HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities

Introduction

This tool helps primary care providers and others supporting adults with intellectual and developmental disabilities (IDD) think about possible contributors when these adults present with emotional distress and behavioral concerns. Clinical presentation of mental distress in patients with IDD, while often seeming to be 'psychiatric', might turn out to be associated with undiagnosed medical conditions, unrecognized support issues, or related to past adversity and trauma.[1] This tool provides a systematic and sequential exploration of four areas relating to biopsychosocial circumstances that might underlie or be contributing to emotional distress and behaviors of concern, including distressing behaviors that risk harm*: Health, Environment, Lived Experiences, and Psychiatric Disorders (HELP). Apply this tool with careful scrutiny, repeated as necessary over time.

*Behaviors that put the patient or others at risk of harm.[2,3]

How to use this tool

When a patient with IDD presents with mental distress or behavioral concerns, follow the HELP diagnostic framework.

This tool is based on Understanding behaviours that challenge. A guide to assessment and treatment. By E. Bradley and M. Korossy, *Journal on Developmental Disabilities*, Volume 22(2): page 103, 2016.

H **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 behavior or daily functioning. ▸ Perform a complete review of systems, physical examination, and necessary testing to determine whether emotional distress and concerning behaviors might be related to a medical condition, pain, or painful or scary medical tests, procedures or treatments.
E **ENVIRONMENT AND SUPPORTS**	People with IDD are often 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 distressing behaviors. Enabling environments to meet unique needs can diminish emotional distress and eliminate concerning behaviors. [2,3] ▸ Consider whether a patient feels safe, and identify and address a person's needs with input from an occupational therapist, speech-language pathologist, behavior 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.
L **LIVED EXPERIENCES**	Adversity and traumatic life experiences are common in the lives of people with IDD. These experiences often underpin ongoing emotional distress and remain unrecognized unless specifically identified.[7] Systems interventions (e.g., trauma-informed supports, trauma-informed care providers, and individual treatments such as psychological therapies) need to be considered. ▸ Identify everyday stressors and triggers, investigate a person's lived experiences (e.g., past and current adversity or trauma) and if possible, find out whether they feel physically and psychologically safe in their present living arrangement. ▸ Seek input from a social worker or similarly trained professional experienced in trauma and the IDD population.
P **DISORDERS**	A review of physical health, environments, past traumas, and life events, and implementation of needed interventions may diminish emotional and behavioral concerns, unless these are associated with a psychiatric disorder. ▸ Assess remaining emotional and behavioral concerns and determine any change from baseline. ▸ If these changes from baseline suggest a significant change in mental health and specific psychiatric disturbance, a diagnosis-specifc intervention (e.g., medication, psychological therapies) might be offered as a trial and response carefully monitored. ▸ Using the HELP approach, consider whether previous psychiatric diagnoses are still valid and treatments are appropriate. [2,3]

Summary of Clinical Approach (HELP FORMULATION)

- Explore the four areas in the HELP approach in a systematic order, so that circumstances contributing to distressing behaviors are identified and addressed.
- Identify the most likely contributor(s) to the person's distress and consider appropriate intervention(s).
- Be attentive and engaged with patients and family/support person perspectives as concerned are being sorted out.
- Adversity and trauma are ubiquitous in the lives of people with IDD. The impact of trauma is often unrecognized.
- Advocate for resources and supports, if needed.

HELP with Emotional and Behavioral Concerns in Adults with Intellectual and Developmental Disabilities

Name		Date of Birth
First	Last	

EMOTIONAL AND BEHAVIORAL CONCERNS IDENTIFIED BY THE PATIENT OR FAMILY/SUPPORT PERSON

Concerning Behavior(s)	Start Date	An issue in the past?
1.		☐ Yes ☐ No
2.		☐ Yes ☐ No
3.		☐ Yes ☐ No
4.		☐ Yes ☐ No

Emotions observed by clinician or others and feelings expressed by the patient, verbal or nonverbal, when engaged in the concerning behavior(s) (e.g., agitated, anxious, angry, sad, playful)

Baseline: Identify a date when the patient was last doing well, feeling their usual self. Describe a "day in the life of the patient" to establish baseline daily functioning (e.g., ADLs, level of independence, social engagement, communication)

Past intervention(s) (Include medication trials)	Dates	Helpful Y/N
		☐ Yes ☐ No
		☐ Yes ☐ No
		☐ Yes ☐ No
		☐ Yes ☐ No

Current intervention(s) (Include medication trials)	Dates	Helpful Y/N
		☐ Yes ☐ No
		☐ Yes ☐ No
		☐ Yes ☐ No
		☐ Yes ☐ No

Comments

HEALTH - REVIEW POSSIBLE MEDICAL AND MEDICATION-RELATED CONDITIONS

Pain, injury or discomfort

PRACTICE TIP: If the patient is unable to self-report, involve someone who knows the person well.

