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Implementing the Caregiver Benefit Program in Nova Scotia: Supporting Unpaid Caregivers at Home

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Abstract

Nova Scotia is the only province in Canada to implement the Caregiver Benefit Program, an allowance of \$400 a month to eligible caregivers if both the caregiver and care receiver qualify for the program. In response to Nova Scotia's aging population—a population with increasingly complex chronic conditions—more attention was given to home care and unpaid caregivers through the *Continuing Care Strategy*, which set the stage for implementation of more caregiver supports. The goals of the Caregiver Benefit are to acknowledge the contributions of eligible caregivers in providing assistance to a family member or friend, help sustain the support these caregivers provide, and keep people in their homes and out of long-term care. A policy window was created in 2009 for the New Democratic Party (NDP) to implement the Caregiver Benefit quickly after their election win by building on a previous Progressive Conservative initiative, thus fulfilling the NDP's promise to support seniors and caregivers. While no official evaluation has been conducted, it is the role of the Executive Director, Risk Mitigation of the Continuing Care Branch to provide accountability and monitoring of the policy. The Caregiver Benefit helps caregivers feel recognized and supported, however it potentially excludes a vulnerable population of caregivers and does not provide enough support to cover lost wages.

La Nouvelle-Écosse est la seule province canadienne à avoir mis en place un programme d'aide financière aux aidants informels, d'un montant de \$400 mensuel donné aux aidants, sous conditions à vérifier par l'aidant et la personne aidée. Parce que la population de Nouvelle-Écosse vieillit et, de ce fait, souffre d'un nombre accru de maladies chroniques complexes, les soins à domicile et les aidants informels ont attiré une attention croissante, notamment à travers la Stratégie pour les services de soins continus, qui a préparé le terrain pour accroître le soutien aux aidants. Les objectifs de l'aide financière aux aidants sont de reconnaître leur contribution dans l'assistance aux membres de leur famille ou à leurs amis, d'aider à conforter l'aide ainsi fournie, et de maintenir les patients à domicile plutôt qu'en institution. Une fenêtre de tir politique s'est ouverte en 2009 permettant au Nouveau Parti Démocratique de mettre en place l'aide financière aux aidants juste après leur victoire électorale, en s'appuyant sur une initiative lancée par le précédent gouvernement Conservateur Progressiste, et de tenir ainsi leur promesse d'aider les aînés et leurs aidants. Alors qu'aucune évaluation officielle n'a été menée, il entre dans les missions du Directeur de la Gestion du Risque de la Branche des Services de Soins Continus de rendre compte et de suivre le développement de cette politique. L'aide financière aux aidants leur permet de se sentir reconnus et soutenus, mais il est possible qu'elle exclut une population d'aidants vulnérables et n'offre pas assez pour couvrir les pertes de salaire.

Key Messages

- The Caregiver Benefit Program was developed in Nova Scotia in 2009 and is the only program in Canada to provide a monthly allowance of \$400 to unpaid caregivers to recognize their contributions and help them continue to support their family and friends.
- Access to the Caregiver Benefit allows care recipients to remain in their homes for longer and out of long-term care, which decreases health care spending overall.
- The success of and demand for the Caregiver Benefit is seen through its continued growth to include care recipients with less disability and higher income.

Messages-clés

- *Le Programme d'aide financière aux aidants a été développé en Nouvelle-Écosse en 2009 et est le seul programme au Canada à fournir une aide de \$400 aux aidants informels pour reconnaître leur contribution et les aider à poursuivre leur soutien à leur parents et proches.*
- *L'accès à l'aide financière aux aidants permet aux patients de vivre chez eux plus longtemps et de repousser leur institutionnalisation, ce qui coûte moins cher au système de santé*
- *Le succès du programme et la demande pour l'aide se traduisent par son extension à des catégories de patients moins dépendants et de revenu plus élevé.*

