

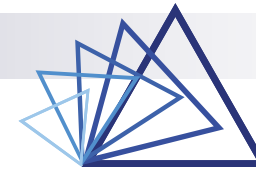
# OCD and Anxiety Disorders in Individuals with Down Syndrome

## Risk Factors, Interventions and Family Supports

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[www.cbtassociates.com](http://www.cbtassociates.com)



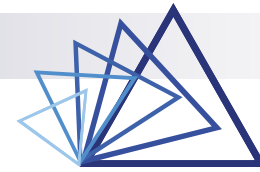
# Objectives

- Learn why individuals with Down Syndrome are at increased risk for Obsessive-Compulsive Disorder (OCD) and other Anxiety Disorders throughout development.
- Understand ways in which cognitive-behavioral treatments (CBT) can be effective for individuals to use on their own and with support by family members and care providers.



# Outline

- Well-being and *good* mental health
- Understanding Anxiety Disorders and OCD
  - Diagnostic criteria
- Next steps
  - Prevention, assessment and treatment options
- Discussion and questions



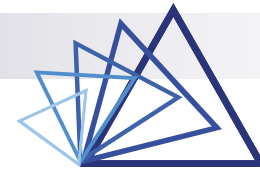
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# WELL-BEING AND GOOD MENTAL HEALTH



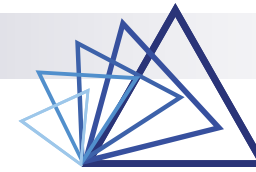
# What is Mental Health?

- Mental health conditions/problems vs. “good mental health”
- World Health Organization (WHO):
  - *“a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully and is able to make a contribution to his or her community.”*



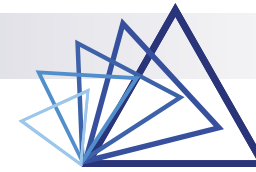
# Mental Health and Down Syndrome (DS)

- In the past, mental health conditions in people with DS were often disregarded as part of the “diagnosis”
- Currently, about 50% of children and adults with DS experience some mental health concern in their lifetime and additional vulnerabilities are known



# Well-Being and Mental Health Development

- **Normal vs. Abnormal Behavior**
  - Importance of knowing usual vs. unusual behaviour on a continuum
- **Additional Considerations**
  - Developmental age and cognitive capacities
  - Language skills and delays
  - Environmental stressors and experiences



## Mental Health (Problems)

### Internalizing Disorders

“Over Control”

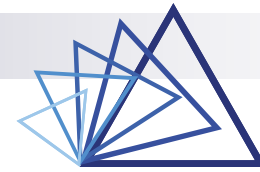
- Anxiety
- Depression
- Social Withdrawal

### Externalizing Disorders

“Under Control”

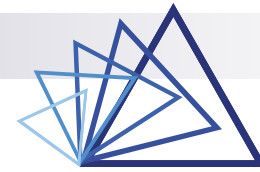
- ADHD
- Conduct Disorders
- Delinquent Behaviour





# Vulnerabilities for Poor Mental Health

- Multiple medical problems lead to higher rates of mental health problems
- Most common mental health concerns include:
  - General anxiety, repetitive and obsessive-compulsive behaviors
  - Oppositional, impulsive, and inattentive behaviors
  - Sleep related difficulties
  - Depression
  - Autism spectrum conditions
  - Neuropsychological problems characterized by progressive loss of cognitive skills

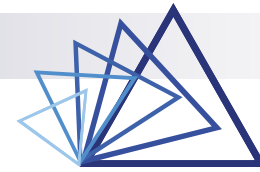


# Vulnerabilities for Poor Mental Health

- Differences in language and communication, cognition leads to different risks for:
  - Young and early school-aged children
    - E.g., Disruptive and impulsive disorders
  - Older school-aged children, adolescents and young adults
    - E.g., Depression, generalized anxiety disorder
  - Older adults
    - E.g., Generalized anxiety disorder, social withdrawal

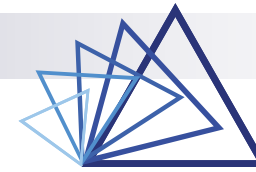


# **ANXIETY DISORDERS AND OCD (DIAGNOSIS AND CRITERIA)**



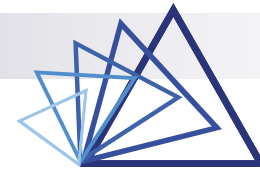
# Anxiety and Obsessive Compulsive Disorders

- **What is anxiety, fear and phobias?**
  - What are the common features?
- **What is an Anxiety Disorder?**
  - How do you identify or diagnosis an Anxiety Disorder?
- **What is a compulsion or obsession?**
  - How do you identify a Obsessive-Compulsive Disorder?



