



Ontario Caregiver Coalition

Research & Advocacy Committee

MPP Meeting Materials

October 8, 2021

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MEETING REQUEST EMAIL

TO: (Find your MPP's email address [here](#))
CC: ontariocaregivercoalitionocc@gmail.com

Dear MPP (LAST NAME),

My name is (NAME), and I am a caregiver for (provide context of who you care for, if you'd like to share it) as well as a volunteer with the Ontario Caregiver Coalition who lives in your riding. I'm reaching out to you today to request half an hour of your time to discuss the experiences of caregivers and highlight the supports that are needed to enable caregivers to fulfil their role while maintaining their own health and wellbeing. In particular, we would like to discuss the opportunities we see to remove barriers to accessing Direct Funding programs.

About 3.3 million Ontarians are currently providing physical, emotional, or navigational supports to a family member, neighbour, or friend. It is estimated that informal or family caregivers in Ontario provide 70% of all caregiving, and nearly 850,000 of them provide more than 10 hours of care per week. The intensive demands of caregiving make it difficult to balance work and family demands, and there can be significant out-of-pocket costs associated with caregiving. As a result, many family caregivers experience financial distress. Caregivers also commonly experience impacts on their physical, emotional, mental, and spiritual health due to the challenges associated with providing care.

The Ontario Caregiver Coalition 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 individual caregivers, care providers, and health charities across the province.

I understand that as a Member of Provincial Parliament you have a very busy schedule, but I would greatly appreciate half an hour of your time to discuss this matter. Please contact me at (email) or (phone number) to let me know when you would be available and I, or another member of the OCC, will do my best to accommodate your schedule.

Thank you very much for your consideration of this meeting request and I hope to hear back from you soon.

Sincerely,

NAME HERE

CONTACT INFO (include postal code to show you live in your MPP's riding)

MPP MEETING AGENDA

1. INTRODUCTIONS (5 MINUTES)

- ◆ Thank the MPP for taking the time to meet.
- ◆ Introduce each member of the group:
 - Who are you? Why is caregiving important to you? How are you connected to the OCC?
- ◆ Introduce the OCC
 - The OCC is a member-driven coalition, powered by the efforts of volunteers and focused on ensuring that caregivers have access to the supports that they need to fulfil their vital role
 - OCC members include health charities, care providers, and individual caregivers
- ◆ Establish any personal connections
 - Share if you are from the community they represent
 - What experiences does the MPPs have with caregiving?

2. OUTLINE THE IMPORTANCE OF SUPPORTING CAREGIVERS (5 MINUTES)

- ◆ Share the following key messages:
 - Caregivers are vital in supporting the healthcare system and in maintaining positive lives for millions of Ontarians who are aging or live with disabilities or acute illnesses
 - Caregiving has a significant impact on caregivers – financial distress, physical, mental, and emotional health, putting their life on hold
 - Caregiver members and those we surveyed have told us time and again that financial and home care supports are the top priorities they see that would help caregivers support and sustain themselves and their loved ones

3. PRESENT DIRECT FUNDING PROGRAMS (10 MINUTES)

AGENDA CONTINUED

- ◆ Outline what is Direct Funding and why does it have a positive impact on many caregivers
- ◆ Outline the barriers to access to Direct Funding (focus will depend on the role and areas of interest of the MPP)
- ◆ Outline what changes we would like to see to address these barriers

4. OPEN CONVERSATION (5 MINUTES)

- ◆ What questions does the MPP have? Are there ways that we can support them (e.g. providing further information)?
- ◆ Are they interested in raising this issue with decision makers in government? In their party?
- ◆ What next steps should we take in terms of who to contact? Can they make that introduction?

