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Presentation

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Current issues in autism research and practice

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 at London South Bank University and University College London.

- Chair of the Participatory Autism Research Collective (PARC).

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- The aims of this talk will be to give an overview of recent autism research from across differing disciplines, some of which challenges long held ideas around autism, and the potential implications for practice of such innovations.

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Autism research and community priorities

- 'A future made together' report (Pellicano et al. 2013).

- Investment in new areas of autism research.

- Strategic partnerships.

- Listening, engaging and involving.

- Shaping Autism Research UK seminar series.

- Participation, translation to practice.

- Health inequalities research.

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Setting research priorities: James Lind Alliance

1. Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted for the needs of autistic people?

2. Which interventions are effective in the development of communication/language skills in autism?

3. What are the most effective ways to support/provide social care for autistic adults?

4. Which interventions reduce anxiety in autistic people?

Setting research priorities: James Lind Alliance

5. Which environments/supports are most appropriate in terms of achieving the best education/ life/ social skills outcomes in autistic people?

6. How can parents and family members be supported/educated to care for and better understand an autistic relative?

7. How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?

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Setting research priorities: James Lind Alliance

8. How can we encourage employers to apply person-centred interventions & support to help autistic people maximise their potential and performance in the workplace?

9. How can sensory processing in autism be better understood?

10. How should service delivery for autistic people be improved and adapted in order to meet their needs?

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Areas of enquiry and implementation

- Biology, genetics, medical treatments.

- Psychology, cognition and behaviour.

- Sociology and social policy.

- Arts, humanities and design.

- Interdisciplinary work and converging theories.

- Participatory research.

- Translation into practice.

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Biological research and ethical controversies

- EU-AIMS and AIMS-2 Trials.

- Health inequalities, mortality.

- Ethical concerns.

- How best to help with such issues? Case example: mental health.

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Psychological research

- Mental health and suicide (work of Sarah Cassidy in particular) – feelings of being a burden, social isolation, 'intolerance of uncertainty'.

- Criticisms of dominant psychological theories of autism such as Theory of Mind.

- Recognition of sensory processing differences.

- Converging ideas between accounts by autistic scholars and neuroscientific theory.

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An 'interest model' of autism

- Autism and monotropism (Lawson, 2010; Lesser and Murray, 1998; Murray et al. 2005).

- Attention as a scarce resource.

- Monotropic attention strategies and the 'attention tunnel'.

- Monotropism, repetitive behaviour and interests, and 'flow states' (McDonnell and Milton, 2014).

- Interests and the autistic 'spiky profile' (Milton, 2017).

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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).

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The double empathy problem

- Building bridges between people of autistic and non-autistic dispositions is not always an easy process (Milton, 2012; Chown, 2014).

- Empathy problems as a 'two-way street' (Sinclair, 1993).

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

- 'Fork 'andles'!

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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.

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- Edey et al. (2016) asked autistic and non-autistic participants to manipulate two triangles to create animations depicting mental state interactions such as 'coaxing' or 'mocking'.

- Non-autistic observers who viewed the animations were better at identifying the mental state depicted for animations created by other non-autistic participants than autistic participants.

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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.

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- In a study using a much larger sample of adult participants, 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.

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Studies of metaperception

- Sasson et al. (2018) investigated metaperception using the same videos from Sasson et al. (2017a/b).

- Video 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 their video.

- 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.

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- While Sasson et al.'s (2018) study asked participants about how they come across to others in general, 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.

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- Metaperception has also been investigated between dyads of autistic and non-autistic people who know each other well.

- Heasman and Gillespie (2017) used the Interpersonal Perception Methodology (IPM) to investigate 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.

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- 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.

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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.

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Examples of sociological work or closely related fields

- Grinker – anthropological studies / prevalence studies.

- Qualitative and action research in the field of education: Anat Greenstein, Carmel Conn, Rebecca Wood.

- Large-scale quantitative analysis – Paul Shattock.

- Building collaborative communities (Wenger, 1998): the work of the Autism Education Trust.

- Media studies and representations of autism.

- The work of many autistic scholars and activists: Larry Arnold, Steve Graby, Melanie Yergeau, Hannah Ebben.

- Critical Autism Studies (e.g. Runswick-Cole et al., 2016).

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Participation and insider knowledge

- "...right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced." (Williams, 1996: 14).

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Participatory research

- A range of theoretical and methodological approaches.

