UQÀM | Université du Québec à Montréal

CRISE

Centre de recherche et d'intervention sur le suicide, enjeux éthiques et pratiques de fin de vie

Centre for Research and Intervention on Suicide, Ethical Issues and End-of-Life Practices

Understanding and preventing suicide risk in people living with IDD – recommendations from our research program

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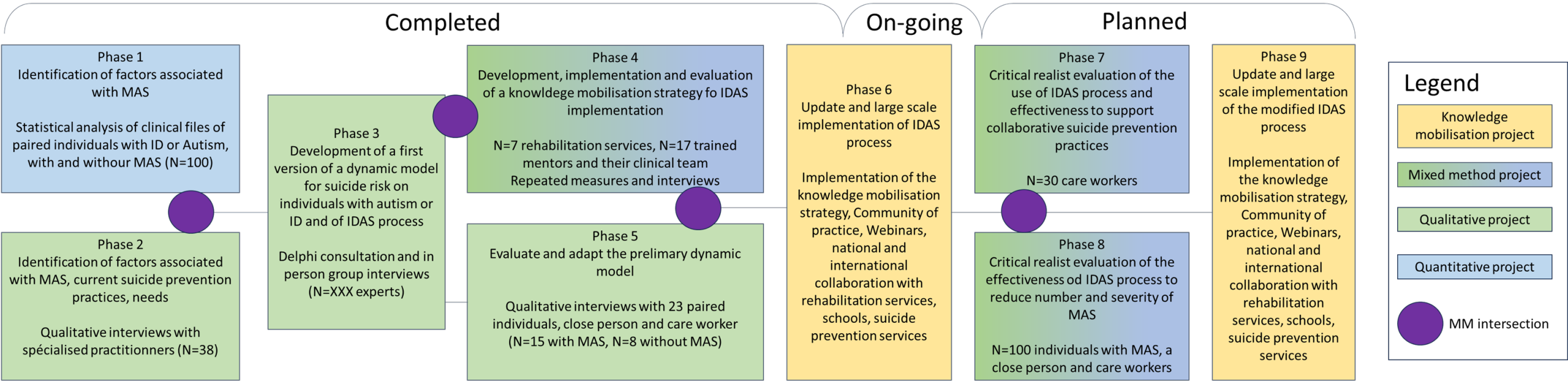
The ARC of Illinois, 14-11-2024

Context: Collaborative research programme



And team / collaborators:

- Researchers: Diane Morin, PhD, Xenia Halmov, MA
- Research centers / infrastructures: CRISE, Institut DITSA, Chaire DI-TC
- Students : S.Thomas-Persechino, L.Millette, LP.Côté, M.Boulé, G.Lord, N.Moussa
- Collaborators: Centre intégrés de santé et services sociaux – directions DI-TSA-DP (N=12)

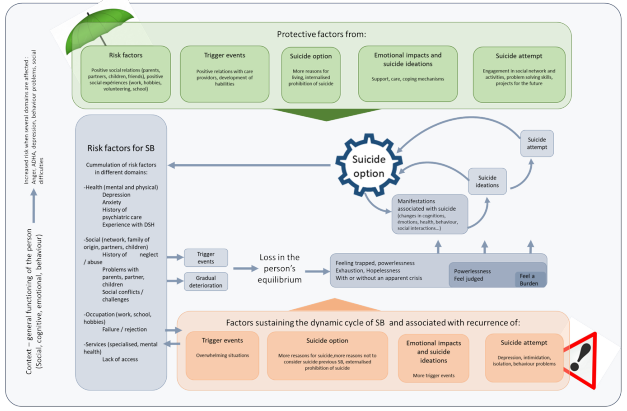
Research outcomes

Objectives

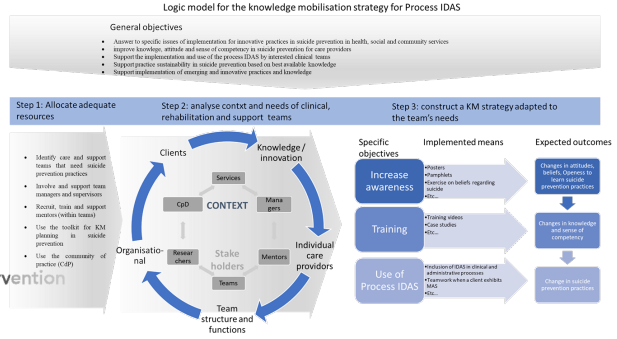
- Structure suicide prevention activities in a collaborative continuum
- Screen and manage SB
- Implement the adequate level of long-term intervention
- Reduce the number and severity of SB
- Support autonomy, implementation and sustainability of process IDAS

