



Lead.
Support.
Empower.

Solutions to Further Empower Young Caregivers in Canada

*Written Submission for the Pre-Budget Consultations
in Advance of the Upcoming 2023 Federal Budget*

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OUR RECOMMENDATIONS

1. **Awareness:** That the government, with leadership from Young Caregivers Association, develop and implement a national response to the needs of young caregivers in Canada.
2. **Capacity Building:** That the government provide funding for the development and delivery of training programs for professionals in health care, education, and community services to increase the identification and support of young caregivers in Canada.
3. **Research and Data:** That the government provide funding for improved data collection on young caregivers in Canada.
4. **Service Delivery:** That the government provide funding to Young Caregivers Association to expand Powerhouse™ programs and services for young caregivers across Canada.

Solutions to Further Empower Young Caregivers in Canada



Who are Young Caregivers?

Young caregivers are children, youth, and young adults ages 5 to 25 who provide care for a family member due to a chronic illness, disability, mental health concern or substance misuse. Young caregivers help their family members in various ways by caring for their siblings or providing personal, emotional, or financial support. On average, young caregivers provide between 14 and 27 hours of care per week.¹

Meet Hana. Before she leaves for work this afternoon, she must help her dad get dressed and put on his prosthetic legs, translate for her mom at a medical appointment, and finish an assignment for school.

There are an estimated 1.25M young caregivers in Canada²

This data, however, excludes Northern Canada and children under the age of 15, leaving out a significant number of children and youth who provide care for a loved one. Due to a lack of current data or research, we do not know the scope of young caregivers who need support across Canada.

1 IN 4

One in four Canadians aged 15+ are caregivers³

StatsCan does not account for Canadians aged 5 to 14 years, leaving out a significant percentage of young caregivers.



52% of young caregivers do not feel supported

A study conducted by the Carers Trust in the UK found more than half of young caregivers say they 'never' or 'not often' received support from their school, college or university in balancing studies with their caring role.⁴



The impacts from COVID-19

- 81% of young caregivers felt more isolated and lonelier during the pandemic
- 65% were not able to take a break from caregiving
- 72% had caregiving responsibilities increase⁵

1 Chalmers, 2008, 2017; Stamatopoulos, 2018.
2 General Social Survey, 2012; Stamatopoulos.
3 StatsCan, Caregivers in Canada, 2018.
4 Carers Trust, Supporting Students with Caring Responsibilities, March 2022.
5 Young Caregivers Association, Young Caregiver Survey, 2020.

OUR VISION is a Canada where young caregivers and their families are recognized, supported, and empowered to achieve their full potential.

INTRODUCTION

Since 2003, Young Caregivers Association (YCA) has transformed the lives of young caregivers, the hidden population of family caregivers. The terms young carer and young caregiver are interchangeable and refer to children, youth, and young adults who provide care for a family member due to a chronic illness, disability (physical or intellectual), mental health, or addictions. Young caregivers support their family members in various ways including: providing personal care (e.g. grooming, medication administration and dressing), caring for siblings, providing financial and practical care and emotional support, and translating at medical appointments. They can have siblings with autism or developmental disability, a parent with MS, addictions or brain injury, or a grandparent that requires elder care or has dementia. There are a variety of reasons for the care that young caregivers provide to help their families.

As the first young caregiver program in Canada, YCA collaborates with community partners to bring our specialized programs and expertise to professionals and organizations across Canada, giving them tools they need to positively impact these hidden and vulnerable children and youth. Powerhouse™ is an award-winning, evidence-based program developed by the YCA that teaches young caregivers (ages 5-25) life and personal development skills, including coping and stress management; these programs build their resilience and help them to be successful by reducing the negative impacts of caregiving. Our response to COVID-19 included providing virtual programs and services, which widened our reach to young caregivers across Canada. Canadian research further validates Powerhouse™ as the most advanced and sophisticated model for such supports across the country.

