CAREGIVERS’ PERSPECTIVES IN A MENTAL HEALTH CRISIS:
WHAT WE HEARD FROM THE COMMUNITY

The Mental Illness Caregivers’ Association (MICA)

MICA
Mental Illness
Caregivers Association
of Canada

DRAFT 4

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Table of Contents

ABOUT THIS REPORT

New mental health crisis response models aimed at connecting people to more effective and robust mental health systems are being considered and developed by many Canadian cities, including Ottawa. Caregivers are often at ground zero of the mental health crisis of their loved ones and so their perspective and the perspective of organizations serving those living with a mental illness are critical to the redesign of a crisis response. Failing to include these perspectives risks missing the mark.

The Mental Illness Caregiver Association[1] (MICA), wishing to have input to the design of a new mental health crisis response for Ottawa, recently put out an 8 stage model with recommendations that describes the thoughts, feelings and expectations of caregivers when a 911 mental health crisis call is made. It was sent to caregivers as well as organizations serving caregivers and those living with a mental illness, with the ultimate goal to dig deeper into caregivers' needs, to understand what other organizations are working on and possibilities for collaboration.

This "What We Heard" report begins with the initial 8 stage model and recommendations sent out to our community. It is followed by the questions we asked of individuals and organizations. We provide a general summary of what we heard and conclude with an Action Plan.

We are grateful to several individual caregivers for their careful reading and input. We thank the following organizations for taking the time to engage with us: The Royal Ottawa Mental Health Centre, the Canadian Mental Health Association, Ontario Family Caregivers' Advisory Network, TEAM to Effect Change, Ottawa's 613-819 Black Hub, Home on the Hill, the Ottawa Paramedic Service, the Ontario Caregiver Organization, OASIS, the BC Schizophrenia Society.

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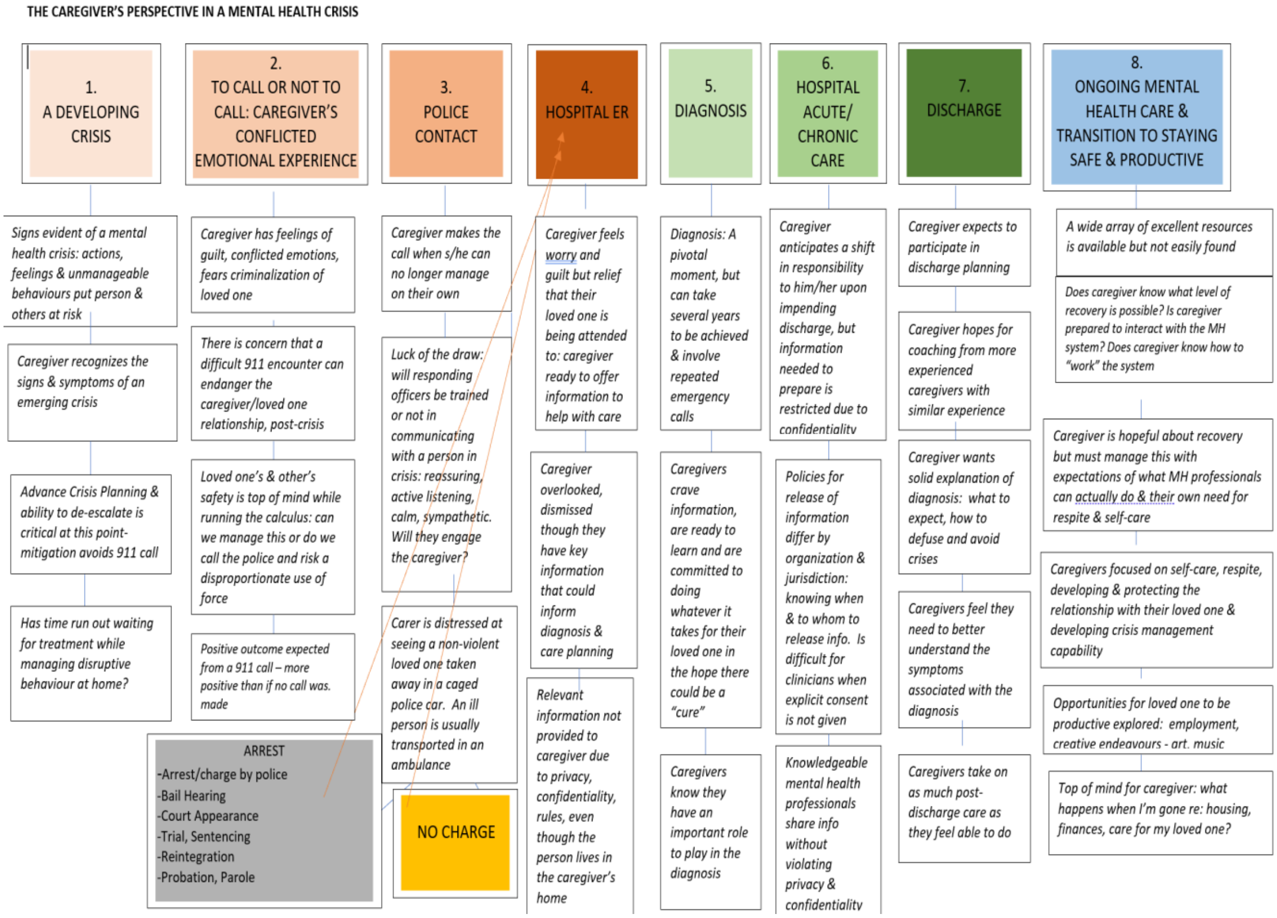
[1] The Mental Illness Caregiver Association (MICA) is a non-profit organization comprised of family members and caregivers committed to ensuring that caregivers are aware of and can access resources to provide support and lifelong care for their loved ones living with a mental illness. The goal of our work is to develop and implement solutions that have a lasting and positive impact on the quality of life of caregivers and their loved ones living with a mental illness.

