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Becoming Autistic: a Father's Story

Dr. Damian E M Milton



Introduction

- This presentation gives a personal perspective on the formation of autistic identity.
- Reflects on methods used in projects exploring self-identity.
- And some of the issues involved more broadly when discussing identity in relation to autistic people.

Born into an unusual family, Summer 1973



Early days

- “[My father]...came to see the boys yesterday...[my brother]...seemed pleased to see him and after an hour of watching [them both] together, Damian finally decided to say hello. I’m convinced Damian just didn’t remember...[my father]...and refused to be friendly all afternoon.” (My mother, 27/08/75).
- “Must admit to feeling rather miserable – reasons why: just over a week ago Damian got ill and finally I called the doctor...and evidently it was an attack of asthma. He’s much better now, but it was so frustrating sitting up all night with him with one hand being clutched, totally unable to do anything positive to ease his breathing for him.” (My mother, 11/07/77).

My first school sports day, July 1978



An unusual boy

- What was up with him though? He seemed sensitive, silly, yet serious and bright.
- The ‘silent volcano’.
- Avoidance of ‘everyday demands’.
- Neologisms and list making.
- Fact and science fiction.
- Obsessive interests.
- Memory ‘tricks’.
- “He finds little difficulty tackling new mechanical arithmetical processes, or indeed with new mathematical concepts. Mental Arithmetic: A.” (Maths teacher, 22/07/82).



Secondary school

- First term went okay, mostly B and C grades, enjoyed History, and got an A in Art, but a D in Chemistry: “He needs to concentrate much harder.” Only a C in Maths though:
- “Surely he can do better than this with more concentration.” (Maths teacher, Autumn term, 1984).



The accident and the aftermath

- Road traffic accident in December 1984.
- “He has become very lethargic this term. His presentation is dreadful. He really must try harder. The work is getting on top of him again.” (French teacher, Spring term, 1985).
- “Rather struggling at times.” (Biology teacher, Spring term, 1985).
- Being accused of cheating.



The blame game

- By Autumn term 1985 things had gotten much worse and I had D's and E's across the board...
- “Dear Mrs. Milton, I intend to put your son on report because of – English, History, Geography, Latin, French, Physics, Chemistry, Biology and Music. This means that he will have to carry a card and present it in class for signing by his subject masters.” (Form teacher, 25/10/85).
- I was on report for the next four years until I left the school in July 1989.

School reports

- “Damian is content to let the lessons go on around him without really getting involved.” (R.E. teacher, Autumn term, 1985).
- “He seems completely lost and there seem no signs ever of any degree of interest.” (Classics teacher, Autumn term, 1985).
- “Unfortunately he seems to have neither any aptitude for the subject nor any desire to improve.” (Physics teacher, Autumn term, 1985).
- “Despite encouragement, cajoling, threats and eventual punishment, nothing seems to get through to him. He seems to lack drive or any will to improve.” (Form teacher, 1985).

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).
- The Geek gang.



My fate was sealed?

- Psychiatric encounters and the ongoing court case.
- The tutelage of Mrs. Socrates: “Damian always produces good work when present.” (Mrs. Socrates, Spring term, 1987).
- And yet, by now my identity had been sealed:
- “He seems to have little energy, enthusiasm or ambition. Instructions are ignored, work is never handed in on time, if at all, and he seems to have no explanation for any of this.” (Head of Middle School, 20/11/87).
- “It does not appear that Damian is very bright and therefore lack of effort only compounds the problem.” (Form teacher, Autumn term, 1987).
- But to quote my friend and colleague Dr. Dinah Murray: “Perseverance furthers’.

