

Autism and Mental Health

A brief introduction-

Thanks to Rachel Moody and Clair Haydon for using some of their material

Ian Davidson

RCPsych Autism Champion

Consultant Psychiatrist Adult Autism service

Cheshire and Wirral Partnership NHS FT

@psychautismcham

National Picture

More than 1 in 100 people are thought to have Autism. That means approximately 700,000 people in the UK. Including families, Autism touches the lives of 2.8 million people every day in the UK. (www.autism.org)

Between 48% - 56% of autistic people do not have a learning disability. (www.autism.org)

Autism costs the UK economy £32 billion a year, more than heart disease, stroke and cancer combined. (London School of Economics 2014)

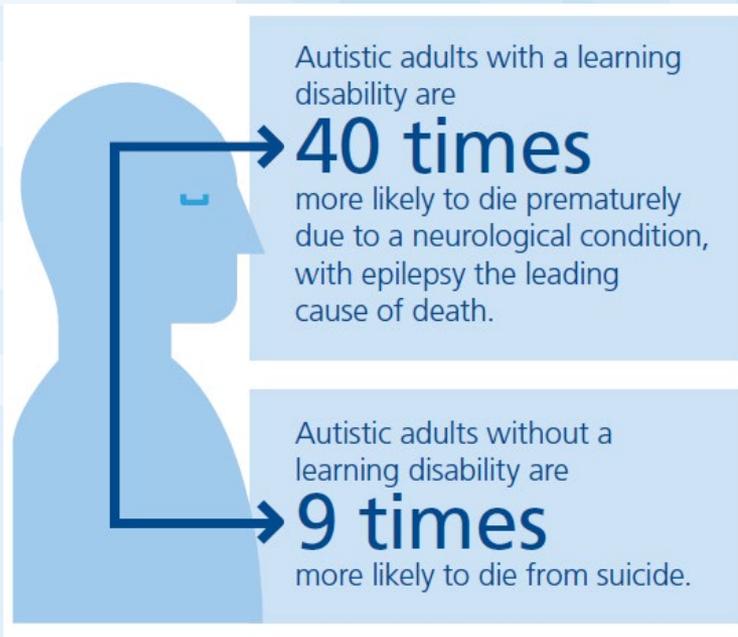
At least 1 in 3 autistic adults are experiencing severe mental health difficulties due to a lack of support (Rosenblatt, M (2008). *! Exist: the message from adults with autism in England*. London: The National Autistic Society, p3

70% of autistic adults say that they are not getting the help they need from social services. 70% of autistic adults also told us that with more support they would feel less isolated. (Bancroft et al (2012). *The Way We Are: Autism in 2012*. London: The National Autistic Society)



***“I’ve always felt like the odd one out, that everyone communicates with information I don’t have”
(user feedback)***

WHY IS UNDERSTANDING AUTISM NECESSARY?



- **PREMATURE MORTALITY**

Autistic people die on average **16 years** earlier than the general population. For those with autism and learning disabilities, the outlook is even more appalling, with this group dying more than **30 years** before their time!!

- **STATUTORY GUIDANCE AND LEGISLATION**

Each Jurisdiction has its own approach which are increasingly diverging

- England <https://www.skillsforhealth.org.uk/services/item/945> and <https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy#history>
- N. Ireland <https://www.health-ni.gov.uk/austismstrategy-progressreports>
- Scotland <https://www.gov.scot/publications/scottish-strategy-autism/>
- Wales <https://www.asdinfoales.co.uk/resource/Training-Framework-digital-eng.pdf>

WHAT IS BEING AUTISTIC LIKE?

The negative and positive impacts of having autistic traits under the three main domains of an Autism diagnosis in ICD10:

- Social Interaction
- Communication
- Rigidity/focal repetitive interests



AND how a person experiences sensory information

Strengths related to autistic traits:

Absorb and retain facts-

excellent long term memory, superb recall

Observational skills-

listen, look learn approach, fact finding

Attention to detail-

thoroughness, accuracy

Deep focus-

concentration, freedom from distraction

Visual skills-

visual learning and recall, detail focussed

Methodical approach-

analytical, spotting patterns and repetition

Novel

approaches-

unique thought processes and innovative solutions

Creativity-

distinctive imagination, expression of ideas



Tenacity and

resilience-

determination, challenge opinions

Integrity-

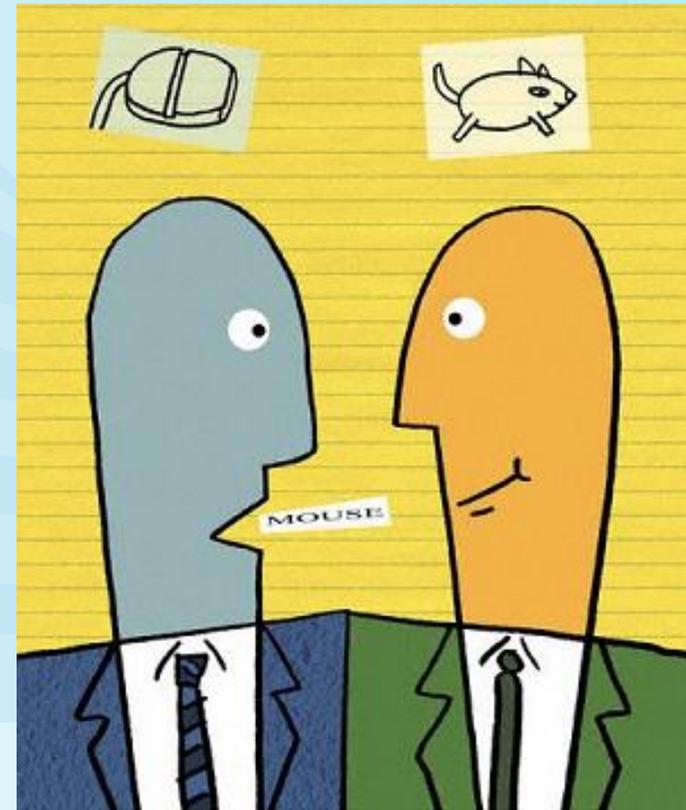
honesty, loyalty, commitment.

Barriers for autistic people accessing healthcare

- **Autistic people being able to recognise and communicate their needs**, eg identification of emotions/feelings, communication difficulties
- **Autistic people not being listened to or taken seriously** when they are trying to communicate their mental health distress, eg, camouflaging, non conventional non-verbal communication
- **Problems with the basic accessibility** of GP surgeries and mental health services, eg, the environment, location and means of access, unpredictability
- **A lack of understanding of autism** amongst health professionals, eg, limited training, misconceptions, differential diagnosis

Considerations in relation to what the autistic person is trying to communicate to you

- Avoid making assumptions based on body language
- Check you have interpreted the autistic person correctly
- Understand that an autistic person may struggle to identify or express emotions and ask for help
- Consider the atypical ways an autistic person may communicate distress
- Offer strategies for allowing an autistic person to communicate when they are distressed, including using wristbands, writing notes etc



**WHY
DOES IT
MATTER**



Autism in adults is still poorly understood

- Prevalence rates are estimated in the range 0.8-1.5% of population reflecting current lack of knowledge
- Most Autistic people alive today weren't diagnosed at school
- Autism diagnosed in childhood doesn't disappear in adult life
- Most Autistic adults have not been diagnosed yet. In 2015 JSNA East Cheshire only 40% of those aged 0-25 known if prevalence 1.5%
- Very few postdiagnostic services for people without Learning Disability i.e. the majority of autistic people – Scottish census study suggests as low as 15% may have Learning Disability. England assumption is higher up to 30%
- Most Autistic people of all ages will therefore be accessing mainstream services for physical and mental health care needs