THE MODEL AND RECOMMENDATIONS SENT OUT FOR DISCUSSION



THE CAREGIVER'S PERSPECTIVE IN A MENTAL HEALTH CRISIS

1. A DEVELOPING CRISIS

Signs evident of a mental health crisis: actions, feelings & unmanageable behaviours put person & others at risk

Caregiver recognizes the signs & symptoms of an emerging crisis

Advance Crisis Planning & ability to de-escalate is critical at this point- mitigation avoids 911 call

Has time run out waiting for treatment while managing disruptive behaviour at home?

2. TO CALL OR NOT TO CALL: CAREGIVER'S CONFLICTED EMOTIONAL EXPERIENCE

Caregiver has feelings of guilt, conflicted emotions, fears criminalization of loved one

There is concern that a difficult 911 encounter can endanger the caregiver/loved one relationship, post-crisis

Loved one's & other's safety is top of mind while running the calculus: can we manage this or do we call the police and risk a disproportionate use of force

Positive outcome expected from a 911 call – more positive than if no call was. made

ARREST
-Arrest/charge by police
-Bail Hearing
-Court Appearance
-Trial, Sentencing
-Reintegration
-Probation, Parole

3. POLICE CONTACT

Caregiver makes the call when s/he can no longer manage on their own

Luck of the draw: will responding officers be trained or not in communicating with a person in crisis: reassuring, active listening, calm, sympathetic. Will they engage the caregiver?

Carer is distressed at seeing a non-violent loved one taken away in a caged police car. An ill person is usually transported in an ambulance

NO CHARGE

4. HOSPITAL ER

Caregiver feels worry and guilt but relief that their loved one is being attended to: caregiver ready to offer information to help with care

Caregiver overlooked, dismissed though they have key information that could inform diagnosis & care planning

Relevant information not provided to caregiver due to privacy, confidentiality, rules, even though the person lives in the caregiver's home

5. DIAGNOSIS

Diagnosis: A pivotal moment, but can take several years to be achieved & involve repeated emergency calls

Caregivers crave information, are ready to learn and are committed to doing whatever it takes for their loved one in the hope there could be a "cure"

Caregivers know they have an important role to play in the diagnosis

6. HOSPITAL ACUTE/ CHRONIC CARE

Caregiver anticipates a shift in responsibility to him/her upon impending discharge, but information needed to prepare is restricted due to confidentiality

Policies for release of information differ by organization & jurisdiction: knowing when & to whom to release info. Is difficult for clinicians when explicit consent is not given

