

The Science of Autism & Women Course #6

with Dr Rachel Moseley

Stream: 5pm | Talk Starts: 5:05pm

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28 CPD hours 15/11/2024



William McLean

WILLIAM MCLEAN Founder, Seed Talks

> 26) Briston Road, London, England, SWH-Email: melo@seedtafks.ci Web; seedtafks.ci

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THE PATHS AND PITFALLS OF SEEKING AN AUTISM DIAGNOSIS

Autism & Women: A six-week course Dr Rachel Moseley

A QUICK INTRO FROM YOUR HOST



Dr Rachel Moseley (she/her)

PhD in cognitive neuroscience;

Principal Academic in Psychology;

Late-diagnosed autistic with a spicy psychiatric background



THIS TALK WILL COVER:

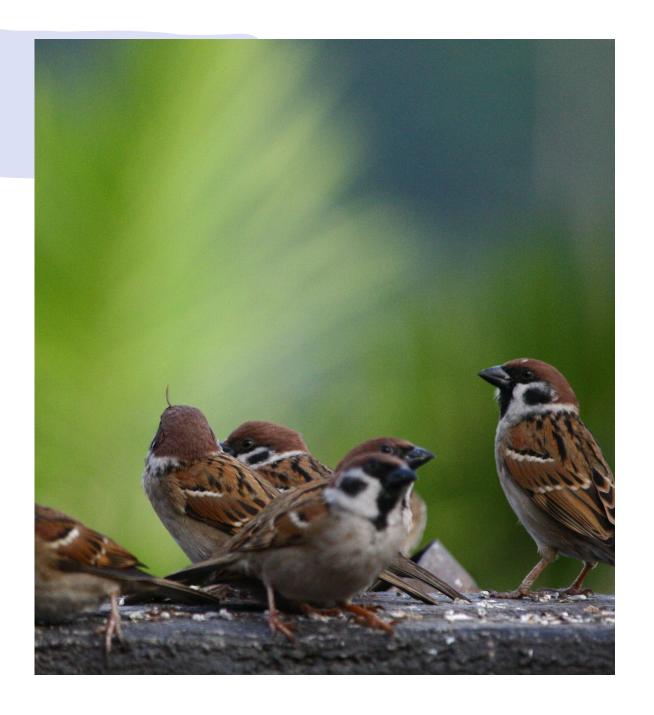
- Diagnosis... what's the big deal?
- The diagnostic pathway screening and assessment
- The challenges of differential diagnoses – who slips through the net, and what misdiagnoses happen?
- Advice for the diagnostic process
- Open forum to discuss diagnosis issues and questions.



Slides, papers and resources available at the end!:)

- Diagnosis... what's the big deal?
- The diagnostic pathway screening and assessment
- The challenges of differential diagnoses – who slips through the net, and what misdiagnoses happen?
- Advice for the diagnostic process
- Open forum to discuss diagnosis issues and questions.

DIAGNOSIS - IS IT WORTH IT?



Imagine that you're a sparrow, living in a family of sparrows in a town of sparrows in a world of sparrows.

But you're kind of a shitty sparrow. Kind of the worst sparrow, actually.

You can't fly. You've been to doctors who have prescribed medicine to help with flying. But you still can't. You try every day, and every day you fail and this thing which all the other sparrows tell you is critical.

You continue to try, and fail, to fly. You try harder. You try as hard as you can. Sometimes mean birds make fun of you because you're a terrible screw-up. This is what your life is.

