# FACT SHEET

# FINANCIAL SUPPORT FOR CAREGIVERS

# Fact sheet Financial support for caregivers

This document is part of a series of fact sheets created to inform decision-makers and those who work with caregivers and care receivers about the kinds of caregiver support available.

The following pages summarize the different forms of financial support available to caregivers in Quebec. We also look at the challenges related to accessing support and the impacts such support may have. Lastly, various avenues for action are proposed to decision-makers and professionals who work with caregivers and care receivers.

This fact sheet was developed jointly by the Centre for Research and Expertise in Social Gerontology (CREGÉS) and the Quebec Observatory on Caregiving, both of which are part of the Directorate of Academic Affairs and Research Ethics of the Integrated Health and Social Services University Network for West-Central Montreal (CIUSSS West-Central Montreal). It is based on literature reviews conducted by the CREGÉS under the provincial mandate granted to the CIUSSS West-Central Montreal by the Ministère de la Santé et des Services sociaux (MSSS).





For details on the methodology used, see (only in French): <a href="https://www.creges.ca/en/publication/entre-les-services-les-bonnes-pratiques-et-les-mesures-mise-en-perspective-du-soutien-aux-personnes-proches-aidantes/">https://www.creges.ca/en/publication/entre-les-services-les-bonnes-pratiques-et-les-mesures-mise-en-perspective-du-soutien-aux-personnes-proches-aidantes/</a>

For other fact sheets on caregiver support, see <a href="https://observatoireprocheaidance.ca/fiches-syntheses-soutiens-en-proche-aidance/">https://observatoireprocheaidance.ca/fiches-syntheses-soutiens-en-proche-aidance/</a>

https://www.creges.ca/en/publication/soutien-financier-aux-personnes-proches-aidantes-in-french/

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To cite this document: Reiss, M. and Van Pevenage, I. (2022). Fact sheet. Financial support for caregivers. Centre for Research and Expertise in Social Gerontology and Quebec Observatory on Caregiving, Directorate of Academic Affairs and Research Ethics, Integrated Health and Social Services University Network for West-Central Montreal.

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## **DEFINITIONS**

#### General definition





Support for caregivers in the form of financial assistance.

#### Definitions per type of financial support

There are varying forms of financial support available to caregivers.

**Allowances/benefits:** financial support in the form of cash transfers to caregivers to help cover caregiving responsibilities and/or allow them to procure services

In Quebec, benefits are available to:

- > Parents of children with disabilities
  - Supplement for Handicapped Children
  - Supplement for Handicapped Children Requiring Exceptional Care
  - Family support for the parents of a child or adult with a physical or intellectual disability. The support provided is for the purchase of respite services, childcare, occasional assistance, and support for parenting through assistance with daily activities.
- ➤ Persons eligible for social assistance through the Temporarily Limited Capacity program (caregiver component)
- > There is currently no direct compensation or caregivers' allowance in Quebec.

#### Tax credits: financial support in the form of tax deductions

- Caregiver tax credits may be refundable or non-refundable.
  - > Refundable tax credits are paid even if the person has no income tax to pay.
  - Non-refundable tax credits can reduce or cancel the payable income tax.
- There are caregiver tax credits at both the provincial and federal levels.
  - > Provincial: the tax credit is refundable.
  - > Federal: the tax credit is non-refundable.
  - Caregivers who are eligible can apply for both.

- Revenu Québec also offers:
  - ➤ A tax credit for childcare expenses (applicable to dependent children with a physical or mental disability)
  - > A tax credit for medical expenses (applicable to dependents)
  - A non-refundable tax credit for medical expenses to cover care not available in the caregiver's area of residence (applicable to dependents)
  - > A non-refundable tax credit for other dependents

**Cash-for-care:** financial support in the form of cash transfers to the care recipient to allow them to purchase services or pay a home care service provider (this person may be a caregiver, though the MSSS does not recommend it).

➤ In Quebec, the Service Employment Paycheque is a form of cash-for-care.

#### Other forms of financial support are also available.

> For example, withdrawals from a Registered Retirement Savings Plan (RRSP) for the benefit of a person with a functional impairment.



## A FEW FINDINGS<sup>1</sup>

In Canada in 2018, about 30% of caregivers who received support for their caring duties (e.g. help from family members, financial assistance) said there was another type of support they would have liked to have received in the past year.

