

Thanks for coming along! This webinar will begin shortly.

The webinar will be recorded so it is accessible to others after the live session.

Dawn will not be able to see the chat during the presentation. Questions put into the chat will be combined by our team members into "umbrella" questions at the end of the session.

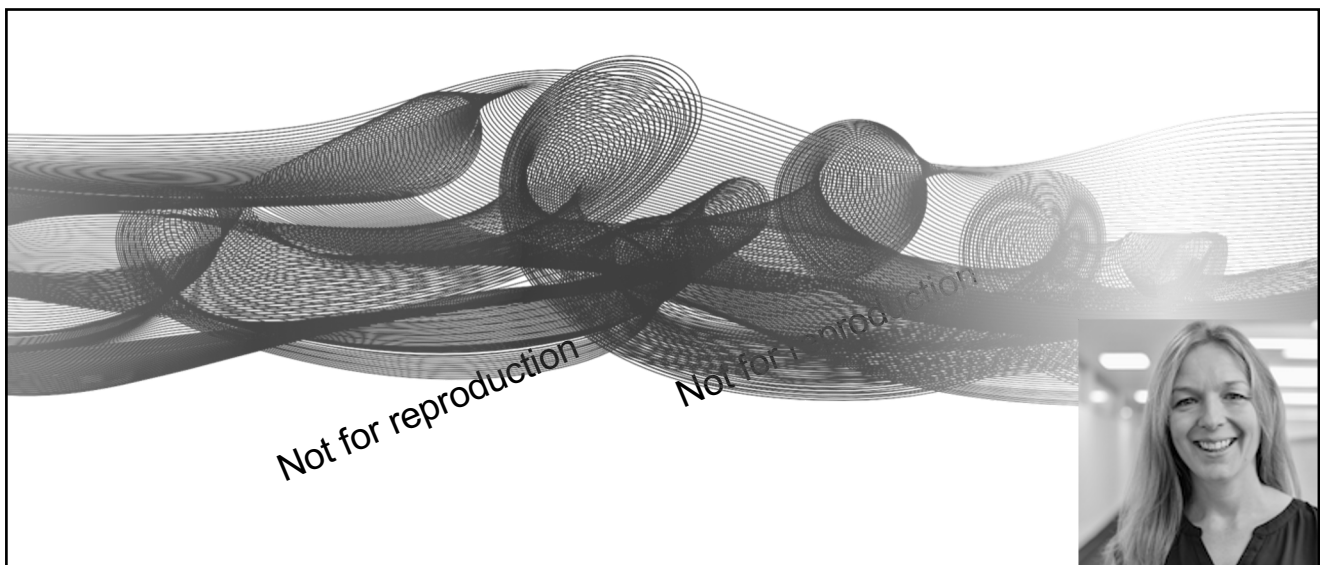
Please be aware of spammers or scammers in the chat box. This event is free and we will not ask for any personal information in the chat box.

Anxiety with autism – what do we know and what works?

Assoc. Prof. Dawn Adams: Autism Centre of Excellence




1



Anxiety with autism – what do we know and what works?

Assoc. Prof. Dawn Adams: Autism Centre of Excellence



2



This talk aims to increase your knowledge and understanding about the research findings related to anxiety in autism

It is still recommended that you seek professional, individual advice or input if you have worries about the mental health of yourself or a person you care for/work with.

I am a Clinical Psychologist and a researcher and can talk about knowledge but not about first hand experience of autism (or autism and anxiety). I definitely recommended that you seek out and listen to those with a diagnosis on the autism spectrum.

3

Autism Centre of Excellence, Griffith University

- Multi-disciplinary team
- Teaching and Masters/PhD programs
- Leading research in:
 - Anxiety and well-being
 - Preschoolers Anxiety prevention trial
 - 5-year longitudinal study of anxiety in adolescence
 - Participation and strengths
 - Academic and communication skills
- Passionate about sharing knowledge and working with the autism community to improve outcomes



4

Why this presentation?

Why this presentation?

Research Article

Parent descriptions of the presentation and management of anxiousness in children on the autism spectrum

Dawn Adams^{1,2}, Kate Young¹, Kate Simpson^{1,3} and Deb Keen^{1,3}

Research in Autism Spectrum Disorders

Journal of School Psychology

Journal of Autism and Developmental Disorders

International Journal of Disability, Development and Education

Journal of Child and Family Studies

Journal of Anxiety Disorders

Journal of Autism and Developmental Disorders

Exploring anxiety symptomatology in school-aged autistic children using an autism-specific assessment

Jacqueline den Houting^{1,2}, Dawn Adams^{1,2}, Jacqueline Roberts^{1,3}, Deb Keen^{1,3}

School-related anxiety symptomatology in a community sample of primary-school-aged children on the autism spectrum

Deb Keen^{1,2}, Dawn Adams^{1,2}, Kate Simpson^{1,3}, Jacqueline den Houting^{1,2} and Jacqueline Roberts^{1,3}

Teacher responses to anxiety-related behaviours in students on the autism spectrum

Dawn Adams^{1,2}, Libby McDonald¹, Deb Keen^{1,3}

Parent Perspectives on the Presentation, Triggers, Impact, and Support of Anxiety in Young Children on the Autism Spectrum

Kate Simpson^{1,2}, Dawn Adams^{1,2}, Elizabeth Wheelley¹, Deb Keen^{1,3}

Brief Report: Investigating the Impact of Anxious Symptomatology in Autistic Children

Jacqueline den Houting^{1,2}, Dawn Adams^{1,2}, Jacqueline Roberts^{1,3} and Deb Keen^{1,3}

Parent perspectives of what helps and hinders their child on the autism spectrum to manage their anxiety

Megan Clark^{1,2}, Dawn Adams^{1,2}

Exploring profiles of anxiety symptoms in male and female children on the autism spectrum

