ascertain. Is the conclusion that, because autism stood in such marked contrast the goals and ideals of the Nazi party, it is inherently anti-fascist? Or if Nikolas Rose (echoing Canghuilhem) was right and for psychology ‘health is life in the silence of the authorities’ (1985: 231) is the important point that the shape of autism only makes sense when cut from a fascist cloth? Sheffer is aware of the importance of this question and, in a statement which chimes with Emily Martin’s inquiries into the co-emergence of particular understandings of bi-polar disorder and neoliberal capitalism (2007), asks how it is that autism came to ‘resonate with an individualistic society in the late twentieth century?’ (AC, p. 246). Sheffer is, understandably although certainly disappointing, reluctant to provide answers. Asperger’s Children is framed as ‘a cautionary tale in the service of neurodiversity – revealing the extent to which diagnoses can be shaped by social and political forces, how difficult those may be to perceive, and how hard they may be to combat’ (ibid.: 16) but what exactly is to be combated is left for another day.

While it ultimately speaks to Sheffer’s question concerning the relationship between political economy and diagnostic entity, Bonnie Evans’ book, The Metamorphosis of Autism (MA) departs from AC in many, many ways. Sheffer frequently intermingles personal story with the sweep of history and it is easy to imagine it finding a popular audience. MA, in contrast, is unforgiving in scale, style, scope. Sheffer zeroes in on an historical figure we currently
understand to be of huge importance, while Evans almost entirely ignores elements that we might assume to be key to the story of autism: Evans is largely dismissive of the importance of both Kanner and Asperger (between them they make an appearance on fewer than ten of the book’s five hundred or so pages) while the novelty of the neurodiversity movement is downplayed and is described as ‘merely an affirmation’ (MA, p. 21) or ‘just a natural progression’ (ibid.: 431-2) of other historical changes. Informed by Nikolas Rose, and following a broadly Foucauldian approach, Evans forsakes these assumed drivers of history and finds importance in unexpected places.

It is widely agreed that what ‘autism’ is has changed significantly since its first description. What Evans argues is that this change should not be understood as simply a tinkering around the edges, nor as a matter of gradually moving away from a point of origin in a process of Hacking-esque looping (Hacking, 2007). For Evans, at the centre of the history of autism is a conceptual rupture wherein the nature of ‘autism’ changed completely. This rupture, which opened in the 1960s and was fully institutionalized by the 1990s, involves nothing less than the complete re-description of autism.

As Evans sees it:

...by the end of the 1960s, the initial meaning of the word ‘autism’ was completely annihilated. In fact, the new ‘autism’ that was developing during the 1960s had the exact opposite meaning of that which had prevailed until the end of the 1950s. Whereas autism and its conceptual cousins – primary narcissism, autoeroticism, etc. – had previously always referred to hallucinatory dreamlike imaginary thought that preceded the establishment of realistic thinking, ‘autism’ from the 1960s was used to refer to a lack of
imagination, a lack of hallucinatory thought, a lack of creativity and a lack of dreams. (MA, p. 189-90, italics in original)

What Evans describes, then, is a ‘first autism’ which was dominant before 1959 and a ‘second autism’ which continues to live with us today. It is the first goal of MA to articulate the nature of those two autisms and to explain why one came to supplant the other. As is befitting of a Foucauldian analysis, understanding the above rupture requires that attention be paid to the role of institutions (in particular the Tavistock Clinic and Maudsley Hospital), their patients, their methods of choice (case studies and epidemiology, respectfully), and their relationship to governmental policy more generally.

