Building Connections with Autistic People

Dr. Damian E M Milton

A Mismatch
of Salience

Explorations of the
Nature of Autism from
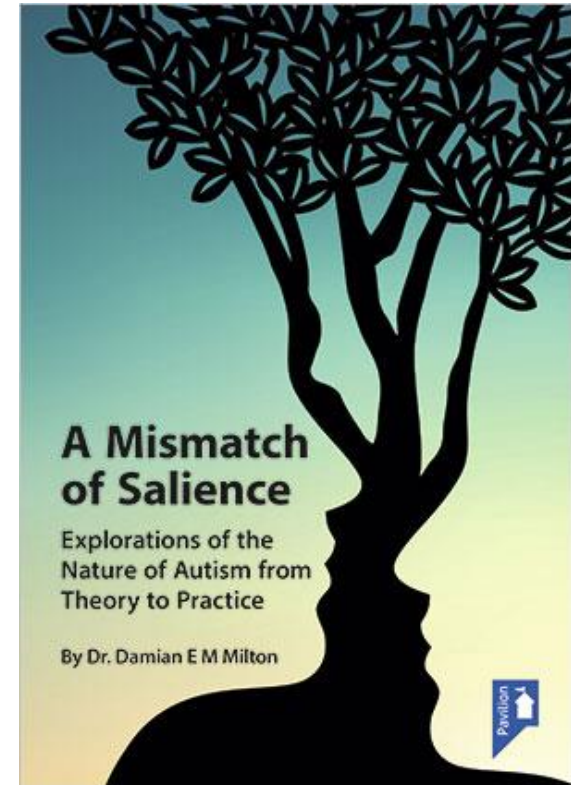Theory to Practice

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.

- Autism Knowledge and Expertise Consultant, National Autistic Society.

- Visiting Lecturer, London South Bank University.

- Director at the National Autistic Taskforce.

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

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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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Introduction

- Alternative explanations of autism

- The concept of 'flow states' and the 'double empathy problem'

- Autism and mental health

- Support strategies

- Building connections

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Autism – a history of the term

- Origins of the term – Bleuler, Kanner and Asperger.

- How was 'autism' defined before it was called 'autism'?

- Changing psychiatric lens – Bettleheim, Rimland and Wing and Gould.

- Parent activism and charities.

- The neurodiversity movement and autistic self-advocacy.

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Current controversies

- Models of disability.

- Prevalence and changing diagnostic criteria.

- Diversity of people on the spectrum and the 'spiky profile'.

- Gender and sexuality.

- How best to support people on the autism spectrum?

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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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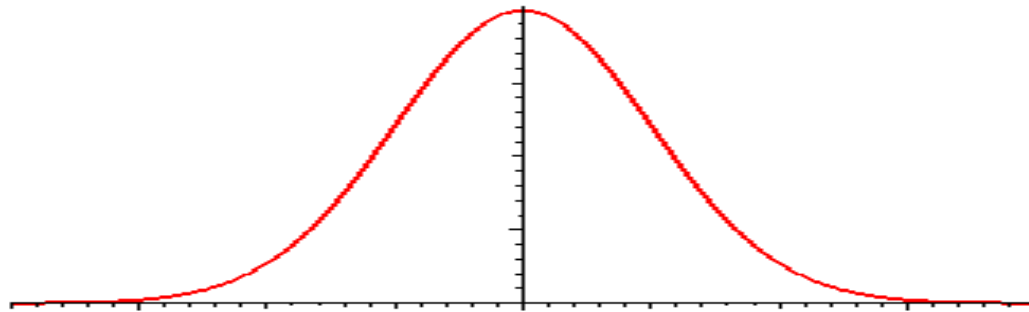
The neurodiversity 'paradigm'

- 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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A different way of thinking

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Executive functioning theory

- Refers to the ability to maintain an appropriate problem-solving strategy in order to attain a future goal.

- Yet – there may be a difference within the way autistic executive processing operates, rather than an impairment or deficiency?

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Central coherence

- Refers to problems with processing overall contextual meanings, whilst simultaneously having advantages in processing details or parts of an overall context.

- Yet – many autistic people are able to process gist meaning and whole pictures.

