Autistic Adults & Psychiatry

Experiences & barriers to access

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Autscape 2020

Edit profile

The Autistic Doctor

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Anaesthetist. Mother. Autistic. Back on the frontline after career break. Linking #AutisticDoctors & Researching Barriers to Healthcare in #Autistic community

Ireland facebook.com/AutisticDoctor... Joined September 2018

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Barriers to healthcare for autistic adults: Consequences & policy implications. A cross-sectional study.

Mary Doherty, Jane D. O'Sullivan, Stuart D. Neilson

Autistic Adults and Psychiatry;

EXPERIENCES AND BARRIERS TO ACCESS

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Autistic Doctors International

April 1, 2019 ·

Trigger warning

Mental Health & Suicide

Barriers to Healthcare for Autistic Adults

- **Background:** Autism is associated with reduced life expectancy, poor physical and mental health.

- **Methods:** A survey, “What do you wish your GP knew about autism?” was conducted at Autscape 2018.

Results:

- **Difficulty visiting a GP was reported by 78.2% of autistic adults**, 51.4% of parents and 34.9% of controls.
- deciding if symptoms warrant a GP visit (71.9%)

- **difficulty using the telephone to book appointments (60.7%)**

- not feeling understood (55.5%)
- difficulty communicating with their doctor (53.0%)

Consequences:

- A higher rate of adverse health outcomes was reported by autistic adults
- untreated physical and mental health conditions
- not attending specialist referral or screening programmes
- requiring more extensive treatment or surgery due to late presentations
- untreated potentially life threatening conditions

What helps?

- Autistic adults reported a need for:
- online or text based appointment booking
- facility to email in advance the reason for consultation
- first or last clinic appointment
- a quiet place to wait

Conclusions:

- Reduction of healthcare inequalities for autistic people requires that healthcare providers **understand autistic culture and communication needs**

- Adjustments for autistic communication needs are analogous to wheelchair ramps for the physically disabled

- https://insar.confex.com/insar/2020/meetingapp.cgi/Paper/34774
- https://insar.confex.com/insar/2020/adult/eposter.cgi?eposterid=442

Consequences of undiagnosed autism

- Personal distress
- Professional difficulties
- Career progression
- Change of career
- Stress leave
- Early retirement
- Physical & mental health
- Early mortality

Mental Health

- Mental ill health up to 80%
- Excess mortality
- Suicide – an autistic crisis
  - 66% ideation
  - 35% attempted
  - 15% of hospitalized
  - 11% of completed suicides

