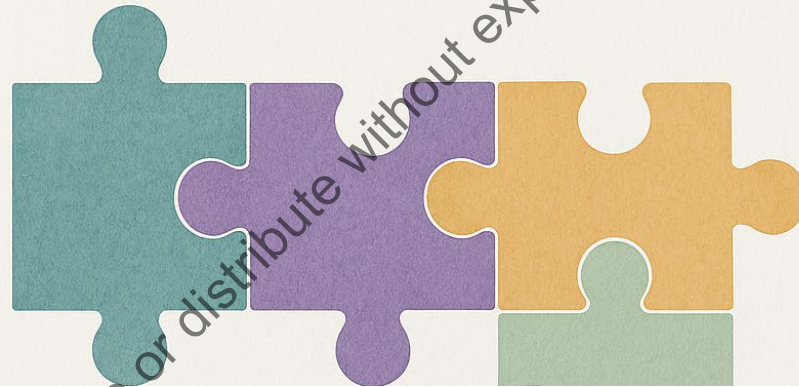


Unique, Not Broken:

Autism Spectrum Disorder, OCD and Anxiety



Recognising Strength, Supporting Struggle, Redefining Normal
'Normal is just a setting on the washing machine'

DR ALICIA PORTER
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DISCLAIMER

- The contents of this presentation have been independently prepared by Dr Alicia Porter
- Confirmation of no conflict of interests

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OBJECTIVES

1

Understand ASD as a **neurodiverse** rather than a “disordered” condition.

2

Recognise **the overlap between OCD, anxiety, and ASD** in clinical practice.

3

Differentiate **true OCD vs. ASD-related repetitive behaviours.**

4

Improve management and referral strategies for ASD patients with co-occurring conditions.

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GUIDING PRINCIPLES

These shape mental health assessments in children and adolescents:

Developmental understanding:

- Children are not “little adults.”
- Their symptoms, behaviours, and coping strategies are embedded in a rapidly evolving developmental context.
- Understanding that children show distress differently than adults.
- Need to consider if the symptoms or behaviours are developmentally normal or not.

Individual uniqueness:

- Every child's story is different.
- What may appear as rigidity or defiance in one child could be anxiety in another—or a sensory processing challenge in a child on the spectrum.
- Looking beyond symptoms to context, strengths, and stressors.

Holistic and collaborative care:

- Assessment must go beyond a checklist of symptoms. (DSM is limiting with regards to children)
- Requires a careful, exploration of the child's inner world, environment, relationships, strengths, and struggles.
- Knowing when to support in primary care and when to refer to mental health services

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THE CHALLENGES

- Symptom overlap can obscure diagnosis.
 - Is this social withdrawal a sign of depression, anxiety, or autism?
- Stigma and misinformation can delay help-seeking and create fear around labels-unable to access care independently
- Time constraints, limited access to trained professionals, and systemic barriers often hinder early identification and appropriate intervention.
- Diagnostic criteria used are often the same as the criteria used for adults
- Co-morbidity is the rule rather than the exception- often multiple co-morbidities
- Cultural considerations in how distress is expressed and interpreted add another layer of complexity.
- The pressure to manage both physical and emotional health
- Complexity of navigating complex mental health systems

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WHY IS THIS IMPORTANT?

Early signs are frequently subtle.

Symptoms can be masked or misinterpreted.

Families often present with concerns that don't fit neatly into diagnostic boxes.

It might be a child who's refusing school, a teenager struggling with sleep and stomach aches, or a parent who says, 'Something just doesn't feel right.'

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CASE VIGNETTE

Sipho is a 10-year-old boy brought in by his mother, who says he's refusing to go to school. Over the past few months, he's become increasingly withdrawn. He's struggling with sleep, complains of constant tummy aches, and has started insisting on very specific routines at home—his clothes must be folded a certain way, his toothbrush can't be moved from its spot, and he becomes distressed if these aren't followed exactly.

