Initial Management of a Behavioral Crisis in Intellectual and Developmental Disabilities

Introduction

Behavioral 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 health care 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 behavioral crisis in patients with intellectual and developmental disabilities (IDD), followed by practice tips and tools.

Behaviors may communicate emotional distress, physical ailments, and unmet needs

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

Behavior 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 behavioral crisis. When a person with IDD is in distress, new behavior issues can emerge, or prior behavior patterns can escalate.

Keep everyone safe

Changes in behavior 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 an overarching care pathway to understanding and identifying what underlies the complexities that underpin emotional and behavioral distress. It may take several weeks or even months to fully identify all factors contributing to patient distress, behaviors of concern, and behavioral 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 clinician, 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.

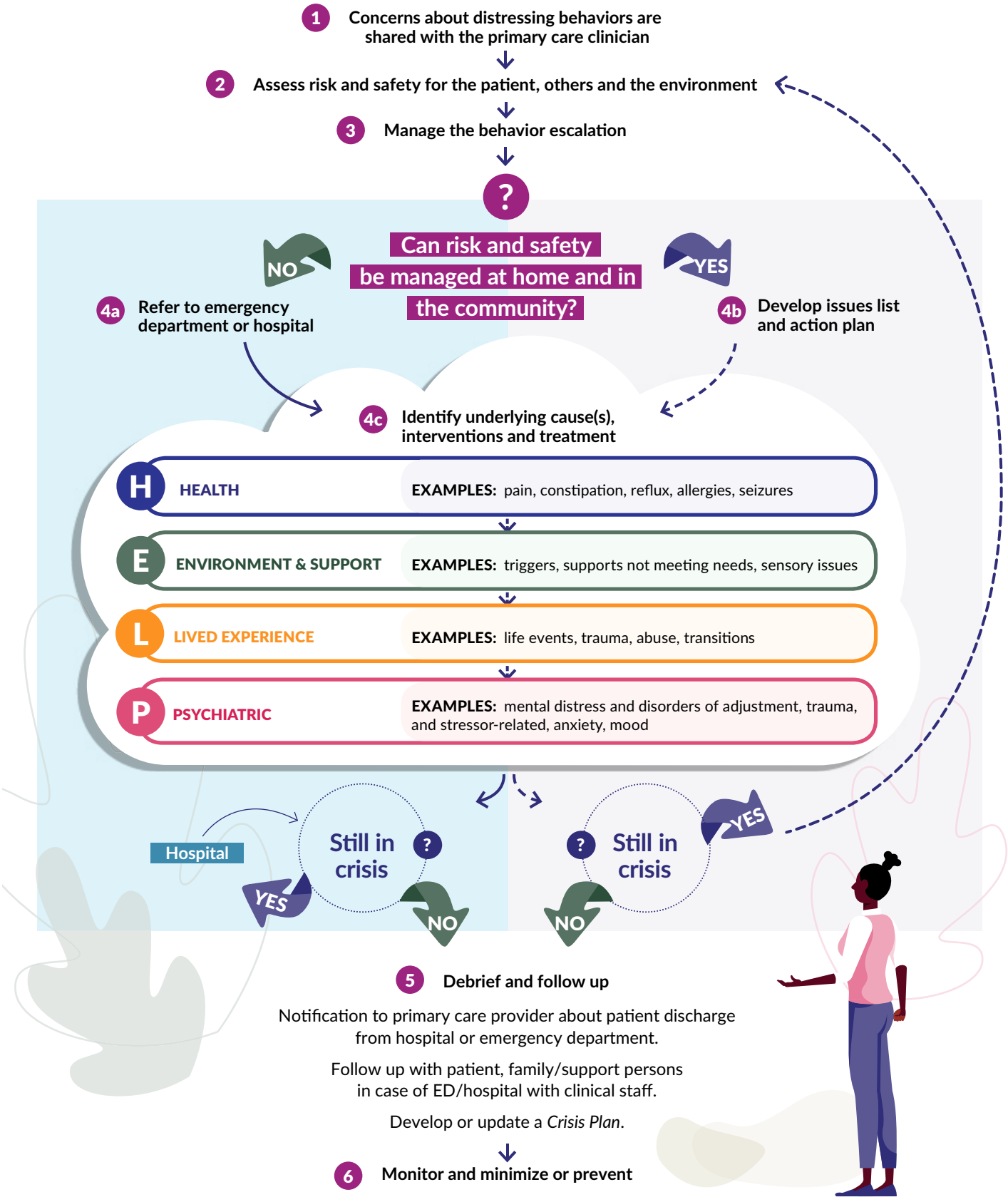
Advocate

The clinician's 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 the United States, resources may include Medicaid Waivers, Adult Protective Services, behavior analysts, social workers, speech or occupational therapists. In the absence of a dedicated specialist team for adults with IDD for whom there are concerns about emotional and behavioral distress, the primary care clinician 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 behavioral crises, prevents medicalization of mental distress consequent to unmet developmental, social, emotional and other daily needs, as well as trauma, neglect or abuse.

Figure 1: Initial Management of a Behavioral Crisis in Intellectual and Developmental Disabilities



1 The primary care clinician may become aware of a behavioral concern or crisis when:

- family/support persons, or the patient, bring concerns about behaviors directly to the clinician's attention;
- addressing a different medical issue and family/support persons share their concerns about behavior.

Figure 1 provides a clinical pathway to follow when a behavioral 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 family/support persons able to de-escalate and manage the patient's distress and behaviors of concern?
- Do they know what to do if the patient's behaviors escalate beyond what they can manage and to keep everyone safe?
- Is the patient showing new behavior issues or does it concern an escalation of a previous pattern of behaviors?
- Does the patient have a crisis management plan?
- Does the patient feel safe in their current environment?

PRACTICE TOOLS