A growing political consciousness

- “My major worries about the future are foreign affairs and the environment. These are issues that endanger the Human Race. The world has many groups in conflict...This kind of competition I feel is not beneficial to any of us. If we all worked together to create a better life and tried to understand one another’s beliefs and ideas, things would become much easier.”
(Letter to Sir George Young MP, 1990)

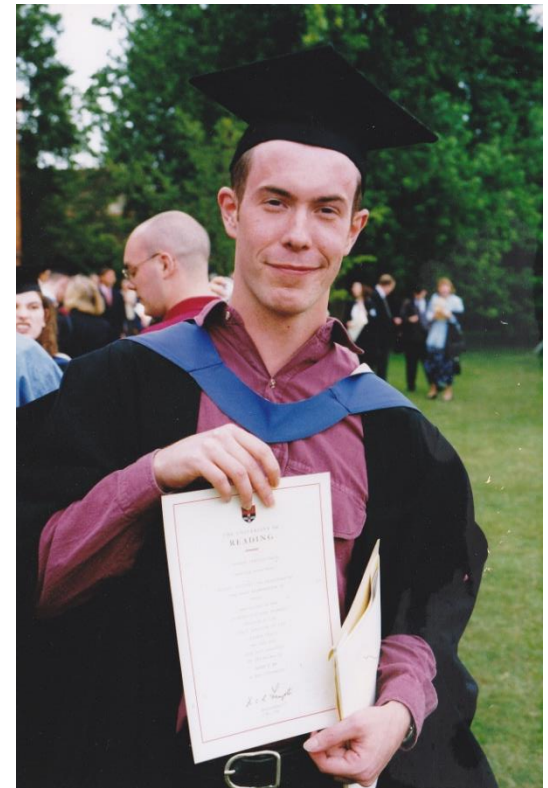
First attempt at studying a degree

- “I have become increasingly concerned over your absence from lectures and failure to submit valuable coursework. With examinations starting on 1st June and the threat of failing the Degree Course, I am keen to speak with you urgently about your future...” (Course tutor, 01/05/92).
- Dropping out.



Studying Sociology

- “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').

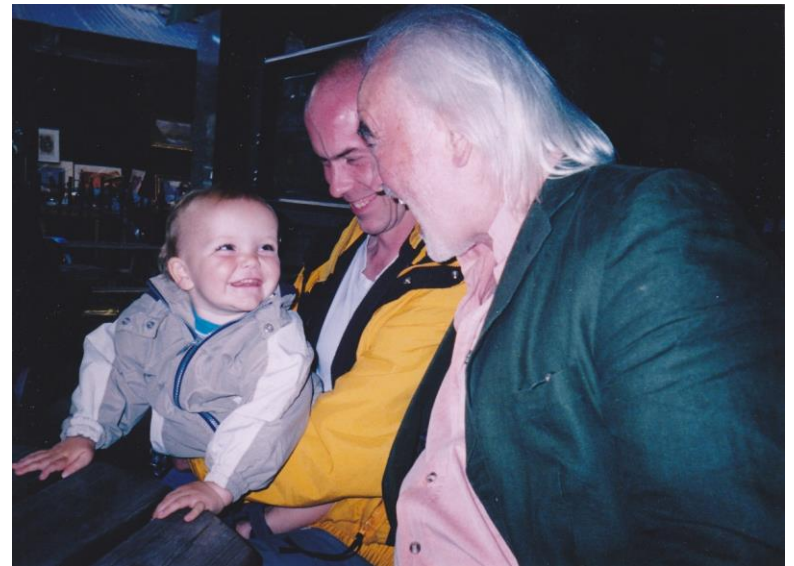


Dropping out again...and retracing myself

- “One of the shocks is that the voice of the ‘other’ is being heard, rather than the voice of unity and harmony usually alluded to in the ‘perfect norm’ family narrative – papering over the cracks of the past.” (Milton, D., cited in Milton, C., 2002).
- “Expressions of discontinuity are more likely found in individual artistic expressions or from the socially marginalised or from the eccentric dynamic character.” (Milton, D., cited in Milton, C., 2002).

Becoming a dad

- Initial worries over 'ventricular enlargement in the brain'.
- Born with an abnormally large head circumference.
- Finding work as an FE lecturer.
- Gift for numbers and puzzles.
- Another 'proud dad'.
- The day nursery encounter.
- 'Regression'.