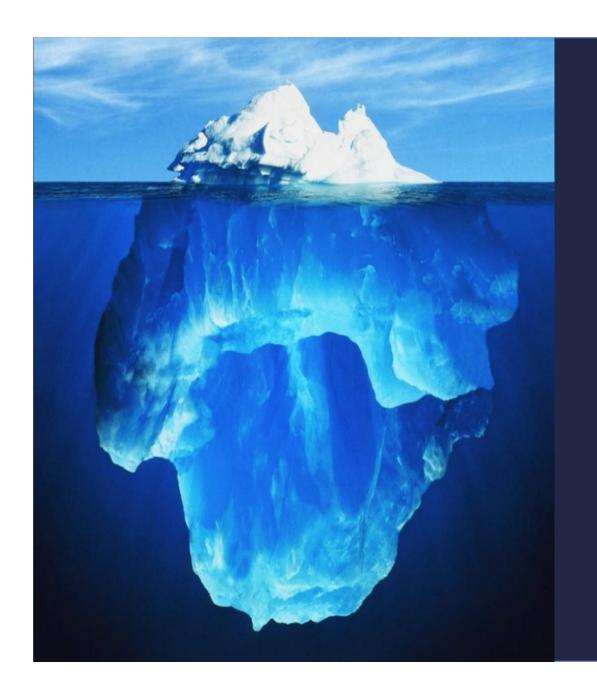
One day ... a doctor says, "by the way, you're a penguin."

Holy shit! You're not a failure. You're not lazy or stupid or weak. There's nothing wrong with you, you're a beautiful penguin. You give yourself permission to stop trying to fly. Not failing all the time improves your mood and overall function.

Knowing you're a penguin means knowing where you fit in a world you never felt like you fit into. It means all the things penguins can't do, it's not a personal failing when you can't do them. You're not supposed to be able to. You can do other things instead.

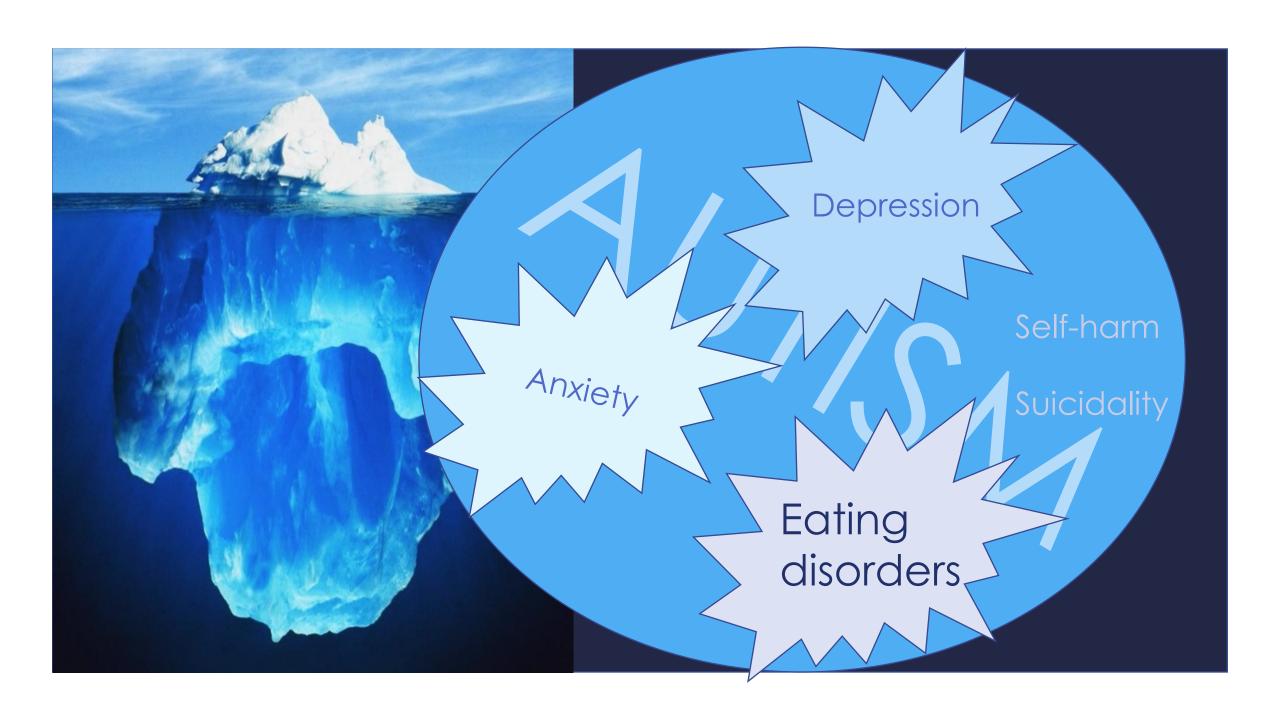
This is why I think labels are important. This is how my autism diagnosis was like breathing, after holding my breath for 26 years.