- Yet with the main objective of ceding 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.

- The Research Autism mentoring project and the use of Personal construct theory (PCT).

- The Participatory Autism Research Collective (PARC).

- The National Autism Project (NAP) and National Autistic Taskforce (NAT).

- Shaping Autism Research UK seminar series.

Types of Participation in Communities of Practice

outsiders

tangential

peripheral

episodic

experts

regular

beginners

leaders

core

adapted from Wenger, 2002

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Current controversies

- Models of disability.

- Prevalence and changing diagnostic criteria.

- Diversity of people on the spectrum and the 'spiky profile'. Dynamic vs. categorical distinctions?

- Gender and sexuality.

- How best to support autistic people?

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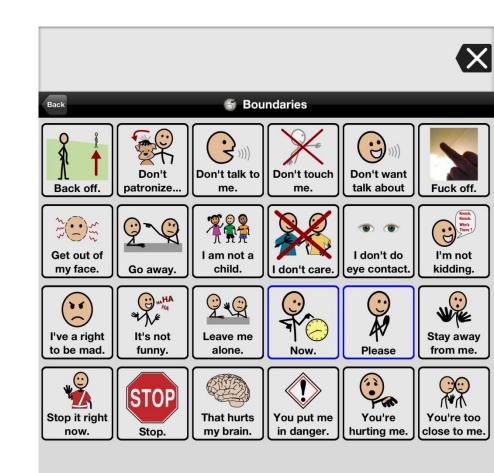
The concept of neurodiversity

- Variations in neurological development as part of natural diversity, rather than something to be pathologised using a purely medical model of disability, defined by one's deviation from statistical or idealised norms of embodiment or observed behaviour.

- This is not to say that those who identify as autistic people or other forms of neuro-identity do not find life challenging. Autistic people are significantly disadvantaged in many aspects of life (Milton, 2020).

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Converging ideas

- Interests, monotropism and neuroscientific theory (Jurgens, 2020).

- The 'dialectical misattunement hypothesis' (Bolis et al. 2017).

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Aims and objectives – controversies in the field

- Normativity or the acceptance/celebration of diversity?

- Behavioural outcomes and 'social skills' or understanding and autonomy?

- Baggs (2012) - communication page.

- Positivist RCTs and/or building collaborative communities of practice (Wenger, 1998).

The goal of intervention

- "I had virtually no socially-shared nor consciously, intentionally expressed, personhood beyond this performance of a non-autistic 'normality' with which I had neither comprehension, connection, nor identification. This disconnected constructed facade was accepted by the world around me when my true and connected self was not. Each spoonful of its acceptance was a shovel full of dirt on the coffin in which my real self was being buried alive..." (Williams, 1996: 243).

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Relationship / lowering stress based approaches

- Intensive Interaction.

- Focuses primarily on building trust and rapport on the child's own terms.

- Following a child's interests and learning their 'language'.

- Low-arousal approach.

- PACT research.

- The nuances of the SPELL framework…

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SPELL framework: Very brief summary

	Structure	Positive approaches and expectations	Empathy	Low arousal	Links
What ?	-Reducing anxiety through increased predictability	-Play to strengths -Assume 'can do' - but with help	Mutual understanding of perspective of others	-Recognise stress caused by sensory differences -Confrontation	-Promote consistency -Promote involvement
Underlying Difficulties ?	-Organising, sequencing and planning – self monitoring	-Uneven skill development -Low or imposed expectations	-Mutual understanding / misunderstanding of other minds -Judgement of social situations -Literal interpretation	-Sensory processing -Stress -High anxiety	-Uneven processing of information - Detail v bigger picture -Response to change
Some examples	-Written or pictorial timetables/ instructions/ Diaries -Clear sequencing	-Positive /direct clear language -Use strengths and interests as motivators and to build confidence	-Reflection – Discussion -Pictorial aids -'Social stories' -Keep promises	-Audit sensory environment -Reduce noise/ clutter -Reduce confrontation	-Inclusive meetings - Access to 'mainstream' facilities - Consistent communication

- "We need to see the world from the autistic perspective and apply approaches based on a mutuality of understanding that are rational and ethical – which respect the right of the individual to be different – yet recognises and deals with distress and offers practical help. We should encourage and motivate the person to develop strengths rather than focus on 'deficits'. This will mean offering opportunity for development while supporting emotional stability." (Mills, 2013).

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