



Canadian Centre for  
Caregiving Excellence

# Giving Care

An approach  
to a better  
caregiving  
landscape  
in Canada

Executive  
summary



# Executive summary

Caregivers are the unseen and unacknowledged foundation upon which our health-care, social services and disability supports systems are built. Their labour to support care recipients from every walk of life make our economy tick and our society run. If all caregivers took a week off, every Canadian would experience the collapse of our care systems before noon on the first day.

Unpaid caregivers and paid care providers make up the largest part of Canada's health-care and social supports systems. Research shows that they provide approximately three hours of care for every hour provided through the rest of our systems. They help seniors living in the community or in long-term care settings; children and adults with physical, intellectual, or developmental disabilities; people with medical conditions; people experiencing mental illness; and people with changing support needs related to aging.

The sustainability of Canada's health-care and social systems relies on caregivers and care providers, but they are at a breaking point.

The existing patchwork of provincial, territorial and federal caregiving policies is failing. The systems caregivers, care providers and care recipients rely on are overextended and fraying as they struggle to meet unprecedented demand. As a result, caregivers face significant financial, physical and emotional consequences, due to insufficient support. Care providers are burned out and care recipients suffer from a revolving door of unpredictable care. Every day, we see that our already limited caregiving infrastructure is being further stressed by significant policy and program gaps. For example:

- Services for caregivers and care recipients are insufficient, fragmented and difficult to access
- Financial supports are insufficient and ineffectively designed
- The care provider workforce is in crisis
- Supports for caregivers do not meet their current and future needs
- Leaves and protections for employed caregivers are inadequate



The Canadian Centre for Caregiving Excellence (CCCE) is committed to working with people with lived experience, researchers and experts to help develop policies that will help caregivers and care providers. Federal and provincial governments need to make the reforms necessary to improve outcomes today to ensure a strong caregiving ecosystem for the future.

Canadians are living longer with disabilities and multiple medical conditions. As our population ages, our systems will be further stretched as more people access services not designed for increasing demand. We urgently need a policy regime that meets our current and future needs for caregiving and support. To meet this challenge, we must:

**Create a co-ordinated approach to caregiving**, through: a common and inclusive definition of caregiving; a national caregiving strategy; provincial caregiving legislation; and international caregiver recognition

**Improve, expand and invest in services for care recipients and caregivers**, through: home and community care funding; mandatory assessment of caregiver needs; integrated care across services and sectors; and public navigator roles

**Develop strategies for supporting employed caregivers**, through: expanded leaves and benefits, flexible work legislation and promotion, caregiver-friendly workplaces; and government leadership

**Develop financial supports that reflect the value of caregiving**, through: inclusive tax credits and benefits; caregiver allowances or income; and increased supports for people with disabilities

**Develop the workforce and improve conditions for care providers**, through: competitive wages and increased funding; professionalization of care provider roles; support and protection for migrants to fill workforce gaps; and a workforce development strategy.

Caregiving is the next frontier of public policy in Canada. This policy whitepaper aims to ignite a public conversation on the state of caregiving and how we can do better. Over the coming months, CCCE will work with caregivers, care providers, care recipients, policy makers and stakeholders across the country to help shape the caregiving future we need.

## Key definitions

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### Caregiving

Providing help or care to another person, including: people with physical, intellectual, or developmental disabilities; people with medical conditions; people experiencing mental illness; and/or people with changing support needs related to aging.<sup>1</sup>

### Caregiver

An unpaid family member, friend, or other support for someone who needs care due to physical, intellectual, or developmental disabilities; medical conditions; mental illness; or needs related to aging. Caregivers provide care because of a relationship, not as a job or a career. This definition does not include parents or guardians providing care to a child without a disability, medical condition or illness.

### Care provider

A person who is trained and paid to provide care to people who need it, due to physical, intellectual, or developmental disabilities; medical conditions; mental illness; or needs related to aging. This includes such professionals as Direct Support Professionals (DSPs), Personal Support Workers (PSWs), attendants for people with disabilities and respite workers.