Theoretical framework

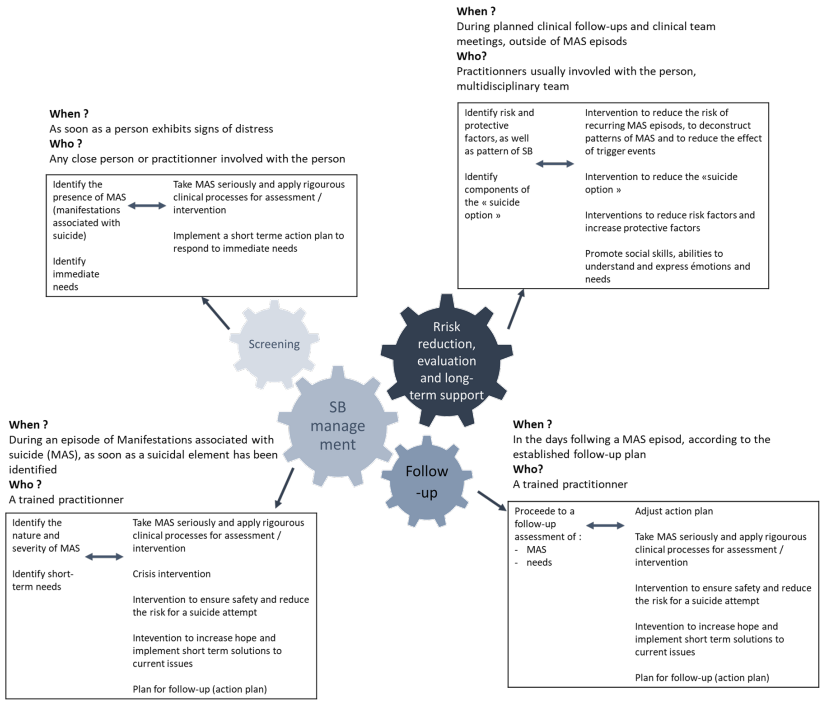
- Motivation – volition model
- Collaborative suicide prevention practices (based on CAMS)
- Validated model of suicide risk in individuals with autism or intellectual disabilities
- Integrated service continuum



- Implementation science (CFIR model and Toolkit for knowledge mobilisation in suicide prevention)



Clinical process



Context: Incidence and characteristics of suicide behaviours in individuals with IDD

	Autists (in general)	Autists (with low levels of needed support)	Intellectual disabilities
All ages	▪ Deaths by suicide ▪ + 10 % of death by suicide had a Dx of autism, but autists represent 1,1 % of the population (Cassidy et al., 2022) ▪ 2-4 times higher than Gen.pop. (Jokiranta-Olkoniemi et al., 2021 ; Kõlves et al., 2021) ▪ Especially prevalent in women (3 times more than men) ▪ Suicide attempts ▪ 19 % (Dow et al., 2021) ▪ 1-35 % (Hedley et al., 2018) ▪ Suicide ideations ▪ 40 % (Balfe et al., 2010) ▪ 11-66 % (Hedley et al., 2018)	▪ Death by suicide ▪ (?) ▪ Suicide attempts ▪ 35 % (Paquette-Smith et al., 2014; Cassidy et al., 2014) ▪ Suicide ideations ▪ 66 % (Cassidy et al., 2014)	▪ Death by suicide ▪ (?) ▪ Suicide attempts ▪ 11 % (Lunsky, 2004) ▪ Suicide ideations ▪ 23 % (Lunsky, 2004)
Youth	▪ Death by suicide ▪ QC : 2 times higher than gen.pop (Diallo et al., 2017) ▪ Suicide attempts ▪ 3,9 % (Chen et al., 2017) ▪ 6 times more the gen.pop. (Moses, 2018) ▪ Suicide ideations ▪ hospitalised : 22 % (Horowitz et al., 2018) ▪ between 2 % and 9,6 % visited emergency rooms (Cervantes et al., 2022 ; Hunsche et al., 2020).	▪ Death by suicide ▪ (?) • Suicide attempts ▪ < 12 months : 18 %, 6 times more than gen.pop. (Moses, 2018) ▪ Suicide ideations ▪ (?)	▪ Death by suicide ▪ (?) ▪ Suicide attempts ▪ 17-48 % (Ludi et al., 2012) ▪ Suicide ideations ▪ 22-60 % (Ludi et al., 2012; Weinheimer, 2019) ▪ 1,3 % visited emergency rooms (Cervantes ket al., 2022).

