

Ontario Caregiver Recognition Act

The Right of Caregivers to Access Health Information of Relatives with Mental Health and Addiction Issues

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Outline

- Objectives and key provisions of the proposed OCRA
- Definition of key terms
 - Allied caregiver
 - Informal Health Information Custodian
- Overview of proposed OCRA
- Rationale and justifications
 - Best practice approach
 - Federal and provincial mental health strategies
- The Vision



OBJECTIVES AND KEY PROVISIONS

Objectives of the proposed Ontario Caregiver Recognition Act (OCRA)

- Establish a legislative framework to recognize
 - The roles and contributions of caregivers
 - The right of **allied caregivers** to access health information of the Person they care for, while respecting the right to confidentiality of the Person
 - Broader aspects of recognition and supports to caregivers

Key Provisions of (proposed) OCRA

- Designate **allied caregivers** as informal health information custodians
- Develop procedures to **safeguard right of allied caregivers** to access health information of the Person **and right of the Person** to maintain confidentiality
- Establish OCRA Council to oversee implementation and monitoring of the Act
- Periodic review and consultation to **expand recognition and support** to caregiver

DEFINITION OF KEY TERMS

Key definitions

- The Person: An individual living with mental health and addictions issues
- Caregiver: An individual within the Person's social network who provides care and support without financial compensation
- Allied caregiver: A **designated** caregiver who provides support to, and often live with the Person


Key definitions

- Health Information Custodian (HIC)
 - a person or organization who has custody or control of personal health information as a result of their formal (usually paid) duties stipulated in PHIPA (2004)

- Informal HIC
 - A designated caregiver in the social network who has knowledge of health information of the Person as a result of providing unpaid care and support to the Person

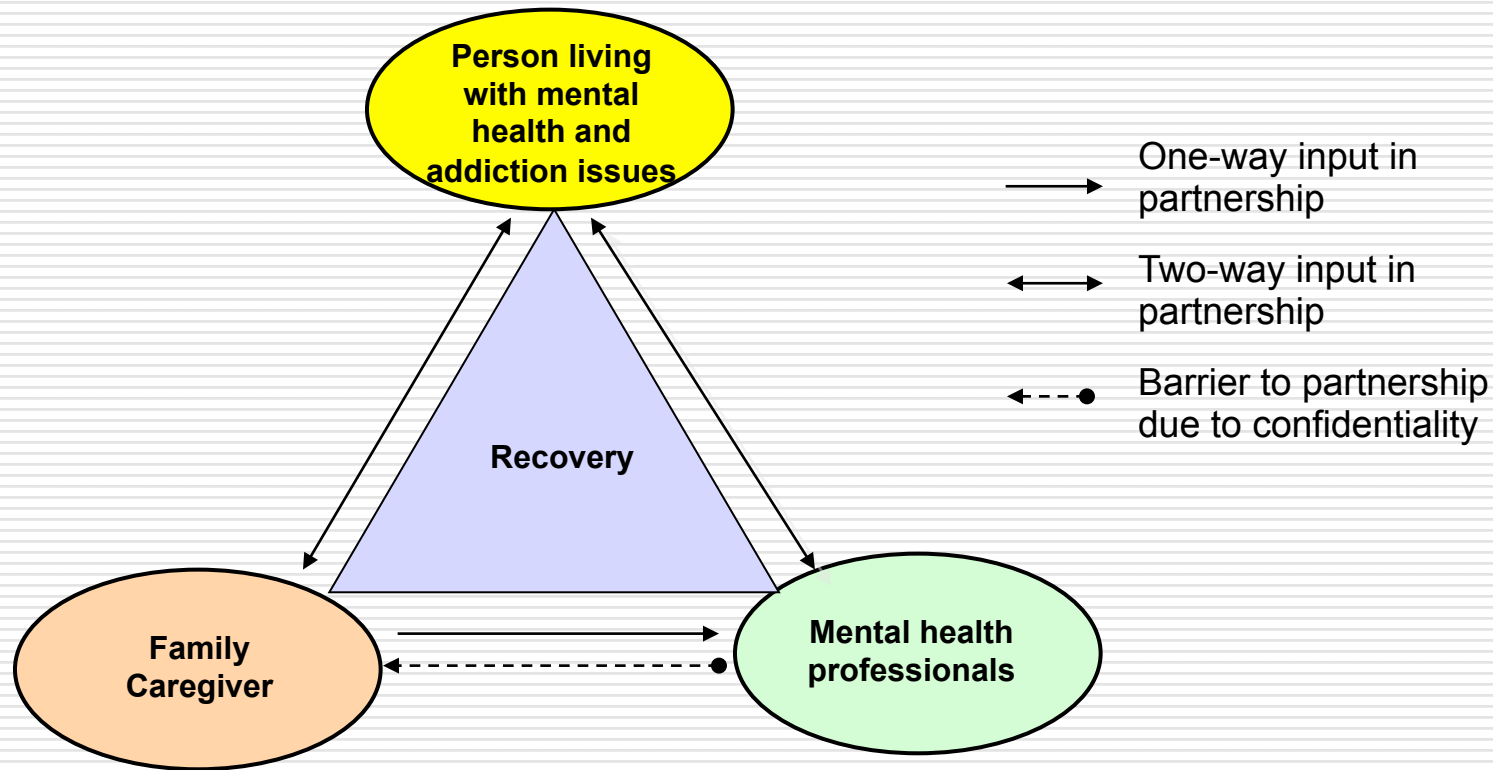
Allied caregiver as informal Health Information Custodian (HIC)

