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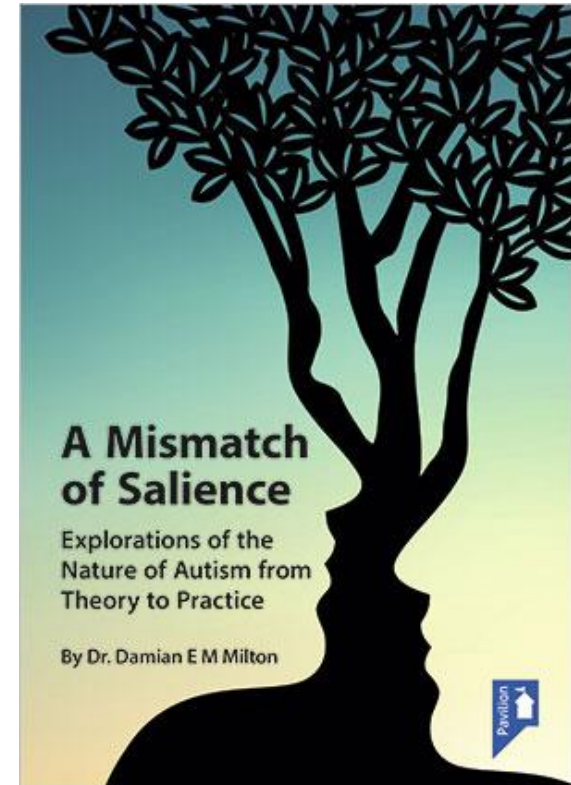
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Mentoring and peer support for autistic students

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

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

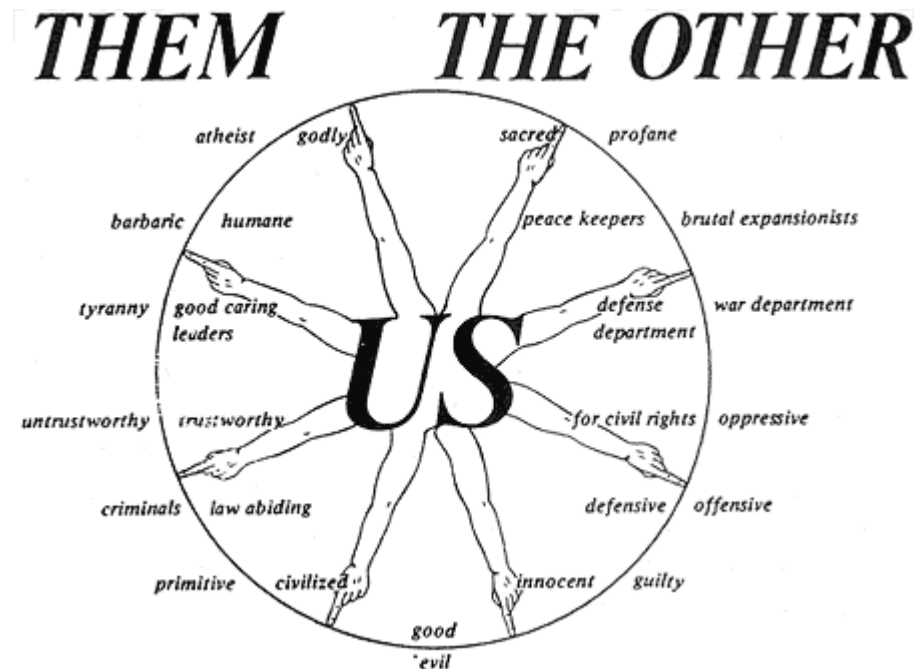
- Paramount within this theme was the minimisation of stress and sensory overload, and personal fulfilment through the pursuit of interests.
- *'It makes me a very visible case of 'sensory issues', when a spectrumite's body is discomfited by certain clothes and fabrics.'* (Maurice, 'Sensitivity and Clothing', 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).
- Importance of peer support and work being done at the University of Kent.

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.

Why mentoring?

- Living with almost constant stress and social disjuncture, can result in alienation, isolation and withdrawal from society.
- An effective adequately supported mentor can help an autistic person to cope, thrive and progress in education, employment and participation in their community on their terms.
- This is potentially quite a cheap solution and a way to avoid wasting talent.

Evidence of need

- The National Audit Office's (2009) report 'Supporting People with Autism' through Adulthood highlighted the dearth of services for autistic adults.
- At the 2007 forum 'Successful Futures for Adults with Autism' many said that they would benefit from one-one, time-limited, goal-oriented support, akin to life coaching or mentoring.
- Specialist mentoring schemes autistic people are rare.

The Research Autism Mentoring project

- A two year pilot project designed by autistic people to evaluate a mentoring intervention.
- After mentor training, selection, matching and completion of the Melbourne Personal Wellbeing Index (PWI), 12 pairs met for one hour per week over 6 months. Supervision was built in throughout.
- 3 Goals are set initially and reviewed later using the Salmon Line.
- Meeting record sheets are jointly completed and a reflective journal is individually completed after each session.

Data analysis

- After the final mentoring session, research assistants completed another evaluation, PWI and interview with participants.
- Data was collected and analysed by the research team with input from the Advisory Group.

PWI findings

PWI	All (pre)	Pre (finished)	Post	Difference
Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole?	5.1	6	7.8	1.8
How satisfied are you with what you are achieving in life?	5.1	5.4	7	1.6
How satisfied are you with how safe you feel?	6.4	7.4	8.8	1.4

Progress toward goals

All (pre)	Pre (finished)	Post	Difference
3.75	4	8	4

Qualitative findings

- The involvement of autistic people throughout the project in the research team and advisory group was beneficial.
- The importance of good person-centred and insider-informed training.
- The importance of matching mentors with mentees and flexibility to change.
- Boundaries need to be supervised with care.
- Supervision from the research team.
- Mixed use and benefit from the Salmon Line.

- *“...this helped me dig my way out of a life threatening hole that I could not see any way out of. It reminded me to make progress towards goals. [The mentor] Listened when I needed it, was a regular weekly marker in my chaotic life, provided an opportunity to reflect and plan and self manage. I wouldn't have done this otherwise.”*

Main findings

- Time limited goal orientated mentoring is of value to mentees.
- Boundaries have to be supervised with care.
- Training / supervision must be managed.
- Involvement of autistic people in all aspects of project was a particular strength.

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