"It's always one thing after another with you!"





SMALL WONDER, THEREFORE, THAT SOME AUTISTIC PEOPLE CALL GETTING A DIAGNOSIS:





"I'm autistic, I'm quirky. I'm a pretty good person. And actually, I like me."

''The Single Most Important Thing That Has Happened to Me in My Life''

(Arnold et al., 2020)

"It allowed me to see myself as a perfectly normal, average, Autistic person instead of a weird, failed, flawed non-Autistic person."

"I belong somewhere with other people who are like me".

"overwhelming relief of knowing I was born this way and that there is nothing wrong with me"

"What do we want this for? Is it so that you've got a rubber stamp? Something that someone says to you, why do you need this reasonable adjustment at work and go, I have my certificate here... I think for me as a 41-year-old, mostly it's so I understand me!"

"having that knowledge was such a powerful thing because I could understand and forgive myself"

A LOT IS WRITTEN
ABOUT THE POSITIVE
IMPACT OF A DIAGNOSIS:

TO A LARGE EXTENT, THE POSITIVE IMPACTS OF DIAGNOSIS ARE AROUND TAPPING INTO AUTISM AS A SOCIAL IDENTITY

(Davies et al., 2024)



(Davies et al., 2024)

"I've spent my whole life striving to be normal so finding out it's a neurological difference meant this hope died in an instant. But then there was relief knowing that for the first time I have evidence... I'm not making it all up..."

"Because autism is still classified as a 'disorder', I found that aspect very difficult to integrate into my life and sense of self without feeling down about myself and the world."

"Disappointment, deeply felt, that I had to wait until I was 45 years old to get a diagnosis. Saddened, too, for all the lost opportunities..."

"Everyone was like 'oh no, I don't think you're autistic' in a sympathetic or reassuring way... obviously that made it feel like they thought it was something that would be 'wrong' with me if I was."

"great feelings of inadequacy; that I must've been a really bad carer for my parents"

"started doubting my ability to do my job"

"It has left me a little bereft of a life that could've been"

BUT THERE'S ALSO THE BITTERSWEET OR PLAINLY DIFFICULT EMOTIONS...

"This diagnosis (BPD) is damaging, and it covers up the real issue that we have"

"'Oh, you've got BPD, it's all down to that' . . . any symptoms you have, whether mental or physical or social, all put down to BPD"

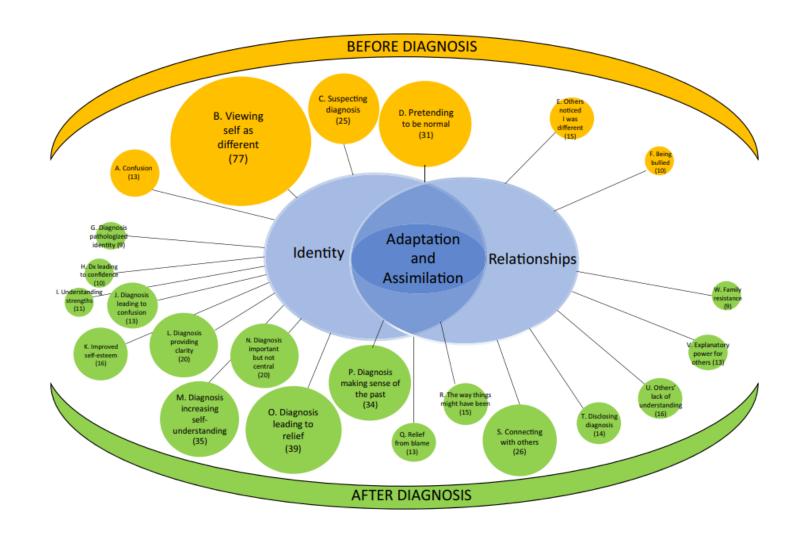
"It makes you even less certain of yourself and your identity"

"... I was misdiagnosed but no one would listen to me and I was told I was lying when I tried to explain."