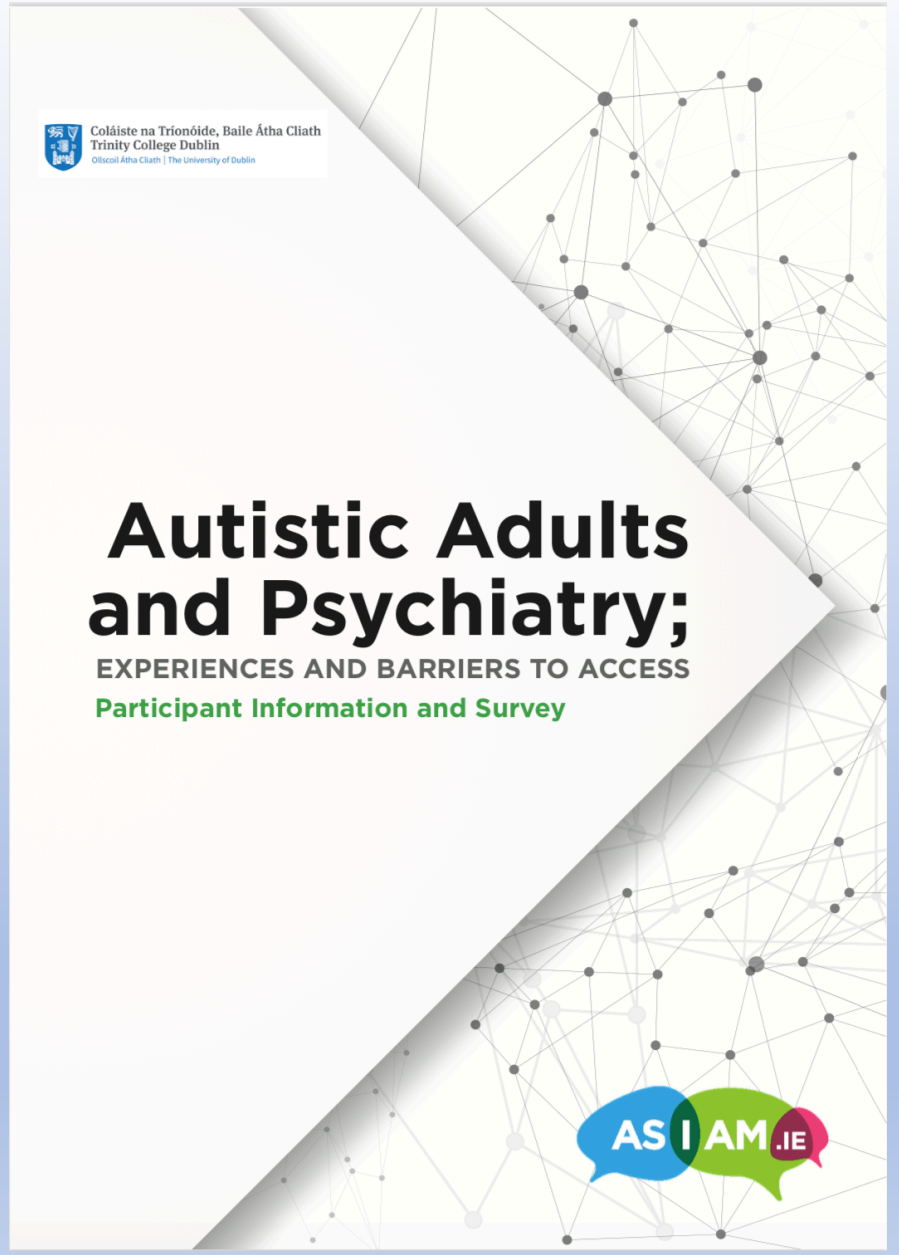
- Anxiety
- Depression
- Bipolar Disorder
- OCD
- Eating Disorder
- Substance abuse
- Personality Disorder *BPD*
- ADHD/Dyslexia/Dyspraxia

OUR Mental Health

- N = 101

- Currently attending psychiatrist 18%
- Attended in past 61%
- Difficulty attending 43%

- Male 30
- Female 39
- Non-binary 23



Defining our population

- Autscape is a conference organised by and for autistic people
- attended by autistic people with low to moderate support needs
- with and without carers

- Inclusion criteria: ability to fill out an online or paper questionnaire alone or with assistance

- If you have completed either of the surveys and feel this description is inaccurate or doesn’t include you, please let me know

OUR Mental Health

- Suicide
  - 86% ideation
  - 47% attempted
  - 65% self harm
  - 21% medical care

Inpatient	27%
Sectioned	11%
Restraint	10%
Alcohol	28%
Illicit drugs	11%

OUR Mental Health

- Qualitative data analysis in progress

- Access difficulties
- Lack of understanding
- Misdiagnosis
- Burnout

Consequences	Autistic	Parent	Control
Mental health condition remain untreated	65.3%	31.4%	16.7%
Physical health condition remain untreated	64.9%	41.5%	26.1%

So what to do?

- Awareness within autistic community
  - Physical health
  - Medical health
- Awareness within medical community
- Awareness within psychiatry / mental health services

Autistic Doctors International

Our Stories

- General Practice
- Anaesthesia
- Internal medicine
- Psychiatry
- Public health
- Pathology
- Surgery

