



# Submission to the Ontario Human Rights Commission

Consultation on Discrimination on the Basis of Family Status

Ontario Caregiver Coalition

## ABOUT THE ONTARIO CAREGIVER COALITION

The Ontario Caregiver Coalition (OCC) is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. Our members include both caregivers from across Ontario and organizations that support them. For more information about the OCC and our work, please see our website at [www.ontariocaregivercoalition.ca](http://www.ontariocaregivercoalition.ca) or follow us on social media.



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## INTRODUCTION

*“The Ontario Human Rights Code is nice in theory, but employers are not actually following it and do not understand it. There is no enforcement so employers do not feel they need to follow it — it leaves employees (usually women) in a vulnerable situation where they are trying to fight for their rights against 3 or 4 managers. Women often give up because they know they can't win and they don't have time to fight and do all of the research/paperwork while trying to care for a loved one.”<sup>1</sup>*

The Ontario Caregiver Coalition (OCC) is grateful for the opportunity to participate in the Ontario Human Rights Commission (OHRC) consultation on its Policy and Guidelines on Discrimination Because of Family Status (the Policy).

The OCC, a non-partisan non-profit, is the voice of caregivers in Ontario. We advocate for recognition and support for the family, friends, and neighbours whose unpaid care is the hidden backbone of Ontario's health system. The OCC has been working to advocate for caregivers since 2009. Our membership includes caregivers, care providers, and health charities across the province. Our organization members include the Alzheimer Society of Ontario, MS Canada, Baycrest, the Young Caregivers Association, Ontario Shores, the Ontario Association of Social Workers, and many more.

Our mission is to improve the lives of caregivers by advocating for fair access to needed supports. Our vision is for an Ontario where caregivers are valued, respected, recognized, and supported. More information on the OCC is available at [www.ontariocaregivercoalition.ca](http://www.ontariocaregivercoalition.ca).

The OCC's advocacy is grounded in the experience of our members and caregivers across Ontario. Our 2024 survey of over 600 caregivers presents comprehensive data on the state of family caregivers and the changes to policies and programs needed to adequately support them. Providing unpaid care to loved ones is necessary work, and it is often emotionally satisfying and uplifting. At the same time, caregivers report elevated levels of financial distress, emotional exhaustion and poor mental health, and utterly inadequate support for in-home supports, respite, and care coordination.

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<sup>1</sup> All quotes are from caregivers who completed the Ontario Caregiver Coalition's 2024 Caregiver Survey

To address these issues, the OCC has developed a series of policy briefs that provide government with a comprehensive plan to support caregivers, improve their capacity to support their loved ones, and enhance their critical contribution to health care and other publicly supported human service systems.

### The policy briefs published to date address the following topics:

- Designing services and supports in a way that includes, respects, and responds to caregiver experiences ([Brief 1](#))
- Alleviating the financial impacts of caregiving ([Brief 2](#))
- Improving access to mental health supports ([Brief 3](#))
- Ensuring that caregivers get a break ([Brief 4](#))
- Developing a caregiver inclusive workplace, accompanied by a [Policy Options Report](#) that considers, among other issues, the role of the Code in supporting caregivers in the workplace ([Brief 5](#)).

The OCC is currently developing a final Policy Brief focused on **access to supports in the community**, which we will be launching in **fall 2026**.

In these policy briefs and in all OCC advocacy, we demonstrate that there is a strong public interest in recognizing and supporting the role of caregivers. For example, maintaining workforce attachment for those caregivers who choose to work increases access to workplace benefits, enhances overall workforce participation rates, and supports the well-being of many caregivers. We can identify many publicly-funded service systems where service demands would be exponentially greater without the contributions of informal caregivers (healthcare, developmental services, dementia care, et cetera).

But caregiving is not only a pressing public policy issue. It is also a human rights issue, a truth which is often overlooked. A better understanding of the human rights of family caregivers is required at all levels of society. The OHRC, with its central role in advancing rights for all, has an important role to play in increasing understanding and implementation of the rights that family caregivers have under the Ontario Human Rights Code (the Code). This Submission seeks to support the work of the OHRC by providing a brief overview of the caregiver rights as human rights and the systemic challenges that underlie the challenges to equality faced by caregivers. The Submission

then provides more in-depth information and analysis of the specific barriers in employment, education, and health and community services.

## CAREGIVING AS A HUMAN RIGHTS ISSUE

Caregiving is at the core of the grounds of family and marital status. Providing care for family members who require temporary or permanent assistance to perform activities of daily living is not unusual or aberrant; it is fundamental to the legal, ethical, and practical understandings of being a family member. It is expressed most clearly in the legal duty of care that is required of parents. Child neglect in its most extreme form is a criminal offence. There is a similar obligation expressed in law to exercise a duty of care to those who are under the care of another person. Far beyond any legal responsibility, however, is the expectation that family members will provide care to those in their family who require support because of age, acute illness, or disability.

There is growing attention to caregiving as a pressing issue in health, economic, and social policy, but there is very little understanding of caregiving as a human rights issue. And yet caregiving is at the root of many issues which we do acknowledge as pressing human rights concerns.

The OHRC's Policy acknowledges that, at the time of its development, there was a profound lack of awareness among the public about rights and responsibilities related to family status, and its associated ground under the Code, marital status. Issues related to family and marital status are not typically viewed as "real" human rights issues, equal in importance to other Code grounds. This has not changed in the 20 years since the Policy was developed. Indeed, the OHRC itself has devoted little attention to these grounds, which makes the revision of the Policy an important opportunity to advance human rights related to family and marital status.

While the number of male caregivers increases every year, caregiving remains an overwhelmingly female responsibility. Without protections and accommodations as described in human rights legislation, women are significantly more likely to be impacted by discrimination on the basis of family caregiving responsibilities. The pandemic offered an extraordinary natural experiment of the impact of caregiving on women. In the spring of 2020 — when schools shut down and the overall caregiving burden increased dramatically — the impact on women was dramatically different than the impact on men. A study from RBC reported that "[i]n a matter of weeks during the

spring [of 2020], COVID-19 rolled back the clock on three decades of advances of women’s labour-force participation...”

Caregiving is fundamentally gendered, not just in terms of who carries out caregiving roles, but in how we conceive of care. Care, as an expression of nurture and requiring the qualities of patience, compassion, and self-sacrifice, is conceived of as a “feminine” activity, and so is seen as being of lower value and belonging to the private sphere of the family, rather than to the public sphere where economics and public policy hold sway. The association of women with care, in addition to the disproportionate role that women play in providing caregiving, has the effect of marginalizing women, both economically and socially. It also has the effect of reducing public investment in the care of persons with disabilities and older persons, because care is seen as the private responsibility of families, and in particular the responsibility of mothers, daughters, sisters, and granddaughters.