- Thoughts (non observable if not communicated)
  - Thinking about one's own death when sad
  - Thinking about hiding a knife in one's bedroom
  - Having suicidal flashes, when seeing oneself dead
  - Thinking about relatives' reactions if one was dead or disappeared

- Verbal communications
  - Direct verbal communications: "I want to die", "I want to kill myself"
  - Indirect verbal communications: "I want to join my grandmother at the cemetery", "I would like to be dead", "You would be better off without me", "I want to go far away and not come back", "I want to go away with the birds", "I want to do like… (a person who died by suicide)",…
  - Texts or social media communications

- Non-verbal communications
  - Drawings representing a violent act, a suicidal act, tombs, pain, objects to commit suicide, etc.
  - Miming cutting or strangling oneself

- Self-aggressive behaviour without injury
  - Trying to push an object through the skin (branch, spoon, etc.)
  - Swallowing non-toxic substances or pills without knowing the level of actual danger
  - Trying to strangle oneself with hands or holding breath

- Self-aggressive behaviour with injury or death
  - Swallowing potentially toxic substances or pills
  - Injuring oneself by cutting
  - Strangling or hanging with towel, belt or rope
  - Jumping from a window or a high place
  - Jumping in front of a vehicle
  - Jumping in the water

Observable indicators associated with increased risk of SB

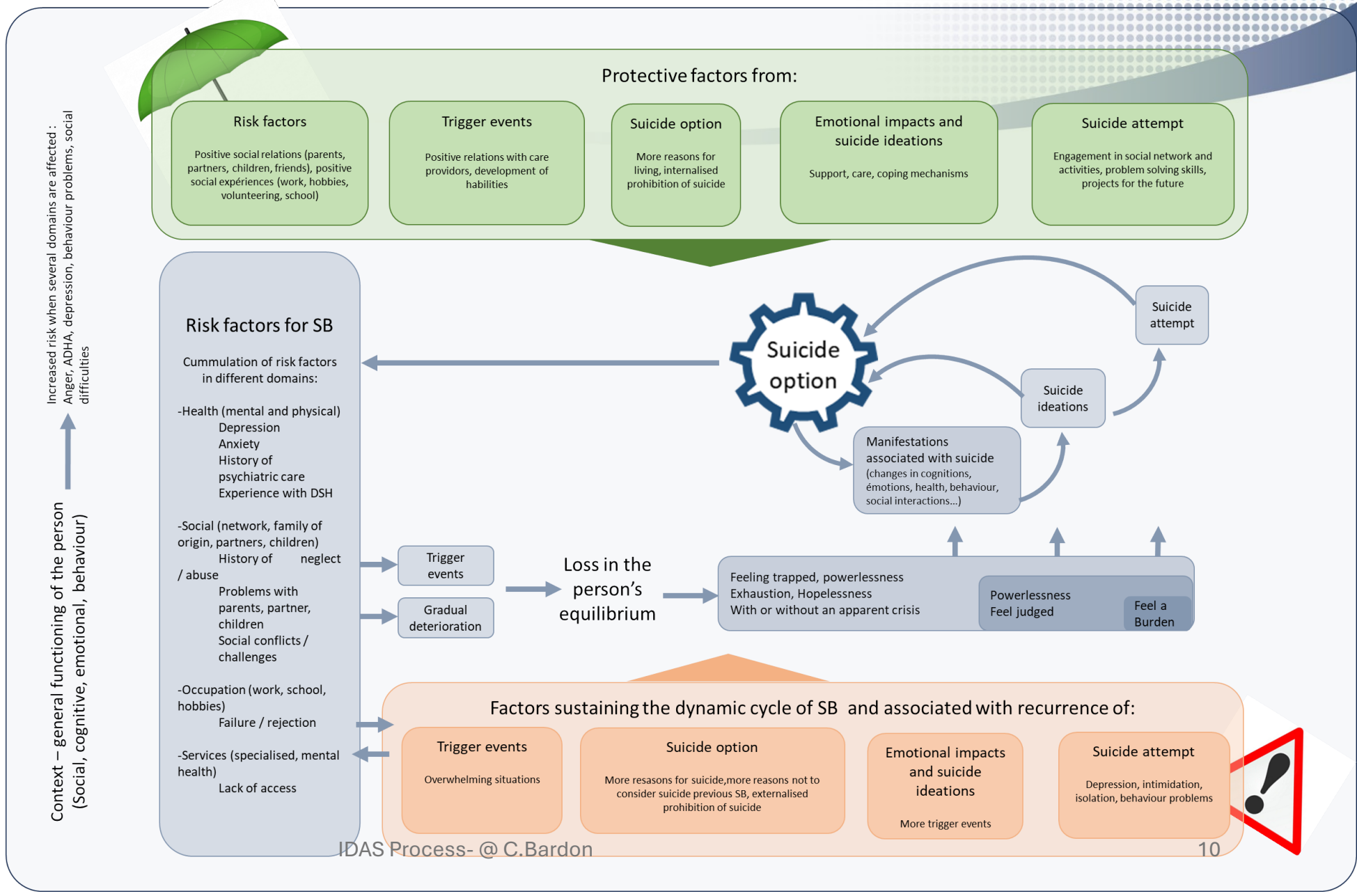
- **Cognitive**: confusion, difficulties concentrating, indecisiveness.
- **Emotional**: mood swings, sadness, anger, irritability, increased worries, fears and insecurities about upcoming situations, anxiety, increased aggressivity, dissatisfaction, disappointment, feelings of incompetence.