Kathryn Ambrose^{1,2}, Dawn Adams^{1,2}, Kate Simpson^{1,3}, Deb Keen^{1,3}

Anxiety in Children with Autism at School: a Systematic Review

Dawn Adams^{1,2}, Kate Young¹, Deb Keen^{1,3}

RESEARCH ARTICLE

Exploring Anxiety at Home, School, and in the Community Through Self-Report From Children on the Autism Spectrum

Dawn Adams^{1,2}, Kate Simpson^{1,3}, and Deb Keen^{1,3}

5

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6

Ways to hear about our research outputs



or reproduction

<https://research-repository.griffith.edu.au> – select by author or search for keyword

Lay summaries on our Facebook page and blog posts (Autism research talk)

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7

Language has power

- Person first, identify first – “on the autism spectrum” will be used throughout as identified by broad number of groups as acceptable term (Bury et al., 2020; Kenny et al., 2016)
- Move away from the labels “high-functioning” or “low-functioning”
 - Using the label ‘high-functioning’ may underplay the challenges individuals experienced on a day-to-day basis and leads to misleading expectations about their abilities to function in the environment, whether that’s at school, work or elsewhere (or not recognise the “pay” off for that).
 - The term “low-functioning” also dismisses any strengths or skills each individual may have.

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8

Topics you asked us to cover

- The autism spectrum
 - Females (→ masking/camouflaging)
 - Adults and the complexity of diagnosis
- The presentation/experience of anxiety in autism
 - Autism-specific anxiety
 - Anxiety in those with minimal verbal language
 - Measurement
 - School anxiety, school refusal
 - Control, fear of failure
- Treatments and options
 - Supports and strategies
 - CBT – what do we know and why is it hard?
 - Medications
- Where to from here?



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9

If you feel lost – keep with me!



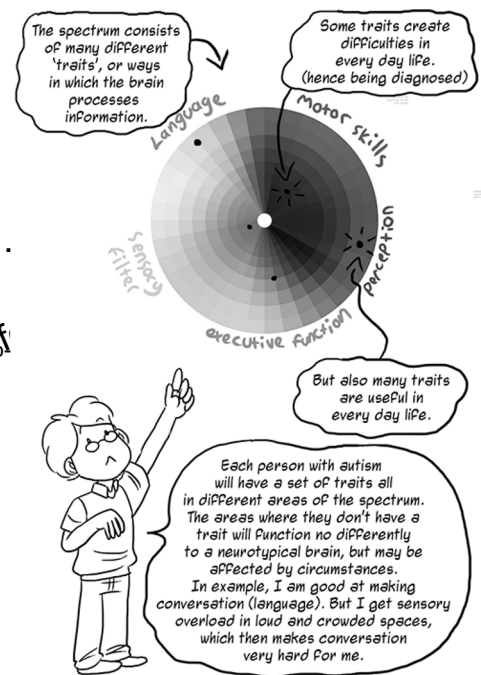
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10

When we talk about the autism spectrum...

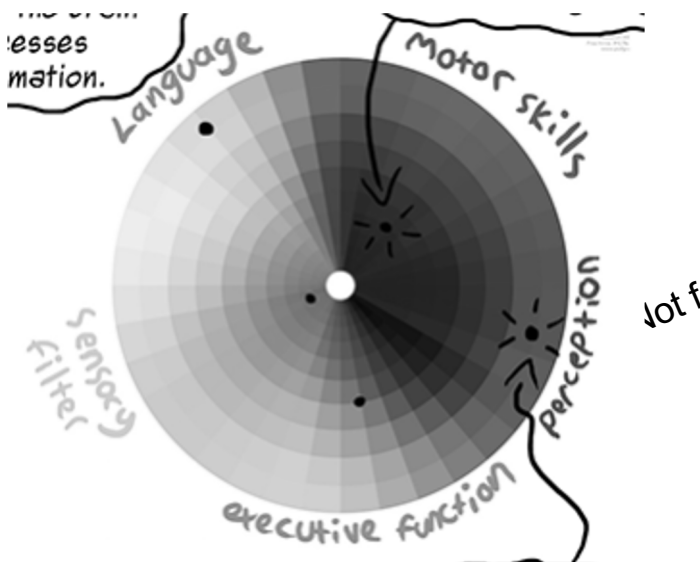
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11



<https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/>

12

Autism in females and adults

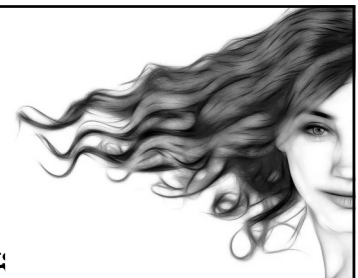


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13

Identifying autism in females

- Girls are less likely to
 - Be referred for an autism assessment
 - Receive an autism diagnosis using standardised assessment
 - Less likely to have their repetitive behaviours noticed
 - Be seen as “shy” “passive” or “coping” (see work by Allely)
- Even the DSM-5 recognizes this as a potential factor
 - *“girls without accompanying intellectual impairments or language delays may go unrecognized, perhaps because of subtler manifestations of social and communication difficulties” (APA, 2013, pp. 57).*
- Measures give gender-biased examples (e.g. cars, spinning wheels)
- Delay in knowledge impacting practice



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14

Females on the spectrum: the need for careful observation

- Girls may have less obvious restricted interests or repetitive behaviours
 - May like things “neat” or “tidy” - make-up or fashion can be strength
 - Collections of specific dolls – it’s the intensity that’s different, not the focus
- Social communication challenges may be higher than males and may increase across adolescence.
- High overlap with eating disorders (23% of those with anorexia have autism)
- “Champagne” approach – holding it all together during the day and letting it all out in the evening.



