

Uncovering the Hidden Causes: Medical Screening as the First Step in Management of Interfering Behaviors

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Objectives

By the end of this session, participants will be able to

1. List three medical conditions that may manifest as interfering behaviors in individuals with intellectual and developmental disabilities (IDD)
2. Use a stepwise medical assessment approach to correctly distinguish between potential medical, psychiatric, and environmental causes of interfering behavior.
3. Identify risks associated with polypharmacy in individuals with IDD and outline one actionable strategy for medication review or monitoring that can be implemented with a provider.

**“It is health that is real wealth
and not pieces of gold and silver”**

--Mahatma Gandhi

What are Interfering Behaviors?



Interfering Behaviors aka Challenging Behaviors

- Aggression
- Attention seeking
- Sexually inappropriate
- Self-injurious
- Property destructions
- Hyperactivity
- Socially Inappropriate

Interfering Behaviors

They are not a diagnosis or diagnostic category—used to quantify the needs of an individual; information about impairment



They will vary in their presentation



They are a form of communication



It is also critically important to understand to whom is the behavior challenging?

How do health and interfering behaviors intersect?

Higher Prevalence of Health Conditions

- Gastrointestinal disorders:
 - GERD: 13-50%
 - Constipation: 20-50%
- Immune System
 - Allergies/Sinus Infections: 21-45% (Aldinger, et al., 2015; Haverman et al., 2011)
 - Asthma: 16-42% (Lyall et al., 2015; Xie et al., 2020)
- Central Nervous System
 - Epilepsy/Seizures: 14-44% (Amiet et al., 2008; Bowley & Kerr, 2000)
 - Headaches/Migraines: 11-43% (Schieve et al., 2012; Underwood et al., 2019)
 - Sleep Dysregulation: 9-53% (Richdale & Schreck, 2009; vande Wouw et al., 2012)

Associations Between Health and Interfering Behaviors (Symons & Kennedy, 2012)

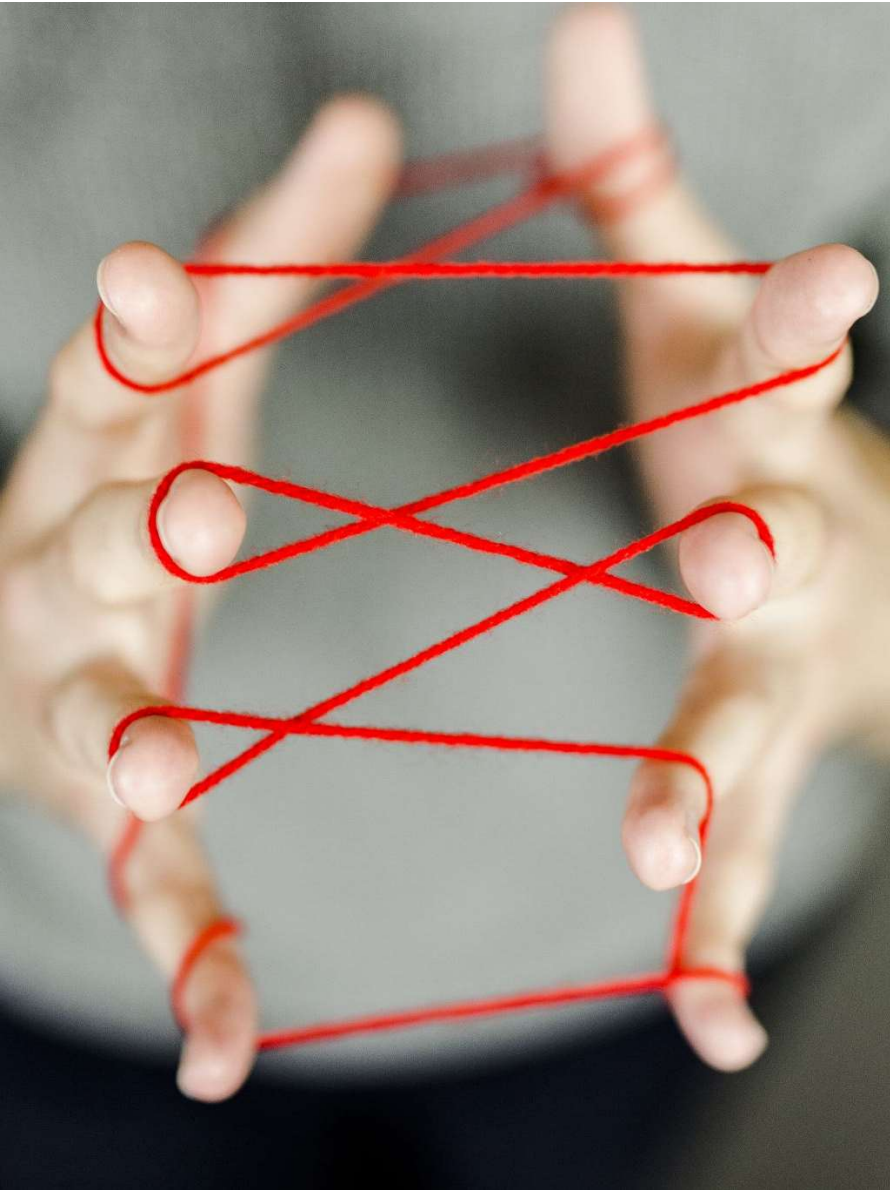
Constipation and aggression, self injury and/or property destruction (Carr & Blakeley-Smith, 2006; Christensen et al., 2009)

