

# Caregiver Financial Distress: Recommendations for Change

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## *The Ontario Caregiver Support Benefit*

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# OVERVIEW



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# ACKNOWLEDGEMENTS

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## James Janeiro

Canadian Centre for  
Caregiving Excellence

## Michael Mendelson

Maytree

## Deb Matthews

Former Deputy Premier  
at Province of Ontario

## Jenny Theriault

Caregivers Nova Scotia

## Daniel Nowoselski

Canadian Cancer  
Society

## Research & Advocacy Committee

Ontario Caregiver  
Coalition

## Janet Fast

University of  
Alberta

## Rachel Smith

Family Advocacy  
Network of  
Manitoba

& the **numerous caregivers** who  
shared their experiences.

## Sherri Torjman

Social Policy Expert

## Tracy Claeys

Alzheimer Society of  
Manitoba



01

PROJECT PURPOSE,  
BACKGROUND &  
METHODOLOGY



# PROJECT PURPOSE

To design an effective policy option to address the **many sacrifices** and **out-of-pocket expenses** caregivers face to care for an individual in-need.

## Key Objectives for Program Design Recommendation:



Who should be targeted by such a policy?



How should the benefit be designed?



How should it be delivered?

# WHAT IS A CAREGIVER?

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The **Canadian Centre for Caregiving Excellence** defines a *caregiver* as:

“An unpaid family member, friend, or other support for someone who needs care due to physical, intellectual, or developmental disabilities; medical conditions; mental illness; or needs related to aging. Caregivers provide care because of a relationship, not as a job or a career.”

# EXISTING ONTARIO TAX CREDIT

Administered via the tax system; you may be able to claim this amount for an [eligible relative](#) who was dependent on you because of a mental or physical impairment at any time in the year. Your dependant's net income must be *less than* \$21,577.

An [eligible relative](#) is a dependant 18 years of age or older before the end of the year who is your (or your spouse's or common-law partner's):

- child or grandchild
- parent, grandparent, brother, sister, aunt, uncle, niece or nephew who was resident in Canada at any time in the year.

Note: This credit is non-refundable with the maximum amount available to claim **\$5,593**.

# THE CRUCIAL ROLE OF CAREGIVERS

Ontario's health care system & broader economy cannot function without caregivers.

**3.3 Million**

The number of Ontarians providing unpaid care to a family member or friend.

**\$26 Billion Dollars**

The amount of savings generated by caregiving as estimated by the Change Foundation.

**\$97.1 Billion Dollars**

The amount caregivers contribute to Canada's economy; 3x expenditures on home, community care & LTC.

**\$842 = Cost of Hospital Bed**

**\$42 = Care at home cost**

\$800 in daily savings generated by caregiving at home.



# CAREGIVER FINANCIAL DISTRESS MATTERS

BACKGROUND

Lack of government action will have social and economic repercussions.

## Labour force impacts

37% of caregivers are considering reducing their work hours or quitting their jobs.

## Well-being impacts

63% of caregivers feel they have reached their breaking point.

## Out-of-pocket expenses

20% of Ontario caregivers reported taking out a loan/line of credit to finance caregiving expenses in 2020.

## Canada's population is aging

The population of available caregivers is decreasing, exacerbating caregiver financial distress and its consequences.

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There is NOT one magic fix to  
ensure caregivers are  
adequately supported to sustain  
their vital role.



# METHODOLOGY



## Program Review:



Canada Caregiver Tax  
Credit



Manitoba Caregiver Tax  
Credit



Nova Scotia Caregiver  
Allowance



## Interviews:

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Semi-Structured  
Key Informant  
Interviews

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Semi-Structured  
Caregiver  
Interviews

## Testing Recommendations:

Proposals “tested” with  
the OCC’s Research &  
Advocacy Committee,  
comprised of caregivers,  
caregiver-supporting  
organizations, and with  
selected individuals.