> For 68% of them, the most commonly reported need was financial support.



## **CHALLENGES**

#### Concerning financial support in general

#### A great many caregivers suffer from financial insecurity<sup>2</sup>

- Some populations are particularly vulnerable to this:
  - Women, who are more apt to reduce their working hours or leave their jobs altogether to assume caregiving responsibilities<sup>3</sup>
  - People who had financial difficulties prior to assuming caregiving responsibilities<sup>4</sup>
  - People living in rural regions<sup>5</sup>

 Immigrants, who are ineligible for certain benefits and whose financial situations are often affected by costs related to the immigration process<sup>6</sup>

#### Financial support is therefore critical for caregivers, since it:

- Offers a form of compensation to caregivers who face additional expenditures (e.g. transportation, the need to purchase medication) or financial loss (e.g. lower income due to reduced hours worked).
- ➤ Is a form of recognition for the contribution of caregivers<sup>7</sup>.
- Lessens the financial burden on caregivers and helps reduce short-term impoverishment<sup>8</sup>.

#### Nonetheless, there are a number of important considerations.

- Barriers to accessing financial support:
  - Restrictive eligibility criteria (e.g. related to the care recipient's age, their diagnosis<sup>9</sup>, their income or that of the caregiver, the caregiver/care receiver relationship)
    - Criteria based on the relationship between caregiver and care receiver are often limited to immediate family members (partner, parents, children), which effectively bars caregivers who are not immediate family members from accessing the available support.
    - ➤ This may particularly penalize caregivers from the LGBTQ+ community or who care for an LGBTQ+ person, for whom the concept of "family" can refer to a non-biologically related group of people<sup>10</sup>. It can also affect caregivers from ethnocultural communities where "caregiving" can be provided by extended family (e.g. aunts, uncles, cousins) and/or community members<sup>11</sup>.
  - · Lack of information on the financial support available
  - Lack of information on programs and their requirements (e.g. days allocated, eligibility criteria, information poorly adapted to literacy levels)<sup>12</sup>
  - Procedures for accessing financial support, which can be lengthy and complex (e.g. requests for medical certificates, forms)<sup>13</sup>
- > The compensation provided is often inadequate or minimal<sup>14</sup>.
- Caregivers must often cut back on their working hours to support the care receiver. However, the compensation offered is generally short-term, with no long-term compensation that could offset reduced working hours when calculating retirement benefits—a situation that can lead to long-term impoverishment<sup>15</sup>.
- > Differentiated impact of financial support according to gender<sup>16</sup>
  - Financial support is a way to recognize and provide partial/short-term remuneration for the invisible work of caregivers, who are predominantly female.
  - However, it also reinforces the assignment of women as carers, who—being more apt to reduce their working hours or leave their jobs—are at greater risk of long-term impoverishment.

#### Regarding benefits

Along with the challenges concerning financial support in general, benefits may:

- > Among some caregivers, heighten the sense of obligation to provide care<sup>17</sup>.
- ➤ Professionalize caregivers who receive some form of remuneration for the care they provide¹8.
- Reproduce existing social inequalities<sup>19</sup>:
  - Benefits may encourage unskilled or low-income workers to withdraw from the labour market in order to provide care.
  - However, returning to the labour market after a long absence—which is very often the case with caregivers—is difficult.
  - In the dearth of any compensation measures (and particularly concerning pension schemes), absence from the labour market can entail the risk of long-term impoverishment.

#### Regarding tax credits

Beyond the issues related to financial support in general, tax credits can be hard to access, given the differing eligibility criteria in the Quebec and Canadian tax systems.

Non-refundable tax credits may also serve to reinforce existing social inequalities:

➤ Caregivers must pay tax to claim a deduction. However, though financial insecurity affects most caregivers, it more particularly targets low-income carers for whom non-refundable tax credits are of little to no use<sup>20</sup>.

#### Regarding cash-for-care

This form of support allows care receivers to hire someone to support their existing caregiver or directly compensate the caregiver.

Cash-for-care programs have some advantages:

- They give the care receiver the autonomy to choose their own home care service provider (i.e. choose someone who they feel they can trust)<sup>21</sup>.
- They provide more options to people living in rural areas<sup>22</sup>.
- > They can develop new jobs (personal assistants, cash-for-care managers)<sup>23</sup>.
- They can give the caregiver a break by allowing an external home care service provider to be hired for certain tasks.