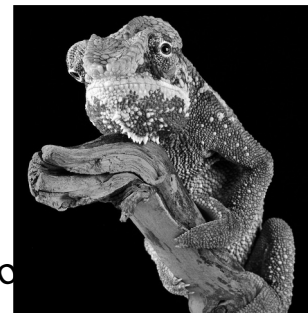
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15

Camouflaging “Putting on your best normal”

- Up to 70% of females report regularly camouflaging.
- May involve learned and automatic responses learned through copying/mimicking.
- Systemises social interactions.
- Sometimes described as an “obligation” rather than choice. Aims to avoid negative perception or outcome.
- Associated with exhaustion, stress, anxiety, depression and identity confusion



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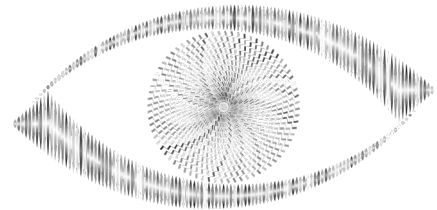
16

Identifying autism in adults (Huang et al., 2020 review)

- Increasing diagnoses in adults. The decision to seek an adult diagnosis is impacted by
 - Cost
 - Fearing not being believed
 - Difficulty finding a specialist/long waiting times
- Depression (13-50%) and anxiety (10-50%) high amongst those seeking adult diagnosis. 5-15% ADHD, eating disorder or personality disorder.
- Importance of information, explanation and support.
- "My whole life up to that point finally made sense... I wasn't a failed neurotypical person, I was a perfectly good autistic person": Jac den Houting Ted Talk
<https://youtu.be/A1AUdaH-EPM>

17

Take home message 1



- Autism is a spectrum condition
 - "If you've met one person with autism, you've met one person with autism" – personality, profiles, age, gender, environment can influence presentation.
- To understand autism with anxiety, we first need to understand autism.
 - DSM-5 criteria is not matched for listening and understanding the experience
- We need to try to understand behaviours and social challenges outside of our cultural (gender/age) bias.

18

Autism with anxiety

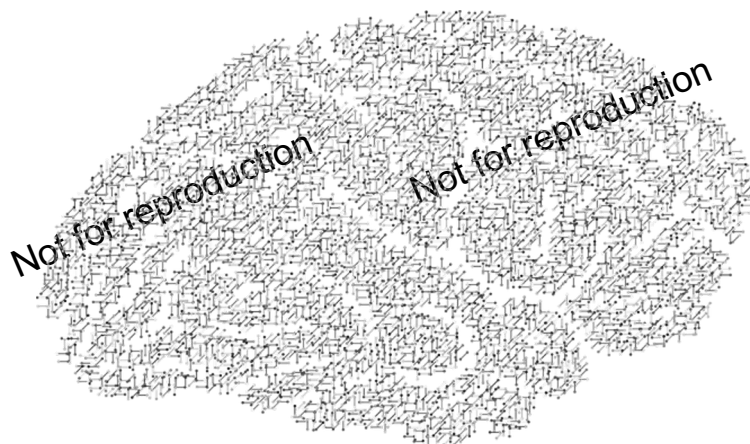


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19

Before we think about anxiety, we need to acknowledge that low/no anxiety is an active process



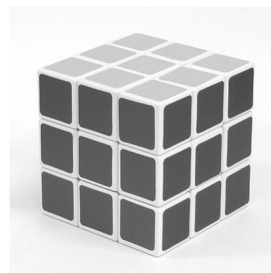
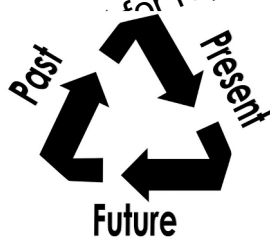
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20

Things that you will be doing to stop yourself being anxious and may not even know



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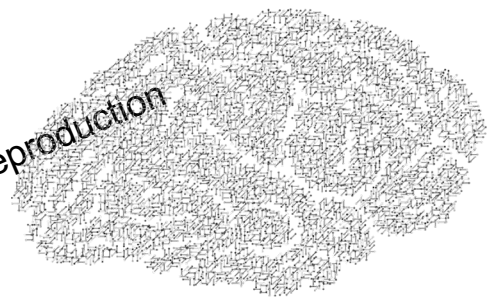
21

Take home message 2

No or low anxiety is not simply the opposite of having anxiety.

It is an active process requiring a range of skills.

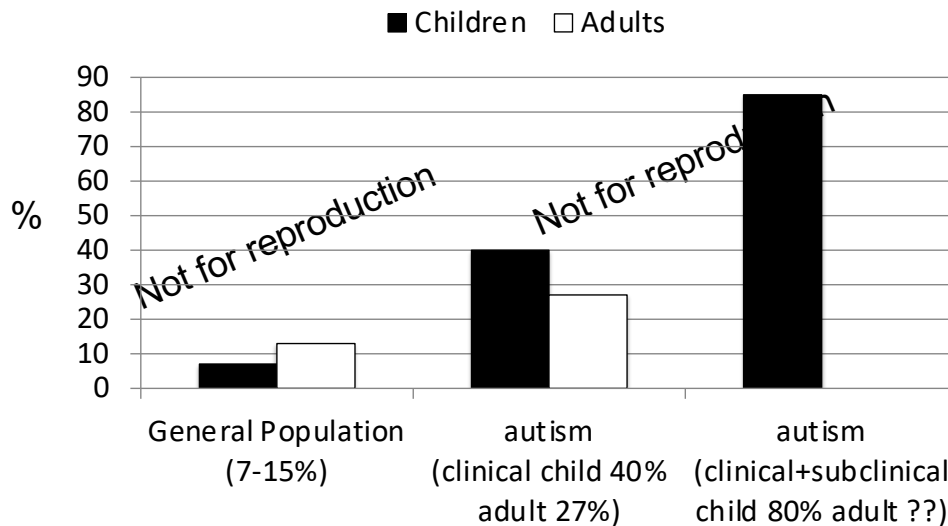
Therefore you don't "remove" anxiety, you develop the tools to (1) identify and (2) reduce it.



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22

How common is anxiety in autism?