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1 BRIEF DESCRIPTION OF THE HEALTH POLICY REFORM

Nova Scotia implemented the Caregiver Benefit Program in 2009 and is the only province in Canada to provide an allowance for unpaid caregivers. The program is aimed at low income adults with high levels of disability or impairment and their caregivers (Nova Scotia Department of Health and Wellness 2018). The Caregiver Benefit offers \$400 a month directly to eligible caregivers if both the caregiver and care receiver qualify for the program. Both the caregiver and receiver must be residents of Nova Scotia, over 19 years of age, and have a caregiving relationship that is longer than 90 days (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018). The Caregiver Benefit includes spouse or child caregivers and does not require the caregiver to live with the care recipient (O’Hara 2014). The caregiver must provide 20 or more hours of unpaid assistance per week to one care recipient in the community (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018). Presently, the care recipient must have a net annual income under \$22,125 if single or \$37,209 if married or common-law, and be assessed as having high care needs. (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018). Having high care needs means the recipient has some combination of moderate to significant problems with memory loss, decision-making and communication that affects daily functioning, high level of physical impairment, many challenges in managing their personal needs, serious behaviour problems, a high risk of falls, and a high risk of long-term care placement. A care coordinator assesses the eligibility of each caregiving relationship (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018). The Caregiver Benefit Program has an allocated provincial budget each year (\$2.7M in 2009), and is available to all caregivers who meet all eligibility criteria until the budget is spent (Committee of the Whole House on Supply 2010).

2 HISTORY AND CONTEXT

Demographically, Canada, alongside several other countries, has been experiencing a shift towards an aging population (Bastawrous 2013; McMaster Health Forum 2014). In addition, a higher incidence of chronic disease and longer life expectancies is expected to result in unprecedented demand for older adult care (O’Hara 2014). The majority of care that elderly and other individuals with high care needs receive in the community is provided by family caregivers (Bastawrous 2013). It is estimated that unpaid family caregivers provide three quarters of patient care in Canada, contribute between \$26B to \$72B a year to the health care system, and help keep patients in their homes for longer (The Change Foundation 2018a). Caregivers, in particular those who are providing unpaid care to family or friends with high care needs, often experience financial strain. Many are forced to leave the workforce or participate in it at reduced hours (Williams et al. 2009). Additionally,

caregivers can experience psychological and physical burdens which can negatively impact their emotional well-being (Nova Scotia 2012; O’Hara 2014). This emotional strain can be exacerbated if they do not feel supported by their community or government and can lead to poorer quality of care to care receivers (O’Hara 2014).

In 2006, the Government of Nova Scotia released a *Continuing Care Strategy* that highlighted the need for better home care and support to caregivers (Cousins et al. 2016). A caregiver allowance was piloted by the Progressive Conservative (PC) government. Following the 2009 election, the New Democratic Party (NDP) implemented the Caregiver Benefit Program.

3 GOALS OF THE REFORM

3.1 Stated

The stated goal of the Caregiver Benefit Program Policy is to acknowledge the contributions of caregivers “in providing assistance to a family member or friend” and “to assist the caregiver in sustaining the support they provide” (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018).

3.2 Implicit

Implicitly, the Caregiver Benefit helps keep people in their homes longer and keeps them out of long-term care (O’Hara 2014; Canadian Institute for Health Information n.d.). This extends the caregiving relationship at home, which benefits the care recipient and decreases health care cost to the system. By offering support to caregivers, the Benefit may help improve the mental health of caregivers and prevent burnout (O’Hara 2014). Additionally, the Benefit raises awareness of caregivers’ needs and improves their access to other supports, such as training or respite.

4 HOW AND WHY THE ISSUE CAME ONTO THE GOVERNMENT’S AGENDA

Providing support to unpaid caregivers is a particularly important issue in Nova Scotia as the province has one of the oldest populations in Canada. Younger generations are leaving rural areas, and the province in general, in search of work, which leaves behind older generations of lower income (O’Hara 2014). Indeed, Caregivers Nova Scotia, the first-province wide caregiving organization in Canada was founded in 1998 in response to the needs of unpaid family and friend caregivers (Caregivers Nova Scotia Association 2016).

In 2006, the Progressive Conservative government introduced the 10-year *Continuing Care Strategy* in Nova Scotia. Through this strategy, the government committed to investments, improvements, and expansions in key areas including supporting individuals and

families by developing a caregiving strategy and strengthening continuing care services by expanding home care, self-managed care, and respite options (Nova Scotia 2006). Findings from the *2008/2009 Community Health Survey* estimated that there were 3.8 million unpaid caregivers over the age of 45 in Canada (O'Hara 2014) and *2008 Statistics Canada Eldercare: What We Know Today* reported that the majority of senior primary care receivers (78%) continue to live in their homes and that approximately 1 in 5 Canadians 45 years or older provide care to a senior (Cranswick and Dosman 2008). These findings, along with the fact that the front edge of the Baby Boomer generation would reach retirement in 2011, may have added to the sense of urgency.