However, cash-for-care schemes can also have disadvantages for the caregiver and care receiver.

If the cash-for-care scheme specifies that the cash cannot be used to remunerate the caregiver, then the tasks of seeking, hiring and scheduling the home care support fall to the care receiver. However, should the care receiver not be in a condition to do so, then these tasks will fall to the caregiver, thus increasing their burden<sup>25</sup>.

Financial Support

- Cash-for-care schemes that do allow the caregiver to be directly remunerated can bring the risk of:
  - Exhaustion on the part of caregivers who feel the need to do more for the person being cared for<sup>26</sup>.
  - Making the caregiver financially dependent on the care receiver<sup>27</sup>.
  - Formalizing a previously informal relationship by monetizing and professionalizing it<sup>28</sup>.
  - Encouraging the caregiver to leave their regular job<sup>29</sup>.
- ➤ The amounts allocated often fall short of meeting the full needs of the care receiver<sup>30</sup>.
- The quality of care may be compromised if there is no regulated quality control (e.g. by a CISSS/CIUSSS)<sup>31</sup>.
- The challenges related to this measure must be fully disclosed if an informed decision is to be made about using a cash-for-care scheme; however, such information is often incomplete or lacking<sup>32</sup>.



# POSSIBLE SOLUTIONS

#### As a professional working with caregivers or care receivers, you can:

- ➤ Provide clear, straightforward information to caregivers/care receivers about the financial support<sup>33</sup> available to them:
  - The different types of support
  - Eligibility requirements
  - The challenges, advantages and disadvantages of each type of support
- ➤ Offer to help with the process of accessing or completing applications for financial support<sup>34</sup>.

#### As a decision-maker, you can:

- ➤ Assess the differentiated impacts of financial support according to gender and demographics (e.g. minority and racialized populations)<sup>35</sup>.
- ➤ Adapt the eligibility criteria<sup>36</sup>:
  - By reducing the number of criteria
  - By simplifying requirements
  - By reducing the number of documents required to obtain financial support<sup>37</sup>
- ➤ Protect caregivers from long-term impoverishment, in particular by including periods devoted to caregiving in retirement pension calculations<sup>38</sup>.
- > Develop more comprehensive solutions in terms of financial support<sup>39</sup>.
- ➤ Incentivize cash-for-care schemes to offer care receivers recourse to the professional and formal sectors (creation of new diplomas, priority given to professionals in the case of care receivers with high needs, etc.)<sup>40</sup>.



# TO FIND OUT MORE

- Keefe, J., Glendinning, C., & Fancey, P. (2008). Financial payments for family carers: Policy approaches and debates. In A. Martin-Matthews & J. Philips (Eds.), Ageing at the intersection of work and home life: Blurring the boundaries (pp. 185-206). New York: Lawrence Eribaum
- Keefe, J. et Rajnovich, B. (2007). To pay or not to pay: Examining underlying principles in the debate on financial support for family caregivers. Canadian Journal on Aging / La Revue Canadienne Du Vieillissement, 26(S1), 77–89.
- Colombo, F., et al. (2011). Policies to Support Family Carers. In OECD Health Policy Studies, *Help Wanted?*: Providing and Paying for Long-Term Care (p. 121-158). Éditions OCDE: Paris



# ADDITIONAL INFORMATION ON FINANCIAL SUPPORT

Along with the supplements paid directly to the parents of children with disabilities, the transitional measure for children aged 5 with disabilities is a benefit paid to a subsidized educational childcare provider to allow children with disabilities to remain in childcare for an additional year before entering school. For more information: <a href="https://www.quebec.ca/en/family-and-support-for-individuals/childhood/childcare-centres/childcare-centres-for-children-with-disabilities/transitional-measure-children-aged-5-with-disabilities/

#### ALLOWANCES/ BENEFITS

For more information on the Supplement for Handicapped Children: <a href="https://www.rrq.gouv.qc.ca/en/enfants/enfant\_handicape/supplement-enfant-handicape/Pages/admissibilite.aspx">https://www.rrq.gouv.qc.ca/en/enfants/enfant\_handicape/supplement-enfant-handicape/Pages/admissibilite.aspx</a>

