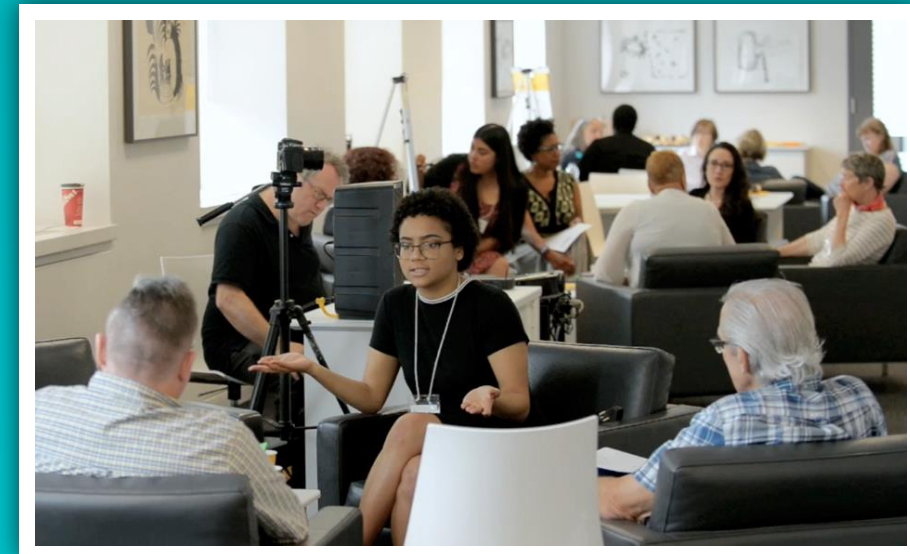
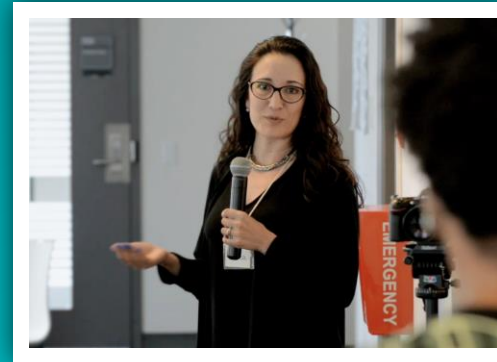


The Family
Caregiving
Project

FAMILIES & CAREGIVING: Family Systems

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

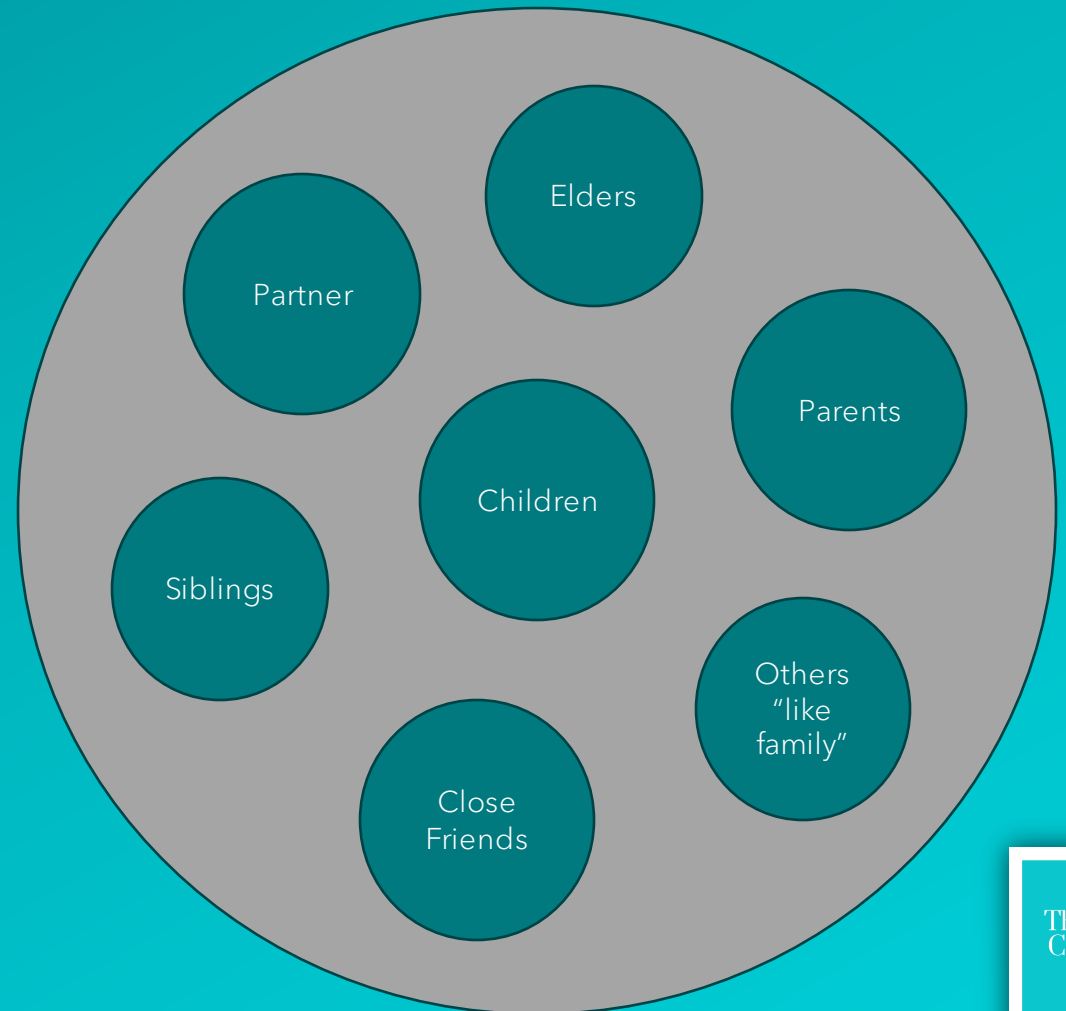
What defines a family?