WHAT WE KNOW

- Young caregivers are a hidden and at-risk population that must be recognized.
- Compared to their non-caregiving peers, young caregivers experience risks that include increased stress and depressive symptoms, low self-esteem, high anxiety levels, loneliness and isolation, difficulty relating to peers, self-harm and even suicidal ideation.
- Young caregivers are not recognized by professionals (i.e., health care, teachers, social workers, homecare workers) and therefore go unidentified and unsupported, putting their own mental health and wellbeing at risk.
- Young caregivers are shown to be held back from pursuing professional and academic opportunities; employment is a challenge because of the on-call nature of their caregiving and due to the responsibilities at home. Education is affected by lack of sleep and concentration, truancy, and a lack of time for homework and studying.
- International young caregiver research highlights how caregiving youth have relatively high levels of unemployment, lower rates of labour force participation, and higher rates of government support.
- Canada trails behind other countries that support young caregivers.

The current Government of Canada has made a commitment to young Canadians, evident in the current development of a youth policy. Given that young caregivers represent more than 27% of our population (Stamatopoulos, 2015a), and that Canada trails behind other countries that currently support young caregivers, improving the recognition and support of young caregivers in Canada is imperative.

ECONOMIC AND SOCIAL IMPACTS OF YOUNG CAREGIVING

Through Canadian research we know that young caregivers are providing an average of 14–27 hours of care per week, equivalent to a part-time job. We know that the unpaid care being given by young caregivers saves \$25,000–\$50,000 for the family and/or healthcare system. We know that supporting young caregivers will enable them to continue to care for their loved ones at home while potentially reducing hospital visits, homecare needs, and delaying long-term care admission, resulting in meaningful, long-lasting impact for society as a whole. Most importantly, we know that without sufficient recognition and support, young caregivers are at risk of increased stress and depressive symptoms, low self-esteem, high anxiety levels, loneliness and isolation, difficulty relating to peers, self-harm and even suicidal ideation. The *‘young carer penalty’* has long-term negative effects that affect education and employment for young caregivers. Supporting young caregivers to reduce the negative impacts of early caregiving is thus a cost-effective strategy that can prevent future social, psychological, and economic penalties experienced by such youth across the lifespan.

OPPORTUNITY FOR SOCIAL IMPACT

According to Dr. Stamatopoulos, the “*young carer penalty*” incurred by such child and youth caregivers poses short- and long-term harm to their academic, social, and professional development, ultimately compromising their well-being and development in the absence of national supports and safeguards. **Supporting young caregivers to reduce the negative impacts of early caregiving is thus a cost-effective strategy that can prevent future social, psychological, and economic penalties experienced by such youth across the lifespan.**

“Powerhouse Project is the reason I am who I am today. Nothing else has always been there for me to teach me how to be less stressed and help with my anxiety and depression. Powerhouse Project is the reason I have been able to come out of my shell and be who I am today.”

– YOUNG CAREGIVER

OUR ASK

The current Government of Canada has made a commitment to young Canadians, evident in the current development of a youth policy. **With funding to support awareness, capacity building, research, and service delivery, the Federal Government of Canada has the opportunity to be global leaders in supporting young caregivers through partnership with YCA.** Supporting young caregivers in their early lives is an upstream intervention which may lead to prevention of mental health and addiction issues, school failure, unemployment, and other downstream consequences crossing multiple health and social sectors.

“It is very difficult as a mom being ill and having your own child take on so much responsibility and have the maturity to assume the role of your caregiver. Our children can feel isolated and alone in a role that we didn't intend on them assuming. Powerhouse Project has been a great support system and I try to encourage other parents/families of caregivers to join.”

– PARENT

1. Awareness: That the government, with leadership from YCA, develop and implement a national response to the needs of young caregivers in Canada.

