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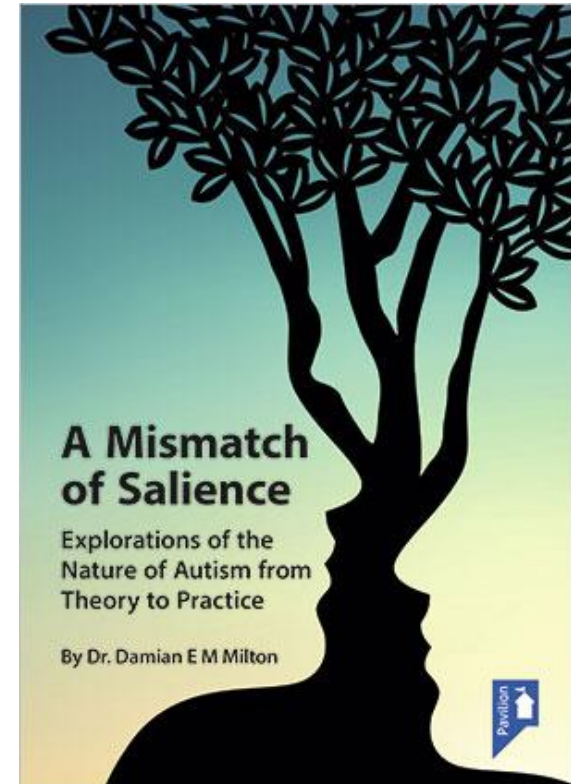
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Autistic wellbeing: from flow to belonging

Dr. Damian E M Milton



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

What did they know?

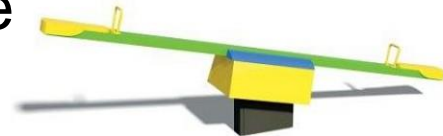
- “Appalling, I fear I am at a loss to know where to begin and what to try next. Fortunately, he enjoys his table-tennis.” (French teacher, Autumn term, 1985).



- “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).

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.



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.

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 autistic people experience.

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).

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.

Meeting personal needs

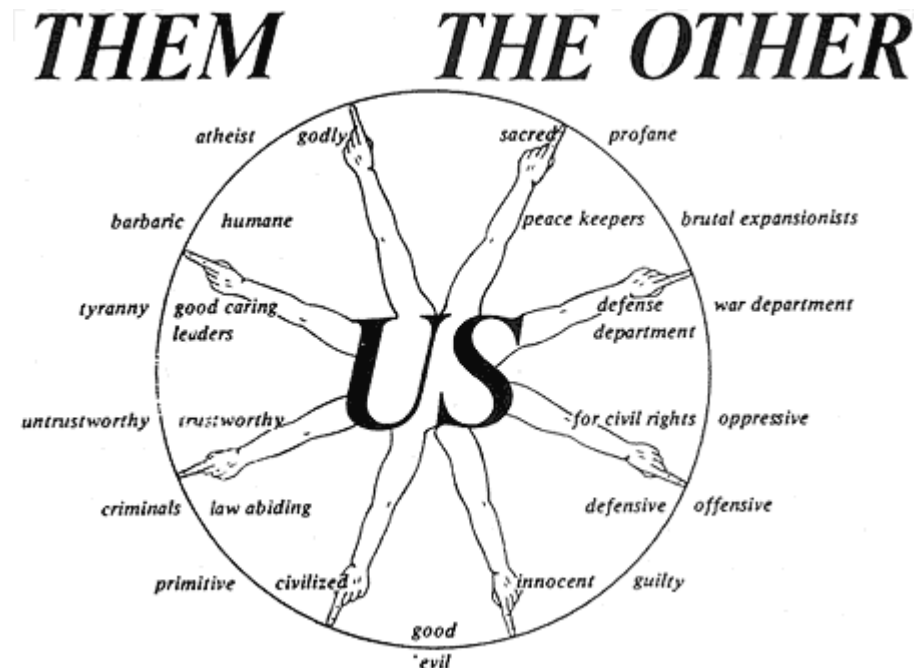
- Paramount within this theme was the minimisation of stress and sensory overload, and personal fulfilment through the pursuit of interests.
- *'It makes me a very visible case of 'sensory issues', when a spectrumite's body is discomfited by certain clothes and fabrics.'* (Maurice, 'Sensitivity and Clothing', issue 66, 4).
- *'I have always been happiest when absorbed in very detailed problem solving.'* (Tom, 'Work Detail', issue 66, 10).

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).

Social stigma

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



Masking

- *‘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).*

The double empathy problem

- *'Yet NTs find it impossible to empathise with us.'* (Robert, letter to the editor, issue 74, 9).

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).

Connection and recognition

- *'I cannot talk about my real experience of life to most people, because they wouldn't understand or be interested. That makes me feel, as the saying goes, 'lonely in a room full of people' and I'm fed up with it. I would like to talk to caring, intelligent, honest people who understand Asperger's well and with whom I can talk openly. My hobbies include cycling, walking in the countryside, and rational thinking.'* (Daniel, Pen Pal 95, issue 68, 7).

Acceptance and autistic-led spaces

- *‘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).

Relationships and advocacy

- *‘Now, close personal relationships and I have what you might call a nodding acquaintance. I usually manage one every ten years or so, on average.’* (Mark, ‘Don’t Really Go in for Titles, Best Just Read On’, issue 76, 11).
- *‘We’re all positive and that positivity has helped us cope with everything in life. We’re a strong unit: we help others and each other.’* (Paul, ‘Family on the Spectrum’, issue 67, 20).
- Advocacy and self-advocacy – and in relation to research.

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

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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