- “...access to their family member’s care plan
- to be included respectfully by physicians and others in discussions of how and by whom that plan will be implemented” (Senate Committee Report, 2006, p. 29)
- The “need to know” principle (Szmukler & Bloch, 1997) to assist them in their caring and supportive role.

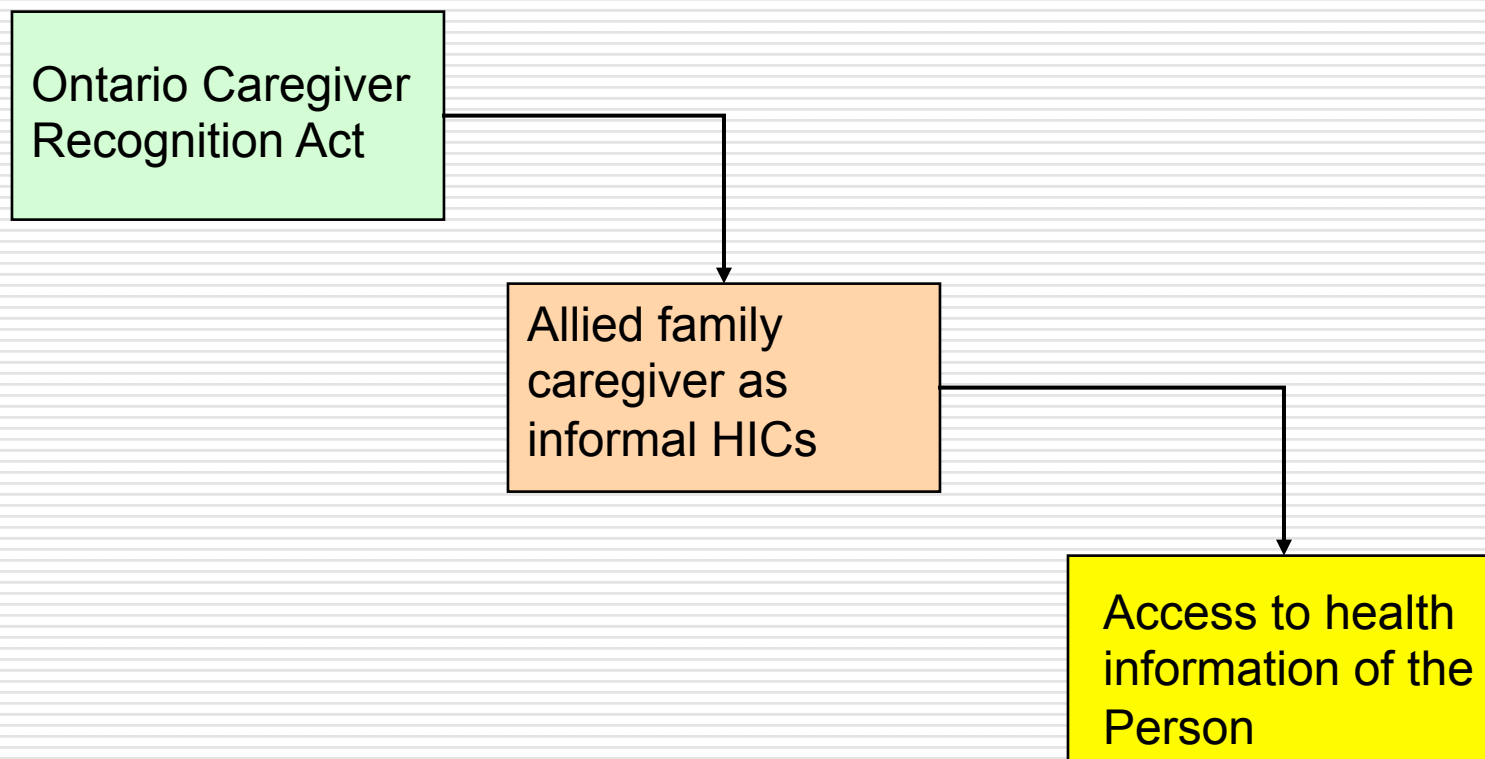


OVERVIEW OF PROPOSED OCRA

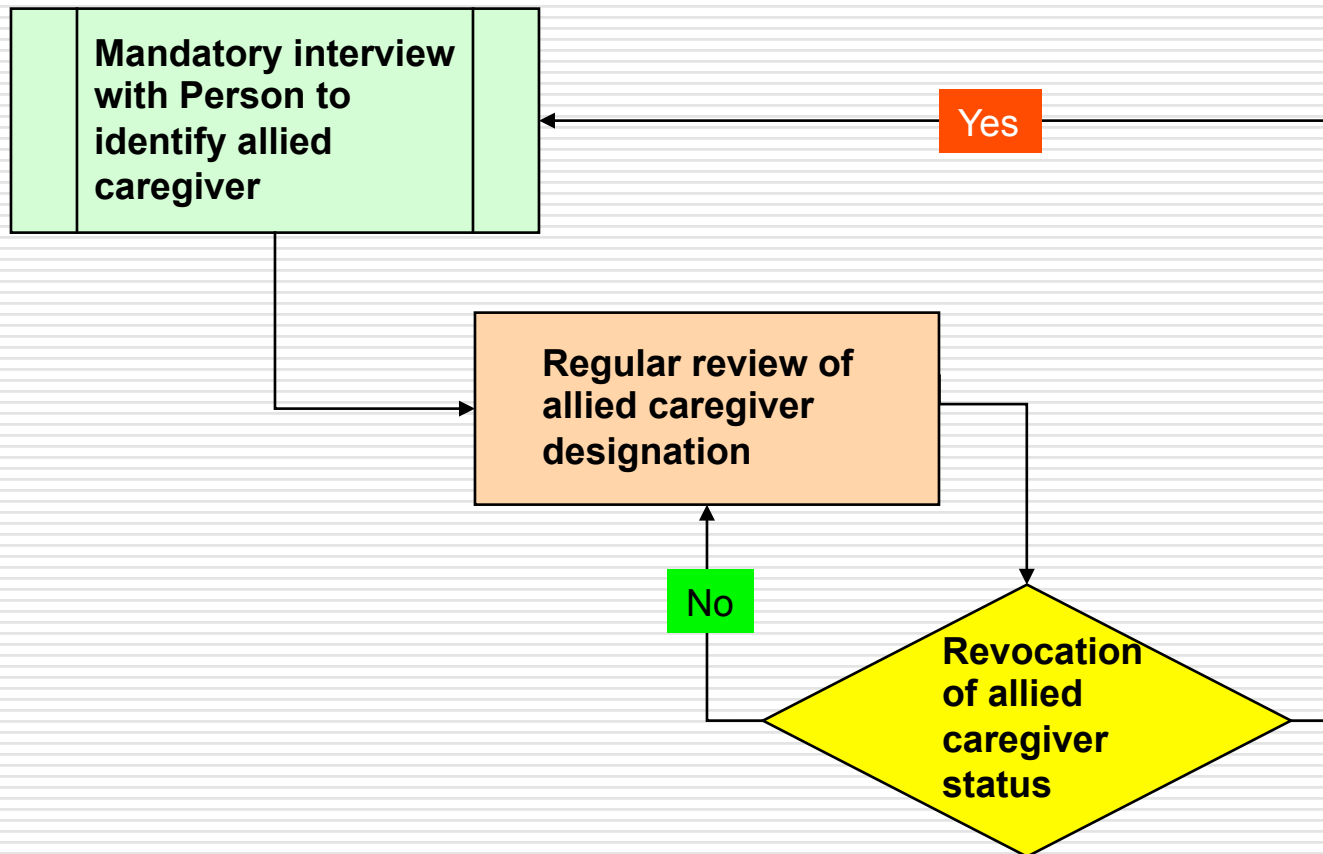
Confidentiality: A major barrier to partnership in Recovery