This lack of investment in systems of care has profound implications not only for the equality of women, but also for older persons and persons with disabilities. We all exist in relations of care and interdependency. The idea of a totally self-sufficient “Marlboro Man” who neither gives nor receives care is a fantasy. This is particularly visible in the lives of persons with disabilities, those living with acute illness, and older persons living with frailty, all of whom rely on relations of care and interdependence to achieve security, autonomy, dignity, and inclusion. So long as the vital role of caregivers in supporting lives of dignity for persons with disabilities and older persons is not acknowledged, valued, and supported, the barriers to equality for these groups will be insurmountable.

A society that recognizes and values care is one that understands that we are all interdependent and potentially vulnerable, that respects the fundamental role of relationships in building society, and that puts a premium on providing lives of dignity for all. A society that values care and caregivers has laid the foundations of the vision expressed in the Preamble of the Code, of a society that recognizes “the inherent dignity and the equal and inalienable rights of all members of the human family.”

**The OCC calls on the OHRC to recognize caregiving, as protected by the grounds of family and marital status, as a vital human rights issue and the foundation of the equality rights of women, persons with disabilities, and older persons.**

## SYSTEMIC AND SOCIETAL ISSUES: CAREGIVING IN ONTARIO

*“Physically I can’t do it all. Emotionally I can’t do it all. It’s my partner who has Alzheimer’s and I have to do it all, his meds, keep track of appointments, advocate for better care for him, for different medications, for more services. Then do the cleaning, the laundry, the shopping, the supporting, etc. Sometimes I don’t eat all day, I forget to take my medications, I feel exhausted and don’t realize it. And I do all this without my best friend and confidant, making major decisions alone.”*

To understand the discriminatory barriers that caregivers face in employment and in accessing educational and health services, it is necessary to have some understanding of the context of caregiving in Ontario, and the broader systemic challenges that caregivers face. **While acknowledging that the lack of recognition and supports for caregivers does not itself fit within the Code’s anti-discrimination framework, this context is essential to understanding why caregivers need accommodations and supports when interacting with Code-protecting social areas, and why caregivers who are members of Code-protected groups, such as those who are racialized, newcomer, Indigenous, or 2SLGBTQ+, will face additional systemic barriers in accessing those limited services that are intended to support caregivers.**

While each caregiving situation is unique, the complexity and responsibilities associated with caregiving are often poorly understood. Caregiving can include providing emotional and mental health supports, housekeeping and home maintenance, meal preparation, medication management, facilitation of social and recreational activities, assistance with the activities of daily living such as eating and dressing, organizing access to care, scheduling and facilitating appointments, transportation, assistance with finances, substitute decision-making, assistance with medical tasks, advocacy, ensuring safety, and more. Many caregivers describe a sense of 24/7 responsibility for the person they care for. Because caregiving is such an intimate activity, it relies on a sense of trust between caregiver and care recipient, and a commitment to respect and responsibility on the part of the caregiver. Caregiving involves a significant ethical commitment.

According to the Ontario Caregiver Organization’s [2025 Spotlight Report](#), there are approximately 4.2 million caregivers in Ontario. Thirty-eight percent of caregivers are providing more than 10 hours of care a week, and on average they are spending \$758 per month on their caregiving role. The costs of this role for caregivers are high: 25% have taken out a loan or are using a line of credit to manage the financial strain; 41%

are considering leaving their job because of the difficulties in balancing roles; and 72% say they are unable to maintain their own healthy behaviours. Over two-thirds feel so burnt out that they are unsure how they can continue. Ontario's caregivers are in a crisis arising from the pervasive lack of supports available for both those who give and those who receive care.

## Growing Demands on Caregivers Amid Insufficient Supports

*“It’s not enough to try to ‘increase resilience’ for caregivers or help them to ‘navigate’ to supports that don’t actually exist. Caregivers need concrete, practical systems of support — good homecare, financial backstops, proper housing options. This cannot be dealt with as an individual problem. It’s a systems problem.”*

Caregivers care for individuals living in a range of settings, including their own homes, retirement homes, and long-term care homes. However, for many families, avoiding institutional settings is a primary goal. Given the [lengthy waitlists for long-term care in Ontario](#) and the high cost of building and providing long-term care, supporting Ontarians who are aging or living with disabilities to remain in the community is also a government priority. Supporting care in the community is also a response to the intense pressures on Ontario's hospitals. For example, Ontario's [Home First](#) strategy is focused on discharging patients from hospital with supports from the home and community care system, including while waiting for placement in long-term care.

While the goal of supporting community-based care is widely shared, and recent government investments in home care are welcomed, community supports continue to be fragmented, rationed and often insufficient. As a result, the pressures on caregivers continue to increase. Caregivers find that publicly funded home care services (e.g., in-home nursing, personal support, and rehabilitation services) and community care services (e.g., adult day programs, caregiver respite, Meals on Wheels, transportation) are overstretched, often providing limited and minimal support that do not meet families' needs. As the OHRC is doubtless aware, services and supports for youth and adults with developmental disabilities entail long wait lists and complicated processes.

The increasing policy priority on discharging patients from hospital into the community as quickly as possible adds more pressure to the caregivers who are expected to fill the gaps. Home First practices sometimes emphasize “rapid placement, standardized offers, or limited refusals,” all of which can place caregivers in impossible positions.

Thus, accepting unsuitable housing that compromises care or risking penalties within the housing system are common dilemmas encountered by caregivers. When Home First implementation prioritizes system efficiency without flexibility for caregiving realities, it risks undermining both family stability and the well-being of caregivers. The OCC believes that a Home First approach must also align with putting care first. The supports needed to achieve this are often difficult to find, are not funded to meet current demand, and fail to meet the needs of caregivers and care recipients.

## Navigating Fragmentation and Complexity: A Systemic Burden for Caregivers

*“The ‘system’ is broken. Totally shattered. Refer yourself, they say, and then refuse to take your call because... we don’t know why. Don’t tell me that there is a system in place, because there is not... If you work in one of these ‘systems’, get out of your office and visit the people who need you and learn from them and help implement the ‘supports’ that you feel exist.”*

Caregivers report that finding adequate supports and navigating Ontario’s complex and fragmented health and social systems is their biggest challenge. In addition to providing direct care, **caregivers are often required to take on the part-time job of acting as system navigators, patient advocates, case managers, and system safety nets.**

It is clear from the responses to the OCC’s 2024 Survey that many of the existing programs and services are not designed to be effective for caregivers. Respondents describe a bewildering and frustrating maze of outdated information, multiple fruitless referrals, narrow eligibility requirements, burdensome processes and lengthy waitlists, all to be traversed in order to access services and supports that may be unreliable, provide limited supports, or are too rigid to meet the actual need. Caregivers speak about “navigating to nowhere,” as they are repeatedly referred to multiple organizations or services, only to ultimately find that the service they needed was not available in their region, is not available to families in their particular circumstances, is so inflexible in its rules that it is not meaningful for them, or has such a lengthy waitlist that they can not rely on receiving supports within any reasonably foreseeable future. Caregivers living in rural, remote, or Northern settings emphasize the additional difficulties they face in accessing supports, for example, driving many hours to access services.

