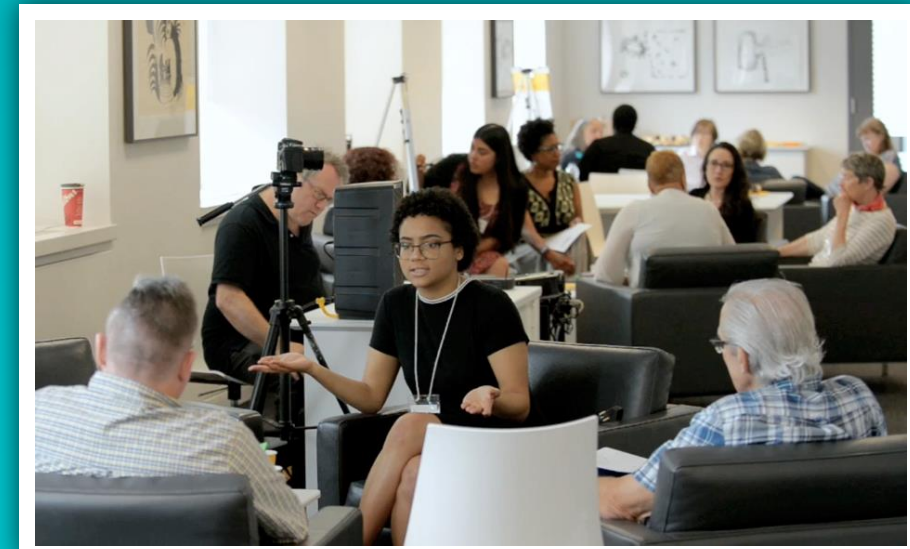
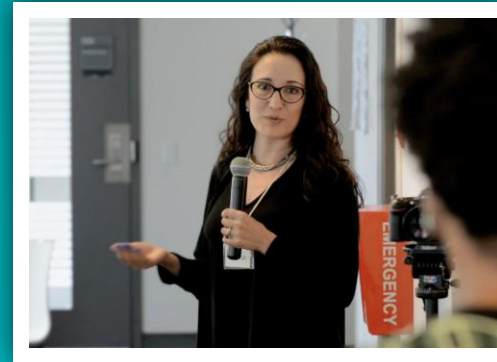


The Family
Caregiving
Project

FAMILIES & CAREGIVING: Social Issues

By Charmaine C. Williams, PhD



The Family Caregiving Project

The Family Caregiving Project is a research study exploring the experiences of families affected by mental illness. The study was conducted in Ontario, Canada from 2018-2021. The project was funded by the Social Sciences and Humanities Research Council of Canada.

For more information about the project, please go to www.familyguidetomentalhealth.com/family-caregiving-project or contact Charmaine Williams, PhD at charmaine.williams@utoronto.ca

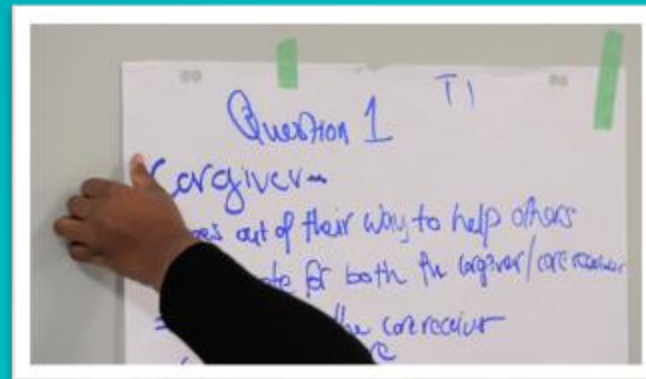
What defines a family?

- Definitions can be biological, social, and cultural
- Institutional definitions focus on parental ties, legal connections
 - Kinship ties and families built on choice are less recognized
- Families are defined by a group of individuals who may be legally or biologically linked and:
 - Self-identify as connected to each other
 - Have an expectation of that connection continuing over the long term
 - Have an expectation and commitment to caring (emotional support, concern, assistance, etc.) for each other



What defines a “caregiving family”?

- Caregivers are people who regularly provide health, protection, welfare, and maintenance care for a child or adult who is sick, elderly, or has a disability
- The 2018 Canadian General Social Survey showed that 1 in 4 people aged 15 and over were in a caregiving role for an adult with a long-term illness or disability
- Caregiving families provide care for one or more adults in addition to managing other needs in the family



Caregiving families

- The needs associated with caregiving affects family members and family system functioning
- Illness or disability bring families into contact with specific systems and institutions, e.g., healthcare organizations, community support services, government services
- Diversity of caregiving families often means addressing more concerns and facing potential barriers



Why don't we hear more about caregiving families?