"We get diagnosed with a really horrible mental health disorders like bipolar personality disorder or borderline personality disorder when we actually don't have them. We just have autism, and you know [psychologists] are less apt"

INCLUDING THOSE
WHO'VE BEEN
DAMAGED BY
MISDIAGNOSES ALONG
THE WAY...

KIEHL AND COLLEAGUES CAME UP WITH A CONCEPTUAL MODEL ABOUT THE IMPACT OF DIAGNOSIS:



BUT LET'S STEP BACK A BIT - HOW IS AUTISM DIAGNOSED?

THE DIAGNOSTIC

PROCESS HAS AT

LEAST TWO STAGES.

a) Referral to autism diagnostic services
 via a general healthcare practitioner
 (GP) – a non-autism specialist.

May involve you doing some kind of screening test, e.g.:

- Autism-Spectrum Quotient (most common)
- Social Responsiveness Scale
- Ritvo Autism Asperger Diagnostic
 Scale–Revised

*Note: whether you go private or through the NHS, most autism diagnostic services require you to be referred by your GP (even if you're paying for the assessment yourself).



PROCESS HAS AT

LEAST

Sensitivity?
Yay.
Specificity?
Nay.

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THE DIAGNOSTIC

PROCESS HAS AT

LEAST TWO STAGES.

b) Autism diagnostic assessment by a clinician specializing in autism – though *not necessarily* gender differences!

Ideally, the assessment process involves both informant-interview and observational methods.

THERE ARE A WEALTH

OF ASSESSMENT TOOLS

/ PROTOCOLS:

- Autism Diagnostic Interview-Revised (ADI-R)
- Autism Diagnostic
 Observation Schedule
 (ADOS-2)
- Diagnostic Interview for Social and Communication Disorders (DISCO)
- Childhood Autism Rating Scales (CARS)
- Developmental,
 Dimensional and Diagnostic
 Interview (3di)
- Adult Asperger Assessment (AAA)

A MAJOR PROBLEM WITH MANY DIAGNOSTIC TESTS IS THAT THEY MEASURE SOMEONE'S BEHAVIOURAL PRESENTATION... NOT THEIR INTERNAL



THE ADOS-2 IS A PRIME EXAMPLE...

Coming soon

ADHD & WOMEN COURSE

6 Weeks, Online

Now available on-demand at seedtalks.co.uk

Hosted by

Dr Anneka Tomlinson

Clinical Academic Psychiatry Fellow at the University of Oxford specialising in ADHD.







Here's the link for the CPD certificate for this course, if you missed it before!



Let's have a quick break

HOW DO AUTISTIC PEOPLE EXPERIENCE THE ADOS?

"[The ADOS] was a bit weird. [...] This children's book, it was pretty much a picture book with minimal text about some frogs that were suddenly flying through the night. And it was quite entertaining. I didn't mind it. It was a bit bizarre [...]. The fact that autism is diagnosed behaviorally, it seems absurd to me."

"The experience of trying to tell a story and making objects something they were not, was excruciating."

"it's so child-like and it's not something that I would ever do and so it doesn't assess my life if that makes sense, whereas for a child it might do"

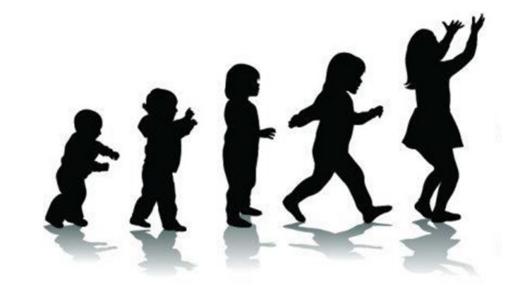
HOW DO AUTISTIC
PEOPLE EXPERIENCE THE
ADOS?

There is a "huge disparity for me for how I feel inside and how I mask on the outside with play"

HOW DO AUTISTIC
PEOPLE EXPERIENCE THE
ADOS?

"Notably, X scored zero on the stereotyped behaviours and restricted interests during this observation, but these were indicated from her self-report. For example, X reported eating a narrow range of food, repetitive thoughts, or 'thinking in a loop', and sensitivities to sounds."