Thus, accessing services and supports requires time, resources, system knowledge, and access to networks. Caregivers who most need supports are often those who have the greatest difficulty navigating the complex maze of eligibility requirements, referrals, and administrative expectations that are required. They are therefore the most likely to be without supports or services, to the detriment of their own physical, mental, social, and financial health, as well as to the detriment of those they are caring for.

## Recommendations

The OCC recommends that the revised Policy explicitly recognize the systemic context that underlies the barriers that caregivers face in attaining equality in employment, education, and health and community services by:

- Explicitly recognizing that gendered understandings of care underlie the lack of public supports for caregiving, and that this lack of support contributes to systemic disadvantages for caregivers.
- Recognizing the profound connections between equality for caregivers and equality related to gender, disability and age, and that the failure to respect the value of care and its impact on caregivers contributes to the challenges in advancing equality on these other Code protected grounds.

While the OCC recognizes that the OHRC is currently consulting only on revisions to the Policy, the OCC urges the OHRC to consider exercising its powers under section 29 of the Code to raise public awareness through programs of public education and information, advise government on statutes and regulations, and promote programs among employers and service providers to address the human rights of caregivers.

## DEFINING THE GROUNDS OF “FAMILY STATUS” AND “MARITAL STATUS”

### Code Definitions

The Code does not directly protect the human rights of caregivers. Rather, it prohibits discrimination based on marital and family status. While the definition of marital status is broad, including “the status of being married, single, widowed, divorced or separated and includes the status of living in a conjugal relationship with a person outside of marriage”, the definition of family status is narrowly defined as “the status of being in a parent and child relationship” (section 10(1)).

Caregiving exists across the full range of human relationships. In addition to those caring for children with complex needs, parents with disabilities or diseases associated with aging, and spouses with a diverse range of illnesses and conditions, the OCC’s membership includes those caring for siblings, aunts and uncles, grandparents, grandchildren, cousins, friends, and neighbours. According to the [Ontario Caregiver Organization](#), while 47% of caregivers are caring for parents and in-laws, 11% for a child, and 21% for a spouse or partner, 27% are caring for extended family and 7% for a friend, neighbour, or colleague. Many caregivers fall outside the protections of the Code.

This diversity reflects the diversity of family structures in Ontario. As the OHRC acknowledged in its 2007 Consultation Report, *The Cost of Caring* (“the Report”), the family structures embraced or adopted by those who are 2SLGBTQ+, Indigenous, or from various cultural or ethnic groups often do not reflect the narrow definition of the nuclear family. As well, older persons and persons with disabilities may rely on very broad networks of support to sustain their independence and well-being. Indeed, as families become smaller and more dispersed, we anticipate that it will become more common for care recipients to rely on a very diverse range of caregivers, simply because there is no one else to give care.

Thus, the traditional nuclear family that is reflected in the Code definitions of family and marital status reflects an ever-shrinking percentage of Ontario families. It is for this reason that the Vanier Institute of the Family, in a widely adopted definition, now defines families by what they do rather than what they look like. The Vanier Institute defines a family as:

any combination of two or more persons who are bound together over time by ties of mutual consent, birth and/or adoption or placement, and who together assume responsibilities for variant combinations of some of the following: physical maintenance and care of group members; addition of new members through procreation, adoption or placement; socialization of children; social control of members; production, consumption, distribution of goods and services; and affective nurturance (i.e. love). [The Vanier Institute of the Family. (2024). Definition of family. <https://doi.org/10.61959/d232856f>]

This is a flexible definition that focuses on relationships that manifest sustained commitment over a period of time. Families undertake similar tasks and roles, though they may look very different and may perform those tasks quite differently. It puts the care that we provide for each other at the centre of our understanding of family.

The existing Code definitions create boundaries for human rights protections of those who provide care. In 2007, the OHRC recommended to the government that the Code be amended to include broader definitions of family and marital status. The OCC urges the OHRC to use its powers under section 29 of the Code to bring these issues to the attention of the government and to advocate for change.

But even within the boundaries of the Code, a broad and purposive interpretation of the existing grounds can assist in including more caregivers within human rights protections. Specifically, the OCC advocates that, drawing on the concepts in the Vanier Institute definition, the interpretation of the definition of family status should focus not on legal status or blood ties, but on who is performing the functions of a parent-child relationship. If a grandparent or uncle is effectively in a parental relationship with a child, that should be considered a parent-child relationship, regardless of whether there is formal documentation allocating legal parental or guardianship responsibilities. If a caregiver is caring for an aunt who is frail, ill or living with a disability in the same manner as an adult child would provide care, the interpretation of the Code should be broad enough to include that as a parent-child relationship.

## Relationships to Other Code Grounds

Earlier in this Submission, the OCC highlighted the profound connections between the Code grounds of family and marital status, and the grounds of sex, age, and disability. The forms of disadvantage experienced on the basis of these connected grounds are, in the view of the OCC, so profoundly linked that they cannot be understood separately.

Given the limitations in the Code definition of family status, the OCC urges that the grounds of sex, disability, and age be interpreted in a manner that is sensitive to the caregiving dynamics that surround the experience of sex, disability and aging.

As with other Code grounds, it is important that the grounds of family and marital status be understood as intersecting with other grounds of the Code to produce compounding disadvantage.

**2SLGBTQ+ caregivers:** Quebec's Fondation Emergence has [conducted research](#) on the experiences of the chosen families who are caregivers to members of Quebec's 2SLGBTQ+ community, finding that provision of care to those who are not blood relations is a common experience; that they continue to face discrimination in accessing health and social services because of their sexual orientation, gender identity and gender expression; that as a result they are less likely to access available services and supports; and that they are more likely than other caregivers to experience elevated levels of distress.

**Newcomers:** Navigating Ontario's very complex and fragmented health and social systems of support is complex and resource-intensive for all caregivers, but is especially challenging for newcomers who will have less understanding of how our health and social systems are structured, fewer networks and connections to give them entry points to the system, and frequently are also navigating linguistic and cultural barriers. As well, because newcomers are disproportionately working in precarious employment, they are less likely to have access to the flexibility, benefits, EAP programs, and workplace status that can help to cushion the challenges of balancing care with employment.

**Linguistic and cultural minorities:** As is described in more detail later in this Submission, in the section on access to community services, there is a dearth of services and supports accessible to linguistic and cultural minorities. Members of these groups may need services that are provided in their own languages or that respect cultural norms, and these are rare and hard to find. Members of these groups may therefore wait longer for and experience more barriers to receiving supports such as home and community care or long-term care. The barriers to receiving these supports may have knock-on effects on their employment prospects.

There are family caregivers in Ontario from all ethno-racial communities. But the definition of family responsibility can vary greatly across ethnicities and nationalities. One clear expression of these differences is the multi-generational family, where the

expectations of responsibility for children, the infirm, and the elderly are a fundamental part of family life. Statistics Canada reports that immigrants and racialized families are significantly more likely to live in multi-generational families than the rest of the Canadian population.