Caregivers Nova Scotia were strong advocates for the Caregiver Benefit and worked closely with the Department of Health and Wellness to raise their caregiving concerns and implement the Benefit (O'Hara 2014). Dr. Janice Keefe, another important advocate for supporting caregivers in Canada, published several papers on the caregiving landscape, caregiver roles, and financial supports (Keefe and Rajnovich 2007; Keefe, Glendinning and Fancey 2008). In 2008, she prepared a background paper on caregiving in Nova Scotia, funded by the Department of Health and Wellness.

The PC government began piloting a caregiver allowance before the election in 2009 in parts of the province—an election it lost. The new NDP government rebranded the initiative and created the Caregiver Benefit Program only a month after being elected. This new policy fit well with its mandate of helping seniors stay in their homes longer. One of the key commitments of the NDP platform was to “give seniors options to stay in their homes and communities longer” in order to “avoid much more costly nursing home care” (Dexter 2009). The plan included the implementation of a “self-managed care allowance” along with “home adaption funds” and “ending security deposits for long-term care facilities” (Dexter 2009), however the Caregiver Benefit was intended for those that did not or could not use other supports or preferred to take on a caregiving role.

The NDP government increased the budget for the Caregiver Benefit from \$2.7M to \$4.6M in its first year in power (Committee of the Whole House on Supply 2010). The proposal was compatible with NDP and PC platforms and also garnered support and enthusiasm from the Liberal Party (Order of the Legislature by Hansard Reporting Services 2009). The proposal also appears to have met with little opposition from professional caregiver organizations. Given that personal support workers are unregulated, their opinions or concerns may not have been voiced adequately. From the perspective of unpaid care providers, the Benefit was viewed as a step in the right direction even though the amount of compensation may not be enough to fully compensate their work or financial burdens. Lack of opposition, ability to build on a previous initiative, and being viewed positively by the public likely contributed to the quick implementation of this policy.

5 HOW THE REFORM WAS ACHIEVED

5.1 Policy instruments

The previous care allowance initiative piloted by the PC government in the province was a stepping-stone for the NDP to develop the Caregiver Benefit. The new NDP program maintained most of the same criteria for eligibility; however, the previous criteria that the care receiver had to already be on a wait list for long-term care was removed (Order of the Legislature by Hansard Reporting Services 2009). This change made it easier for individuals to qualify for the benefit.

In 2011, the budget for the Caregiver Benefit was increased by \$1.8M, followed by further increases in 2015 of \$1.8M to the Benefit, alongside an increase of \$3.8M in home-care support and \$1.5M for the Seniors Assistance Program (March of Dimes Canada n.d.). In 2016, the Canadian Federal Government expanded its Compassionate Care Benefits, an Employment Insurance benefit for people who must take time off work to provide care to a gravely ill family member, from six weeks to 26 weeks (Baarda n.d.). This policy change signalled intention at the federal level to reduce the financial burden of caregivers that must take time off work (Baarda n.d.). Shortly after, Nova Scotia was the first province to increase their Compassionate Care Leave benefit from eight to 28 weeks (Baarda n.d.). The 2018-19 Nova Scotia provincial budget included an additional \$5.5M increase in home care services and increased funding for the Caregiver Benefit to allow further expansion and support 600 additional caregivers (March of Dimes Canada n.d.).

5.2 Implementation plan

The Caregiver Benefit Program is administered through the Continuing Care Branch of the Department of Health and Wellness (Drummond 2010). A continuing care coordinator, as an employee of the Nova Scotia Health Authority, is responsible for case management including determining the initial eligibility of caregivers and care receivers, intake, coordination of care, and ongoing assessment of eligibility (Cousins et al. 2016).

The Department of Health and Wellness in Nova Scotia used data from the Resident Assessment Instrument for Home Care to help build a business model for the implementation of the Caregiver Benefit Program (Canadian Institute for Health Information n.d.). Before implementation, the Department of Health and Wellness used this data to project how many people would benefit from such a program (Canadian Institute for Health Information n.d.). The Department of Health and Wellness continues to monitor the implementation of the Caregiver Benefit to allocate resources to those with the greatest need (Canadian Institute for Health Information n.d.).

5.3 Communication plan

Communication about the program has been done predominately by the Department of Health and Wellness Continuing Care Branch through their webpage and news releases. As strong advocates for caregivers in the province and an ally of the Nova Scotia Health Authority, Caregivers Nova Scotia was instrumental in communicating the Caregiver Benefit through their online resources, such as the *Caregivers Handbook*.

6 EVALUATION

There has been no official evaluation of the Caregiver Benefit Program (Cousins et al. 2016). The Caregiver Benefit was compared against the Manitoba Tax Credit in a Masters thesis (O’Hara 2014) through secondary-data analysis and interviews with policy experts. The thesis cited an unpublished study which found that “clients who receive the caregiver benefit are 56% less likely to be admitted to long term care facilities” (O’Hara 2014).