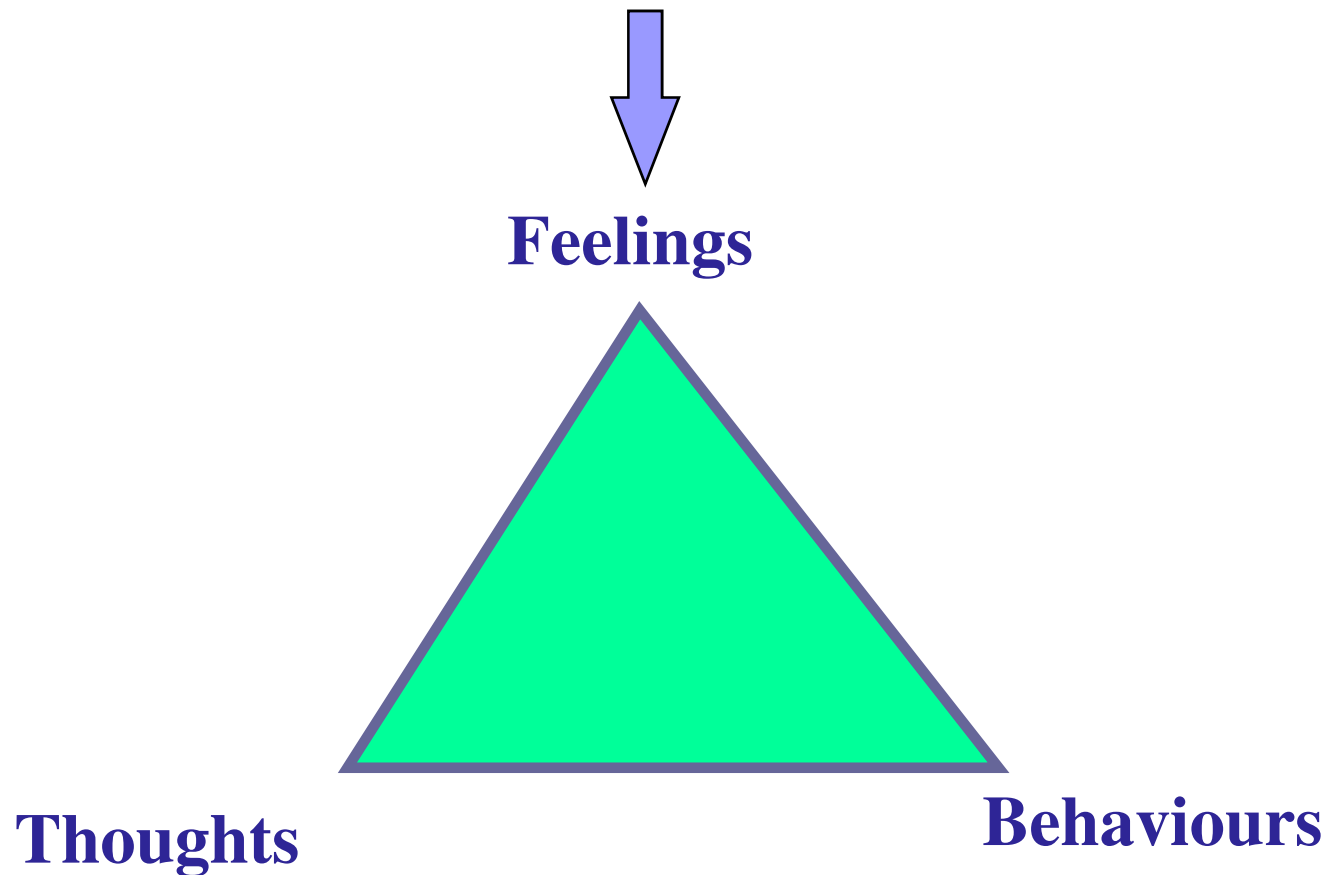
# Anxiety Features

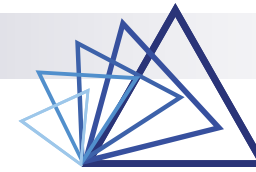
- **What is Anxiety?**
  - 3 components
    - Physical
    - Mental
    - Behavioural
  - Purpose of Anxiety = Protection
    - E.g., Walking through a dark alleyway
- **Flight, Fight, Freeze**



# Anxiety Features: Three Components of Anxiety

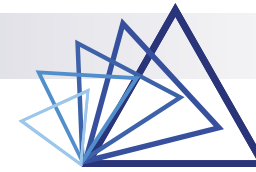
Event: Internal/External





# Anxiety Features

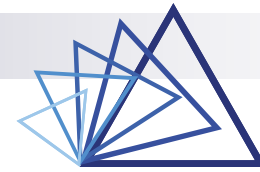
- **Fear**
  - Response to real, immediate danger
- **Anxiety**
  - Different from fear
  - Low levels can be adaptive
- **Maladaptive Anxiety**
  - High levels of diffuse negative emotion
  - Sense of uncontrollability
  - Shift in attention to state of self-preoccupation
- **Neuroses**
  - Unrealistic anxiety and associated problems



# Anxiety Disorders: Overview

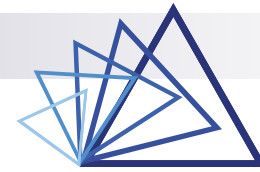
- Anxiety is a protective mechanism, but becomes a *disorder* when ongoing and interfering with day-to-day functioning
- **SP = Specific Phobia**
  - Fear of “something”
- **GAD = Generalized Anxiety Disorder**
  - Fear of “everything,” worries
- **Panic Disorder = Panic Disorder**
  - Fear of anxious symptoms
- **Agoraphobia**
  - Fear of being in certain places





# Specific Phobia: Criteria

- Such fears are quite common among very young children, are generally not debilitating, and tend to disappear as the child grows older
