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, or follow us on social media.

September 2026 Newsletter

At the OCC

OCC Annual General Meeting on October 1st, 2026

Our next Annual General Meeting will be held on Thursday, October 1st, from 11.00 a.m. – 1.00 p.m. We will be gathering our membership to discuss our activities and status, reflect on the previous year, and look at our plans for the upcoming year. Meeting materials, including the agenda, have been shared. We will be welcoming new members to our Board of Directors and covering the OCC's new five-year Strategic Plan, our Resource Development Strategy, and more. We hope to see you there! If you have not received your calendar invitation, please reach out to us at ontariocaregivercoalitionocc@gmail.com. We will also send out a reminder email with a Zoom link to join before the meeting.

OCC to Launch our Final Policy Brief: Making Caregivers Matter in the Community Systems They Navigate

Caregivers play an essential role in supporting those they care for to remain where they want to be — in the community – not only by providing hands-on care and assistance, but also by organizing an often complex mix of community supports around their person or persons. In an environment where community services are limited, complex and fragmented, this is one of the most challenging and time-consuming roles that caregivers play. Caregivers may find themselves acting as unpaid and untrained care coordinators and system navigators, roles that they find exhausting and frustrating. And yet this important work is often unrecognized.

It is therefore not surprising that, in the OCC's 2024 Caregiver Survey, system navigation and access to supports in the community were among the most frequently identified priorities for reform. Caregivers described confusing pathways to support, long waitlists and complicated processes. Long-term planning can be impossible in these contexts, with supports devolving into crisis management. Families that are less equipped to navigate complex systems, whether because of linguistic, knowledge or resource barriers, face additional disadvantages.

The OCC will soon be launching our sixth and final Policy Brief in the series arising from our 2024 Caregiver Survey. This Brief reviews barriers to accessing supports in the community and identifies six goals for reform. We will be integrating the findings of this Brief into our ongoing advocacy work. We encourage you to share this Brief widely with your networks, and to make use of it in your own efforts to make change.

How the Communications and Awareness Committee Spent The Summer

Our Communications and Awareness Committee was hard at work over the summer!

We recruited new members to our Board of Directors who are welcome additions to the OCC team, and we look forward to working together to bring the OCC's vision to light and continue to ensure caregiver voices are heard across Ontario.

We have been mobilizing our Policy Brief series, and with the completion of our sixth and final Policy Brief (coming soon!), we will be sharing a campaign across our social media channels. As our social media engagement continues to grow, particularly on LinkedIn and Instagram, we hope to bring more attention to the important advocacy efforts of our Policy Briefs, in which we use caregiver feedback to make policy recommendations that will build a better Ontario for caregivers. Keep a close eye on our social media to learn more. You can find links to our social media at the bottom of this newsletter.

The OCC's website revitalization project is making headway as we continue to develop and redesign the website to make it easier for caregivers to get the information they need, simplify navigation, increase the OCC's visibility, and drive engagement to our advocacy campaigns.

Our annual Member Spotlight campaign has concluded. It celebrated and highlighted the important work of our member organizations and provided our audience with a chance to learn more about our Member Organizations and the contributions they make outside of the OCC. Take a look at our social media or our website to see the full campaign! Thank you to all of our Member Organizations for your support of the OCC and for the tireless work you do!

We also shared our submission to the Ontario Human Rights Code (OHRC) across our social channels and on our website to bring awareness and engagement in policy change. Our OHRC submission demonstrated that caregiving is not only a pressing public policy issue; it is also a human rights issue, a truth which is often overlooked. Our submission sought to support the work of the OHRC by providing a brief overview of caregiver rights as human rights and the systemic challenges that underlie the challenges to equality faced by caregivers. You can read the full submission on our website or find a summary on our social media.

Member Initiatives

Dr. Allison Williams to Lead Seven-Year SSHRC Partnership to Support Canada's Carer-Employees

A new seven-year research partnership, *The Care Economy, Aging and Policy: A Partnership Approach*, has received $2.47 million in funding from the Social Sciences and Humanities Research Council of Canada (SSHRC). Led by McMaster University professor and OCC member, Dr. Allison Williams, this initiative brings together an extraordinary international and multidisciplinary team of 73 co-investigators, collaborators, and partners to advance research and action supporting carer-employees — the millions of Canadians who balance paid employment alongside unpaid caregiving responsibilities.

