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Autism, stress and the low-arousal approach

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
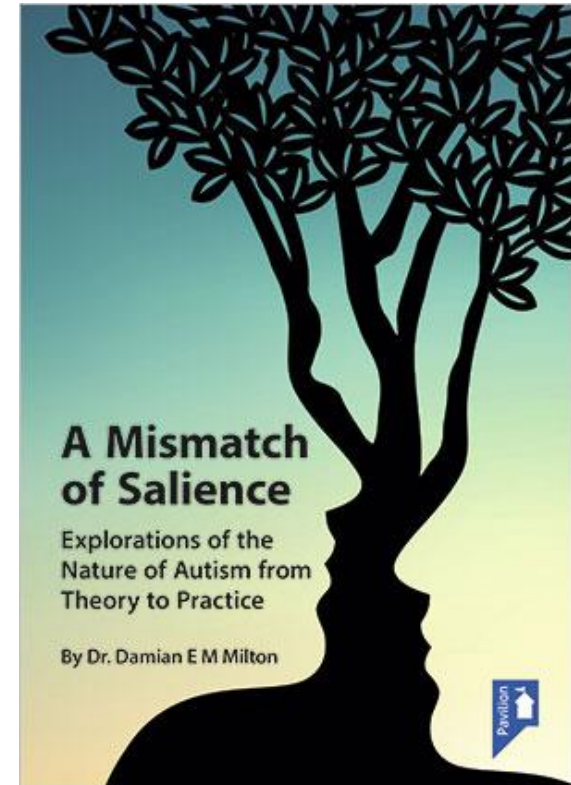
A bit about me

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

- A background in Social Science (initially Sociology).

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

- Visiting Lecturer, LSBU and UCL.

- Director, National Autistic Taskforce.

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

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Introduction

- Autism – through autistic-led theory.

- Stress and its consequences.

- Flow states and reversing the negative spiral of stress.

- Low-arousal approach referred to throughout.

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Normalcy and the bell curve

- "Extremes of any combination come to be seen as 'psychiatric deviance'. In the argument presented here, where disorder begins is entirely down to social convention, and where one decides to draw the line across the spectrum." (Milton, 1999 - spectrum referring to the 'human spectrum of dispositional diversity').

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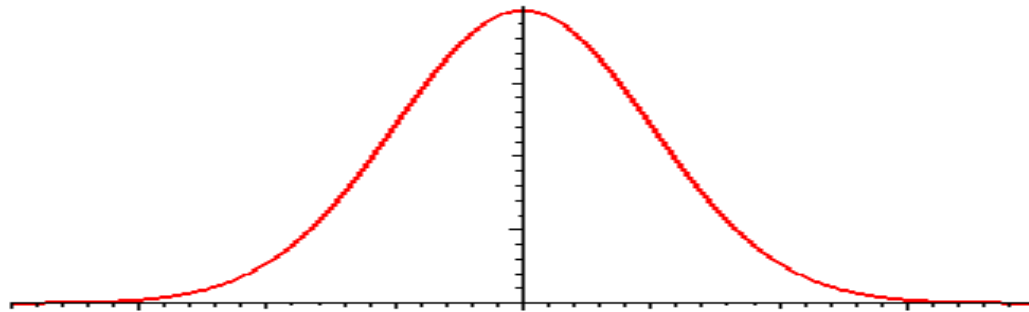
Panel 1: Have you heard about that Social Model of Shape Difference all the squares are talking about? / You mean the idea that all differences between shapes are imaginary?

Panel 2: Exactly. See that guy over there? According to this theory, he can't roll as well as we do because of our *attitudes* toward him! / Have you ever heard anything more ridiculous?

Panel 3: I guess when we are not looking, they bounce around like basketballs. Ha Ha Ha Ha!! / Oops, I thought I saw four right angles on that one. I must be hallucinating! Ha Ha Ha Ha Ha!

Panel 4: Actually, that's not at all what the social model is about. It's about how minority shapes are excluded from decision making roles, and therefore our needs are considered extraordinary while yours are seen as normal.

Panel 5: It's about power. The ways squares are silenced or ignored. How some shapes are subjected to treatments that would be considered abusive if they were done to circles.

Panel 6: So the social model is all about how squares are superior to other shapes. Can you believe he had the nerve to say that? / That's what I call rectangular logic. Ha Ha Ha Ha. / He probably bounced too high and hit his head on something! Ha Ha Ha Ha Ha Ha Ha Ha! / Look at me! I've got corners! I'm invincible! Ha Ha Ha Ha Ha Ha.! / Please get off of me!

Square Talk   Asperger Square 8

The neurodiversity 'paradigm'

- 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.

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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'.

- Links with predictive coding theory and enactivism (embodied, embedded, enacted, extended).

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What did they know?

- "Appalling, I fear I am at a loss to know where to begin and what to try next. Fortunately, he enjoys his table-tennis." (French teacher, Autumn term, 1985).

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Sensory perception

- Sensory integration and fragmentation.