### CAREGIVER PROGRAM REVIEW

Key Aspects	Canada Caregiver Credit	Nova Scotia Caregiver Allowance	Manitoba Primary Caregiver Tax Credit
Benefit level	<ul style="list-style-type: none"> <li>▪ Non-refundable credit</li> <li>▪ The maximum claim is \$7348 for dependents 18 or older</li> <li>▪ \$2295 for children under 18</li> </ul>	<ul style="list-style-type: none"> <li>▪ Receive Cash Transfer \$400 per month on the first day of every month.</li> </ul>	<ul style="list-style-type: none"> <li>▪ <b>Refundable</b> income tax credit of \$1,400 per year per caregiver - for providing the unpaid care</li> </ul>
Application process	<ul style="list-style-type: none"> <li>▪ Claimed on tax returns</li> <li>▪ The CRA may require a signed statement from a medical practitioner showing when the impairment began and what the duration of the impairment is expected to be</li> <li>▪ A medical note is not needed if the CRA already has a Disability Tax Credit certificate on file</li> </ul>	<ul style="list-style-type: none"> <li>▪ A referral will need to be made to a care coordinator who will meet with the care recipient and conduct an assessment to identify care needs and determine qualifications for the program.</li> <li>▪ Applicants who are assessed as having high care needs have some combination of:               <ul style="list-style-type: none"> <li>○ Mild to significant problems with memory loss, decision-making and communication that affect daily functioning.</li> <li>○ High level of physical impairment.</li> <li>○ Many challenges in managing their personal needs.</li> <li>○ Serious behavioural problems.</li> <li>○ A high risk of falls.</li> <li>○ A high risk of long-term care placement.</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>▪ Submit a copy of the registration form to the Manitoba Tax Assistance Office</li> <li>▪ Claim the credit on personal income tax return beginning in the year of registration (even if earning no income)               <ul style="list-style-type: none"> <li>○ One of three avenues through which care recipient can access tax credit: home care assessment, physician or nurse practitioner assessment, or disABILITY services</li> </ul> </li> </ul>
Care recipient eligibility	<ul style="list-style-type: none"> <li>▪ Care recipients may include:               <ul style="list-style-type: none"> <li>○ A spouse or common-law partner</li> <li>○ A child, grandchild, parent, grandparent, brother, sister, uncle, aunt, niece, or nephew who is dependent on the caregiver for support because of a physical or mental impairment</li> </ul> </li> <li>▪ An individual is considered dependent if they rely on the taxpayer regularly and consistently to provide them with some or all of the basic necessities of life</li> </ul>	<ul style="list-style-type: none"> <li>▪ Be 19 years of age or older</li> <li>▪ Be a Nova Scotia resident</li> <li>▪ Be in a care relationship with a caregiver</li> <li>▪ have a net annual income of \$26,165 or less if single, or a total net household income of \$41,165 or less, if married or common-law</li> <li>▪ Been assessed by a Nova Scotia Health Authority care coordinator as having a high level of impairment or disability requiring significant care over time</li> </ul>	<ul style="list-style-type: none"> <li>▪ Be a resident of Manitoba;</li> <li>▪ Reside in an area under the jurisdiction of a Regional Health Authority;</li> <li>▪ Reside in a private residence (e.g., not a group home, foster home, hospital, or personal care home, in supportive housing, or on a reserve);</li> <li>▪ Assessed as having care level requirements equivalent to level 2 or higher (see Registration Form); <b>and</b></li> <li>▪ Designate only one primary caregiver to claim this credit</li> </ul>

# PROGRAM REVIEW

Now published and available on the [OCC website!!](#)