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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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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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- "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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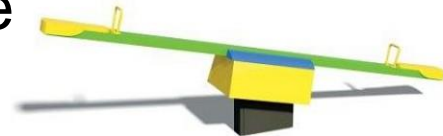
Key aspects of flow states

- 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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Autistic flow states

- DSM-V (2013) diagnostic criteria: autism in part defined by 'restricted and repetitive' patterns of behaviour, interests, and activities.

- From this psychiatric viewpoint, such activity is deemed as dysfunctional and a pathologised abnormality.

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- People on the autism spectrum are often said to be 'tuned out' from the social world operating around them.

- Sometimes this is a large mischaracterisation, at times it is because the individual in question is fully engaged in a given activity and could be said to have achieved a state of flow.

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Flow and the relieving of stress

- Many people on the autism spectrum experience high levels of stress for a number of reasons (Caldwell, 2014). This is explored in more depth later in the workshop.

- By engaging with passion in their interests, all people can become absorbed in an activity that gives them a sense of achievement.

- In addition, certain repetitive tasks can help people achieve a flow-like state of mind. These tasks can become absorbing and can become areas of meaning.

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Interests and wellbeing

- When looking at the accounts of people on the autism spectrum, '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 people on the autism spectrum experience.

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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 people on the autism spectrum.

- Non-verbal social flow.

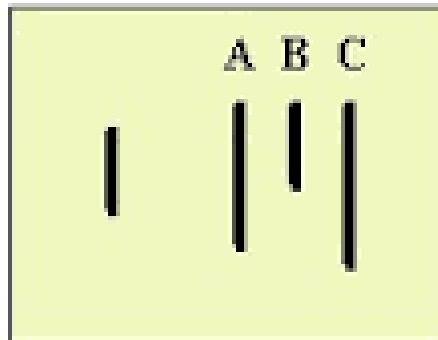Dr. Damian E M Milton

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The downside

- The opposite of flow-like states: such as when flows become blocked and entangled (Milton, 2013b).

- Blockages may account for high levels of stress and resultant 'challenging behaviours' (McDonnell, 2010).
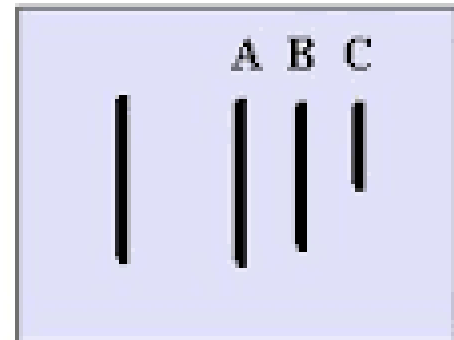
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Sensory perceptions and autism

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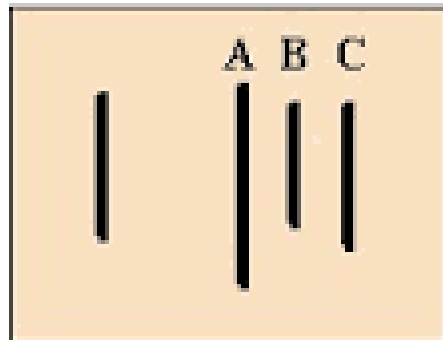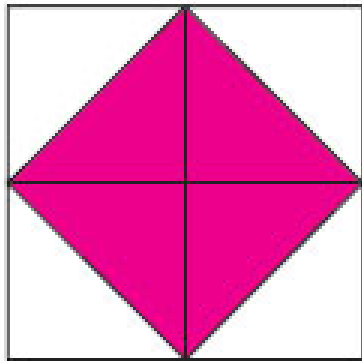
Sensory perception

- Sensory integration and fragmentation.

- Hypo and hyper sensitivity.

- Context and motivation.

- Stressful stimuli.

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

- Synaesthesia.

- "Aren't all autistic people visual thinkers?". Pattern thinking and Hyperlexia.