- Hypo and hyper sensitivity.

- Context and motivation.

- Stressful stimuli.

- Stress, arousal and sensory overload – 'meltdown' and 'shutdown'.

- Synaesthesia.

- Pattern thinking and Hyperlexia.

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Autistic dispositions

- As with the rest of the population – great deal of diversity in personality and temperament.

- Often with differing responses to stressful experiences when encountered.

- The 'fight or flight' response – 'meltdowns' and 'shutdowns'.

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Meltdown

- The 'meltdown' response and misunderstandings of it.

- 'Challenging behaviour'.

- No choice in the matter.

- Non-autistic people meltdown too – e.g. road rage.

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Shutdown

- Noticing the less obvious - such as more passive natured autistic people and the 'shutdown' response.

- Characterised by withdrawal.

- Often unable to think clearly or to express oneself at all.

- Again – no choice in the matter.

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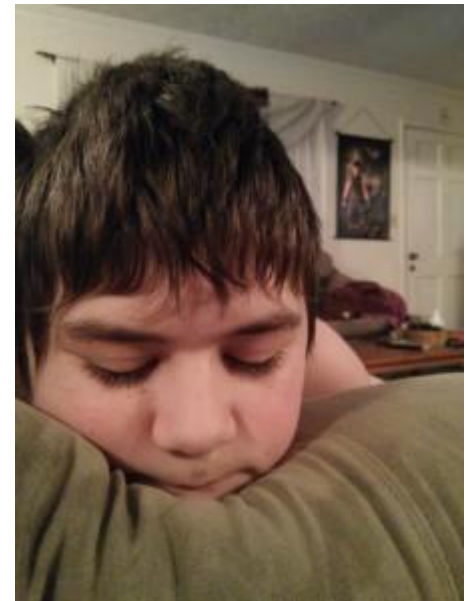
Information overload

- The 'monotropic' focus (Murray et al. 2005, Lawson, 2010).

- Multi-tasking, integrating information, and fragmentation.

- Interruptions to the 'attention spot light'.

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Social stigma

- The denigration of difference (Tajfel and Turner, 1979).

- 'In' and 'out' groups, stigma and discrimination.

THEM   THE OTHER

atheist / godly   sacred / profane

barbaric / humane   peace keepers / brutal expansionists

tyranny / good caring leaders   defense department / war department

US

untrustworthy / trustworthy   for civil rights / oppressive

criminals / law abiding   defensive / offensive

primitive / civilized   innocent / guilty

good
evil

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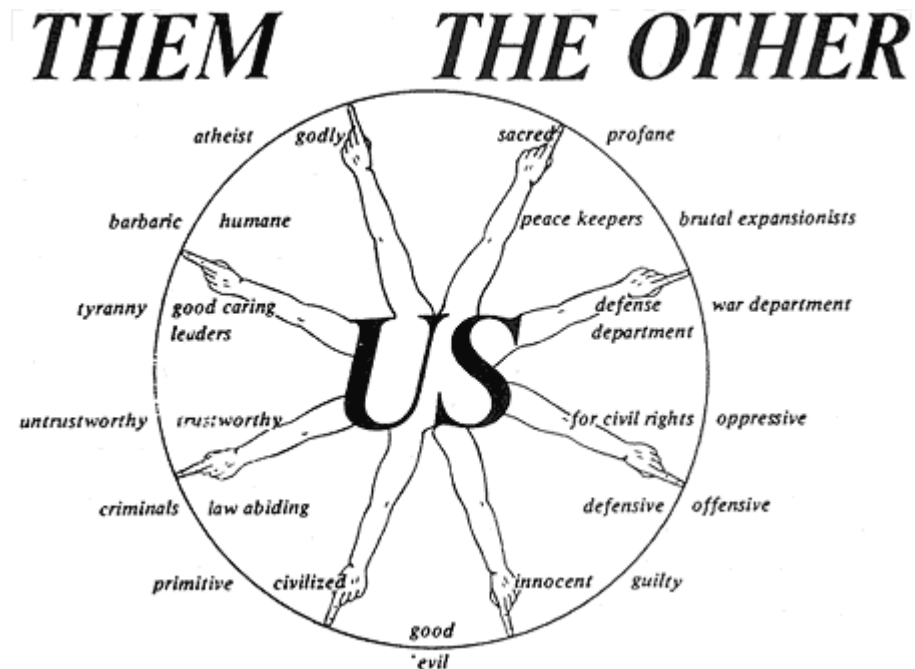
Chronic stress and mental ill-health

- Living with almost constant stress and social disjuncture, can be even more highly damaging when unrecognised.

- Alienation and isolation, withdrawal from society.

- Mental ill-health.

- Remember – the outward manifestation of stress may be a lack of expression too.

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Flow states

- "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 concept of 'flow states'

- 'Going with the flow' and being 'in the zone'.

- A form of optimal experience that can be beneficial to feelings of happiness and wellbeing.

- Described as being so involved in an activity that nothing else seems to matter.