- 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



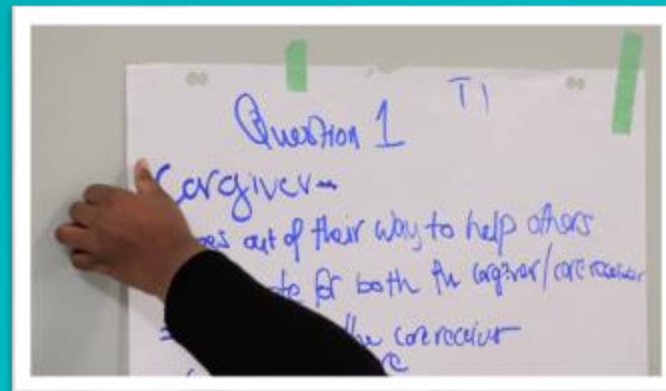
The Family System

- A group of individuals working together to meet family needs, mobilize family resources, carry out family tasks
- Boundaries that define the family include and exclude others
- Individuals within the family system have an impact on each other
- Individuals, groups, and institutions outside the family system affect the family unit
- The family system changes over time



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



Caregiving and mental health

- Mental illness can be unpredictable and long-term
 - Episodes of illness emerge in context of usual family stressors
 - Usual family stressors can be precursors to episodes of illness
- Mental health and physical health concerns can co-exist, can affect multiple family members
- Periods of hope, worry, crisis affect the mental health of the entire family
 - Young children especially may feel all these things but without having knowledge or understanding of mental health to provide context



Caregiving models guiding service provision for families

- **Family burden** (defined in the 1960s, post-deinstitutionalization) refers to physical, psychological, social, financial, and other consequences of caregiving
 - Some caregivers and family members place the needs of the diagnosed individual ahead of their own
 - **Objective burden:** Negative effects on the household and caregiving demands placed on family members, e.g., labour, time, tasks, disruptions, etc.
 - **Subjective burden:** Feelings about caregiving, perceptions of the toll of caregiving, emotional impact
- Some attention to positive aspects of caregiving



Service design based on burden

Support caregiving, reduce family stress, manage problematic behaviours

+

Support and management of diagnosed individual, individual's symptoms/behaviour

Primary
Caregiver

Care
Receiver

Missing: Experiences of diagnosed individuals

- Diagnosed individuals are rarely included in research about caregiving
- The person with a diagnosis is defined as “the stressor”
 - Perpetuation of stigma and stereotypes
- Conventional approaches reinforce the exclusion of diagnosed individuals
 - False divisions between ‘independent/dependent’, ‘stressed/stressor’, ‘caregiver/care receiver’ are constructed and reinforced