Please share any takeaways with the Research & Advocacy Committee –
lmgbates@gmail.com

5. CLOSING (5 MINUTES)

- ◆ Thank the MPP for spending the time with us
- ◆ Reiterate one or two key takeaways from the meeting
- ◆ Take a photo or a screenshot of the virtual meeting of the MPP, with the consent of the folks in the meeting

Please share the photo with the Communications & Awareness Committee
with the name of the people you met with and the date by email to:
daniel.nowoselski@gmail.com

KEY MESSAGES

Caregivers play a crucial role in sustaining the health care system

- ◆ In Canada, it is estimated that family caregiving is worth \$30-40 billion in “free” labour
- ◆ It is estimated that 70% of home care is provided by Ontario’s unpaid and family caregivers, with nearly 850,000 of them providing more than 10 hours of care per week

Caregivers need additional financial and home supports to continue their vital role in caring for their loved ones

- ◆ According to Statistics Canada, 22% of caregivers receive some form of financial support to help them with caregiving – but 68% said they needed more support.
- ◆ Caregivers have described financial barriers as the main determining factor that led to premature admissions into long-term care
- ◆ 41% of caregivers report their caregiving duties have reduced their ability to engage in paid work
- ◆ Without adequate home care and respite supports, caregiving can have significant impacts on mental and physical health: more than 90% of caregivers report the time they spend with other family and friends or leisure and community activities is reduced because of their caregiving responsibilities

Direct funding programs can provide important enhancements to existing home and community care supports

- ◆ While some caregivers benefit from traditional home care and respite programs, with their associated administrative and supervisory supports, others will fare better with Direct Funding programs, sometimes referred to as self-directed and family-managed programs
- ◆ Direct Funding programs provide **choice and flexibility** to families, allowing them to tailor the timing and nature of supports to the needs of their loved ones and their families, so they can prioritize what is most important to them. This is a person-centred model.

- ◆ Direct Funding programs allow families to **select the person(s)** who will provide respite and support, to ensure a good and stable match. This allows strong, stable, and trusting relationships to develop, essential to wellbeing and family peace of mind.
- ◆ Where PSWs are in short supply, such as in rural and remote communities, Direct Funding programs allow families to be **creative** in sourcing supports
- ◆ Direct Funding can help families to ensure that supports are **culturally and linguistically appropriate**, which is increasingly important in a diverse province.

We can build on Ontario's existing programs by learning from Direct Funding programs successfully implemented across Canada and around the world. This is a proven model.

- ◆ In Canada, there are models in British Columbia, Alberta, Saskatchewan, Manitoba, Quebec, Nova Scotia, New Brunswick, PEI and Newfoundland & Labrador
- ◆ Internationally, there are also comprehensive models in Australia and Scotland
- ◆ Our proposals are based on learnings from these models, to meet the expressed needs of our members

We are advocating for enhancements to make Direct Funding programs more equitable and accessible for caregivers who can benefit from them, including:

- ◆ Reforming eligibility requirements to allow substitute decision-makers and caregivers to take on application and administrative processes. Requiring recipients to self-manage excludes a large population living with intellectual and cognitive impairments, such as dementia, from programs that could benefit them.
- ◆ Enhancing program flexibility to better meet needs. For example, allowing recipients to hire family members can enable creative solutions to the PSW shortage and provide stable, trusting supports.

- ◆ Moving programs paid for by MCCSS from reimbursement to reconciliation funding. Reimbursement models create barriers for families who are low- or moderate-income. Using the Ministry of Health's installment model across all programs would improve accessibility.
- ◆ Improving navigation. The current patchwork of programs is difficult to locate and access because very few caregivers are aware or get told about these programs.
- ◆ Reducing waitlists. Over time, transitioning increased funding to self-directed programs will enable families to avoid or delay the use of institutional care.

Caregivers play a crucial role in sustaining the health care system

- ◆ In Canada, it is estimated that family caregiving is worth \$30-40 billion in "free" labour
- ◆ It is estimated that 70% of the care in home care is provided by Ontario's caregivers, with nearly 850,000 of them providing more than 10 hours of care per week

Caregivers need additional financial and home supports to continue their vital role in caring for their loved ones

- ◆ According to Statistics Canada, 22% of caregivers receive some form of financial support to help them with caregiving – but 68% said they needed more support. Caregivers have described financial barriers as the main determining factor that led to premature admissions into long-term care
- ◆ 41% of caregivers report their caregiving duties have reduced their ability to engage in paid work
- ◆ Without adequate homecare and respite supports, caregiving can have significant impacts on mental and physical health: more than 90% of caregivers report the time they spend with other family and friends or leisure and community activities is reduced because of their caregiving responsibilities

