# Risk Assessment for Adults with Intellectual and Developmental Disabilities in Crisis

## Introduction

This tool helps primary care providers determine whether a patient with intellectual and developmental disability (IDD) who is experiencing a crisis (e.g., emotional or behavioural distress) can be managed safely in their current living or work environment or should be referred to the emergency department or crisis care. It considers the risk to self and to others (e.g., peers and caregivers) during a crisis escalation in the context of available supports. It helps identify unique risk and protective factors.

## How to use this tool

### Identify risk factors

When a patient with IDD and caregivers present to the family physician with concerns about an emotional or behavioural crisis, the first step is to determine how to keep the patient and others safe. See *Initial Management of a Behavioural Crisis in Intellectual and Developmental Disabilities*[i].

Use this tool to identify triggers or causes that result in harm by the patient to self (e.g., pain), others, or the environment, as well as harm to the patient from others (e.g., exploitation, abuse, neglect from peers, family, other care providers or public).

### Weigh risk factors against protective factors

Emotional and behavioural crises occur in the context of an imbalance between patient needs and supports (e.g., the environment and caregiver, or other interpersonal resources). Therefore, consider patient context, environment-related, and interpersonal supports for a full risk assessment.

Take into account how the patient's IDD influences both risk and protective factors. Examples of protective factors for patients with mild IDD living independently include a sense of purposeful engagement in activities, meaningful and supportive connections with others, strong social supports, easy access to supports and interventions, restricted access to means of harm. Protective factors for adults with more severe IDD living in supported settings are mostly associated with the skills and resources of caregivers, in particular their capacity to provide supports appropriate to the emotional developmental needs and co-regulation of the patient's dysregulated emotional states.

### Consider the current context

Although some patients might already have a crisis management plan (e.g. *My Coping Tool*)[iii] that decribes their unique triggers and behaviour management strategies, always and continuously (re-) assess risk and protective factors in light of the current crisis and context.

Note any trauma history and treatment plan, recent life events, caregiver burn-out, or changes in risk and protective factors.

### Provide safety first

If the risk assessment indicates that the patient in emotional or behavioural crisis cannot be managed safely in the current environment, discuss options and consider urgent assessment and management in an alternative setting (e.g., Emergency Department, crisis care). If the patient experiences repeated crises, a different crisis response may be needed (e.g., developmental disabilities specialist crisis response service). Always follow up with the patient and caregivers after an Emergency Department visit and re-assess risk and protective factors.

Based on the risk assessment, if you conclude that physical and psychological safety (i.e., people "feel safe", including the patient) of the patient and those around them remain at risk, contact those at the appropriate level of authority who are ultimately responsible for the care of incapable adults (e.g., agency management, provincial government, ombudsman, police) to alert to a situation that is beyond the scope of family medicine for effective intervention.

- The recommendations 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 30: Behavioural crises.

# Risk Assessment for Adults with IDD in Crisis

Surrey Place Developmental
Disabilities Primary Care Program

## 1. PATIENT INFORMATION

| Name | | DOB |
|---|---|---|
| First | Last | |

| Date/period of assessment | Review date [dd/mm/yyyy] | Information provided by |
|---|---|---|
| | | ☐ patient ☐ caregiver ☐ other |

**Presenting concerns**

**From the patient's perspective:**

**From the caregiver's perspective:**

## 2. RISK AND PROTECTIVE FACTORS CHECKLIST

Consider the risk domains in this list and indicate when a factor is present (yes/no/unknown). Involve the patient as much as possible. Involve the patient's network of support if further information is needed. Consider the unique risk factors against protective factors and supports in the context of the patient's current crisis.

### Suicide

**Patient**

| | |
|---|---|
| Communicates or shows behaviours about ending their life | ☐ Yes ☐ No ☐ Unknown |
| Feels hopeless and is unable to identify reasons to continue living | ☐ Yes ☐ No ☐ Unknown |
| Shows poor judgment or mental illness | ☐ Yes ☐ No ☐ Unknown |
| Has a history of suicidal or para-suicidal behaviours | ☐ Yes ☐ No ☐ Unknown |

**Caregivers and environment**

| | |
|---|---|
| Means are available for the person to end their life | ☐ Yes ☐ No ☐ Unknown |
| Caregivers are able to supervise and protect the person | ☐ Yes ☐ No ☐ Unknown |

### Self-harm

**Patient**

| | |
|---|---|
| Verbalizes thoughts or intent to self-harm | ☐ Yes ☐ No ☐ Unknown |
| Engages in self-harm (current state or evidence) | ☐ Yes ☐ No ☐ Unknown |
| Has known triggers to self-harm behaviours | ☐ Yes ☐ No ☐ Unknown |
| Has a history of self-harming behaviour | ☐ Yes ☐ No ☐ Unknown |