For more information on the Supplement for Handicapped Children Requiring Exceptional Care: <a href="https://www.rrq.gouv.qc.ca/en/enfants/enfant\_handicape/seh-necessitant-soins-exceptionnels/Pages/seh-necessitant-soins-exceptionnels.aspx">https://www.rrq.gouv.qc.ca/en/enfants/enfants/enfants/enfants-exceptionnels/pages/seh-necessitant-soins-exceptionnels.aspx</a>

For more information on the Family Support Program: <a href="https://www.quebec.ca/en/health/health-system-and-services/assistive-devices-disabilities-and-handicaps/family-support-program">https://www.quebec.ca/en/health/health-system-and-services/assistive-devices-disabilities-and-handicaps/family-support-program</a>

For more information on the benefits for temporarily limited capacity for employment (as applicable to caregivers): <a href="https://www.mani.mess.gouv.qc.ca/?sujet=42445">https://www.mani.mess.gouv.qc.ca/?sujet=42445</a>

TAX CREDITS	For more information on non-refundable tax credits: <a "="" citizens="" en="" href="https://www.revenuquebec.ca/en/citizens/income-tax-return/completing-your-income-tax-return/how-to-complete-your-income-tax-return/line-by-line-help/350-to-398-1-non-refundable-tax-credits/&lt;/a&gt; For more information on the Tax Credit for Caregivers: &lt;a href=" https:="" tax-credit-for-caregivers="" tax-credits="" www.revenuquebec.ca="">https://www.revenuquebec.ca/en/citizens/tax-credits/tax-credit-for-caregivers/</a> For more information on the Canada caregiver credit: <a "="" 350-to-398-1-non-refundable-tax-credits="" citizens="" completing-your-income-tax-return="" en="" how-to-complete-your-income-tax-return="" href="https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/about-your-tax-return/tax-return/completing-a-tax-return/deductions-credits-expenses/canada-caregiver-amount.html&lt;/a&gt; For more information on the Tax Credit for Childcare Expenses:&lt;/th&gt;&lt;/tr&gt;&lt;tr&gt;&lt;td&gt;https://www.revenuquebec.ca/en/citizens/tax-credits/tax-credit-for-childcare-expenses/requirements/  For more information on the Tax Credit for Medical Expenses: https://www.revenuquebec.ca/en/citizens/tax-credits/medical-expenses/  For more information on the Tax Credit for Medical Services Not Available in Your Area: https://www.revenuquebec.ca/en/citizens/tax-credits/medical-services-not-available-in-your-area/&lt;/td&gt;&lt;/tr&gt;&lt;tr&gt;&lt;th&gt;&lt;/th&gt;&lt;th&gt;For more information on Tax Credits — Amount for Other Dependents: &lt;a href=" https:="" income-tax-return="" line-367="" line-by-line-help="" www.revenuquebec.ca="">https://www.revenuquebec.ca/en/citizens/income-tax-return/completing-your-income-tax-return/how-to-complete-your-income-tax-return/line-by-line-help/350-to-398-1-non-refundable-tax-credits/line-367/</a>
	CASH-FOR- CARE
OTHER FORMS OF FINANCIAL SUPPORT	When withdrawals from a Registered Retirement Savings Plan (RRSP) are made for the benefit of a person with a functional impairment, certain tax rules governing to the Home Buyers' Plan (HBP) and the Lifelong Learning Plan (LLP) have been relaxed.