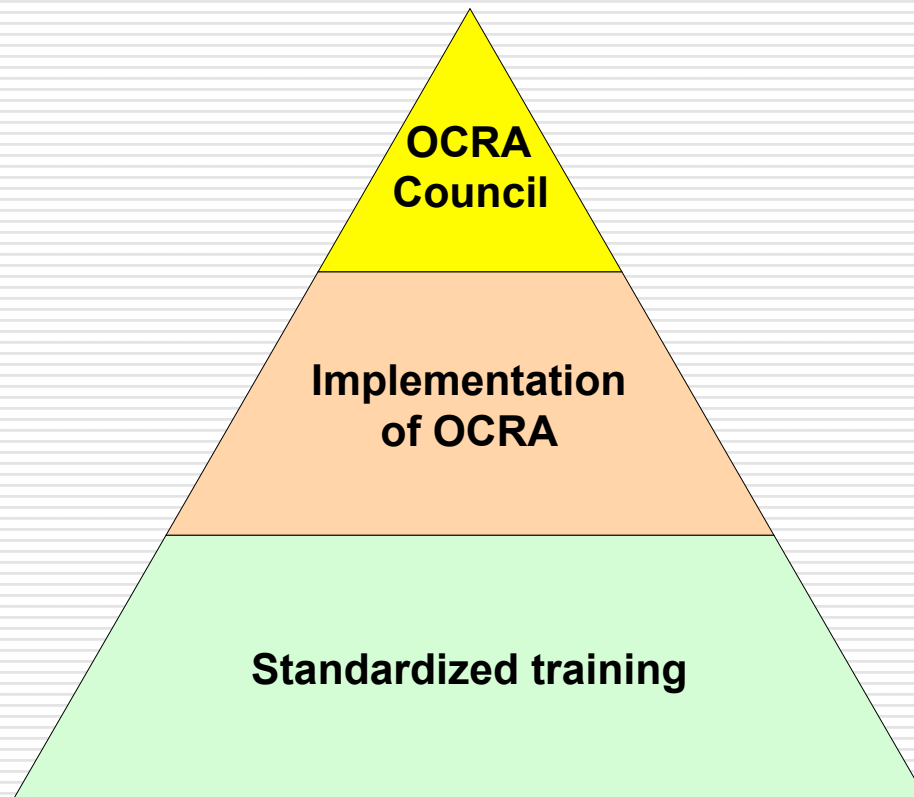
Allied family caregivers as informal Health Information Custodians