At school, his teachers report that he avoids group activities, rarely speaks unless spoken to, and becomes overwhelmed by noise. His mom is worried he's being bullied, but he won't say much. She wonders if it's anxiety. A teacher mentioned the word "autism." Another family member asked if he could have OCD.

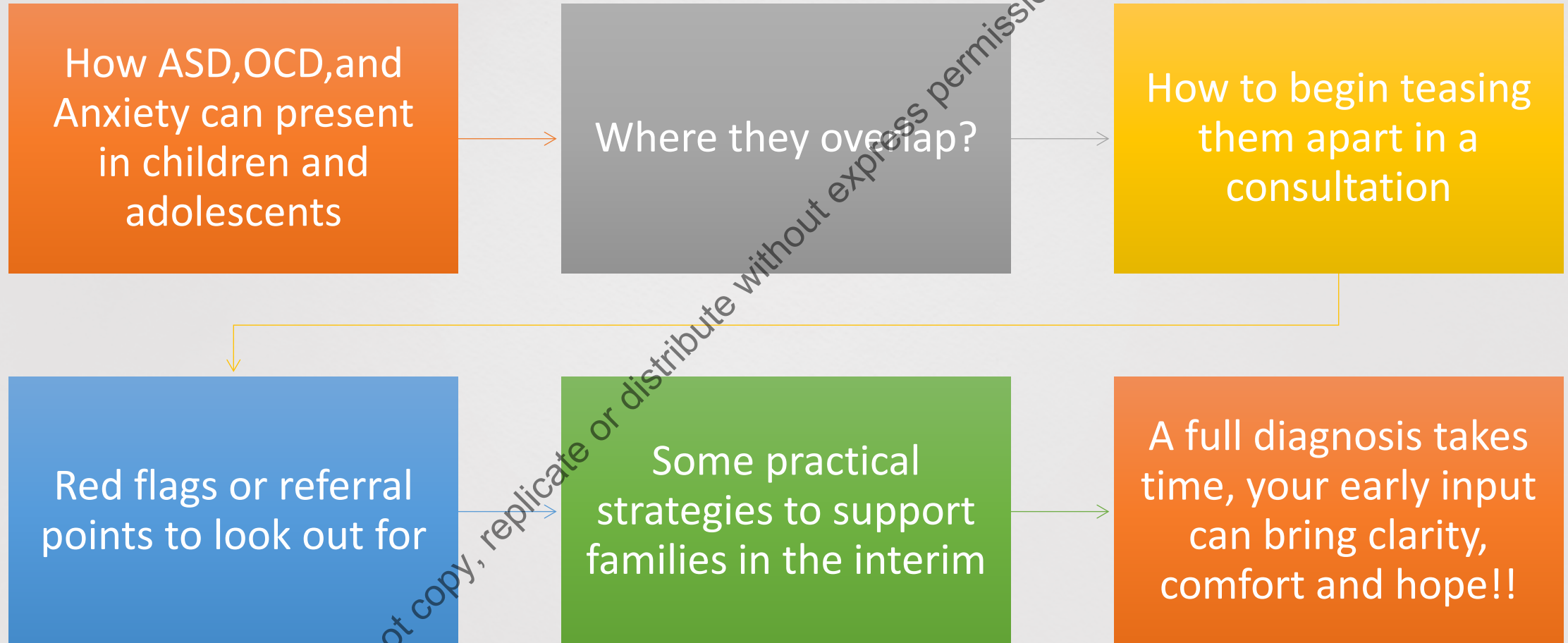
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WHERE DO WE BEGIN?

- This case captures the **grey zones** we often work in:
 - Is Siphho anxious?
 - On the spectrum,
 - Struggling with obsessive-compulsive behaviours
 - Or All of the above?
 - How do we **assess holistically**, decide when to refer, and offer the family some clarity and support while they wait?

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WHAT WILL WE UNPACK?