Research on caregiving experiences of diagnosed individuals

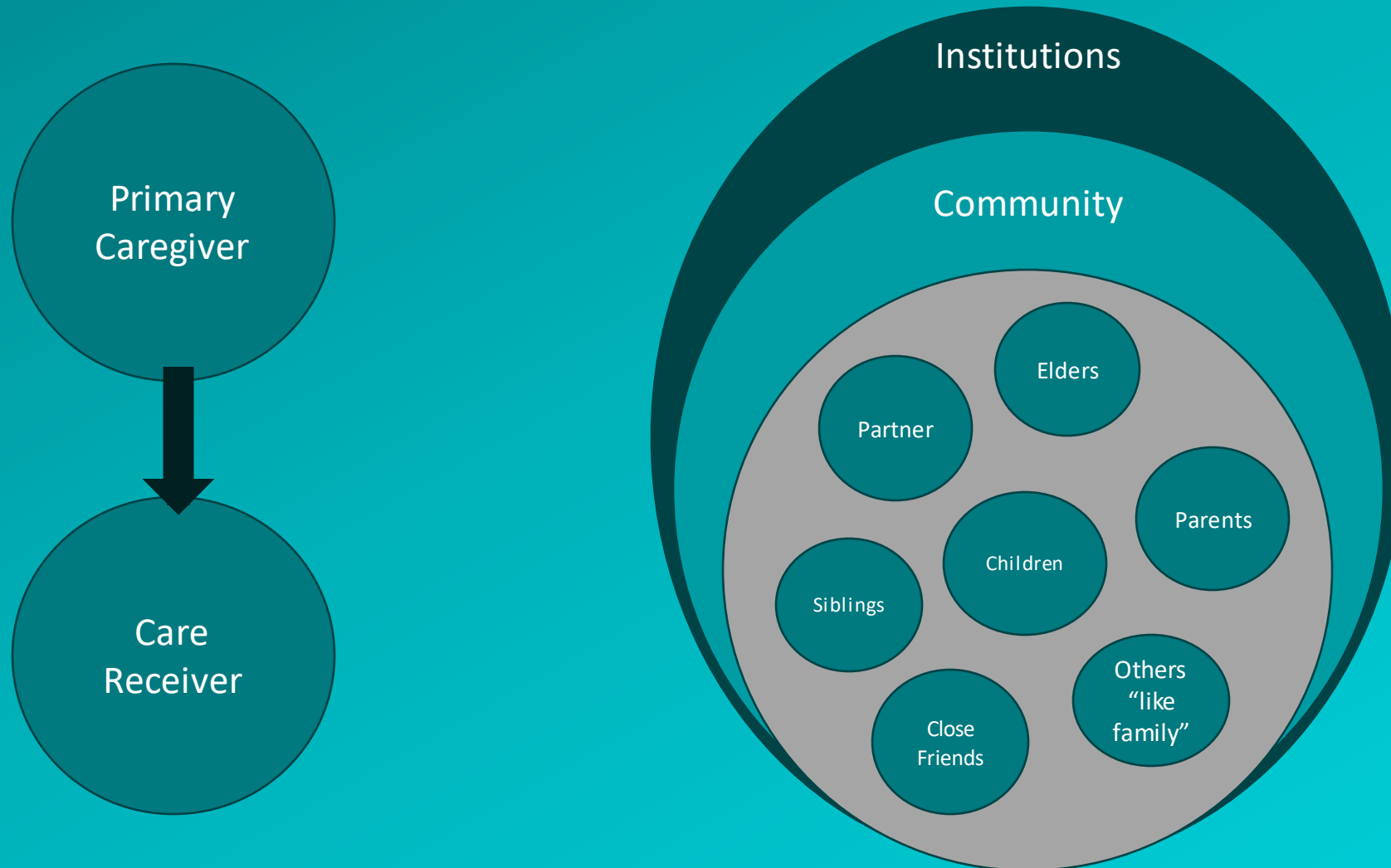
Diagnosed individuals:

- Express concern about impact of caregiving on other family members
- Experience stress about receiving care
- Dislike passive, dependent positioning in families
- Value roles in the family system
- Contribute to care for others in family, as able
- Expect to give and receive care over the long-term



See Williams & Mfoafo-M'Carthy (2006) for more information about this study

Family system perspective: Managing caregiving family stressors



Family support and services

- Need for caregiving family support and services that:
 - Include diagnosed individuals as part of the family system
 - Seek out family system perspectives on management of stressors
 - Assess and address family mental health
- Need for policies that:
 - Recognize diverse family forms and processes
 - Increase resources and services to support whole family health
 - Support a long-term view of caregiving families as changing, adapting family systems



The logo for 'The Family Caregiving Project' is a teal square with a white border. Inside the square, the text 'The Family Caregiving Project' is written in a white serif font, with 'The Family' on the first line, 'Caregiving' on the second line, and 'Project' on the third line.

The Family Caregiving Project

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