

### **Kent Academic Repository**

Milton, Damian (2018) What is an aut-ethnography and what might one look like? In: Autism, Anthropology and Lived Experience: An interdisciplinary symposium, 22nd March 2018, Edinburgh, UK. (Unpublished)

### **Downloaded from**

https://kar.kent.ac.uk/66544/ The University of Kent's Academic Repository KAR

### The version of record is available from

http://www.san.ed.ac.uk/edcma/events/autism,\_anthropology\_and\_lived\_experience\_an\_interdisciplinary

### This document version

Presentation

**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 <a href="ResearchSupport@kent.ac.uk">ResearchSupport@kent.ac.uk</a>. 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 <a href="Take Down policy">Take Down policy</a> (available from <a href="https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies">https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies</a>).



What is an aut-ethnography and what might one look like?

Dr. Damian E M Milton



### Introduction

- "I may lack a social imagination, but I have a sociological one." (Milton, 2011a).
- This presentation will explore a number of issues:

- The embodied sociality of autistic people
- Explore concepts of auto and aut-ethnography
- Issues related to interactional expertise and cultural imperialism

### Ethnomethodology and autism

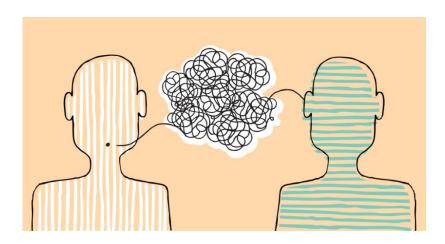
 "It is argued here that 'empathy' is a convenient illusion, and the phenomenon that people speak of when referring to it has more to do with language and a sense of 'shared' cultural meanings/symbols (or their 'ethno')." (Milton, 2011b).

### Sociality and concepts of self

- Collins (2010) states that a notion of 'self' is dependent on the ability to carry out polymorphic actions, requiring different instantiations and interpretations depending on context.
- This ability is no doubt a difficulty and challenge for many autistic people. Indeed, difficulties in episodic memory and the construction of 'self' have often been commented upon in relation to autism (Milton, 2012b).
- The differing sociality that is produced from autistic ways of being are often stigmatised for not abiding by so-called 'simple' ubiquitous expertise, leading to a lack of opportunities for extension into the social world, finally resulting in alienation, anomie, 'problems in living' (Milton, 2012c), and a vicious cycle of psycho-emotional disablement (Milton, 2012d).

### Interactional expertise

- The imitation game
- Contributory expertise
- How much interactional expertise is possible?

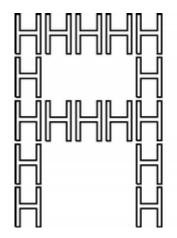


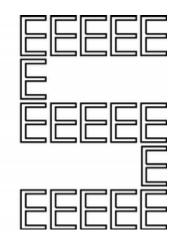
### **Autism from the 'inside-out'**

• "...right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced." (Williams, 1996: 14).

### **Autistic 'Umwelt'**

- Schutz (1967) four aspects of the 'lifeworld': **Umwelt** (directly experienced social reality), Mitwelt (contemporaries), Vorwelt (predecessors), and Folgwelt (successors).
- Transition from direct to indirect experience – increasing anonymity of the lifeworld.





- Monotropism (Murray et al. 2005).
- Pirsig (1991) dynamic and static quality.
- Merleau-Ponty (1945) suggested that all consciousness was perceptual, with a sense of the world and oneself as an emergent phenomena – an ongoing 'becoming'.
- Embodied sociality dissolving the mind/body distinction.

# Sociological and ethnographic study in the field

- Grinker anthropological studies / prevalence studies.
- Qualitative and action research in the field of education:
   Anat Greenstein, Jill Smith
- Building collaborative communities (Wenger, 1998): the work of the Autism Education Trust.
- Media studies and representations of autism.
- The work of many autistic scholars and activists: Larry Arnold, Steve Graby, Melanie Yergeau, Hannah Ebben.
- Links to Critical Disability Studies and Mad Studies (see McWade et al. 2015).
- Critical Autism Studies (e.g. Runswick-Cole et al., 2016).

 "Although there is a biological aspect to this condition named autism, the social factors involved in its identification, representation, interpretation, remediation, and performance are the most important factors in the determination of what it means to be autistic, for individuals, for families and for society." (Nadesan, 2005: 2).