Knowledgeable mental health professionals share info without violating privacy & confidentiality

7. DISCHARGE

Caregiver expects to participate in discharge planning

Caregiver hopes for coaching from more experienced caregivers with similar experience

Caregiver wants solid explanation of diagnosis: what to expect, how to defuse and avoid crises

Caregivers feel they need to better understand the symptoms associated with the diagnosis

Caregivers take on as much post-discharge care as they feel able to do

8. ONGOING MENTAL HEALTH CARE & TRANSITION TO STAYING SAFE & PRODUCTIVE

A wide array of excellent resources is available but not easily found

Does caregiver know what level of recovery is possible? Is caregiver prepared to interact with the MH system? Does caregiver know how to "work" the system

Caregiver is hopeful about recovery but must manage this with expectations of what MH professionals can actually do & their own need for respite & self-care

Caregivers focused on self-care, respite, developing & protecting the relationship with their loved one & developing crisis management capability

Opportunities for loved one to be productive explored: employment, creative endeavours - art, music

Top of mind for caregiver: what happens when I'm gone re: housing, finances, care for my loved one?

Recommendations for action and change were proposed for each of the 8 stages in the model above. They are summarized as follows:

Training/Preparing caregivers	Mental Health Crisis Response Teams	Diagnosis	Discharge & Discharge Planning	Ongoing Care & Recovery
• Provide information on various mental illnesses, treatment options, legislation and recovery action planning • Train caregivers in Cognitive Behaviour Therapy (CBT) & other concepts useful in managing difficult situations • Train caregivers to document/describe mental health crisis behaviours in order to provide input to response teams & to the diagnosis	• Develop a mobile crisis response team of mental health-trained professionals to respond to mental health crisis calls • Consider whether un-uniformed team members & an ambulance might be a preferred visual • Improve the preparedness of responders by training them on anti-stigma education, how to defuse/de-escalate interactions • Include caregivers in crisis team training to share their perspectives	• With due regard to the rights of the person living with a mental illness, establish protocols in the treatment facility that involve caregivers in developing a diagnosis based on their observations & documented behaviour • Convene caregivers with the treatment team to discuss the diagnosis & prognosis • Prior to discharge, make family peer support & education available in the treatment facility for caregivers	• Orient & train new/inexperienced caregivers to the new reality of being a caregiver • Provide support & acknowledgement for those continuing in the role of caregiver • Formalize a collaborative discharge planning process between the treatment team & the caregiver • Provide post-discharge coaching & support to caregivers	• Make financial support information available especially for caregivers facing additional financial challenges due to their caregiving role • Support caregiver organizations in their efforts to develop employment strategies & other productive skills such as art, music, & woodworking for those living with a mental illness • Provide supports to organizations planning for housing, finances & other necessities that will be needed when the caregiver is "gone"

QUESTIONS WE ASKED OF CAREGIVERS AND CAREGIVER ORGANIZATIONS

Based on the model and recommendations we put the following questions to caregivers and caregiver organizations.

QUESTIONS FOR CAREGIVERS	QUESTIONS FOR ORGANIZATIONS DELIVERING MENTAL HEALTH PROGRAMS/SERVICES
- What have we missed in the stages depicted in our model?	- What are your thoughts on the information presented here: gaps, missed opportunities
- What could be better explained?	- What is your organization working on that aligns with this work presented here?
- Thinking about how to increase understanding and support for caregivers and their loved ones living with a mental illness, where should MICA present this information, i.e., what audiences, events organizations?	- How can you help MICA to circulate this document wider, i.e., can you share it with your audiences/members and if so how and when?

WHAT WE HEARD

While input from caregivers themselves was not as exhaustive as we had wished, participation from organizations serving caregivers was enthusiastic and encouraging. Recognizing the importance of deeper and wider consultations with caregivers themselves, we will find ways to reach out to caregivers and have their voices heard.

We heard from caregivers, organizations working with caregivers, and groups working towards changes in mental health legislation, procedures and service delivery. In answer to the questions we posed, the community identified gaps in our model, identified projects in progress that align with the work presented here and around which we could make common cause. They recommended and shared our model with other audiences, organizations and people who they thought should be engaged in this discussion. The "each one tell one" approach to the distribution of our paper yielded a rich picture of projects underway to better serve those living with a mental illness and their caregivers. This approach served to spread the news about what organizations are doing and sowed the seeds for collaboration among groups and individuals.