**Caregivers and environment**

| | |
|---|---|
| Means are available for the person to harm themselves | ☐ Yes ☐ No ☐ Unknown |
| Caregivers are able to supervise and protect the person | ☐ Yes ☐ No ☐ Unknown |
| Prior triggers to self-harm are present | ☐ Yes ☐ No ☐ Unknown |

## Self-care and neglect

### Patient

| | |
|---|---|
| Does not engage in basic self-care | ☐ Yes ☐ No ☐ Unknown |
| Declines assistance with self-care | ☐ Yes ☐ No ☐ Unknown |
| Shows self-neglect and behaviours that put the person at risk | ☐ Yes ☐ No ☐ Unknown |
| Is unable to manage medical conditions and medications | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Caregivers are available and able to assist in personal care | ☐ Yes ☐ No ☐ Unknown |
| Caregivers are available and able to assist in medical care | ☐ Yes ☐ No ☐ Unknown |

## Risk to others

### Patient

| | |
|---|---|
| Communicates thoughts or intent to harm others (makes threats) | ☐ Yes ☐ No ☐ Unknown |
| Gestures about hurting others | ☐ Yes ☐ No ☐ Unknown |
| Has sufficient mobility and strength to potentially harm others | ☐ Yes ☐ No ☐ Unknown |
| Shows aggression and threatening behaviour that escalates quickly or unpredictably | ☐ Yes ☐ No ☐ Unknown |
| Has a history of causing physical or emotional harm to others | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Caregivers are able to recognize cues and to intervene safely | ☐ Yes ☐ No ☐ Unknown |
| There are vulnerable individuals in the setting who cannot protect themselves | ☐ Yes ☐ No ☐ Unknown |
| Safe support is possible in current setting without caregivers being at risk of harm while trying to prevent harm to others | ☐ Yes ☐ No ☐ Unknown |

## Risk to environment

### Patient

| | |
|---|---|
| Verbalizes thoughts or intent to damage property | ☐ Yes ☐ No ☐ Unknown |
| Engages in behaviour(s) that could damage property | ☐ Yes ☐ No ☐ Unknown |
| Has mobility and strength to be able to cause damage | ☐ Yes ☐ No ☐ Unknown |
| Has a history of damage to environment in recent past | ☐ Yes ☐ No ☐ Unknown |
| Escalates quickly or unpredictably | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Caregivers are able to recognize an escalation and to intervene effectively | ☐ Yes ☐ No ☐ Unknown |
| Caregivers feel comfortable about their ability to predict and prevent risks to the environment | ☐ Yes ☐ No ☐ Unknown |
| Caregivers are able to provide a safe and supportive environment (e.g., de-escalate the patient's dysregulated emotional state through co-regulation) | ☐ Yes ☐ No ☐ Unknown |

## Victimization or exploitation

### Patient

| | |
|---|---|
| Shows signs of possibly being victimized or exploited | ☐ Yes ☐ No ☐ Unknown |
| Does not ask for help | ☐ Yes ☐ No ☐ Unknown |
| Lacks insight into possible dangers of the situation | ☐ Yes ☐ No ☐ Unknown |
| Is vulnerable and does not protect self emotionally or physically | ☐ Yes ☐ No ☐ Unknown |
| Has a history of being victimized or exploited | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Caregivers are present, recognise the person's vulnerabilities, and able to supervise and protect the patient | ☐ Yes ☐ No ☐ Unknown |