- Flow experiences require complete immersion in an activity, whether playing a musical instrument, completing a complex technical task, or reading a book.

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- Flow can also happen within social interactions, for example: when one is talking to a good friend (see later).

- Activities that lead to a flow experience can be called autotelic (from Greek: auto=self, telos=goal), as such activity is often seen as an 'end-in-itself' for the individual experiencing it, with end rewards often being just an excuse to participate in the activity.

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Flow states and challenging experiences

- A flow state can be achieved when the skills and resources available to an individual are fully engaged in managing an activity.

- If an activity is not challenging enough it can lead to boredom, yet flow can return if the level of challenge increases.

- Equally, if an activity is too difficult it can quickly lead to frustration, and returning to flow would require a reduction in the difficulty of the challenge presented.

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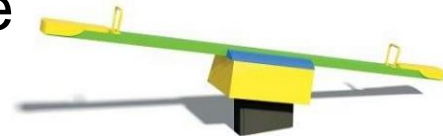
Key aspects of flow states

- Clear goals and immediate feedback on progress.

- Total focus on what one is doing in the present moment (with no room for attention on anything else).

- Actions and awareness become merged: skilled activities can become seemingly automatic and effortless.

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- Losing awareness of sense of oneself.

- A sense of control over one's actions and a reduction in anxiety about possible failure.

- Time dilation: time seems to pass faster and go by unnoticed – however, the reverse can also be true, where people feel that their awareness is somehow working in 'slow motion'.

- The activity is experienced as intrinsically rewarding.

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Interest and avoidance

- "We suggest that the uneven skills profile in autism depends on which interests have been fired into monotropic superdrive and which have been left unstimulated by any felt experience." (Murray et al. 2005: 143).

- Experiences of 'failure' or the condemnation and mocking of others, can be devastating.

- This can be highly influential on which interests are followed through, and which are stopped through feelings of fear and anxiety.

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Interests and wellbeing

- When looking at the accounts of autistic people, 'special interests' are rarely framed as troublesome obsessions (although this is on occasion remarked upon).

- More often than not, such interests are regarded as essential to the wellbeing and sense of fulfilment that autistic people experience.

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- When autism is also often characterised by sensitivity to external stimuli and difficulties in processing multiple sources of information, such a strategy in one's use of attention is rendered rational, rather than dysfunctional.

- By entering into a 'monotropic' flow state, autistic people can gain predictability and control over their immediate environment, a sense of achievement, and in-the-moment fun.

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Disruptions to flow and sensory overload

- Disruptions to this flow can lead to a fragmented perception of incoming stimuli, feelings of an unwanted invasion, and reactions of meltdown, shutdown, and panic attacks.

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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'

- 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.

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Social flow

- One way in which many people can experience flow-like states is from having social interactions with well acquainted others, such as a close friend.

- This often taken-for-granted flow-like state experienced by non-autistic people on a frequent basis is but a rarity in the lives of many autistic people.

- Social disjuncture often not due to a lack of social motivation.

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Non-verbal social flow

- Not all sources of shared flow states rely on verbal communication – e.g. the 'jam session'.

- The importance of engaging with individuals without recourse to the over use of language has long been acknowledged in building rapport.

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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).

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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Universal design

- "Universal design is the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design."

- In order to make design, whether bespoke or universal in orientation, one must endeavour to understand the needs of autistic people.

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Core Domains of Quality of Life	Indicators
Self-Determination	Autonomy, Choices, Decisions, Personal Control, Self-Direction, Personal Goals/Values
Social Inclusion	Acceptance, Status, Supports, Work Environment, Community Activities, Roles, Volunteer Activities, Residential Environment
Material Well-Being	Ownership, Financial, Security, Food, Employment, Possessions, Socio-economic Status, Shelter
Personal Development	Education, Skills, Fulfillment, Personal Competence, Purposeful Activity, Advancement
Emotional Well-Being	Spirituality, Happiness, Safety, Freedom from Stress, Self-concept, Contentment
Interpersonal Relations	Intimacy, Affection, Family, Interactions, Friendships, Support
Rights	Privacy, Voting, Access, Due Process, Ownership, Civic Responsibilities
Physical Well-Being	Health, Nutrition, Recreation, Mobility, Health Care, Health Insurance, Leisure, Activities of Daily Living

Key points in reducing stress

- Acceptance of the autistic way of being, work with the autistic person and not against their autism.

- Watch out for 'triggers' in the environment.

- Explore interests and fascinations together.

- Having strong rapport and building mutually fulfilling and trusting relationships.

- Encourage autistic companionship.

- Encourage understanding of non-autistic people and culture, rather then teaching how to poorly mimic what one is not.

- 'Low arousal' is not 'no arousal' – many sensory experiences are fun!

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Five key points

- **Respect** the autistic way of being – work with it, not against it

- Always consider **sensory issues**

- Always consider how you process **information** may be very different to that of the person in your care (utilise interests)

- **Stress** is a key issue – reduce input when people are over stressed

- **Collaborate** for consistency in approach

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