The double empathy problem: from theory to practice

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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.
- Implications for practice.

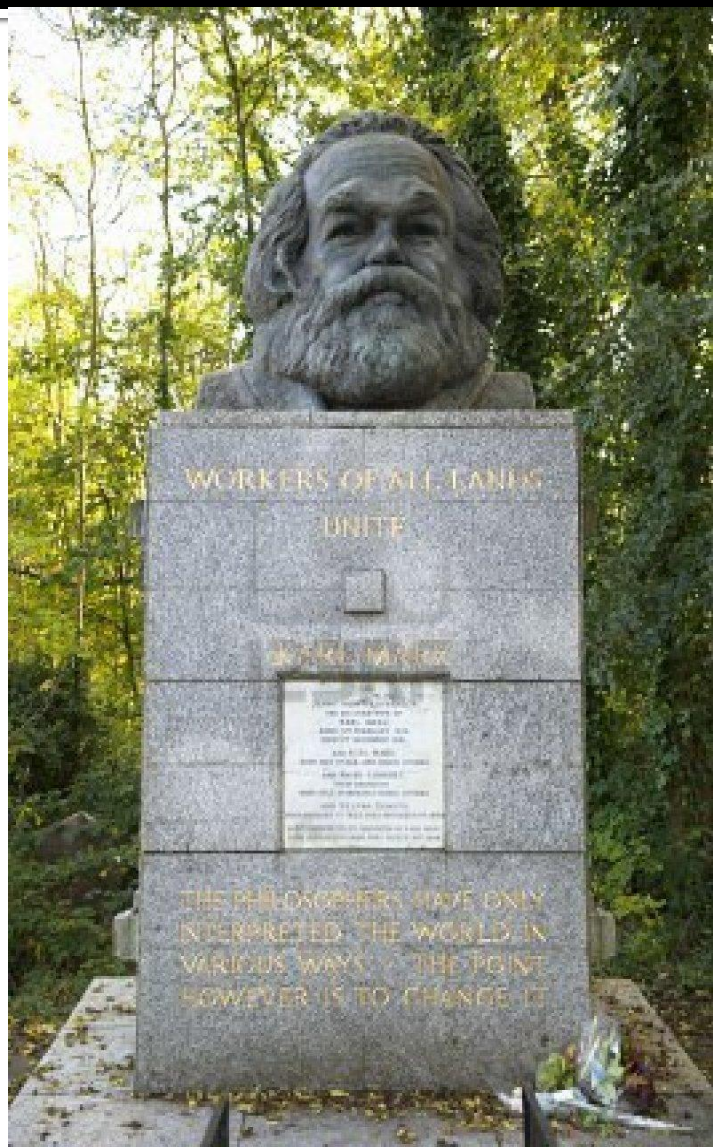
- *Socrates: …Can you point out any compelling rhetorical reason why he should have put his arguments together in the order that he has?*
- *Phaedrus: You do me too much honour if you suppose that I am capable of divining his motives so exactly. (Plato, 1973: 78).*

The contested status of what autism is

- The triad of dominant theories: theory of mind, executive function, and weak central coherence.
- Positioning of autism as a neurological disorder, a pathological deviance from expected functional stages of development.
- This approach when applied to the support of those diagnosed often becomes a 'treatment program' of modifying the autistic person as 'best one can' to fit in with the mainstream culture of society.

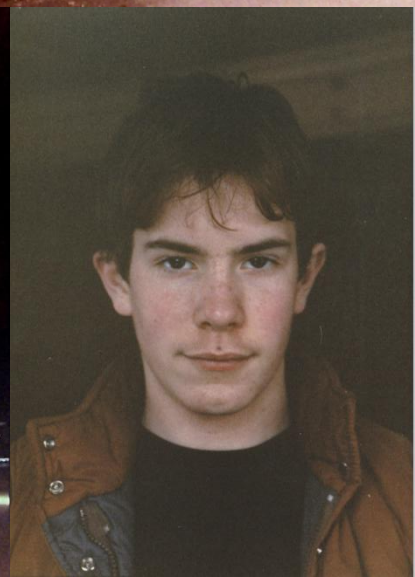
Conditioned are we…

- ‘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).
- Conditioned within an ‘his’torical and cultural context.