- Risk Assessment Tool for Behavioral Crisis

3 Manage the behavior escalation

When a behavioral crisis is identified:

- Ask if the patient has a crisis management plan (e.g., *Crisis Management Plan, My Coping Tool*) and learn what has been helpful or not in past crises.
- Consider immediate de-escalation strategies that reflect the uniqueness of the developmental needs of the patient. For example:
  - » Consider possible medical conditions, sensory issues, identifying triggers, and coping strategies.
  - » 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 behavioral crises can be considered 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 interdisciplinary treatment plan. Consider PRN use carefully, follow clear protocols for use, and regularly review effectiveness and continued need.

PRACTICE TOOLS

- Crisis Prevention and Management Plan
- My Coping Tool

? 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., ER, hospital).

4a Refer to emergency services

When referring the patient to emergency or crisis services:

- Ask the patient and family/support person if they have a written summary of the patient's needs (e.g., *About My Health, Hospital Form*). This information helps health 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 hospital staff.
- Alert health care providers that the patient has IDD, has difficulty communicating and that his/her distress is manifested in behaviors.
- Let emergency department staff know when a family member/support person 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 department will be able to assist, for example, investigating possible medical conditions giving rise to the behaviors of concern.

PRACTICE TOOLS

- About My Health
- Hospital Form

4b Develop issues list and action plan

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

- Work together with the patient and family/support persons to identify what makes them feel safe from their perspectives, stabilize the situation and to manage the patient's distress and concerning behavior(s).
- Review and implement any existing policies and plans (e.g., crisis management, behavior support plan).
- If a written plan is not available, start identifying issues and an action plan, involving the patient, family/support persons and supports.

4b

- If available, involve a behavior therapist who can conduct a functional analysis of what may be triggering the distress and behaviors of concern and what helps the patient feel safe.
- Work with family/support persons to document incidents, antecedents, and responses (see Antecedent-Behaviors-Consequence Chart). Identify life events and triggers that may be contributing to the crisis.
- Discuss and know what to do if symptoms worsen or family/support persons are unable to manage, and when and how to use emergency services.

