

# From finding a voice to being understood: exploring the double empathy problem



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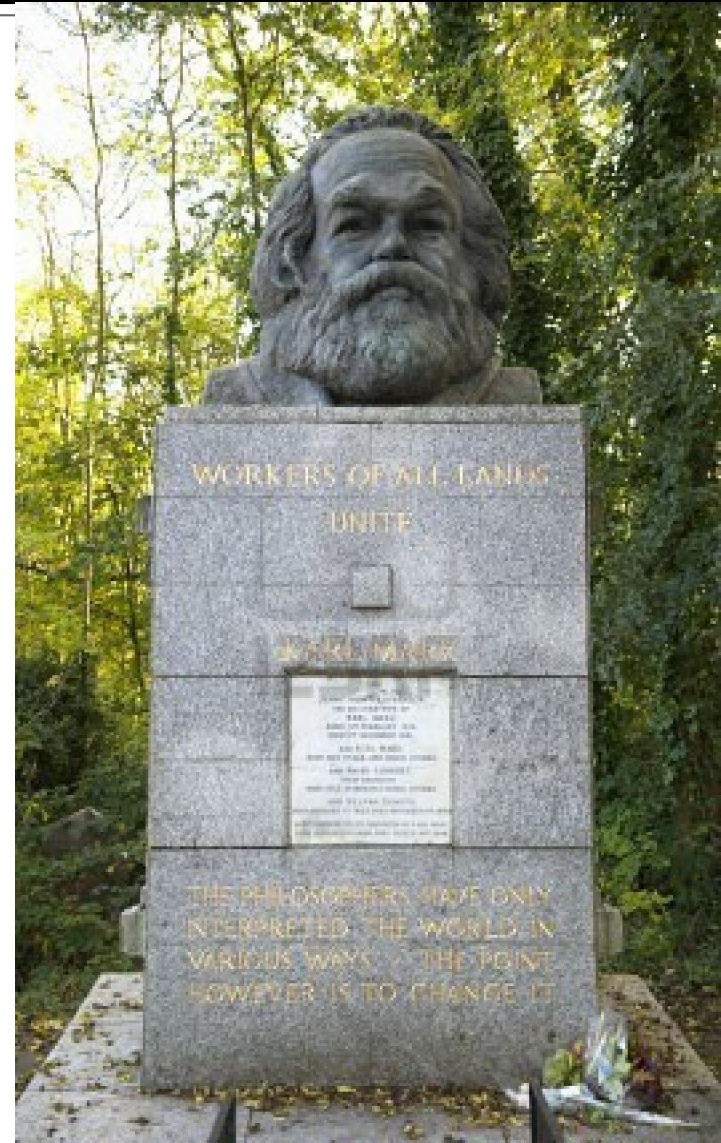
# Introduction

- Whilst it is of great relevance for autistic people to find ways of expressing themselves, there can still remain a gap in terms of being listened to and being understood.
- An overview of the 'double empathy problem' theory.
- How autistic voices are presented and perceived within the field of autism studies.
- Barriers to autistic voices being 'found', or at least understood on their own terms.
- What counts as, as well as how one acquires, various forms of 'expertise', with the view of exploring the perennial topic of 'who should speak for autistic people?'.

- *Socrates: ...Can you point out any compelling rhetorical reason why he should have put his arguments together in the order that he has?*
- *Phaedrus: You do me too much honour if you suppose that I am capable of divining his motives so exactly. (Plato, 1973: 78).*

# Conditioned are we...

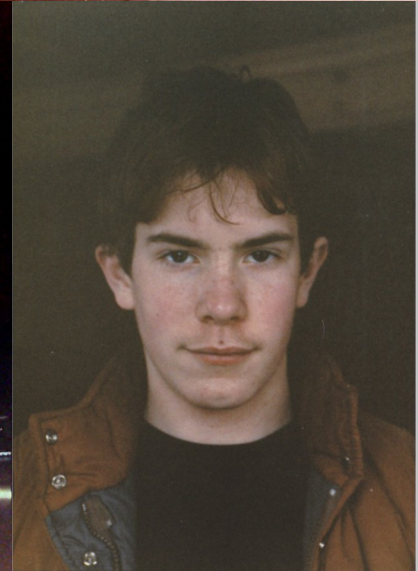
- 'Men make their own history, but they do not make it just as they please...The tradition of all the dead generations weighs like a nightmare on the brain of the living' (Marx, 1852/1970:15).
- Materially and discursively conditioned within an 'his'torical and cultural context.



# ...but uniquely and relativistically



- Insider and outsider perspectives
- Positionality
- Situated knowledge
- Neurodiversity



# Assumptions of social relationality

- The 'subtext' of a social situation is actively created by people in context.
- The 'theory of mind' and 'empathy' utilised in normative psychological models of human interaction, refers to the ability an individual has to assume understandings of the mental states and motives of other people.
- When such 'empathy' is applied toward an 'autistic person' however, it is often wildly inaccurate in its measure.
- Such attempts are often felt as invasive, imposing and threatening by an 'autistic person', especially when protestations to the contrary are ignored by the person doing the 'empathising'.