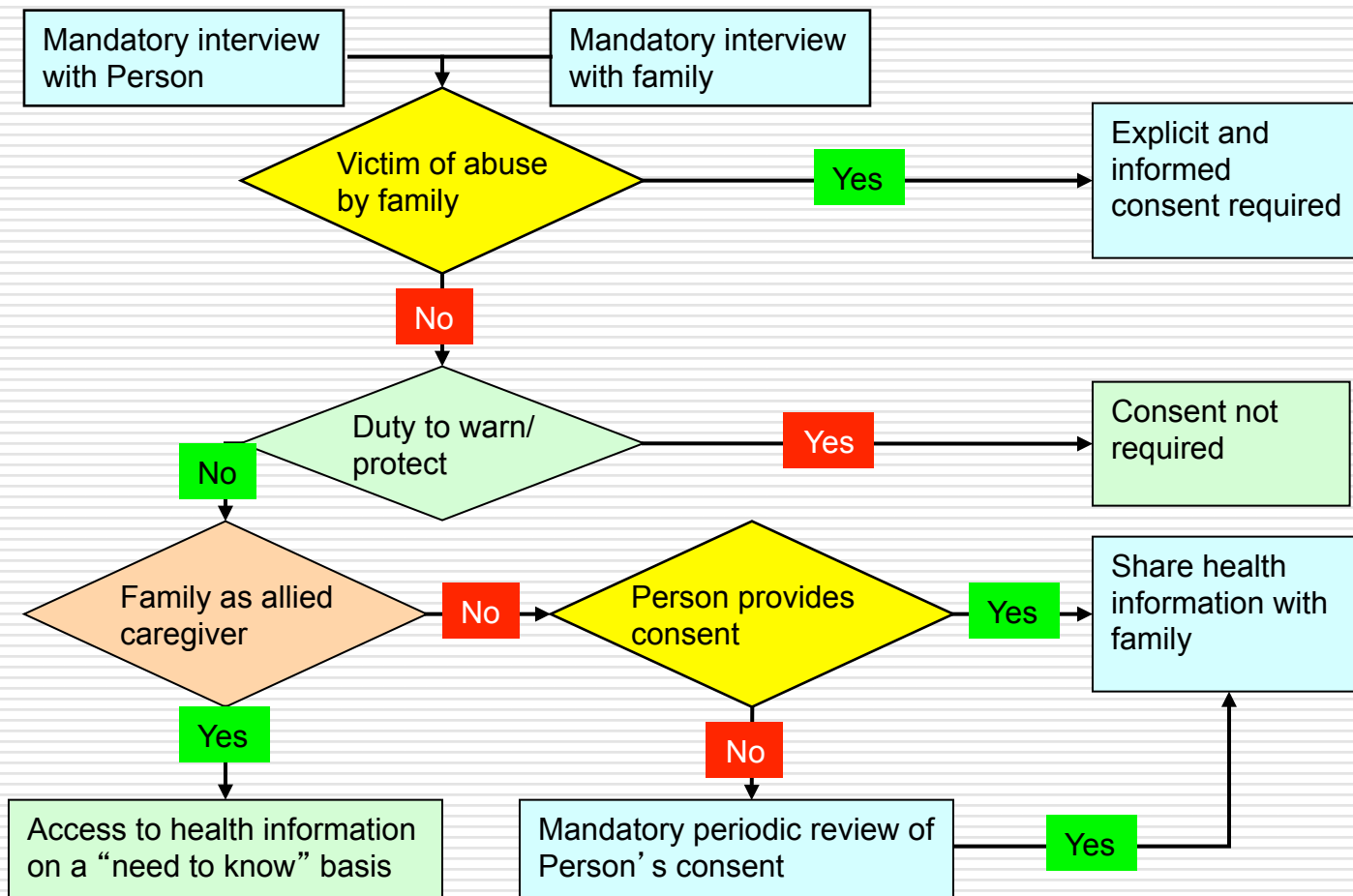
Mandatory procedure to designate allied caregivers