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The block design and embedded figures tests

original
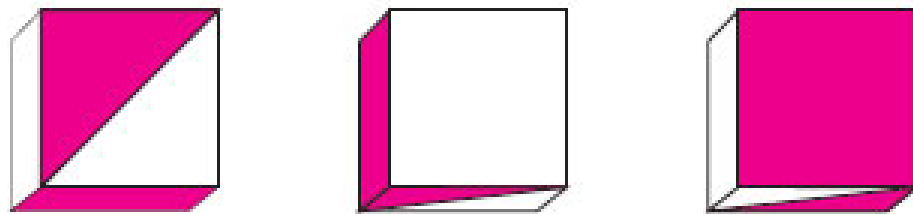
Types of block available for making the pattern

(a)

(b)

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Non-verbal intelligence

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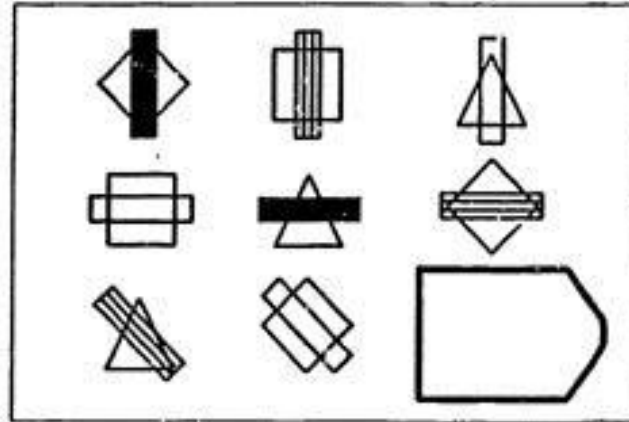
Interaction and communication
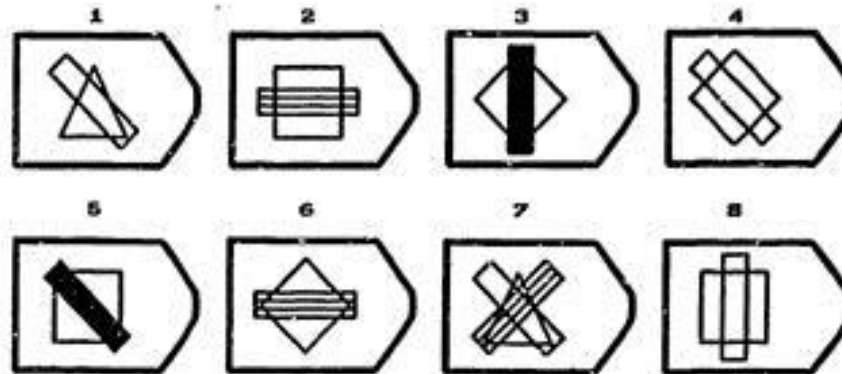

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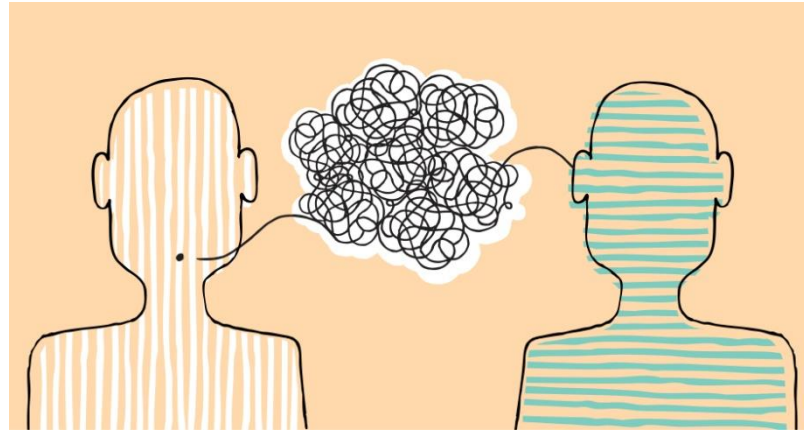
Theory of mind

The ability to empathise with others and imagine their thoughts and feelings, in order to comprehend and predict the behaviour of others (also called 'mind-reading' and 'mentalising').

This is Sally. Sally has a basket.

This is Anne. Anne has a box.

Sally has a marble.

She puts the marble into her basket.

Sally goes out for a walk.

Anne takes the marble out of the basket and puts it into the box.

Now Sally comes back. She wants to play with her marble. Where will she look for her marble?