# **REFERENCES**

- 1 Hango, Darcy. (2020). Support received by caregivers in Canada. Statistiques Canada: Insights on Canadian Society.
- 2 Hango, Darcy. (2020). Support received by caregivers in Canada. Statistiques Canada: Insights on Canadian Society.
  - Regroupement des aidants naturels du Québec. (2018). Valoriser et épauler les proches aidants, ces alliés incontournables pour un Québec équitable : stratégie nationale de soutien aux proches aidants. <a href="https://rang.gc.ca/wp-content/uploads/2018/03/Strategie-nationale\_RANQ.pdf">https://rang.gc.ca/wp-content/uploads/2018/03/Strategie-nationale\_RANQ.pdf</a>
- 3 Commission des droits de la personne et des droits de la jeunesse. (2018). Paper presented to the Commission de l'économie et du travail de l'Assemblée Nationale in consideration of Bill 176, An Act to amend the Act respecting labour standards and other legislative provisions mainly to facilitate familywork balance.
  - Hébert, G. (2017). L'armée manquante au Québec: les services à domicile. Institut de recherche et d'informations socioéconomiques.
- 4 Carmichael, F. et Ercolani, M. G. (2016). Unpaid caregiving and paid work over life-courses: Different pathways, diverging outcomes. *Social Science & Medicine*, 156.
- Hussain, R., Wark, S. et Ryan, P. (2018). Caregiving, employment and social isolation: Challenges for rural carers in Australia. *International journal of environmental research and public health, 15*(10), 2267. <a href="https://doi.org/10.3390/ijerph15102267">https://doi.org/10.3390/ijerph15102267</a>
- Van Pevenage, Isabelle and Reiss Margaux (2020). Entre les services, les bonnes pratiques et les mesures: mise en perspective du soutien aux personnes proches aidantes. Integrated Health and Social Services University Network for West-Central Montreal, Centre for Research and Expertise in Social Gerontology (CREGÉS).
- Keefe, J. and Rajnovich, B. (2007). To Pay or Not to Pay: Examining Underlying Principles in the Debate on Financial Support for Family Caregivers Canadian Journal on Aging / La Revue canadianne du vieillissement, 26(S1), 77-89. <a href="https://doi.org/10.3138/cja.26.suppl\_1.077">https://doi.org/10.3138/cja.26.suppl\_1.077</a>
  Keefe, J., Glendinning, C. and Fancey, P. (2008). Financial payments for family carers: Policy approaches and debates. In A. Martin-Matthews and J. Philips (Eds.), Ageing at the Intersection of Work and Home Life: Blurring the Boundaries (pp. 185-206). Lawrence Eribaum.
- 8 Centre d'intégration au marché de l'emploi. (2018). Guide sur la proche aidance et l'emploi pour le personnel d'intervention en employabilité travaillant auprès de personnes proches aidantes. <a href="https://cime-emploi.com/wp-content/uploads/2018/10/Guide-proche-aidance\_2018-06-04.pdf">https://cime-emploi.com/wp-content/uploads/2018/10/Guide-proche-aidance\_2018-06-04.pdf</a>
- 9 However, receiving a medical diagnosis can take months, even years, leaving caregivers bereft of financial support during this period. See Dumais, L., Ducharme, M.-N., Prohet, A., Université du Québec à Montréal and Laboratoire de recherche sur les pratiques et les politiques sociales. (2014). Identification des coûts supplémentaires généraux liés aux déficiences, incapacités et situations de handicap assumés par les personnes handicapées et leur famille. École de travail social, Université du Québec à Montréal.
- 10 Fondation Émergence. (2020). Reconnaître et inclure les personnes proches aidantes LGBTQ+. Paper presented as part of the special consultations and public hearings Information and recommendations on Bill 56, An Act to recognize and support caregivers and to amend various legislative provisions.

Wardecker, B. M. and Matsick, J. L. (2020). Families of Choice and Community Connectedness: A Brief Guide to the Social Strengths of LGBTQ Older Adults. Journal of Gerontological Nursing, 46(2), 5-8. <a href="https://doi.org/10.3928/00989134-20200113-01">https://doi.org/10.3928/00989134-20200113-01</a>

Hawthorne, O., Camic, P. and Rimes, K. (2020). Understanding the structure, experiences and challenges of social support for older lesbian, gay and bisexual people: A systematic review. *Ageing and Society*, 40(2), 282-305.

Gabrielson, M. L., Holston, E. C. and Dyck, M. J. (2014) Are they family or friends? Social support instrument reliability in studying older lesbians. *Journal of Homosexuality*, 61(11), 1589–1604. <a href="https://doi.org/10.1080/0018369.2014.944050">https://doi.org/10.1080/0018369.2014.944050</a>

Mahoney, K. J., Mahoney, E. K., Morano, C. and DeVellis, A. (2019). Unmet needs in self-directed HCBS programs. *Journal of Gerontological Social Work*, 62(2), 195–215. <a href="https://doi.org/10.1080/01634372.2018.14">https://doi.org/10.1080/01634372.2018.14</a> 51421

- 11 Brotman, S. et Ferrer, I. (2015). Diversity within family caregiving: Extending definitions of « who counts » to include marginalized communities. *HealthcarePapers*, 15(1), 47-53. <a href="https://doi.org/10.12927/htt
- 12 Ragnat, A., Parsons, J. et Radhakrishnan, R. (2018). The barriers determining the use of the carer supportsubsidy in the Northland region of New Zealand—A qualitative study. *Journal of geriatric care and research*, 5(1), 28-35.