PRACTICE TOOLS

- About My Health
- Antecedent-Behaviors-Consequence (ABC) Chart

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

Assess and manage the behavioral crisis by working with the patient, family/support persons, 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).

IDENTIFY CAUSE(S)

- Consider the patient's level of socio-emotional development and whether supports are adapted accordingly (e.g., able to remain calm, offer validation and provide emotional support).
- Monitor behaviors and collect data.
- Consider sensory sensitivities, underlying autism, trauma, adversity, abuse and adjustment issues as contributing factors.
- Review regular and PRN psychotropic medication, including new medications prescribed to manage the distressing behaviors.
- 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 patient's behaviors settle and all contributing causes of the behavioral crisis have been addressed.

PRACTICE TOOLS

- HELP with Emotional and Behavioral Concerns
- Psychotropic Medication Review
- Identifying Symptoms and Sign of Mental Distress

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, 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. x
- 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 behaviors, consider whether these are underpinned by a psychiatric disorder.
- Ask family/support persons to monitor the patient's sleep, weight, appetite, mood, anxiety and compare against baseline prior to the onset of the distressing behaviors. (See *Monitoring Charts*).
- Develop or update a crisis management plan. A well-formulated plan involving all stakeholders, helps to understand the communicative function of the patient's behaviors, provides guidance when the patient's distressing behaviors escalate, helps to determine the cause of crisis behaviors, and documents the effectiveness of interventions. The structure of the plan and a systematic monitoring of target behaviors and ongoing clinical review is often an important therapeutic intervention resulting in stress reduction and anxiety in both the patient and family/support persons.
- Continue to manage risk and safety until all contributing causes of the patient's distress and behavioral crisis have been addressed. Work with family/support persons to identify cues of safety and cues of danger from the patient's perspective.

PRACTICE TOOLS

- Monitoring Charts
- Mental Health Interventions
- Crisis Prevention and Management Plan
- My Coping Tool

? Still in crisis? Repeat the steps outlined in the HELP algorithm until causes are, if possible, identified and appropriate interventions and treatments initiated. Sometimes admission to an emergency department or hospital may be needed. Also, sometimes it may only be possible to manage or minimize the crises.

5 Debrief and follow up

Schedule an appointment with the patient and key stakeholders (e.g., family/support persons, interprofessional team, key 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 behaviors 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.
- Contact the local emergency department or ED clinicians when a patient frequently visits the ED with behaviors that raise concerns about risk and safety.

PRACTICE TOOLS

- Crisis Debrief Conversation: Guide for Primary Care Providers [Surrey Place]
- My Coping Tool

6 Monitor and prevent

When the situation has stabilized, advocate for preventive strategies:

- Encourage family/support persons to monitor behaviors, 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 behavioral 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 TOOLS

- Antecedent-Behaviors-Consequence (ABC) Chart
- Monitoring Charts
- My Coping Tool

Supporting materials

i. **Risk Assessment for Adults with Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/risk-assessment/

ii. **My Coping Tool: How I Deal With Stress**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/my-coping-tool/

iii. **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.

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

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

vi. **My Hospital Form for Patients With Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/hospital-form/

vii. **Antecedent-Behavior-Consequence (ABC) Chart**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/abc-antecedent-behavior-consequence-chart/

viii. **HELP with Emotional and Behavioral Concerns in Adults With Intellectual and Developmental Disabilities**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/help-with-emotional-and-behavioral-concerns/

ix. **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/

x. **Monitoring Charts**
Health Care for Adults with Intellectual and Developmental Disabilities iddtoolkit.vkcsites.org/physical-health-issues/monitoring-charts/

xi. **Mental Health Interventions for Adults with Intellectual and Developmental Disabilities.**
Health Care for Adults with Intellectual and Developmental Disabilities
iddtoolkit.vkcsites.org/mental-health-interventions/

xii. **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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