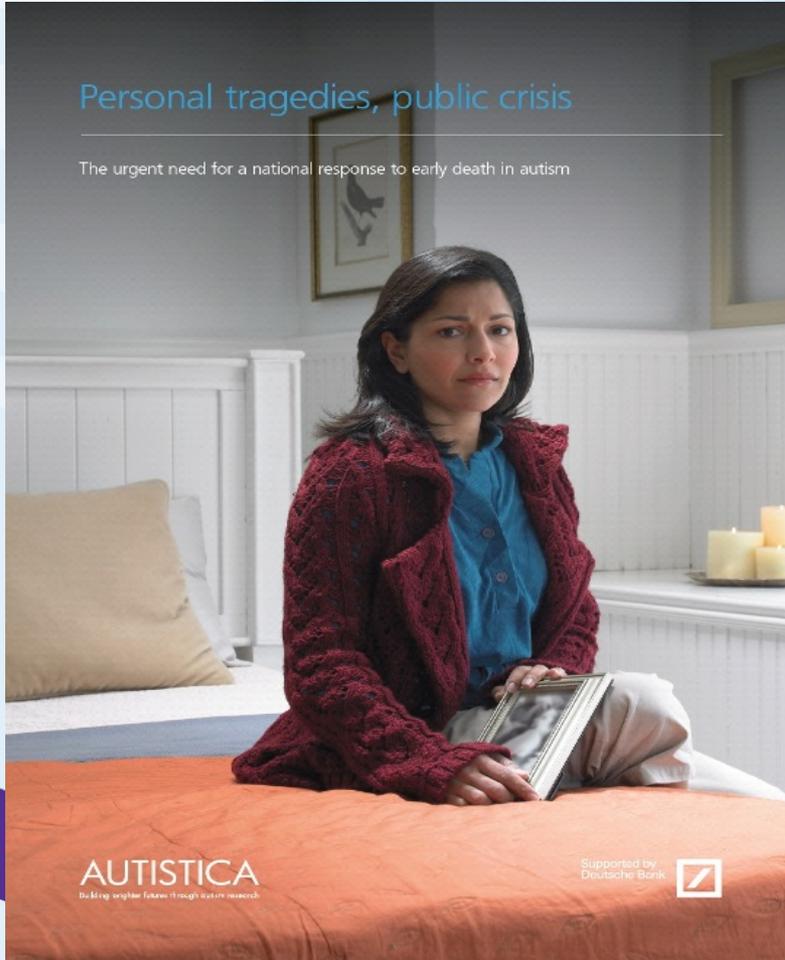
The Result is.....

- Little is known about the course of Autism in adults and what promotes success
- Research evidence increasingly suggests that it is comorbidities and the impact of negative life experience that create the major health issues
- The research data suggest high rates of co-occurring mental and physical disorders and up to 20 years premature mortality.

Early death and physical health

Personal tragedies, public crisis

The urgent need for a national response to early death in autism



- The largest ever autism mortality study (ASD n = 27,122; OR:2.56)

Study	Country	Total n ASD	Risk ratio
Mouridsen	Denmark	341	1.9 (1.3-2.8)
Pickett	USA	13111	2.5
Gillberg	Sweden	120	5.6 (2.5-10.5)
Bilder	USA	305	9.9 (5.7-17.2)
Schendel	Denmark	20,492	2.0 (1.4-3.0)

We need to mitigate risks

- Much of this additional morbidity and premature mortality is avoidable or treatable
- Autistic people can struggle with communication and social interaction so problems often missed or misunderstood
- Autistic people experience very high rates of social exclusion including bullying and often develop mood and anxiety problems and increased rates of suicide

Is it Autism or a co-occurring disorder?

- Social communication and social interaction difficulties are common secondary changes in many disorders
- Ambitious about Autism had a campaign “Know your normal”
- Hilde Guerts 2018 – little hard evidence of how Autistic traits and peoples presentation changes through adult life (if at all) – major change in presentation especially of recent onset likely to be impact of a new problem or disorder – not “its just their Autism”

Differential Diagnosis

- Co-morbidities are common - either lifelong such as ADHD, epilepsy or intermittent such as anxiety/depression.
- Anxiety disorder, depression, hallucinations, delusions, suicidal ideation etc are not part of Autism they are due to co-occurring conditions
- Autistic people are much more likely to have been told through their lives they are odd, weird, getting it wrong, “don’t get it” so learned helplessness and low self esteem common but are secondary to above not a normal part of being Autistic
- Autistic people typically have much smaller social networks so if things go wrong they have less access to informal support and advice especially if their key trusted person is not available e.g. has died or is themselves ill or has moved away.

