HELP with Emotional and Behavioural 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) conceptualize aetiological contributors when these adults present with emotional distress and behavioural 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 (see Figure 1) relating to biopsychosocial circumstances that might underlie or be contributing to emotional distress and behaviours of concern, including behaviours that challenge*: Health, Environment, Lived Experiences, and Psychiatric Disorders (HELP). Apply this tool with careful scrutiny, repeated as necessary over time.

*Behaviours that challenge are behaviours 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 behavioural concerns, follow the HELP diagnostic framework as in figure 1.

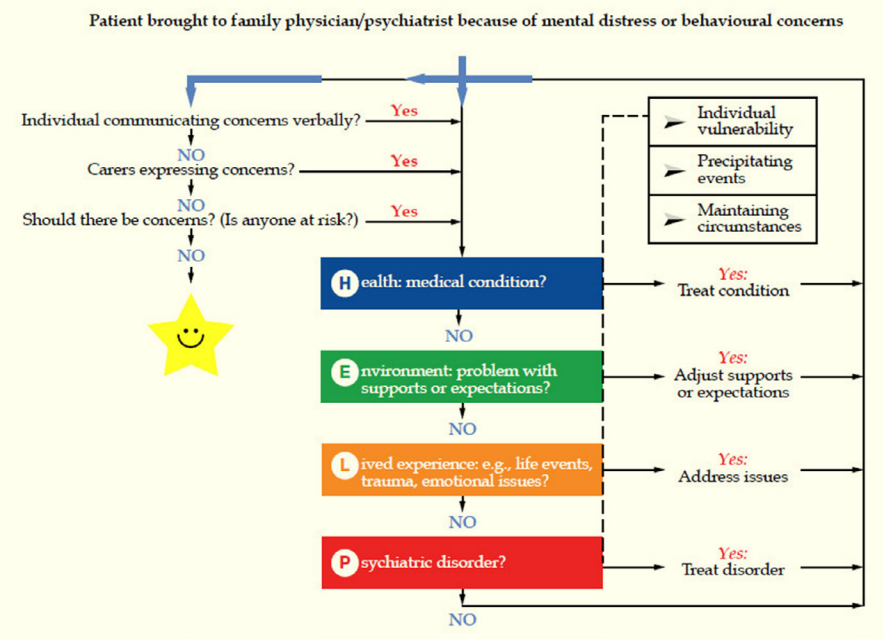

Figure 1: Understanding behaviours that challenge. A guide to assessment and treatment. Reproduced from E. Bradley and M. Korossy, Journal on Developmental Disabilities, Volume 22(2): page 103, 2016.

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 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, pain, or painful or scary medical investigations or treatments.

E — ENVIRONMENT AND SUPPORTS

People with IDD are much more dependent on their environments and supports 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.[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, 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]

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.[8] 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 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 IDD population.

P — PSYCHIATRIC DISORDERS

A review of physical health, environments, past traumas, 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 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.
- 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]

SUMMARY OF CLINICAL APPROACH (HELP FORMULATION)

- Identify the most likely contributor(s) to the person's distress and consider appropriate intervention(s). It is likely that there is no single contributor but rather a combination of circumstances.
- Explore the four areas in the HELP approach in a systematic and sequential order, so that circumstances contributing to behaviours that challenge are identified and addressed before assuming unusual or problematic behaviour may be of psychiatric origin.
- Loop through HELP as often as is necessary to identify issues and concerns which, if attended to, will diminish emotional and behavioural distress.
- Be attentive and engaged with the patient and caregivers perspectives as concerns are being sorted out.
- Collaborate with an interprofessional team, if possible (e.g., behaviour therapists, speech-language pathologists, occupational therapists, psychiatrists, physical therapist, nurse, psychologist, psychiatrist).
- Advocate for resources and supports. Clinical implementation of the above by the family doctor, relies on provincial leadership to provide appropriate services that support interprofessional delivery of care.

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

Surrey Place Developmental Disabilities Primary Care Program

Name		DOB
First	Last	

EMOTIONAL AND BEHAVIOURAL CONCERNS IDENTIFIED BY THE PATIENT OR CAREGIVERS

Concerning Behaviour(s)	Start Date	Presented in past
1.		☐ Yes ☐ No
2.		☐ Yes ☐ No
3.		☐ Yes ☐ No
4.		☐ Yes ☐ No
5.		☐ Yes ☐ No

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

Baseline Identify a day, date, or event, 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 op independence, social engagement, communication, interests

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

Current intervention(s) (Include medication trials)	**Dates**	**Helpful Y/N**
		☐ 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], including CPS-NAID[9] for physical pain, and DisDAT[10] for physical, emotional, and psychological distress.