- Exposure to the phobic stimulus almost invariably provokes an immediate anxiety response
  - E.g., Panic Attack or panic-like symptoms



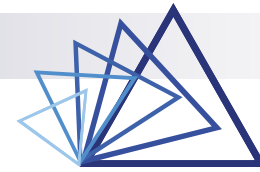
# Specific Phobia: Subtypes

- **Animal Type**
  - Animals, insects
- **Natural Environment Type**
  - Heights, storms, water
- **Blood-Injection-Injury Type**
  - Blood, needles, injuries
- **Situational Type**
  - Public transportation, elevators, tunnels
- **Other Type**
  - Open spaces?



# Generalized Anxiety Disorder: Criteria

- Characterized by excessive or unrealistic anxiety or worry over a number of issues including family matters, friendships, future activities, past performance, keeping schedules or routines, and health of self and others
- Difficult to control the worry
- Associated with “1” (or more) of:
  - restlessness or feeling keyed up or on edge
  - being easily fatigued
  - difficulty concentrating or mind going blank
  - irritability
  - muscle tension
  - sleep disturbance



## Panic Disorder: Criteria

- Anxiety without obvious threat
  - E.g., Due to “stress”
  
- We need an explanation
  - Search inward
  
- “Something must be wrong with me”



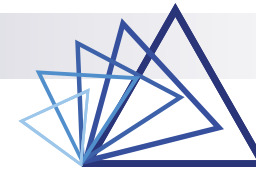
# Panic Attacks: Criteria

## **Panic Attack**

- Sudden fear or discomfort
- Peaks within 10 min.