# Auto-ethnography and aut-ethnography (Milton, 2014a)

- Unlike auto-ethnography which often seeks to construct a coherent narrative of self over time, to me an autethnography (at least my experience/version) is a fragmented one, where snippets of information are formed into 'rhizomatic' patterns of shifting meanings.
- Interestingly, Melanie Yergeau, an American autistic scholar and activist, referred to an essay she had written as an 'autie-ethnographic narrative' (Yergeau, 2013).
- 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).

### Standpoint epistemology

- 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, 2012e; 2014b) one of the consequences of which being the 'double empathy problem' (Milton, 2012f, 2014c, Chown, 2014).

### Fragments and clumps

- Despite many talking of the difficulties and crises that humans can have in forming a sense of self-identity, it is often assumed that such identities are placed within a coherent narrative story.
- My own experience of identity has been nothing of the sort however.
- Indeed, my experience of identity has had much more in common with postmodernist notions of 'fragmentation' and incoherence, although not an experience of fluidity or of an easily changeable or disposable identity (Milton, 2013).

# "I know that I exist, the question is: what is this 'I' that I know?" (Descartes, 1641).

- Jo Spence (1986) highlighted issue: feelings of powerlessness and being infantilised by medical practice.
- Alexa Wright (1999) exhibition called 'I' – examined social expectations of beauty – placing the disabled body in a context where it is not usually seen.
- Barthes (1977) 'Studium' (obvious symbolic meaning) and the 'Punctum' (personal to the individual – that 'pierces the viewer').



# Constructions, re-constructions and deconstructions

- Kelly (1955) personal construct theory ordering experiences – discovering, and when needed re-evaluating constructs.
- Garfinkel (1967) breaching of the natural attitude – the re-construction of constructs.
- Derrida (1988) deconstruction and discontinuity.

### Subverting the 'functional' family album

- Single photographs accompanied by narratives written in hindsight by both myself and my mother.
- Focusing on the traumatising effects of the road-traffic accident.
- Charting the history of the effects and continuation of the process (rather than resolution).
- Trauma as a breach which does not 'heal' (Garfinkel, 1967). Trauma as permanent discontinuity with previous sense of self.

# 'Views' (Blay, 2004)

- Severe head injury in 1985 leading to both working and long-term memory difficulties.
- Dissertation project 'Views' perceptions of 'being and spirituality'.
- Black and white portrait photograph followed by a translucent sheet with personal narratives written in own handwriting, and then a photograph depicting how that person wanted to be seen.

# **Utilising photographs**

- The 'Photo Book'.
- Photo taking and reporting.
- Photo sorting.
- Photo-montage and collage (Ridout, 2014).

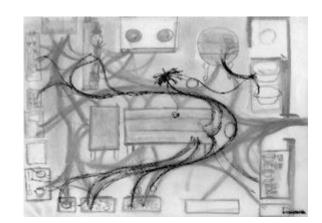


# Subverting the narrative

 "Due to the logic of power structures – the most powerful individuals with 'control' of social processes will usually have a vested interest in the norms of society and giving the impression of unity and common purpose...There is an obvious need for both unity and discontinuity – for resolution and non-resolution - in the course of human history. What is fascinating socially speaking is where these needs are expressed." (Milton, D., cited in Milton, C., 2002).

### Tracing the wander lines

 "But these impasses must always be resituated on the map, thereby opening them up to possible lines of flight. The same applies to the group map: show at what point in the rhizome there form phenomena of massification, bureaucracy, leadership, fascisation, etc., which lines nevertheless survive, if only underground, continuing to make rhizome in the shadows. Deligny's method: map the gestures and movements of an autistic child, combine several maps for the same child, for several different children." (Deleuze and Guttari, 1980).



### The work of Fernand Deligny

- For Deligny, despite the dogmatic pursuit of the "Humans-that-we-are" that is imposed onto autistic people, he thought that autistic people would continue to operate in the mode of being of the network.
- A mode of being outside of notions of self and autobiographical narrative.
- "An autistic child traces; you can always ask yourself what, and answer your own question in the same breath." (Deligny, 2015: 93).
- The maps were seen as interactive living entities, not static pieces of art to make a coherent meaning from, and yet also, as a way of attempting to engage with the way of being of non-verbal autistic people.

### Violation through interpretation

- "To communicate? I understand well, or rather the word, as I understand it is doubled...In order to make the tacit speak, what is required is to want, to do violence and to violate, and not at all a secret or something that would resist being said." (Deligny, 2015: 91).
- "When analytic thought, the knife, is applied to experience, something is always killed in the process." (Pirsig, 1974: 86).

