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Understanding autism and stress, from avoidance to flow states.

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, UCL and LSBU.
- Chair of PARC and Director at NAT.
- Editorial team of the Autism Journal.



### Introduction



- An exploration of autistic interests and avoidance and relation to stress.
- The concept of flow states in relation to autistic experience with practical examples of how these are accomplished.
- Practical strategies to help autistic people and their families reduce stress.
- Signpost where you can find more information on these topics.

# The sensory onslaught



- Sensory integration and fragmentation.
- Hypo and hyper sensitivity.
- Context and motivation.
- Synaesthesia.
- Stress, arousal and sensory overload 'meltdown' and 'shutdown'.
- Stress build up: coming back from Denmark.

### 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'.

### Information overload



- The 'monotropic' focus (Murray et al. 2005, Lawson, 2010).
- Multi-tasking, integrating information, and fragmentation.
- Interruptions to the 'attention spot light'.
- Interest and avoidance.



# The 'double empathy problem'



- A case of mutual incomprehension?
- Breakdown in interaction between autistic and nonautistic people as not solely located in the mind of the autistic person.
- Theory of autistic mind can often leave a great deal to be desired.



### **Emotional overload**



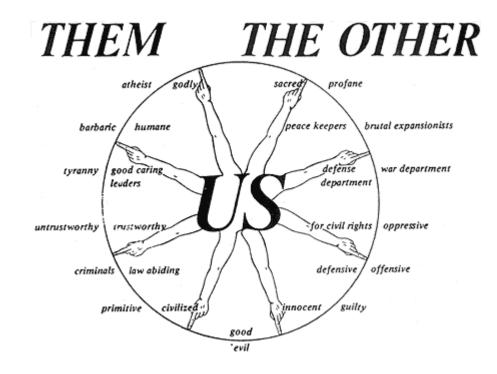
- How others see you and how you see yourself.
   Emotional disjuncture, 'identity crisis' and stigma.
- 'Exposure anxiety' (Williams, 1996).



# Social stigma



- The denigration of difference (Tajfel and Turner, 1979).
- 'In' and 'out' groups, stigma and discrimination.



### **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.
- The AMASE report: Too complicated to treat?

### From avoidance to interest



 "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).

### 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.



- 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.

# 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.

### 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.
- The activity is experienced as intrinsically rewarding.

# Flow and the relieving of stress



- 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.

# Monotropism, flow and spiky profiles



 "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).

# 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).



# Disruptions to flow and sensory overload



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



### Monotropism and social context



- 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.

### **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.

### 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 (Caldwell, 2014).

# The downside: one-way tracks, clumps and blockages



- Gambling on horse races or card games have all the necessary parameters with regard to producing a flow state in those who participate in them.
- More morally neutral activities such as playing non-gambling games can also become addictive.



- The opposite of flow-like states: such as when flows become entangled and 'clumped' (Milton, 2013b).
- Blockages may account for high levels of stress and resultant 'challenging behaviours' (McDonnell, 2010).



 "According to the accounts of people on the autism spectrum, the flow-like states brought about by the pursuit of 'special interests' or the repetition of actions can be seen as a necessary coping strategy for people and not 'behaviours' to be controlled or regulated." (McDonnell and Milton, 2014).

### 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 person's own terms.
- Following a person's interests and learning their 'language' and centres sensory needs.
- Phoebe Caldwell moving beyond initial model in her practice.

### **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<br>Difficulties ? | -Organising,<br>sequencing<br>and planning –<br>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           | -Positive /direct clear language -Use strengths and interests as | -Reflection – Discussion -Pictorial aids                                                                        | -Audit sensory<br>environment<br>-Reduce noise/<br>clutter     | -Inclusive meetings - Access to 'mainstream'                                    |

### 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.



# **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. If the environment is causing distress, than change it.
- 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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