- **Behavioural**: changes in behaviours (for better or worse), agitation or withdrawal, increase in usual disruptive behaviours, increase in substance use or in compulsive behaviours, social isolation, increase in help-seeking behaviours, absenteeism.
- **Somatic**: new or increased physical complaints (digestive, back pain, headaches,…)
- **Psychiatric**: increase in symptoms.
- **Autonomic**: increased problems with sleep, appetite, energy,…
- ***Loss of capacities – adaptation difficulties (current)***: *stagnation or regression*
- **Signs of hopelessness**: negative communications regarding the future, resignation, self-depreciation, discontinuation or refusal of treatment, refusing help.

Specificites of IDD in relation to SB

- Cognitions
- Emotions
- Communication
- Social context
  - Required support and autonomy
- Suicide process and associated factors
  - Impulsivity, Substance use, Recurring SB
- Inadequacy of instruments developed for the general population

A dynamic model of MAS in people with IDD

Based on the Motivation – Volition model of suicide behaviour



Suicide option

Experiences with death

- Death of someone close or in the environment
- Exposure to suicidal behaviors in the environment or media
- Hearing about suicide in positive terms in the environment or media

Suicide behavior history

- History of indicators associated with SB
- History of suicidal behavior
- History of self-harm

Understanding and perception of death

- Degree of understanding of death
- Hearing about death in positive terms
- Concerns about death
- Fascination with death or suicide

Reasons to consider suicide

Examples : stop suffering, stop being sick, feel less bad, feel good, go and meet a loved one, change a situation, be heard, etc

Or not to consider suicide

Examples: forbidden by religion, it would make a family member sad, etc.