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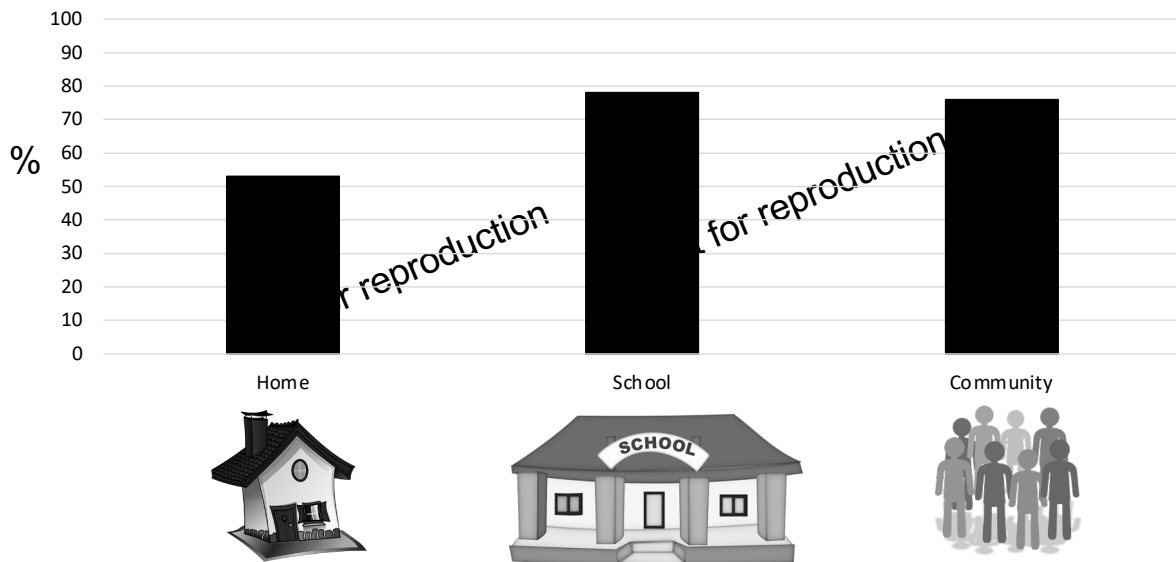
23

Type of anxiety	Description (% for autism <18 years, van Steensel et al., 2011)
Generalised Anxiety Disorder	Feeling anxious about a wide variety of things on most days, over an extended period of time ("worry wort") – seek reassurance (10-15%)
Social anxiety	Worry about social situations or times being judged, criticised, embarrassed or humiliated, e.g. speaking publicly, eating in public, or taking a test. (13-16%)
Specific phobia	Fearful about a particular object or situation and may go to great lengths to avoid it, e.g. spiders, flying (25-30%)
Panic disorder	Hallmarked by panic attacks" intense, overwhelming and often uncontrollable feelings of anxiety combined with a range of physical symptoms. (1-2%)
Obsessive Compulsive Disorder	Ongoing unwanted/intrusive thoughts/fears that cause behaviours/rituals to alleviate fear or protect against harm/outcome (12-18%)
Separation anxiety	Frightened of being away from person or item of safety. Anticipated separation can be as challenging as actual separation. (3-9%)

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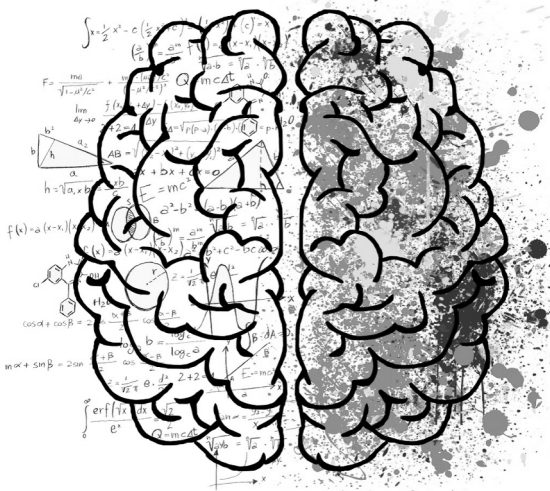
24

Anxiety impacts differently in different places



Adams et al. (2018)

25

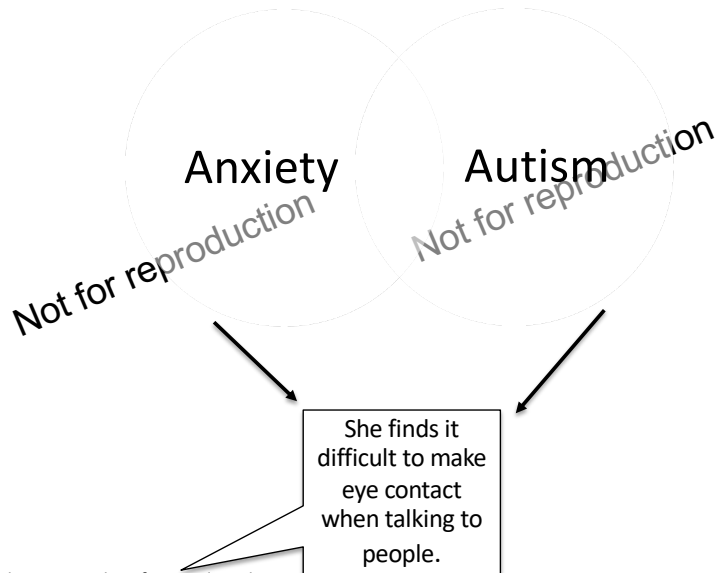


Autism with anxiety

“What’s makes anxiety in autism different?”