Direct funding programs can provide important enhancements to existing home and community care supports

- ◆ While some caregivers benefit from traditional home care and respite programs, with their associated administrative and supervisory supports, others will fare better with Direct Funding programs, sometimes referred to as self-directed and family-managed programs
- ◆ Direct Funding programs provide choice and flexibility to families, allowing them to tailor the timing and nature of supports to the particular circumstances of their loved ones and their families, so they can prioritize what is most important to them. This is a person-centered model.
- ◆ Direct Funding programs allow families to select the person(s) who will provide respite and support, to ensure a good and stable match. This allows strong and trusting relationships to develop, essential to wellbeing and family peace of mind.
- ◆ Where PSWs are in short supply, such as in rural and remote communities, Direct Funding programs allow families to be creative in sourcing supports
- ◆ Direct Funding can help families to ensure that supports are culturally and linguistically appropriate, which is increasingly important in a diverse province.

We can build on Ontario's existing programs by learning from Direct Funding programs that have been successfully implemented across Canada and around the world. This is a proven model.

- ◆ In Canada, there are models in British Columbia, Alberta, Saskatchewan, Manitoba, Quebec, Nova Scotia, New Brunswick, PEI and Newfoundland & Labrador
- ◆ Internationally, there are also comprehensive models in Australia and Scotland
- ◆ Our proposals are based on learnings from these models, to meet the expressed needs of our members

We are advocating enhancements to make Direct Funding programs more equitable and accessible for caregivers who can benefit from them.

Reform eligibility requirements to allow substitute decision-makers and caregivers to take on application and administrative processes. Requiring recipients to self-manage excludes a large population living with intellectual and cognitive impairments, such as dementia, from programs that could be beneficial.

Enhance program flexibility to better meet needs. For example, allowing recipients to hire family members can enable creative solutions to the PSW shortage and provide stable, trusting supports.

Move programs funded by MCCSS from a reimbursement to reconciliation funding. Reimbursement models create barriers to access for families who are low or moderate income. Using the installment model adopted by the Ministry of Health across all programs would improve accessibility

Improve navigation. The current patchwork of programs is difficult to locate and access. There is very low awareness among caregivers about these programs.

Reduce waitlists. Over time, transitioning increased funding to self-directed programs will enable families to avoid or delay use of institutional care.

LEAVE BEHINDS

Briefing Note: Direct Funding

About the OCC

Direct Funding – In the Words of Caregivers

BRIEFING NOTE: DIRECT FUNDING

What are Direct Funding Programs?

Direct Funding programs allow clients, sometimes with the help of caregivers, to take an active and central role both in defining their needs and in determining how those needs are met. Instead of funding professionals or agencies to deliver services to a client, governments directly fund clients who opt into these programs to purchase services from providers of their choice. Ontario has four Direct Funding programs, each with its own structures and requirements:

MCCSS PROGRAMS	MOH PROGRAMS
<p>Passport Program - supports adults with developmental disabilities to be involved in their communities and live as independently as possible, as well as funding for caregiver respite services and supports for the primary caregivers of the client.</p>	<p>Family Managed Homecare - provides funding for individuals assessed as in need of homecare</p>
<p>Special Services at Home - serves children with developmental or physical disabilities by providing funding for personal growth and development and family respite.</p>	<p>Self Managed Attendant Services - funds adults with physical disabilities to employ their own attendants to support the activities of daily living.</p>

Why are these programs important to caregivers?

Research finds direct funding programs lead to greater care continuity, fewer unmet needs, innovative use of public resources, and higher overall user satisfaction compared to traditional home care services. Caregivers emphasize the benefits of choice and flexibility in developing creative solutions to meet unique family needs, developing trusted and stable care-providing arrangements, and ensuring care is delivered in accordance with cultural and linguistic needs.

What is the Ontario Caregiver Coalition asking for?

Ontario can build on its existing programs by learning from successes across Canada and around the world. Enhancing Direct Funded programs can provide caregivers with the respite and homecare supports they need to carry out their vital role while protecting their financial, physical, mental and emotional health. This in turn will help delay or avoid institutionalization and support our healthcare system.

