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Reflecting upon the double empathy problem: new directions and practical implications.

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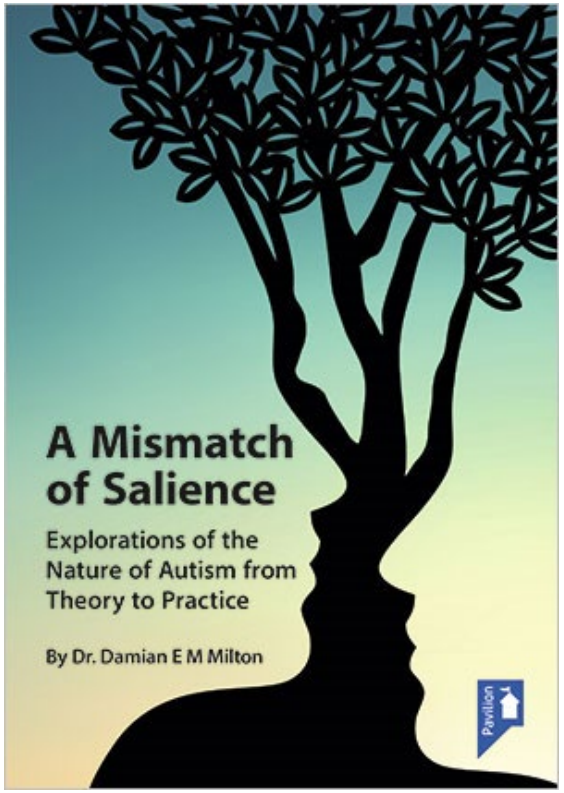


A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005) and one of my daughter's (diagnosed 2023).
- A background in Social Science (initially Sociology).
- Senior Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent.
- Visiting Lecturer at LSBU and often at other Universities.
- Chair of PARC and Director at NAT.

- “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).

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.

The ‘double empathy problem’

- “A disjuncture in reciprocity between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perceptions of the lifeworld - perceived as a breach in the 'natural attitude' of what constitutes 'social reality' for ‘neuro-typical’ people and yet an everyday and often traumatic experience for ‘autistic people’.” (Milton, 2012: 883).

The evidence-base

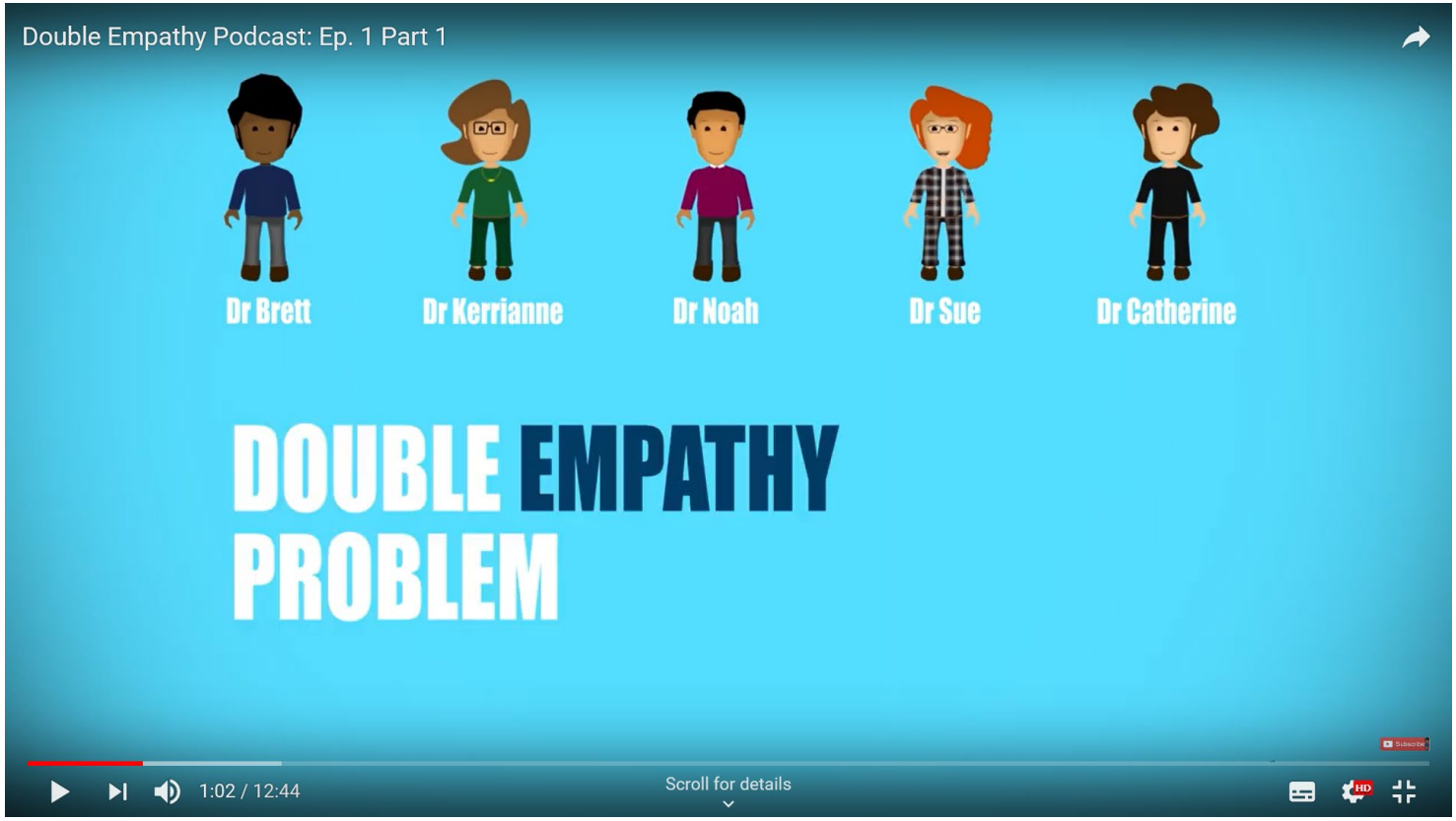
- Sheppard et al. (2016) investigated non-autistic participants' ability to interpret the behavioural reactions of autistic people in naturalistic social interactions.
- Non-autistic participants who viewed the recorded videos were less able to guess which event the video participant had experienced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

