Initial Management of a Behavioural Crisis in Intellectual and Developmental Disabilities

Introduction

Behavioural crises can arise from complex circumstances. This tool presents a systematic and sequential assessment of contributing factors, such as Health issues, Environment and supports, Lived experiences and emotional issues, and Psychiatric disorders (HELP). It points to practice tips and tools for healthcare providers to ensure the patient's safety while assessing and managing the crisis situation. Observation and information collected during this process is a first step in illuminating what might have contributed to the crisis; this in turn offers opportunities for prevention of further crises.

How to use this tool

This tool presents a clinical pathway (Figure 1, page 2) with key steps to managing a behavioural crisis in patients with intellectual and developmental disabilities (IDD), followed by practice tips and tools per step.

Behaviours communicate emotional distress, physical ailments, and unmet needs

Always consider the function of a patient's non-verbal behaviours and aim to understand underlying causes. A behaviour change might be the only way that some patients with IDD can express that something is wrong.

Behaviour is a symptom, not a disorder

People with IDD require a fine balance between their needs (e.g., developmental, health, emotional) and environmental, social, and interpersonal supports. Changes in any of these can upset the balance and lead to patient distress and a behavioural crisis. When a person with IDD is in distress, new behaviours can emerge or prior behaviour patterns can escalate.

Keep everyone safe

Changes in behaviour may be difficult to manage, posing a risk to the person and others. Decisions about risk and safety, and where best to provide care, will inevitably arise.

Identify contributing factors systematically

The HELP approach (Health, Environment, Lived experience, Psychiatric disorder) provides a care pathway to understanding and identifying what underlies the complexities that underpin emotional and behavioural distress. It may take several weeks or even months to fully identify all contributing factors contributing to patient distress, behaviours of concern, and behavioural crises. ***Treatment*** with psychotropic medication is inappropriate without a robust psychiatric diagnosis. Temporary ***management*** with medication to ensure safety is sometimes used.

Collaborate within a continuum of care

A shared understanding of how people with IDD express distress through nonverbal and verbal expression is essential. A continuum of medical care (i.e., between primary care provider, emergency services, hospital, and community care) is usually needed. This requires a collaborative approach to assessment, intervention, treatment, and prevention shared by health care, developmental disabilities services, and community supports.

Advocate

The physician role, whether in primary care, emergency service, or hospital, involves addressing medical conditions, as well as advocacy for appropriate psychosocial and emotional supports to ensure optimal health. The availability of resources will depend on the local context (e.g., geography, demographics, policies). In Canada, possible local resources include specific regional and local government services (e.g., in Ontario, the Community Networks of Specialized Care), developmental service worker, case manager, social worker, adult protective worker, employment support, community nursing, community pharmacist, behaviour therapist, occupational therapist, communication therapist, First Nations settlement workers. In the absence of a dedicated specialist team for adults with IDD for whom there are concerns about emotional and behavioural distress, the family physician might be left to draw on limited supports and medicate the crisis. Explore the availability of local or remote community resources, either in-person or virtually, and find out the referral process to access these services.

Prevent (over) medicalization

Overall, the above approach to behavioural crises, prevents medicalization of mental distress consequent to unmet developmental, social, emotional and other daily needs, as well as trauma, neglect or abuse.

- The recommendations and practice tips in this tool are based on the publication *Primary Care of Adults with Intellectual and Developmental Disabilities: 2018 Canadian Consensus Guidelines*, Canadian Family Physician, 2018, Vol 64: 254-279. In particular, guideline 27: Behaviours that challenge.

