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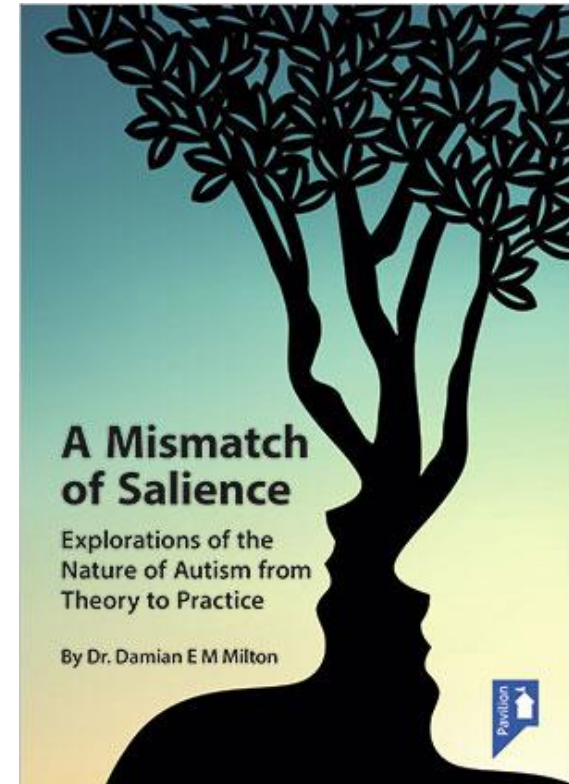
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The double empathy problem - towards mutual understanding in a neurodiverse world

Dr. Damian E M Milton



Introduction

- Overview of the double empathy problem and some of the evidence base to support it.
- Participatory practices in autism research.
- Building mutual understanding.

- *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).*
- The 'theory of mind' model and what it leaves out.

Early days and how the theory developed

- “Embodied sociality and the conditioned relativism of dispositional diversity” (Milton, 2014b) – reflections on work from the 1990s.
- By late 2000s had come across the work of autistic authors such as Jim Sinclair and Claire Sainsbury and had started to use the term ‘double empathy problem’ at a parent group I was a part of as a response to ideas regarding ‘theory of mind’
- First presentations on topic in 2010, and first publication in a journal in 2012.
- Yet not alone in way of thinking – see Ian Hacking, Luke Beardon, and Rachel Cohen-Rottenberg among others.

Mutual incomprehension

- *“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'

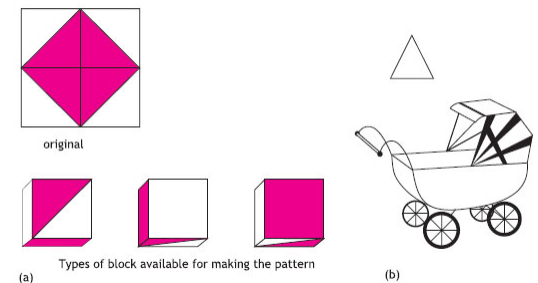
- A case of mutual incomprehension?
- Breakdown in interaction between autistic and non-autistic people as not solely located in the mind of the autistic person. The theory of the double empathy problem sees it as largely due to the differing perspectives of those attempting to interact with one another (Milton, 2012a; 2014a; Milton et al. 2018; Chown, 2014).
- Theory of autistic mind can often leave a great deal to be desired.
- Fork handles!

Dyspathy

- 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).

An 'interest model' of autism

- Autism and cognitive models of deficit.
- Autism and monotropism (Murray et al. 2005; Lawson, 2010).
- Attention as a scarce resource.
- Monotropic attention strategies and the 'attention tunnel'.
- Monotropism, repetitive behaviour and interests, and 'flow states'.



Interactional expertise

- The imitation game.
- Contributory expertise.
- How much interactional expertise is possible (Milton, 2014)?
- How much effort has been made by researchers and those designing practice models?

The evidence-base

- Sheppard et al. (2016) investigated non-autistic participants' ability to interpret the behavioural reactions of autistic people in naturalistic social interactions.
- Non-autistic participants who viewed the recorded videos were less able to guess which event the video participant had experienced for autistic than non-autistic participants, apart from for reactions to a joke.