## **4 or more of following:**

- Chest pain or other chest discomfort
- Chills or hot flashes
- Choking sensation
- Derealization
- Depersonalization
- Dizzy, lightheaded, faint or unsteady
- Fear of dying, loss of control or becoming insane
- Heart pounds, races or skips beats
- Nausea or other abdominal discomfort
- Numbness or tingling
- Sweating
- Shortness of breath or smothering sensation
- Trembling



# Panic Disorder: Criteria

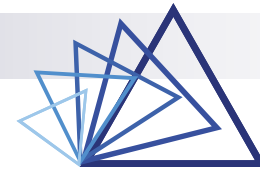
## ➤ Panic Disorder

- Recurrent panic attacks that are not expected
- For a month or more after at least 1 of these attacks, the person has had 1 or more of:
  - Ongoing concern of more attacks
  - Worry about significance/consequences
  - Significant change in behavior
- Panic Disorder with Agoraphobia
- Panic Disorder without Agoraphobia



# Agoraphobia

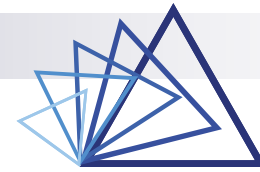
- Fear of being in certain places or situations, typically because of some previous negative experience associated with the situation/place.
- Often includes refusal to leave home due to fear or worry about going to feared situation/place



# Obsessive-Compulsive Disorder (OCD)

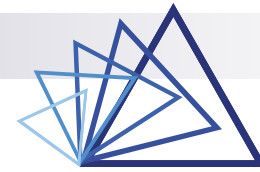
- What are repetitive behaviours and thoughts?
- What is OCD?
- How is OCD diagnosed?





# Obsessive-Compulsive Disorder (OCD)

- People with Down Syndrome and tendency for repetition and sameness
  - Beneficial (e.g., self-care, routines)
  - Problematic (e.g., stuck with thoughts, rigidity)
- Diagnosis of OCD may or may not be related to the “grooves”
- 1.5-2.3 % of population; ~6% of People with DS



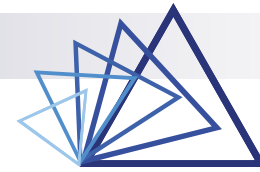
# Obsessive-Compulsive Disorder (OCD)

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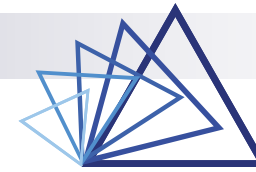
# OCD: Obsessions

- Recurrent/persistent thoughts, images, or impulses that are intrusive, inappropriate, and cause anxiety/distress
- Not simply excessive worries about real life problems
- Person attempts to ignore/suppress/neutralize them
- Person recognizes them as their own



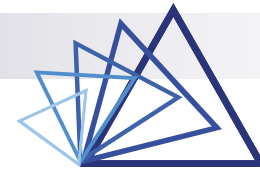
# OCD: Compulsions

- Repetitive behaviours or mental acts performed in response to an obsession or according to rigid rules
- Aimed at reducing distress or preventing a dreaded event
- Not connected in any realistic way with what they are designed to prevent
- Objectively excessive



# OCD: Criteria

- **General criteria:**
  - Presence of obsessions and compulsions
  - Significantly impact your daily life
  - You may or may not realize that your obsessions and compulsions are excessive or unreasonable
- **Obsessions must meet specific criteria, including:**
  - You may or may not know that your mind simply generates these thoughts and that they do not pose a true threat
- **Compulsions must meet specific criteria, including**
  - Take up a least one hour or more per day

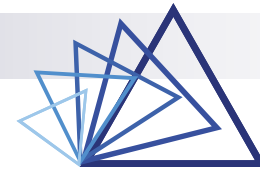


# NEXT STEPS



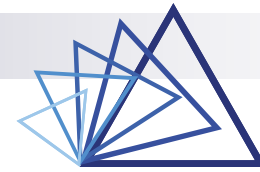
## Next Steps

- Prevention
- Assessment
- Treatment



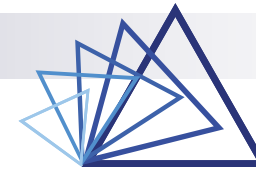
# PREVENTION





# Prevention

- Tips for Good Mental Health
- Factors that contribute to good mental health are the same for people with or without DS, include:
  - Feeling good about one's self = Self-Esteem
  - Understanding self
  - Positive role models
  - Supports and family structure,
  - Control (lack of helplessness)
  - Opportunities



# Prevention

## ➤ Healthy Self-Esteem

- Accepting who you are as a person
- Most youth at any point, struggle with self-esteem (with or without DS)

## ➤ Tips for developing Healthy Self-esteem

- Identity – simple and concrete, focus on talents and strengths and personality.
- Support person to take as much control over their own life as possible.
- Encourage friendships, independence and social interaction with people their own age.