Caregiving expectations within families may be culturally dependent. In Canada, childhood is viewed as a time of 'becoming' or 'dependency'. Young caregivers contradict this view and the traditional understanding of child and adult roles within the family. As a result, young caregivers and their families are often stigmatized and remain a hidden and at-risk population that must be acknowledged. Both the Vanier Institute of the Family Report (2012), and the Action Canada Task Force Report (2013) **identified young caregivers as a priority area in need of acknowledgement and support.** If young caregivers and their role are recognized, their role will become more valued in society and feelings of isolation and loneliness and experiences of bullying decrease.

"I wish my teachers could understand my caregiving responsibilities. I wish they could see my 'other' homework"

– YOUNG CAREGIVER

2. Capacity Building: That the government provides funding for the development and delivery of training programs for professionals in health care, education, and community services to increase the identification and support of young caregivers in Canada.

Canada lacks the necessary training and education of professionals to allow young caregivers to thrive while continuing to provide the support needed to keep their loved ones at home. Currently, there are no formal training opportunities for professionals to increase their proficiency with addressing the needs of young caregivers, and we do not have the necessary cultural competency to offer appropriate services to all Canadians. This is a large gap in Canada's ability to address this **at-risk population.** Supporting young caregivers to reduce the negative impacts of early caregiving is a cost-effective strategy that can prevent future social, psychological and economic penalties. YCA is currently developing training modules for professionals in response to the expressed need we have heard from other provinces. However, we lack the funding to launch a robust training program.



"I wish medical professionals would listen to me and know that when I talk about my father, I know what I am talking about. I see it every day. I am the one caring for him every day."

– YOUNG CAREGIVER

3. Research and Data Collection: That the government provide funding for improved data collection on young caregivers in Canada.

Little is known about young caregivers throughout the world and even less is known in Canada. Young caregivers were first recognized in England in 1993. However, the first studies conducted in Canada were in Ontario in 2008 by Dr. Chalmers; in British Columbia in 2012 by Dr. Charles, and recently, the first trend analysis of youth-based caregiving at the national level was conducted by Dr. Stamatopoulos. Canada has an opportunity to be a leader in supporting young caregivers. An investment in research will ensure our work is **evidence-based, effective, and sustainable**. Further, the gaps in our understanding regarding caregiving within a cultural context and the impacts on development over the lifespan, will be examined to further inform best practice.

4. Service Delivery: That the government provide funding to Young Caregivers Association to expand Powerhouse™ programs and services for young caregivers across Canada.

“It’s one thing to ask questions and listen, but another thing to actually do something about it.”

– YOUNG CAREGIVER

Supporting young caregivers allows their family member to be home longer. On average Canadian young caregivers are providing 14–27 hours of care per week, the equivalent of a part-time job, in their caregiving role. This informal care provided by them corresponds to a cost savings of \$25,000–\$50,000 annually for the family and/or healthcare system through avoiding the costs of accessing formal private or public healthcare. By ensuring young caregivers are supported,

we can reduce the negative impacts associated with unsupported caregiving such as increased stress and depressive symptoms, low self-esteem, high anxiety levels, loneliness/isolation, difficulty relating to peers, self-harm or suicidal ideation, in addition to both short and long-term harm to their academic, personal, social, and professional development. Further, it is in the government’s best interest to support young caregivers to ensure they remain healthy and able provide care without the need for their family members to be escalated to costlier care within the public system. Supporting young caregivers now in order to reduce the negative impacts caregiving is a proactive strategy that can prevent future negative impacts (social, psychological, and economic) as they get older.

“Powerhouse is the reason I am who I am today. Nothing else has always been there for me to teach me how to be less stressed and help with my anxiety and depression.”

– YOUNG CAREGIVER

With your partnership, we can have a nation in which young caregivers:

- are no longer hidden;
- can access appropriate supports including counseling and respite care
- have improved resilience, coping skills, self-esteem and confidence and a decrease in social isolation, stress and caregiver fatigue;
- are better connected to supports and services;
- are recognized by professionals Canada-wide;
- have improved educational outcomes and have better employment opportunities;
- have improved long-term health and mental wellness.