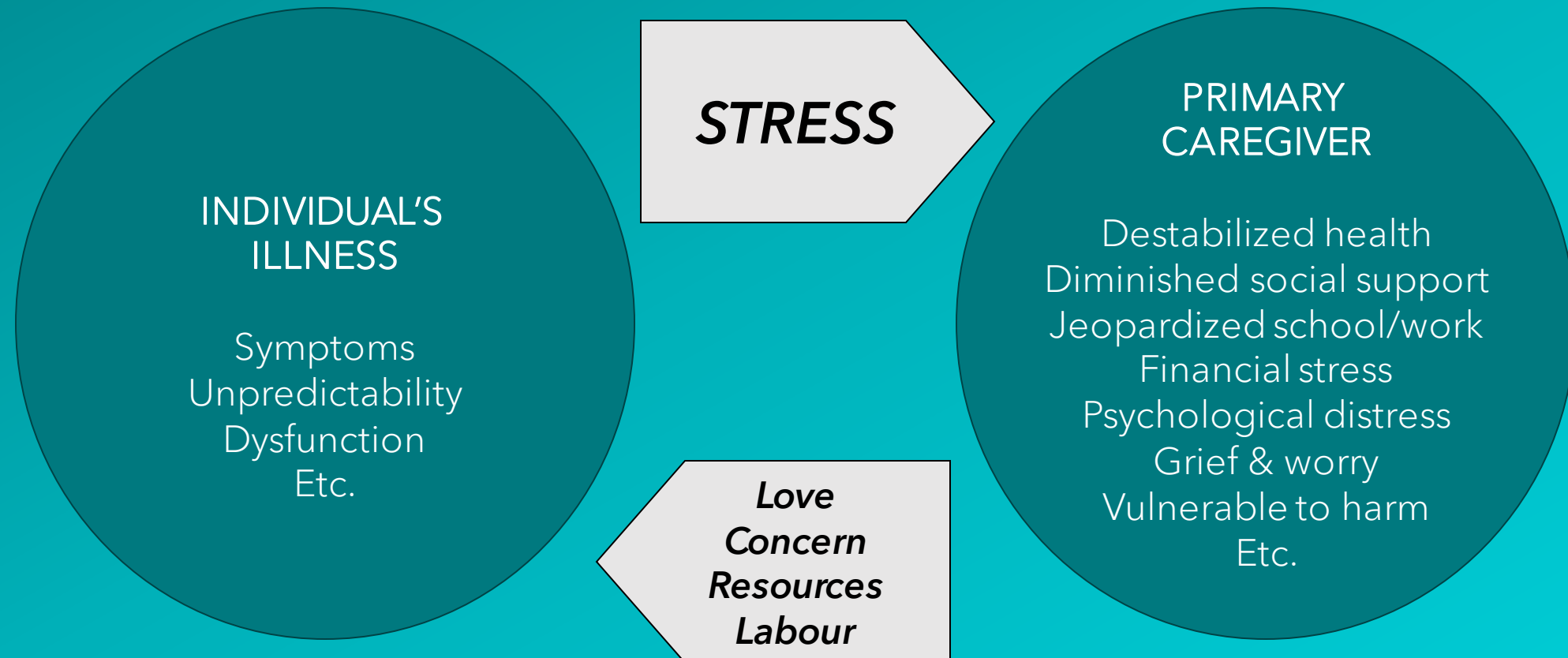
- We treat the challenges and demands of family caregiving as a personal issue to be managed within families
- However, because many families are engaged in caregiving for family members, the needs of caregiving families should be recognized as a community concern and priority in public policy



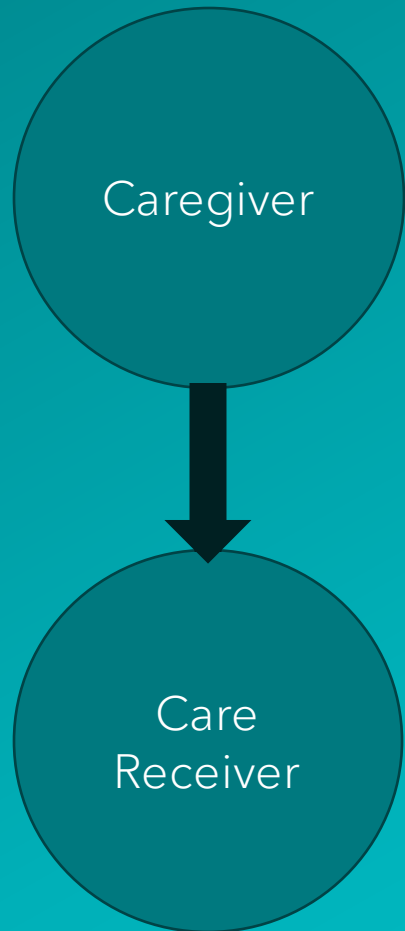
Caregiving families and stigma

- **Mental illness stigma:** Negative beliefs and prejudices about mental illness that can lead to isolation, discrimination, reluctance to seek help or support
- **Social stigma:** Caregiving families are not welcomed to share their experiences and may be rejected by others if they do
 - Being associated with mental illness may risk social status, social opportunities, and social inclusion
- **Vicarious stigma:** Suffering experienced by stigma affecting a family member
- **Institutional stigma:** Mental illness is marginalized in the provision of resources and attention in healthcare, community settings, and public policy

Caregiving families and the healthcare system



Caregiving families and public policy



Caregiving for adults living with chronic illness is mostly absent in public policy

In public policy, relationships within caregiving families are configured as:

- Active giver vs. passive receiver of care
- Labourer vs. labour
- Independent vs. dependent
- Productive vs. disruption to productivity

Caregiving families need to be recognized as:

- Members of our communities; family members, neighbours, friends, coworkers who deserve to be seen and heard
- A growing population that needs support from services, trained professionals, and resources that will facilitate their caregiving, especially as prevalence of chronic illnesses increases
- Diverse in form and in their arrangements for caring and family needs



The logo for The Family Caregiving Project, featuring the text "The Family Caregiving Project" in a white serif font centered on a teal square background with a white border.

The Family Caregiving Project

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