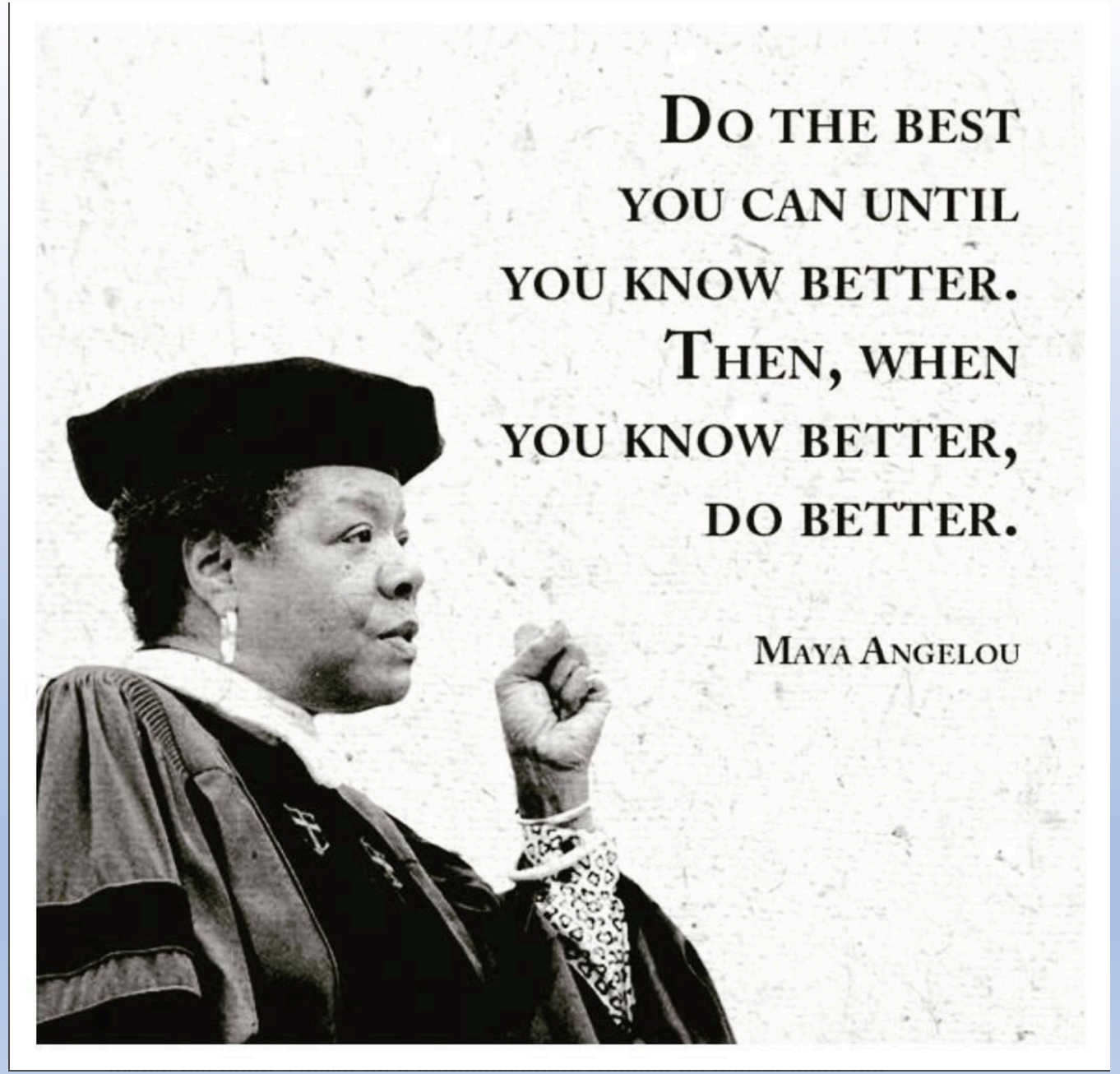
Medical Specialties

Autistic Doctors International

Our Stories

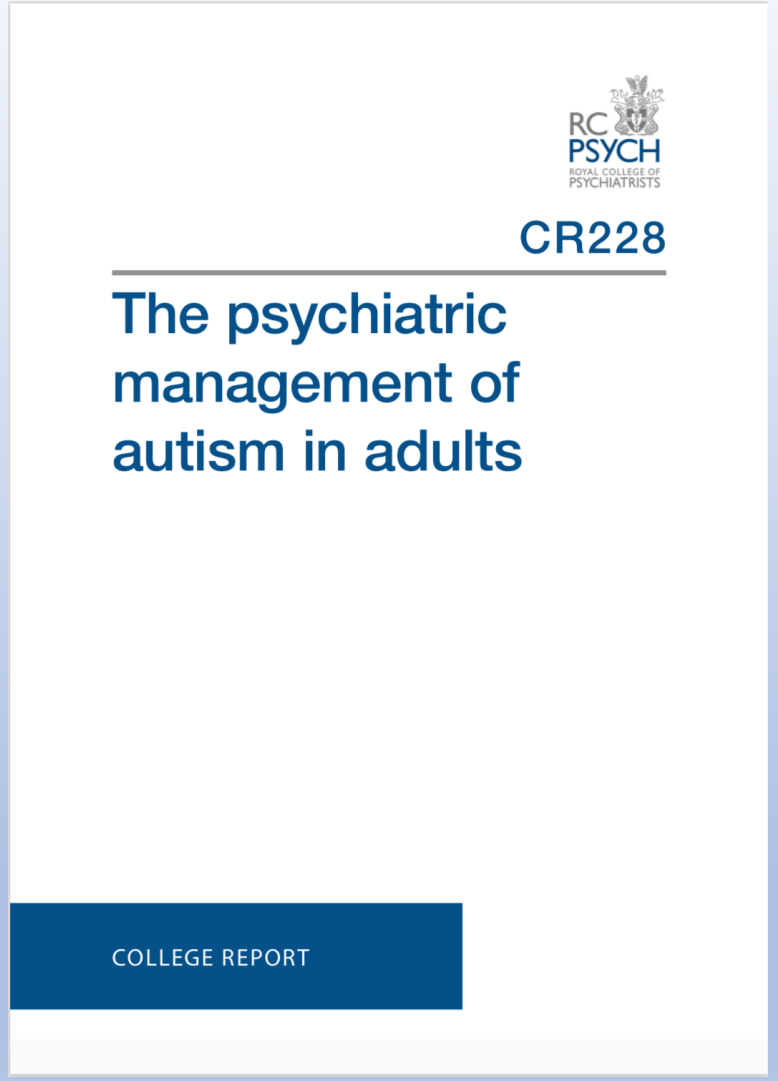
- Stigma
- Unconscious bias
- Ableism

- Double Empathy Problem
- Start where we are
- Write respectfully
- Write collaboratively
- Resist tragedy narrative
- Be an ally



CR 228

- 2 year project
- Working group
- 13 Psychiatrists
- 1 Gender Specialist
- 4 autistic adults
  - All Autscape Participants



https://www.rcpsych.ac.uk/improving-care/campaigning-for-better-mental-health-policy/college-reports/2020-college-reports/cr228

Executive summary

- Recognition and management of autistic adults without intellectual disability
- part of the College's broader programme to improve mental health services for autistic adults
- all services should make the necessary adaptations to enable access
- about 5% of the users of UK mental health services
- unnoticed, overshadowed by the presence of co-occurring disorders
- misdiagnoses: schizophrenia, obsessive-compulsive disorder and personality disorder (notably borderline personality disorder), such errors more likely in women, autism less readily recognised

Co-occurring conditions

- *Emotional disorders*, such as anxiety
- *Depression*: autism complicates the assessment of suicidality, a major contributor to the increased mortality
- ***Burnout***, the informal label for a state of exhaustion that comes from the stress of coping with difficult sensory and social settings; it is distinct from anxiety and depression;
- *Schizophrenia*, a recurrent problem in differential diagnosis
- *Eating disorders* - distinguish between avoidant/ restrictive food intake disorder (ARFID) and anorexia nervosa

Recommendations

1. All psychiatrists should continue to improve their expertise in autism through training and experience, **and particularly, by familiarity with the autistic world.**

2. All psychiatrists should be able to recognise and treat psychiatric disorder in autistic people, **distinguishing it from the features of autism**, and be able to make the appropriate adjustments to their treatment, care and follow-up.

3. All psychiatric services should aim to have a close working relationship with their local specialist autism resources.

Recommendations

4. There should be a programme to **improve diagnostic consistency** across the UK, something that requires those involved to develop networks, an initiative which the College should support.

5. All psychiatrists should facilitate and engage in autism research wherever possible and **encourage the meaningful involvement of autistic people in its design and development**.

Language

- Throughout this report, the term ‘autism’ is used to include all conditions on the autism spectrum, whether autism spectrum disorder (ASD), autism spectrum condition (ASC), or other terms such as Asperger syndrome, atypical autism or pervasive developmental disorder.

- **In line with current practice, this report uses identity-first language** (‘an autistic person’ rather than ‘a person with autism’).