Functions of suicidality in interaction with others

- Having secondary benefitsassociated with previous suicidal behaviors
- Imitation

Strategies to collect relevant informations for suicide risk assessment

- Use diverse communication strategies and sources of information
  - Direct open questions
  - Indirect questions
  - Visual support (drawings, pictograms,…)
  - Observations
  - Activities
- Attitude
  - Caring, warm, reassuring, patient, welcoming
  - Adapt to the person's emotional level – take their understanding of emotions into consideration – adapt to intensity of crisis
- Validate communication and help seeking
- Reassure the person

Facilitators to exploring suicidal behaviours:

- Adjust to cognitive and social capacities
- Ask unequivocal and clear questions
- Adapt language to the person's capacities
- Start from what the person does and understands (their own words)
- Use a neutral tone in the discussion and questions
- Be sensitive to non-verbal indicators (yours and theirs)
- Reassure the person that they will not be punished, that you are trying to understand in order to help
- Remain open in order to understand without diverting the thinking process with too many questions (tolerate silences, be patient)
- Listen to the person's story from their point of view, encourage them to express their distress
- Use familiar communication strategies

Try to avoid:

- Putting words in the person's mouth
- Suggesting (ex.: did you think about suicide to stop suffering?)
- Disapproving (ex.: I hope you are not thinking about suicide)
- Implying (ex.: did you hide this knife to kill yourself?)
- Interrupting the person's thoughts by asking too many questions
- Interpreting what the person says
- Stigma and guilt (ex.: did you think about the pain people would feel if you died?)
- Too many questions on intent: it may not be the most reliable risk indicator in persons with an ID or ASD
- Give privileges or sanctions because of suicidality.

Other elements to keep in mind

Tendency to acquiesce

- Some persons tend to answer “yes” because they think it is what you want to hear.
- Important: ask several questions differently to assess the actual perception of the person

Refusal to collaborate

- Sometimes, when the person calmed down, they may refuse to discuss what happened and will not collaborate to risk assessment
- Multiply / vary information sources: observe, talk to relatives, friends and colleagues to complete information
- Establish an environment that promotes trust and tolerance to discuss the MAS episod

Follow-up

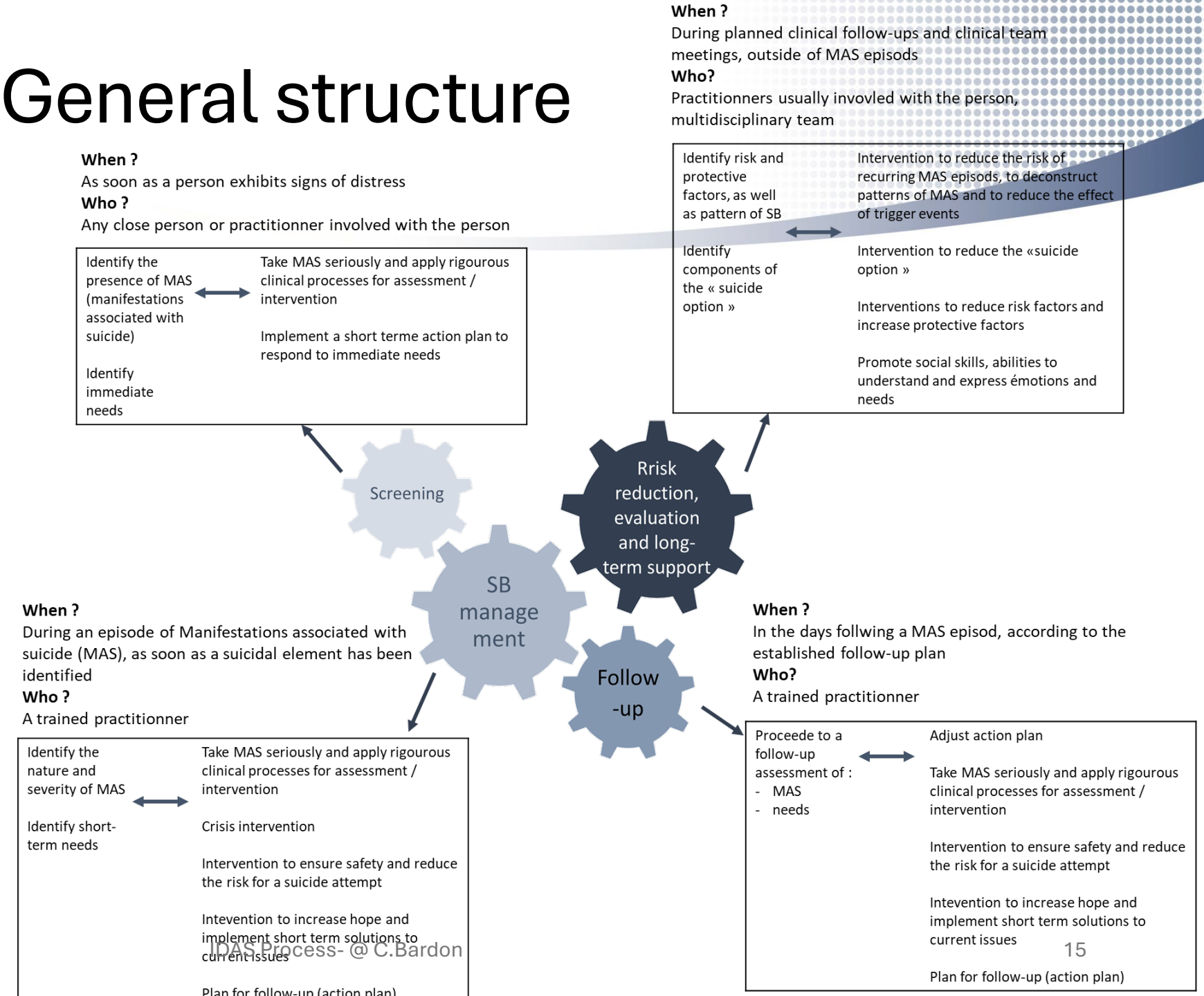
- Wait until the person is calm and safe to come back to the issue of the MAS episod
- Address your perspective and express your needs to support the person