**Disability and older age:** Attention should also be paid to the experiences of caregivers who are themselves often in need of supports — that is, caregivers who are themselves living with disabilities or who are aging into frailty. The OCC heard in our survey that supports are often not provided in accessible ways, or do not take into account the limitations in the capacities of caregivers with disabilities. For example, older caregivers may struggle with automated systems, particularly when, as so often is the case, accessing supports requires extensive and complex administrative requirements.

**Young caregivers:** There is growing attention to the experiences of young caregivers. While definitions vary, the [Young Caregiver Council of Canada](#) includes in its membership young carers between the ages of 14 to 30. Young caregivers may be caring for siblings, parents, grandparents, or other close family members or friends. As with all caring, caregiving as a young person can be both a source of strength and meaning, and a cause of challenges and struggles. Providing services and supports for young caregivers can help to minimize any long-term negative effects on the social, economic, and psychological well-being of these individuals. Because we don't imagine young people as caregivers, they and their needs are often invisible, and existing services are often not tailored to their needs. For example, young caregivers who are at the beginning of their careers may struggle to gain entry points to work when they must balance their career aspirations with their care responsibilities, and may have less leverage to request accommodation from employers. Caregivers who are minors are often not eligible for government supports and services for caregivers. Service providers, educators, and employers should actively consider and design policies and programs to include the particular barriers experienced by young carers. The Young Caregivers Association has developed a helpful [suite of tools and resources](#) for educators, health professionals, and social workers who may encounter young caregivers.

**Indigenous caregivers:** Like caregivers in general, Indigenous caregivers face a broad array of challenges and inequities. However, many of these challenges are much more pronounced for Indigenous caregivers, and Indigenous caregivers also face unique challenges that many other caregiver populations might not be exposed to. These

challenges are documented in various reports from organizations like the [National Collaborating Centre for Indigenous Health \(NCCDH\)](#) or the [Alzheimer Society of Canada](#), literature reviews [e.g., [Hillier & Al-Shammaa \(2020\)](#), [Racine et al. \(2021\)](#)], and original studies (e.g., [Ward et al., 2023a](#), [Ward et al., 2023b](#), [Hammond et al., 2022](#)). Importantly, caregiving in Indigenous communities is viewed very differently than in non-Indigenous communities and by our health and social systems. Rather than a dyadic relationship of one caregiver caring for one individual in need of care (the mainstream approach), Indigenous communities view caregiving as a shared community responsibility. In particular, the [NCCDH report](#) and [Hammond et al. \(2022\)](#) illustrate how caregiving in Indigenous communities is shared by circles of care. It is an activity that is central to cultural preservation and community identity, extending beyond humans to include animals, plants, and land, and is often understood as core traditional teaching.

All of the resources cited above highlight that anti-Indigenous racism is deeply engrained in our health and social support systems, which creates barriers in accessing services and supports, as well as poor experiences when interacting with these services and supports. Colonialism, displacement, residential schools, poor treatment, neglect, and abuse have disrupted Indigenous family relationships and caregiving, and have triggered deep, ongoing generational trauma, and severe mistrust of colonial health and social systems. For these reasons, Indigenous families may avoid accessing supports and services they perceive as culturally unsafe, amplifying challenges for Indigenous caregivers. Other access barriers ([Ward et al., 2023a](#)) include overlapping, complex, and intertwined federal, provincial, municipal, and Indigenous community-based responsibilities and policy frameworks, making access extremely challenging. Services vary widely and Indigenous ways of being, knowing, and understanding are often not incorporated. Caregivers struggle with identifying the right services, navigating siloed and complex community, healthcare, policy, and funding systems, and are often confronted with delayed assessments and treatments.

As such, caregiving in Indigenous communities is a deeply political matter, an act of political citizenship to reclaim Indigenous sovereignty, and a means of anti-colonial resistance ([Hammond et al., 2022](#)). Therefore, remaining within their communities for as long as possible and receiving culturally safe services and supports is even more crucial for Indigenous Peoples than it is for many other populations ([NCCDH 2018](#), [Alzheimer Society of Canada 2024](#), [Hillier & Al-Shammaa, 2020](#), [Racine et al., 2021](#), [Hammond et al., 2022](#)). A shift in perspective is required to focus on supporting the well-being of communities via collective health action, rather than supporting individuals.

## Recommendations

The OCC recommends that:

- The OHRC raise with government the limitations arising from the current definition of family status, and recommend an amendment to the definition that reflects a functional approach to family;
- The revised Policy advance an interpretation of the ground of family status that focuses on the functional aspect of a parent-child relationship, and that protects all those who are undertaking responsibilities associated with a parent-child relationship;
- The revised Policy clearly address the inextricable relationship between family and marital status, and equality rights based on sex, disability, and age;
- The revised Policy clearly address the intersectional experiences of caregivers who are young, old, living with a disability, 2SLGBTQ+, newcomers, or members of linguistic and cultural minorities.
- The revised Policy specifically address Indigenous understandings of care, the effects of colonialism and anti-Indigenous racism on access to supports for caregivers, and the importance for Indigenous caregivers of receiving supports in a manner that is culturally safe and respects connections to community.

## UNDERSTANDING THE DUTY TO ACCOMMODATE FOR NEEDS RELATED TO FAMILY AND MARITAL STATUS

In this Submission, specific instances of and barriers to accommodation are dealt with in the sections addressing employment and housing, as in each sector there are different dynamics at play. This section will make only some brief comments on the duty to accommodate for family and marital status in general.

There is relatively little case law addressing the duty to accommodate for family status, and much of that addresses the situations facing parents raising minor children who are living without complex needs, acute illness, or ongoing disability. There are shared challenges between those who are parenting children without special needs, and those who are caring for those living with illness, disability, or frailty. Most importantly, they share an experience of a culture and institutions shaped around gendered expectations of care, in which caregiving is a private family matter which should not impinge on the public sphere, and which remains largely a feminized role. But there are particular circumstances affecting caregivers for those who are living with acute illness, disability, or frailty which are worthy of consideration in understanding what the duty to accommodate may mean in this context.

### Understanding the Accommodation Needs of Caregivers

Caregiving in this context is often very intensive and frequently unpredictable. While child-rearing is in general associated with growth through a relatively foreseeable set of stages, needs, and institutions, the needs of those who are acutely ill or in the last stages of long life are often unique, may change with great suddenness, and may vary considerably from day to day or week to week. Well-laid plans may be interrupted by an unexpected phone call. The services and supports that have previously been adequate may no longer meet the need, may become unreliable due to funding challenges, or may be defunded entirely. An accommodation plan may need to be updated on a frequent basis.

Caregiving in this context is inextricably associated with grief and mourning. It is very often associated with an anticipated loss of a loved one, whether in the near or medium term, or with diminished life prospects for that loved one. Relationships around which the caregiver has organized their lives may change profoundly: a parent or sibling or spouse on which the caregiver has relied for emotional or practical support may not only

no longer be able to provide that support, but may now need support themselves. As well, the intensity of this type of caregiving may require significant and unwanted life changes for the caregiver. Caregivers may find it necessary to give up long-held hopes for their careers or cherished hobbies, and may see friendships and community activities fall by the wayside. Caregivers often undergo a deep transformation in their sense of their own identity. Rarely do people plan to provide this type of caregiving; it is a role that is taken on because it is necessary. Caregiving therefore is often associated with impacts on mental, physical and emotional health. Caregivers, focused as they must be on the needs of the care recipient, may not recognize their own needs for support, or may not have the time or energy to seek assistance.