The second goal of MA is to ask ‘why autism, in particular, as opposed to any other descriptive concept in psychology, has grown in such immense proportions and gone on to achieve such a celebrity status within popular culture’ (MA, p. 4, italics in original). This, it strikes me, is an excellent and under-examined question for it is common to hear that diagnostic substitution explains the increase in autism prevalence, far more unusual to hear an explanation of why autism, amongst an almost infinite number of alternatives, found favour. Evans’ answer to this is that the new autism, undergirded by statistical knowledge of entire populations rather than clinical samples, ‘was used to affirm absolutely the rights of autistic individuals to participate in social life and to have their rights acknowledged and appreciated on a par with those without such impairments’ (ibid.: 327). Here, Evans’ work seems to offer a possible answer to the question posed by Sheffer regarding autism and its relationship to different social configurations:

The second autism encouraged the recognition of individuals with atypical forms of ‘social development’ and ultimately did not seek to enable their
compliance as social subjects. This is why the rise in autism, the rise in recognition in children’s rights and the rise in neoliberalism go hand in hand.

(ibid.: 432)

Between them MA and AC only begin to map the contours of this question of the relationship between political economy and autism but it is hard to shake the idea that the authors have got at something important here, and that future productive work remains to be done in this area. Evans has described this conceptual rupture before, including in a widely cited piece in this journal (2013). What a monograph-length treatment of the issue allows is for Evans to more fully map the seismic activity, to explore the contours and fissures that constitute the geography surrounding the main event. Indeed, it is this elaboration that is both MA’s strength and its weakness. There are frequently unparalleled articulations of early research into autism. Evans’ consideration of the concept of autism before Kanner, with significant attention devoted to the importance of Bowlby, Freud and Piaget, is a crucial and important corrective to a body of literature which frequently does little more than pay passing mention to Bleuler (I stand guilty as charged). The methods, institutions, disagreements, and epistemological commitments of various schools of thought are mapped in such a way that, all being well, those of us writing about autism will never again reduce psychoanalysis to Bettelheim or cognitive psychology to Baron-Cohen. At the same time, coming with Evans on this journey is not always easy. While Evans is an exceptionally clear writer, not many concessions are made to fellow travellers. Chapter 5, which is largely concerned with the period since the 1980s and about which I know most, is 80 pages of more-or-less solid text, has 243 endnotes, and contains and covers governmental reports, conceptual change, and scientific research in an amount of detail which is sometimes overwhelming.
The same cannot be said of Des Fitzgerald’s Tracing Autism (TA), less than half the length of MA (less than a third of the length of IDK) and without doubt one of the best written and engaging books I’ve read in a long time. The title term tracing autism is, in fact, not Fitzgerald’s but an interviewee’s. Right at the beginning of the book, said interviewee tells us that: ‘You can, without doubt, trace it [autism] up – now, not very easily. But you can’ (TA, p. 11). That Fitzgerald takes the title of his book from a participant is, I think, important. Fitzgerald says that ‘we’ (sociologists, anthropologists, and historians) need to start thinking of neuroscientists as ‘…authors, methodologists, and theoreticians in their own right’ (ibid.: 182) and it thus seems fitting that – as was the case in another recent examination of the emerging neurosciences, Tobias Rees’ Plastic Reason (2016) – the terminology offered by neuroscientists is put to conceptual work.

Fitzgerald’s treatment of the ‘tracing autism’ quote is also suggestive. Fitzgerald makes no comment on the ‘without doubt’ which is perhaps indicative of a cocksure confidence in neuroscientific explanation and advancement. Neither is Fitzgerald particularly concerned with the ‘up’ which strongly suggests a neurological reductionism – albeit, perhaps, in an enlightened form (cf. Hedgecoe, 2001) – and a distinctly non-entangled declaration that we need to start from a neurological core. Indeed, Fitzgerald isn’t even interested with the ‘it’ and is very open (TA, p. 170) about the fact that his book has a lot more to say about neuroscience than it does about autism. Instead, nearly all of the epistemological weight is placed upon the word ‘tracing’.

