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Autism and mental health in a social context

Dr. Damian E M Milton

A Mismatch of Salience

Explorations of the Nature of Autism from Theory to Practice

By Dr. Damian E M Milton
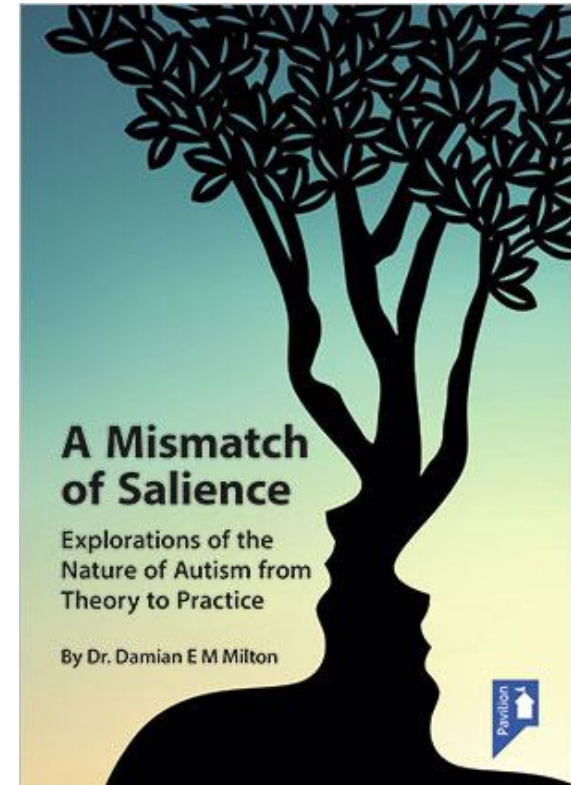
A bit about me

- I'm autistic (diagnosed 2009) – as is my son (diagnosed 2005).

- A background in Social Science (initially Sociology).

- Lecturer in Intellectual and Developmental Disabilities, Tizard Centre, University of Kent.

- Autism Knowledge and Expertise Consultant, National Autistic Society.

- Visiting Lecturer, London South Bank University.

- Project Leader, National Autistic Taskforce.

- Chair of the Participatory Autism Research Collective (PARC).

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- "Some of us aren't meant to belong. Some of us have to turn the world upside down and shake the hell out of it until we make our own place in it." (Lowell, 1999).

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Normalcy and the 'spiky profile'

- "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').

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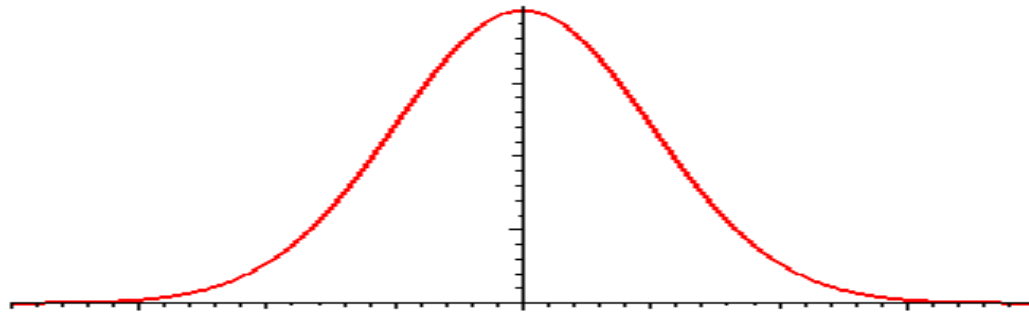
The neurodiversity 'paradigm'

- Variations in neurological development as part of natural diversity, rather than something to be pathologised using a purely medical model of disability, defined by one's deviation from statistical or idealised norms of embodiment or observed behaviour.

- This is not to say that those who identify as autistic people or other forms of neuro-identity do not find life challenging. Autistic people are significantly disadvantaged in many aspects of life.

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A triad of autism theories

- Executive functioning theory

- Weak central coherence

- Context blindness

- An interest model / monotropism

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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'.

- You will be shown a clip from the film 'My Autism and Me' – this will be followed by an open discussion about the clip.

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Flow states

- "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).

- "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).