# ASSESSMENT



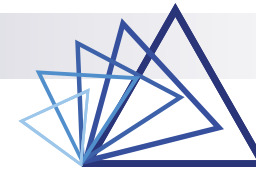
# Assessment

- In general, continued improvement of mental health concerns for children and adults
  - Diagnostic screening tools, structured assessment protocols
- Improvement in ability to assess given differences in developmental age groups, in terms of measurement of domains such as:
  - Non-verbal problem-solving abilities, language and communication and adaptive and behavioral functioning.



# Assessment

- How do you distinguish medical conditions from Anxiety Disorders?
- Rule-outs? Some examples, include:
  - Thyroid function
  - Sleep related difficulties
  - Underlying contribution of constipation or bowel related difficulties
- Caveats to treating potential “medical concerns”

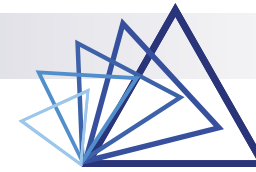


# Assessment

- Potential providers with experience in working with children and adults with developmental disorders
  - Ideal mental health provider (i.e., behavioural therapy)
  - Ideal psychiatric provider (i.e., medication)
- Balance between diagnostic criteria and knowledge of the individual's typical behaviour and level of interference in daily life
- Multiple sources of information
  - Tracking information, recording logs of behaviour etc,



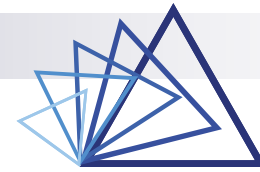
# TREATMENT



# Cognitive Behavioural Therapy (CBT) Fundamentals

- Individualized
- Time-Limited
- Educational
- Self-Directed
- Skills Training
- Contracting
- Goal Setting
- Recognizing and Controlling Cues
- Self-Talk
- Graded Exposure
- Monitored
- Evaluated
- Family involvement





# Treatment

- **Counselling and Psychoeducation**
  - Goal to express concerns and ideas
  - Understand the ABCs
    - Antecedents, behaviours and consequences
  - Involve other care providers or support workers



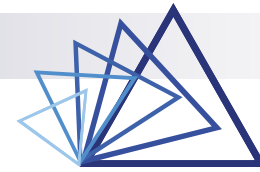
# Specific Phobia: Treatment

- Effectively treated with Behaviour Therapy
- Exposure treatment
  - Counter-conditioning: relaxation + exposure
    - Systematic desensitization
  - Anxiety Hierarchy
  - Modeling: Social learning theory
  - Rewards (natural and specific)



# Generalized Anxiety Disorder: Treatment

- Acknowledging worry as bothersome or worth addressing
- Challenging worries (when possible)
  - Coping Cards
- Attention to heightened worry (or triggers) to allow for:
  - Increased awareness and “prevention”
  - Dedicated **relaxation strategies** and time



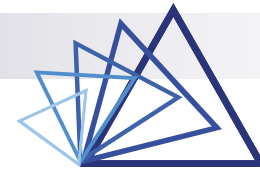
# Generalized Anxiety Disorder: Treatment

- **Relaxation Exercises**
  - Progressive Muscle Relaxation (PMR)
  - Belly Breathing (Diaphragmatic Breathing)
    - Practice, Practice, Practice!
  - Visualization (Imagery)



# Panic Disorder + Agoraphobia: Treatment

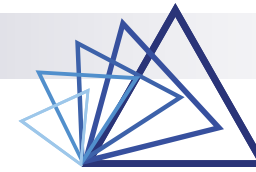
- Time, patience and “detective work” to understand situations (or locations) that cause fear in individual
  - May or may not be based on a previous experience (i.e., re-experienced trauma?)
- Risk of facing feared-situation can be reduced (when suitable or identified) or focus on desensitization