Case law regarding access to accommodations based on family status at times references a binary division between needs versus preferences, with accommodation required only where a “need” can be demonstrated, sometimes in the form of a legal obligation or responsibility. This type of analysis is a poor fit for the realities of caregiving in Ontario, where caregivers are often the final safety net to ensure dignity, inclusion and safety for the people with disabilities and older persons that they provide care to. In our experience, caregivers often live with a sense of profound responsibility for the lives of people who are very vulnerable. Indeed, existing systems tend to be built on the assumption that family members and friends will act out of altruism and a sense of ethical responsibility. Caregiving is relational and trust-based. It may be useful to consider whether questions of need versus preference could be replaced with considerations of the ethics of care.

Finally, caregivers are often tasked with supporting their loved ones through systems that are fragile and over-stretched. As was noted above, caregivers, in addition to the physical, mental and social aspects of direct care, are often required to act as adjuncts to or extensions of health and social systems. These are roles for which caregivers are not trained, and for which they may not be well suited. They are also largely invisible to employers, educators or other service providers, who do not understand what caregiving entails.

**Understanding these realities is essential to accommodating those who are living with them.**

## Inclusive Design and the Duty to Accommodate in the Context of Caregiving

As was noted above, caregiving is already ubiquitous in Ontario, with an estimated 4.2 million Ontarians providing care. With an aging population and smaller families, caregiving will become an ever more dominant part of the lives of Ontarians.

The very prevalence of needs for accommodation for caregiving can form a barrier to accessing accommodation. Caregiving can be seen as too common to be a true barrier or human rights issue, but rather something that employees or students should manage themselves in the regular course of family life. As well, employers or educators may fear that addressing an accommodation request may lead to a flood of similar requests.

This points to the very high importance of inclusive design in accommodating needs related to caregiving. Indeed, because flexibility and the need for time are at the heart of accommodating caregivers, an inclusive design approach that centres flexibility can obviate most needs for tailored accommodation. Resorting to an individualized accommodation process can be onerous, stressful and time-consuming. It should be clear that employers and service providers cannot require caregivers to undergo the rigours of an individualized accommodation process without first looking to inclusive design and barrier removal.

## Recommendations

The OCC recommends that in revising the Policy, the OHRC build upon existing language to:

- Specifically address the particular challenges faced by those caring for those who are aging, acutely ill, or living with a disability, to ensure that those responsible for providing accommodation understand the realities of this experience and the ways in which it differs from raising a child who does not have special needs;
- Address the heightened importance of inclusive design in responding to the needs of caregivers, and re-emphasize that those responsible for

providing accommodation must demonstrate efforts to design inclusively and to remove barriers before resorting to the intensive process of individualized accommodation;

- Move beyond considerations of needs and preferences to a stronger grounding in the realities of caregiving in an overstretched system and in the ethics of care.

## IDENTIFYING AND ADDRESSING DISCRIMINATION IN THE WORKPLACE

*“It is extremely difficult to do both caregiving and work.”*

*“I had to drop to part-time employment as a registered nurse to care for my sister as it was too much for me. I now have no sick or vacation time.”*

### Understanding Discrimination Against Caregiver Workers

Working caregivers face multiple systemic barriers to equal participation in the labour force. People who combine paid work with unpaid caregiving responsibilities face constant and unpredictable demands that make stable employment difficult to maintain. Most employment protections still focus on short, time-limited leaves rather than the longer-term and individualized accommodations many caregivers require. To address these systemic challenges, the OCC has recommended reforms to Ontario’s employment standards laws, which would create a stronger floor of minimum standards that caregivers could rely on. Until such reforms take place, however, Ontario’s caregivers must rely on the protections of the Code and the goodwill of employers.

In the two decades since the development of the Policy, there have been some strides in awareness of the experiences of working caregivers, and some employers have adopted best practices for creating carer-inclusive workplaces. However, advances have been decidedly modest, and given the increasing strain within health and social systems, working caregivers are struggling. The lack of flexible scheduling, remote work options, or adaptable workloads remains one of the greatest barriers to maintaining employment while providing care. Employers may lack awareness of the demands of caregiving and the impact on caregiver-employees, and fail to design workplaces that are inclusive of their needs. Because of the negative attitudes and assumptions associated with caregiver-employees, as noted in the current Policy, some caregivers prefer to hide their caregiving responsibilities for fear that asking for accommodations could result in judgement from peers and reprisal from employers.

The OCC supports the current provisions of the Policy that focus on the responsibility of employers to address negative attitudes and assumptions, adjust workplace policies and practices to remove barriers for persons with family care responsibilities, and provide individualized accommodations to caregivers based on their circumstances. We also see opportunities to build on the current Policy to more concretely address the very practical struggles currently faced by working caregivers.

The negative attitudes and assumptions based on family status in the workplace, as outlined in the Policy, have persisted and continue to create barriers for caregivers in the workplace. While the Policy provides guidance and examples on addressing these negative attitudes and assumptions, in reality many caregivers still recognize the stigma associated with their caregiving roles and are reluctant to ask for support from their employers, especially given the lack of supportive organizational cultures that openly acknowledge and create safety for caregivers to self-identify. According to the Ontario Caregiver Organization's 2025 [Spotlight Report](#), almost half of caregivers feel they cannot speak openly at their workplace about their caregiving role, and 62% wish they had more support from their employer. Approximately one-third fear they will lose their job due to their caregiving responsibilities. To achieve equality for caregivers in the workplace, more needs to be done to encourage workplace cultures that proactively recognize and support the needs of caregivers.

In their search for flexibility, caregivers are disproportionately more likely to move into part-time, casual or contract employment, connected to broader shifts in the labour market away from traditional full-time employment. These caregivers find themselves with fewer workplace protections and benefits (such as paid and unpaid leaves and access to extended health benefits) at the very time when they need them most. It's important that the updated Policy recognize these barriers and provide guidance to employers on the fair treatment of caregivers in part-time and contract roles.

