FAMILIES & CAREGIVING: Social Issues
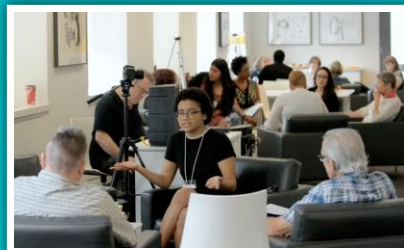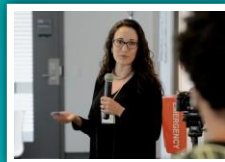
The Family Caregiving Project

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

The Family
Caregiving
Project

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
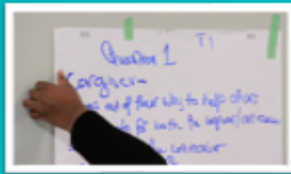
The Family Caregiving Project

Our definitions of family have changed over time. While this term might once have referred exclusively to people who were biologically or legally connected to each other, we now recognize that families come in many forms and can be created in many ways.

Although cultural definitions of family may be highly variable and flexible, when families interact with institutions (e.g., schools, hospitals, citizenship, employment), they can discover that these systems only recognize family members that fit traditional forms. Families can encounter difficulties in institutions that do not accept their definitions of who is included or excluded from the people they consider family members.

The Family Caregiving Project has chosen an inclusive definition of family that prioritizes individuals defining the relationships that create their family. We understand family to be defined: 1) by the people within it, 2) based on feelings of connection to each other, 3) by the expectation that connection will last for a long time, and 4) by an expectation of caring for each other over that time. That caring can take many forms and is part of the everyday life of families.

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

The families this project calls "caregiving families" are in family systems that have been impacted by the need to provide caregiving for one or more adult family members with a long-term illness or disability.

We know from the census research and other surveys that many families provide caregiving for adults. It is likely that we all know families that could be identified as caregiving families.

Caregiving is a usual part of family life. Over a lifetime, families anticipate caregiving for children when they are young and for elders as they age. Caregiving families do that type of caring and they also manage caregiving needs for adults who are affected by long-term illness or disability.

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

The Family Caregiving Project

When one or more family members are affected by health challenges, energy and resources in the family adjust to support those family members. This, inevitably, affects the energy and resources that are available to other family members and their availability to deal with things outside of the family.

The family system is brought into contact with systems and services that they may never have imagined would be part of their lives. Doctors, hospitals, case managers, rehabilitation, and related services may all become part of family life.

Mental illness affects families across the range of diversity. Families may navigate the personal, social, and institutional experiences associated with health problems while also navigating stressors and problems like racism, homophobia, classism, and other forms of oppression and discrimination. Families that are members of groups that are marginalized, disadvantaged, or stigmatized in society face additional challenges and barriers to getting help and support.

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

The Family
Caregiving
Project

The caregiving that happens within families may be seen as a personal concern that does not require the attention of people outside the family. Families manage all kinds of caring activities relying only on the people and resources within the family. However, it is strange that so many families are managing caregiving for adults and this is seemingly not known by members of the public. This contributes to those families feeling isolated.

Caregiving families are numerous in our communities and their experiences should be known and shared so people do not feel isolated. The growing number of caregiving families in our communities also means that their needs and concerns should be visible in public policy and planning of community services.

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
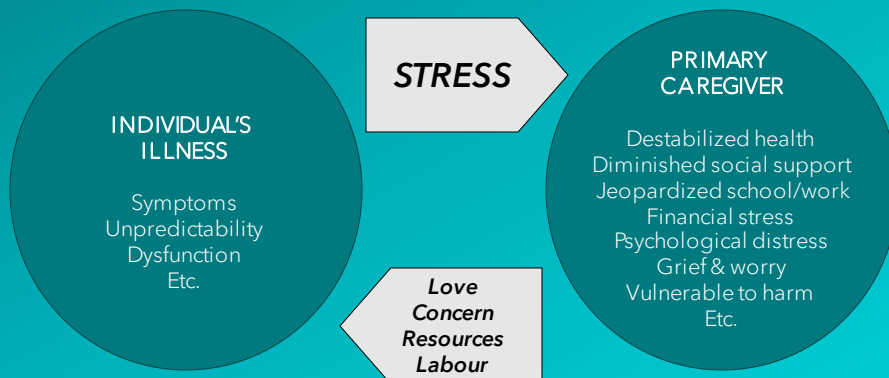
The Family
Caregiving
Project

Stigma against mental illness is a social injustice that is perpetuated by negative stereotypes, negative portrayals, and prejudice against people living with mental illness. Although mental health is being discussed more openly now than it was in the past, negative ideas still circulate through media, entertainment, etc. and can lead to discrimination against people diagnosed with mental illnesses.