Tracing, says Fitzgerald:

…allows me… to describe the active way that these neuroscientists work to establish lines of connection within a complex and often ambiguous research
area, while being faithful to how they refuse to relinquish the sense of a distinctive and singular neurobiology of autism as an organic phenomenon that is actually quite independent of this labor. (TA, p. 12, italics in original)

Across the course of the book, and following this method, Fitzgerald traces the nuanced and affectively charged discourse of neuroscientists as they talk about autism and their own work. In an indicatively beautiful passage, Fitzgerald says of neuroscientists that:

Where I expected simplification, I found complexity; where I expected certainty, I found only ambiguity; where I expected arrogance, I found self-effacement and awkwardness; where I expected optimism and expectation, I found anxiety about the future; where I expected unbending scientism, I found affectively weighted ways of understanding, narrating, and thinking about scientific practice. Most important: where I expected a kind of committedly reductive organic materialism, I found a group of neuroscientists who were intensely aware (far more than I ever was) of the capacious thing they were dealing with, and who were profoundly open to figuring out a mode of scientific practice and experimentation that would remain alive to that complexity. (TA, p. 16)

In the wake of these conclusions, Fitzgerald argues that we don’t need a critical social study of neuroscience (TA, p. 80) because neuroscientists are already as, or more, nuanced that the social scientists who study them. Indeed, neuroscientists largely embody (ibid.: 158) the queered modest witness demanded by Donna Haraway (1997), whose work is central to Fitzgerald’s own.
Fitzgerald is more-or-less open that he has his thumb on the scales when making his reading of contemporary neuroscience quite so generous. Primarily interested in a ‘reparative’ rather than ‘paranoid’ mode of engagement (TA, p. 17), Fitzgerald actively holds ‘suspicion in abeyance’ (ibid.: 180), and has little patience for those who are less generous: nearly all readers, I imagine, will share my feeling of being personally chastised in a particularly damning final paragraph. The question which I expect the majority of us will ask when finishing the book, though, is whether the work and labour which Fitzgerald says goes into his reparative approach (ibid.: 176) is worth the constitutive exclusions and absences it, or any method, necessarily brings.

For a book which is both polemical and spends so much time thinking carefully about how scientists’ work involves ambiguously, uncertainly muddling through the space between poles, it’s perhaps fitting that I’m occupying both affectively-charged ends of the spectrum simultaneously. I am actively jealous of a scholar who is this self-evidently nimble; who is quite such an insightful interviewer; whose prose is quite so lucid, insightful, and lyrical. I am also grateful that those like myself studying – not only autism and neuroscience but the contemporary sciences in general – have this book to learn from and engage with. The plea to be more open, to give the word ‘tracing’ its due regard, is one we would do well to heed.

At the same time, I am highly wary of an approach which suggests that scientists, at least some of whom quite openly describe autistic individuals as less than human (e.g. TA, p. 45) and, not-unrelatedly, continue to see autism in terms prescribed by a straightforward medical deficit model (e.g. ibid.: 90), are to be understood en masse as latter day Barbara McClintocks (cf. Keller, 1984). I am even more wary of reparative readings/methods if speaking about such matters is ‘counter to the spirit’ (TA, p. 113) of the thing. There are, of course, notes in TA about how the politics of such statements is ‘complex’ and an acknowledgement that Fitzgerald is ‘troubled’ by them (ibid.: 45). I think the term ‘troubled’
is of particular import here: Eva Haifa Giraud (2019) discusses at length the increasing frequency with which Haraway’s injunction to ‘stay with the trouble’ ends up as a more-or-less straightforward defence of the status quo and that, too often, ‘[doing] nothing is what trouble looks like’ (p. 122). My own suspicion, is that we are close to that point here.

There is a fascinating exchange around halfway through TA wherein a Professor being interviewed by Fitzgerald tells him that the correct ‘object of psychology [is]… a biological organism’ (TA, p. 122, italics in original). In order to prove this point, the Professor says that ‘…you know, we have to piss and shit and sleep and have sex and stuff like that’ (ibid.). Fitzgerald, absolutely correctly, notes that this ‘laceratingly biological image of human animality’ (ibid.: 123) is oriented inwards towards the biological needs of the professor, the interviewee, and not autistic persons. Yet when read with and against Melanie Yergeau’s book Authoring Autism (AA) the passage, which so clearly ties animality and non-sociality to excrement, assumes a particular resonance.

