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Introductions

- Maya Matheis, PhD, MSW
 - Clinical psychologist
 - Specialization in assessment of neurodevelopmental disorders and mental health treatment for neurodivergent individuals across the lifespan
- Jessica McCullum
 - Founder of Autism Moms of Kona
 - Mother of a child with both ASD and OCD



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Today's Agenda



- Conceptualizing OCD & ASD
- Similarities & differences
- Diagnostic considerations
- Treatment considerations
- Resources



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Conceptualizing OCD



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Defining OCD and ASD

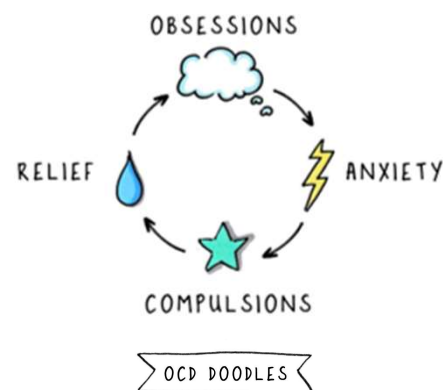
- **Obsessive-Compulsive Disorder (OCD):** Intrusive thoughts (obsessions) and repetitive behaviors (compulsions) to reduce anxiety. Causes significant distress.
- **Autism Spectrum Disorder (ASD):** Neurodevelopmental condition marked by social communication challenges and repetitive behaviors. Highly variable presentation.



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OCD

- Obsessions: Intrusive, unwanted thoughts/images/urges that cause distress and anxiety.
- Compulsions: Repetitive behaviors or mental acts performed to reduce anxiety related to the obsessions.
- **Key to OCD: The compulsive behavior is linked to an internal fear or obsession.**



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Common Types of OCD Obsessions

- Contamination fears
- Harm or violence
- Symmetry or "just right"
- Religious or moral
- Sexual or inappropriate thoughts
- Health anxieties



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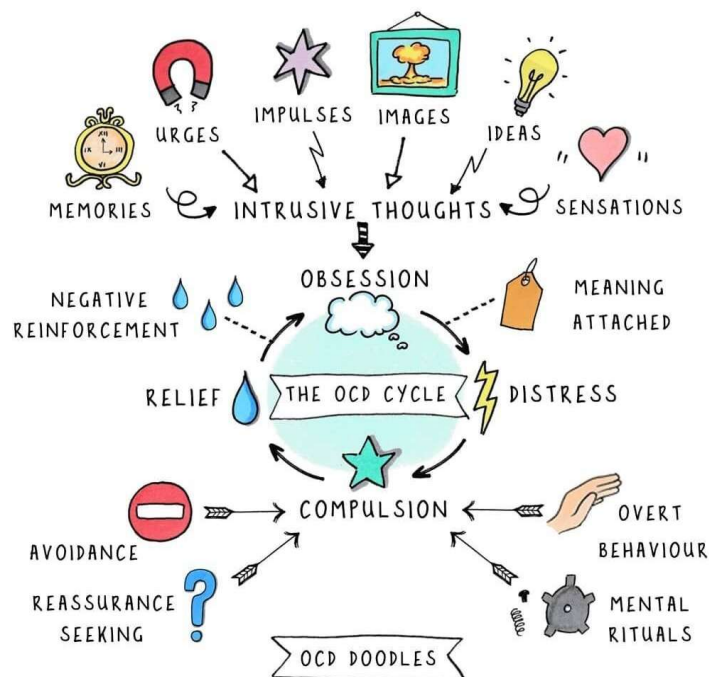
Common Types of OCD Compulsions

- Cleaning and washing
- Checking
- Repeating actions
- Arranging and ordering
- Mental compulsions
- Seeking reassurance



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The OCD Cycle



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Prevalence and Rates of Co-Occurrence

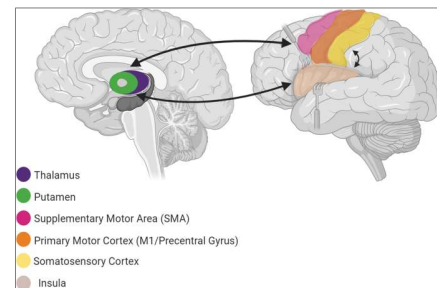
- Approximately 2.3% of individuals have OCD.
- Between 17-37% of individuals with ASD are estimated to experience OCD symptoms.
- People with OCD have a fourfold increased risk of also being diagnosed with ASD.