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UNDERSTANDING AUTISM SPECTRUM DISORDER

- A **neurodevelopmental condition** that affects communication, social interaction, and behaviour.
- It is **spectrum-based**—presentation varies widely in severity, strengths, and challenges.
- **Core Features (DSM-5):**
- **Persistent social communication and interaction difficulties**
- Trouble with back-and-forth conversation
- Difficulty understanding social cues and nonverbal communication
- Struggles with developing, maintaining, and understanding relationships
- **Restricted, repetitive patterns of behaviour or interests**
- Repetitive movements or speech
- Inflexibility with routines
- Intense, focused interests
- Sensory sensitivities (e.g. sound, textures, smells)

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KEY MESSAGES TO CONSIDER

- **ASD is not caused by poor parenting or trauma**
- **Girls and high-functioning children** are often underdiagnosed due to masking and compensatory strategies
- **Comorbidities are common:** anxiety, ADHD, OCD, learning difficulties\
- Early identification and **referral for multidisciplinary assessment** can improve long-term outcomes
- South African Context:
 - Many children remain undiagnosed or misdiagnosed due to limited access to specialists, stigma, and cultural factors
 - GPs play a **critical role in screening, supporting families, and coordinating care**

'When you've met one child with autism, you've met one child with autism'

Dr Stephen Shore

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UNDERSTANDING THE OVERLAP BETWEEN ASD, OCD AND ANXIETY



These conditions often co-occur and share features:

- Rigid thinking
- Repetitive behaviours
- Distress with change
- Social withdrawal
- Emotional Dysregulation



Differentiating between them can be difficult- especially in primary care settings

PREVALENCE

Autism Spectrum disorder:

- 1-2% globally.
- Under-identified in South Africa, especially among girls and black children

Obsessive Compulsive disorder:

- Affects 1-3% of children worldwide,
- Often presents with anxiety, secrecy and shame

Anxiety disorders:

- Among the most common in children and adolescents
- South African Studies estimate prevalence as high as 22%

SA Context:

- Limited access to child mental health specialists-rural and underserved areas
- Stigma and cultural interpretations of behaviour and under-recognition delay diagnosis and care

FOOD FOR THOUGHT

'When a child presents with anxiety, rigidity or social withdrawal, think beyond labels-consider what the behaviour is trying to communicate'



'WHEN SILENCE SPEAKS'

'Understanding anxiety in children
with ASD'

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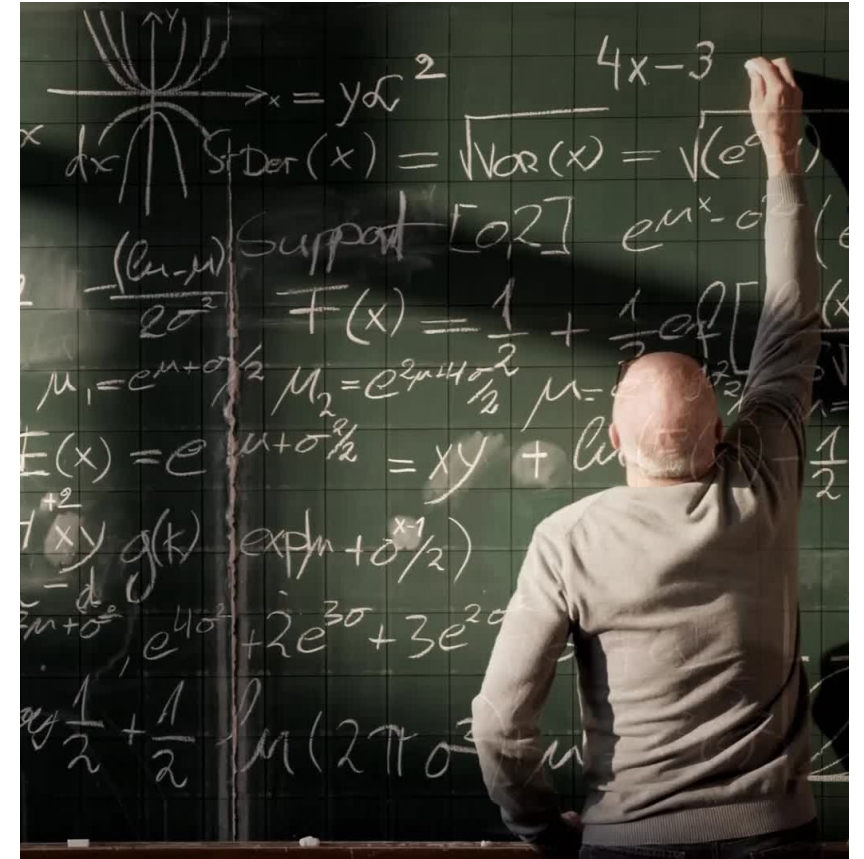
ANXIETY IN ASD: 'THE SILENT STRUGGLE'