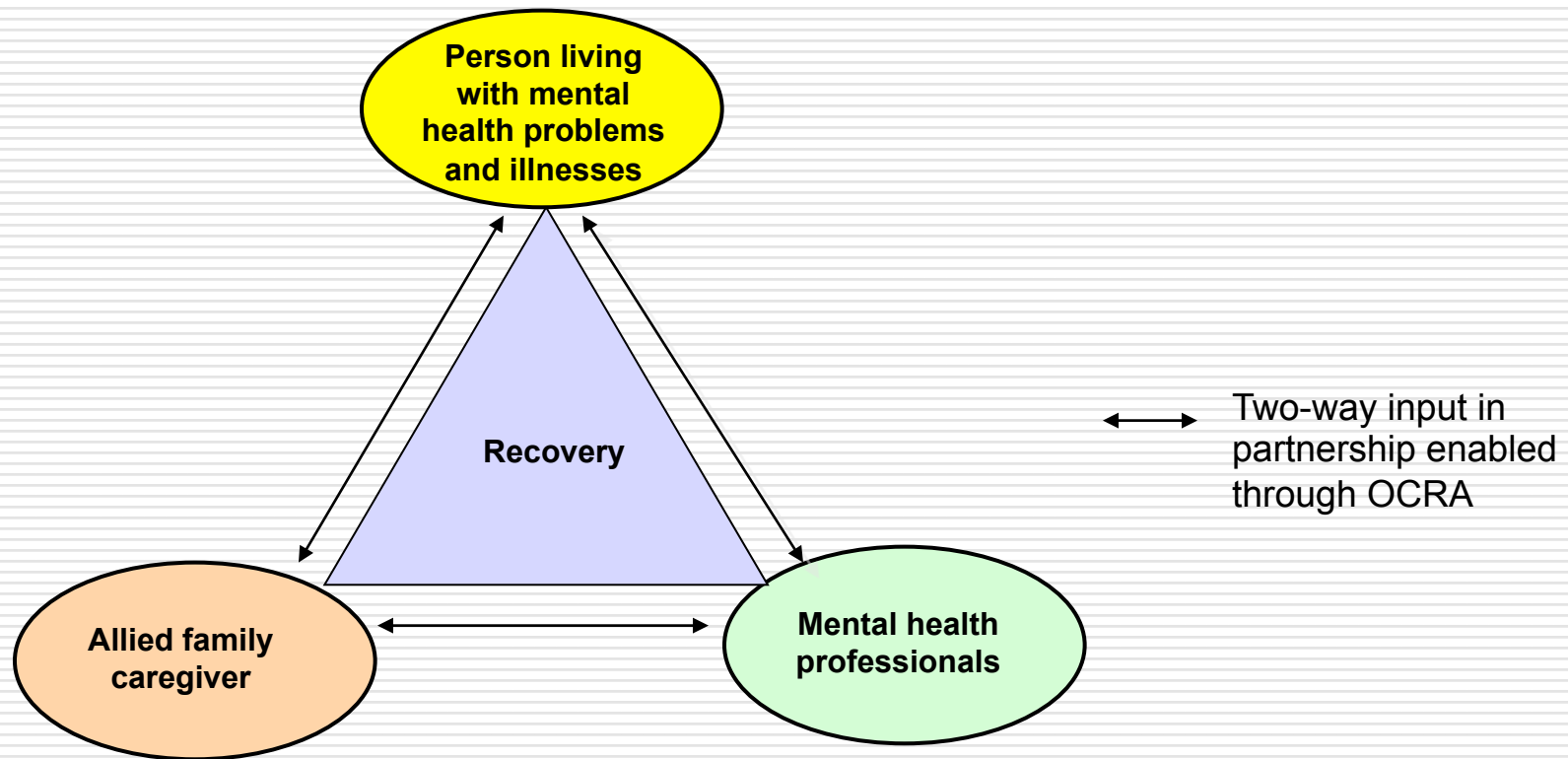
Establish an OCRA Council to monitor progress



Safeguards to balance the rights of allied caregivers and the person



Goal: Partnership through (proposed) OCRA to promote recovery



The Vision

□ Bill ???



□ Caregiver
Recognition Day,
Ontario: First
(weekday) of
(Month), 201?

RATIONALE

More responsibilities, less rights

- Compared to mental health professionals, caregivers have
 - **Less** support from the system
 - **Less** rights to health information
 - **More** burden in the care of their ill relatives (Canadian Mental Health Association, undated)

Between a rock...

- “First, they (caregivers) must **suffer with their loved ones** through their daily hardships and use their limited personal resources to try to alleviate them
- Second, they must contend with a mental health system that often **excludes them** from involvement in the information-gathering and decision-making processes...

And a hard place

- while simultaneously leaving them to serve as the fail-safe mechanism **to provide unlimited, unpaid care, filling in the cracks** that open when any part of the so-called system fails” (The Standing Senate Committee, 2006, p. 34)

JUSTIFICATIONS

Best practice approach

- ❑ Carer Recognition Act (Government of Western Australia, 2004)
- ❑ Carer Recognition Policy (Queensland Government, 2007)
- ❑ Caring for Carers (UK Department of Health, 2008)
- ❑ Manitoba Caregiver Recognition Act (2011)

Manitoba Caregiver Recognition Act (2011)

- “These caregivers provide a valuable service to their families and to their communities, and in many cases, it comes at a **physical, emotional and sometimes financial cost** to individuals and families
- Our legislation recognizes both **the value of their contribution** and the need to work with caregivers **to provide a network of supports”**

THE FEDERAL GOVERNMENT

The Standing Senate Committee Report (2006)

□ Recommendation #2

- That health care professionals **take an active role in promoting communication** between persons living with mental illness and their families

The Standing Senate Committee Report (2006)

□ Recommendation #3

- That health care professionals have **discretion to release personal health information**, without consent, in circumstances of clear, serious and imminent danger **for the purposes of warning third parties and protecting the safety of the patient**

The Standing Senate Committee Report (2006)