(Ivarsson et al., 2015; NIMH, 2022)

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Shared Neurology of ASD and OCD

- **Neural pathways:** Both involve higher activity in the cortico-striatal-thalamo-cortical (CSTC) circuit.
 - Regulates cognitive control, motor output, and behavioral flexibility.
- **Neurotransmitters:** Both conditions show dysregulation in serotonergic and glutamatergic systems.
 - Serotonin regulates mood, anxiety, sleep
 - Glutamate regulates learning and memory



(Carlisi et al., 2017; O’Loghlen et al., 2024)



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Similarities & Differences



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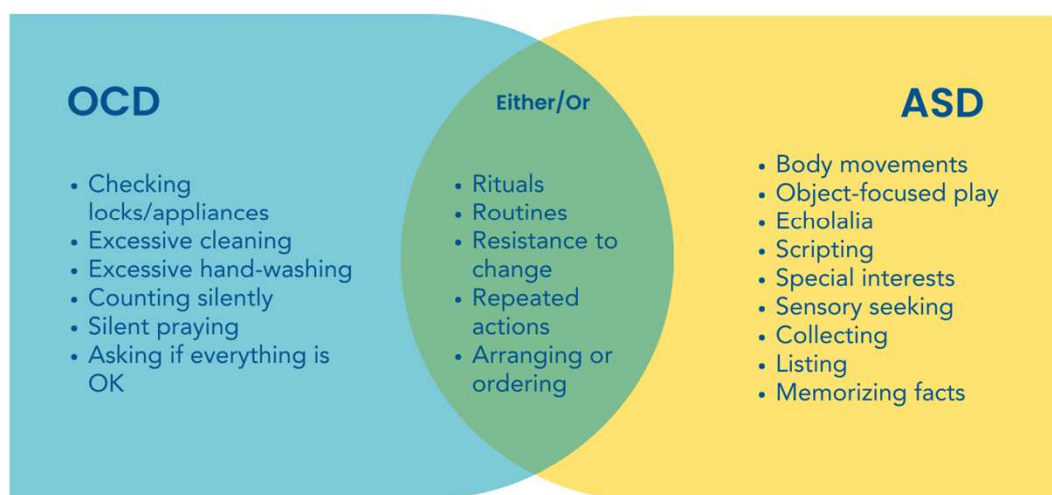
Similarities Between OCD and ASD

- Individuals with either condition might struggle with social interactions.
- Both may exhibit repetitive behaviors and a need for routine.



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Overlap in Repetitive Behaviors



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ASD vs. OCD: Repetitive Behavior Comparison

	ASD	OCD
Purpose	Self-soothing, sensory input, enjoyment	Reduce anxiety from obsessive thoughts
Emotion	Calm or regulated afterwards; only distressing if interrupted or stopped	Emotional distress before the behavior; highly distressing if not "completed"
Trigger	Sensory environment, internal state, interests	Intrusive thought or image
Insight	Limited concern about behavior	Often recognizes excessiveness



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Defining Ava's Needs



We learned early on about restrictive and repetitive behaviors, but it took a while to understand and differentiate the function of the behavior.

Reducing Distress



- Neutralizing fear - Tapping her seatbelt
- Opening and closing the car door
- Tapping her plate and interoception with hunger cues
- Salivation when she's distressed for sensory control
- Elopement and opening / closing doors

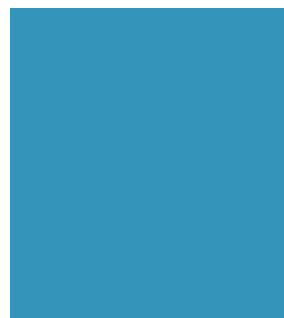
Repetition that is **Comforting, Enjoyable** or **Regulating** from a Sensory Perspective

- Stimming Behavior - teeth tapping, rocking, or "counting her rice"
- Proprioception and Water - plugging sinks
- Organizing by color
- Playing with balloons or figurines



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Diagnostic Considerations



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Diagnostic Considerations

- Differentiating OCD and ASD is crucial due to the need to determine best supports and the need for intervention.
 - Difficult due to the overlap in repetitive behaviors.
 - Risk of 'diagnostic overshadowing' where one diagnosis masks the other.
 - Comprehensive assessments are needed for accurate diagnosis.
- (International OCD Foundation, 2023)



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OCD in Non-Speaking Individuals

- OCD symptoms may be hard to detect without verbal expression.
- Behaviors may be misinterpreted as ASD-related repetitive behavior.
- Behavioral cues and caregiver input are essential for identifying obsessions.