- Key points on atypical anxiety in ASD
- **Different Manifestations:**
- **Meltdowns instead of classic panic attacks:** Children with ASD may show sudden behavioural outbursts (tantrums) when overwhelmed rather than verbalizing fear or panic.
- **Sensory Overload:** Anxiety can be triggered by overstimulation—loud noises, bright lights, or crowded spaces—which may not be as prominent in non-ASD anxiety disorders.
- **Rigid Routines:** A strong need for sameness and predictability often masks underlying anxiety; when routines are disrupted, the response can be intense. (often labelled as oppositional defiant etc)
- **Social Withdrawal:** Instead of overt social anxiety, some children may retreat further into solitary activities due to difficulty navigating social nuances.
- **Somatic Complaints:** Complaints like stomach aches or headaches may be expressions of anxiety that do not fit the typical anxiety narrative.
- **Emotional Expression:**
- Some children may not be able to articulate feelings of anxiety verbally; instead, they express distress through behaviour (e.g., repetitive movements, self-injurious behaviour).
- **Overlap with ASD Traits:**
- The behaviours associated with anxiety (e.g., insistence on routines, avoidance of certain stimuli) may be mistaken as inherent features of ASD rather than an additional co-occurring anxiety disorder.
- **Key differentiator:** Anxiety in ASD is often triggered by **change, unpredictability, and sensory overload.**

CASE STUDY 1: THANDI'S STORY

Background:

- *Thandi, 9 years old, diagnosed with ASD.*
- Known for her love of art and meticulous attention to detail.
- **Presentation:**
- Thandi becomes visibly distressed when her classroom routine is unexpectedly changed.
- Instead of expressing verbal concerns, she becomes non-verbal and retreats to a quiet corner, which teachers initially interpreted as defiance.
- **Intervention:**
- After a careful evaluation it was determined that her reaction was driven by anxiety related to change and sensory overload.
- Implementation of a visual schedule and advance warning about changes led to a reduction in episodes.
- **Outcome:**
- Thandi's anxiety decreased with these adjustments, emphasizing the need for structured transitions and clear communication.





CASE STUDY 2: THABO'S EXPERIENCE

- *Thabo, 10 years old:* Diagnosed with ASD, labelled as “difficult” in school.
 - Struggles with **loud environments, changes in routine.**
 - Appears **rigid and resistant** but is actually **anxious and overwhelmed.**
 - **Misdiagnosed with oppositional defiant behaviour disorder.**
 - **Your role:** Recognize anxiety-driven behaviours and recommend accommodations.
-

STATISTICS AND DATA ON ANXIETY IN ASD: SOUTH AFRICAN FOCUS

WHAT DOES THE DATA SHOW:

- **Prevalence Estimates:**

- International studies suggest that approximately 40-50% of autistic individuals experience significant anxiety, local South African research indicates similar trends.
- Preliminary studies in urban centres like Johannesburg report that **up to 45%** of children with ASD also exhibit clinically significant anxiety symptoms.