Studies of forming first impressions

- Research has also asked a more general question of how autistic people are perceived by non-autistic others.
- If autistic people are perceived less favourably then this could result in avoidance and social exclusion, contributing to the social difficulties experienced.
- Stagg et al. (2014) found that non-autistic adults rated autistic children as less expressive and less attractive than the non-autistic children based on brief videos of them.

- Sasson et al. (2017a) carried out three studies in which they showed that non-autistic adults rated autistic adults and children less favourably than non-autistic adults and children on a wide variety of evaluative dimensions, as well as indicating reduced intentions to engage with them.
- Further research by Sasson et al. (2017b) examined the impact of providing diagnostic labelling information on the impressions formed and found this to have a positive effect.

Studies of metaperception

- Sasson et al. (2018) participants were asked to estimate how they thought others would perceive them on a wide range of personality traits, then observers judged them on the same traits after viewing a recording of them.
- They found that autistic participants were less accurate than non-autistic participants in judging how they would be perceived as others, because they overestimated how positively they would be perceived.

- Usher et al. (2018) studied impressions formed by dyads of adolescents where one member of the dyad was autistic and one was not, who engaged in a five-minute conversation.
- Autistic participants were found to be more accurate in judging whether the non-autistic partner liked them than non-autistic participants were.

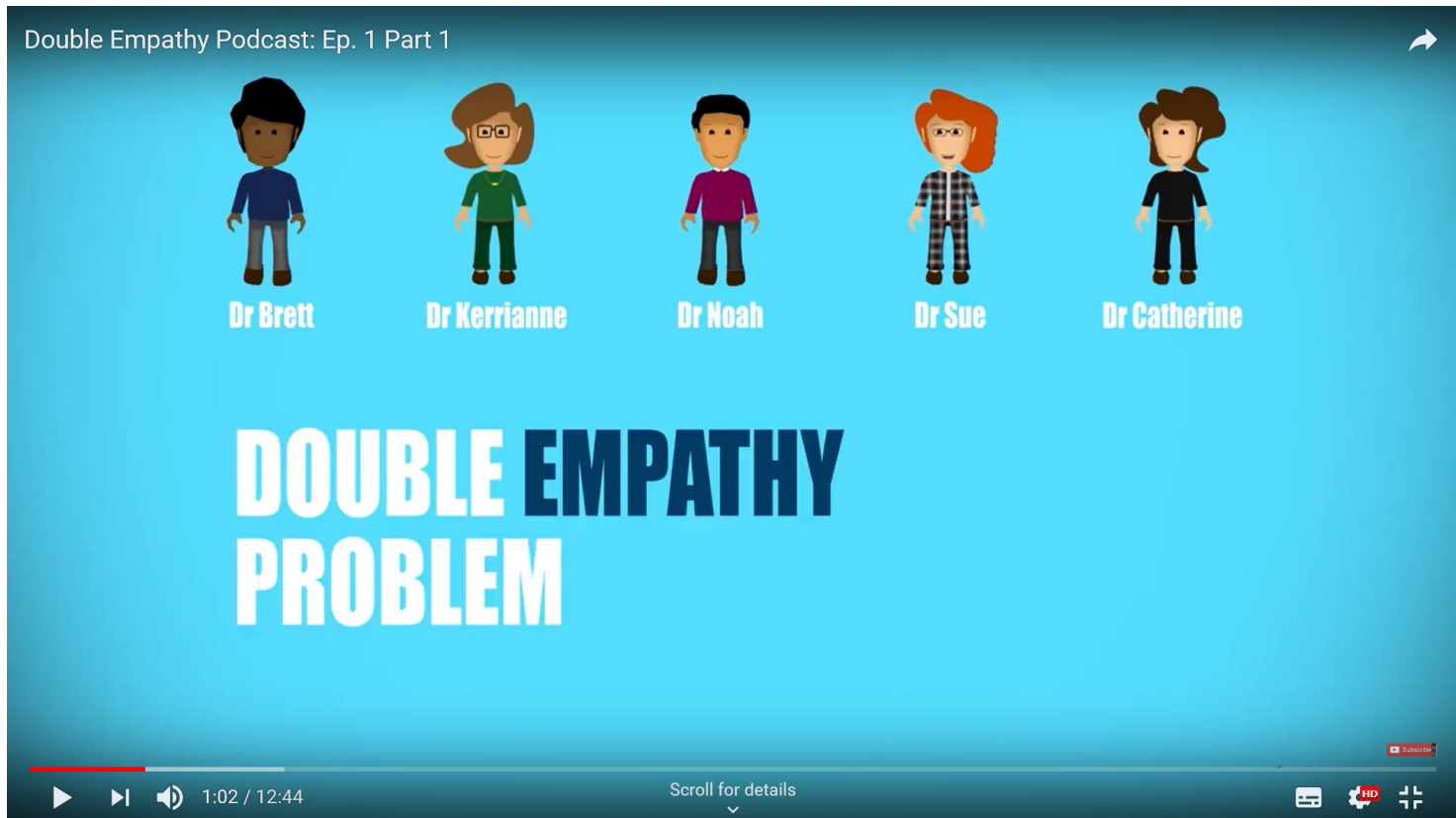
- Heasman and Gillespie (2017) investigated perceptions and misperceptions for dyads of autistic individuals and their family members.
- When asked about reasons for misunderstandings, family members tended to cite an extreme impairment in social understanding of the autistic person, while autistic participants themselves reflected on both the self and other as causes of misunderstandings.