Families that include people facing mental health concerns can face stigma in many ways. Families may experience social stigma in the form of prejudice and discrimination. Families can be discouraged from sharing their experiences, can be avoided by others, and may be blamed by others for the mental illness in the family or for not managing the illness well. Families can also experience vicarious stigma, feeling distressed by the stigma they see affecting their family members.

An additional layer of stigma that affects families is reflected in institutional practices and policies that do not account for mental health and do not devote resources to inclusion of services for people with mental illnesses.

Caregiving families and the healthcare system

INDIVIDUAL'S ILLNESS

Symptoms
Unpredictability
Dysfunction
Etc.

STRESS

PRIMARY CAREGIVER

Destabilized health
Diminished social support
Jeopardized school/work
Financial stress
Psychological distress
Grief & worry
Vulnerable to harm
Etc.

*Love
Concern
Resources
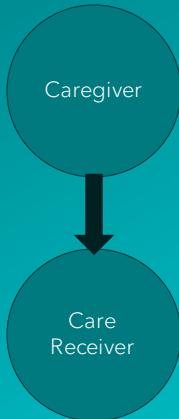Labour*

The Family Caregiving Project

In our dominant thinking about caregiving experience, persons who are living with mental illness are primarily identified as a source of stress and burden for family members. This characterization of diagnosed individuals perpetuates stigma and marginalization for these individuals. In this framing, the person who is living with a mental illness is not seen as a functioning, contributing part of the family system. Instead, those individuals are seen as dependent, stressing and a drain on the caring resources for the family.

Caregivers are expected to provide care that the healthcare system does not provide. In turn, caregivers are provided with limited services to support their caregiving efforts. These services are often focused on an individual (usually a woman) who is identified as a primary caregiver and who carries most of the responsibility of providing care, interacting with services and otherwise attending to the needs associated with managing the mental health of a family member. Services usually focus on reducing the caregiver's stress caused by the illness of the family member. This is illustrated in the above diagram.

Others included in the family system are mostly overlooked unless there is an identified need to address stress on the system and problems arising from that stress that affect the person with mental illness. This model does not give enough attention to the family system as a whole. Both the individual and the person called a primary caregiver are isolated within the family system.

Caregiving families and public policy

Caregiver

Care Receiver

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

The Family Caregiving Project

Policy development for caregivers is directed at care of elders and children, with little consideration for caregiving for adults with episodic or chronic illnesses. Policy recognizes caregiving families in one form: primary caregiver caring for a dependent. Other family forms or configurations of giving and receiving care are not recognized. Individuals diagnosed with mental illness must meet a threshold of dependence, assumed to be permanent, for the family to receive state support.

Caregiving policy is directed at reducing the stress that caregiving places on family caregivers. Tax benefits, labour policies, and income support are designed to support caregiving families comprised of an overburdened family caregiver who is unable to participate fully in the labour force, and a dependent incapacitated adult whose condition is a source of stress and a drain on familial and community resources. Although these interventions provide some relief, caregiving families still face significant financial and social difficulties, especially if they do not have the personal resources to purchase additional support or services.

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 Family
Caregiving
Project

Caregiving families are members of our communities who deserve to feel accepted and welcomed in society. They also deserve to be supported and helped through public policy.

Social attitudes, healthcare services, and public policies all need updating to reflect modern, destigmatizing views of mental health and caregiving experiences as they are lived in different family forms, within diverse cultural experiences, and with needs that change as families change.

For more information:

Amir, E. (2016). New developments for family caregivers in the context of mental health in Canada. *Canadian Journal of Community Mental Health*, *34*(4), 143-149.

Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health*, *13*(6), 537-548.

Labrum, T. (2020). Persons with serious mental illness help relatives: rates and correlates of assistance. *Journal of Mental Health*, *29*(3), 328-335.

Public Health Agency of Canada. (2015). Report from the Canadian chronic disease surveillance system: Mental Illness in Canada, 2015. Ottawa, ON: Her Majesty the Queen in Right of Canada, as represented by the Minister of Health.

Thompson, K. (2003). Stigma and public health policy for schizophrenia. *Psychiatric Clinics*, *26*(1), 273-294.

Turcotte, M. (2013). Family caregiving: What are the consequences? *Statistics Canada*. https://www150.statcan.gc.ca/n1/en/pub/75-006-x/2013001/article/11858-eng.pdf?st=KZTaDkbt

Statistics Canada. (2018). *Caregivers in Canada*. https://www150.statcan.gc.ca/n1/en/pub/11-627-m/11-627-m2020001-eng.pdf?st=EVnvEH1L

Williams, C. C. (2018). Caregiving under siege: An argument for critical social work practice with families. *Canadian Social Work, 20(1),* 72-87.

Wong, Y. L. I., Kong, D., Tu, L., & Frasso, R. (2018). "My bitterness is deeper than the ocean": understanding internalized stigma from the perspectives of persons with schizophrenia and their family caregivers. International journal of mental health systems, 12(1), 14.

The Family
Caregiving
Project