26

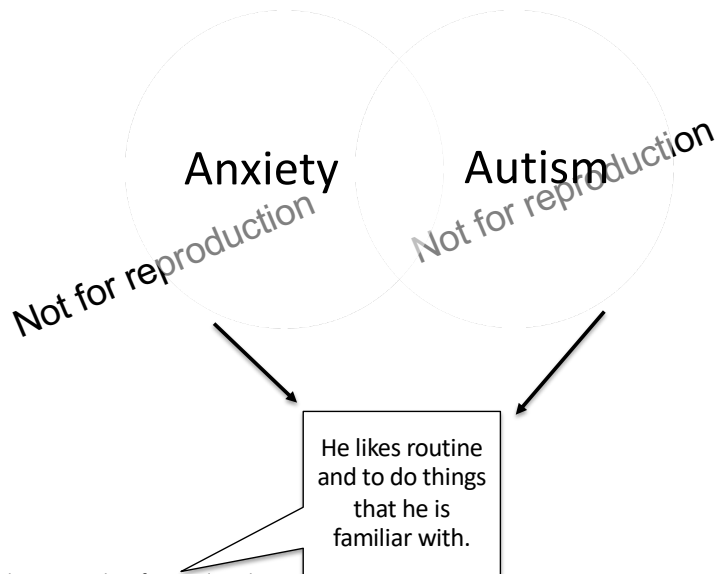
1. Overlap between characteristics of autism and anxiety



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27

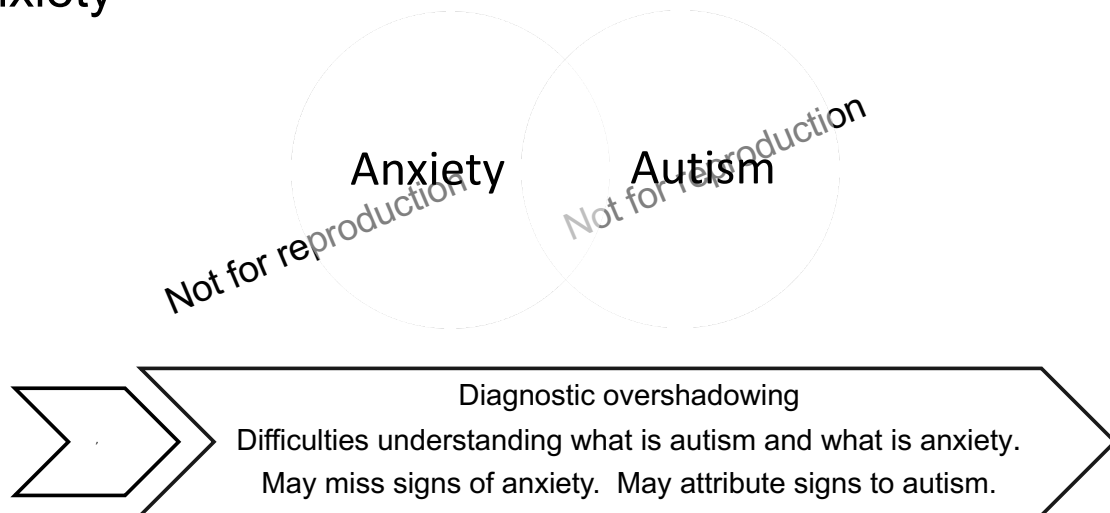
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28

1. Overlap between characteristics of autism and anxiety



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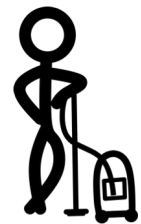
2. Presence of “typical” and “autism-specific” signs of anxiety (Kerns et al., 2014)

Typical

- Negative Automatic Thoughts
- Hypersensitivity and vigilance

Autism-specific (“Atypical”)

- Anxiety around routine, novelty and restricted interests
- Unusual specific fears
- Social fearfulness
- Compulsive/ritualistic behaviour
- Fear of sensory experience