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Information overload and stress

- Multi-tasking, integrating information, and fragmentation.

- Interruptions to the 'attention spot light'.

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Sensory perception

- Sensory integration and fragmentation.

- Hypo and hyper sensitivity.

- Context and motivation.

- Stressful stimuli.

- Stress, arousal and sensory overload – 'meltdown' and 'shutdown'.

- Synesthesia.

- "Aren't all autistic people visual thinkers?". Pattern thinking and Hyperlexia.

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The block design and embedded figures tests
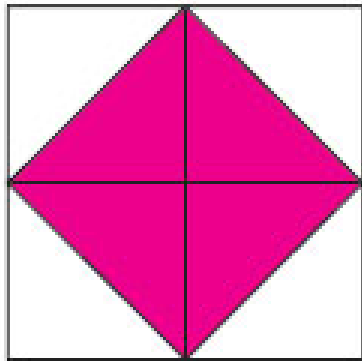
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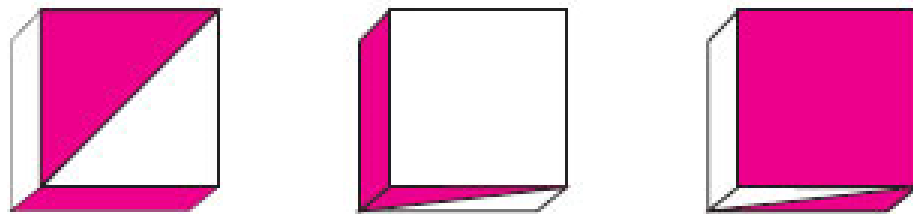
Types of block available for making the pattern

(a)

(b)

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Non-verbal intelligence

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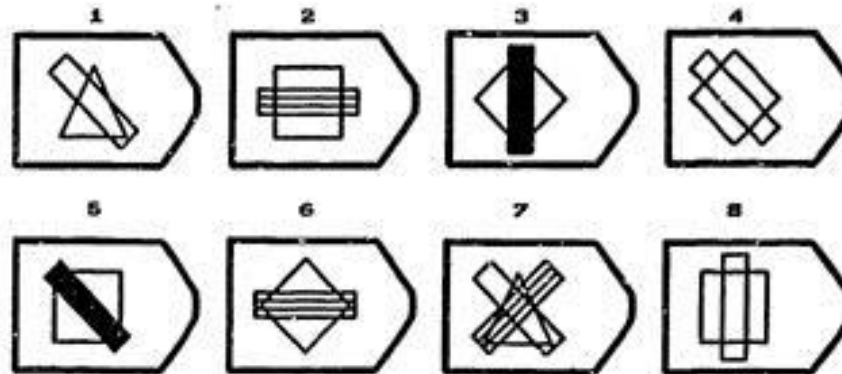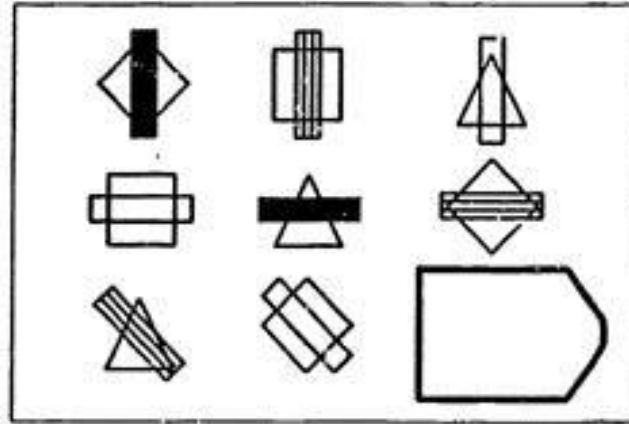
Sensory perceptions and conformity