Yergeau begins their book by talking about shit. Their own shit, to be precise. Recounting Yergeau’s infancy, the author’s mother describes how:

‘I’d come to your crib on Saturday mornings’, she shudders, ‘and I’d find you with poop up your neck’. She pauses for dramatic effect. ‘Up to your neck.’ Sometimes, she recounts how I’d grab my feces and lob them at the wall, or smear them on my face, or rub them against the bars of my crib. (AA, p. 1, italics in original)

Upon being diagnosed with autism in early adulthood, Yergeau details how their shitting – alongside a whole host of other behaviours and body movements – became, and to borrow from a pertinent analysis by Ian Hacking (1995: 234), an action under a new description:
My hand and full-body movements became self-stimulatory behaviors; my years-long obsession with maps and the Electric Light Orchestra became perseverations; my repetition of lines from the movie Airplane! became echolalia... This, my body, this was autism – and suddenly, with the neuropsychologist’s signature on my diagnostic papers, I was no longer my body’s author. (AA, p. 1)

Yergeau’s argument here is that, because ‘autism is medically construed as a series of involuntarities’ (ibid.: 7) and a more-or-less straightforward lack of capacity, their diagnosis significantly curtails their ability to be (read as) a wilful subject.

Of course, it is not just Yergeau who is transformed under a diagnosis: Yergeau doesn’t remark upon it, but they themselves re-describe their mother’s personal experience as an example of a genre, ‘poop talk’ (AA, p. 3), which circulates amongst parents, clinicians, and disability services. Neither is Yergeau’s argument one which applies exclusively to autism: the aforementioned work by Ian Hacking, which pertains to PTSD and has been extensively discussed in HHS (e.g. Fuller, 2002; Hacking, 2003; Roth, 2002; Sharrock and Leudar, 2002) maps on perfectly. Nonetheless, Yergeau argues that there is something particular here: Because autism is often defined ‘as that which contrasts with language, humanness, empathy, self-knowledge, understanding and rhetoricity’ (AA, p. 2) the stakes are particularly high for those diagnosed with autism because they are, in some sense, expelled from humanity.² Those who clear up shit are humanized through shared, horrific experience while the autistic subject is construed ‘as unknowable, as utterly abject and isolated and tragic, as a figure whose actions are construed less like actions and more like neuronally willed middle fingers’ (ibid.).
This is a bravura opening and while shit, as a synecdoche for autism, is flushed after the introduction it nicely captures the three dominant moves in AA. First, the ontology of autism ascribed by medical science (and particularly, although not exclusively, the theory of mind theory of autism) is ‘decidedly inhumane’ in ‘all incarnations’ (AA, p. 19). Second, the battering ram of inhumanity is Applied Behaviour Analysis (ABA), the ‘gold standard’ treatment for autism and a ‘form of intensive rhetorical intervention’ which seeks to ‘contain, tame, and redirect the neurologically queer… ABA is rhetorically and thereby materially violent towards all things queer’ (AA, p. 94). Third, and drawing upon crip theory, Yergeau presents an alternative: a neuroqueer form of rhetoricity which may not always be intentional, or meaningful, or intelligible but which does ‘question long-held notions about rhetoric and its privileged topoi’ (ibid.: 206). Yergeau, in a characteristically caustic passage, draws again upon abjected bodily fluids in order to demonstrate how we might neuroqueerly re-think rhetoricity: ‘I may not intend to vomit when watching a Jenny McCarthy video on vaccine conspiracy theories, but my emesis is most certainly effectual’ (ibid.: 87).