- **Under-Recognition in Primary Care:**

- Surveys among South African GPs reveal that **nearly 60%** feel under-equipped to differentiate between ASD-related behaviours and anxiety symptoms, underlining the importance of education and training in this area.
- Recent research (e.g., from the University of Cape Town and Stellenbosch University collaborations) emphasizes that **sensory and routine-related triggers** are frequently reported by caregivers as primary sources of anxiety in autistic children.

- **Impact on Daily Functioning:**

- Data from local mental health clinics indicate that children with ASD and co-occurring anxiety are **twice as likely** to require emergency behavioural interventions compared to those without significant anxiety symptoms.
- These statistics reinforce the need for early recognition and tailored interventions to prevent crisis situations.

IMPLICATIONS FOR GP's

- **Early Identification:**
- Be alert for signs of atypical anxiety in autistic patients, such as increased rigidity, sensory overload, and non-verbal distress.
- **Tailored Interventions:**
- Use structured communication strategies, environmental adaptations, and clear routines
- **Referral Pathways:**
- Collaborate with specialists and occupational therapists to address the multifaceted nature of anxiety in ASD.
- **Local Resources:**
- Leverage local support networks and recent research from South African universities to stay updated on best practices.

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OCD OR ASD?

‘When repetition speaks different languages’



OVERVIEW

- Obsessive compulsive disorder can co-occur with ASD, often under-recognized
- In ASD, repetitive behaviours are typically comforting and routine-driven
- In OCD, compulsions are distressing, fear-driven, and performed to reduce anxiety
- Key Challenges:
 - Differentiating comfort from compulsion-difficult
 - Children with both conditions may present with high levels of rigidity, anxiety and resistance to change
 - OCD in children with ASD- less stereotypical, and insight may be reduced compared to neurotypical peers

WHY IT MATTERS?

Untreated OCD can significantly :

- impact functioning,
- exacerbate anxiety and
- worsen behavioural outbursts

Early recognition and targeted treatment can lead to improvements in quality of life

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OCD vs REPETITIVE BEHAVIOURS IN ASD: HOW TO TELL THE DIFFERENCE?

- Both OCD and ASD can involve repetitive behaviours
- The underlying drivers
- Emotional responses and
- Functional meanings of these behaviours are very different
- Differentiating between them is crucial for:
 - Accurate diagnosis
 - Treatment



CLINICAL CLUES IN PRACTICE

Ask about	<p>Ask about the purpose of the behaviour</p> <ul style="list-style-type: none">• What happens if you don't do it?• OCD-fear of something bad happening.• ASD-distress or discomfort not always easily explained
Observe	<p>Observe affect and resistance:</p> <ul style="list-style-type: none">• OCD children often feel frustrated and ashamed of their compulsions• ASD children often resist interruption of their routines but aren't ashamed of them
Look	<p>Look for co-occurring symptoms</p> <ul style="list-style-type: none">• If the child also has social and communication difficulties, sensory issues or developmental concerns- suggest ASD

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IMPORTANT TO NOTE:



Some children with ASD also have OCD:
makes assessment more complex



OCD is treatable with CBT and SSRI's, while
ASD requires a MDT development approach



Early referral for neurodevelopmental or
psychiatric assessment is key



'Behaviour is communication- look deeper
than the surface'