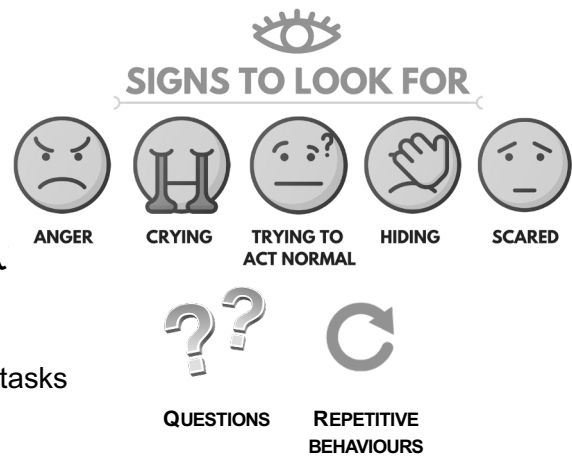


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30

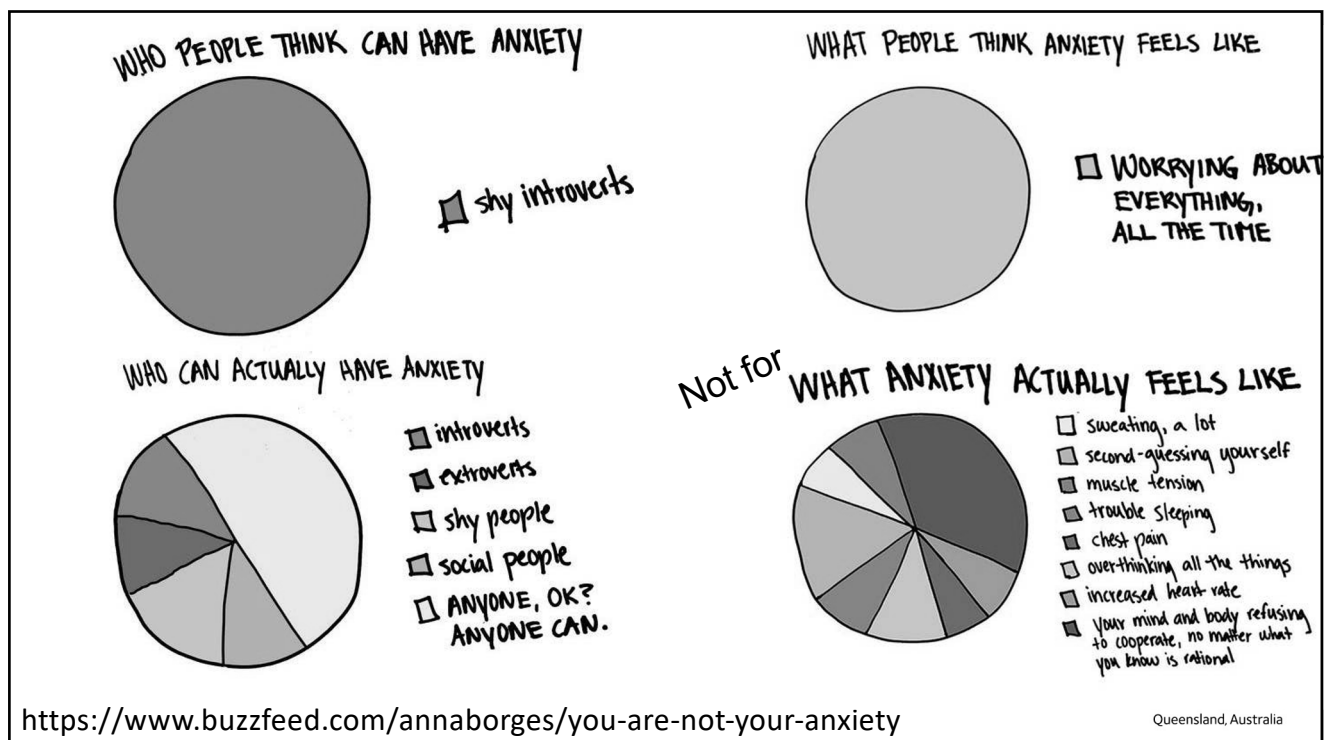
Our research shows that:

- Presentation of anxiety
 - Most common – challenges with uncertainty: "needing to know"
 - Least common – physiological markers
- Clearest markers of anxiety may be in a child's behaviour rather than words
 - Change in realisations
 - Hiding or shutting down, unable to complete tasks
 - Changes in mood, affect or emotions
 - Changes in movement or running away
 - Behaviour changes ("bracing for the worst")
 - Repetitive behaviours and questions
 - (Physiological changes)



Adams et al. (2018)

31



32

Take home message 3

It's not autism AND anxiety, it's autism **WITH** anxiety

It's the interaction between that we need to understand

Importance of autism-focused measure/assessment

Anxiety is a common but not inevitable or "part of autism"

Know what you're looking for – understand what you see not what you think should be there.



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33

School anxiety



- Although 80% of children and 72% of parents tell us the children on the spectrum are anxious at school, only 20-30% of teachers rate children above the cut-off.
- Only 50% of children think anyone at school can recognize their anxiety
- Most frequently endorsed symptoms by teachers
 - 32.6% hesitant in starting tasks or asking whether they understood the task before starting.
 - 27.2% worries about things
 - 27.2% scared of making mistakes



34

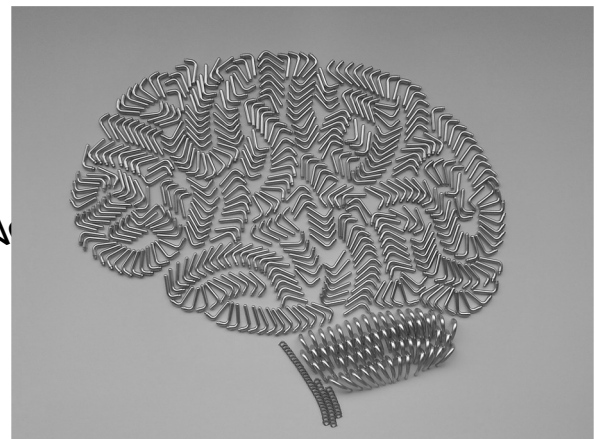
Fear of failure and of making mistakes

- Trying something new isn't just about pass/fail
 - It's a challenge to the need for routine and predictability
 - It may be about failing to meet an expectation, not an outcome
 - It may be a challenge to specific cognitive skills e.g. ability to visualize end result, problem-solving skills
 - Challenges with interoception can make "gut instinct" harder



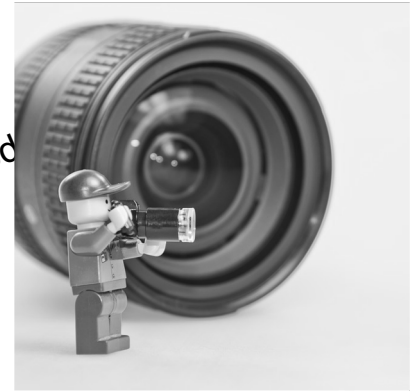
Interoception and alexithymia

- Interoception: recognizing inside feelings e.g. pain, hunger, anxiety.
- Alexithymia: labelling of your own inner state(s) by incorporating inner feelings with information from situation
- Managing emotions (emotion regulation) requires both of these + (+ inhibition control + planning etc. etc.)

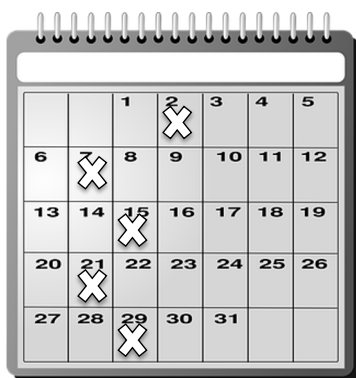


Fear of failure and of making mistakes

- Remove our neurotypical view and use our autism-informed lens to hypothesise about the barriers → support
- Won't do, or can't do? (yet)
- Each task avoided, although it may bring immediate relief, can impacts self-esteem.



School non-attendance and school refusal



- 43% due to non-problematic absence (e.g. medical appointments) → still impacts!
- 43% due to school refusal
- 9% school exclusion and 9% school withdrawal
- Factors influencing school refusal are more environmental/situational than child-centric.
- More work needed – watch this space!