Yergeau’s ‘fuck you’ (AA, p. 91-2) to psychology and ABA evidently stands, in many ways, in contrast to Fitzgerald’s reparative mode. Yergeau’s general argument is one to which I’m highly sympathetic and, albeit less forcefully and eloquently, and from a quite different standpoint, have made myself (Hollin, 2017b: 628–9). Nonetheless, some of the generosity that Fitzgerald affords his interviewees may have sharpened some analyses here. As an example, the work of Francesca Happé, an eminent British psychologist who sat on the DSM-5 panel for autism, is taken as emblematic of disastrous academic work. The pieces cited here, however, are (almost) exclusively twenty or twenty-five years old and, without being an apologist or ignoring the ongoing violence of that work (which I too explore in the above cited piece), Happé’s more recent output has evidently been shaped by critique, including critique from autistic advocates. The response of Happé and psychology more generally may well be
insufficient or entirely misguided, but the lumping of ‘all incarnations’ together, smoothing out some of the chronological and ontological differences so aptly traced in Evans’ MA (for example), does mean that nuances are lost.

And this, finally, brings us back to In a Different Key. I mentioned previously that IDK was a book entirely shaped by a parental gaze; one which understands autism almost entirely through the eyes of parents and examines questions of ethics and epistemics under that light. There are times when this works well, times less so. It is when IDK finally (and it really is finally, around p. 515) turns to the neurodiversity movement that the limits of the parental gaze are made most evident: IDK betrays little more than incomprehension. The chapter veers wildly off topic; it is noted that autistic self-advocates are wary of searches for a cure (IDK, p. 519) but this is followed by a breathless page-and-a-half which revels in just such research. The discussion of the place of Asperger’s Syndrome in DSM 5 (ibid.: 528) gestures towards Asperger’s as an identity but does little to tie the discussion into neurodiversity as a social movement. The parental gaze, it seems, is simply not able to see what has happened to autism in recent years. I have little doubt that Yergeau’s intervention would be met with little else but disbelief. I have similarly little doubt what Yergeau’s response would be. Evans may well be correct that the neurodiversity movement is ‘merely an affirmation’ (MA, p. 21) of previous change, but this divergence demonstrates that there are serious questions to be asked about who gets to write and make autism, and how they get to do it.

IDK also provides some important context to all of this. As noted above, the book begins with a chapter about Donald Triplett, Case 1 in Kanner’s study. The book ends, over 600 pages and 46 chapters later, with Donald who seems to be continuing to live a fulfilling life in his home town in Mississippi eighty-odd years later. It is, frankly, both remarkable and life-affirming to see pictures of Donvan and Zucker presenting their book alongside Triplett. It is similarly remarkable to think that, pre-history aside, everything written about autism in these
five books – everything ever written – about autism has happened in a single lifetime, within Donald Triplett’s lifetime. It may be too much to ever expect consensus, maybe it isn’t even desirable, but in this context it should be no surprise to anyone that we’re not there just yet.

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Notes

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1. Sheffer is clear that Asperger’s use of Gemüt ebbs and flows with the prevailing ideology. Prior to the annexation of Austria, Gemüt is largely peripheral to Asperger’s work and, at the end of the war, he once again distances himself from the concept. Readers will draw their own conclusions about what to make of this.

2. Yergeau wryly notes the irony that they have the language to describe the lack of language ascribed to them. This in itself is taken by various non-autistic actors to be evidence that those, like Yergeau, who are able to narrate the experience of autism are not ‘really’ or ‘severely’ autistic enough to truly talk for autism. Yergeau calls this ‘demi-rhetoricity’: the argument that ‘(1) …autistic people are not autistic enough to make claims about autism; and (2) they can likewise argue that autistic people are too autistic to make claims about people’ (AA, p.32).

3. Yergeau details the institutional (UCLA), personal (Ivar Loovas), and methodological links between the first attempts to cure autism via aversive-heavy ABA and the ‘Feminine Boy Project’ which sought to intervene ‘in the lives of so-called effeminate boys perceived to be at risk for homosexuality, transsexualism, and transvestism’ (AA, p.103). See Kirkham (2017) for a historical analysis of Loovas’ work in relation to autism.

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