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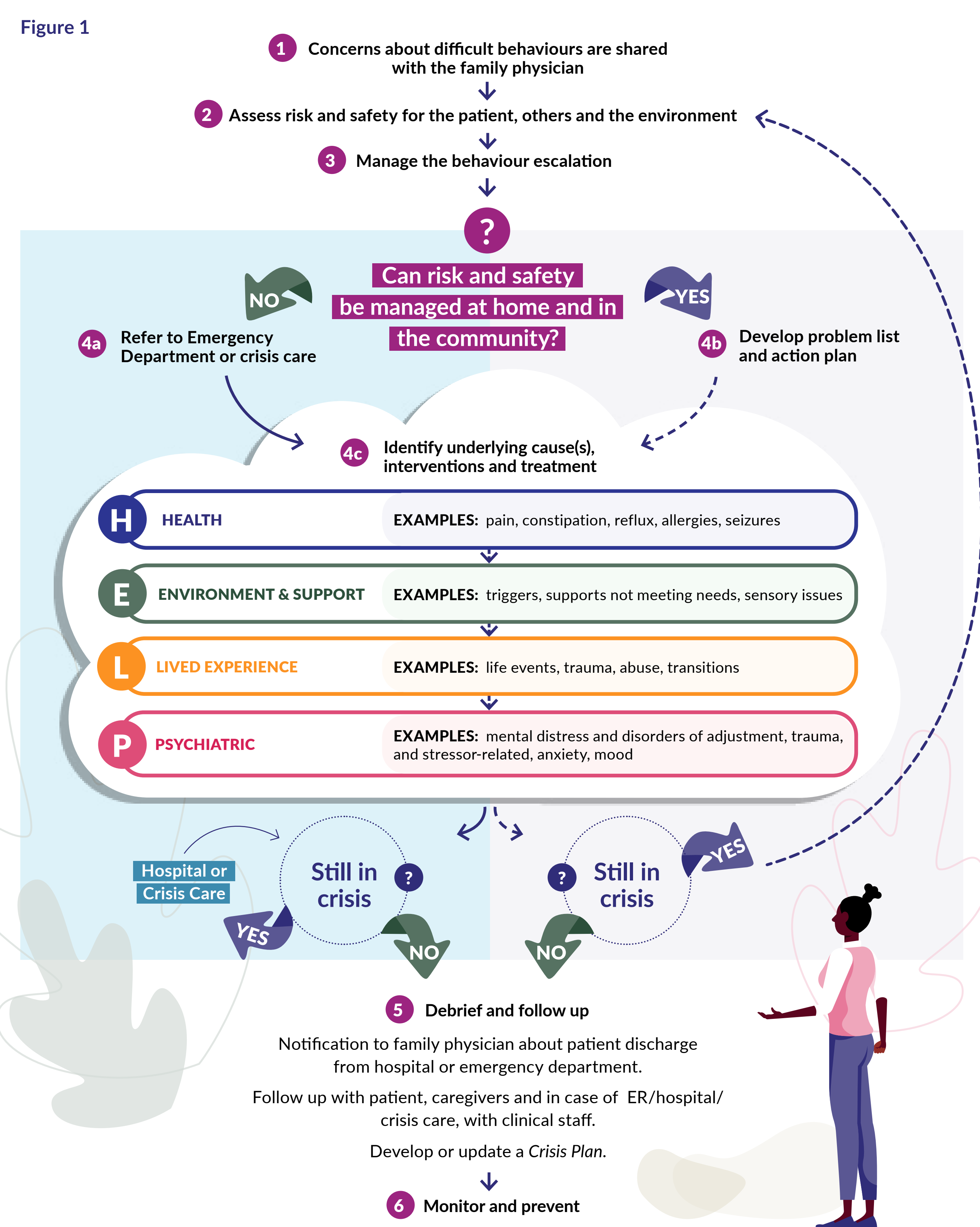
Figure 1



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1 The family physician may become aware of a behavioural concern or crisis when:

- care providers or the patient bring concerns about behaviours directly to the physician's attention;
- addressing a different medical issue and care providers share their concerns about behaviour;
- providing service to others related to the patient (e.g., roommates, group home residents, caregivers, partners, siblings) who appear negatively impacted by the patient's behaviour (e.g., frightened, stressed, sleep deprivation).

Figure 1 provides a clinical pathway to follow when a behavioural crisis arises. Detailed steps are outlined below.

2 Assess risk and safety

Identify known triggers or causes that result in harm by the patient to self (e.g., pain), to others, or to the environment, or harm to the patient from others (e.g., exploitation, abuse) or resulting from the environment (e.g., neglect). Identify also protective factors. Weigh the level of risk against factors that will keep everyone safe. Consider:

- Are care providers able to de-escalate and manage the patient's distress and behaviours of concern?
- Do care providers know what to do if the patient's behaviours escalate beyond what they can manage and to keep everyone safe?
- Is the patient showing new behaviour or is this an escalation of a previous pattern of behaviours?
- Does the patient have a crisis management plan?
- Does the patient feel safe in their current environment?

PRACTICE TOOLS

- Risk Assessment
- Trauma-informed health care

3 Manage the behaviour escalation

When a behavioural crisis is identified:

- Ask if the patient has a crisis management plan (e.g., *My Coping Tool)* and learn what has been helpful or not in past crises.
- Consider immediate intervention strategies that reflect the uniqueness of the developmental needs of the patient. For example:
  - Consider possible medical conditions, sensory issues, identifying triggers, coping strategies, and caregiver resources.
  - Modify environmental factors (e.g., direct the patient to a place that they would consider quiet and safe, without triggers).
  - Increase environmental and interpersonal supports (e.g., family, skilled staff and agency supports). Reduce expectations being placed on the patient.
  - Medications (regular and PRN) used to manage recurrent behavioural crises can be consired chemical restraint, particularly in the absence of an ongoing effort to identify the underlying cause of the crisis. Such PRN medication should only be used as part of a comprehensive interdiciplinary and multiperspective treatment plan. Consider PRN use carefully, follow clear protocols for use, and regularly review effectiveness and continued need.