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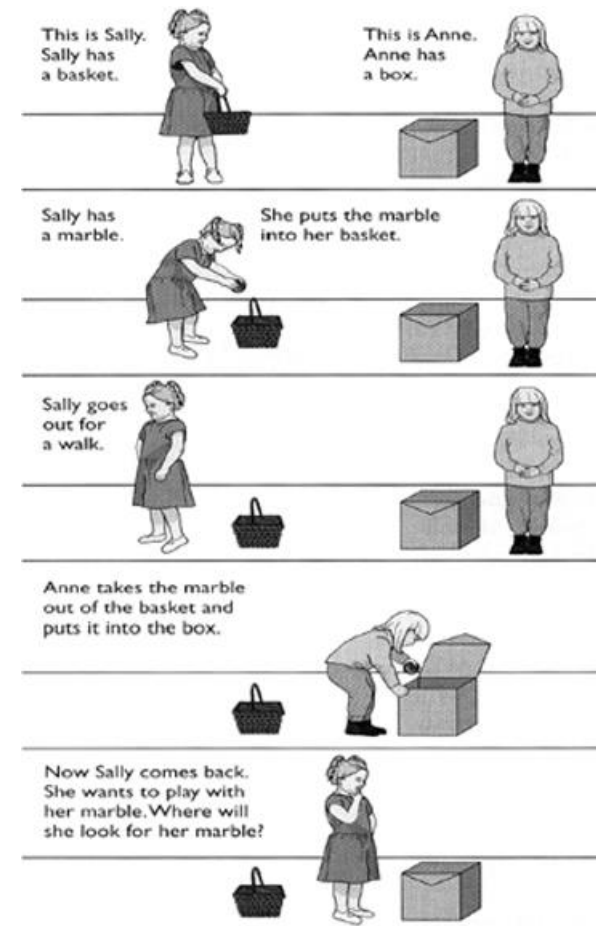
Mutual incomprehension

- "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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Tea break

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Stress and anxiety

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'.

YOU CAN FIGHT..
ME UM FLIGHT!..

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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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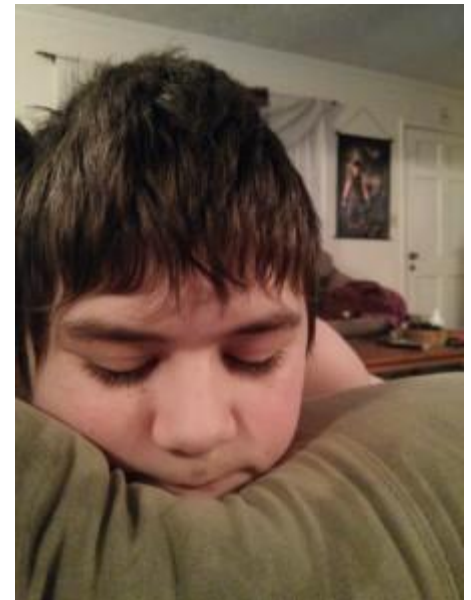
Information overload

- 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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Disruptions to flow and sensory overload

- Disruptions to 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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Emotional overload

- How others see you and how you see yourself. Emotional disjuncture and 'identity crisis'.

- 'Exposure anxiety' (Williams, 1996).

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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
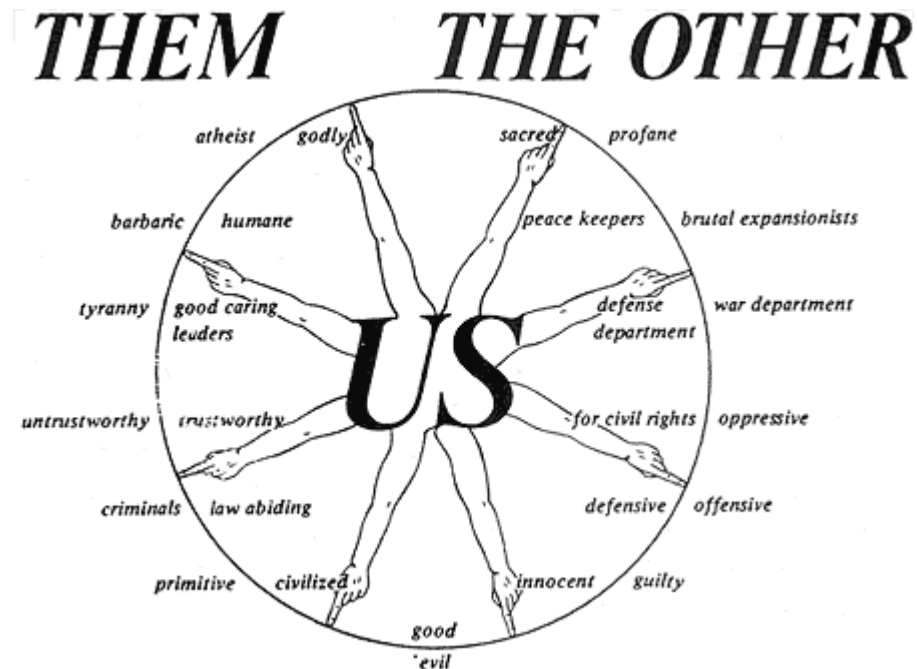
Chronic stress and mental ill-health

- 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 – from social anxiety issues to depression and catatonia.

