

Kent Academic Repository

Milton, Damian (2015) *Aut-ethnography: working from the inside out.* . The Autism Anthropologist Blog.

Downloaded from <u>https://kar.kent.ac.uk/62686/</u> The University of Kent's Academic Repository KAR

The version of record is available from https://theautismanthropologist.wordpress.com/2015/01/19/aut-ethnography-working-from-the-inside-out/

This document version Pre-print

DOI for this version

Licence for this version UNSPECIFIED

Additional information

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal*, Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact <u>ResearchSupport@kent.ac.uk</u>. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our <u>Take Down policy</u> (available from <u>https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies</u>).

Aut-ethnography: working from the inside out.

By Damian E M Milton

The Autism Anthropologist.

https://theautismanthropologist.wordpress.com/2015/01/19/aut-ethnography-working-from-the-inside-out/

"And you may ask yourself, well - how did I get here?" (Talking Heads - 'Once in a Lifetime').

Many readers of this blog will be aware of how some sociological and anthropological scholars have been turning their gaze toward autistic ways of being in the world. What readers may be less aware of is that there are also a number of autistic scholars who have been working in such fields for many years, often on the margins of academia (Arnold, 2012; Milton, 2014a). One can see expressions of how autistic people have sought to inform knowledge production in the field through their lived experience since the inception of autistic self-advocacy (e.g. Sinclair, 1993), to more recent academic commentary pieces on the potential epistemological value of autistic people being fully involved throughout the research process (Milton and Bracher, 2013; Milton, 2014b).

In this article, I will be sketching a path through some of my own work in the field and how this work links in with wider efforts within the autistic community. Instead of starting at the 'beginning' in the sense of usual, coherent linear narrative, I will 'begin' in the recent past and work backwards / sideways / 'any-old-which-ways' – p.s. this is not an 'overview'.

In a recent article (Milton, 2014c) aimed primarily for an audience of psychiatrists and medical practitioners working with autistic clients, I gave an account of my own experiences with the psychiatric profession and the fragmented sense of self-identity that I have experienced. In doing so, I gave what I referred to as an 'aut-ethnography'. Unlike auto-ethnography which often seeks to construct a coherent narrative of self over time, to me an aut-ethnography (at least my experience/version) is a fragmented one, where snippets of information are formed into 'rhizomatic' patterns of shifting meanings. Interestingly to me, Melanie Yergeau, an American autistic scholar and activist, referred to an essay she had written as an 'autie-ethnographic narrative' (Yergeau, 2013).

For me, much autistic scholarship (albeit those who have become involved in 'hard science' disciplines) has unsurprisingly argued for, and highlighted the value of, subjective lived experience in learning about what it is to be autistic (Williams, 1996; Lawson, 2010). Many autistic activists refer to the social model (or indeed post-social models) of disability and critique purely deficit model definitions of what autism 'is', whilst not wishing to detract from the huge challenges that autistic people in, all our diversity, experience in navigating social life. This 'standpoint epistemology' and

arguments over the value of such knowledge can be seen as reminiscent of previous debates in social science regarding insider/outsider interpretations, Orientalism, situated knowledge, and so on. Autism does not just represent a form of cultural understanding however (although yes – autistic communities and culture do 'exist' for anyone still not sure), but also refers to differing neurological embodiments and dispositional affordances that shape one's interactions with social life (Milton, 2014a) – one of the consequences of which being the 'double empathy problem' (Milton, 2012, 2014b, Chown, 2014).

My own theorising regarding the 'double empathy problem' came about owing to the disjuncture I felt with the dominance of 'theory of mind' or 'mentalising' theory within the field. Such theorising leads to the framing of the social interaction difficulties autistic people face as primarily located within the brain/mind of the autistic person, rather than in a breakdown in reciprocity and communication between two differently disposed 'social actors' (Milton, 2012). According to 'double empathy' theory, it is a problem experienced by both parties, otherwise why would autistic ways of being be such an 'enigma' to non-autistic 'experts' in the field. This breakdown in understanding has been remarked upon in some form or another by many autistic writers (e.g. Yergeau, 2013) with the theory of the 'double empathy problem' attempting to situate such an understanding within sociological and social psychology theory, leaning heavily on the work of Goffman and Garfinkel amongst others.

Since this initial formulation, the theory has been expanded by other autistic scholars (Chown, 2014), and in my own work, on the acquiring of 'interactional expertise' influenced by the work of Harry Collins and Rob Evans (Milton, 2014b). The 'seed' of how I came to these ideas came from working on philosophical ideas of disposition and difference that I had been developing all my academic life, including the years before I came into contact with the concept/construction of 'autism' (Milton, 2014a). As autistic people, whether academically oriented or not, one often becomes acutely aware that one is not one of the 'in crowd' but a cultural 'outsider'. After time, some realise that their perceptions are markedly different to other peoples, but with effort one can learn systematically to at least build a level of 'interactional expertise' and, this goes for non-autistic people attempting to interact with autistic people too! On a pragmatic level, this means that one may not be able to 'walk the walk', but one may be able to gain a level of understanding of autistic 'talk' (whether verbally articulated or not).

In order to build interactive expertise in both directions, and to build bridges across the 'double empathy' divide, means the discovery of ways to work together, consequently this would mean building inclusive communities of practice where autistic expertise (Milton, 2014b) is neither devalued nor tokenised (Milton and Bracher, 2013). To build trusting and practically workable partnerships however, means establishing equal status between those working on such projects and for autistic people to no longer be stuck behind the 'glass sub-heading' (Milton and Bracher, 2013), and 'fishbowled' (Moon, cited in Milton and Moon, 2012) for the benefit of non-autistic researchers.

References

Arnold, L. (2012) Autism: its relationship to science and to people with the condition. *Autonomy: the Critical Journal of Interdisciplinary Autism Studies*. Vol. 1(1): http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR2/html

Chown, N. (2014) More on the ontological status of autism and double empathy. *Disability and Society.* Vol. 29(10): 1672-1676.

Lawson, W. (2010) The Passionate Mind: how people with autism learn. London: Jessica Kingsley.

Milton, D. (2012) On the Ontological Status of Autism: the 'Double Empathy Problem'. *Disability and Society.* Vol. 27(6): 883-887.

Milton (2014a) Embodied sociality and the conditioned relativism of dispositional diversity. *Autonomy: the Critical Journal of Interdisciplinary Autism Studies.* Vol. 1(3): http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR10/html

Milton, D. (2014b) Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism* DOI:10.1177/1362361314525281

Milton, D. (2014c) Becoming autistic: an aut-ethnography. Cutting Edge Psychiatry in Practice. Issue 4: *Autism Spectrum Disorder*: 185-192.

Milton, D. and Bracher, M. (2013) Autistics speak but are they heard? *Medical Sociology Online*. Vol. 7(2): 61-69.

Milton, D. and Moon, L. (2012) "And that Damian is what I call life changing": findings from an action research project involving autistic adults in an online sociology study group. Good Autism Practice. Vol. 13(2): 32-39.

Sinclair, J. (1993) "Don't Mourn For Us", http://www.autreat.com/dont_mourn.html, – accessed 17/01/15.

Williams, D. (1996) Autism: An Inside-Out Approach. London: Jessica Kingsley.

Yergeau, M. (2013) Clinically significant disturbance: on theorists who theorize theory of mind. *Disability Studies Quarterly.* Vol. 33(4): http://dsq-sds.org/article/view/3876/3405