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Document Version

Presentation

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Autism in the academy: a personal reflection

Dr. Damian E M Milton

A Mismatch of Salience

Explorations of the
Nature of Autism from
Theory to Practice

By Dr. Damian E M Milton
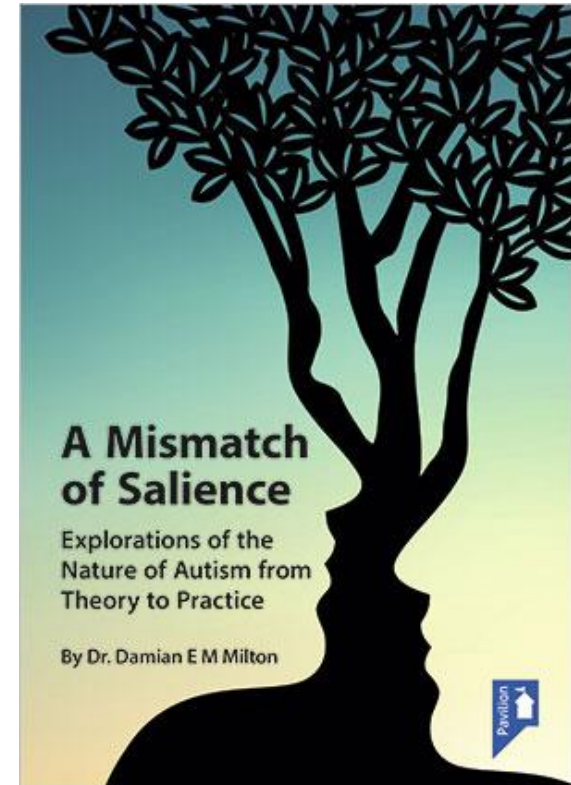
A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).

- A background in Social Science (initially Sociology).

- Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent.

- Visiting Lecturer, UCL and LSBU.

- Chair of PARC and Director at NAT.

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- "Some of us aren't meant to belong. Some of us have to turn the world upside down and shake the hell out of it until we make our own place in it." (Lowell, 1999).

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My employment history pre-diagnosis

- 1989 – Paper rounds.

- 1991 – Became a student.

- 1992 – Withdrew from course and became unemployed.

- 1995 – Became a student again.

- 1996 – First job in a wool-packing factory (£2.12 an hour).

- 1998 – Graduated.

- 1999 – Gained a Masters Degree.

- 2000 – Started PhD and Teaching assistant at a University (part-time).

- 2001 – Withdrew from course, reliant on money from DJ'ing music.

- 2002 – Cashier in a bookies.

- 2003 – Market research – field researcher.

- 2004 – FE Lecturer in Sociology and Academic Skills.

- 2008 – Made redundant. Distance learning courses.

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After diagnosis

- 2009 – Start of PhD course.

- 2010 – Volunteer role for Ambitious about Autism.

- 2012 – First consultancy work and work for the NAS and Autism Education Trust.

- 2014 – Appointed as a Research Assistant at London South Bank University.

- 2015 – Appointed Head of Autism Knowledge and Expertise (Adults and Community) at the NAS.

- 2016 – Appointed as a Researcher at the University of Birmingham.

- 2017 – Appointed as a Lecturer at the University of Kent.

- Much better – yet all in the area of autism and none have been full-time posts.

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Some key issues relating to employment

- The sensory environment.

- Autism and the 'spiky profile'.

- Passionate interests and flow states.

- An exacting gaze / systematic logic.

- The 'double empathy problem'.

- Stress, anxiety and comfort.

- The need for predictability and transparency.

- Hierarchy and authority – respect and rules.

- Academia or bust!

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Becoming qualified

- The right courses.

- 2nd or 3rd time lucky?

- Part-time or full-time.

- The supervisor.

- Mentors and advocates.

- Career advice.

- Continuing professional development.

- Learning the 'landscape' and one's (shifting) place in it.

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Ways to find work

- Job advertisements – 'scatter-gun' approach or targeted applications?

- Showing your worth – work placements and the 'portfolio' approach.

- Being persistent and following passions.

- Not being afraid of being open – if you are rejected for it, it is likely you will be rejected at some point later on and at greater personal cost.

- Although – not talking yourself out of a job.

- Working with others that can advocate for you, and who one can learn from.

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Advice often given regarding job interviews

- Dressing for success

- Grooming tips

- How and when to give a handshake

- Sitting up on one's chair

- Facing the interviewer

- Using an 'upbeat tone of voice'

- Smile and make eye contact

- My advice – do not focus on any of these things too much, but focus on what you can do and meeting the job specification.