- Most autistic people are adult, do not have an intellectual disability and are likely to be undiagnosed
- Of those known to services, many have a wide variety of co-occurring physical and mental conditions
- While there are specialist autism services, they are patchy and with limited funding and remits
- An autistic person has the same right to access a generic physical and mental health service
- Common for clinicians to use autism as a justification for denying someone treatment for a psychiatric disorder, attributing all their symptoms to autism

- This document is to help psychiatrists to recognise autism
- distinguishing it from co-occurring disorder
- to treat their patients appropriately
- making reasonable adjustments
- avoiding discrimination

- By their nature, accounts of the diagnostic features will be selective, omitting a wide range of associated characteristics, skills and strengths

- There is a great variability in the nature and intensity of the constellation of features that go to make up autism
- continuum of presentation that shades from severe and obvious disability, through variants (which, although subtle, may still bring social disadvantage) to blend into traits found in the general (neurotypical) population
- diagnostic threshold of a significant impairment in current functioning across a variety of settings
- innate characteristics
- current circumstances and mental state.

- autism as a *disorder*
- autism as a *disability*

- autism as one element in the range of *neurodiversity*, an innate difference (much as someone might be left-handed) rather than a deficit

- it is better expressed by the term ‘condition’ rather than ‘disorder.’

- Autistic characteristics are usually most pronounced in early childhood, becoming less obvious as the individual moves into adulthood

- may become sub-clinical, only to emerge in a crisis or an adverse environment

- Although the trajectory in later life has yet to be determined **prevalence doesn’t appear to change significantly with age**

- Those whose traits fall short of the diagnostic threshold may well retain disabilities in areas such as perception, cognition, communication and motivation which, although ‘hidden’, can be a substantial hindrance in everyday life.

- While intellectual disability is an important determinant of support needs, normal (or above normal) IQ does not guarantee a favourable outcome.

Associated conditions

- Autism is one of a range of neurodevelopmental conditions ranging from specific learning disabilities (e.g. in language, dyslexia or dyscalculia) to more complex syndromes that include attention deficit hyperactivity disorder (ADHD) and developmental coordination disorder (DCD).
- Autism is associated with these other conditions,
- ADHD being present in 30% of autistic children (as against 4% in the general population), tics in 10% (vs 6%), developmental coordination disorder in 70% (vs 5%) and epilepsy in 5% (vs 1%).

Associated conditions

- The data for adulthood is more limited
- most neurodevelopmental disorders improve with age
- in the general population, ADHD reduces to about 2.5% and tics to 0.7%
- We do not know how the presence of autism affects this pattern of change
- indications that ADHD is present in 30-45%
- epilepsy in 5% of those autistic adults who do not have an intellectual disability

Gender

- Gender dysphoria (DSM 5) / Gender incongruence (ICD-11)
- Autistic traits appear over-represented in gender identity clinics
- suggested that there may be an association
- Overall the assessment and management of gender dysphoria should be in line with existing guidance (Royal College of Psychiatrists, 2012
- although the neurodevelopmental state may be relevant, it should not hinder access to a gender identity service.

Associated conditions

- The association with psychiatric disorder may stem partly from an adolescence characterised by victimisation and bullying
- affecting the development of self-esteem, social confidence, identity and the potential to live independently.
- Autism is over-represented among individuals presenting with eating disorder and with substance abuse
- Mood & anxiety disorders
- Schizophreniform psychosis
- Catatonia
- Personality disorder

- Genetics
- Legal aspects of psychiatry
- Offending behaviour
  - Most autistic people are law-abiding (and even rule-bound) and there is no real evidence to suggest that they are more likely to offend than others
- Policy
- England & devolved nations
- Channel Islands

Lack of services

- an autistic individual will have a personal profile that includes a mix of neurodevelopmental disabilities, strengths and skills
- co-occurring psychiatric disorder can reduce the ability to manage the activities of daily living, potentially to the point of needing long-term support.
- Adults can find themselves in limbo between psychiatric specialties: too able to be included within the contracted services for intellectual disability, but with developmental disabilities and support needs unfamiliar to the various mental health specialties

Service provision

- Disorder or disability should not bar anyone from access to any clinical services
- autistic individuals should be managed within mainstream mental health services with suitable adjustments for autism
- For some, these services will need to be buttressed by more specialist provision
- Consequently, all mental health services, including specialist services (e.g. psychotherapy, forensic and old age psychiatry), must consider how they will meet the needs of their autistic patients effectively, and from where they will obtain specialist support.

