



DISCOVERY PHASE REPORT

Over the summer, the Changing CARE: Embrace team set out to engage a large and representative number of family caregivers and health providers across Cornwall, Stormont, Dundas, Glengary and Akwesasne.

Listening to family caregivers:

If you were one of the 200 family caregivers who shared your experience with us, you understand how in-depth our conversations were and the effort we made to understand the challenges of family caregivers when they interact with health providers and the addiction and mental health system. We appreciate not only the time that you took to share your experiences with us but also your ideas about what can be done to improve the experience for family caregivers moving forward.

Listening to health providers:

We appreciate the individual contributions of 300 addiction and mental health providers, too. Some attended focus group discussions and others responded to our lengthy survey. We explored how health providers were interacting with caregivers and what benefits providers derive from working with caregivers. We also explored in detail what gets in the way of more widespread relationships and partnerships between patients, family caregivers, health providers, and the broader health and community care system.

New projects are underway:

Now, we have results to share. In this report, we highlight health system barriers and what can be done to create a better experience for family caregivers, health providers and patients. We also have exciting news to share about five new projects that are getting started to improve the situation for everyone in our addiction and mental health system.

Read on to learn where we have been and what we are doing to support family caregivers and health providers in adopting a more collaborative and coordinated approach to patient care across Cornwall, SDG and Akwesasne.



What Makes a Good Experience for FAMILY CAREGIVERS

We interviewed 200 family caregivers across Cornwall, Stormont, Dundas, Glengary and Akwesasne, Ontario, to discover what could be done to improve their experience in the addiction and mental health system. We discovered a number of unmet needs, some universal barriers, and a health system culture in need of some repair.

To improve their overall experience, 87% of family caregivers need:

1. Information, education and support groups that meet the specific needs of families affected by addiction and mental health

Four health system barriers that caregivers struggle to overcome:

1. Access to a healthcare professional that can make a referral for addiction and mental health services
2. Navigating the addiction and mental health system
 - Family caregivers often have difficulty understanding the various parts of the addiction and mental health system
 - Discovering all available addiction and mental health services is equally tough
3. Lengthy wait times for their loved ones to receive the necessary specialized care
4. Not being involved in discharge planning, especially when caregivers have concerns about the safety of their loved one or members of their family unit

A culture shift will be needed to meet the expectations of caregivers:

1. When the problem is addiction or mental health, caregivers and their loved ones feel that they are labelled and stigmatized within the health system
2. At times, caregivers feel that providers lack the knowledge and sensitivity training they need to support family caregivers
3. Caregivers report that more immediate information about the diagnosis of their loved one would help, so that they can understand what is happening and start to gather information and support
4. When the mandate of each healthcare service or facility is not clearly stated, caregivers are often sent in circles when trying to coordinate care



What are the Benefits and Barriers for HEALTH PROVIDERS

We asked 300 addiction and mental health providers across Cornwall, Stormont, Dundas, Glengarry and Akwesasne, Ontario, about their relationships with family caregivers and discovered that they currently engage about half (55%) of their patient's caregivers. That said, a remarkable 92% of all providers recognize the value caregivers bring and would like to connect more often, if the barriers can be overcome.

Health providers told us about four ways they benefit from family caregiver involvement:

1. Information that helps providers understand the patient as a whole person
2. Assistance with treatment planning
3. Support with the continuing care of the patient
4. Improved health outcomes for the patient

Providers sometimes find that caregiver involvement is not beneficial, due to:

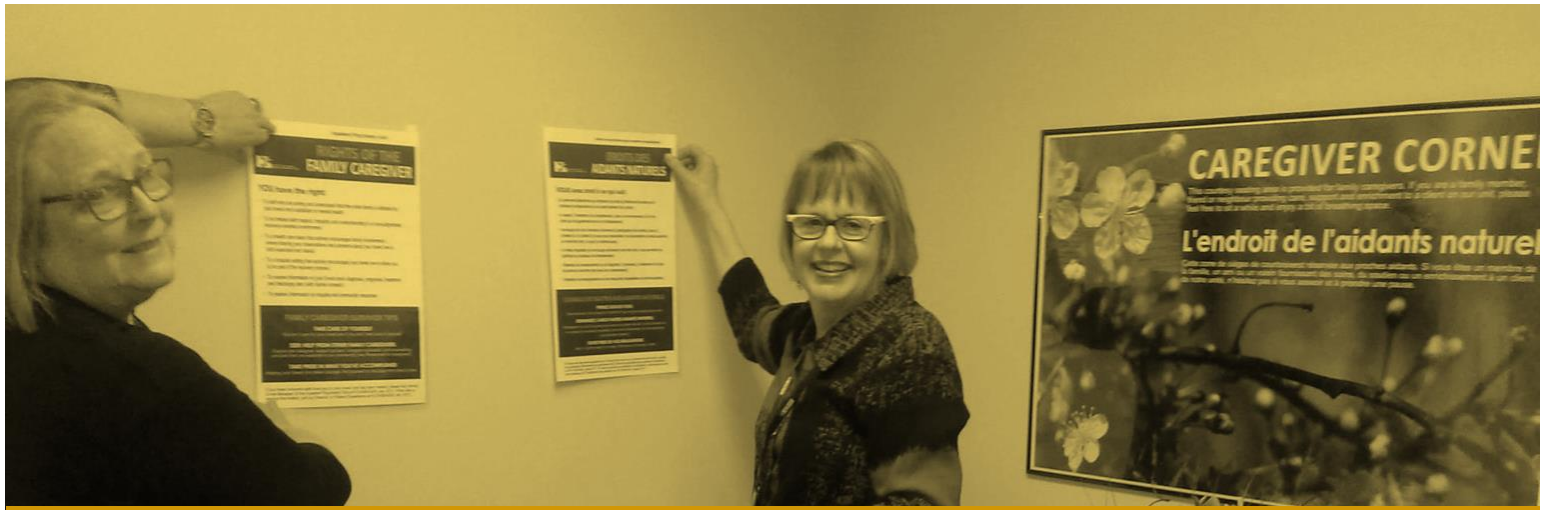
1. Unhealthy family dynamics that affect the patient's progress in treatment
2. Caregiver actions that can disrupt patient care

What prevents providers from doing more?

