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# How is a sense of wellbeing and belonging constructed in the accounts of autistic adults?

*Dr. Damian E M Milton*

# Introduction

- Report upon a small-scale exploratory study.

- Sought to develop an understanding of the meaning of wellbeing and social belonging as represented within the narratives of adults on the autism spectrum.

- Employing an interpretive approach, the project involved a thematic analysis of issues of the magazine Asperger United (AU).

- Study co-written with Dr. Tara Sims and published in *Disability and Society,* Vol. 31(4): 520-534.

# Measuring wellbeing

- Extent to which standardised measures of wellbeing capture autistic experience and sensibilities is debatable (Robertson 2010).

- Theorists such as Timimi, Gardner, and McCabe (2011) and Runswick-Cole (2014) have questioned the use of medicalised labels such as autism and also concepts such as neurodiversity, and the possible detrimental effects of a politics of identity.

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# Wellbeing and the double empathy problem

- In contrast, Beardon and Edmonds (2007) found that 83% of autistic adults they surveyed identified one of their greatest challenges as being a lack of understanding and recognition of their differing needs from other people.

- The same issue has been highlighted by autistic children and young people (Milton and Giannadou, 2012).

- Such gaps in understanding could be argued to arise from differing dispositional perceptions and ways of being in life, a mismatch of what is salient or of interest within any given context, the 'double empathy problem' (Milton, 2012, 2014, 2017; Chown, 2014, 2016).

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# The social context of autistic wellbeing

- For all of these researchers however, when professionals look at the barriers autistic people face in social life, they rarely focus on how social attitudes and norms can create them.

- One of many examples Robertson (2010) gives refers to autistic people attaining and sustaining employment, e.g. where efforts are often concerned with adapting the autistic employee to fit into social contexts rather than adapting such contexts to meet the needs of the autistic person.

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# The study

- Themes and issues relevant to adults on the spectrum and expressed through the articles within AU were collated and analysed, with particular attention given to references made to factors that have influenced, either positively or negatively, an individual's sense of wellbeing or social belonging.

- At the time of analysis, 79 editions of AU had been published. Twenty-one editions of AU were sampled from the issues available from the National Autistic Society information service, ranging over a six-year period from issue 54 (April 2008) through to issue 78 (April 2014).

- In total 78 articles, 81 letters to the editor, 37 reviews, 121 penpal entries and 44 announcements were analysed.

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# Themes identified

- Four broad main themes (encompassing various sub-themes) were identified: meeting personal needs, living with the consequences of an 'othered' identity, connection and recognition, and relationships and advocacy.

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# 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 discomforted 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).

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# Living with the consequences of an 'othered identity'

- Societal othering encompassed: 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).

- *'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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# Interactions with psych-professionals

- Often seen as extremely negative, with many reporting that their needs were not recognised or were misinterpreted, with some saying that they were forced by such professionals into actions they did not want.

- Others reported how they were blocked from seeing their families or made more ill by being under psychiatric surveillance, with one contributor to AU stating how one psychiatrist had labelled them as 'evil'.

- *'I formed a high regard for all the therapists; however, none had experience of treating a person with AS so that, in some respects, their efforts were ineffective or even counter-productive.'* (Tony, 'Anxious Thoughts', issue 76, 4).

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# Employment

- Various issues, including not being able to achieve the qualifications that their ability warranted, being undervalued at work, a lack of job satisfaction, social alienation at work and underemployment through skills not being recognised:

- *'I had the same to offer employers as other students looking for work, I was only ever offered the worst paid and hardest temporary positions in factories such as working in a noisy dairy or packing department whilst a friend landed office work.'* (Richard, 'The Challenges of Employment', issue 74, 12).

- *'I work in retail, which is a notoriously pressured environment. It seems to proliferate with NTs who have no insight into their behaviour, let alone understand anyone else's.'* (Anon, letter to the editor, issue 75, 14).

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# The double empathy problem (again)

- Although some contributors to AU mentioned difficulties in terms of understanding the intentions of others within social interactions, it was far more common that a lack of understanding from others was of more difficulty, indicative of what Milton (2012, 2014, 2017) and Chown (2014, 2016) have previously theorised as the double empathy problem:

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

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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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# Connection and recognition

- The third theme 'connection and recognition' pertains to when adults on the autistic spectrum had found a sense of connection and recognition with/from others, and better understanding of their subjective viewpoint from those around them.

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# Sharing interests

- *'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).

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# Acceptance and autistic-led spaces

- *As in previous Autscapes, I found the spontaneous discussions to be even more interesting than the scheduled presentations, as the spontaneous discussions allowed me to get to know other autistics, to explore our commonalities and differences, and to somewhat quench my insatiable thirst for meeting other autistics and for building bridges.'* (Chen, 'Autscape 2011', issue 69, 17).

- *'When I meet my people, I know, because I feel it. And my people were there at Autscape and the whole thing was imbued with love, expressed autistically, but love nonetheless…Autscape has meant I see my differences as part of the differences that make up the whole of humanity and as something to be celebrated, not something I need to get away from…there was no fear or ridicule. I had never before experienced such a feeling of coming home.'* (Amanda, 'Autscape', issue 76, 14).

# 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.

# Discussion of key points

- The themes identified in this study highlight the many barriers and challenges faced by people on the autism spectrum in achieving wellbeing and a sense of belonging.

- Many differing narratives have been analysed, but commonalities persist.

- The findings from this study indicate that thinking of autistic wellbeing purely in terms of efforts to remediate the challenges faced by autistic people as if they are a set of 'deficits' is highly limited and potentially counterproductive.

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- Perhaps standardised measures could be used without much adaptation, yet what interventions researchers explore in order to improve feelings of wellbeing in the perceptions of autistic people may need to focus on the personal constructions and interests of the autistic person, rather than being based on normative assumptions.

- Autistic identities can be said to be constructed within a context of an uneven distribution of power, with a medicalised view of autistic difference and remediation at times acting as a hindrance to feelings of wellbeing and belonging.

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- Issues such as 'masking' and 'passing' become a conflicted discursive space, in which some feel that it is sometimes easier to conform (although with great difficulty), whereas others feel unable to do so or perceive attempts to do so as inherently disabling.

- The opportunities created by autistic-led spaces are obviously beneficial to many, yet so are relationships that accept and celebrate one's way of being in the world, wherever such relationships are fostered and nurtured.

# Conclusion

- The findings from this research may not be representative of the views and experiences of a wider constituency of adults on the autism spectrum, but do indicate potential issues and priorities of those within the autistic community who are verbally articulate, and as a group are likely to have experienced forms of social exclusion, or at least misinterpretation of their social experiences and felt needs (Milton 2012, 2014; Chown, 2014).

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- This study has brought attention to the many commonalities in what contributes towards wellbeing for both autistic and non-autistic people. However, it has also highlighted the considerable differences in the barriers to achieving it.

- This study has demonstrated a need for less focus on remediation and more focus on limiting the social isolation of autistic people.

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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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