### **Cultural imperialism**

- The process of cultural imperialism according to Young (1990) involves the establishment of ruling class ideology as the hegemonic norm.
- Those that have power in society can determine how those in a position of powerlessness are interpreted and talked about.
- Notions such as 'ableism' and 'mansplaining' can be seen as having roots in similar notions of a taken-for-granted unconscious frame of reference which renders the 'other' invisible.



- A very familiar form of oppression for autistic people is that of cultural imperialism (Milton and Bracher, 2013).
- Indeed, the entire neurodiversity movement could be seen as a response to such a way of being and emergent cultures being wholly pathologised within a medical model perspective.

# **Psychsplaining**

"Those categorised by psychprofessionals are often reduced within such relationships to that of the 'sick role' (Parsons, 1951), with one's own interpretations of oneself undermined by the 'expert knowledge' being projected upon the autistic person, who by default is positioned in a relatively powerless social position of medical 'patient'." (Milton, 2016).

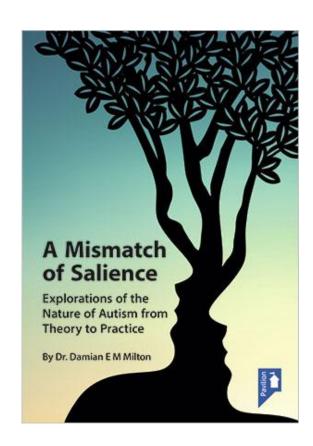


### **Building collaborative communities of practice** with autistic voices at the core

 "Grant me the dignity of meeting me on my own terms...Recognise that we are equally alien to each other, that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build bridges between us." (Sinclair, 1993)

# Where next for me? What next for the autistic community?

- To mix two old sayings together:
- Watch this space...because you ain't seen nothing yet...



- Barthes, R. (1977) Camera Lucida: Reflections on Photography. New York: Hill and Wang.
- Becker, H. (1963) Outsiders. New York: The Free Press.
- Blay, A. (2004) Views [BA dissertation project unpublished]. University of Portsmouth.
- Chown, N. (2014) More on the ontological status of autism and double empathy. Disability and Society. Vol. 29(10): 1672-1676.
- Collins, H. (2010) Tacit and Explicit Knowledge. London: University of Chicago Press.
- Collins, H. and Evans, R. (2007) Rethinking Expertise. London: University of Chicago Press.
- Deleuze, G. and Guttari, F. (1980) A Thousand Plateaus (trans. Brain Massumi, 1987). Minneapolis: University of Minnesota Press.
- Deligny, F. (2015) The Arachnean and Other Texts (trans. Drew S. Burk and Catherine Porter, 2015). Minneapolis: Univocal publishing.
- Derrida, J. (1988) Limited Inc. Evanston: Northwestern University Press.
- Descartes, R. (1641/1985) The Philosophical Writings of Rene Descartes. Cambridge: Cambridge University Press.
- Garfinkel, H. (1967) Studies in Ethnomethodology. Englewood Cliffs: Prentice-Hall.
- Kelly, G. (1955/1991) The Psychology of Personal Constructs, volumes 1 and 2. London: Routledge.
- Lawson, W. (2010) The Passionate Mind: how people with autism learn. London: Jessica Kingsley.
- McWade, B., Milton, D. and Beresford, P. (2015) Mad Studies and Neurodiversity: a dialogue. Disability and Society, vol. 30(2): 305-309.
- Merleau-Ponty (1945) Phenomenology of Perception. London: Routledge.
- Milton, C. (2002) Beyond the Frame [MA project unpublished]. University of Portsmouth.
- Milton, D. (2011a) 'Who am I meant to be': in search of a psychological model of autism from the viewpoint of an 'insider'. Critical Autism Seminar 18/01/11. Sheffield Hallam University.