Sleep deprivation and challenging behavior

Seizure activity (pre and post) and aggression or self-injury

Associations Between Health and Behavior

- Many of these associations are for behaviors that are negatively reinforced: Behaviors serve as a means of avoiding or reducing events that are unpleasant to the individual
 - A woman experiencing cramps related to her menstrual cycle may be more aggressive than typical when asked to complete a work task.
 - The presence of congestion related to an allergy may make a student intolerant of classroom expectations that they would otherwise be compliant



Associations Between Health and Behavior

Pain

**But what about
behavioral health?**

Mental Health Comorbidity and IDD

About 40% of youth with ID present with a mental health problem, either diagnosed or at **diagnosable levels**.

Arriving at a MH diagnosis for youth with IDD can be challenging (!)

Mental Health Comorbidity and IDD

(Siegel et al., 2020)

- Attention Deficit Hyperactivity Disorder: 20%
- Anxiety Disorders: about 22%
- **Trauma:** 70% (90% on multiple occasions)
- Autism Spectrum: 38%
- Mood Disorders
 - Depression: Up to 8%; Bipolar Disorder: Unknown
- Impulse Control Disorder: Unknown
- Stereotypic Movement Disorders: Up to 16%

Making the Diagnosis: Oh, the Overlap!



Significantly impacts our daily functioning and quality of life.



Characterized by difficulties in thoughts, feelings and behaviors.

Prevalence: Adults

- People with ID/DD are known to have higher rates of mental health conditions compared to people without ID/DD
 - In 2016, Reichard (2019) reported 59% of Medicaid beneficiaries with IDD had at least one mental health conditions
 - Ranges 37%-45% (Scott & Havercamp, 2014; Esler et al., 2019)
 - Compared to 21 % of adults without IDD with a diagnosable mental health condition



**ADULTS WITH DISABILITIES REPORT
FREQUENT MENTAL DISTRESS
ALMOST 5 TIMES AS OFTEN AS
ADULTS WITHOUT DISABILITIES**

Screen patients for mental health concerns

Assessment of Interfering Behaviors

How to Approach Assessment of Interfering Behaviors

- ▶ Use your assessment tools (e.g., HELP)
- ▶ Remember the “why” of behavior
- ▶ Communication is key to understanding. Attempt many forms/modes of communication
 - ▶ Don't assume lack of vocal speech means a lack of understanding or ability to communicate
- ▶ Talk before touch: ask permission to touch. Tell the patient where you will touch him and how it will feel
- ▶ Always pre-teach. You don't always know what the individual does and doesn't understand. You also don't know their history
- ▶ Even when you are stressed, to the best of your ability, use calming voice tones and empathy statements

The H.E.L.P Framework



How to Approach Assessment of Interfering Behaviors

What do I need to know about this person?