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

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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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Autism and mental health

- Anxiety

- OCD

- Depression

- Catatonia

- Psychosis and hearing voices

- Post-traumatic stress disorder

- Eating disorders

- Misdiagnosis and missed diagnosis

- Suicide

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Study of Asperger United Magazine

- Four broad main themes (encompassing various sub-themes) were identified:

- Meeting personal needs

- Living with the consequences of an 'othered' identity

- Connection and recognition

- Relationships and advocacy

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Societal othering

- Societal othering encompassed issues including being excluded from social activities, attempts of others to 'normalise behaviour', problems with authority figures (expectations of obedience and conformity), stigma and bullying.

- *'Growing up in this way, it can lead to feeling as though we are 'wrong' or 'defective', and for me that led to low self-esteem and depression, as well as an intense need to find a way to improve myself and make myself acceptable to others.'* (Sian, 'Asperger's and Anorexia', issue 68, 15).

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- *'Throughout my life I have developed an 'act' to be 'normal', which has allowed me to interact with people, but this negates the possibility of friendship due to the fact it's not the real me.'* (Robert, 'Relationships', issue 77, 16).

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Social navigation

- *'Far from being loners, most of us are lonely.'* (Ruth, 'Relationships', issue 77, 14).

- *'I started attending a social group for people with autism. It has helped a great deal with my confidence.'* (Paul, 'Family on the Spectrum', issue 67, 20).

- *'I was wondering how other people in the same position have 'embraced' their Asperger's personality and shed the masks that have to be worn every day – I feel that mine will have to be surgically removed, as they've grown to be a big but uncomfortable and ill-fitting part of me.'* (Karen, letter to the editor, issue 76, 20).

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Psycho-emotional disablism

- The concept of psycho-emotional suggests that there are dimensions of disability that constitute a form of social oppression, operating at both a public and personal level, affecting not only what people can 'do', but what they can 'be'.

- Responses to the experience of structural disability.

- In the social interaction one has with others.

- Internalised negativity and low self-esteem.

- These issues can be particularly marked in a marginalised group stigmatised by their differences in 'social interaction' itself.

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- *'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).

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Autism and support strategies

- "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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So what exactly are autism interventions, intervening with?

- Research Autism website lists of 1,000 named interventions.

- What is the goal of these interventions?

- Are there ethical issues regarding these purposes, or the means by which one tries to achieve them?

- An overview of the spectrum of ideology regarding interventions.

- Tensions between views and why they exist.

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Normalisation

- "Another way to decide what to teach a child with autism is to understand typical child development. We should ask what key developmental skills the child has already developed, and what they need to learn next. The statutory curriculum in the countries of the UK also tells us what children should learn. Then there are pivotal behaviours that would help further development: teaching communication, social skills, daily living or academic skills that can support longer-term independence and choices." (Prof. Richard Hastings, 2013: http://theconversation.com/behavioural-method-is-not-an-attempt-to-cure-autism-19782).

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Applied Behavioural Analysis (ABA)

- Early Intensive Behavioural Intervention (EIBI).

- Discrete Trial Training (DTT).

- Functional assessment (ABC method) – the teacher describes a 'problem behaviour', identifies antecedents for why the behaviour is occurring, and analyses the consequences of the behaviour. This analysis is thought to indicate what influences and sustains such behaviours.

- Positive Behaviour Support (PBS).

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Criticisms of ABA

- The Loud Hands Project (2014).

- Accounts of harm.

- Who decides which behaviours are to be deemed as either positive or negative? How much does this take into account autistic subjectivity and learning styles?

- Intensity leads to overload, particularly when staged in a face-to-face manner, and distress can be ignored when viewed as inappropriate behaviour.

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Relationship and developmental interventions

- Alternatives to Behavioural approaches are often categorised as Relationship-based or Developmental approaches.