- Overall, studies of metaperception suggest that autistic people are quite good at estimating how specific others perceive them, but may have some difficulty judging how they come across in general. Consistent with the DEP, non-autistic people may have difficulty working out how they are perceived by autistic people whom they have just met.

Neurodiverse interactions

- It has been observed that autistic people appear to have a greater affinity with other autistic people than non-autistic people generally do (Chown, 2014).
- This raises the possibility that autistic people may show improved, if not superior, understanding of other autistic people and may consequently show fewer signs of 'social impairment' in the company of their in-group (Tajfel, 1981).
- This is indeed what has been shown in work carried out by Catherine Crompton at the University of Edinburgh.

The Double Empathy Problem Virtual Symposium



New directions

- The work of Robert Chapman, Gemma Williams, and designers such as Wendy Keay-Bright, Katie Gaudion and Jelle van Dijk.
- Crossover with neuroscientific theory regarding ‘predictive coding’:
- The dialectical misattunement hypothesis:
“...views psychopathology not merely as disordered function within single brains but also as a dynamic interpersonal mismatch that encompasses various levels of description.”
(Bolis, 2017).
- A ‘mismatch of salience’.

Cultural imperialism

- Those that have power in society can determine how those in a position of powerlessness are interpreted and talked about (Young, 1990).
- 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.



Power

- Important to remember that the double empathy problem is situated within wider unequal (and intersectional) power relations.
- Avoiding tokenism and ceding power. Humility and rapport (tacit knowledge) building.
- Reducing imposition of social expectations.

The autistic voice in academia

- People on the autism spectrum rarely in the role of researcher.
- The ‘glass sub-heading’ (Milton and Bracher, 2013).
- *“Of over \$314 million in research funding, only 3% went to research into services, supports and education and less than 1% went to research into the needs of adults.”* (Ne’eman, 2011).

Participatory research

- A range of theoretical and methodological approaches.
- Yet with the main objective of handing power from the researcher to research participants, who are often community members or community-based organisations.
- In participatory research, participants have control over the research agenda, the process and actions taken.
- Most importantly, people themselves are the ones who analyse and reflect on the information generated, in order to obtain the findings and conclusions of the research process.

Collaboration

- Setting the research agenda.
- Design and development of strategies and methodologies.
- Avoiding tokenism...
- The Participatory Autism Research Collective (PARC):
www.PARCAutism.co.uk



A couple of quotes to conclude:

- *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).*

- *When I am in an environment I feel comfortable in, with people who are kind and tolerant, and doing things I enjoy, then I am as happy as the next person. It is when people tell me I should think, speak or behave differently that I start to feel different, upset, isolated and worthless. So surely the problem is a lack of fit with the environment rather than something inside my brain that needs to be fixed? (Victoria, 'Are You Taking Something for It?', issue 76, 12; cited in Milton and Sims, 2016).*

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