(Scahill et al., 2016; van Steensel et al.; 2011)



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Ava is Non-Speaking

Did you know? People with profound autism often experience stigma due to their disabilities, which in turn creates barriers to social inclusion and quality of care.

- Why we say she is non-speaking vs. Non-verbal
- The importance of presuming competence
- A flood of OCD and Stimming
- Non-verbal Communication and Validating Expressive Communication
- She deserves human connection



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Assessment

- Use behavioral patterns data and caregiver input in addition to self-report to answer these questions:
 - Are intrusive thoughts/images causing distress?
 - Is there emotional distress linked to specific triggers?
 - Are there any illogical beliefs related to the behavior?
 - Do the repetitive behaviors present as urgent rituals?
 - Do the behaviors appear enjoyable, calming, or sensory-driven?
 - What happens if the behavior is interrupted?
 - How interfering is the behavior in daily living?



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Patterns That Suggest a Behavior Is Linked to an Obsession

- Preceding anxiety or visible distress before the behavior begins
- Avoidance of specific triggers and frequent reassurance seeking
- The behavior does not appear to be enjoyable or entertaining
- The individual tries to resist or hide the behavior



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Stigma in Mental Health Diagnoses

- Individuals with multiple diagnoses may face compounded stigma.
- Stigma can delay treatment and worsen mental health outcomes.
- We must promote understanding and reduce stigma related to mental health.

(Turnock et al., 2022)



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The Power of Empathy & Compassion

Empathy is the ability to understand and share the feelings, thoughts, or experiences of another person. It involves both recognizing what someone else is going through and emotionally connecting with their experience.

Compassion is the emotional response of caring for someone who is suffering, combined with a desire to help alleviate that suffering. It goes beyond empathy by not just feeling or understanding another's pain, but also being *motivated to take action* to relieve it.

Indigenous cultures saw mental illness as an imbalance—not a disorder. Isolation was never used, like in modern psychology. They used community, ritual, & nature to heal. Maybe the 'primitive' ones weren't them, but us.

Dr. Nicole LePerra

WILD WOMAN SISTERHOOD



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The Journey is a Voyage

"For some, people can ask you questions and you can answer them. For others, they can't talk so it's up to us to answer the questions to help them. The best way to do this is to understand their behavior so you know how to help them. Ava can grow as fast or as slow as she likes, but it's important for her to see the things that she likes, that brings her joy, and that ends up with self love."

- Rodeo Denis, 17-year-old self advocate

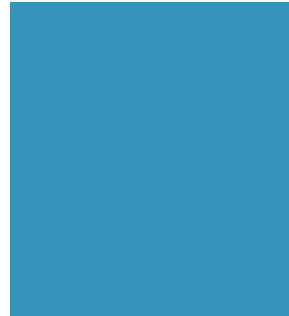


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Case Examples



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Case Example #1

- **Liam**, a 7-year-old boy, has difficulty with peer interactions and frequent meltdowns during transitions at school.
 - He is highly verbal but tends to monologue about his interests (airplanes) without responding to social cues.
 - Liam lines up toys at home, insists on eating with the same plate and spoon daily, and becomes distressed when routines change.
 - He does not report any internal distress or fears related to his routines.
 - His repetitive behaviors appear calming and sensory-driven.



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Case Example #2

- **Jasmine**, a 12-year-old girl, presents with increasing anxiety, taking over an hour to leave the house each morning due to repeated checking of doors, light switches, and her backpack.
 - She reports intense fears of "something bad happening" if she doesn't complete these rituals "just right."
 - She is aware the fears are irrational but feels unable to stop.
 - There are no signs of social communication difficulties or sensory sensitivities.



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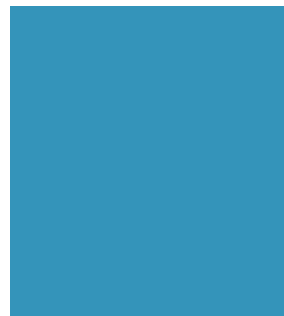
Case Example #3

- **Koa** is a 10-year-old child referred for evaluation due to difficulties with communication and escalating distress at school.
 - Koa has some words but mostly communicates with an AAC device.
 - Each morning, he insists on tapping the four corners of the classroom in a specific sequence before sitting down. If this routine is interrupted, he becomes extremely agitated, screams, and attempts to start the sequence over from the beginning.
 - Parents report that his rituals have become increasingly rigid and disruptive at home and school.
 - He also lines up toys while playing and flaps his hands when excited.