- This is a very broad category however which encompasses a number of differing approaches.

- Examples include RDI, Intensive Interaction and the DIR/Floortime method.

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Intensive interaction

- A relationship-based model which seeks to make functional gains in communication.

- However, the focus here is primarily building trust and rapport on the child's own terms.

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

- Phoebe Caldwell (2014) – moving beyond initial model in her practice.

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Evidence-base

- There is certainly not enough evidence to suggest a one-size-fits-all approach

- Common factors between approaches?

- Beneficial factors within them?

- Influential factors such as maturation which have little to do with what approach one takes.

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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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- *"Because otherwise he is trapped in a world where he cannot communicate his hopes and fears, particularly when I am dead and cannot look out for him."*

- *"Difference should be accommodated, accepted and celebrated."*

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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

Support for autistic people in mental distress

- Psycho-social therapies

- CBT and PCT

- Medications

- Social connections – circles of support and peer groups

- Social change

Conclusion

- "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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Five key points

- **Respect** the individual, work with them, not against their 'autism'

- 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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References

- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders* (4th edition) (DSM-V). Washington: APA.
- Asperger Square 8 blogsite (2014): http://4.bp.blogspot.com/_1vPB2M2IMiI/SucK5Gau3TI/AAAAAAAAACeQ/X8ANAC-forQ/s1600-h/social.model.png
- Caldwell, P (2014) *The anger box*. Hove: Pavilion Press.
- Chown, N. (2014) More on the ontological status of autism and double empathy, *Disability and Society,* Vol. 29(10): 1672-1676.
- Csikszentmihalyi, M (1990) *Flow: The psychology of happiness*. London: Random House Books.
- Durkheim, E. (1897/1951) *Suicide.* New York: The Free Press.
- Lawson, W. (2010) *The Passionate Mind: how people with autism learn.* London: Jessica Kingsley.
- McDonnell, A (2010) *Managing aggressive behaviour in care settings: Understanding and applying low arousal approaches.* London: Wiley.
- McDonnell, A and Milton, D (2014) Going with the flow: reconsidering 'repetitive behaviour' through the concept of 'flow states'. In G. Jones and E. Hurley (Eds): Good Autism Practice: Autism, Happiness and Wellbeing, pp. 38-47.
- Mills, R. (2013) *Guidance for Considering a Treatment Approach in Autism.* Accessed 11/02/14: http://www.autism.org.uk/living-with-autism/strategies-and-approaches/before-choosing-an-approach/guidance-for-considering-a-treatment-approach-in-autism.aspx
- Milton, D. (1999) *The Rise of Psychopharmacology [Masters Essay – unpublished].* University of London.
- Milton, D (2012a) *So what exactly is autism?* Autism Education Trust. www.aettraininghubs.org.uk/wp-content/uploads/2012/08/1_So-what-exactly-is-autism.pdf
- Milton, D (2012b) On the ontological status of autism: the double empathy problem. *Disability and Society*, 27(6), 883–887.
- Milton, D (2013a) 'Filling in the gaps', a micro-sociological analysis of autism. *Autonomy: the Journal of Critical Interdisciplinary Autism Studies,* 1 (2). www.larry-arnold.net/Autonomy/index.php/autonomy/article/view/7/html (accessed 27 August 2014).
- Milton, D (2013b) *'Clumps': An autistic reterritorialisation of the rhizome.* In, Theorising Normalcy and the Mundane. 4th International Conference, Sheffield Hallam University, 4 September 2013.
- Milton, D (2014) Autistic expertise: A critical reflection on the production of knowledge in autism studies. *Autism*, Epub ahead of print.
- Murray, D., Lesser, M. and Lawson, W. (2005) Attention, monotropism and the diagnostic criteria for autism. *Autism.* Vol. 9(2), pp. 136-156.
- Sinclair, J. (1993) "Don't Mourn For Us", http://www.autreat.com/dont_mourn.html
- Singer, J. (1998; republished 2016): "NeuroDiversity: The Birth of an Idea". Faculty of Humanities and Social Science, Sydney: University of Technology.
- Tajfel, H. and Turner, J. (1979) An integrative theory of intergroup conflict. In D. Langbridge and S. Taylor (ed's) *Critical Readings in Social Psychology.* Milton Keynes: Open University.
- Williams, D. (1996) *Autism: An Inside-Out Approach.* London: Jessica Kingsley.

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