- That this discretion be governed by a clearly defined **legal standard set out in legislation**, and subject to review by privacy commissioners and the courts (The Standing Senate Committee Report, 2006, p. 69)

Mental Health Strategy for Canada (2012)

□ Priority 2.1

- It is critical that they (families) have access to the information and resources they need to sustain themselves, and that **their voices be heard** in the mental health system (Mental Health Commission of Canada, 2012, p. 29)

Mental Health Strategy for Canada (2012)

□ Priority 3.5

- Caregivers need **increased access to financial supports** like tax credits, caregiver allowances, and respite care, as well as to workplace policies—such as allowing caregiver leaves and flexible hours—that would ease their burden (Mental Health Commission of Canada, 2012, p. 55)

THE ONTARIO GOVERNMENT

February 28, 2013

Family Council 2013 Annual
General Meeting

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Selection Committee Final Report to Ontario Legislature (2010)

□ Recommendation # 21

- A task force to incorporating **adequate representation from caregivers** to propose **changes in involuntary admission and treatment**

Selection Committee Final Report to Ontario Legislature (2010)

□ Recommendation # 22

- A task force to investigate and propose changes to PHIPA to ensure caregivers have **access to personal health information** of their ill relatives

Selection Committee Final Report to Ontario Legislature (2010)

□ Recommendation #16

- **Increased availability of respite care** to allow family members the time and freedom to pursue personal, social and recreational endeavours in order to maintain their own mental health

Accountability: A two-way street

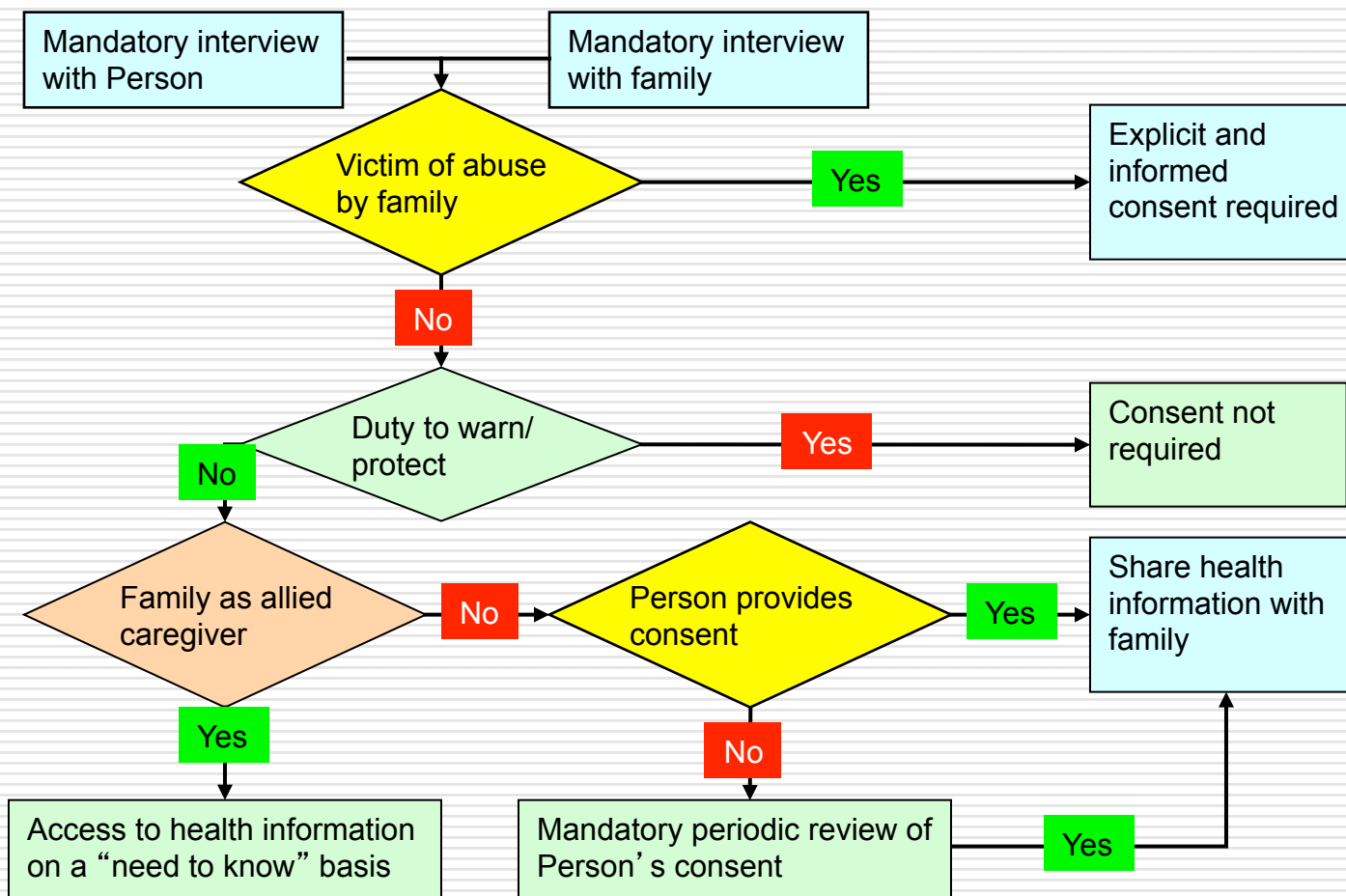
□ MOHLTC:

- All mental health and addiction programs and services are based on the best available evidence from **lived experience, practice and research** (The Minister's advisory group on the 10-year mental health and addictions strategy, 2010, p. 17)
- Ontario will build on effective mental health and addictions programs and services with **the best available evidence from lived experience, practice and research**. Services must improve quality of life in a sustainable way (Ministry of Health and Long-term Service, 2011. p. 9)

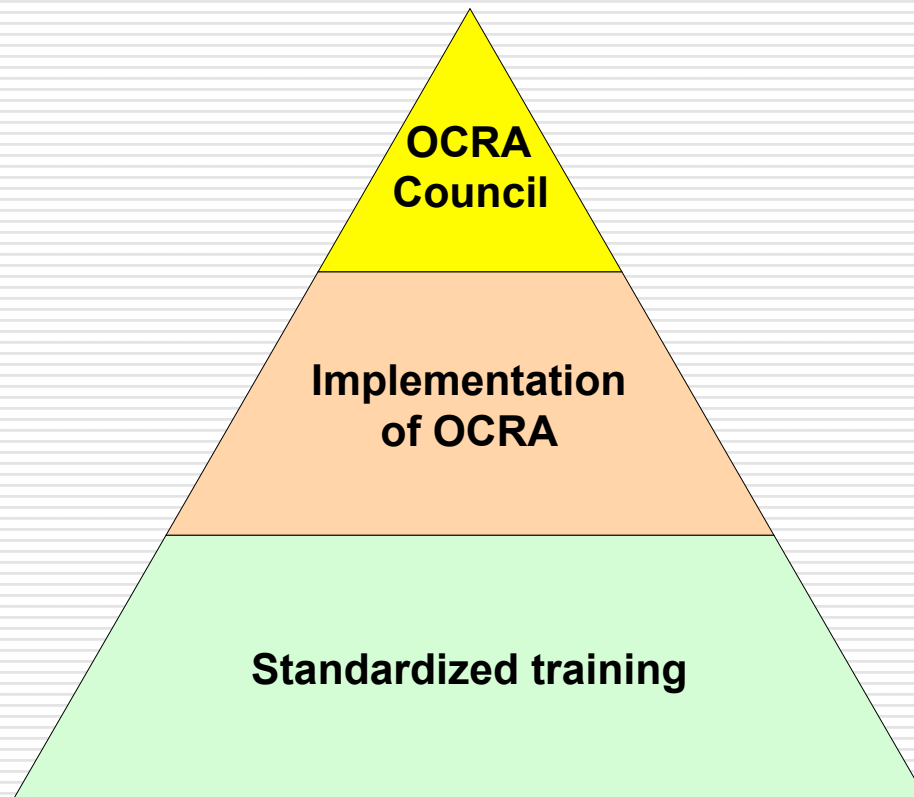


THE VISION

Safeguards to balance the rights of allied caregivers and the person



Establish an OCRA Council to monitor progress



The next step...

- Minister of Health to introduce a Government Bill
 - Family Council
 - CAMH
 - Other Family Councils and mental health organizations within Ontario
 - OCSWSSW
- Contact MPP to introduce a private member's public bill
 - Caregivers (Legislative Research Service, 2011)

The Vision

□ Bill ???



□ Caregiver
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References

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