

# 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 who is experiencing an emotional or behavioral crisis can be managed safely in their current living or work environment or should be referred to the emergency department or possible crisis care options. It considers the risk to the patient and to others (e.g., peers, family, or support staff) during an 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 family/support persons present to the primary care clinician with concerns about an emotional or behavioral crisis, the first step is to determine how to keep the patient and others safe. See [Initial Management of a Behavioral Crisis in Intellectual and Developmental Disabilities](#).

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, support staff or public).

### Weigh risk factors against protective factors

Emotional and behavioral crises occur in the context of an imbalance between patient needs and supports (e.g., the environment and family/support persons, 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 family/support persons, in particular their capacity to provide supports appropriate to the emotional developmental needs and to maintain a

calm, empathic demeanor during the person's dysregulated emotional states.

### Consider the current context

Although some patients might already have a crisis management plan, such as [Crisis Prevention and Management Plan](#) and [My Coping Tool](#), that describes their unique triggers and behavior management strategies, (re-) assess risk and protective factors in light of the current crisis and context.

Note any trauma history and treatment plan, recent life events, possible family/support persons burnout, or changes in risk and protective factors.

### Provide safety first

If the risk assessment indicates that the patient 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 crisis response service if available). Always follow up with the patient and family/support persons 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, including the patient, "feel safe") 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, state or local government, ombudsman, police) to alert to a situation that is beyond the scope of family medicine for effective intervention.

# Risk Assessment for Adults with IDD in Crisis

1. PATIENT INFORMATION		
<b>Name</b> First _____ Last _____		<b>Date of Birth</b> _____
<b>Date/period of assessment</b> _____	<b>Review date:</b> / /	<b>Information provided by:</b> patient      family/support person      other
<b>Presenting concerns</b> From the patient's perspective: _____ From the family's/support person'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.			
<b>Suicide</b>			
<b>▶ Patient</b>			
Communicates or shows behaviors 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 behaviors	Yes	No	Unknown
<b>▶ Family/support persons and environment</b>			
Means are available for the person to end their life	Yes	No	Unknown
Family/support persons are able to supervise and protect the person	Yes	No	Unknown
<b>Self-harm or Self-Injurious Behavior</b>			
<b>▶ Patient</b>			
Verbalizes thoughts or intent to self-harm	Yes	No	Unknown
Engages in self-harm/self-injurious behavior (current state or evidence)	Yes	No	Unknown
Has known triggers to self-harm/self-injurious behavior	Yes	No	Unknown
Has a history of self-harming/self-injurious behavior	Yes	No	Unknown
<b>▶ Family/support persons and environment</b>			
Means are available for the person to harm themselves	Yes	No	Unknown
Family/support persons are able to supervise and protect the person	Yes	No	Unknown
Prior triggers to self-harm/self-injurious behavior are present	Yes	No	Unknown
<b>Self-care and neglect</b>			
<b>▶ Patient</b>			
Does not engage in basic self-care	Yes	No	Unknown
Declines assistance with self-care	Yes	No	Unknown
Shows self-neglect and behaviors that put the person at risk	Yes	No	Unknown
Is unable to manage medical conditions and medications	Yes	No	Unknown
<b>▶ Family/support persons and environment</b>			
Family/support persons are available and able to assist in personal care	Yes	No	Unknown
Family/support persons 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 behavior that escalates quickly or unpredictably	Yes	No	Unknown
Has a history of causing physical or emotional harm to others	Yes	No	Unknown

### ▶ Family/support persons and environment

Family/support persons 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 family/support persons 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 behavior(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

### ▶ Family/support persons and environment

Family/support persons are able to recognize an escalation and to intervene effectively	Yes	No	Unknown
Family/support persons feel comfortable about their ability to predict and prevent risks to the environment	Yes	No	Unknown
Family/support persons are able to provide a safe and supportive environment (e.g., de-escalate the patient's dysregulated emotional state by maintaining a calm demeanor and encouraging calming responses)	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