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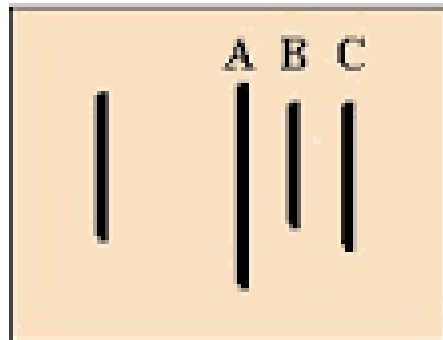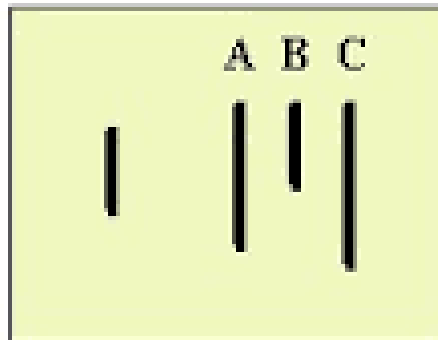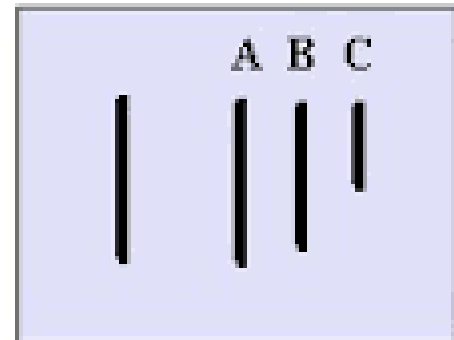
Theory of mind

- The ability to empathise with others and imagine their thoughts and feelings, in order to comprehend and predict the behaviour of others (also called 'mind-reading' and 'mentalising').

- Empathising-Systemising theory and the 'extreme male brain'.

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Mutual incomprehension

- "95% of people don't understand me".

- "Friends are overwhelming".

- "Adults never leave me alone".

- "Adults don't stop bullying me".

- Quotes taken from Jones et al. (2012).

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The 'double empathy problem'

- A case of mutual incomprehension?

- Breakdown in interaction between autistic and non-autistic people as not solely located in the mind of the autistic person. The theory of the double empathy problem sees it as largely due to the differing perspectives of those attempting to interact with one another.

- Theory of autistic mind can often leave a great deal to be desired.

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Social stigma

- The denigration of difference (Tajfel and Turner, 1979).

- 'In' and 'out' groups, stigma and discrimination.

THEM   THE OTHER

atheist / godly   sacred / profane

barbaric / humane   peace keepers / brutal expansionists

tyranny / good caring leaders   defense department / war department

untrustworthy / trustworthy   US   for civil rights / oppressive

criminals / law abiding   defensive / offensive

primitive / civilized   innocent / guilty

good
evil

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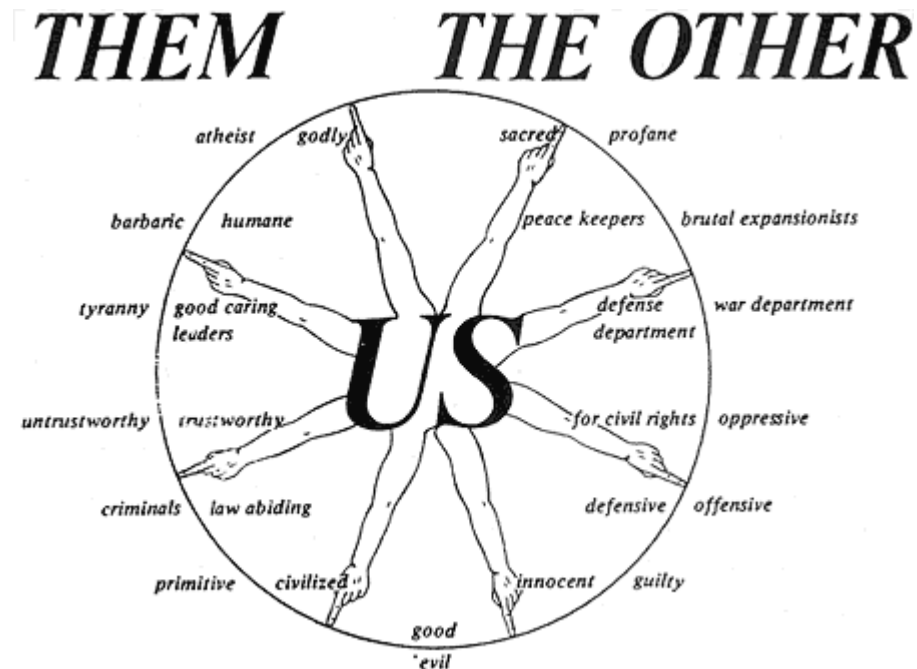
Autism and Mental Health

- 25% of people

- 40% of learning disabled people

- 70% of autistic people

- Why so high?