IDAS Process – General structure

Objectives:

Support clinical judgment for MAS identification, management and prevention

Support collaborative work for MAS prevention



Screening individuals with IDD and MAS

- Screening aims to:
  - Identify the presence of MAS
  - Orient action for suicide risk assessment

- Can be performed by trained gatekeepers in the community

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Identify an at-risk person– IDAS screening process

When? Once a person presents a cause for concern and is not clearly presenting MAAS.
If suicidal behaviours or ideations are clearly present, the screening is complete.

Last name, Name:	Screening date :	Date and context of MAAS:
Name of person conducting screening:	Relationship with person:	

Information to collect: Indicators on which to base your **clinical judgment** about the presence of MAAS.

Existing MAAS:
- Verbal and non-verbal communication (indicate exact wording)
- Behaviours
- Thoughts

Elements of suicidal planning
- Method/means, time, location, preparations for death

Danger Assessment
- Access to means, lethality of means (real and perceived by the person), planning ability

Recent changes in the person's normal functioning that are causing concern about the possibility of MAAS. (Including the period in which changes were observed)
- Cognitions, behaviours, emotions, neurovegetative indicators, somatic indicators, psychiatric indicators, loss of skills and a difficulty in adapting to their current situation

Current signs of hopelessness and distress

Reasons and trigger events of the current MAAS episode
- Apparent reasons of the MAAS episode or observed changes.

Observe

Decide

Act

Observe: Collected information
Source: Questions to person, observations, questions to professionals or close persons, person's file

Decide: Decisions resulting from the screening process

The person presents MAAS
- **Yes** – go to the estimation of danger of attempting suicide and analysis of the suicidal episode
- **No** –implement interventions to reduce the person's distress

Act: Intervene to manage the suicidal episode based on the person's needs.