PRACTICE TOOL:

- Pain Assessment of Adults with IDD[i]

Ways the patient expressed distress in the past in response to painful injuries or painful procedures	
☐ Verbally ☐ Points to place on body ☐ Non-specific behavior disturbance:	Other:

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) or procedure-related distress/trauma be contributing to the behavior change(s)?	
☐ Yes ☐ No ☐ Possibly	Explain

Completed pain assessments
Results:

Medications

PRACTICE TIP: Careful attention to accurate diagnosis and appropriate prescribing practice (especially antipsychotics) is essential for overall well-being in patients with IDD.[4-6]

PRACTICE TOOL:

- Psychotropic Medication Review

Medication review and audit	**Completed** ☐ Yes ☐ No **Date:**
☐ Adherence:	
☐ Side effect(s) or adverse reaction(s):	
☐ Change in medications:	
☐ Psychotropic medication:	
☐ Polypharmacy: *If you have concerns, check with the prescribing clinician*	
☐ As needed medication (PRN use):	
☐ OTC prescribed, OTC self-prescribed or supplements:	

Health screen

PRACTICE TIP: Medical conditions and health problems are often undertreated in patients with IDD. Conduct a "head-to-toe" review of common causes of distresssing behaviors.[2]

PRACTICE TOOL:

- Health Watch Tables for syndrome specific conditions
- Cheetham's Checklist

Health Screen	**Completed** ☐ Yes ☐ No **Date:**
Results:	

ENVIRONMENT - REVIEW ENVIRONMENT, SUPPORTS, AND EXPECTATIONS

PRACTICE TIP: Review this section with the patient, support staff and family caregivers. Describe what accommodations are in place in the person's home and work environment (e.g, adjusted lighting, extra time). Provide adjustments and supports based on identified needs. Consult with other disciplines (e.g., speech and language pathologist, occupational therapist, behavioral therapist, physical therapist, psychologist).

PRACTICE TOOL:

- Communicate CARE for tips on communication strategies
- Health Watch Tables for syndrome specific needs
- Sensory differences - a guide for all audiences

Sensory impairments and communication needs	
☐ Hearing impairments ☐ Vision impairments ☐ Communication difficulties	Accommodations and communication strategies:

Syndrome-specific needs	
☐ Autism diagnosis ☐ Other diagnosed syndrome	Syndrome specific support needs:

Hypersensitivities	
☐ Not observed ☐ Auditory (e.g., covers ears, dislikes thunderstorms) ☐ Visual (e.g., dislikes dark or bright lights) ☐ Other (e.g., tactile, olfactory, taste)	Accommodations:

Hyposensitivities	
☐ Not observed ☐ Auditory (e.g., bangs objects, doors, likes vibration) ☐ Visual (e.g., looks intensely at objects or people, is attracted to light) ☐ Tactile (e.g., seeks pressure by crawling under heavy objects, enjoys rough and tumble play) ☐ Proprioceptive (e.g., bumping into things, fidgeting, tripping, posture instability)	Accommodations:

The patient is triggered by sensory events (sound, visual, touch, smell, proprioception, vestibular, internal, emotional) ☐ Yes ☐ No
Explain:
Triggering is avoided by:

Sensory assessment	**Completed** ☐ Yes ☐ No **Date:**
Results and recommendations: Describe if, and how, recommendations were implemented:	

Mobility	
☐ Mobility problems ☐ Physical restrictions	Accommodations:

The physical environment (home and work)	
☐ Meets the patient's mobility needs ☐ Is too physically demanding for the patient (e.g., too many stairs) ☐ Meets the patient's sensory and communication needs	Concerns:

The patient has enough opportunities for appropriate physical activities	☐ Yes ☐ No
Explain:	

Suggested supports or programs not in place that might help this patient

Family/Support Persons	
☐ Recognize and adjust supports to meet identified patient needs ☐ Overestimate patient's abilities (frustration, refusal, confusion) ☐ Underestimate patient's abilities (boredom, understimulation)	Concerns:

A Care Plan, Crisis Plan, Behavioral Support Plan or similar document is	
☐ In place ☐ Being followed ☐ Helpful	Concerns:

Staff and Family Supports	
☐ Resources are adequate to implement treatment, recreational, employment and leisure programs ☐ Family/Support persons are adequately trained/educated for optimal support	Concerns:
Signs of possible family/support person fatigue or burnout: ☐ negative attitudes towards person with IDD ☐ impersonal care ☐ difficult to engage with staff ☐ no or poor follow-through of treatment recommendations ☐ other:	

Comments

LIVED EXPERIENCE - REVIEW LIFE EVENTS, TRAUMA, AND EMOTIONAL ISSUES

PRACTICE TIP: Review with the patient and family/support persons familiar with the patient's past and present lived experience. Identify possible causes of emotional distress. Seek input from a social worker or other professional experienced in trauma and IDD.