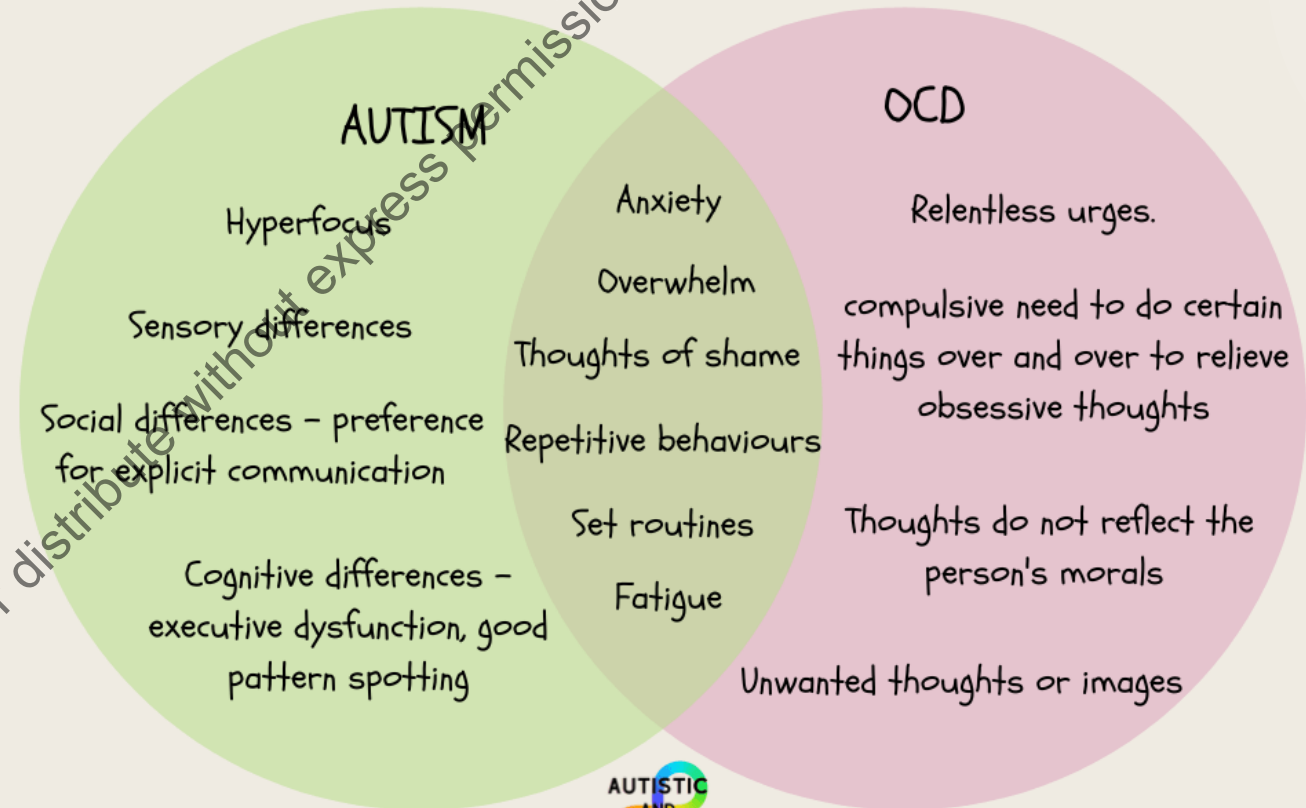
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KEY DIFFERENCES

Feature	OCD	ASD
Purpose of Behaviour	Reduce anxiety from intrusive thoughts (e.g. harm, contamination)	Self-soothing, sensory regulation, enjoyment, or routine
Emotional Experience	Distressing and unwanted (ego-dystonic)	Comforting and preferred (ego-syntonic)
Insight	Often aware it's irrational and feels ashamed	Limited or no awareness that behaviour is unusual
Flexibility	Rigid, rule-bound; fear if not performed	Rigid, but more about predictability than preventing danger
Reaction to Disruption	Anxiety and fear of harm	Distress, sensory overload, emotional dysregulation
Associated Features	High anxiety, reassurance-seeking, fear-driven thoughts	Social communication issues, sensory sensitivities, narrow interests

ASD VS ANXIETY VS OCD

AUTISM AND OCD



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‘Not all repetition is created equal. In autism, it soothes. In OCD it torments’

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CASE VIGNETTE

- *Musa is a 9-year-old boy with a diagnosis of autism. His teacher notices he gets extremely upset if the desks are not arranged in straight rows. He also taps each corner of his desk before starting work. When asked why, he says, "Something bad will happen if I don't."*
- **Discussion Points**
- Is this more consistent with **ASD ritual** or **OCD compulsion**?
- What questions would you ask to clarify?