## Recommendations

The OCC recommends that the updated Policy:

- Reinforce that employers have a clear duty to provide a workplace culture that is caregiver-inclusive, where caregivers feel safe in self-identifying and asking for the supports that they need
- Clarify that, as part of preventing systemic discrimination against caregivers, employers should ensure that part-time and contract employees have access to pro-rated benefits and supports

## THE DUTY TO ACCOMMODATE CAREGIVERS IN THE CONTEXT OF EMPLOYMENT

*“Employers and managers need to be trained on family accommodation and the Human Rights Code. There is a gross misunderstanding of this in the working world and no system in place to support it — it should not be left up to the whim of each employer if they feel like being generous to allow flexibility for caregivers. There should be an equal and legal standard province-wide that gives caregivers options like flexible hours, work from home, reduced schedule, EI support without fearing they will lose jobs.”*

### The Central Role of Inclusive Design

This Submission earlier described the particular importance of inclusive design in the context of caregiving. Unfortunately, our current moment is one where employers in particular appear to be retreating from inclusive design. The proliferating return-to-office policies, for example, often pay little heed to the barriers that are being created for caregivers, and fail to consider whether these requirements reflect actual essential duties associated with jobs, or whether they simply reflect the employer preferences. Vague references to corporate culture and productivity cannot be taken as in themselves sufficient to deny flexibility to employees who require it due to family or marital status, particularly where they are not grounded in data and best practices. Employees who require flexibility should have a right to individual assessment prior to the imposition of an inflexible in-office requirement. The recent case of *Cosentino v. Octapharma Canada Inc.*, 2024 HRTO 860 highlights the inappropriateness of these carte blanche approaches to in-office requirements.

### Expectations Related to “Self Accommodation”

The OCC is aware that the case law related to the employer duty to accommodate for family status remains unsettled, in particular related to the extent to which “normal family obligations” may rise to such a level that the employer has a duty to accommodate. Some adjudicators appear to be attempting to narrow the ground of family status to apply only in the most exceptional situations. The OCC has highlighted above why these understandings of the ground of family status fundamentally misconceive the nature of caregiving responsibilities, and fail to address the systemic context and barriers associated with caregiving. Indeed, decisions such as that in

Canada (Attorney General) v. Johnstone, 2014 FCA 110 (CanLII), in which caregiving obligations need only be respected when they rise to the level of a legally sanctionable responsibility, reinforce the very attitudes that create barriers to equality. It is worthwhile highlighting the incoherence of policy approaches that on the one hand place primary responsibility for families for providing care, including through the Home First and Aging in Place policies, and on the other hand suggest that families are only entitled to recognition and support for such care in the rarest of circumstances. This policy incoherence significantly contributes to the social, financial, and economic marginalization of caregivers, as well as to the declines in physical, mental, and emotional health among caregivers.

The OCC wishes to particularly address the notion that caregivers have a duty to self-accommodate to avoid even the most minimal impingement on employment responsibilities. Employers often have only a very minimal understanding of the caregiving context, and unrealistic notions both of what kinds of support are available, and of how easy such supports are to locate and access. We have heard from caregivers who are asked to research and pursue options for community services that are not appropriate or do not exist, or to privately purchase services beyond their means, as an alternative to the employer simply providing some flexibility in hours or work locations. Employers often do not understand that caregivers are frequently already navigating a very complex maze of providers, eligibility requirements and admission processes, and that this navigation can be in itself a part-time job. The accommodation process is intended to be a joint search for solutions. Employers can contribute to this joint search by, for example, providing through their benefits EAP programs that include caregiver-specific supports.

We have also heard from caregivers who have been pressured to place their loved ones in institutional care, a misunderstanding of the restrictive criteria for admission to institutional settings, the often very lengthy wait lists, and the settled public policy understanding — including in the guidance of the Ontario Ministries of Health, Long-Term Care, and Community and Social Services — that community settings are preferable for older persons and persons with disabilities in almost all cases. We strongly support the current position of the Policy that “caregivers should not be required to place their loved ones into situations of significant risk of physical, emotional or psychological harm in order to meet the needs of their employer, landlord, or service provider”, and would strengthen this to clarify that caregivers should not be required to pursue or undertake solutions that would undermine the dignity, inclusion, participation and security of the person with disability or older person that they are caring for.

As the decision in *Misetich v. Value Village Stores Inc.*, 2016 HRTO 1229 (CanLII) highlights, a realistic understanding of the supports available to caregivers can assist in determining whether a workplace rule has a discriminatory impact. But caregiver employees should not be required to “bear the onus of finding a solution to the family/work conflict.” Caregivers should not be required to explore an unlimited number of options in order to satisfy the employer of the need for accommodation, and employers should ensure that options for alternative approaches that they suggest to caregivers are well-considered and based in knowledge of the actually existing system.

## Undue Hardship

The OCC endorses the current provisions of the Policy with respect to undue hardship, with the following additional consideration.

As is highlighted in the submission of Dr. Allison Williams, there is significant evidence that creating carer-inclusive workplaces is a net benefit to employers. Employers who claim undue hardship due to costs associated with accommodating caregiving need should be required to demonstrate that, in calculating the costs associated with accommodation, they have also taken into careful account the associated financial and other benefits to their workplace.

## Recommendations

The OCC recommends that the provisions of an updated Policy related to the duty to accommodate in the employment context:

- Specifically address issues raised through the current trend towards full-time, across-the-board return-to-office policies.
- Clarify that a request for accommodation does not require an employee to have first exhaustively researched all available options for “self-accommodation,” and that employers have a responsibility to themselves be reasonably well-informed about potential supports and systems prior to pressing employees to have recourse to them.

- Emphasize that caregivers should not be required to pursue or undertake solutions that would undermine the dignity, inclusion, participation, and security of the person with disability or older person that they are caring for.
- Indicate that the assessment of undue hardship for accommodating needs related to family and marital status explicitly address the benefits, financial and otherwise, of providing a carer-inclusive workplace.

## Preventing and Responding to Discrimination in Employment: Organizational Policies and Practices

Since the development of the original Policy, considerable work has been completed to understand the experiences of working caregivers, to identify best practices for including and accommodating caregivers in the workforce, and to provide practical and flexible guidance to employers seeking to recruit, retain, and advance caregivers within their workforces. The OCC points in particular to the extensive work of Dr. Allison Williams of McMaster University in this field, including the development of the complimentary Canadian Standards Association B701-17 (R2021) Carer-Inclusive and Accommodating Organizations Standard and B701HB-18 Implementation Guide 'Helping worker-carers in your organization' policy on carer-inclusive workplaces.<sup>2</sup> The Standard and Guide is the foundation for the complimentary [10-hour online course](#) "Creating Caregiver-Friendly Workplaces" offered through McMaster Continuing Education, and specifically targeting HR, employers, and occupational health and safety professionals.

The OCC strongly endorses the submission of Dr. Williams and recommends that the OHRC build on the CSA Standards in expanding on the limited material on organizational policies and practices provided in the current Policy.

It remains relatively uncommon for employers to explicitly recognize and address the human rights of caregivers as part of their human rights and anti-discrimination policies. Embedding caregiver inclusion into core people practices is an essential first step to respecting and advancing rights related to marital and family status. Employers must recognize that caregiving happens at every stage of life and career, across all genders, ages, and family types. As well, employers should recognize that some caregivers, such as Indigenous caregivers or young caregivers, will have very specific experiences and support needs.