We heard about the following projects:

- a new model of mental health crisis response being piloted by paramedics

- a proposal for community-led, independent of police crisis response that is respectful of diversity and marginalized people

- current crisis stabilization and walk-in clinics and long-range interest in developing similar clinics

- development of tips and strategies for caregivers in police-led crisis response calls

- suicide and suicide prevention strategies

- efforts to revisit the Ontario all-party committee's Recommendations 21 and 22 which recommended the province set up a task force to reform laws on involuntary treatment and privacy and consent and capacity

- a mobile friendly web app designed by family caregivers for family caregivers

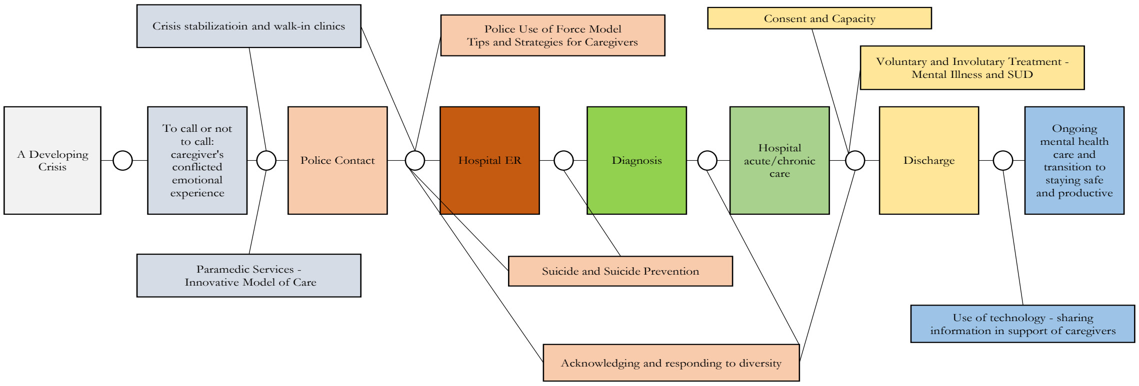
We also received very useful and encouraging comments on the 8-step model itself: ways to adapt it to other uses and ways to flesh it out to provide further information/education for readers. Most notable of these are:

- Add a box on preventing crisis and recovery
- Include the issue of consent and capacity
- Add the issue of voluntary/involuntary treatment
- Depict the model as an iterative process
- Use the power of presentation technology to allow readers to over on and blow-up boxes to get more information/explanation of an issue

We will examine these, and our resources to determine what is achievable.

With respect to the projects we were told about, though we've attempted to report on projects against the relevant boxes in our model, some projects (such as caregiver education) transcend boxes and are relevant to the entire model. The diagram below links the projects we were told about to our model.

What We Heard - Along the Path to Recovery



1 - Draft - 23 March 2022

We conclude our report with a plan we wish to put into action in partnership with some of the organizations we engaged.

MICA is a small organization with limited resources and so must choose its projects based on its capacity and on the willingness and ability of its partners to collaborate. In developing the Action Plan below, the following were considered:
- what we heard from respondents
- how our involvement might further work already underway by others
- how we might repurpose existing materials to meet our community's needs
- the extent to which our work in an area might have a ripple effect and deliver wider and more encompassing benefits to those living with a mental illness

ACTION PLAN

Caregivers' Perspective in a Mental Health Crisis – Draft Action Plan	
Action	**Potential Partners**
Emergency Preparedness Plan	MICA and interested partners
Involuntary Treatment and Consent and Capacity Call to action in response to the 2011 commitment made by the province of Ontario to set up a task force focused on reforming our laws on involuntary treatment and privacy	MICA and interested partners
Organize a Caregiver Summit to be held in Toronto on 10 September – Police Use of Force Model Outcome – call to action with recommendations regarding changes to the police use of force model	MICA and interested partners
Conduct preliminary research - crisis stabilization and walk-in clinic	MICA in consulation with organizations supporting similar initiatives