Studies of forming first impressions

- 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.
- Supported by work of Sasson et al. (2017a; 2017b; 2018).

- 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.

The Double Empathy Problem Virtual Symposium



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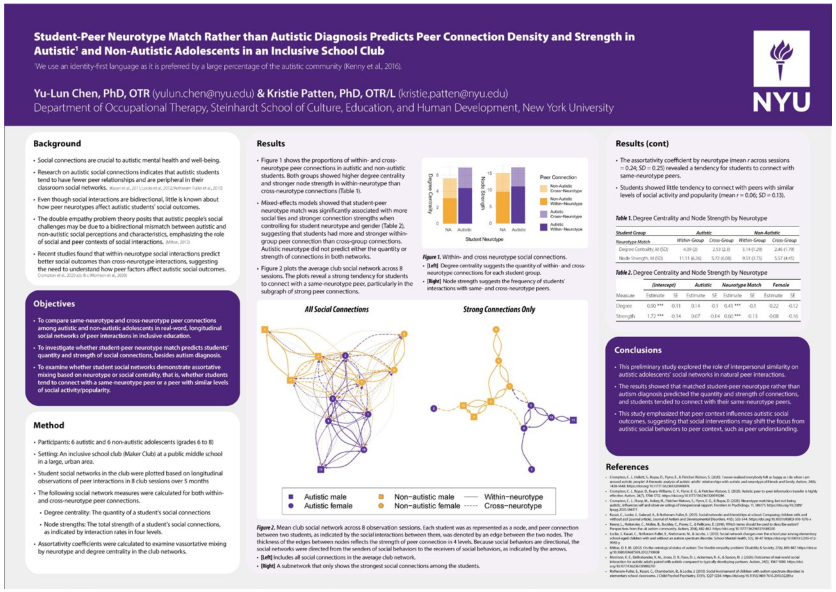
New directions

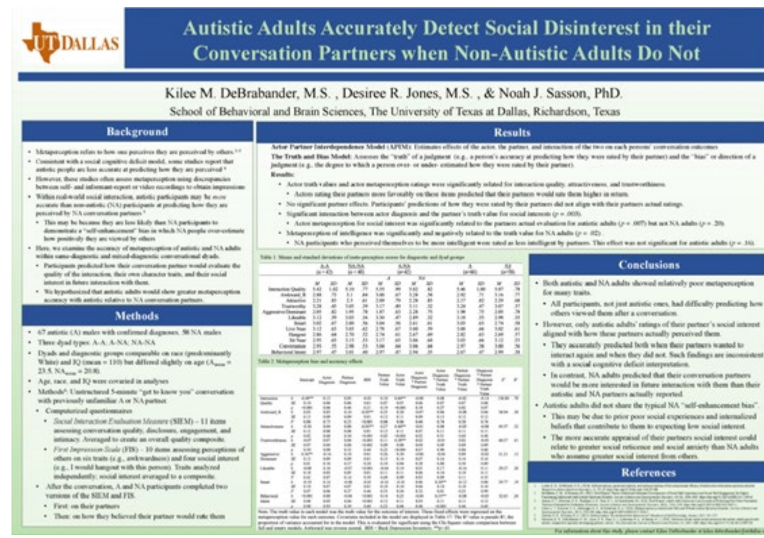
- Crossover with neuroscientific theory regarding 'predictive coding':
- The dialectical misattunement hypothesis: *"…views psychopathology not merely as disordered function within single brains but also as a dynamic interpersonal mismatch that encompasses various levels of description*." (Bolis et al., 2017).
- A 'mismatch of salience'.

New directions

- Using interpretative phenomenological analysis in autism research - Katie Howard, Napoleon Katsos, Jenny Gibson, 2019 (sagepub.com)
- An Expert Discussion on Autism and Empathy | Autism in Adulthood (liebertpub.com)
- Frontiers | Mutual (Mis)understanding: Reframing Autistic Pragmatic “Impairments” Using Relevance Theory | Psychology (frontiersin.org)
- Autism and the double empathy problem: Implications for development and mental health - Mitchell - 2021 - British Journal of Developmental Psychology - Wiley Online Library
- Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study | medRxiv
- Non-Autistic Children Do Not Object to Autistic-Like Behaviors – YouTube

New directions – Yu-Lin Chen and Kristie Patten; Debrander et al.





Power

- Important to remember that the double empathy problem originated from lived experience and social theory and is thus conceptualised as situated within wider unequal (and intersectional) power relations.
- Avoiding tokenism and ceding power. Humility and rapport (tacit knowledge) building.
- Reducing imposition of social expectations.
- This to me is ‘translation into practice (and other) settings’.

Collaboration

- Setting the 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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