Employers often have very limited understanding of the Code grounds of family and marital status, or of the connection between caregiving and human rights. This is a primary cause of the struggle that caregivers often experience in being included in their workplaces and in accessing accommodations. Education and training is therefore

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<sup>2</sup> The package (Standard + Guide) can be accessed here:  
<https://www.csagroup.org/store/product/B701%20PACKAGE/>

essential. Unlike 20 years ago, there are now many resources available for employers to assist not only in their own understanding, but in creating workplaces where caregivers are not stigmatized and silenced.

## Recommendations

The OCC recommends that the following be considered as minimum standards for employer policies and processes:

- All employers should have an explicit workplace policy for including and accommodating caregivers. This policy should take guidance from the CSA Standard for Carer-Inclusive Workplaces as a baseline framework for organizational policy and inclusive design.
- Employers explicitly include family and marital status in anti-discrimination policies with clear accountability mechanisms.
- HR professionals receive targeted training on caregiving as a human rights issue and their obligations under the Code.
- Flexible and remote work arrangements be recognized as a primary and practical accommodation tool for caregiver employees, not a last resort.
- Caregiver-specific supports be included in Employee Assistance Programs as a standard offering, not an optional add-on.
- Policies recognize caregiving responsibilities across all career stages and employment forms, including precarious and part-time roles.
- Organizations serving or employing Indigenous caregivers incorporate culturally safe and reconciliation-informed practices.

## IDENTIFYING AND ADDRESSING DISCRIMINATION IN THE PROVISION OF EDUCATION

Young caregivers are children and youth who take on a caregiving role at home due to a family member having a physical or intellectual disability, chronic illness, mental health concern, or addiction challenge. Young caregivers provide physical, personal, and/or emotional support daily to their loved one. Research suggests that [young caregivers spend on average between 7 and 27 hours per week providing care](#), a significant time commitment and level of responsibility.

At the time of the 2018 National General Social Survey, there were approximately 1.5 million young Canadians aged 15 – 30 supporting a family member with a health condition. [Young caregivers comprise one in five individuals in their age group](#). About one-third were providing care primarily to grandparents in the 12 months preceding the survey. Another 31% were caring for parents, while 19% were caring for friends, colleagues, or neighbours and 12% for other family members.

For young caregivers, their role can be [both a source of strength and meaning, and at the same time a barrier to employment, education, and social inclusion](#). Research indicates that there is a [“young carer penalty”](#) associated with this role.

### Primary and Secondary School Students

Minors who are in a caregiving role at home [may struggle at school, both socially and academically](#). Their responsibilities may leave them distracted in class, tired during school hours, frequently absent or late with their assignments. They may be unable to participate in after school or social activities because of their responsibilities at home, and may be isolated or withdrawn. These barriers and struggles may have a significant impact on the life course of young carers, leaving them less prepared to access post-secondary education or to successfully enter the workforce.

This suggests that interventions and accommodations may be important in ensuring that young caregivers have equal access to education. However, educators may be ill-equipped to support young caregivers, as they very often have limited knowledge about them. They may not be able to identify them, and may not be prepared to offer appropriate supports or referrals once identified. This lack of knowledge and skills can

lead to inappropriate or harmful interventions, such as unnecessary referrals to child welfare authorities.

More broadly, there is a lack of supports within the educational system for young caregivers. Educators may not themselves have resources to call upon to provide them with information or advice, and there may be no specific supports within the educational system to which educators can refer young caregivers.

The Young Caregivers Association has identified a variety of [steps that educators can take to support and accommodate young caregivers](#). Educators can consider inclusive design steps, such as scheduling activities during the school day and ensuring a welcoming and inclusive classroom environment. For example, including information about young caregivers within curriculum activities may help to remove stigma and to create an atmosphere where young carers are comfortable to seek the supports that they need.

Educators should also consider developing individual accommodation plans for young caregivers, as the situation of each young caregiver is unique. [Academic accommodations could include](#) providing a quiet place for study, a homework buddy, access to copies of notes, and flexible timelines. Young caregivers may also benefit from supports such as provision of information, access to a phone during the day to check in with the care recipient, a trusted adult to speak to, or connection to supports such as the school social worker or programs offered through the Young Caregiver Association or Young Caregiver Council of Canada.

One of the barriers for young caregivers within the secondary school system is the requirement for [40 hours of volunteer work in order to graduate](#). The significant responsibilities that are already being carried by these students may make it impossible to take on this additional requirement. Provision should be made either for these students to have their caregiving responsibilities recognized as their 40 hours of community service, or to have the requirement waived.

## Recommendations

The OCC recommends that the updated Policy:

- Specifically identifies the barriers for young caregivers within the education system;
- Identify best practices for educators to identify, accommodate, and support young caregivers;
- Encourage educational authorities to include young caregivers in their human rights frameworks and in their equity and inclusion planning, including by:
  - Identifying and redressing systemic barriers for young caregivers, such as the requirement for mandatory community service;
  - Developing individualized supports for young caregivers that enable them to participate fully in and benefit from their education;
  - Creating an inclusive and welcoming environment for young caregivers within the classroom and the school system more broadly;
  - Providing training and education on the needs of and supports for young caregivers to educators, school administrators, guidance counsellors, and school social workers.

## Post Secondary Students

Similarly to working caregivers, caregivers who are students in post-secondary institutions also face multiple systemic inequities in their access to education and in their ability to meet the expected educational standards. Ontario's recent decision to end the seven-year tuition freeze and to reduce student financial aid (OSAP) disproportionately affects students who are caregivers. Caregiving is often associated with substantial costs for the caregiver. At the same time, caregiving responsibilities affect a caregiver's ability to work a paid job. Due to the competing demands of

caregiving and studying, caregivers often require more time for their degrees, further increasing the financial pressures ([Lieu, 2023](#); [AARP, 2021](#), [Rawlinson, 2026](#)).

Therefore, the increased debt load through tuition hikes, decreased financial aides, and ever increasing costs of living create immense financial burden and substantial access barriers to education for caregivers.

The competing demands of studying and caregiving affect student caregivers in multiple ways (for the following, see [Lieu, 2023](#); [AARP, 2021](#), [Rawlinson, 2026](#), [Olenick, 2023](#)). In-person classes and exams/assignments require caregivers to be absent from the care recipient for large amounts of time. This problem is amplified by long commuting times due to poor public transportation, traffic congestion, and the fact that caregivers may have to live far away from their educational institution to be able to afford housing costs or to live close to the person they care for. Caregivers are required to find someone to care for their person during their absence (often associated with additional out-of-pocket costs), or to miss classes and exams or assignments. Inflexible class and exam/assignment schedules may further increase caregivers' already substantial workload, and they may make it difficult for caregivers to respond to crises (e.g., increased care needs of the person in need of care or caregivers' own deteriorating health). Finding a quiet space to study at home with the care recipient around may also be challenging. Therefore, caregiver students often face impossible choices between the recipient's care needs, their own health and well-being, and academic deadlines and demands.