Emotionally Unstable Personality Disorder or Autism

- Emotionally unstable personality disorder (EUPD)– key aspects of this are difficulties in the domains of social communication and social interaction.
- EUPD is an acquired condition usually secondary to major trauma such as abuse.
- In EUPD people will typically have had conventional social interaction and social communication until after the impact of abuse when they develop coping strategies that over time become maladaptive.
- They don't typically have the focal and repetitive interests and don't typically have the same range and depth of sensory sensitivities as Autistic people.
- The social communication and social interaction difficulties are essentially learned behaviours so are amenable to interventions whereas Autistic traits aren't and forcing the person to suppress them does harm not good.
- Autistic people can develop EUPD

Autism or Psychosis

- Psychosis is not a euphemism for schizophrenia. It clearly is a key part of schizophrenia but can occur in multiple conditions e.g. depression, epilepsy, delirium, sleep deprivation, sensory over stimulation etc etc. So psychotic symptoms may occur in Autistic people for a wide variety of reasons.
- It is important to identify the correct diagnosis so as to deliver the correct interventions.
- Be careful about how “symptoms are elicited” e.g. do you hear voices will almost certainly lead to a yes answer from an autistic person. If they have increased auditory acuity they will say yes to do you hear voices other people don't hear. So again precise language as they will answer precisely what the question asks and usually no more than that.
- If psychosis is a long term severe mental illness symptom then again normal treatment is appropriate with high alertness for side effects and making reasonable adjustments.

Obsessive Compulsive Disorder (OCD) or Autism

- The key differential between a focal intense Autistic trait and OCD is whether the interest/act is one which is interesting/enjoyable to the person.
- Someone kicking a ball against a wall for hours on end because they enjoy it/ it relaxes them is intense focal interest. Feeling they have to kick the ball against the wall to prevent harm falling to their family is a compulsion.
- Please do use language precisely saying OCD is not fine unless you have properly diagnosed it.
- Autistic people can have OCD and if left inadequately treated OCD is not just a crippling illness, it can be fatal.

Autism and Catatonia

- Catatonia is not a diagnosis it is a state which can be brought about by many underlying conditions.
- It is essentially a state of extreme hyperarousal.
- Look for what is causing it and treat accordingly.
- It is not a normal part of Autism – at the very least it is a sign of extreme anxiety disorder and coping strategies being overwhelmed but it can also be a sign of all the other causes of catatonia.

Autism and Suicide

- If you ask directly about suicidal thoughts an autistic person will nearly always answer directly and precisely. If they say yes then they mean it and rates of suicide are higher than non-autistic population.
- Always then ask when and under what circumstances, as bringing them into hospital because they are suicidal when they are referring to a set of circumstances way into the future will do harm not good.
- If they are self harming as a repetitive behaviour or as a stress relieving mechanism they generally can logically and precisely differentiate from trying to die by suicide.

Other potential diagnoses

- **Post Traumatic Stress Disorder** –this is more common for Autistic people than general population.
- **Eating disorders** – Autistic people can have Anorexia Nervosa/Bulimia Nervosa etc but also may have Avoidant Restrictive Food Intake Disorder (ARFID) – this can be life threatening but requires a different approach as at the core is not abnormal body image but rigidity about food types/sensations
- **Pathological Demand Avoidance**- is not a diagnosis – caused by many things. Can occur in Autistic people but isn't diagnostic of Autism.

Autistic without having a learning disability

- **Autism is not a learning disability.**
- A minority of Autistic people have LD/ID – a recent Scottish national study estimated it at 15% have ID – looking at methodology probably low side of estimates so may be up to 30%.
- A major issue for the majority of Autistic people is therefore being considered to have LD when they don't and for people to refer them to LD services or use LD approaches.
- Easy read for most autistic people is extremely unhelpful as to make it easy read it is made imprecise. With autistic people use precise language. Say what you mean and mean what you say.
- If you are not open and precise they will quickly distrust you (and by inference your team) so likely to actively or passively disengage to try to protect themselves from more hurt.

Diagnostic Overshadowing

- Autism gives no protection against any known physical or mental health disorder so all can occur.
- Diagnostic overshadowing is common and harmful.
- Autistic people can and do benefit from the full range of MH treatments.
- Their reactions may be more idiosyncratic and they may be less confident to flag up problems so staff need to be more explicit and vigilant about side effects of talking therapies, social therapies and pharmacological therapies.
- Reasonable adjustments have to be made around interventions of all types.