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CHALLENGES IN THE SOUTH AFRICAN CONTEXT

- **Underdiagnosis of both conditions due to:**

Limited specialist availability

Cultural perceptions of behaviour (e.g., “naughty” or “disobedient” vs. neurodivergent)

Language barriers impacting symptom expression

Diagnostic overshadowing:

Once ASD is diagnosed, new concerns (e.g., handwashing or checking) may be wrongly attributed to autism, delaying OCD treatment

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WHAT CAN YOU DO?

1. Be Curious About the Function: Ask:

- “Why do you do that?”
- “How do you feel if you don’t do it?”
- “What happens in your body or mind when you stop?”

2. Use Screening Tools:

- *CY-BOCS* (*Children’s Yale-Brown Obsessive Compulsive Scale*) for OCD
- *SCQ* (*Social Communication Questionnaire*) for ASD
- Consider dual referral to paediatrics and mental health if uncertain

3. Treat What You See:

- Don’t “wait and see” if distress is high
- OCD often responds well to **CBT and low-dose SSRIs**
- ASD requires a **developmental, multidisciplinary approach**

4. Support Families:

- Explain the difference between comfort-seeking and fear-based behaviours
- Use language that respects cultural beliefs and builds trust in mental health services

MANAGEMENT STRATEGIES

- **Screening and Identification**
- Use tools like AQ-10 (Autism Spectrum Quotient) and GAD-7 (Anxiety Scale) or SCARED scale
- Ask parents and teachers about behaviour patterns.
- **Non-Pharmacological Management**
- Support sensory needs (ear defenders, visual schedules, movement breaks).
- Cognitive Behavioural Therapy (CBT) modifications – more visual, structured, and direct.
- Routine and predictability – key interventions for reducing anxiety.
- **Pharmacological Considerations**
- SSRIs (e.g. fluoxetine) cautiously for anxiety or OCD (start low, go slow).
- Avoid benzodiazepines due to risk of paradoxical agitation.
- **When to Refer**
- *Diagnostic clarification:* If unsure about ASD vs. OCD vs. anxiety.
- *Severe distress or impairment:* When anxiety or OCD disrupts functioning.
- *Lack of response to first-line interventions.*
- *Speech, OT, or behavioural therapy needs.*

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SUMMARY AND KEY TAKEAWAYS

Autism is a different neurotype, not a disorder to “fix.”

Anxiety in ASD can present atypically –
meltdowns, avoidance, perfectionism.

OCD and ASD-related repetitive behaviours are
different – consider intent and distress levels.

GPs play a crucial role in early identification,
reassurance, and referral.

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CONCLUSION: UNIQUE NOT BROKEN

Children with ASD, OCD, and anxiety experience the world through a different lens—not a lesser one.

Our role as clinicians is not to “fix” them, but to understand, support, and empower them.

Early recognition, empathy, and appropriate interventions can change the trajectory of a child’s life.

“Children are not things to be moulded, but people to be unfolded.” – Jess Lair

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FROM LABELS TO LIVES: BRIDGING THE GAP BETWEEN DIAGNOSIS AND DAILY LIFE

'The moment we choose to listen, truly listen, we begin to heal more than the child, we begin to heal the system'

- This guiding principle reminds us that our work goes beyond identifying conditions or managing symptoms.
- When we pause long enough to hear the story beneath the behaviour:
 - the anxiety behind the silence
 - the fear within the repetition
 - the need beneath the rigidity
 - we begin to practice medicine that is not only informed, but deeply human.

Let this be our lens as we navigate the intersection of Autism, OCD and Anxiety:

- Curiosity before judgement
- Connection before correction
- Listening before labelling

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“Are we nearly there yet?”

THE END

QUESTIONS?????