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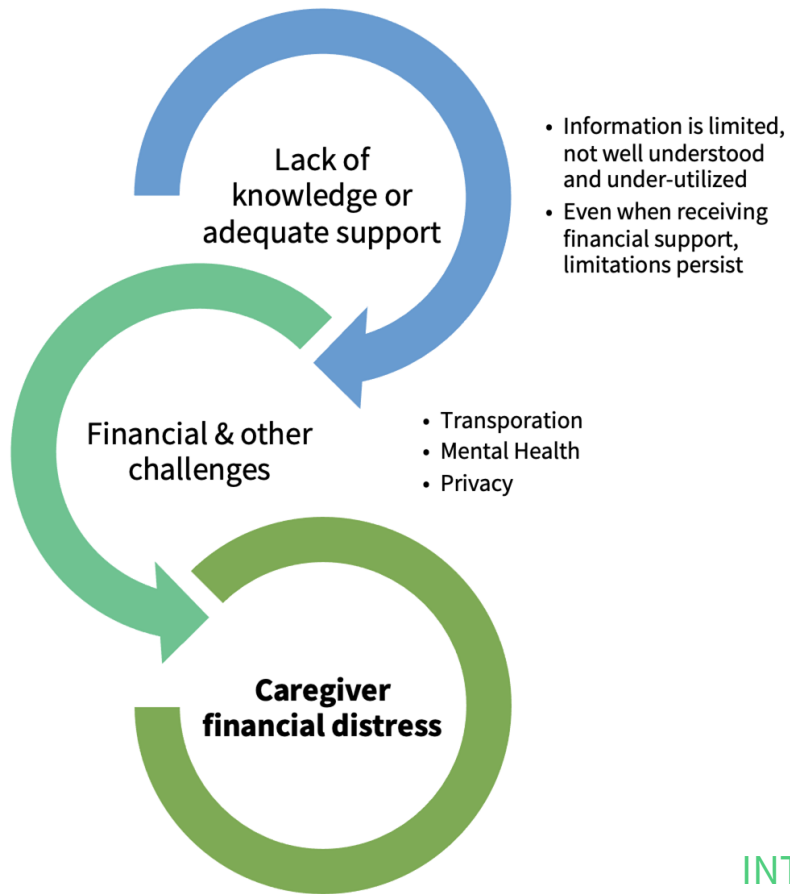
KEY FINDINGS

FROM QUALITATIVE INTERVIEWS

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# CAREGIVER INTERVIEWS



INTERCONNECTIVITY OF THEMES

# CAREGIVER INTERVIEWS

LACK OF KNOWLEDGE/ADEQUATE  
SUPPORT

“

*I do get that [Caregiver Tax Credit] every year... when I put this note to my [caregiver Facebook] group, not everyone had the same information. I had some people tell me, “Oh I didn’t even know I was entitled to it”... I was kind of excited but then when I actually started to think about the fact that I’ve left a job, I don’t have any income, and \$1200 for the entire year is what they give you. And is it nice to have \$1200? Sure, I’d rather have it than not have it, but when you think about the hours that go into caring for somebody with a disability... the fact that **he’s in my care 24/7, 365 days a year - other than when he goes to school - I don’t think they’re paying me very well.***

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“

*I'd say the tax credits aren't that effective when not everyone is given the info. My daughter is 10 and I **just** got the primary caregiver tax credit [in Manitoba]. I **missed many years though.** Also having to reapply every 3 yrs even though her disability won't change seems ridiculous.*

# CAREGIVER INTERVIEWS

## FINANCIAL AND OTHER CHALLENGES

“

*Often you end up paying for a lot of things out of pocket just because it's really **challenging to jump through the hoops that you have to to get any coverage**... it's expensive... on the one hand, **time-wise**, it's challenging... so I felt compelled to leave a paid job to be able to do everything, but then we have all these added expenses in our life. We've had to do without a lot of things.*

“

*The bath seat that we have... I think that **cost me \$1500**. So right there I've **spent my entire credit and then some** to buy a thing that.... everyone needs to bathe.*

“

*If you have **more than 1 child [with a disability]**, you still **only get 1** primary caregiver credit. The amount is ridiculously small as it is but then it feels they're saying "meh, you're home with the 1 already, we don't care if its actually 2 or 3".*

“


*My son is 27 and I've spent much of my retirement savings (**approx. \$300,000**) on **equipment, therapies**, and things that are not covered. I'm 54 and will not be able to retire by 65, if ever.*