PRACTICE TOOLS

- My Coping Tool: How I Deal With Stress
- Psychotropic Medication Issues (2011, under revision); See also Dhandapani et al (2021).

? Decide whether remaining at home is safe for the patient and others (e.g., peers and care providers), or whether the patient needs to be referred to emergency services (e.g., crisis care, ER).

4a Refer to emergency services

When referring the patient to emergency or crisis services:

- Ask the patient and caregiver if they have a written summary of the patient's needs (e.g., *About My Health*, health passport). This information helps care providers who do not know the patient well to make reasonable accommodations (e.g., use communication aids, comfort items to reduce anxiety, provide a quiet space).
- If available, share the patient's *Hospital Form* with the Emergency Department or crisis care providers.
- Alert medical care providers that the patient has IDD, has difficulty communicating and that his/her distress is manifested in behaviours.
- Let Emergency Department staff know when a caregiver is an essential support who knows the patient well, can provide additional information, and can help alleviate any patient anxiety and distress.
- Outline how you hope the Emergency Deparment will be able to assist, for example, investigating possible medical conditions giving rise to the behaviours of concern.

PRACTICE TOOLS

- About My Health
- My Hospital Form

4b Develop problem list and action plan

If the crisis can be safely managed in the patient's home:

- Work together with the patient and caregivers to identify what makes them feel safe from their perspectives, stabilize the situation and to manage the patient's distress and concerning behaviour(s).
- Review and implement any existing policies and plans (e.g., agency safety response plans, crisis management, behaviour support plan). If a written plan is not available, start identifying problems and an action plan, involving the patient, caregivers and supports.
- If available, involve a behaviour therapist who can conduct a functional analysis of what may be triggering the distress and behaviours of concern and what helps the patient feel safe.
- Develop a behavioural escalation scale, including early interventions.
- Work with care providers to document incidents, antecedents, and care provider response (see ABC Monitoring Chart). Identify life events and triggers that may be contributing to the crisis.
- Discuss and know what to do if symptoms worsen or caregivers are unable to manage, and when and how to use emergency services.

PRACTICE TOOLS

- About My Health
- Monitoring Chart: Antecedent – Behaviours – Consequence

4c Identify underlying cause(s), treatment, and interventions

Assess and manage the behavioural crisis by working with the patient, caregivers, and available interprofessional team members. Apply an ongoing systematic and sequential biopsychosocial assessment and diagnostic formulation, assessing Health, Environment, Lived Experience and Psychiatric Disorders (HELP)[ix].

Identify cause(s)

- Consider the patient's level of socio-emotional development and whether supports are adapted accordingly (e.g., need for co-regulation of emotional dysregulation).
- Monitor behaviours and collect data.
- Consider sensory sensitivities,concurrent disorders, trauma, adversity, abuse and adjustment issues as contributing factors.
- Review regular and PRN psychotropic medication, including new medications prescribed to manage the behaviours of concern.
- Review the use of alcohol and recreational drugs, and any over-the-counter medications.
- Identify and monitor target symptoms and signs.
- Continue to manage risk and safety until the crisis resolves and all contributing causes of the behavioural crisis have been addressed.

PRACTICE TOOL

- HELP with Emotional and Behavioural Concerns
- Psychotropic Medications Review
- Identifying Symptoms and Signs of Mental Distress
- Trauma-informed health care

Treatment and interventions for underlying causes

- Treat any underlying medical conditions.
- Assess if the daily living environment matches the needs of the patient (e.g. sensory, physical activity, care provider support, communication) and attend to mismatches.
- Attend to emotional circumstances, for example, past trauma triggered by current environment and supports. Consider if the patient's developmental profile is adequately understood and whether needed support in emotional regulation is available.
- Attend to issues related to access, equity of access, inclusion, participation, fairness, and justice that may be impacting negatively on the patient's sense of belonging and connection with others.
- Attend to interpersonal circumstances (e.g., abuse, exploitation, emotional neglect).
- If health, environment and lived experience do not appear to be contributing to the patient's distress and concerning behaviours, consider whether these are underpinned by a psychiatric disorder.
- Ask care providers to monitor the patient's sleep, weight, appetite, mood, anxiety and compare against baseline prior to the onset of the distress and behaviours of concern (see *Monitoring Charts*). Ask if a community or practice nurse may be able to assist care providers with monitoring.
- Develop or update a crisis management plan (e.g., *My Coping Tool).* A well-formulated plan involving all stakeholders helps to understand the communicative function of the patient's behaviours, provides guidance when the patient's distress behaviours escalate, helps to determine the cause of crisis behaviours, and documents the effectiveness of interventions. The structure of the plan and a systematic monitoring of target behaviours and ongoing clinical review is often an important therapeutic intervention resulting in stress reduction and anxiety in both the patient and care providers.
- Continue to manage risk and safety until all contributing causes of the patient's distress and behavioural crisis have been addressed
- Work with caregivers to identify cues of safety and cues of danger from the patient's perspective.