Autism in women

- Currently autism is reported as less prevalent in *females*.
- might reflect a greater male vulnerability to neurodevelopmental disorder
- characteristics in females are less pronounced or better concealed
- male interest in Lego or trains may be obviously unusual in its quality and intensity
- female preoccupation with handbags, horses or people may accord with cultural expectations and pass unnoticed
- women may be more attentive to social conventions and better at mimicking social behaviour, camouflaging their autism
- misdiagnosed more frequently, for example as borderline personality disorder (emotionally unstable personality).

Aging & autism

- Little published evidence that autistic people differ as a group in their susceptibility to *the effects of old age*.
- Although a lifetime of learnt adaptive mechanisms and social skills may prepare the individual to cope, innate rigidity may make it more difficult to manage the variety of change (physical, mental, social or environmental) that comes with age or frailty
- Whilst the prevalence of autism in the community does not appear to change with age, the impact of certain core features are likely to evolve, as well as being unmasked by the loss of supportive family members, or declining mental and physical health.
- At the same time, the diagnosis may be obscured by isolation, the loss of informants and the development of ill health.

Co-occurring conditions

- Although the symptoms of a wide range of anxiety disorders (including specific phobias, obsessions and compulsions, situational and social anxiety as well as general anxiety) are common in autistic individuals, they are **not an intrinsic part of autism and must be treated in their own right.**
- Depression is easily overlooked
- Suicide risk
- PTSD
- Burnout
- Schizophrenia

Diagnosis

- There is no definitive biomarker and no laboratory test
- Diagnosis is a clinical judgement - decision is binary (‘is this autism or not)
- plan of management must be tailored to the individual
- a wide range of potential disability, co-occurring disorder, and circumstances
- reassured to learn that although **different they are not disturbed**, can move on, better able to ask for acknowledgement or support when it is needed.

Support

- Some who need extensive support and care
- Some will need a pathway of stepped care which, at different times, may shift from ‘watch and wait’ through to substantial multidisciplinary/multi-agency involvement
- Finally, there are those for whom the process did not diagnose autism (the majority in some centres) who will need guidance and, where necessary, management or re-referral.

Eating Disorders

- Avoidant/restrictive food intake disorder (ARFID)
  - sensory sensitivities, a resistance to any dietary change or an intense interest in a specific diet or in specific dietary components
  - a pattern of eating which is difficult to change and potentially dangerous
  - a preoccupation with fitness and exercise
  - distinct from anorexia nervosa and body dysmorphic disorder.
- Anorexia nervosa
  - associated with autism although the relationship is complicated
  - difficulty in identifying autism in adult women in the presence of co-occurring psychiatric disorder. Second, being underweight may, of itself, lead to the development of reversible autistic symptomatology or may simply unmask previously unrecognised autism

The process of diagnosis

- Cannot assume most autistic people will be diagnosed by children's services
- perception of autism is an evolving one and the diagnostic threshold varies
- environmental pressures of work or independent living, redundancy/retirement, a change in social or marital relationships, a loss of support following bereavement, entanglement with the law, the onset of co-occurring psychiatric disorder, physical illness, or frailty with a deterioration in physical or cognitive ability
- A move to an unfamiliar setting or routine, for example on going into hospital or care, can result in a catastrophic decompensation, with the emergence of previously unnoticed characteristics
- significance of a childhood diagnosis may have been lost as they move between services.

- familiarity with autism in its various manifestations and circumstances
- familiarity with a wide range of psychiatric disorders, both to recognise co-occurring conditions and to avoid their misdiagnosis as autism
- a developmental perspective in taking the history

- Interview adaptations and accommodations

- Reduce anxiety, consider sensory needs, adapt communication style

- Diagnostic Instruments
- different clinicians in different settings can achieve a recognised, consistent threshold as well as adapt to changing criteria and practice.

- Legal aspects of psychiatry
- Offending behaviour
- Most autistic individuals respect order, are keen to avoid trouble and do not offend

- The management of autism itself (as distinct from that of co-occurring disorder) is primarily about the provision of the education, training and social support/care required to live independently and to function in the everyday world
- Psychiatric input is largely about the treatment of the co-occurrent disorders that frequently accompany autism.
- The presenting difficulties of an autistic individual, including their autistic characteristics, will be improved by anything that reduces their anxiety or increases their physical comfort and sense of well-being.