Self-identification

- Textbook and autobiographical accounts.
- Self-identification, Autumn 2004.
- Initial service provision.
- Statements and forms – disabled by bureaucracy.
- Being made redundant, Summer 2008.

Diagnosis day, Autumn 2009

- “Appearance and behaviour: Mr. Milton was tall and thin with a long face. He was wearing an anorak, tracksuit bottoms and trainers. He had very little eye contact, a markedly reduced range of facial expressions and made little use of gesture.”
- “Speech: Mr Milton’s speech was low and flat with little modulation...”
- “Physical examination:...fell over during tandem walk.”
- No mention of Dyspraxia or possible need for assessment though.
- On the ADI-R I scored well above the cut-off on all areas.
- “Unequivocal on all counts.”

Back to the 'drawing board'

- Finding out about the self-advocacy and neurodiversity movements (Sinclair, 1993; Sainsbury, 2000; Murray et al. 2005, Arnold, 2010).
- Finding practitioners and academics in the field who seemed to be 'on the right path'.
- Further study and starting a PhD...again (Autumn 2009).

Subverting the 'functional' family album

- Single photographs – accompanied by narratives written in hindsight by both myself and my mother.
- Focusing on the traumatising effects of the road-traffic accident.
- Charting the history of the effects and continuation of the process (rather than resolution).
- Trauma as a breach which does not 'heal' (Garfinkel, 1967). Trauma as permanent discontinuity with previous sense of self.

Alternative means of communication / research

- The 'Photo Book'.
- Photo taking and reporting.
- Photo sorting.
- Photo-montage and collage.
- Linear narrative and deconstruction: the 'auto-ethnography'.
- Tangible alternatives – 'objects of reference'.

Identity and the social model of disability

- “Because most of us are not ill at all, but have injuries or genetic conditions of a permanent nature, the goal of ‘getting better’ is impossible to achieve, but changing the way we are treated as disabled people is possible. Therefore the social model is full of hope for us.”
(Mason, 2000: 57).

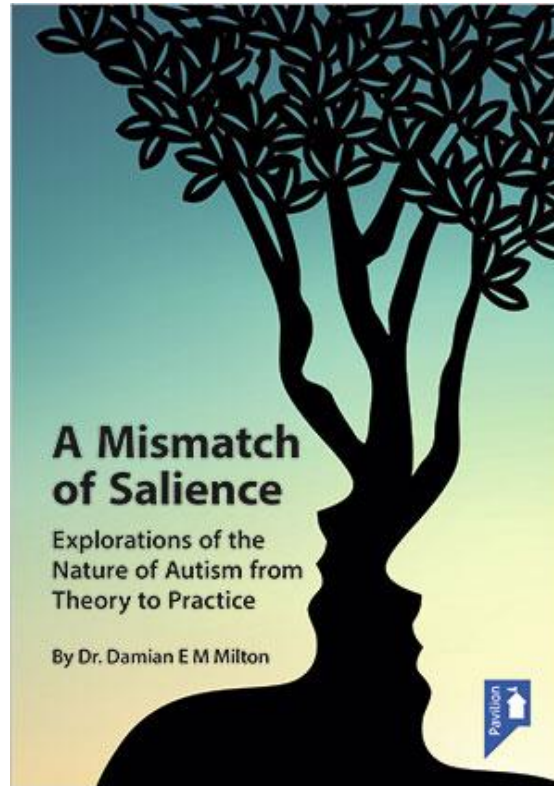


Wider themes and ‘social issues’

- How much use is a pathologising deficit model diagnosis?
- How much use is a cultural identity and sense of belonging? Clue: the answer should be obvious.
- The psycho-emotional disablement of autistic identity.
- Autism itself is not a ‘problem’ that can be remedied, the problem is how to build understanding and communication in both directions (limiting the effects of the ‘double empathy problem’ – Milton, 2012).

Where next for me? What next for the autistic community?

- To mix two old sayings together:
- Watch this space...because you ain't seen nothing yet...



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