THIS IS WHY DIAGNOSIS IS USUALLY MULTI STAGE, IDEALLY INVOLVING AN INFORMANT



Don't worry they do have ways around this THE POINT OF THESE ASSESSMENTS?

DIFFERENTIAL DIAGNOSIS

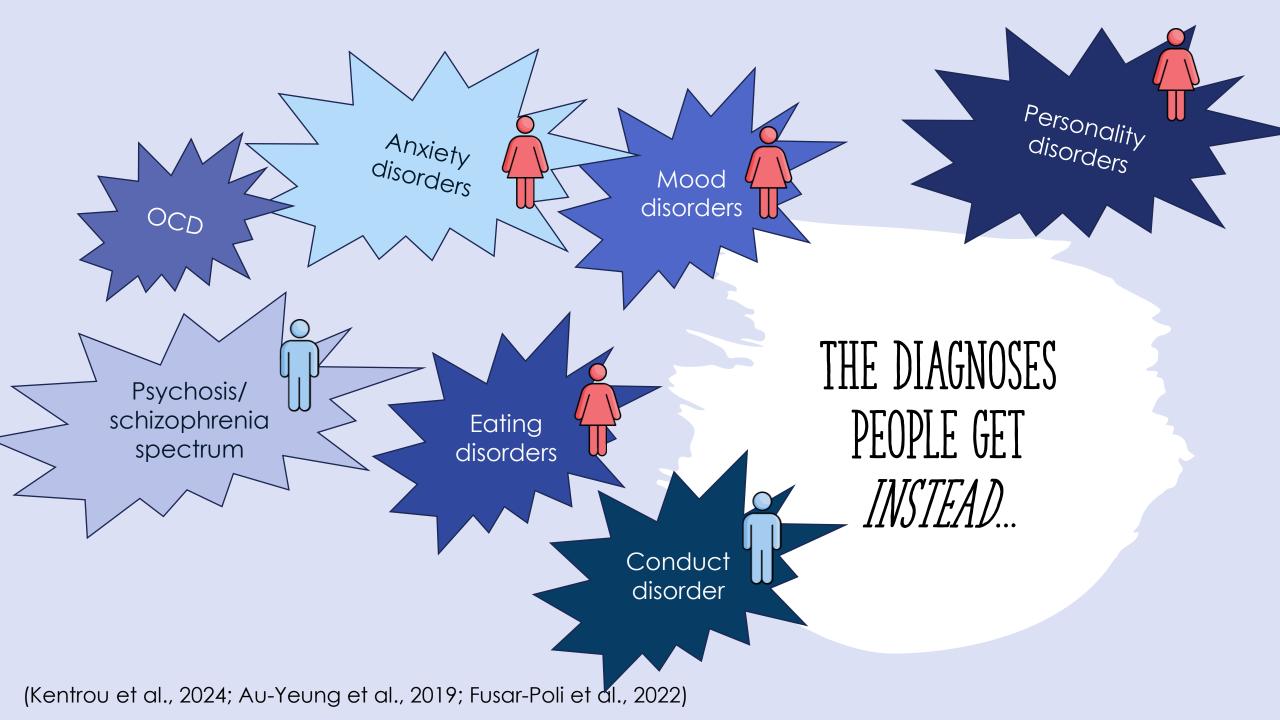


(Adamou et al., 2021; Christiansen & Pedersen 2024)

WHO FALLS THROUGH THE CRACKS?

Girls and women Ethnic, race and cultural minorities People with lower socioeconomic status LGBTQIA+ people assigned female at birth

(Adamou et al., 2021; Christiansen & Pedersen 2024; Tromans et al., 2021; Tien et al., 2025)



BORDERLINE PERSONALITY DISORDER: "A SHAMEFUL DISEASE"



Table 2. An I-poem exploring the emotions of participants upon receiving a BPD/EUPD diagnosis.