…but uniquely and relativistically

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



Assumptions of social relationality

- The subtext of a social situation is actively created by people in context.
- The 'theory of mind' concept utilised in psychological models of human interaction, refer 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.
- Such research supports 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).
- 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.

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 disposition. Not 'context blind', but a mismatch in salience.

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 disposition 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 social beings (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 and practitioners?
- It could be said that being autistic is a 'state-specific expertise' (Collins and Evans, 2007).

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).

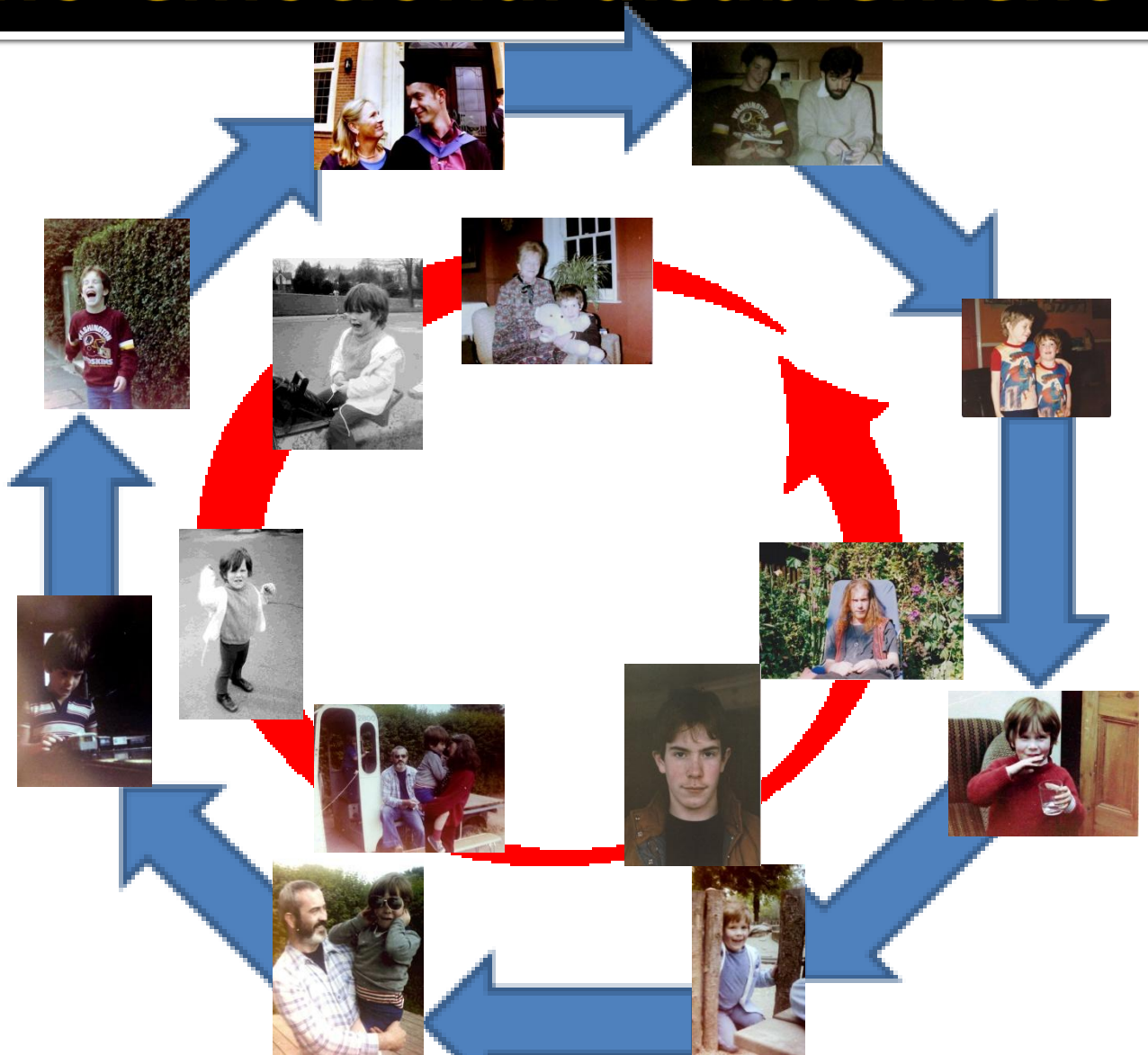
What if the gap is more cultural then biological?