Danger assessment, complete analysis and management of the suicidal episode

Even in the absence of MAAS, it is important to intervene to:
- Explore the sources of change in the normal functioning
- Identify the distress and its sources
- Implement procedures to reduce distress

Managing a MAS episode

assessing level of danger, analyzing the episode, and acting to reduce the danger and distress associated with the current situation

Objectives for MAS episode management

Suicide risk assessment

- Qualify danger of a suicidal act
- Identify presence, nature and intensity of suicidal ideations
- Identify risk and protective factors (including mental health problems)
- Identify trigger events
- Document the person's and their family's history of suicidal behaviour
- Describe hopelessness
- Understand intent and impulsivity
- Understand what is happening without prejudice

Intervention during a suicidal episode

- Ensure safety
- Prevent a suicide attempt
- Increase hope
- Reduce risk of future suicide attempt
- Strengthen proximal protective factors
- Reduce proximal risk factors

➢ **Guide and support intervention**

Allocate the right services at the right time with the right intensity

Elements to consider in suicide risk assessment / intervention with individuals with IDD

- Danger and lethality of considered suicide method
- Self-mutilation and its interaction with suicide
- Importance of clinical judgment when direct verbal communications are difficult
- Tools will never replace clinical judgment, they aim to support it
- Adapt intervention intensity to the actual level of danger and risk
- Do not ignore MAS
- Do not overreact
- Do not reinforce MAS by an inadequate intervention (misplaced increase in attention, positive side effects, overreaction)
- Adapt intervention to language, cognitive, affective capacities
- Use also non-verbal interventions

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Managing the suicidal episode- Suicide prevention plan -Episode (PPS-E)

When? Once a person raises concern regarding a suicidal risk

Name, last name :	PPS-E date :
Name of the person managing the suicidal episode:	Relationship with person :

Information to collect: Indicators on which to base your **clinical judgment** about the suicidal episode and risk of an attempt.
Proximal factors that may increase danger or be protective in the current situation

Episode risk factors:

- History of MAAS (which ones? When?), suicidal behaviours or death, by suicide or otherwise, in the environment (less than 1 year), level of impulsivity/aggressiveness, mental health disorders and associated issues (**behavioural disorders**, ADHD, etc..), type and level of ID and ASD, negative interpersonal relationships or isolation, risk-taking behaviours or injury proneness, current state of disorganization, current state of intoxication, hopelessness, exasperation, discouragement (short, mid-term), planning ability (generally and in relation to suicide behaviour)

Episode protective factors:

- Varied options for expression (needs, emotions, frustrations, asking for help), and problem solving, presence of support during predictable or stressful events, reasons for living, ambivalence in relation to suicide, social support

Critical moments/ trigger events related to the current MAAS episode:

- Recurring situation of powerlessness, accumulation of apparently minor events, major predictable events, major unpredictable emotional events

Environmental demands

- Mismatch between the person's current capacities and the environmental demands

Consequences of the MAAS episode on relationships, activities, emotions, cognitions, entourage, etc.

Observe

Decide

Act

Observe: Collected information
Source: Questions to person, observations, questions to professionals or close persons, person's file

Decide: Decisions resulting from the danger assessment process

- Is there a foreseeable danger of an attempt if the person is left alone?
- Is there a foreseeable danger of an attempt within the next few days?
- Does the person have serious suicidal ideations?
- Could the situation change quickly for the person?

Act: Intervene to manage the suicidal episode based on the person's needs.

Ensure security
Reduce risk of an attempt
Close monitoring
Increase hope
Find solutions to current problems
Take (MAAS) seriously, do not trivialise or minimise

Concluding the process of managing the suicidal episode:
Ensuring that the person understands and feels comfortable with the conclusions reached by the intervention process
Check with the person on how they feel about their suicidal ideations, on the changes made and with the action plan
-The person's ease with the action plan (including the solutions), their willingness and engagement with the action plan, their ability to put the plan into action, help them to put the plan into action (how to help, who will do what? When?), critical moments to monitor in the next hours, days, weeks, status of suicidal ideations and suicide plan
Verify the potential effects of having addressed the subject of MAAS
-Check how the person feels after having talked about their MAAS, explore what was helpful and what made them uncomfortable, support and **intervene with** the person if they are having difficulties with the discussion on suicide, reinforce protective factors, emphasize effective coping strategies, validate help seeking, emphasize strengths and qualities, remind of reasons for living, indicate that you are happy that the person no longer thinks (or less so) of suicide in this moment, that this is positive for them.