# ELIGIBILITY CRITERIA



## Insights from Key Informant and Caregiver Interviews

- There may be lower participation in caregiver financial programs due to tight eligibility criteria:
    - 1) Relationship requirements;
    - 2) Income requirements & cut-offs; and,
    - 3) Narrow definition of care.
  - Informants reported that eligibility should be made as broad as possible.
- 

# PROGRAM DESIGN

## Insights From Key Informants

- Manitoba Primary Caregiver Credit provides multiple access points, including home care assessment, physician or nurse practitioner assessment, or disABILITY services - which reflects the diversity of needs and pathways to support for caregivers.
- **Promising Pathways:**
  - Build on Nova Scotia model's use of care coordinator supports and effective appeal process;
  - Make eligibility as automatic as possible to smoothen access;
  - Ensure access systems reflect diversity of caregiver pathways; and
  - Allow for retroactive access to acknowledge lack of knowledge and navigational barriers.


# COMPENSATION



## What We Know From Research

- The average caregiver in Canada reported spending \$5,800 each year on care-related expenses.
- Caregivers bear financial costs due to lost income, lost future earnings, reduced benefits, out-of-pocket expenses and time spent on caregiving responsibilities.

## Insights From Key Informants

- **Promising Pathways:**
    - The caregiving benefit should focus on compensating the services/work associated with caregiving;
    - Financial support should supplement the income caregivers are currently earning; and,
    - Build on Nova Scotia's cash transfer level as \$400 is great, but not enough.
- 


# COMPENSATION



## Insights From Caregivers

- Amount of time allocated to caregiving is huge and results in many personal and financial sacrifices.
- Cost of devices, services, or even parking alone exceeds the potential financial benefits available from existing supports.
- Many wish they could hire a PSW to help assist with appointments, etc. and would like to have the financial flexibility to hire someone they trust to assist with various tasks.
- One caregiver noted that adequate financial support would be \$800-\$1,000 a month.

“*For me, having a big chunk of money once a year on income tax is nice but **it'd be nicer** to have regular, monthly pay outs of money ... spread out over a period of time. Rather than, “here's this... this big chunk”.*”