In her announcement, Dr. Williams shares, "One of the greatest strengths of this Partnership is the breadth of expertise and experience around the table. Our team spans universities and research institutes, governments, caregiver advocacy organizations, unions, occupational health and safety organizations, employers, and other stakeholder sectors across Canada and internationally. Together, we will undertake 10 interconnected research projects focused on building, scaling, and advocating for policies and practices that better support carer-employees."

The work responds to a significant and growing challenge: 5.2 million Canadians balance paid employment with unpaid caregiving. The partnership aims to improve work-life balance for these employees while helping employers strengthen recruitment, retention and workplace productivity. This Partnership builds on more than two decades of work focused on understanding the experiences of carer-employees and, importantly, translating that evidence into meaningful change in workplaces and public policy. You can read more about the Partnership through McMaster University's announcement.

The grant was announced as part of the Government of Canada's 2026 SSHRC funding results, which included more than $289 million for 1,788 social sciences and humanities research projects and partnerships across Canada. You can read the Government of Canada announcement here.

Research Participation Opportunity: Building and Evaluating a Social Prescribing Program for Carer-Employees in Canada

Are you a caregiver living in Hamilton, Ontario? You're invited to participate in a new study!

The team at McMaster University's Caregiver-Friendly Workplaces program is recruiting caregivers to participate in a study testing a social prescribing program designed to support the health and well-being of people balancing caregiving responsibilities with paid employment.

You may be eligible if you:

- Are currently working, or have worked within the last 12 months, in paid employment (full- or part-time)
- Provide unpaid care to an adult aged 18+ or a child with disabilities
- Live in Hamilton, Ontario

Participants will take part in a social prescribing program over 6 weeks and complete two surveys—one before and one after the program. Participants will receive a $30 CAD e-gift card of their choice and will also be entered into a draw for a chance to win an iPad.

Social prescribing connects people with non-medical community services, programs, and resources that can support health and well-being. Through this study, they hope to learn directly from caregivers about what works and how these supports can be improved to better meet their needs.

Interested in participating? Contact Reemal Shahbaz at reemal.shahbaz@mail.utoronto.ca or call (416) 219-3312.

Research Participation Opportunity: Young People Supporting Elder Kin through Mental Health System Access and Response: Young Carers, Storytelling, Madness, and Wisdom (Ages 18-30)

You are invited to participate in a multimedia storytelling research project exploring the stories of young people who support parents or older kin/family through mental health access and responses (sometimes called mental health crises).

This project involves six weekly virtual workshops (2 hours each) where a small group of young people will create multimedia stories together using a video creation software called WeVideo that combines text, voice, images, videos, and more.

Workshops will be collaborative, and storytellers will have ownership over their created stories. Storytellers will be supported in decisions about authorship and identification of their story, including whether they would like to remain anonymous with a pseudonym and how they would like their story shared. Participation in this project will not affect access to any services and/or involvement with young caregiver organizations and/or communities.

This project is in collaboration with the Young Caregivers Collective of Canada, Starlings Community, and Re·Vision: The Centre for Art and Social Justice.

You may be eligible to participate if you:

- are 18 to 30 years old
- support or have supported a parent or older Kin/family member(s) experiencing mental distress, Madness, psychosis, or related mental health challenges
- live in Canada

What participation includes:

- Six 2-hour virtual workshops over six weeks (one workshop per week)
- Optional 1-on-1 support between sessions if needed
- Creation of a multimedia story that you own and control
- Opportunity to use multimedia stories to influence research, practice, and policy

This study has received ethics clearance from the Brock University Research Ethics Board (#25-272).

If you are interested or would like more information, please email Rebekah Gold at rn20sp@brocku.ca. Thank you for your interest in participating!

Call for Papers for the ISBA 2027 International Conference

The call for papers for the ISBA 2027 International Conference, taking place in Galway, Ireland from 22-24 June 2027, is officially open! The conference theme is Respite: A Bridge to Opportunity & Inclusion.