  Simon-Rusinowitz, L., Loughlin, D. M., Ruben, K., Martinez Garcia, G. et Mahoney, K. J. (2010). The benefits of

consumer-directed services for elders and their caregivers in the cash and counseling demonstration and evaluation. *Public policy & aging report*, 20(1), 27–31. https://doi.org/10.1093/ppar/20.1.27

- evaluation. Public policy & aging report, 20(1), 27–31. https://doi.org/10.1093/ppar/20.1.27
- 13 Mot, E. (2010). The long-term care system for the elderly in the Netherlands (ENEPRI Research Report n°90). European Network of Economic Policy Research Institutes.
- 14 Fédération des femmes du Québec. (2015). Pour une réforme fiscale juste envers les femmes et génératrice d'égalité dans la société. Paper presented to the Commission des finances publiques on the Commission d'examen sur la fiscalité québécoise report.
  - Laragy, C., Sanders, F. and Brophy, L. (2015). Implications for family carers when people with psychosocial disability have individualised funding packages literature review. <a href="https://citizen-network.org/uploads/attachment/512/individualised-funding-implications-for-family-carers.pdf">https://citizen-network.org/uploads/attachment/512/individualised-funding-implications-for-family-carers.pdf</a>
  - Laroque, M. (2016). La prise en charge de la dépendance en France et en Allemagne. *Vie sociale,* 15(3), 175-186.
  - Regroupement des aidants naturels du Québec. (2018). Valoriser et épauler les proches aidants, ces alliés incontournables pour un Québec équitable: stratégie nationale de soutien aux proches aidants. <a href="https://ranq.qc.ca/wp-content/uploads/2018/03/Strategie-nationale\_RANQ.pdf">https://ranq.qc.ca/wp-content/uploads/2018/03/Strategie-nationale\_RANQ.pdf</a>
  - Rummery, K. (2011). A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment. Ethics and Social Welfare, 5(2), 138–152. https://doi.org/10.1080/17496535.2011.571064
- Bouget, D., Saraceno, C. and Spasova, S. (2017). Towards new work-life balance policies for those caring for dependent relatives? Social policy in the European Union: state of play 2017.
- 16 Conseil du statut de la femme. (2018). Portrait les proches aidantes et les proches aidants au Québec— Analyse différenciée selon les sexes.
  - Deshaies, M.-H. (2018). L'action publique québécoise à l'égard des personnes âgées vivant avec une incapacité: Une analyse sociologique des discours entourant le partage de la responsabilité des soins (1980-2015). [Thesis, Université Laval].
  - Keefe, J. and Rajnovich, B. (2007). To Pay or Not to Pay: Examining Underlying Principles in the Debate on Financial Support for Family Caregivers. *Canadian Journal on Aging / La Revue canadienne du vieillissement*, 26(S1), 77–89. https://doi.org/10.3138/cja.26.suppl\_1.077
  - Keefe, J., Glendinning, C. and Fancey, P. (2008). Financial payments for family carers: Policy approaches and debates. In A. Martin-Matthews and J. Philips (Eds.), Ageing at the Intersection of Work and Home Life: Blurring the Boundaries (pp. 185-206). Lawrence Eribaum.
  - Seery, A. (2014). Famille et travail: constats et propositions des jeunes féministes au Québec. Enfances Familles Générations. Revue interdisciplinaire sur la famille contemporaine, (21), 216-236.

