

Canadian Centre for Caregiving Excellence

# National Caregiving Survey

Summary of findings



The Canadian Centre for Caregiving Excellence is a new initiative incubated and powered by the <u>Azrieli Foundation</u>. 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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# Introduction

Canada is a nation of caregivers. One in four of us is a caregiver today, and half of all Canadians will become a caregiver in their lifetimes. This bears material impacts on all aspects of life, from the economy to the workplace, to schools and even to our political institutions.

Despite the prevalence of caregivers across the country, little is known about the realities of their lives. Data in this space are scarce and often outdated. If what gets measured gets done, it is no surprise that governments at all levels have yet to recognize caregiving as the next frontier of public policy.

The Canadian Centre for Caregiving Excellence (CCCE) seeks to fill this knowledge gap and spark much-needed action. This past summer, CCCE released the first National Caregiving Survey, which helps to shine a light on the current lived experiences of caregivers and care providers.



#### **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 caring for a child without a disability, medical condition or illness.)



#### Care provider:

Someone 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.

# Background and methodology

CCCE worked with Leger Communications to conduct a nationally significant survey of caregivers and care providers. Questions were prepared by Leger, a panel of expert researchers and CCCE staff. This panel survey was in the field from July to August 2023, engaging approximately 2,100 caregivers and care providers.

At the same time, CCCE ran the same survey from July to September through an open link for any caregivers or care providers across the country. Though not statistically representative of key national demographics (gender, province, age, etc.), the approximately 1,000 responses CCCE received through this medium help paint a comprehensive picture of the diversity of caregiver and care provider experiences. Select highlights from the open link are presented as part of this summary.

Respondents in both survey streams were asked if they would be interested in a followup interview to gather qualitative data. Over 500 people volunteered to continue the conversation. "I didn't receive any information from agencies or other services. I had to look for information on my own. Very little outside help. The various organizations only listen, without directing me to services. Few solutions, lots of listening. Tired of only being listened to, I'd like real help."



# Key findings

## The vast majority deem care policy a voting issue.

In our survey, 76% of care providers and 61% of caregivers say that policy related to caregiving is important to how they vote. While these numbers fluctuate regionally, this trend is nonetheless consistent across Canada.

Given the prevalence of caregiving in Canada – one in four today, one in two eventually – any political party seeking to grow their voter pool cannot ignore the issue of care.

#### **FIGURE 1**

% of care being important for voter intention. Q: Please indicate whether you agree or disagree with the following statement: "Policy related to caregiving is important to how I choose to vote."



## Caregivers lack access to support.

Canadian caregivers are seeking help, but most cannot access existing services. Over three-quarters (76%) of survey respondents reported that they received no support services over the past 12 months – and over half (53%) of caregivers attempted to find information about supports, services, and other benefits reported difficulty . Within this figure, just 20% attempted to access financial support (e.g., tax credits), and only 10% received the supports to which they are entitled. "Tracking down appropriate care services can be compared to the eternal pursuit of the promise. Never actually finding a service that can deliver what you need!"

#### Caregivers seek financial and wellbeing support.

Fully 83% of caregivers said that increased financial support is important to them, with many reporting that it is becoming increasingly difficult to make ends meet. Nearly two-thirds of caregivers (63%) reported experiencing financial hardship connected to their caregiving duties. While nine out of 10 caregivers welcome an income tax credit, just 39% are aware of the existing Canada Caregiving Credit. Even then, only 9% have successfully accessed it.

"I see that there are government tax grants, but they are time consuming, hard to apply for and not easy to qualify for."

An overwhelming 91% of caregivers seek improved home care services – most notably, respite care, over eight in ten caregivers (84%) deemed important. International research shows that routine respite helps prevent burnout among caregivers and lengthens the time they can support loved ones. Knowing that, it is telling that only 8% of caregivers reported using respite services over the last 12 months because such services were simply unavailable to most.

#### Care providers seek higher wages, greater flexibility.

Our health and social care systems depend on the labour of care providers in the community and other settings. Despite a rapidly increasing need for care providers, many have considered leaving their profession due to low wages (35%), burnout/ stress (35%), and/or lack of benefits (24%).

The message is clear: care providers need better pay and better working conditions. Nearly half (42%) of respondents report that higher pay would make their job easier. More than one-third (36%) are seeking more flexible scheduling, and 30% want paid sick leave. Furthermore, about one in five care providers report abuse at work, either from a care recipient (54%) or an employer (44%).

Our care workforce is in crisis. Caregivers and employers across the country are experiencing a critical shortage of frontline staff. The COVID-19 pandemic only exacerbated an existing human resources problem. Comprehensive reform that addresses the wages and working conditions of the care provider workforce would help stabilize the crisis of care in our communities and create new automation-proof jobs for our growing workforce. "I do not feel management understands my job or role. I do not feel respected. I feel I should be getting paid a lot more. I cannot strike due to my job. I rarely get raises like everyone else. Not much motivates me to stay with this job."

## Spotlight: Open link data

The open link survey results help paint a more complete picture of the state of care across Canada. While the panel data is statistically representative of the Canadian population, the open link sample skews predominantly female and older, with respondents who have generally cared for a wider variety of care recipients for a longer period of time. This generally aligns with anecdotal and reported lived experiences of care.

Among these participants, 80% say that caregiving policy is an important factor in their electoral choices. Nearly 60% report some financial hardship tied to their caregiving duties, and many report that their physical or mental health has declined. Nearly three-quarters (71%) have trouble accessing affordable local services.

When coupled with the panel survey results, the areas of need are clear:

- 90% need broader financial support
- 94% need better access to home care services
- 64% of care providers say higher pay is needed for job satisfaction
- Only 25% of care providers feel supported by governments

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# Looking ahead

This summary of findings is only the beginning. The stories and nuances contained within this new dataset will inform our advocacy and public policy agenda as CCCE helps lead the development of a national caregiving strategy. We will continue to analyze the data and share results through a variety of written and graphic media over the coming months.

Visit <u>our website</u> to join our mailing list and follow our social media platforms for the latest updates.





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