ISBA welcomes submissions from everyone involved in respite and short breaks, including researchers, practitioners, service providers, policymakers, families, carers and people with lived experience. Submissions may focus on innovation, inclusion, lived experience, research, practice development, service design, learning from communities, or new approaches that strengthen respite and short break supports.

Submission options include:

- Written abstracts of up to 220 words

- Video submissions of up to 3 minutes as an alternative to written submission

Submission deadline: 23 October 2026. To learn more and submit, go to www.isba.me.

Of Interest

CIBPA Place: A New Model of Dementia Respite Care

CIBPA Place is CHATS' overnight residential respite home for people living with dementia, providing caregivers with trusted relief while their loved ones receive personalized care in a safe, supportive, home-like environment. Located in a beautifully restored historic house in Vaughan, the home features private bedrooms, comfortable shared living spaces, home-cooked meals, engaging activities, and 24/7 support from trained staff. Guests can stay from 2 to 14 nights, giving caregivers peace of mind while taking a well-deserved break.

What makes CIBPA Place different is its small, not-for-profit model. With space for only five guests at a time, the program offers individualized attention, familiar routines, meaningful engagement, and dementia-specific care in a warm, residential setting rather than an institutional environment. It also provides a more affordable option than many private overnight respite programs.

Despite strong demand and positive feedback from families, CIBPA Place faces a funding challenge. The program hasn't been able to secure operating funds, and therefore relies on client fees, grants, fundraising, and community donations to sustain this essential service for caregivers and older adults living with dementia.

When Developmental Services Fail, Caregivers Carry the Cost

By Michael Macpherson

My name is Michael Macpherson. I am a developmental service worker and President of CUPE Local 2276, and much of my work today is focused on one urgent goal: pushing Ontario's developmental services crisis into the public and political spotlight.

On the front line, I see what happens when the system does not provide enough staff, housing or community supports. Too often, families and caregivers become the system of last resort. Parents postpone retirement. Siblings take on responsibilities they never expected. Families reorganize their lives around gaps in care while worrying about what will happen when they can no longer provide that support themselves.

More than 52,000 adults with developmental disabilities are waiting for provincially funded services in Ontario. More than 28,000 are waiting for residential supports and more than 42,000 for community-based services. Tens of thousands are also not receiving their full Passport funding allocation. These lists overlap, but they demonstrate the same fundamental

problem: people are waiting too long for essential supports, and caregivers are carrying the consequences.

My advocacy is about making that reality impossible to ignore.

I have been working with municipal and provincial leaders, labour and disability advocates, journalists, families and community organizations to push for emergency and permanent funding, meaningful Bill 124 wage remediation, better workforce recruitment and retention, supportive housing, adequate Passport funding and measurable reductions in waitlists.
I am also making the fiscal case for investment. When developmental services are underfunded, the costs do not disappear. They move into hospitals, shelters, emergency departments, policing and paramedic services. Ontario's Ombudsman identified 124 people with developmental disabilities occupying hospital beds while waiting for appropriate community placements. That is not only expensive; it leaves individuals in the wrong setting and puts enormous pressure on their families.

The solution requires a broader coalition. Caregivers, self-advocates, developmental service workers, unions, service agencies and municipalities may experience this crisis differently, but we share a common objective: a stable system that allows people with developmental disabilities to live safely, participate in their communities and receive support before their families reach exhaustion or crisis.

I have also tried to bring this message to wider audiences, including an interview with Charlie Angus on *Meidas Canada* and through my article in *Spring Magazine*. Ontario has the knowledge and resources to do better. What is missing is the political urgency.

Caregivers should not have to break down before the system steps up. Families should not have to reach a crisis before support becomes available. My goal is to help build enough public pressure, political accountability and community solidarity that this becomes impossible to ignore.

If you have items that you would like to see included in future issues of this newsletter, please let us know. Sharing the accomplishments and activities of our members is part of our mandate. If you have received this newsletter in error or no longer wish to receive it, please reply to this email to let us know, and we will remove you from our mailing list.