- ▶ What is their home life?
- ▶ Who is important to the person?
- ▶ What are the best ways to greet and interact with this individual?
- ▶ How do I verify their understanding of the information I am giving them?
- ▶ Are they able to complete activities of daily living independently, and if not, how much support will they need?

How to Approach Assessment of Interfering Behaviors

- ▶ Don't ask me, "What's the matter?" Ask me what matters
- ▶ Assistance to navigate a very confusing/complex health care system and how to assess supports
- ▶ Reducing barriers that may be through primary healthcare providers e.g., making and attending appointments; increasing the length of time for consultation

Tools for Assessment

- ▶ Evaluate physical health sources for behaviors of concern.
 - Individuals with IDD experience pain at least as frequently as other patients (Barney et al., 2020).
 - Consider need for subspecialty evaluations, e.g. Neurology



HEALTH

People with IDD vary in their capacity to communicate to others that they are experiencing physical discomfort or are in pain. Many medical conditions present atypically in people with IDD, for example as a change in behaviour or daily functioning.

- ▶ Perform a complete review of systems, physical examination, and necessary investigations to determine whether emotional distress and concerning behaviours might be related to a medical condition or pain.



ENVIRONMENT AND SUPPORTS

People with IDD are much more dependent on their environments for safety, security, meaning and quality of life. A mismatch between a person's unique developmental needs, supports and services provided or care provider understanding and expectations, can result in behaviours that challenge. Enabling environments to meet unique needs can diminish emotional distress and eliminate concerning behaviours including behaviours that challenge.^{2,3}

- ▶ Identify and address a person's needs with input from an Occupational Therapist, Speech-Language Pathologist, Behaviour Therapist, ideally working in an interprofessional team.
- ▶ Some IDD conditions (e.g., autism) are associated with very specific needs. Consult syndrome-specific Health Watch Tables.^[iii]



LIVED EXPERIENCES

Adversity and traumatic life experiences are common in the lives of people with IDD. These might underpin ongoing emotional distress and remain unrecognized unless specifically identified.⁸ Systems interventions (e.g., trauma-informed supports) and individual treatments (e.g., psychological therapies) need to be considered.

- ▶ Identify everyday stressors and investigate a person's lived experiences.
- ▶ Seek input from a social worker or similarly trained professional experienced in trauma and the IDD population.



PSYCHIATRIC DISORDERS

A review of physical health, environments and life events, and implementation of needed interventions will diminish emotional and behavioural concerns, unless these are associated with psychiatric disorder.

- ▶ Assess remaining emotional and behavioural concerns and determine any change from baseline.
- ▶ If these changes from baseline suggest a psychiatric disorder, a diagnosis-specific intervention (e.g., medication, psychological therapies) might be tried.
- ▶ If still concerned, make a referral to a developmental disability specialty service or use.
- ▶ Using the HELP approach, consider whether previous psychiatric diagnoses are still valid and treatments are appropriate.^{2,3}

Health

- Pain?
- Elimination? Constipation?
- GERD? Malnourished
- Dental pain? Chewing problems?
- Infection?

Environmental Experiences

The healthcare environment is novel

- It's noisy, bright and sometimes very boring

Most of the people are strangers and they are very busy

- Multiple, new staff may be coming in and out of the patient's room

Lived Experience

- ▶ Where patient lives? With whom?
 - ▶ Who is his support system?
 - ▶ Who is his “caregiver” (if needed)?
 - ▶ History of hospitalizations?
 - ▶ History of medical trauma?
-
- ▶ Individual with IDD are more often exposed to potentially traumatic events than the general population
 - ▶ Sexual and physical abuse
 - ▶ Experiences within the living arrangements
 - ▶ Early separation from family Individuals

Psychiatric Disorder

- ▶ Anxiety can be a driver of “behaviors of concern” - a growing body of evidence shows many individuals with IDD experience anxiety.
- Estimated prevalence of psychiatric conditions in individuals with IDD range from 10- 39%
 - Assessing the presence of mental health is a complex process

Caution: Diagnostic Overshadowing

Problematic behavior that is a “nuisance” is not necessarily a “Psychiatric Condition”.