To strengthen Ontario's Direct Funding programs, we ask you to:

Reform eligibility requirements to allow substitute decision-makers and caregivers to manage application and administrative processes.

Enhance program flexibility to allow family members to provide care.

Increase accessibility by moving programs from reimbursement to reconciliation funding.

Improve awareness of these programs and ease navigation.

Reduce waitlists by transitioning increased funding to these programs over time.





ABOUT US

The Ontario Caregiver Coalition 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 mission: to improve the lives of caregivers by advocating for fair access to needed support.

Our vision: an Ontario where caregivers feel valued, respected, recognized and supported.

Our members: 3.3 million or 29% of Ontarians are unpaid family caregivers. This includes 500,000 young carers between the ages of 15 – 24 years of age providing on average 14-27 hours of care per week.

In Canada, family or unpaid caregiving is worth an estimated \$30-40 billion in “free” labour. It is estimated that 70% of home care is provided by Ontario's family or unpaid caregivers, with nearly 850,000 of them providing more than 10 hours of care per week.

The intensive demands of caregiving can make it difficult to balance work and family demands, and there can be significant out-of-pocket costs associated with caregiving. As a result, many family caregivers experience financial distress. Caregivers also commonly experience impacts on their physical, emotional, mental, and psychological health due to the strain of caregiving.

Our accomplishments: the Ontario Caregiver Coalition has been working to advocate for caregivers since 2009 and has been incorporated as a not-for-profit organization since 2018. Our membership includes both caregivers, care providers, and health charities across the province and organizations. Recent initiatives include our helping to create the St. Elizabeth CareChannel portal for caregivers, collaborating with The Change Foundation on The Caring Experience project, and playing an instrumental role in the recognition of Family Caregiver Day.

Our advocacy priorities:

Caregivers have told us they need more access to support at home and more support to address financial constraints to keep supporting their loved ones.

We advocate for:

- ◆ Increased financial supports for caregivers, such as through caregiver allowances, refundable tax credits or paid caregiver leave
- ◆ Improved access to Direct Funded care programs
- ◆ Expanded respite supports