# Dyspathy (Cameron, 2012)

- Cameron (2012) uses the term 'dyspathy' to highlight how empathy is often blocked or resisted by people.
- Cameron (2012) cites a number of recent studies using fMRI scanning claim to demonstrate a bias towards in-group members in 'automatic' empathy.
- Such findings support the earlier social psychological theories of Tajfel (1981), which found that people felt increasing emotional connection to those deemed within their social 'in-group', whilst stereotyping 'outsiders'.

- “If we were to be continually tuning into other people’s emotions, we would be perpetually anxious or exhilarated, and very quickly exhausted. We must therefore have very efficient inhibitory mechanisms that screen out most of the emotional empathy being carried out by our brains, without us even noticing.” (Cameron, 2012).

- “95% of people don’t understand me”.
- “Friends are overwhelming”.
- “Adults never leave me alone”.
- “Adults don’t stop bullying me”.

■ Quotes taken from Jones et al. (2012).

# The double empathy problem

- The 'double empathy problem' refers to the mutual incomprehension that occurs between people of different dispositional outlooks and personal conceptual understandings when attempts are made to communicate meaning.
- In a sense it is a 'double problem' as both people experience it, and so it is not a singular problem located in any one person.
- The 'empathy' problem being a 'two-way street' has been mentioned by both 'autistic writers' (Sinclair, 1993) and non-autistic writers alike (Hacking, 2009).

# The autistic 'me' and the autistic 'I'

- The philosophy of George Herbert Mead (1934).
- The autistic 'me'.
- The reclaiming of the autistic 'I'.
- The potential fishbowling of non-autistic perspectives (Milton and Moon, 2012).
- Socially situated as like anyone else, yet often a disjuncture between the way the autistic 'me' and 'I' are constructed.
- The alienation of the autistic voice within knowledge production about autistic people.

# Autistics speak, but are they heard?

- The field of autism studies is a highly disputed territory with competing contradictory descriptions and ideologies abounding.
- Within this disputed territory however, it has been the voice and claims of autistic people to their own expertise in knowledge production that is most recent in the debate, and traditionally the least attended to.

# The ‘machine-like’ metaphor

- Incapable of socialisation?
- “The autist is only himself...and is not an active member of a greater organism which he is influenced by and which he influences constantly.” (Asperger, 1991: 38).
- Sociality is never a ‘zero-sum game’. Not ‘machine-like’, but coming from a different (dis)position.



# The autistic person as social 'outsider'

- "...the individual is a temporary and leaky repository of collective knowledge. Kept apart from society for any length of time and the context sensitivity and currency of the individual's abilities will fade." (Collins, 2010: 133).
- What kind of social knowledge does an autistic person acquire?
- The (dis)position of an 'outsider' (Becker, 1963).



# The nature of expertise

- Expertise as a competence?
- Expertise as something inherent in the person?
- Expertise as embodied experience (Merleau-Ponty, 1945)?
- Expertise as social practice (Collins and Evans, 2007)?
- ‘Collective tacit knowledge’ and ‘interactive expertise’ as the property of the ‘social’ (and machines not being able to mimic this form of knowledge).

# How to gain interactional expertise?

- “...an ideal target for those aiming to do competent fieldwork in sociology of scientific knowledge is the acquisition of interactional expertise.” (Collins et al, 2006: 666).
- The ‘imitation game’ (Collins and Evans, 2007).



# Lost in translation?

- When differences in disposition and social understandings have foundation in neurological diversity, how much interactional expertise is possible? Is something always 'lost in translation'?
- Is some level of expertise in what it is to be autistic on the level of lived experience always beyond the grasp of non-autistic researchers?
- It could be said that being autistic is a 'state-specific expertise' (Collins and Evans, 2007).
- Is understanding autistic experiences, a more nuanced version of understanding the perception of a bat (Nagel, 1974) or attempting to speak to a lion (Wittgenstein, 1953)?

# Autism as identity and culture

- “They [autistic people] are creating the language in which to describe the experience of autism, and hence helping to forge the concepts in which to think autism.” (Hacking, 2009, p. 1467).

# What if the gap is more cultural than biological?

- If autistic people could gain enough interactional expertise they could potentially 'pass' as non-autistic in an imitation game, and vice-versa.
- If autistic and non-autistic people share in the same sociality (albeit in somewhat different ways), then the development of shared interactional expertise becomes possible in both directions and the double empathy gap (Milton, 2012) in understanding can begin to be bridged.
- Embodied differences may act as obstacles to the gaining of interactional expertise. Yet, autistic people are not lions, bats, or aliens, but human and social, albeit idiosyncratically, with diverse experiences of socialisation, or the lack of access into communities of practice to be immersed in.

# Participatory methods in social research

- It would seem clear that by social researchers taking on a more participatory model coupled with the emergence of autistic scholarship, that if such bridges cannot be completely traversed than they can certainly be improved.
- The acquiring of interactional expertise and the closing of the gap would be best served by fully collaborative research projects, leading to less discriminatory practices within social research and from the practitioners that academics seek to inform, thus furthering the interactional expertise of all concerned.
- Non-autistic social researchers still need to remember though who the 'contributory experts' are in the formation of what it is to be autistic...



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