- Milton, D. (2011b) "Filling in the gaps", a micro-sociological analysis of autism". Theorising Normalcy and the Mundane, 2<sup>nd</sup> International Conference. Manchester Metropolitan University.
- Milton, D. (2012a) So what exactly is autism? Autism Education Trust.
- Milton, D. (2012b) Fragments: putting the self back into the picture. Child, Youth, Disability and the Family Conference. Manchester Metropolitan University, 23/05/12.
- Milton, D. (2012c) 'Problems in Living' and the mental well-being of people on the autism spectrum. Asperger United. Editions 71-72.
- Milton, D. (2012d) The normalisation agenda and the psycho-emotional disablement of autistic people. Critical Disability Studies Conference 2012. Lancaster University, 13/09/12.
- Milton, D. (2012e) Embodied sociality and the conditioned relativism of dispositional diversity. Theorising Normalcy 2012. University of Chester, 26/06/12.
- Milton, D. (2012f) On the Ontological Status of Autism: the 'Double Empathy Problem'. Disability and Society. Vol. 27(6): 883-887.
- Milton, D. (2013) 'Clumps': an autistic reterritorialisation of the rhizome. In: Theorising Normalcy and the Mundane. 4<sup>th</sup> International Conference, Sheffield Hallam University, 4<sup>th</sup> September 2013.
- Milton, D. (2014a) Becoming autistic: an aut-ethnography. Cutting Edge Psychiatry in Practice. Issue 4: Autism Spectrum Disorder: 185-192.
- Milton, D. (2014b) Embodied sociality and the conditioned relativism of dispositional diversity. Autonomy, the Critical Journal of Interdisciplinary Autism Studies, 1(3), [online]. http://www.larryarnold.net/Autonomy/index.php/autonomy/article/view/AR10/html, [Accessed 21st February 2016].
- Milton, D. (2014c) Autistic expertise: a critical reflection on the production of knowledge in autism studies. Autism: The International Journal of Research and Practice, Vol. 18(7): 794-802.
- Milton, D. (2016) Disposable dispositions: reflections upon the work of Iris Marion Young in relation to the social oppression of autistic people. Disability and Society, Vol. 31(10): 1403-1407.
- Milton, D. (2017) A Mismatch of Salience: an exploration of autism from theory to practice. Hove: Pavilion Press.

- Milton, D. and Bracher, M. (2013) Autistics speak but are they heard? Medical Sociology Online. Vol. 7(2): 61-69, [online]. http://www.medicalsociologyonline.org/resources/Vol7lss2/MSo 7.2 Autistics-speak-but-are-theyheard Milton-and-Bracher.pdf, [Accessed 06/11/16].
- Murray, D., Lesser, M. and Lawson, W. (2005) 'Attention, monotropism and the diagnostic criteria for autism.' Autism. Vol. 9(2), pp. 136-156.
- Nadesan, M. (2005) Constructing Autism: Unravelling the 'truth' and understanding the social. Abingdon: Routledge.
- Parsons, T. (1951) The Social System. New York: The Free Press.
- Pieper, J. (1989) An Anthology. San-Francisco: Ignatius Press.
- Pirsig, R. M. (1974) Zen and the Art of Motorcycle Maintenance. London: Vintage.
- Pirsig, R. (1991) *Lila: An Inquiry into Morals*. London: Black Swan.
- Ridout, S. (2014) More than Picture-Making: Reflecting on Collage as a Narrative Tool for Opening Discourse on the Involvement of Autistics in Autism Research. Autonomy, the Critical Journal of Interdisciplinary Autism Studies, 1(3), [online]. http://www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/AR14/html, [Accessed 11<sup>th</sup> August 2017].
- Runswick-Cole, K., Mallet, R. and Timimi, S. (Eds) (2016) Re-Thinking Autism: Diagnosis, Identity and Equality. London: Jessica Kingsley.
- Schutz, A. (1967) The Phenomenology of the Social World. Evanston, IL: Northwestern University Press.
- Sinclair, J. (1993) Don't Mourn For Us, [online]. http://www.autreat.com/dont\_mourn.html, [Accessed 21st February] 2018].
- Spence, J. (1986) Putting myself in the picture: a Political, Personal and Photographic Autobiography. London: Camden Press.
- Williams, D. (1996) Autism: an 'inside-out' approach. London: Jessica Kingsley.
- Wright, A. (1999) J. Accessed at: http://www.medphys.ucl.ac.uk/mgi/alexa/ipg.html, on 21/02/12.
- Uexkull, J. (1957), accessed from: http://en.wikipedia.org/wiki/Umwelt, 09/06/12.

- Yergeau, M. (2013) Clinically significant disturbance: on theorists who theorize theory of mind. Disability Studies Quartely, Vol. 33(4).
- Young, I. (2005, first published 1990), "Five faces of oppression", in Cudd, Ann E; Andreasen, Robin O., Feminist theory: a philosophical anthology, Oxford, UK Malden, Massachusetts: Blackwell, pp. 91-104.

# THE UK'S EUROPEAN UNIVERSITY