1. Providers feel pulled in multiple directions and want to make the best use of their time
2. Sometimes providers feel that their hands are tied by privacy and consent policies and laws; and other times, patients will direct providers to withhold information from family caregivers

What more can be done? Health providers suggest:

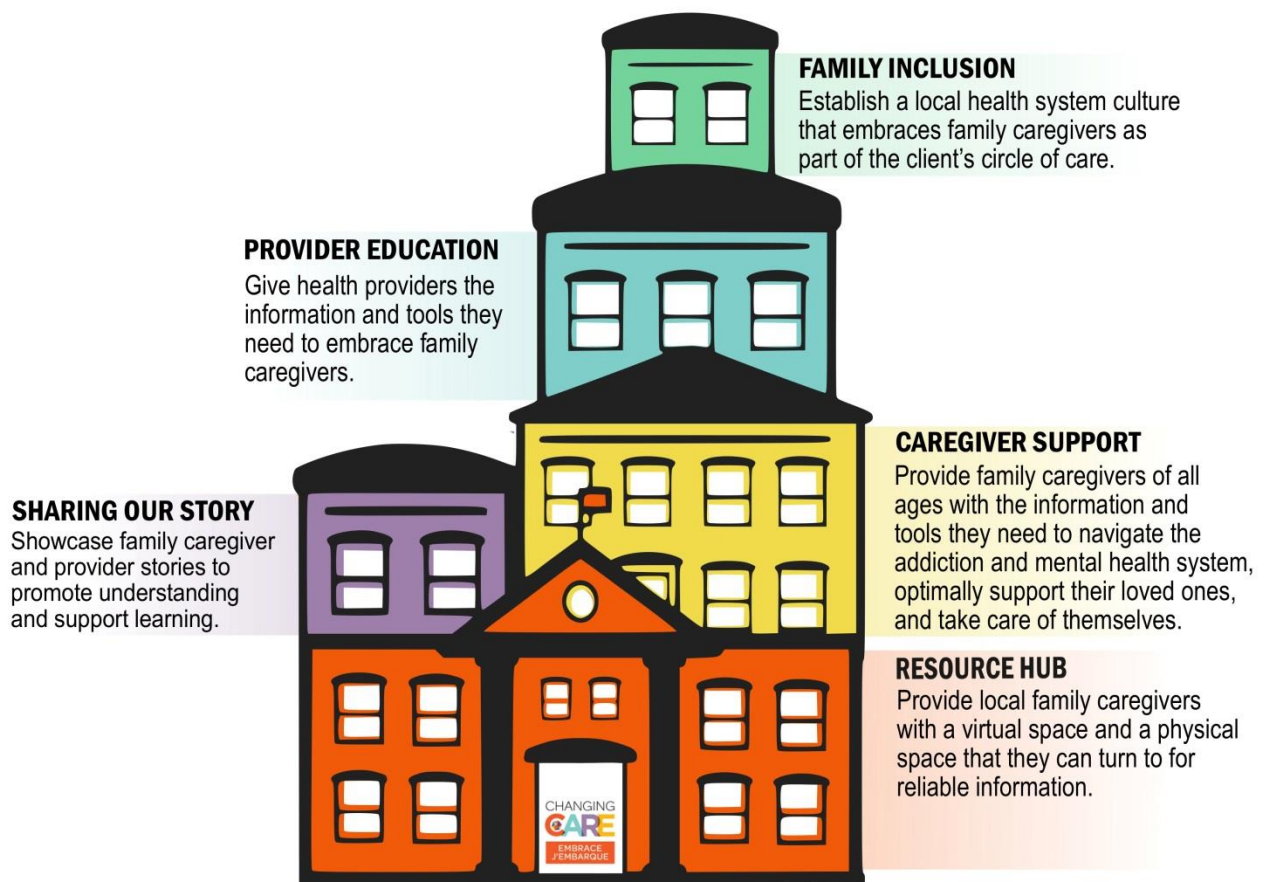
1. Caregiver education and support with:
 - Understanding the health condition affecting their loved one
 - The treatment approach and what to expect
 - The best approach to supporting their loved one
 - Navigating the health system
 - Access to hospital and community resources
 - Self-care for the family caregiver
2. Provider training and support with:
 - Identifying family caregivers
 - Engaging caregivers in patient care
3. Changes to the health system culture:
 - Freeing up time to interact with caregivers
 - Proactive contact with caregivers
 - More frequent family meetings and patient care conferences



Bringing it all Together IMPROVING THE CAREGIVER EXPERIENCE

Having identified the common experiences and challenges of family caregivers in the addiction and mental health system, and understood the frustrations of health providers with the status quo, we are ready to act.

Changing CARE: Embrace is launching five project streams, using an experience-based co-design model that brings family caregivers and health providers together to both plan and do the heavy lifting of changing the addiction and mental health system.



CAREGIVER FRIENDLY FRAMEWORK

Changing CARE: Embrace is committed to bringing caregivers and health providers together to reimagine, redesign and improve our addiction and mental health care system. To learn more or get involved, visit www.cornwallhospital.ca/en/embrace, find us on Twitter @CaregiversSDG and Facebook @EmbraceCareivers.