Ways the patient expressed distress in the past in response to painful injuries or painful procedures

☐ Verbally
☐ Points to place on body
☐ Non-specific behaviour disturbance:

Other:

Could pain, injury or discomfort (e.g., fracture, tooth abscess, constipation) or procedure related distress/trauma be contributing to the behaviour 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[ii]

Medication review and audit	**Completed** ☐ Yes ☐ No **Date:**
☐ Is the diagnosis for which each medication is being prescribed accurate and robust?	
☐ Is current medication appropriate?	
☐ Adherence:	
☐ Side effect(s):	
☐ Adverse reaction(s):	
☐ Change in medications:	
☐ Psychotropic medication:	
☐ Polypharmacy:	
☐ Interactions:	
☐ Other substances and drugs of abuse:	
☐ As needed medication (PRN use):	
☐ OTC prescribed:	
☐ OTC self-prescribed or supplements:	

Health screen

PRACTICE TIP:
Medical conditions and health problems may be unrecognized and may be undertreated in patients with IDD. Conduct a "head-to-toe" review of common causes of behaviours that challenge.[2]

PRACTICE TOOL:
Health Watch Tables[iii] for syndrome specific conditions
Health Screen for Patients Presenting with Behaviours that Challenge[iv]

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

ENVIRONMENT - REVIEW ENVIRONMENT, SUPPORTS, AND EXPECTATIONS

PRACTICE TIP:
Review this section with the patient, staff and family caregivers. Describe which accommodations are in place (e.g, hearing aids, adjusted lighting, extra time). Provide adjustments and supports based on identified needs. Consult with other disciplines (e.g., speech and language pathologist, occupational therapist, behavioural therapist, physical therapist, nurse, psychologist, psychiatrist).

PRACTICE TOOL:
CommunicateCARE[v] for tips on communication strategies
Health Watch Tables[iii] for syndrome specific needs
Learn about sensory differences[vi]

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

Syndrome-specific needs	
☐ Autism diagnosis ☐ Other diagnosed syndrome with a recognized biological basis:	Syndrome specific support needs:

Hypersensitivities	
☐ Not observed ☐ Auditory (e.g., covers ears, dislikes thunderstorms) ☐ Visual (e.g., sensitive to dark and bright lights) ☐ Other (e.g., tactile, olfactory, tase)	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., likes pressure, seeks pressure by crawling under heavy objects, enjoys rough and tumble play) ☐ Proprioceptive dysfunction (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 sensitivity needs
- ☐ Meets the patient's sensory impairment and communication needs

Concerns:

The patient has enough opportunities for appropriate physical activities (e.g. daily walks outside) ☐ Yes ☐ No

Explain:

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

Caregivers

- ☐ 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, Behavioural Support Plan or similar document is

- ☐ In place
- ☐ Being followed
- ☐ Helpful

Concerns:

Staff and family caregiver supports

- ☐ Resources are adequate to implement treatment, recreational, employment and leisure programs
- ☐ Frequent caregiver changes or discontinuities of care
- ☐ Direct care staff is adequately trained/educated for optimal support

Signs of possible caregiver 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:

Concerns regarding staff and family engagement in providing continuity of care:

Comments

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

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

PRACTICE TOOL:
SHARE Transition Plan[vii]

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):
- ☐ Transition (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, caregiver, child)
- ☐ Other:

Comments:

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
- ☐ Being left out of an activity or group
- ☐ Anxiety about completing tasks
- ☐ Stress or upsetting event, at school or work
- ☐ Issues regarding sexuality and relationships
- ☐ Inability to verbalize feelings
- ☐ 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)
- ☐ Non-optimal assistance from care provider with communication needs
- ☐ Life transitions (e.g., moving out of family home, leaving school, puberty)
- ☐ Parenting and loss of, or threat of loss of child(ren)
- ☐ Serious illness of individual or family member
- ☐ Traumatic life events (e.g., victim of crime, hospital admission, new immigrant)
- ☐ Other triggers (e.g., anniversaries, holidays, environmental - sensory, associated with past trauma)
- ☐ Other life events or significant personal or family circumstances (e.g., institutionalization)
- ☐ Non-optimal assistance in emotional regulation from care provider

Comments:

PSYCHIATRIC CAUSES - REVIEW SIGNS, SYMPTOMS, POSSIBLE TRAUMA

PRACTICE TIP:

Document a baseline and how behaviours 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 care providers to track relevant target behaviours (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[viii] for documenting a baseline of behaviours 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:**

Describe

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:
- ☐ Behaviour:
- ☐ 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

Practice tools

i. **Pain Assessment of Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/physical-health/monitoring-charts/

ii. **Psychotropic Medication Review**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/psychotropic-medication-review-2/

iii. **Health Watch Tables**
Developmental Disabilities Primary Care Program of Surrey Place, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/health-watch-tables/

iv. **Health Screen for Patients Presenting with Behaviours that Challenge**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
(in production)

v. **Communicate CARE: Guidance for Person-Centred Care of Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/general-health/communicating-effectively/

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

vii. **SHARE Transition Plan**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/general-health/transitions/

viii. **Identifying Psychiatric Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, Ontario
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/psychiatric-symptoms-and-behaviour-screen/

ix. **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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Some of these supporting materials are hosted by external organizations and the accessibility of these links cannot be guaranteed. The DDPCP will make every effort to keep these links up to date.

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Copyright and Disclaimer

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This tool is developed as a guide only. While great effort has been taken to assure the accuracy of the information provided, Surrey Place, the Developmental Disabilities Primary Care Program, the reviewers, printer and others contributing to the preparation of this document cannot accept liability for errors, omissions or any consequences arising from the use of the information. Primary care providers and other healthcare professionals are required to exercise their own clinical judgement in using this tool.

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