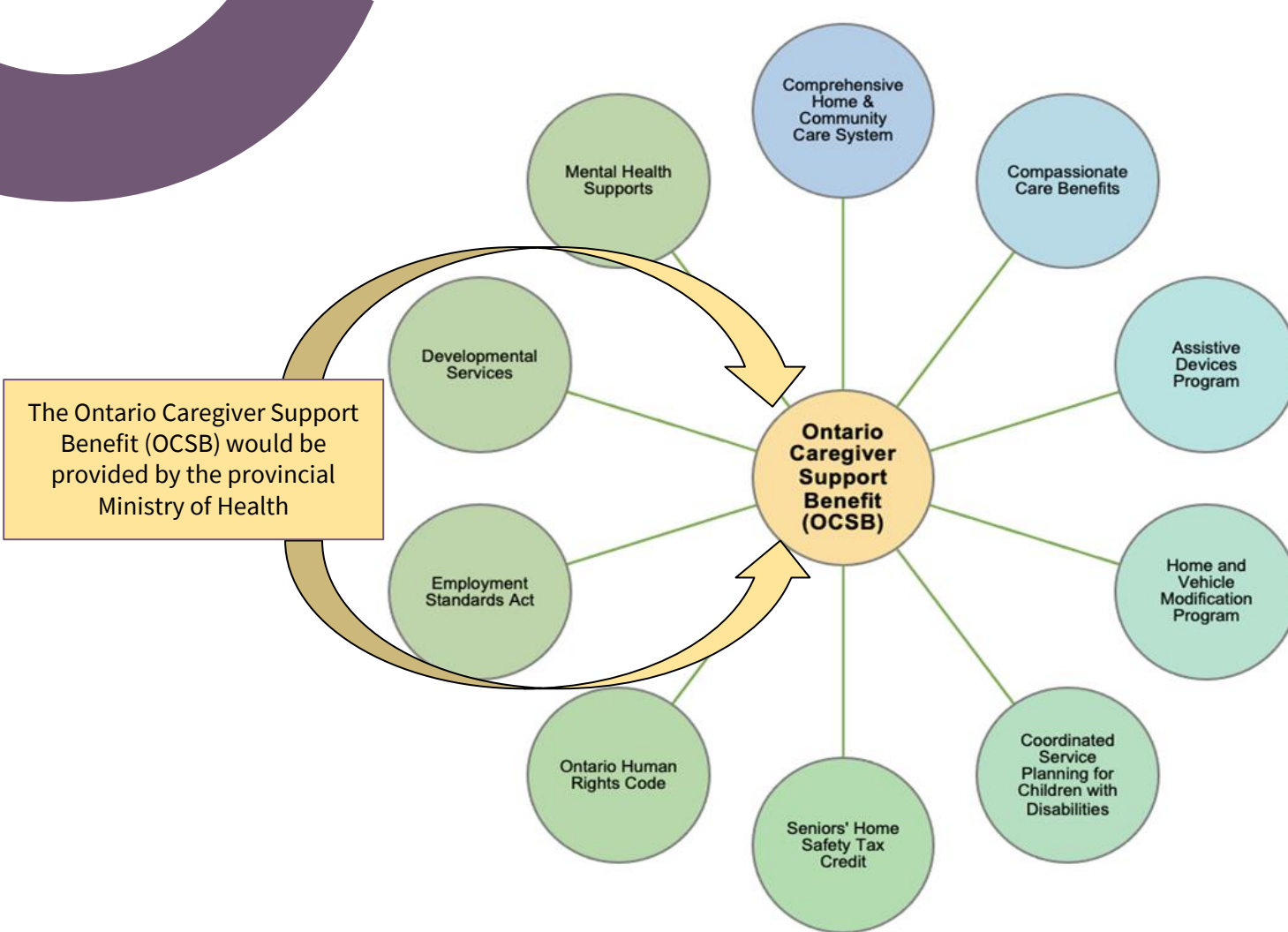


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PROGRAM DESIGN  
RECOMMENDATIONS



**NOTE:** not exhaustive list; only captures provincial; does not include many existing federal systems/programs/regulations



# PHASED RECOMMENDED APPROACH

## Phase 1

Providing The Ontario Caregiver Support Benefit to caregivers providing care to a care recipient **enrolled**, or **approved to be enrolled** (including those waitlisted), in programs illustrating a need for care.

**Improve, expand and invest** in services for care recipients and caregivers.

## Phase 2

**Expand** The Ontario Caregiver Support Benefit to **all** caregivers.

# PHASE 1: ELIGIBILITY CRITERIA

1. Enrolled or approved (including waitlisted) in any program illustrating a need for care, including but not limited to the programs listed below:
  - Disability tax credit (DTC)
  - Canada Caregiver Credit
  - Home and Community Care Support Services
  - Passport Program
  - Ontario Disability Support Program
  - Ontario Seniors Care at Home Tax Credit
  - Special Services at Home program

**Pros:** will allow for automatic access and ease of implementation in providing benefit limiting costs.

**Cons:** Will not provide benefit to all caregivers but will allow for timely implementation



# PHASE 1: PROGRAM DESIGN

- **Monthly benefit** received on the first of every month.
- Through an **online portal** (new or already existing such as My Account CRA) individuals would create an account, provide their information, including unique identifiers, banking information, etc., for direct deposit of the benefit (similar to CERB).
- **An online application** would be filled up on the online portal **or a paper form** of the application would be available at various physical locations such as healthcare providers and service Ontario/Canada locations (similar to CERB).

**Pros:** monthly payments; potential integration into existing systems/entry points; direct benefit streamlining and simplifying the process.