### Care recipient

A person with a physical, intellectual, or developmental disability; medical condition; mental illness; and/or changing support needs and frailty related to aging who receives care. Children without a disability, medical condition or illness are not included in this definition.

### Double-duty caregiver

A person who provides unpaid care to a family member or friend while also being employed in the health-care field.

<sup>1</sup> Statistics Canada, "The Daily — Caregivers in Canada, 2018," January 8, 2020, <https://www150.statcan.gc.ca/n1/daily-quotidien/200108/dq200108a-eng.htm>.

## What is caregiving?

Caregiving is both a rewarding and challenging experience for caregivers and care providers. It is carried out by people of all ages, races and genders, though disproportionately by racialized women. Providing help to someone who needs it can be fulfilling and bring people closer together. This can be especially true when caregivers and care providers offer emotional support to care recipients. At the same time, caregiving takes time and effort; performing such tasks as changing clothes, providing transportation, managing care networks and preparing food can be mentally and physically exhausting. The consequences of caregiving, including financial and emotional stress, are often associated with a lack of support.



### **Caregiving is essential for care recipients and Canadian society**

Caregivers and care providers play a vital role in the everyday lives of people who receive care and in Canada's broader health, community and social service systems. For every hour of professional care, caregivers provide three hours of care to family and friends. At the same time, care providers are essential, but often undervalued, members of Canada's health and social service workforce. They contribute \$97.1 billion annually to Canada's economy. In a recent study, the majority of PSWs in the Greater Toronto Area were considered low income (55 per cent), precariously employed (86 per cent), lacking paid sick days (89 per cent) and without extended health benefits (74 per cent).

### **Caregiving is done by both unpaid caregivers and paid care providers**

Caregivers (care-partners, carers) are unpaid family members, chosen family, friends and other supports of someone who needs care. Caregivers provide care because of a relationship with the person who needs care. Care providers are individuals who are trained and paid to provide care. Care providers include such professionals as DSPs, PSWs and respite workers.

### **Caregiving roles and responsibilities are varied and evolving**

Care providers and caregivers often fill major gaps in broader health and social systems. For example, support professionals now provide educational support, health care, physical therapy and mental health care. Caregivers also bear a wide range of responsibilities, such as: personal care; food preparation; shopping and



housekeeping; transportation and care co-ordination; health-care-related tasks such as dialysis and ventilator management; advocating on behalf of the care recipient; providing care recipients with emotional support; and financial management.

**Caregiving is done by individuals with diverse identities and experiences**

Caregivers and care providers have unique identities and circumstances that shape their individual experiences in providing care to others. For example, 45 per cent of caregivers were born outside of Canada, or their parents were born outside of Canada. Trans-national caregivers face unique challenges providing support and care across distances and borders. Double-duty caregivers provide unpaid care to a family member or friend while also being employed in the health-care field. Some caregivers are young. Siblings of children who are ill or have a disability and children of parents who are ill or have a disability begin their caregiver roles at a young age. There are approximately 1.25 million caregivers aged 15 to 24 in Canada. Care providers are also diverse, with many individuals in the field belonging to racialized groups. In Canada, PSWs are primarily woman-identified and racialized. Moreover, racialized women make up 27 per cent of workers in home health-care services.

**Caregiving is often continuous work and can occur across a person’s lifetime**

Caregivers often support people more than once over the course of their lives. For example, some Canadians take on one caregiving role later in life, while others have taken on multiple episodes of care by the time they reach their late 50s. In other cases, family caregivers spend a significant portion of their adult life providing care. As Canada’s population ages, more and more Canadians are balancing elder care responsibilities with child care responsibilities — this group is often referred to as the Sandwich Generation. The Sandwich Generation, typically made up of Canadians aged 45 to 64, includes 28 per cent of all caregivers.





## Canadian Centre for Caregiving Excellence

The Canadian Centre for Caregiving Excellence is a new initiative incubated and powered by the Azrieli Foundation. The Foundation has long supported innovative initiatives to improve access to quality care. Following a period of building networks and convening stakeholders, the Centre will become a stand-alone organization.



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