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Common barriers

- Social attitudes, prejudice and stigma.

- The design and wording of job descriptions.

- Opportunities to gain experience and being given a chance to prove one's worth.

- Systemic issues.

- 'Selling oneself'.

A different way of thinking

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The spiky profile

- Interests and avoidance

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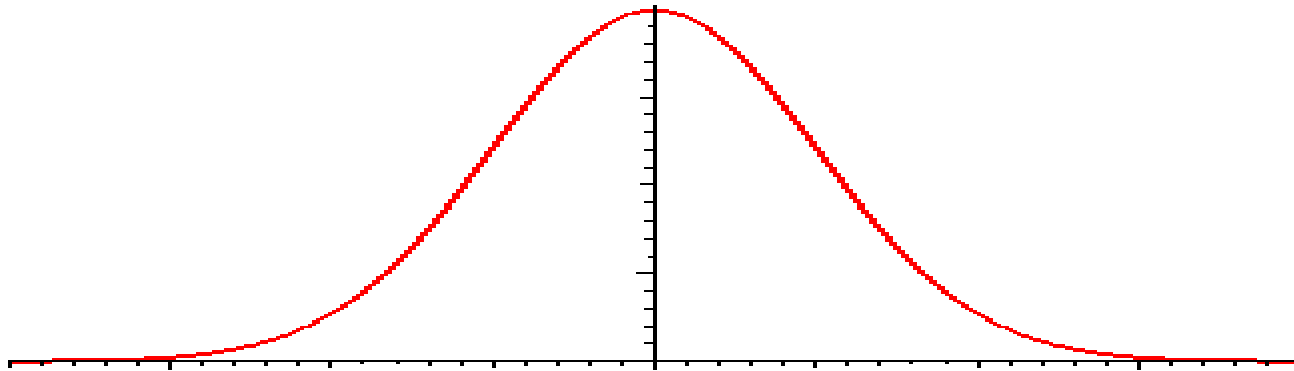
An 'interest model' of autism

- Autism and monotropism.

- Attention as a scarce resource.

- Monotropic attention strategies and the 'attention tunnel'.

- Monotropism, repetitive behaviour and interests, and 'flow states'.

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- "Have you ever decided to spend half an hour on an activity, such as reading e-mails, doing some gardening, or even shopping, only to find out that you have been doing the activity for a number of hours? Then you may well have experienced what Csikszentmihalyi (1990) describes as a 'flow state'." (McDonnell and Milton, 2014).

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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.

- Theory of autistic mind can often leave a great deal to be desired.

- Mismatches in understanding can create many problems within work situations however, especially when with those who are in a position of authority over your work.

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Passing and masking – the dangers

- May have some limited uses – but not good as a general tactic.

- Reputation management and exposure anxiety.

- Exhaustion and burnout.

- Needs continue not to be met.

- Nothing changes regarding the structures and attitudes one works within.

- Does it work? When to disclose? Disclosure is not without its own issues.

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Sustaining employment

- The first 100 days.

- Finding out who your friends are...and those who one might struggle to work with.

- A culture of openness.

- 'Compromise' – how much is reasonable?

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The Research Autism Mentoring Project

- A two year pilot project designed by people on the autism spectrum to evaluate a mentoring intervention.

- After mentor training, selection, and matching, 12 pairs met for one hour per week over 6 months. Supervision was built in throughout.

- 3 Goals were set initially and reviewed throughout project set by mentee.

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	Pre-mentoring	Pre (who finished)	After	Difference
Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	5.1	6	7.8	1.8
How satisfied are you with what you are achieving in life?	5.1	5.4	7	1.6
How satisfied are you with how safe you feel?	6.4	7.4	8.8	1.4

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Average progress toward goals

- Pre-mentoring – 3.75.

- Pre (those who finished) – 4.

- After mentoring – 8.

- Difference over all three goals – 4.

- "…this helped me dig my way out of a life threatening hole that I could not see any way out of. It reminded me to make progress towards goals. [The mentor] Listened when I needed it, was a regular weekly marker in my chaotic life, provided an opportunity to reflect and plan and self manage. I wouldn't have done this otherwise."

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Time management and organisation

- Too much information.

- Multiple systems.

- The impact of other people.

- Energy accounting.

- Taking too much on and being too good at your job!

- Getting help – mentoring and advocacy.

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Recognition of one's work

- Journals and publications.

- Conference events.

- Blogs, vlogs and other media.

- Networking and peer support.