Medication

- At present, there is no place for the routine use of medication in the management of *the core features of autism*
- Medication is used for *co-occurring conditions* as with non-autistic people
- Autism might be a marker for an unpredictable and individual response to psychotropic drugs: sensitivity may be increased or decreased and idiosyncratic and adverse effects are more frequent
- Drugs should be introduced at a low dose, increased cautiously and with careful monitoring, and reviewed regularly.

- provision of therapy should be culturally appropriate and should take account of disability. Therapists need to allow for the possible variations in cognitive style, communication, skills, narrative and value system that might come with autism and adjust their interview accordingly (p33). Therapies applied without awareness of the autism can be harmful or, at the least, ineffective.

- The frequency of bullying, victimisation, and abuse, contributing to a complicated and turbulent life (Balfe and Tantam, 2010), make *trauma informed care* particularly relevant

- Ill-served by a system based on episodes of care, they need the ready contact that comes with long-term over-sight or support: some form of continuity is important rather than a reliance on self-referral to their GP or social worker.
- commissioning groups and care pathways which are beginning to consider post-diagnostic support and access to the wider network of care as well as diagnosis
- Specialist autism teams (SATs) are being established, often complementing or combined with an ADHD team to provide a more comprehensive neurodevelopmental service.

- The risk remains that some autistic adults will continue to fall between the different mental healthcare contracts despite their statutory entitlement to access psychiatric services.

- Therefore it is important that there is explicit provision in each locality, extending beyond the diagnostic process, to provide services for the treatment of their co-occurring mental and physical disorders

- out-of-area placement of those individuals whose high levels of need and disturbance have led to specific additional funding. Such placements can be difficult to monitor, a significant financial burden for their sponsoring health economy, and an additional drain on local services, as well as further dislocating the person from all that is familiar to them: their community, family and acquaintances. The result can be an isolated placement where it is difficult to ensure that the staff have proper managerial supervision and clinical support, a recipe which produced the abuse of Winterbourne View
- Greater success has come from planning tailored community placements, by bringing together specialist autism providers (whose competence is confirmed by their track record) and local teams

- The general practitioner (GP), who should have a comprehensive overview of an autistic individual's circumstances, has a particular key role in the initial recognition and consideration of whether to make a referral (the management of demand), in the physical care of vulnerable adults, and in monitoring medication.

- Autism itself neither requires psychiatric treatment nor warrants admission, but treatment may be needed for co-occurring disorder

- autistic person can find admission more daunting than most

- Without autism training, it is difficult for staff to understand characteristics such as sensory sensitivity, communication overload or the need for rituals and strict routines, let alone to accommodate them.
- many units use cognitive or group approaches that, without adaptation, can cause people to fail or to refuse therapy for reasons that they may not be able to put into words.
- The autism-friendly psychiatric unit
- The specialist autism unit
- Extended hospital admission

Training objectives

- Acquire the ability to recognise the spectrum of features and behavioural characteristics of autism, irrespective of gender, age or ability, both when occurring as a single diagnosis and when accompanied by other neurodevelopmental or psychiatric conditions.
- Demonstrate the ability to interview and work with autistic people and those around them, using a person-centred approach and making appropriate adjustments.
- Acquire a familiarity with the various services available to autistic people
- Acquire an expertise in appropriately adapting the management (psychological, pharmacological, social and environmental) of mental disorders when they occur in autistic people.
- Acquire a familiarity with the legislation of the relevant jurisdiction.

Benefit of Diagnosis

- Not broken normal
- Self awareness

- Sensory challenges
- Social challenges

- Community support – find your tribe!
- Reasonable adjustments

What are the benefits of diagnosis?

- Find your tribe!!
- Learn some skills
- **Self understanding**
- **Re-frame your worldview**
- Avoid unhelpful or even harmful therapies
- Gain the understanding of others
- Autism specific (or even autism aware) services

Conclusion

- Beware knowledge gap
- Think beyond stereotypes
- Heterogenous presentation
- Specialist advice

- Add autism to differential diagnosis
- Recognise and build on the benefits of autism
- Resist tragedy narrative

Thank you for listening!

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Any questions?