Reducing the long-term suicide risk

Risk and protective factors, suicide option, patterns of MAS

Objectives

Assessment

- Complete information
  - Identify more distal risk and protective factors, influencing the construction of suicide risk
- Describe and understand the suicidal process in which the person is engaged
  - Decide what interventions should be implemented to reduce risk

Intervention

- Design and implement the intervention plan to reduce risk factors, reinforce protective factors and modify suicidal processes at play (suicide option, patterns)
  - Interventions to increase well-being, reduce distress

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Intervene to reduce suicidal risk - Suicide Prevention Plan- Risk – SPP-R

When? Outside of any period of disorganization or MAAS

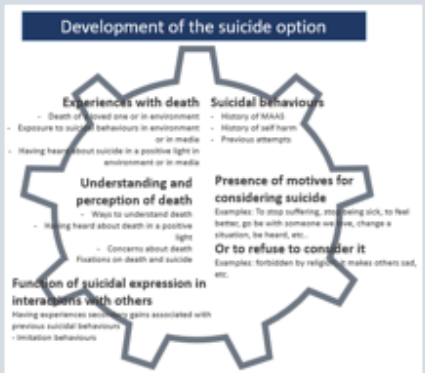
Name, last name :	Period of time covered by SPP-R:
Name of person conducting SPP-R:	Relationship with person :

Information to collect: Indicators on which to base your clinical judgment about:

Risk and protective factors associated with suicidal risk (individual and environmental)

Risk and protective factors are present even in the absence of MAAS. The understanding of these factors broadens with each episode of MAAS. This part of the assessment does not need to be performed with the person at every episode but becomes more complete with each episode and intervention.

Suicide option



The suicide option is built over time and as the person gains experience with suicide and death. It can be developed even if the individual has not had any observable MAAS.

Patterns of MAAS : Understand the patterns and functions, risk of repetition and chronicization in case of repeated MAAS episodes

- Critical moments/ Trigger events and consequences identified during various MAAS episodes, presence of prior MAAS, understanding the function of MAAS by examining one or more episodes (functional assessment), trigger events, types of MAAS, associated distress/ hopelessness elements, consequences

Hypotheses on the links between risk and protective factors, triggers events, MAAS and consequences (In particular answering the question: Why do MAAS play this role for the person rather than other behaviours?)

Observe

Decide

Act

Observe: Collected information
Source: Questions to person, observations, questions to professionals or close persons, person's file

Decide : Decisions made about :

Risk factors
The person has risk factors that are important to address to diminish distress and the risk of MAAS

Suicide option
The person presents elements associated to the suicide option

Patterns of MAAS
The person presents patterns of MAAS that can be acted upon

Act : Intervene to reduce:

Risk factors
- Increase protective factors, decrease risk factors, increase social skills and ability to express emotions and needs, adapt environmental structures, treat health issues (physical and mental), work on self esteem

Suicide option
- Reduce fixations, psychoeducation on death and suicide, work on positive perceptions or on misconceptions on death and suicide, understand and reduce secondary benefits (within interactions with others) of MAAS, reduce the use of MAAS in interactions with others, reframing in relation to suicide, suffering, help seeking and solutions, understanding the impact of MAAS on the entourage (consequences)

Patterns de MAAS
Reduce the risk of recurrence, deconstruct the patterns and functions of MAAS, reduce impact of trigger events

Conclusion

Specificities of suicide risk and suicide risk management in persons with IDD

- Persons with IDD present high levels of risk for SB
- SB can manifest themselves in varied verbal and non-verbal ways that can be difficult to identify
  - Recurring SB is an important issue
- Suicide risk assessment instruments developed for the general population may be inadequate for these groups
- It is important to consider suicide assessment and prevention in a longitudinal process
- Collaboration and interdisciplinarity are key components of suicide prevention
- The IDAS Process can support collaboration in screening, SB episode management and risk reduction

General recommendations for intervention and use of *IDAS Process*

- Intervention objectives must be aligned with assessment results
- Suicide prevention activities should be embedded within usual care routines
- Various activities should be combined within a comprehensive strategy for suicide prevention
- General care and support practices for persons with IDD can include suicide prevention strategies

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Thank you!

Contact us at: bardon.cecile@uqam.ca

To learn more about clinical instruments: www.ditsasuicide.ca