- 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 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.

The stigma of being 'othered' and the normalisation agenda

- To be defined as abnormal in society, is often conflated with being perceived as 'pathological' in some way and to be socially stigmatised, shunned, and sanctioned.
- The denigration of difference (Tajfel, 1981).

Reversing the vicious circle of psycho-emotional disablement



Implications for service providers

- There is a spectrum in theory and practice more generally regarding service provision for 'autistic people'.
- These narratives and practices can be said to be embedded within the wider discursive debate that exists between the medical and social models of disability as played out in the field of autism.
- There is an increasing complacency around the idea that lead professionals and practitioners have a good understanding of what 'good autism practice' entails, for me this is an ongoing imperfect process of interaction and should never be seen as a given.
- Working with the autistic person and not against 'their autism' – humility and building tacit rapport.
- This will require participation and not tokenism…

Participatory methods

- It would seem clear that by taking on a more participatory model, that if such divides in understanding 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 projects, leading to less discriminatory practices, and furthering the interactional expertise of all concerned.
- Non-autistic people still need to remember though who the 'contributory experts' are in the formation of what it is to be autistic…
- Inclusion: belonging within a community of practice and 'being taken seriously'.

References

- Asperger, H (1944/1991)"'Autistic Psychopathy' in Childhood," trans. U. Frith. In U. Frith, *Autism and Asperger Syndrome,* 37-92. Cambridge: Cambridge University Press.
- Becker, H. (1963) *Outsiders.* New York: The Free Press.
- Cameron, L. (2012) *Dyspathy: the dynamic complement of empathy.* The Open University.
- Collins, H., Evans, R., Ribeiro, R. and Hall, M. (2006) Experiments with interactional expertise. *Studies in History and Philosophy of Science.* Vol. 37, pp. 656-674.
- Collins, H. and Evans, R. (2007) *Rethinking Expertise.* London: University of Chicago Press.
- Collins, H. (2010) *Tacit and Explicit Knowledge.* London: University of Chicago Press.
- Hacking, I. (2009) Autistic autobiography, *Philosophical Transactions of the Royal Society: Biological Sciences.* Vol. 364(1522), p. 1467-1473.
- Jones, G., English, A., Jones, G., Lyn-Cook, L., and Wittemeyer, K. (2012) *The Autism Education Trust National School Standards.* Autism Education Trust.
- Marx, K. (1852/1970) The Eighteenth Brumaire of Louis Bonaparte. In R. Tucker (ed), *The Marx-Engels Reader.* New York: Norton, pp. 436-525.
- Mead, G. (1934) *Mind, Self and Society: From the Standpoint of a Social Behaviorist.* Chicago: University of Chicago Press.
- Merleau-Ponty (1945) *Phenomenology of Perception*. London: Routledge.
- Milton, D. (2012) On the ontological status of autism: the double empathy problem. *Disability and Society.* Vol. 27(6): 883-887.
- 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.
- Nagel, T. (1974/1981) What is it like to be a bat? In D. R. Hofstadter and D. C. Dennett (ed's), *The Mind's I: Fantasies and Reflections on Self and Soul.* London: Penguin.
- Plato, trans. Hamilton, W. (1973) *Phaedrus and Letters VII and VIII.* London: Penguin.
- Sinclair, J. (1993) "Don't Mourn For Us", http://www.autreat.com/dont_mourn.html, - accessed 10/11/09.
- Tajfel, H. (1981) *Human groups and social categories.* Cambridge: Cambridge University Press.
- Wittgenstein, L. (1953/2001) *Philosophical Investigations*. Blackwell Publishing.