These multiple competing demands and dilemmas severely affect the student caregiver's mental health (for the following, see [Lieu, 2023](#); [AARP, 2021](#), [Rawlinson, 2026](#), [Olenick, 2023](#)). Focusing on their studies instead of caregiving may trigger feelings of guilt. They feel like they are constantly "on" with no downtime at all. Isolation and lack of social support are common among caregiver students. Levels of anxiety and depressive symptoms are high and ever-increasing, and eventually, the caregiver's physical health suffers. Unfortunately, few colleges and universities have dedicated services for caregivers enrolled as students. They all provide some general support, but caregivers face unique and often greater needs than regular students.

Finally, these competing demands often negatively affect the student's GPA, making them less competitive when looking for a job after completion of their degree. Drop-out rates are higher among student caregivers than among other students, so the potential benefits of higher education cannot be realized and all that remains is the student loan that caregivers must pay back.

## Recommendations

The OCC recommends that the updated Policy specifically consider the needs and experiences of caregivers in post-secondary settings by addressing the following issues:

- Financial supports should be designed to recognize and include the unique needs of student caregivers.
- Accommodation options should include remote or hybrid classes.
- Post secondary institutions should develop specific policies to accommodate caregiver students, including flexible exam/assignment schedules, assignment types that do not require in-person presence, and access to free educational materials or financial supports to purchase required materials (e.g., textbooks or software).
- Mental health supports in the post-secondary setting should address and include the specific needs of student caregivers.

## HEALTH AND COMMUNITY SUPPORT SERVICES

*“Options are important. Caregiving is so varied that certain supports don’t fit the caregiving situations.”*

Because health and community service systems are so rationed, fragmented and complex to navigate, they tend to disadvantage caregivers who are members of Code-protected groups, such as those who are racialized, newcomer, Indigenous, or 2SLGBTQ+ who face additional systemic barriers in accessing those limited services that are intended to support caregivers and the people that they care for. The experiences of caregivers from these Code-protected grounds within the health and community care systems are under-researched and imperfectly understood. This section therefore does not provide a comprehensive overview of all barriers but rather provides some examples of the systemic barriers faced by caregivers who are members of other Code-protected groups in order to highlight the changes required to support the intersectional needs of caregivers.

### Caregivers and Intersectionality in the Health and Community Supports Systems

#### Caregivers with Low Income

*“My work is precarious which makes it difficult to have the financial stability to support my family or to access mental health supports. Costs are high and pay is low which hinders my ability to support myself and my family.”*

As the Policy currently acknowledges, racialized, newcomer, Indigenous, lone parent families, parents with disabilities and parents of children with disabilities are more likely to be low income. As such, we can expect that these caregivers are disproportionately impacted by financial barriers to care.

In the context of overstretched health and social services, caregivers bear substantial [out-of-pocket expenses](#), averaging several thousands of dollars annually, for medical supplies, home modifications, and additional home and community care services.

Funding models for self-directed care programs provide one example of barriers to supports for low-income families. In self-directed care programs, the Ministry of Health may enter into financial agreements with families and/or their caregivers to support their

loved one to live at home. However, there is a lack of consistency across the different programs related to their administration and the methods of flowing the funding. Some of Ontario's self-directed funding programs continue to use a [reimbursement](#) model which requires families to pay upfront. Programs offered through the Ministry of Health (Family Managed Care, Direct Funding) are based on quarterly installments of funding with reimbursements at each quarter.

The necessity to wait for reimbursements for funds already spent jeopardizes the financial stability of families, and for those who are living paycheque to paycheque, this funding model may [render the program inaccessible](#). This often further reinforces the financial challenges and stresses for unpaid caregivers whose participation in the labour force has been reduced or restricted due to their caregiving responsibilities. Caregivers who cannot afford to fill gaps in the public systems through purchasing essential services take on additional, often unsustainable, care responsibilities, putting themselves at risk of experiencing greater caregiver distress and negative impacts to their health and well-being and often forcing them to move to part-time work or leaving the labour market completely (further impacting their financial stability). For this reason, the OCC has consistently advocated that all such programs use a reconciliation model for funding, rather than a reimbursement model.

## Young Caregivers

Young caregivers, children, and young people under the age of 30 often go [unrecognized, unidentified, and unsupported](#) by the health and social service providers in their lives who often hold the common societal view that family caregivers are only adults and are often busy and focused only on their client, rather than the whole family. Young caregivers themselves may not realize they are in fact caregivers, may keep their caregiving secret to avoid stigma, judgement, and unwanted interventions, and might feel guilty about asking for help. Service providers, including those in the health and community care systems, should actively consider and design policies and programs to include the particular barriers experienced by young carers. The Young Caregivers Association has a [suite of tools and resources](#) and the [Young Caregiver Charter](#) for educators, health professionals, and social workers so that they can better recognize, identify and support young caregivers.

## Ethnocultural Minorities

[Research](#) demonstrates that ethnocultural and linguistically diverse caregivers and families face additional systemic barriers to accessing home and community care. Home and community care is not accessible to caregivers and care recipients without English language proficiency. Access to an interpreter varies by language, service providers, and region and information about available services are not available in multiple languages. When care recipients cannot communicate in English with care providers, their caregivers are expected to take on the additional role of interpreter. Home and community care providers do not receive adequate support and training to work with families of different ethnocultural backgrounds. Wait lists for community services, such as adult day programs, that cater to diverse ethnocultural and linguistic backgrounds are often very long.

## Building on Health Equity Frameworks to Advance Equality for Caregivers

Issues of equality and discrimination within health and community care systems are frequently addressed through frameworks that address health equity and the social determinants of health. It is widely recognized that a high-quality health system is one that reduces health disparities and advances [health equity](#). Many health care organizations in Ontario now have health equity frameworks, commitments and action plans. However, it is rare to see caregiver issues specifically addressed within these health equity frameworks. Recognizing caregivers as an equity-deserving group within health equity frameworks is a great opportunity for service providers to recognize and address the needs of caregivers, address their obligations related to family and marital status under the Code, and integrate an inclusive design approach through their organizations, programs and services.

## Recommendations

The OCC recommends that the revised Policy outline states that service providers in the health and community service systems have a responsibility to:

- Name and integrate caregivers as an equity-deserving group within their health equity frameworks and efforts;
- Within those health equity frameworks, further recognize the intersectional barriers and disadvantages experienced by caregivers who are racialized, ethnoculturally diverse, newcomer, Indigenous, 2SLGBTQ+, young caregivers, and caregivers with disabilities;
- Fulfill health equity obligations by proactively identifying and addressing barriers to programs and services experienced by caregivers, by further addressing the unique needs of caregivers through modifying the design of program and services. For example:
  - Allocating resources for interpretation and translation services;
  - Changing organizational and program policies and procedures, like reimbursements policies, that may appear neutral but that have a disparate impact on caregivers who are low income and who are disproportionately racialized, newcomer, Indigenous, lone-parent families, parents with disabilities and parents of children with disabilities;
  - Including caregiver status in socio-demographic data collection in order to better understand and address the inequities experienced by caregivers;
  - Ensuring staff understand the needs of caregivers, the impacts of caregiving on physical and mental health, and the unique needs of caregivers who are members of Code-protected groups.