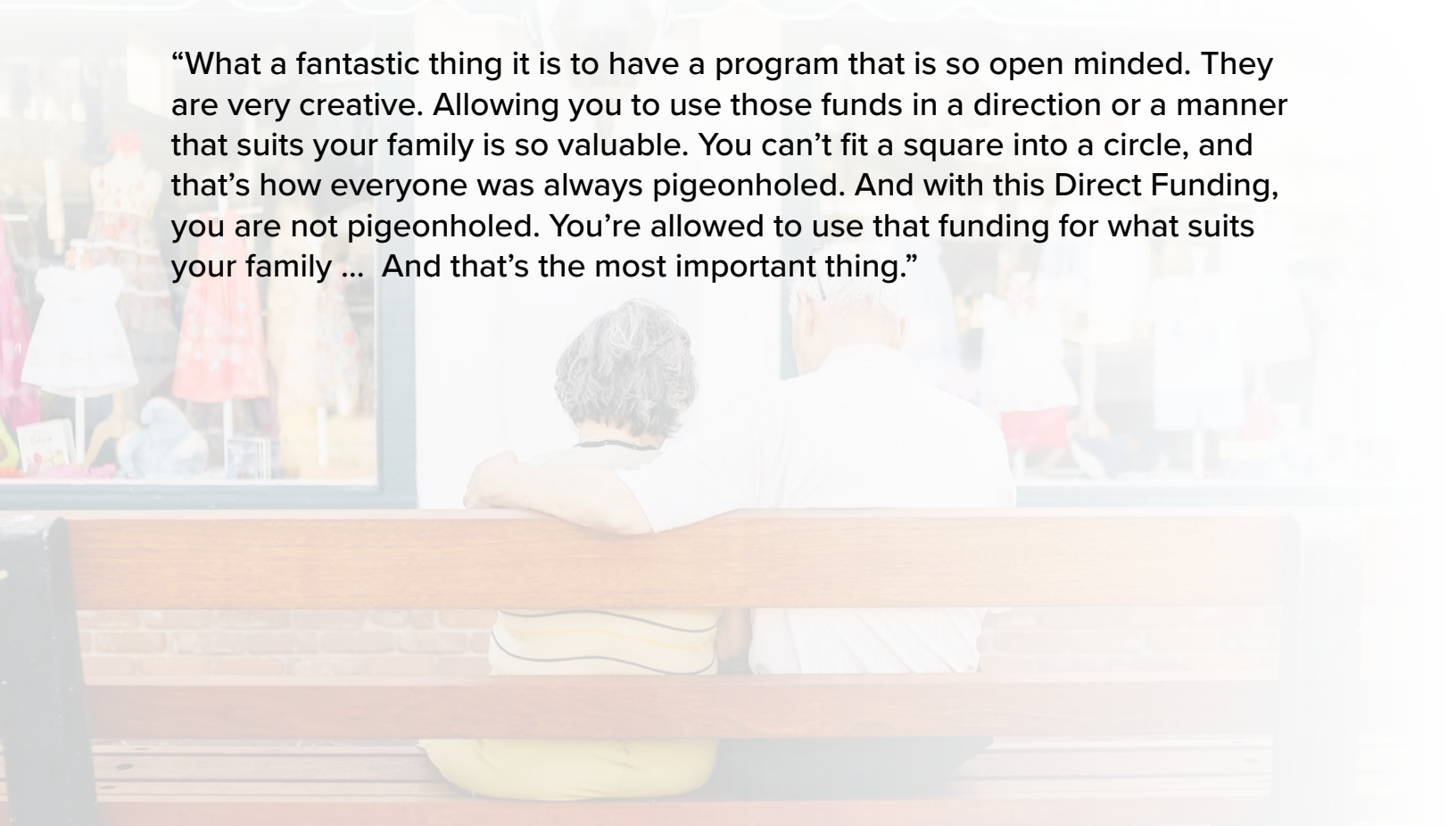
DIRECT FUNDING: WHAT WE HEARD FROM CAREGIVERS

In the summer of 2021, the Ontario Caregiver Coalition carried out a series of focus groups and interviews with users of Direct Funded programs in Northern Ontario. This is what we heard.

“When we started using the Family Directed Funding, I noticed that we could be a little more creative. Just little things. Even knowing, it’s more about [my son] now. Even a simple outing with someone that he knows, and is comfortable with and is not going to lash out against. Because he is comfortable with the people who have been in our lives for a long time. When you’re hiring people, it takes a long time, with my son it takes a good two years before he is well behaved with someone.”

“if we look at it from a Ministry lens, what it costs to support one of our loved ones in one of their funded facilities versus what it costs to support them at home when the family is assisting, or in a creative situation ... it would make dollar sense to help boost family’s pots a little bit. It would end up, probably, over the long haul, being cheaper, to aid families more in supporting their loved ones at home instead of putting them into institutions.”

“What a fantastic thing it is to have a program that is so open minded. They are very creative. Allowing you to use those funds in a direction or a manner that suits your family is so valuable. You can’t fit a square into a circle, and that’s how everyone was always pigeonholed. And with this Direct Funding, you are not pigeonholed. You’re allowed to use that funding for what suits your family ... And that’s the most important thing.”



“It’s peace of mind. The respite was a lifesaver. I was getting to the point where I was very worn down with looking after my wife who I love dearly and who has a very sweet disposition. But I do everything for her and it’s 24/7. So just for me to look forward to those two afternoons a week ... it’s a relief just to be away. And it gives my wife time away for me. We are on top of each other. It’s a break for her as well. But especially for me. I think I would have had a breakdown if I didn’t have this.”

“A lot of relief of the stress there. It’s always weighing on you, what’s going on at home, is he okay. It’s a big stress.”

“We can pick the people we are comfortable with. Especially during the pandemic.... At first I thought that’s kind of weird, but now I see the huge value in it.”

“You can tailor it to your specifics. There’s not all these guidelines and boundary conditions. It’s very open ended and flexible and tailored to what meets your needs. That’s a great feature and benefit.”