'being told that I was personality disordered' (P4) I don't know how to explain that (P5). I was so surprised . . . (P5). I wanted to throw myself in front of a truck (PI). → Shock I was so ashamed (P8). I shut myself away (P6). I just did not lift my face (P6). I never told anyone (P8). → Shame I started getting frustrated (PIO). I was horrified (P6). I was annoyed (P5). I felt angry (P6). → Anger I did not relate to it (PIO). I never felt it related (P6). I didn't agree (P4). I was so adamant that I didn't have . . . (P9). → Identity I think . . . It's quite toxic (P6). I just think that's really insulting (P4). I thought it was offensive (PI). I just felt like a knife to the chest (P3).

→ Offence

I've been handed a life sentence (PI). → Guilt I was not good enough (PI). I hadn't tried hard enough (PI). I felt like very core of me was wrong (P4). I thought I am worse (P4). I was led to believe that I'm insane (P6). → Blame I could not sleep (P8). I remember crying, just crying, absolutely hysterical crying (P2). I felt sad (P6). I felt . . . awful (PI). → Sorrow I felt like I'd lost hope (P4). I was just unable to be helped (P9). I was just so done with life (P2). I don't know how to say or anything else or other than that I'm sorry . . . (P5). → Despair

I felt like. . .it was my fault (P4).

I... felt like I had a criminal record (P4).

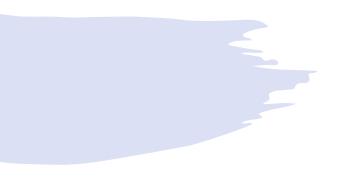
(Tamilson et al., 2025)



HOW DO PSYCHIATRISTS MAKE THE DIFFERENTIATION - BETWEEN AUTISM, PERSONALITY DISORDER, ATTACHMENT DISORDER, TRAUMA...

When trying to tease out autistic women:

- Long assessments in different/challenging social settings
- Test them with spontaneity and humour
- Test subtle understanding of neurotypical social rules
- Do they need time preparing and recovering from social encounters?
- Can they elaborate on their interests?
- Emotional empathy and self-awareness
- What is their professional life like, and their patient-history?
- "Asymmetrical relationships"
- Chronology and timeline is essential as well as the "feeling in the room"



HOW DO PSYCHIATRISTS MAKE THE DIFFERENTIATION - BETWEEN AUTISM, PERSONALITY DISORDER, ATTACHMENT DISORDER, TRAUMA...

	Autism		CPTSD			
Features	Young people	Adults	Young people	Adults	Attachment disorders	EUPD
Family history of neurodevelopmental conditions	X	X				
History of insufficient care by age 5					X	
History of adverse experiences			X	X	X	X
Presents from an early age	X	X			X	
Presents in adolescence or young adulthood						X
Presents following traumatic events			X	X		
Difficulties with insight into own emotions	X	X	X	X	X	X
Co-occurring anxiety	X	X	X	X	X	X
Co-occurring low mood		X		X		X
Mood is typically stable and negative				X		
Mood is unstable						X
Fears of coming to harm again				X		
Varied fears (e.g., rejection, abandonment)						X
Difficulties regulating emotions	X	X	X	X	X	X
Difficulties with sense of identity and/or self-esteem	X	X		X	X	X
Feeling different from others	X		X			
Sense of not belonging and misunderstood		X				X
Difficulties with mentalization		X				X
Difficulties coping with		X		X		X

(Parr et al., 2025)

IS THERE A WAY TO GET A PREVIOUS DIAGNOSIS PREVIOUS QUESTION ANSWERED THROUGH ONE OF OUR AUDIENCE MEMBER'S

"Challenging a historic BPD diagnosis is often difficult. Mental health trusts may say that a past diagnosis cannot be corrected for legal reasons and was based on what was thought at the time of the original assessment. If still under mental health services, then do speak to your team about your thoughts on misdiagnosis in view of suspected or confirmed autism. It would be possible for a psychiatrist and their multi disciplinary team to decide that a diagnosis of EUPD was no longer relevant and for this to be archived on the clinical record. The diagnosis though wouldn't be deleted, and it is still possible that the diagnosis could be added back in future if an assessment was made which resulted in a diagnosis of EUPD. Opinion is still divided among clinicians who may think that EUPD co-exists

Opinion is still divided among clinicians who may think that EUPD co-exists with autism often, due to the link with trauma. Many clinicians may diagnosis someone who is dysregulated and self-harms with EUPD as well as autism.