Reasonable Adjustments

- It helps them and key others to see their strengths and reduces mood and related issues
- It makes it easier to identify and deliver reasonable adjustments
- Reasonable adjustments can enable Autistic people to have much more successful lives
- Many will have contact with multiple physical and mental health and social care services due comorbidities
- Health and social care staff knowing how to respond appropriately to Autistic people including reasonable adjustments can help make significant differences

If an autistic person is in distress or crisis

C

COMMUNICATION

Check if the person can communicate what is wrong?

Are there any communication needs you need to be aware of?

Are you communicating effectively?

Do you need to adapt how you communicate with the person?

H

HEALTH

Check the person's physical and mental health.

Are there physical health issues affecting their presentation?

Are they in pain?

Is there an underlying mental illness?

E

ENVIRONMENT

Check the physical and sensory environment.

Ask the person about their sensory preferences and sensitivities.

Is it too noisy, busy or too bright?

Is the person sensitive to touch?

Can you make changes to minimise distress?

C

CHANGE

Check if there have been any significant or unexpected changes or a build up of small changes in the person's life or routine?

Ask the person and if possible, someone who knows them well what may have caused the distress, what helps in crisis and what are the person's preferences.

K

KNOWLEDGE

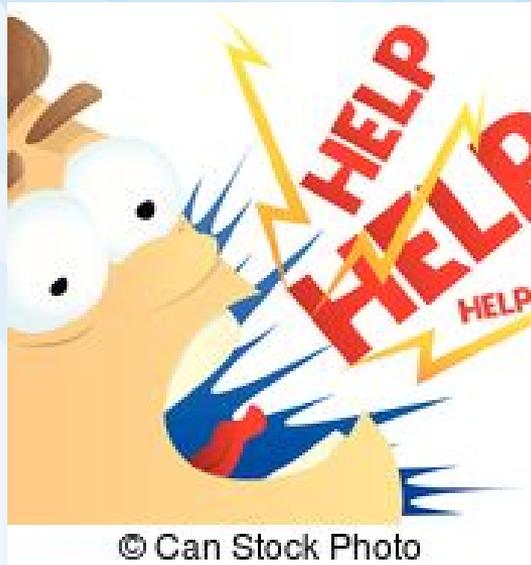
Know the person: Check what is normal for the person.

Are there any co-occurring conditions?

What treatments are they on?

Is there an Informant, a Hospital Passport or Advanced Directive?

If someone has enough self esteem and confidence they can clarify information, ask for reasonable adjustments and ask for help when they need it



One of the biggest impacts health professionals can have is to support someone to recognise their strengths and work to achieve their aspirations

Further Reading/information:

Hospital Passport

<file:///C:/Users/PGUser876/Downloads/My%20Hospital%20Passport.pdf>

RCGP Autism Toolkit

<http://www.rcgp.org.uk/clinical-and-research/toolkits/asd-toolkit.aspx>

RCPsych

<https://www.rcpsych.ac.uk/workinpsychiatry/specialinterestgroups/neurodevelopmentalpsychiatry.aspx>

Lenehan Review

<https://www.gov.uk/government/publications/lenehan-review-into-care-of-children-with-learning-disabilities>

Know your normal

<https://www.ambitiousaboutautism.org.uk/know-your-normal>

Police Autism Guide

<http://www.npaa.org.uk/police-autism-guide/>

Think Autism

<https://www.gov.uk/government/publications/think-autism-an-update-to-the-government-adult-autism-strategy>

Presentation of Autism in children

<http://www.asdinfoales.co.uk/autismchildsigns>

Further reading continued

- The health status of adults on the Autism Spectrum Croen et al 2015 Autism 1-10
- Is Older Age associated with Higher Self and Other rated ASD characteristics Lever and Guerts- 2018 Journal of Autism and Developmental Disorders 48(3)
- Premature Mortality in autism spectrum disorder Hirvikoski et al 2015 B J Psych 208 (3)
- CR228 - <https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228>
- CTR (Care and Treatment reviews) - <https://www.england.nhs.uk/learning-disabilities/care/ctr/>

Thank you

Ian Davidson

Lead Consultant CWP ASD and RCPsych Autism Champion

ian.davidson11@nhs.net

@psychautismcham