**Cons:** doesn't address retroactive piece, requires technological literacy or mailing address.

# PHASE 1: Providing support benefit for those that provide 20 or more hours of care

	Overview	Execution
<b>Eligibility Criteria</b> <i>Who will get it?</i>	Enrolled or approved (including waitlisted) in any program illustrating a need for care.	Application process providing necessary information to validate eligibility.
<b>Program Design</b> <i>How will they get it?</i>	Direct monthly benefit provided on the first of every month.	Caregiver would submit application through online portal or mail paper format. Provider of online portal would verify application and enroll caregiver.
<b>Compensation</b> <i>How much will they get?</i>	\$1,000 monthly	Standard benefit for all caregivers reflecting application processes already completed through other programs

# PHASE 1: Improve, expand and invest in services



## Building on the recommendations provided by the Canadian Centre for Caregiving Excellence → Areas of improvement, expansion & investment:

- Facilitate a coordinated approach to caregiving
- Invest in options to help improve care services
- Develop policy to support caregivers in the workforce
- Improve conditions for care providers

[https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE\\_Giving-Care.pdf](https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf)

# PHASE 2: Providing OCSB to all caregivers


	Overview	Execution
<b>Eligibility Criteria</b> <i>Who will get it?</i>	Number of hours of caregiving required by caregiver	Ensure a provincially coordinated comprehensive approach to caregiving. Level of impairment would determine hours of care needed.
<b>Program Design</b> <i>How will they get it?</i>	Direct <b>monthly benefit</b> on the first of every month.	Transparent evaluation of level of impairment, criteria would determine hours of care necessary.
<b>Compensation</b> <i>How much will they get?</i>	<b><u>Hours Weekly = \$ Monthly</u></b> < 5 hours = \$ 150 5 - 10 hours = \$ 300 10 - 15 hours = \$ 600 15 - 20 hours = \$800 20 - 30 hours = \$ 1,000 OVER 30 hours = \$1,200	Program enrollment does not affect eligibility for other benefits or programs.

# COMPENSATION

Number of Hours		Monthly Transfer
< 5	=	\$150
5 - 10	=	\$300
10 - 15	=	\$600
15 - 20	=	\$800
20 - 30	=	\$1,000
OVER 30	=	\$1,200

# KEY MEASURES OF SUCCESS



- ✓ Improving caregiver well-being; measure burnout and mental health.
  - ✓ Makes it possible to be a caregiver for longer.
  - ✓ Reducing strain on healthcare system & demand on nurses and other healthcare professionals.
  - ✓ Avoiding premature or unnecessary institutionalization.
  - ✓ Providing caregivers with more flexibility to make decisions.
  - ✓ Improving caregivers' financial resilience.
- 



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## AREAS FOR FUTURE RESEARCH

*WHAT MORE DO WE NEED TO KNOW?*





# AREAS FOR FUTURE RESEARCH

- **Equitable and inclusive design:** Ensure that program design and implementation supports equity and inclusion for female, Indigenous, racialized, newcomer caregivers, for persons with disabilities who are also caregivers, and across types of caregiving;
- **Accessible processes:** How to smooth administrative processes to ensure accessibility to the OCSB for all caregivers;
- **Understanding impact:** Build on the OCC's Cost Benefit Analysis to understand the full impact of the OCSB for the Ontario health system and finances;
- **System integration:** Ensure efficiency and effectiveness by developing seamless integration into existing systems as care coordination continues to evolve;
- **Addressing long-term financial impacts:** Develop a stronger understanding of and effective approaches to long-term financial impacts of caregiving such as reduced pensions and retirement savings; and
- **Communication:** How to effectively communicate the OCSB to caregivers, including newcomer, racialized, Francophone and other caregivers, to ensure equitable uptake.



# THANK YOU!

Do you have any comments, concerns, or questions?



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# APPENDIX



# COST SAVINGS DUE TO OCSB

Supporting caregivers who experience financial distress is not only the **right thing to do**, but would also result in a **cost saving** to the provincial government:

- 1) Would reduce the burnout rates of caregivers;
- 2) Would allow for caregiver flexibility regarding time & employment;
- 3) Would enable caregivers to hire professional support for related tasks.



Reduces premature institutionalization

Average daily cost of a hospice/long-term care bed = \$460

Daily cost of The Ontario Caregiver Support Benefit = \$33

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Daily cost saving of \$427