- 17 Keefe, J. et Rajnovich, B. (2007). To pay or not to pay: Examining underlying principles in the debate on financial Support for family caregivers. *Canadian journal on aging / Revue canadienne du vieillissement,* 26(S1), 77–89. <a href="https://doi.org/10.3138/cja.26.suppl\_1.077">https://doi.org/10.3138/cja.26.suppl\_1.077</a>
- 18 Giraud, L., Outin, J.-L. et Rist, B. (2019). Avant-propos. Revue française des affaires sociales, 1, 7-16.
- Bouget, D., Saraceno, C. and Spasova, S. (2017). Towards new work-life balance policies for those caring for dependent relatives? Social policy in the European Union: state of play 2017.
  Riedel, M. and Kraus, M. (2016). Differences and similarities in monetary benefits for informal care in old and new EU member states. *International Journal of Social Welfare*, 25(1), 7-17. https://doi.org/10.1111/jjsw.12157
- 20 Hamel, P. J., Sénécal, G. and Vachon, N. (2018). Une place après 21 ans pour les jeunes adultes polyhandicapés. Institut national de recherche scientifique: Centre urbanisation, culture et société. <a href="https://espace.inrs.ca/id/eprint/7605/1/Une-place-21ans-rapportINRS-final2.pdf">https://espace.inrs.ca/id/eprint/7605/1/Une-place-21ans-rapportINRS-final2.pdf</a>
  Sinha S., Dunning J., Wong I., and Nicin, M. (2018). Why Canada needs to better care for its working caregiver. National institute on aging: Ryerson University. <a href="https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de40b6f82867f0a4729e1/1570628621053/working-caregivers.pdf">https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de40b6f82867f0a4729e1/1570628621053/working-caregivers.pdf</a>
- 21 Reddihough, D. S., Meehan, E., Stott, N. S. and Delacy, M. J. (2016). The National Disability Insurance Scheme: A time for real change in Australia. *Developmental Medicine & Child Neurology*, 58(S2), 66-70. <a href="https://doi.org/10.1111/dmcn.13007">https://doi.org/10.1111/dmcn.13007</a>
  Pike, B., O'Nolan, G., et Farragher, L. (2016). Individualised budgeting for social care services for people with a disability: International approaches and evidence on financial sustainability. Health Research Board. <a href="https://www.hrb.ie/fileadmin/publications\_files/Individualised\_budgeting\_for\_social\_care\_2016.pdf">https://www.hrb.ie/fileadmin/publications\_files/Individualised\_budgeting\_for\_social\_care\_2016.pdf</a>
  Cass, B. et Yeandle, S. (2009). Policies for Carers in Australia and the UK: Social policy ideas, practices and their cross-national transmission: Social movements, parliamentary inquiries and local innovations. <a href="http://www.cccg.umontreal.ca/rc19/PDF/Cass-B\_Rc192009.pdf">http://www.cccg.umontreal.ca/rc19/PDF/Cass-B\_Rc192009.pdf</a>
  Colombo, F., et al. (2011). Policies to support family carers. In Help Wanted? Providing and Paying for Long-Term Care (pp. 121-158), OECD Health Policy Studies. Paris: OCDE Publishing.

  Riedel, M.et Kraus, M. (2016). Differences and similarities in monetary benefits for informal care in old and new EU member states. *International journal of social welfare*, 25(1), 7-17. <a href="https://doi.org/10.1111/jijsw.12157">https://doi.org/10.1111/jijsw.12157</a>
- 22 Purcal, C., Fisher, K. R. et Laragy, C. (2014). Analysing choice in Australian individual funding disability policies. *Australian Journal of Public Administration*, 73(1), 88-102.
- 23 Comas-Herrera, A., Pickard, L., Wittenberg, R., Malley, J. et King, D. (2010). The English long-term care system. (Enepri Research Report No. 74). European network of economic policy research institutes. <a href="https://www.files.ethz.ch/isn/122394/England.pdf">https://www.files.ethz.ch/isn/122394/England.pdf</a>
- 24 Keefe, J. et Rajnovich, B. (2007). To pay or not to pay: Examining underlying principles in the debate on financial support for family caregivers. Canadian journal on aging / Revue canadianne du vieillissement, 26(S1), 77-89. <a href="https://doi.org/10.3138/cja.26.suppl\_1.077">https://doi.org/10.3138/cja.26.suppl\_1.077</a>
  - Ragnat, A., Parsons, J. et Radhakrishnan, R. (2018). The barriers determining the use of the carer support subsidy in the Northland region of New Zealand—A qualitative study. *Journal of geriatric care and research*, 5(1), 28–35.
  - Da Roit, Barbara, Blanche Le Bihan, and August Österle, 'Cash-for-care benefits', in Cristiano Gori, Jose-Luis Fernandez, and Raphael Wittenberg (eds), Long-Term Care Reforms in OECD Countries (Bristol, 2015; online edn, Policy Press Scholarship Online, 19 Jan. 2017), <a href="https://doi.org/10.1332/policypress/9781447305057.003.0007">https://doi.org/10.1332/policypress/9781447305057.003.0007</a>
  - Rummery, K. (2011). A comparative analysis of personalisation: Balancing an ethic of care with user empowerment. *Ethics and Social Welfare*, 5(2), 138–152. <a href="https://doi.org/10.1080/17496535.2011.571064">https://doi.org/10.1080/17496535.2011.571064</a>
- 25 Campéon, A. et Bihan-Youinou, B. L. (2016). Le développement des dispositifs d'aide aux aidants : une démarche d'investissement social ? *Informations sociales*, 192(1), 88-97.