Once discharged by mental health services, a referral back to the service would need to come from a GP. Demand for NHS services is very high and a referral may be assessed to not meet the threshold.

It is possible to seek a private psychiatrist appointment in an attempt to correct a EUPD diagnosis, but costs often start from over £450 for one hour (follow up appointments are usually less). A private psychiatrist's opinion could still be disregarded by an NHS Trust. It is also still possible that a reassessment could result in diagnoses of both EUPD and autism, or EUPD or neither."

WONDERING IF YOU MIGHT BE AUTISTIC?

TOP TIPS FOR PEOPLE SEEKING AN AUTISM ASSESSMENT



1. ARM YOURSELF

- How does autism look in girls/women/nonbinary/trans people?
- What diagnostic process does this clinic follow?

Autism-Spectrum Quotient (AQ):

- I tend to have very strong interests, which I get upset about if I can't pursue.
- When I talk, it isn't always easy for others to get a word in edgewise.
- People often tell me that I keep going on and on about the same thing.

I could say no to all of these, thanks to masking.

- It does not upset me if my daily routine is disturbed.
- I find social situations easy.

I could say 'no', but have I already 'structured' my life in such a way that these questions aren't being truly tested? E.g. maybe I have reduced all social situations to those with just a couple of friends, so now they ARE easy for me?

• Other people frequently tell me that what I've said is impolite, even though I think it is polite.

I could say no because they don't now, but people did think I was rude when I was a child. They did not necessarily TELL ME that, though, so I could still say no if I am answering extremely literally. 2. BE AWARE OF WHAT
THEY'RE DOING/LOOKING FOR...
AVOID POTENTIAL PITFALLS

BY ADDING 'CAVEATS'

Good write-up of the AQ and other tests here.

RAADS-R items:

- I have a hard time figuring out what some phrases mean, like 'you are the apple of my eye.'
- I only like to talk to people who share my special interests.
- 14. I'd rather go out to eat in a restaurant by myself than with someone I know.
- I have been told that I am clumsy or uncoordinated.
- I understand when friends need to be comforted.

You have to respond with "True now and when I was young", OR "True now only", OR "True only when I was younger than 16", OR "Never true".

Gets a bad write-up <u>here</u>

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Gets a bad write-up here

(RELATEDLY - YOU CAN DISCUSS YOUR

RESPONSES TO SCREENING TOOLS WITH THE

DIAGNOSTIC CLINICIAN, WHICH IS

SOMETIMES A USEFUL WAY OF INDICATING

IF YOU'RE A BIG MASKER)



3. CONNECT WITH OTHER

FAMILIES OR AUTISTIC PEOPLE

FOR SUPPORT AND ADVICE

BEFOREHAND AND AFTER.



4. THINK ABOUT HOW YOU WILL COPE WITH THE OUTCOME OF THE ASSESSMENT. KNOW THAT IT TAKES TIME TO ADJUST.

You are likely to experience strong emotions – whatever the outcome. There is rarely any post-diagnostic support for those who are diagnosed. Have your usual sources of support ready.

SPACE FOR QUESTIONS/ DISCUSSION

Week 1: The Many Faces of Autism

Week 2: Autism in Girls, Women and People Assigned Female at Birth (AFAB)

Week 3: Health and wellbeing in autistic people

(1 week break!)

Week 4: Autism and Emotions

Week 5: Lifespan Development and Reproductive Transitions

Week 6: The Paths and Pitfalls of Seeking an Autism Diagnosis

THANK YOU SO MUCH, AND PLEASE TAKE CARE AND BE KIND TO

YOURSELF OUT THERE

Slides, resources and feedback at: www.scienceonthespectrum.net/talknotes

rmoseley@bournemouth.ac.uk

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UPCOMING EVENTS ONLINE

MAR

The Psychology of Identity

10

with Rachel Sparrow

MAR

The Neuroscience of Emotions

with Barbara-A

with Barbara-Anne Robertson

MAR

ADHD & Premenstrual Dysphoric Disorder

V

with Hayley Barker-Smith