PRACTICE TOOLS

- Monitoring Charts
- Mental Health Interventions
- My Coping Tool: How I Deal With Stress

? Still in crisis? Repeat the algorithm *HELP with Emotional and Behavioural Concerns*[ix] until all causes are identified and appropriate interventions and treatments initiated. Sometimes admission to a specialist service may be needed (e.g., community treatment bed, specialist in patient service).

5 Debrief and follow up

Schedule an appointment with the patient and key supports (e.g., caregivers, family, interprofessional team, community supports) to debrief after an Emergency Department visit, hospital stay, or other crisis intervention. If needed, connect with local or regional resources and services to document the support needs, and identify solutions.

- Review effective and ineffective strategies in managing the behaviours during the crisis and update the crisis management plan.
- Review, taper, and discontinue newly prescribed medications unless they are prescribed for underlying medical or psychiatric conditions. Psychotropic medication should only be used for the treatment of an identified psychiatric disorder. In case of pressure to use medication instead of adequate social care, raise this with the management of the care setting where the patient resides.
- Engage the local Emergency Department to be part of an integrated crisis management and treatment plan when a patient frequently visits the Emergency Department with behaviours causing concern about risk and safety and if inpatient admission for more comprehensive assessment is not possible or not appropriate. Integrated care optimizes the assessment of underlying cause(s) of the behavioural distress. Once causes are identified, the appropriate treatment or intervention can be offered.

PRACTICE TOOLS

- Crisis Debrief Conversation: Guide for Primary Care Providers
- My Coping Tool: How I Deal With Stress
- Trauma-informed health care

6 Monitor and prevent

When the situation has stabilized, advocate for preventive strategies:

- Encourage caregivers and other support persons to monitor behaviours, physical health, and life events. This will help identify circumstances in the person's life and environment that might predispose them to emotional distress and behavioural escalation.
- Monitor if the present environment and supports meet the person's developmental needs sufficiently. Advocate if new or different supports are required and encourage a trauma-informed approach.

PRACTICE TOOL

- Monitoring Chart: Antecedent – Behaviour – Consequence
- Monitoring Charts
- My Coping Tool: How I Deal with Stress

Supporting materials

i. **Risk Assessment for Adults with Intellectual and Developmental Disabilities in Crisis**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/risk-assessment-tool-for-adults-with-dd/

ii. **Trauma-Informed Health Care of Adults With Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/trauma-informed-health-care/

iii. **My Coping Tool: How I Deal With Stress**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/my-coping-tool-how-i-deal-with-stress/

iv. **Bradley E, Behavioural and Mental Health Working Group of the Developmental Disabilities Primary Care Initiative**
Psychotropic medication issues. In: *Tools for the primary care of people with developmental disabilities*. Developmental Disabilities Primary Care Program of Surrey Place, Toronto, & MUMS Guidelines Clearing House; 2011. p. 84-7.

v. **Psychotropic Medication Review for Adults With Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023 https://ddprimarycare.surreyplace.ca/tools-2/mental-health/psychotropic-medication-review-2/

vi. **About My Health**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019
https://ddprimarycare.surreyplace.ca/tools-2/general-health/about-my-health/

vii. **My Hospital Form for Patients With Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023 https://ddprimarycare.surreyplace.ca/tools-2/mental-health/hospital-form/

viii. **Monitoring Chart: Antecedent - Behaviour - Consequences (ABC Chart)**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/abc-chart/

ix. **HELP with Emotional and Behavioural Concerns in Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2020
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/guide-to-understanding-behaviour/

x. **Identifying Symptoms and Signs of Mental Distress in Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/psychiatric-symptoms-and-behaviour-screen/

xi. **Monitoring Charts**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2019
https://ddprimarycare.surreyplace.ca/tools-2/physical-health/monitoring-charts/

xii. **Mental Health Interventions for Adults with Intellectual and Developmental Disabilities**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/mental-health-interventions/

xiii. **Crisis Debrief Conversation: A Guide for Primary Care Providers**
Developmental Disabilities Primary Care Program of Surrey Place, Toronto, 2023
https://ddprimarycare.surreyplace.ca/tools-2/mental-health/crisis-debrief-conversation/

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