

THE PATH FORWARD

BACKGROUND

The question of “what will happen to the people we care for when we can no longer care for them?” has long been an issue of concern for families and other caregivers of persons living with mental illness and/or substance use disorder. We believe more needs to be done to support caregivers planning for when they are gone

Our response - a collaborative effort involving Mental Illness Caregivers Association (MICA) and the Association of Relatives and Friends of the Mentally Ill (ARAFMI) - the peak body for unpaid carers of people experiencing mental ill-health in Queensland, Australia) focused on mapping out and developing solutions aimed at addressing this pressing concern

Getting things started – a literature review/environmental scan and a toolkit – a survey and planning guide – used to invite caregivers to share their stories and tell us what would their plan for when you are gone need to include - to address the gaps and at what cost?

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WHAT WE LEARNED AND HEARD ALONG THE WAY

Ontario could benefit from introducing a province-wide future planning initiative adopting a more proactive and integrated approach enhancing coordination between healthcare, housing, financial and legal systems – it is an opportunity to ensure continuity of care and reduce the long-term burden on emergency and institutional services.

Survey results - the most significant gap is continued access to personal supports when the caregiver is gone – at risk, is the mental and physical well-being of those they care for. Majority of respondents in both Australia and Canada indicated they do not have plans in place and would welcome assistance in the preparation of planning that addresses the needs of those they care for when they are gone.

Planning guide - caregivers indicated planning needs to: address gaps in personal and community supports; provide for legal, financial and property management supports as well as ensuring arrangements are in place to provide for a coordinated and collaborative approach to supporting the implementation of their plans

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► **WHAT NEXT – A CAREGIVER FUTURE PLANNING PILOT PROJECT**

“Continuing to explore the possibilities around a caregiver focused approach supported by a coordinating organization with the mandate and resources to support caregivers in developing a sustainable plan and its implementation in partnership with community organizations and others that ensures continuity of care when the caregiver is gone or unable to continue providing care”

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WHAT NEXT – A CAREGIVER FUTURE PLANNING PILOT PROJECT

IT IS AN OPPORTUNITY TO:

- Raise awareness and support advocacy efforts – community outreach and caregiver engagement
- Engage and seek the support of the Ontario government and others
- Focus on service delivery options and core components of support that will inform recommendations regarding a service delivery model
- Build capacity and partnerships based on care planning linking personal and community supports to legal, financial and property management supports
- Co-develop and test tools, test assumptions and develop evaluation metrics

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WHAT NEXT – A CAREGIVER FUTURE PLANNING PILOT PROJECT

How?

Hosting caregiver workshops encouraging caregivers to both complete the survey and to develop plans for those they care for based on the planning guide

Hosting caregiver workshops involving subject matter experts – social workers, financial planners, lawyers and property managers – presenting advice and answering questions for caregivers considering the possibility of completing the planning guide

Linking current practices, services and programs to an expanded mandate that includes the coordination of legal, financial and property management planning

Deliverables

Final draft of survey tool and planning guide; summary of what was heard at workshops; summary of what was learned as caregivers shared their experience completing both the survey tool and the planning guide, and recommendations regarding next steps

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OUR ASK - A LETTER OF SUPPORT

I agree there is an urgent need to support caregivers planning for when they are gone.

I also agree the path forward is the creation of an organization with the mandate and resources to support caregivers in the development of a sustainable plan now and its implementation when they are gone

I support the plan for a Caregiver Future Planning Pilot Project that would be rooted in the following principles:

A caregiver-focused approach supported by provincial funding and policy alignment, giving caregivers access to resources that help them plan for when they are gone or unable to continue providing care.

A coordinating organization with the mandate, authority, and resources to help caregivers develop sustainable care, housing, legal, financial, and property management plans for their loved ones.

Partnerships with community organizations, health and housing agencies, and legal and financial experts to ensure continuity of care, stable housing, and social inclusion for affected individuals for affected individuals