Take home message 4

- Diagnostic overshadowing may make it hard for those at school to recognize the anxiety (in context of autism)
- There's a need to look underneath the surface to understand behaviour
- Co-develop an "anxiety signature" to share with those who may not recognize the anxiety
 - Need to recognize anxiety before it can be supported



Stimming and repetitive behaviours

- "A stim may indicate there is a problem. A stim is not *the* problem"
- For various perspectives, see The Mighty's "11 People With Autism Explain What Stimming Feels Like"
- Stimming may be used to
 - Regulate sensory information
 - Provide predictability, routine or comfort
 - Calm and release
 - Be pleasurable!

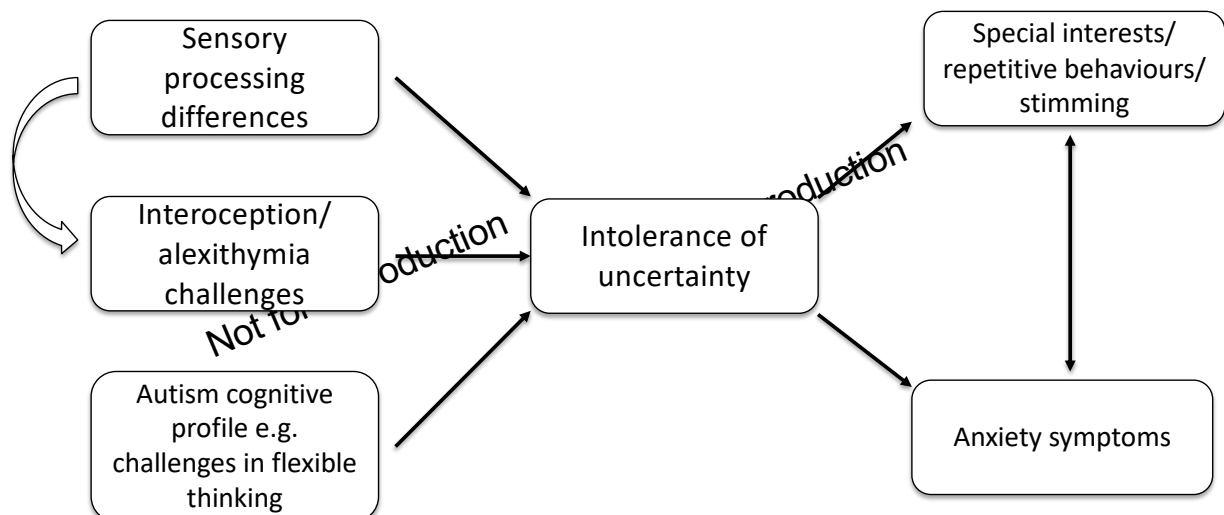


Take a deep breath and stick with me for this next bit!

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Model of autism-specific anxiety: South & Rodgers (2017)





Autism with anxiety

*“So what can we do?
How is intervention different?:*

43

Every day supports and strategies

- Adults on the spectrum have described how
 - It is easier to mentally prepare than recover afterwards – plans get made in great detail to create certainty
 - Adjusting a plan actually means making a whole new plan
 - Multiple changes are cumulative and can multiply rather than add to each other
 - It's not just about the task, but the place, the processing and the predictability of the sensory input that impacts the anxiety.

→ Need for everyday consideration as well as specific interventions



44

Parent-reported helpful strategies differ between settings

Home	School	Community
talking or explaining (26.4%)	parent-teacher collaboration or communication (20.3%)	preparing or practising in advance (30.4%)
providing/ensuring a calm, safe, quiet location or time alone (26.4%)	providing a calm, safe, quiet location or time alone (15.6%)	avoiding specific places or removing anxiety trigger (14.4%)
routines or predictability (22%)	routines or predictability (13.3%)	sensory-related strategies (10.4%)
	preparing or practising in advance (13.3%)	

Adams et al. (2018)



45

Interventions for anxiety – Mindfulness and Cognitive Behavioural Therapy (CBT)

- Mindfulness showing good effects in adults
 - Be Mindful and CBT (Serenity) online self-paced packages show improvements in 50-75% of those who complete them
- CBT is moderately effective in children on the spectrum without ID
 - up to 14 weeks of sessions, no additional benefit after that

Thoughts

Behaviours

Feelings



46

Dawn's reflections on why therapy (and then maybe specifically CBT) may be challenging for anxiety in some individuals on the spectrum



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47

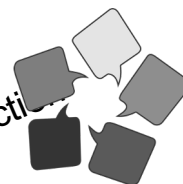
Research has identified many things as general barriers to healthcare/therapy



Environmental



Provider



"Client"

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48

What does CBT ask individuals to do?

- Recognise and identify thoughts, feelings and behaviours
- Hold on to that thought while you question it
- Keep all of those answers in mind and consider possible alternatives
- Use flexible thinking to consider all of those alternatives and identify the most likely outcome
- Reconsider feelings and emotions *(using your interoception and emotion labelling skills)*
- Make a plan of action and act upon it *(using executive functioning skills)*
- Be prepared to be asked a whole range of questions by therapist