- Onwards and upwards – applying for a promotion…

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The Participatory Autism Research Collective

- The Participatory Autism Research Collective (PARC) was set up to bring autistic people, including scholars and activists, together with early career researchers and practitioners who work with autistic people.

- First meeting held in April 2015.

- Our aim is to build a community network where those who wish to see more significant involvement of autistic people in autism research can share knowledge and expertise.

- Not just for researchers!

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Objectives of PARC

- The initial objectives of PARC were set out as to:

- Address the isolation felt by many autistic researchers

- Ensure that research carried out by autistic people can be found and used

- Raise the reputation of participatory research methods in the field

- Critically comment on autism research which does not empower autistic people.

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- In order to achieve these objectives it was suggested that PARC would:

- Encourage autistic people starting out in research

- Provide peer feedback on research and support with accessing funding

- Hold meetings and events.

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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.

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Participatory methods in practice

- The Autism Education Trust (AET) and the Transform Autism Education (TAE) project.

- The Ask autism project.

- The Theorising Autism Project.

- The Autonomy journal.

- Mentoring project based at LSBU and the use of Personal construct theory (PCT).

- The National Autism Project (NAP) and Westminster Commission.

- Shaping Autism Research UK seminar series.

- The National Autistic Taskforce.

- The Participatory Autism Research Collective (PARC).

Types of Participation in Communities of Practice

outsiders — tangential — peripheral — episodic — experts — beginners — regular — leaders — core

adapted from Wenger, 2002
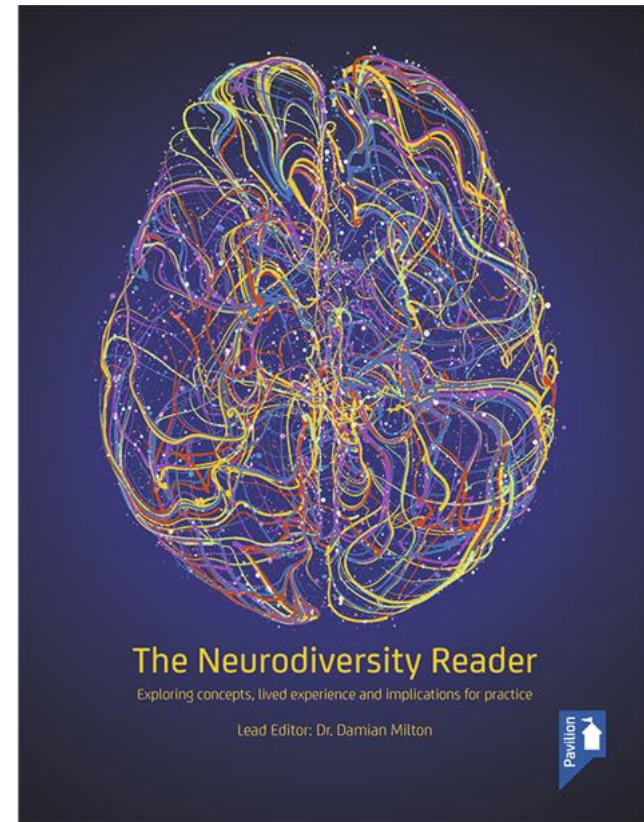
Activity of the PARC group

- The website for PARC continues to attract interest: www.PARCautism.co.uk

- This has included links to events set up by PARC members or other related material.

- Critical blog posts regarding research and practice in the field.

- Events held in London, Birmingham, Sheffield, Nottingham, Glasgow and Kent – with a wide range of contributors.

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Conference streams

- Chairing a stream at the Learning Disability Today conference.

- Chairing a stream on 'Neurodiversity' at the Centre for Disability Research Conference at Lancaster University in September 2018.

- A PARC 'fringe' event partnering Scottish Autism's 50th Anniversary Conference in 2018.

- We also ran our own participatory research conferences at London South Bank University (LSBU) in 2018 and 2019.

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Publications

- Two special editions of Advances in Autism (AIA), work in the field of education and autism.

- Recently published article for the Tizard Learning Disability Review.

- Partnership with Pavilion Press.

The Neurodiversity Reader

Exploring concepts, lived experience and implications for practice

Lead Editor: Dr. Damian Milton

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Conclusion

- What is under your control/influence and what is not?

- Targeting efforts and following interests.

- Disclosure is a personal choice and can be problematic, but not disclosing can also lead to significant issues.

- Mentoring, advocacy and peer support can all be helpful.

- For further information see following links:

- www.PARCautism.co.uk

- https://kar.kent.ac.uk/73208/

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