### ▶ Family/support persons and environment

Family/support persons are present, recognize the person's vulnerabilities, and able to supervise and protect the patient	Yes	No	Unknown
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## Stress, trauma behaviors, 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

## Stress, trauma behaviors, and triggers

### ► Family/support persons and environment

Family/support persons are sufficiently supported in a trauma-informed environment and know how to help the patient feel safe	Yes	No	Unknown
Family/support persons have the resources and supports to make changes that would diminish triggers	Yes	No	Unknown
Family/support persons recognize patient's stage of emotional development and are supporting accordingly	Yes	No	Unknown
Family/support persons are providing autism-friendly supports as needed (e.g., communication and sensory needs)	Yes	No	Unknown
Family/support persons recognize the patient's withdrawn dissociated states and unexpected bowel or bladder accidents as signs	Yes	No	Unknown
Family/support persons recognize triggered states and are able to assist the patient in de-escalation of emotional distress and concerning behaviors (e.g., through the family/support person staying calm, positive behavior supports, and implementation of patient's crisis management plan or My Coping Tool)	Yes	No	Unknown
Triggered states alert family/support persons 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 SNS mobilization or PNS shutdown, distressing behaviors and emotional dysregulation	Yes	No	Unknown
Shows other (trauma) behaviors signaling feeling unsafe, such as targeting, fear of, or aggression towards certain peers or others, GI upsets, bowel or bladder accidents	Yes	No	Unknown

### ► Family/support persons and environment

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

## Other

### ► Patient

Concerns about abuse in current environment	Yes	No	Unknown
Signs of possible abuse: distressing behaviors, dysregulated emotional states, unusual body trauma, targeting, aggression or fearfulness towards peers or family/support persons	Yes	No	Unknown

### ► Family/support persons 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 support persons burnout: disengaged, not following through, absenteeism, high turnover of staff, increase in "serious occurrence" reports	Yes	No	Unknown
Family/support persons 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 <u>HELP with Emotional and Behavioral Concerns</u> to further investigate underlying factors that contribute(d) to the crisis.		
Has a <u>Crisis Prevention and Management Plan</u> or <u>My Coping Tool</u> been completed and shared with patient and family/support persons?	Yes	No
▶ If NO, refer the patient to emergency or crisis services.		
• If possible, follow up with the emergency or crisis service		
• 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, state or local disability services department or office)		

## Supporting materials

- i. **Initial Management of Behavioral Crises in Adults with Intellectual and Developmental Disabilities**  
Health Care for Adults with Intellectual and Developmental Disabilities  
[iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/management-beh-crises/](http://iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/management-beh-crises/)
- ii. **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/](http://iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/help-with-emotional-and-behavioral-concerns/)
- iii. **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/](http://iddtoolkit.vkcsites.org/behavioral-and-mental-health-issues/my-coping-tool/)

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## References

- Banks R, Bush A, Other Contributors. Challenging behavior: A unified approach – update: Clinical and service guidelines for supporting children, young people and adults with intellectual disabilities who are at risk of receiving abusive or restrictive practices. London, UK: The Royal College of Psychiatrists; 2016 April.
- Bowring DL, Totsika V, Hastings RP, Toogood S, Griffith GM. Challenging behaviors 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.
- Doyle M, Garnham M, Carter S, Ventress M. Developing and implementing a digital formulation informed risk management framework in mental health and learning disability services. *J Ment Health Train Educ Pract* [Article in press].
- National Institute for Health and Care Excellence - NICE. Challenging behavior and learning disabilities: Prevention and interventions for people with learning disabilities whose behavior challenges. NICE guidelines [NG 11]. London, UK: NICE National Institute for Health and Care Excellence; 2015.
- Stein W. Modified Sainsbury tool: An initial risk assessment tool for primary care mental health and learning disability services. *J Psychiatr Ment Health Nurs.* 2005 Oct;12(5):620-33.

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