Approximately 60% of care recipients are women (aged 74 on average at enrollment), and 40% are men (aged 63 on average at enrollment) (O’Hara 2014). The majority of caregivers who receive the benefit are children or children-in-law (41%), followed by spouses (33%), other relatives (24%), and friends or neighbours (3%) (O’Hara 2014). These caregivers provide care full time (68.2 hours on average for other relatives, 60.1 hours for children, and 57.5 hours for spouses) (O’Hara 2014).

Accountability for compliance with the policy and monitoring of implementation, performance, and effectiveness of the policy is done by the Executive Director, Risk Mitigation of the Continuing Care Branch (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018).

The Caregiver Benefit went through several revisions and expansions in 2010, 2012, and 2018. In 2012, the government raised the low-income threshold of care receivers from \$18,785 per year to \$22,003 which led to another 100 caregivers becoming eligible to qualify, totalling 1,200 caregivers receiving the benefit (The Change Foundation 2018b; Nova Scotia 2012). In 2015, the number of caregivers increased to 1,890 (Cousins et al. 2016). In 2015, the incoming Liberal government, increased the budget for the Caregiver Benefit by \$1.8M, bringing the total budget of the Caregiver Benefit to \$8,804,000 (Cousins et al. 2016). In 2018, the Caregiver Benefit was revised once again to lower its eligibility criteria of impairment to cover more caregivers. This change in criteria is estimated to have added another 600 caregivers to the program (March of Dimes Canada, n.d.).

The Caregiver Benefit Program Policy states that access to funding is based on the availability of resources and that a provincial wait list may be established if necessary (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018). The waitlist, to be managed by the Department of Health and Wellness, will include those who meet the eligibility criteria and have received authorization from the Care Coordinators. Priority will be given to care recipients with higher scores on assessments for need, organized

by chronological date (Department of Health and Wellness Risk Mitigation – Continuing Care Branch 2018).

7 STRENGTHS, WEAKNESSES, OPPORTUNITIES AND THREATS

A SWOT analysis of the Caregiver Benefit Program in Nova Scotia is presented in Table 1. The parentheses indicate the stakeholder to which each perspective is relevant. Clients of the Caregiver Benefit includes the caregivers and care receivers.

Table 1: SWOT Analysis

STRENGTHS	WEAKNESSES
<ul style="list-style-type: none"> • Does not require caregiver to live with care recipient which allows caregiver to maintain autonomy from caregiving relationship (O’Hara 2014) (<i>clients</i>) • Allows care recipients to access other supports, such as Nova Scotia’s Home Care Services, while part of the Benefit (O’Hara 2014) (<i>clients</i>) • Benefit is not taxed by government because it is income tested (O’Hara 2014) (<i>clients</i>) • Benefit received robust political support by all parties and a lack of opposition (<i>government</i>) • Benefit was supported by several stakeholders including Caregivers Nova Scotia Association (<i>government</i>) 	<ul style="list-style-type: none"> • Amount provided monthly does not cover lost wages (O’Hara 2014) (<i>clients</i>) • Benefit does not take into account whether caregiver must leave work to provide care (O’Hara 2014) (<i>clients</i>) • Eligibility of caregivers to receive the Benefit is based on care recipient’s income which assumes that if the care recipient has a higher income, the caregiver has a high enough income to sustain the care activities or the care recipient will pay the caregiver (<i>clients</i>) • Excludes younger caregivers and parents of young children who require complex care, under the age of 19 (<i>clients</i>)

OPPORTUNITIES	THREATS
<ul style="list-style-type: none"> • Increasing access to the Benefit may decrease long-term health care spending as care recipients are less likely to enter long-term care (O’Hara 2014) (<i>government, clients</i>) • Additional support and recognition of caregivers helps reduce caregiver burnout and extends the caregiving relationship (O’Hara 2014) (<i>clients</i>) • Benefit raises awareness of caregivers’ needs and improves their access to other supports, such as training or respite (<i>clients</i>) 	<ul style="list-style-type: none"> • Lack of evaluation of the Caregiver Benefit for equity, effectiveness, or efficiency (<i>government</i>) • Lack of cost-analysis to determine what caregivers use the money for, if it is enough, and how much more is required to fulfill their needs (<i>government, clients</i>) • Potential for fraudulent behaviour in accessing the benefit (D’Arcy 2008) (<i>government, clients</i>) • Lack of evaluation of caregivers’ perception of support (<i>government, clients</i>)

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