- What are the most common issues and how can one help?

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- Anxiety

- OCD

- Depression

- Catatonia

- Psychosis and hearing voices

- Post-traumatic stress disorder

- Eating disorders

- Misdiagnosis and missed diagnosis

- Suicide

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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.

- Remember – the outward manifestation of stress may be a lack of expression too.

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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

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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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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).

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Masking and passing

- *'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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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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Psycho-emotional disablism

- The concept of psycho-emotional disablism suggests that there are dimensions of disability that constitute a form of social oppression, operating at both a public and personal level, affecting not only what people can 'do', but what they can 'be'.

- Responses to the experience of structural disability.

- In the social interaction one has with others.

- Internalised oppression.

- These issues can be particularly marked in a marginalised group stigmatised by their differences in 'social interaction' itself.

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Durkheim's four types of suicide

- Integration: Egotistic and Altruistic suicide

- Regulation: Anomic and Fatalistic suicide

- The four types and autistic people

- Altruistic and Fatalistic suicide?

- Intolerance of uncertainty (Boulter et al. 2014), austerity politics and anomie

- Social isolation and wellbeing (Milton & Sims, 2016)

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- Beachler (1979) suicide as a result of an attempt to 'solve a problem'.

- Escapism, aggression, 'oblative' suicide (or sacrifice), and 'ludic' suicide (where deliberate risks are taken that could end in death).

- Although Beachler included in his work the accounts of those who had attempted suicide and framed his discussion around 'suicidal behaviour'.

- The personal meanings attached to 'suicidal behaviour' by autistic people may be similar to non-autistic people, or may be quite different, however, in-depth qualitative research would be needed to look further into this issue.

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Connection and recognition

- *'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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So what exactly are autism interventions, intervening with?

- Research Autism website lists of 1,000 named interventions.

- What is the goal of these interventions?

- Are there ethical issues regarding these purposes, or the means by which one tries to achieve them?

- Tensions between views.

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The goals of intervention

- "Another way to decide what to teach a child with autism is to understand typical child development. We should ask what key developmental skills the child has already developed, and what they need to learn next. The statutory curriculum in the countries of the UK also tells us what children should learn. Then there are pivotal behaviours that would help further development: teaching communication, social skills, daily living or academic skills that can support longer-term independence and choices." (Prof. Richard Hastings, 2013: http://theconversation.com/behavioural-method-is-not-an-attempt-to-cure-autism-19782).

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Normalisation

- "I had virtually no socially-shared nor consciously, intentionally expressed, personhood beyond this performance of a non-autistic 'normality' with which I had neither comprehension, connection, nor identification. This disconnected constructed facade was accepted by the world around me when my true and connected self was not. Each spoonful of its acceptance was a shovel full of dirt on the coffin in which my real self was being buried alive..." (Williams, 1996: 243).

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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 child's own terms.

- Following a child's interests and learning their 'language'.

- Phoebe Caldwell (2014) – moving beyond initial model in her practice.

Evidence-base

- There is certainly not enough evidence to suggest a one-size-fits-all approach

- Common factors between approaches?

- Beneficial factors within them?

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Insider knowledge

- "...right from the start, from the time someone came up with the word 'autism', the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced." (Williams, 1996: 14).

- The setting up of the Participatory Autism Research Collective (PARC).

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Support for autistic people in mental distress

- Psycho-social therapies

- CBT and PCT

- Medications

- Social connections – circles of support and peer groups

- Social change

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Too complicated to treat: AMASE report

- Rule one for ensuring 'challenging behaviour': call me complex

- Key themes from survey:

➢ Autistic people being directly denied mental health services due to their autism diagnosis

➢ Autistic people not being listened to or taken seriously when they are trying to communicate their mental health distress

➢ Problems with the basic accessibility of GP surgeries and mental health services

➢ A lack of understanding of autism and the mental health of autistic people amongst health professionals.