Attributing physical and mental health symptoms to the person's intellectual and/or developmental disability

Approaches to Prescribing Psychotropic Medications

How to begin?



Prescribing psychotropic medications in individuals with intellectual and developmental disabilities (IDD) requires:



Ethical, evidence-based, and person-centered care



A nuanced understanding of behavior and context



An interprofessional, collaborative approach

Deb, et al., 2009; Lunsky et al., 2018

We might need to know a few things before prescribing:

- Comprehensive biopsychosocial assessment
- Consider physical discomfort, environmental stressors, and communication challenges (H.E.L.P.)
- Medication is one tool among many, and often not the first



Principles of Prescribing

01

Start low, go slow, and monitor closely

02

Use clear target symptoms and measurable goals

03

Regularly review efficacy and tolerability

04

Involve caregivers and the individual when possible

Monitoring and Polypharmacy

- Monitor for side effects and atypical responses
- Limit polypharmacy
- Avoid unnecessary off-label use
- Use structured tools for medication review
- Incorporate deprescribing strategies when appropriate



Shared Decision-Making

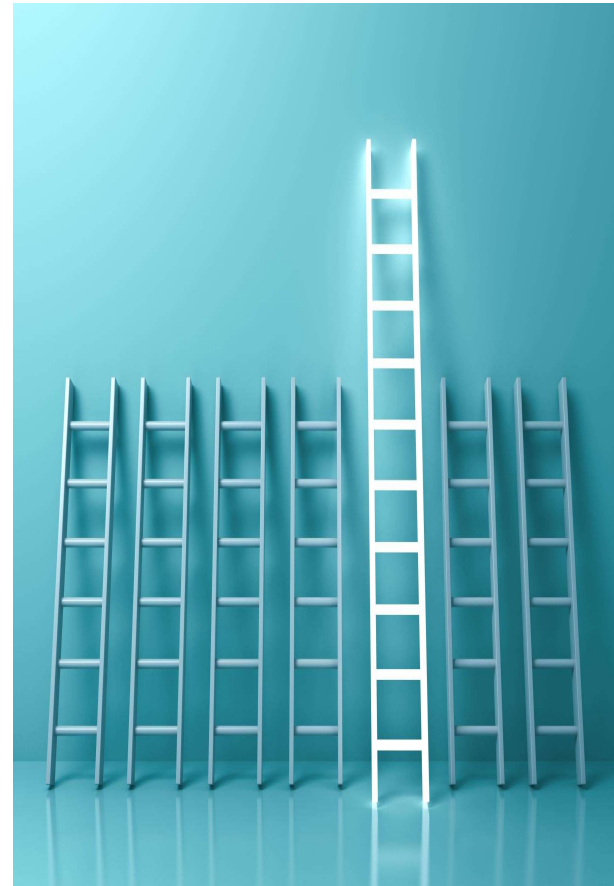
Engage families and caregivers as partners

Provide clear explanations of rationale, benefits, and risks

Informed consent is a conversation, not a checkbox

Goal of Treatment

- **Enhance quality of life**, not just reduce symptoms
- **Align** treatment with the individual's **values and goals**
- **Integrate** pharmacologic treatment **into a broader care plan**



Avoid Polypharmacy: Deprescribe

Steps	Action
What medication is the person taking? What is its purpose	Review the medication list, confirm the indication for each
Are the prescribed medications causing harm?	What is the overall risks associated with the current medication list and how might you prioritize de-prescribing
What are the risks and benefits?	Compare the benefits of the current medication list, now and in the future, against the current or future risks
Consider medications for discontinuation	Identify medications with the lowest risk-benefit ratio, minimal risk of withdrawal or symptom rebound to discontinue first
Make the changes and monitor response	Develop a tapering plan, monitor for changes, positive or negative and adjust the plan as needed

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Thank you



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