## Stress, trauma behaviours, and triggers

### Patient

| | |
|---|---|
| Shows signs of sympathetic nervous system (SNS) mobilization: hyperarousal, hypervigilance, easily triggered into sympathetic survival responses of "fight" (e.g., verbal or physical aggression, self-injury), "flight" (e.g., running away, avoiding, withdrawing), "freeze" (e.g., frozen in actions and thoughts, unable to move forward or initiate) | ☐ Yes ☐ No ☐ Unknown |
| Shows signs of parasympathetic vagal (PNS) immobilization: withdraws, shuts down, collapses, zones out, dissociates, urinary or bowel accidents | ☐ Yes ☐ No ☐ Unknown |
| Experiences triggers that cause feeling unsafe, in danger, or threatened, such as: medical condition(s) and/or pain; sensory sensitivities (e.g., to lights, voices, touch; perfumes, patterned clothes worn by others); triggers from past abuse (physical, emotional, sexual) or neglect in daily life and in supported living | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Caregivers are sufficiently supported in a trauma informed environment and know how to help the patient feel safe | ☐ Yes ☐ No ☐ Unknown |
| Caregivers have the resources and supports to make changes that would diminish triggers | ☐ Yes ☐ No ☐ Unknown |
| Caregivers recognize patient's stage of emotional development (e.g., adult at 6-18 month stage) and are supporting accordingly | ☐ Yes ☐ No ☐ Unknown |
| Caregivers are providing autism friendly supports as needed (e.g., communication and sensory needs) | ☐ Yes ☐ No ☐ Unknown |
| Caregivers recognize the patient's withdrawn dissociated states and unexpected bowel or bladder accidents as signs | ☐ Yes ☐ No ☐ Unknown |
| Caregivers recognize triggered states and are able to assist the patient in de-escalation of emotional distress and behaviours that challenge (e.g., through caregiver-patient co regulation, positive behaviour supports, and implementation of patient's de-escalation hierarchy plan) | ☐ Yes ☐ No ☐ Unknown |
| Triggered states alert caregivers to seek the source of the trigger(s) | ☐ Yes ☐ No ☐ Unknown |

## Feeling and being safe

### Patient

| | |
|---|---|
| Communicates concern about aspects of their current living or work situation and supports | ☐ Yes ☐ No ☐ Unknown |
| Communicates they want to move from current situation | ☐ Yes ☐ No ☐ Unknown |
| Shows sympathetic nervous system (SNS) mobilization or parasympathetic nervous system (PNS) shutdown, behaviours that challenge and emotional dysregulation | ☐ Yes ☐ No ☐ Unknown |
| Shows other (trauma) behaviours signaling feeling unsafe, such as: targeting, fear of, or aggression towards certain peers or care providers, GI upsets, bowel or bladder accidents | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Caregivers are able to provide safe interpersonal relationships (i.e., support the patient in communicating instrumental and emotional needs) | ☐ Yes ☐ No ☐ Unknown |
| Caregivers provide an environment that is safe from abuse (physical, emotional, sexual), neglect and triggers | ☐ Yes ☐ No ☐ Unknown |
| The offered lifestyle is conducive to the patient's homeostatic emotional regulation (e.g., opportunities for regular physical exercise, walking in nature, optimal conditions for privacy, restful sleep, healthy eating, meaningful connection and co-regulation with others) | ☐ Yes ☐ No ☐ Unknown |

## Other

### Patient

| | |
|---|---|
| Concerns about abuse in current environment | ☐ Yes ☐ No ☐ Unknown |
| Signs of possible abuse: behaviours that challenge, dysregulated emotional states, unusual body trauma, targeting, aggression of fearfulness towards peers or caregivers | ☐ Yes ☐ No ☐ Unknown |

### Caregivers and environment

| | |
|---|---|
| Concerns about burnout | ☐ Yes ☐ No ☐ Unknown |
| Signs of family caregiver burnout: exhaustion, fatigue, ill health; loss of trust in services and consequent difficulty asking for help | ☐ Yes ☐ No ☐ Unknown |
| Signs of paid caregiver burnout: disengaged, not following through, absenteeism, high turnover of staff, increase in "serious occurrence" reports | ☐ Yes ☐ No ☐ Unknown |
| Caregivers are fearful of the patient and feel less confidence in being able to manage | ☐ Yes ☐ No ☐ Unknown |

## 3. RISK FORMULATION AND NEXT STEPS

| Risk factors: | Protective factors: |
|---|---|
| | |

**Overall impression of risk:**

**Next steps:**

Is remaining in the home/work environment safe for the patient and others?: ☐ YES ☐ NO

- If YES, use *HELP with Emotional and Behavioural Concerns*[ii] to further investigate underlying factors that contribute(d) to the crisis.
- Has a *My Coping Tool*[iii] or other crisis management plan been completed and shared with patient and caregivers?: ☐ YES ☐ NO
- If NO, refer the patient to emergency or crisis services.
    - Follow up with the emergency or crisis service on: [dd/mm/yyyy]
    - If this is a (repeat) referral to emergency services due to a lack of supports, alert those at the appropriate level of authority (e.g., agency management, provincial government, ombudsman).

## Supporting materials

i. **Initial Management of a Behavioural Crisis 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/initial-management-of-behavioural-crisis-in-family-medicine/

ii. **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/

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

## References

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Bowring DL, Totsika V, Hastings RP, Toogood S, Griffith GM. Challenging behaviours in adults with an intellectual disability: A total population study and exploration of risk indices. Br J Clin Psychol. 2017 Mar;56(1):16-32.

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## Copyright and disclaimer

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