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Co-conditions reported in sample

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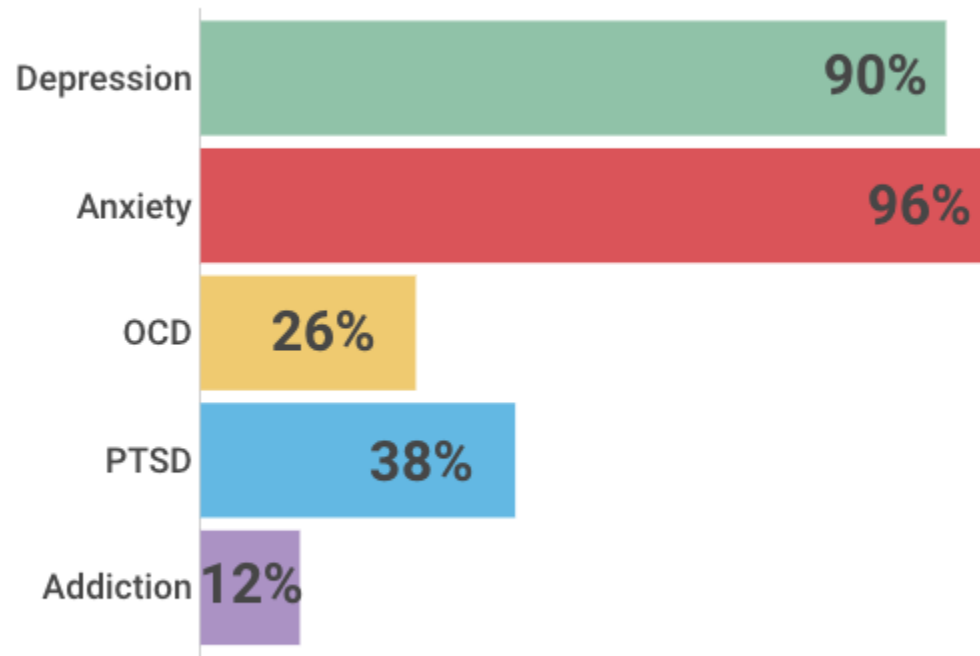
Satisfaction with services

- 52% reported negative overall satisfaction with mental health services compared to 18% reporting positive satisfaction levels.

- Whilst the one-stop-shop offers:

- Non-judgemental support

- A place to talk, be listened to and taken seriously

- Empathy with the autistic experience and reassurance

- Access to peers and allies with good autism knowledge

- Stability in day-to-day life

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Report recommendations: things which can be done immediately

- Be aware that autistic people experience high rates of mental health problems. Offer support to the autistic people you know or meet.

- If you're a mental health practitioner and you don't know much about autism, don't be afraid to provide treatment. Just ask the autistic person what, if any, adjustments they might need and keep the communication channels open

- Take time to listen to what autistic people have to say about their mental health. You might just listen, but if you have advice, try to offer clear, concrete options in return.

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Call to action

- A review of current policy and practice for autistic access to mental health services

- Improved autism training and understanding

- Provide stability for specialist support

- Create post-diagnostic pathways

- Develop treatment with autistic people in mind

- Involve autistic people in planning for change

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- "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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Ten rules to ensure autistic people obtain poor mental health support

- Misunderstand me

- Be dismissive

- Do not accept me for who I am

- Dismiss the concept of neurodiversity (or even autism)

- Ignore or reframe my stress and distress

- Detain me in hospital (preferably against my will)

- Make sure hospital is as stressful as possible

- Treat my anxiety and distress with drugs

- Be inflexible and inconsistent. Do not make any allowances or reasonable adjustments

- There is no rule 10. I promised you one but there isn't one.

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Five key points

- **Respect** – work with the autistic person and not against their autism as if a set of symptoms or behaviours that are separate to them in some way.

- Always consider **sensory issues**

- Always consider how you process **information** may be very different to that of the person in your care (utilise interests)

- **Stress** is a key issue – reduce input when people are over stressed

- **Collaborate** for consistency in approach

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