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49

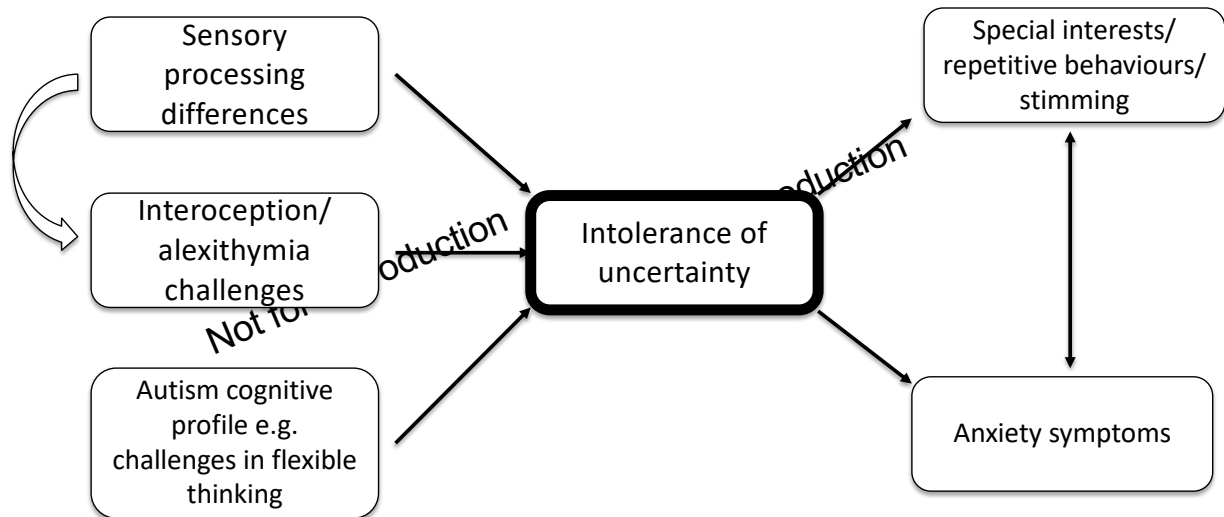
CBT modifications significantly improve outcomes

- Helpful modifications for autism
 - concrete tools and supports;
 - use of hierarchies that also address autism characteristics;
 - incorporation of special interests;
 - parental involvement - Parent involvement in two or more activities almost doubles effectiveness
- Intolerance of uncertainty levels impact effectiveness
 - CBT doesn't necessarily tackle the intolerance of uncertainty

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50

Using the model of autism-specific anxiety to consider other interventions



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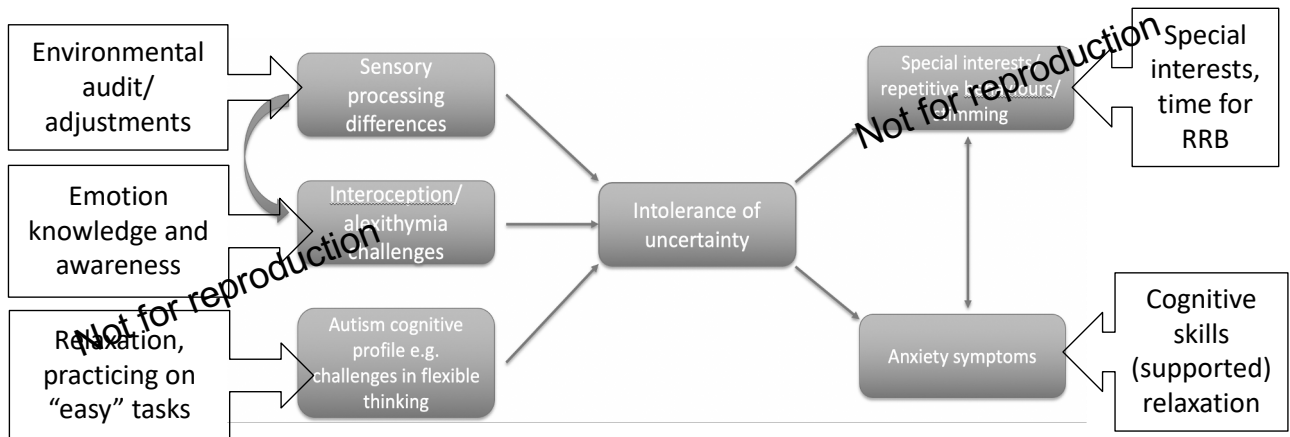
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Treatments focusing on IU to reduce anxiety

- CUES: Coping with Uncertainty in Everyday Situations (Rodgers et al., 2017)
 - parent group intervention to reduce intolerance of uncertainty in children and adults.
 - counters well-meaning, understandable but ultimately unhelpful/counter-productive strategies used by parents to build certainty around the child
 - Reduces child IU and anxiety – but reduces parent IU and anxiety more!
 - Currently being evaluated in RCT in UK (Rodgers et al., 2019)

52

Other ways “in” to the IU/anxiety model?



53

Medications – review Vasa et al., (2014)

- Only identified 4 studies autism-specific. No RCT (blinded) studies of anxiety medications specifically in youth on the spectrum
 - “Large scale and long term RCTs examining psychopharmacological and non-psychopharmacological treatments are sorely needed.”
- “Citalopram resulted in mild to severe side effects, resulting in discontinuation in 6 of 32 (19 %) children. Fluvoxamine resulted in side effects in 13 of 18 (72 %) children with behavioural activation occurring in 9 (50 %) of children. Buspirone resulted in mild side effects”

54

Medications – CBD oil

- “At present, however, there are no convincing pre-clinical or clinical data showing efficacy and safety of cannabinoid treatment in ASD patients.” (Poleg, Golunchik, Offen & Weizman, 2019)
- ” Studies revealed mixed and inconclusive findings of cannabis effects for all conditions [co-occurring with autism], except epilepsy. Adverse outcomes were also reported, which included severe psychosis, increased agitation, somnolence, decreased appetite, and irritability... There is currently insufficient evidence for cannabis use in ASD, which creates an urgent need for additional large-scale controlled studies to increase understanding of risks and benefits” (Agarwal, Burke & Maddux, 2019)

55

Take home message 5

- To support autism with anxiety, we need to understand the autism, autism-specific anxiety and their interaction
- Models
 - Highlight why some therapies (e.g. CBT) don't tackle all of the anxiety experience
 - Gives us lots of avenues to reduce challenges, some outside of formal therapy
- So much more work needed in this area – which we hope to continue!

56

Thank you! Time for some questions

Keep up to date with our research via our Facebook page

Useful links

- www.facebook.com/AutismCentreExcellence
- <https://is.gd/ACEResearchNetwork>
- www.griffith.edu.au/arts-education-law/autism-centre-excellence
- www.griffith.edu.au/autism-studies
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