Stresses from changes in
☐ Physical environment (e.g., home and work environments, such as relocation, renovations):
☐ Daily routines (e.g., change in programs, travel arrangements, mealtimes, staff changes):
☐ Transitions (e.g., change of seasons, youth to adulthood, or adult to retirement or end-of-life):
☐ Other:

Any recent change in relationships with significant others (e.g., staff, family, friends, romantic partner, child)
☐ Addition (e.g., new roommate, birth of sibling, birth of child)
☐ Loss (e.g., staff change, housemate change, loss of child)
☐ Separation (e.g., decreased visits by volunteers, sibling moved out, from child)
☐ Death (e.g., of parent, housemate, support person, child)
☐ Other:

Concerns about abuse				
	Not sure	Past	Ongoing	Dates
Physical	☐	☐	☐	
Sexual	☐	☐	☐	
Exploitation	☐	☐	☐	
Neglect	☐	☐	☐	

Does the patient indicate or seem to feel unsafe (e.g., environment(s), people) ☐ Yes ☐ No ☐ Not Sure

Explain:

Other common stressors	
☐ Teasing or bullying	☐ Issues regarding sexuality and relationships
☐ Being left out of an activity or group	☐ Inability to communicate feelings
☐ Anxiety about completing tasks	☐ Parenting and loss of, or threat of loss of child(ren)
☐ Stress or upsetting event, at school or work	☐ Serious illness of individual or family member
☐ Life transitions (e.g., moving out of family home, leaving school, puberty)	☐ Other triggers (e.g., anniversaries, holidays, environmental - sensory, associated with past trauma)
☐ Traumatic life events (e.g., victim of crime, hospital admission, new immigrant)	☐ Other life events or significant personal or family circumstances (e.g., institutionalization)
☐ Disappointment(s) (e.g., being surpassed by siblings; not being able to meet goals, such as driving or having a romantic relationship)	☐ Growing insight into disabilities and impact on own life (e.g., that he/she will never have children, sibling has boy/ girlfriend)

Comments:

PSYCHIATRIC CAUSES - REVIEW SIGNS, SYMPTOMS, POSSIBLE TRAUMA

PRACTICE TIP: Document a baseline and how behaviors and symptoms have changed over time. If concerns about psychiatric disorder exist, identify the main symptom cluster (e.g., anxiety or mood) and work with family/support person to track relevant target behaviors (e.g., weight, appetite, sleep, agitation, withdrawal) to substantiate the concerns. If still concerned, consider a psychiatric referral.

PRACTICE TOOL:

- Identifying Symptoms and Signs of Mental Distress for documenting a baseline of behaviors and tracking change over time.

Existing and previous psychiatric diagnosis(es)	☐ Yes ☐ No	**Date:**
Diagnosis:		

Previous hospital admission(s) for a psychiatric reason	☐ Yes ☐ No	**Date:**
Diagnosis:		

Recent deterioration or changes in	**Date:**
☐ Functioning (e.g., Activities of Daily Living, self-care, academic, community skills):	
☐ Health problems or concerns (e.g., seizures, continence):	
☐ Movement or mobility (e.g., slow, agitated, coordination):	
☐ Cognition (e.g., attention, thinking, memory):	
☐ Communication:	
☐ Behavior:	
☐ Stamina:	
☐ Sleep:	
☐ Appetite, eating, weight:	
☐ Anxiety or mood (emotional regulation, expressed feelings, thought worries):	
☐ Interest or initiative (e.g., leisure or work):	
☐ Social enagement and involvement:	
☐ Level of independence (e.g., change in supervision or placement):	
Comments: (Add results from Psychiatric Symptoms and Signs tool)	

CLINICAL SUMMARY

Describe HELP findings, clinical formulation, and action plan

Supporting materials

i. **Pain Assessment of Adults with Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/physical-health-issues/monitoring-charts/

ii. **Psychotropic Medication Review**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/psychotropic-medication-issues/

iii. **Health Watch Tables**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/health-watch-tables/

iv. **Communicate CARE: Guidance for Person- Centred Care of Adults with Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/communicate-care/

v. **Sensory Differences**
National Autistic Society, UK [webpage] www.autism.org.uk/about/behaviour/sensory-world.aspx

vi. **Identifying Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/psychiatric-symptoms-and-behaviors-screen/

vii. **HELP When Behaviours Communicate Distress**
Curriculum of Caring, McMaster University, Hamilton, Ontario [video] https://machealth.ca/programs/curriculum_of_caring/m/mediagallery/2225

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