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Treatment Considerations



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How We Help Ava - Finding Balance

- Understanding the Function of the Behavior
- The Importance of a Multi-Disciplinary Approach
- Ava's story of shifting stimming to compliance
- Burnout and Masking presenting as OCD Behaviors



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EBPs for OCD

- Cognitive behavioral therapy (CBT)
 - Across age groups
 - Focus on challenging unhelpful thoughts and behaviors
 - Requires verbal skills
- Exposure and Response Prevention (ERP)
 - Often part of CBT but can be done with ABA or alone
 - Gradual exposure to feared situations while resisting compulsions
- Applied Behavior Analysis (ABA)
 - ERP, gradual exposure, differential reinforcement, token economies, etc.

(McGuire et al., 2015; Neil et al., 2014)



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Treatment Adaptations for Co-Occurring OCD and ASD


- CBT may be less effective without modifications for comorbid ASD.
- Incorporate special interests and use visual supports.
- Use concrete language.
- Collaborative, team-based care models are recommended.

(Flygare et al., 2020)



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Psychopharmacology: SSRIs

-  SSRIs (e.g., fluoxetine, sertraline, fluvoxamine) are first-line medications for OCD.
- They increase serotonin availability in the brain, which helps regulate mood and reduce obsessive thoughts and compulsions.
- Research shows modest efficacy in children and adolescents with ASD and co-occurring OCD symptoms, but more side-effects than in typically developing children.
- Recommendation is to start at low doses and monitor closely for side effects.

(Nanjappa et al., 2022)



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Key Components for Quality Care

Accommodation

Safety

Security



Well-Being

Regulation

Consistency





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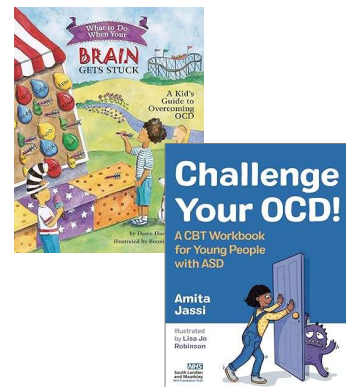
Resources



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Resources for Families

-  What to do When Your: Brain Gets Stuck
 - CBT workbook for children with OCD
-  Challenge Your OCD!
 - CBT workbook for teens and young adults with OCD



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Autism Moms of Kona

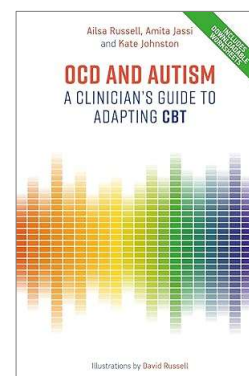
- Support Groups, Therapeutic Alternatives, and Community Advocacy - Hilo and Kona
- www.AutismMomsofKona.com
- Jessica McCullum - 808-937-9008
- Jessica@AutismMomsofKona.com



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Resources for Providers

-  International OCD Foundation (IOCDF):
www.iocdf.org
 - On-demand trainings and webinars on OCD
-  OCD and Autism: A Clinician's Guide to Adapting CBT
 - By Russell, Jassi, & Johnston



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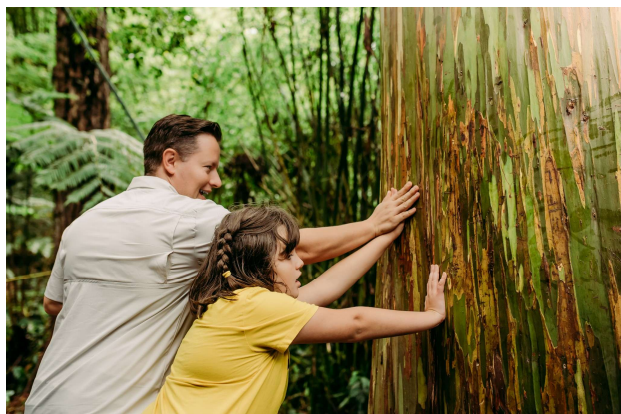
What can you do?

- Advocate for increased awareness of ASD among mental health practitioners.
- Advocate for improved mental health understanding among ASD service providers.
- Promote integrated, individualized treatment approaches.



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Our Vision for Ava's Future



- Improved Access and Quality Care
- Less Silos - Multi-disciplinary service provision with sustainability and continual improvement
- Cultural Perpetuation and Research & Neuroscience behind Cultural Practices
- An intentional living community that is culturally relevant and available to the public



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