# Panic Disorder and Agoraphobia: Treatment

## ➤ Desensitization

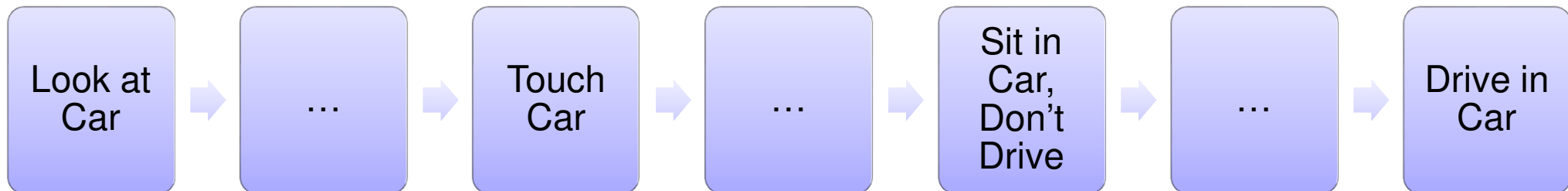
- Gradual exposure to feared situation to reduce fear by increasing tolerance

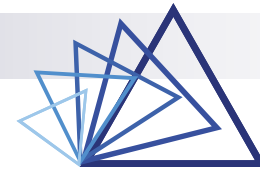


# Panic Disorder and Agoraphobia: Treatment

## ➤ Desensitization

- Replace SPIDER with RIDES IN CAR
- Daily process, repetition, lots of interim steps

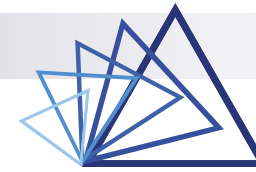




# OCD: Treatment

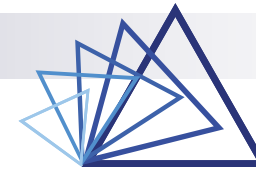
- CBT Educational Phase
- Exposure and Response Prevention
- Exposure
  - Expose the patient to the feared situation or situation that triggers the obsession or urge to ritualize (e.g. dirt, germs)
- Response Prevention
  - Prevent the patient from engaging in ritual behaviour (e.g. washing, cleaning)





## OCD: Treatment

- Understanding possible causes or precipitants (e.g., triggers, people in environment)
- Redirection (before or just after onset of a compulsion or obsession)
  - Gradually introducing a predetermined alternative activity that is rewarded
  - 1 change focus at a time



# OCD: Treatment

- **Compulsions**
  - Ordering of objects
    - Healthy “groove”?
  - Hoarding of items
    - Redirection can be challenging; focus on safety and limit setting
  - Excessive rigidity for routines
    - Incentives for alternatives until new routines are formed
- **Forming alternative ways to experience control in one’s environment and life**



# OCD: Treatment

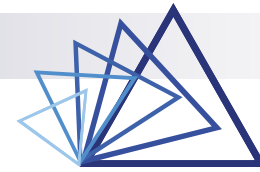
## ➤ Obsessions

- Real “people” or imagined “people” or celebrity
  - May not understand underlying reason

## ➤ Redirecting attention

- E.g., written vs. verbal form

## ➤ Appropriate medication assessment/trial

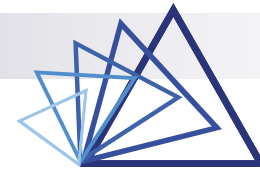


# Treatment: Practical Tips

- Focus on the positives
  - Can do vs. can't do
- Foster strengths and talents
- Opportunities to express feelings
- Support healthy lifestyle
  - i.e., exercise, diet
- Support independence and decision-making
- Remember Change is a Process

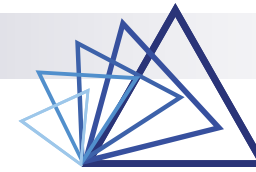


# DISCUSSION AND QUESTIONS



## Discussion and Questions

- Do you have a better understanding of how anxiety and compulsive behaviours are identified and/or diagnosed?
- Do you have a better understanding of the prevention, assessment or treatment for people with developmental disabilities?
- Questions?



## References and Resources

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