Laragy, C., Sanders, F. et Brophy, L. (2015). Implications for family carers when people with psychosocial disability have individualised funding packages – literature review. <a href="https://citizen-network.org/uploads/attachment/512/individualised-funding-implications-for-family-carers.pdf">https://citizen-network.org/uploads/attachment/512/individualised-funding-implications-for-family-carers.pdf</a>

Da Roit, Barbara, Blanche Le Bihan, and August Österle, 'Cash-for-care benefits', in Cristiano Gori, Jose-Luis Fernandez, and Raphael Wittenberg (eds), Long-Term Care Reforms in OECD Countries (Bristol, 2015; online edn, Policy Press Scholarship Online, 19 Jan. 2017), <a href="https://doi.org/10.1332/policypress/9781447305057.003.0007">https://doi.org/10.1332/policypress/9781447305057.003.0007</a>

Ragnat, A., Parsons, J. et Radhakrishnan, R. (2018). The barriers determining the use of the carer support subsidy in the Northland region of New Zealand—A qualitative study. *Journal of Geriatric Care and Research*, 5(1), 28–35.

Institut de la planification des soins et regroupement des aidantes et aidants naturels de Montréal. (2015). Vers la reconnaissance d'un statut légal pour les proches aidants. <a href="https://www.planificationdessoins.org/wp-content/uploads/2019/04/daniellechalifoux-publications-reconnaissance-statut-procheaidant-2015.pdf">https://www.planificationdessoins.org/wp-content/uploads/2019/04/daniellechalifoux-publications-reconnaissance-statut-procheaidant-2015.pdf</a>

- Le Bihan, B. (2012). The redefinition of the familialist home care model in France: The complex formalization of care through cash payment. *Health & social care in the community*, 20(3), 238-246.
- 27 Keefe, J. et Rajnovich, B. (2007). To pay or not to pay: Examining underlying principles in the debate on financial support for family caregivers. *Canadian journal on aging / Revue canadienne du vieillissement,* 26(S1), 77–89. https://doi.org/10.3138/cja.26.suppl\_1.077
  - Keefe, J., Glendinning, C. and Fancey, P. (2008). Financial payments for family carers: Policy approaches and debates. In A. Martin-Matthews and J. Philips (Eds.), *Ageing at the Intersection of Work and Home Life: Blurring the Boundaries* (pp. 185–206). New York: Lawrence Eribaum.
  - Ragnat, A., Parsons, J. and Radhakrishnan, R. (2018). The barriers determining the use of the carer support subsidy in the Northland region of New Zealand—A qualitative study. *Journal of Geriatric Care and Research*, 5(1), 28–35.
  - Zigante, V. (2018). Informal care in Europe: Exploring formalisation, availability and quality. Commission européenne. <a href="https://data.europa.eu/doi/10.2767/78836">https://data.europa.eu/doi/10.2767/78836</a>
- 28 Graham, K. (2015). Cash payments in context: (Self-)regulation in the new social relations of assistance. *Disability & society*, 30(4), 597-613.
  - Keefe, J. and Rajnovich, B. (2007). To Pay or Not to Pay: Examining Underlying Principles in the Debate on Financial Support for Family Caregivers. *Canadian Journal on Aging /Revue canadienne du vieillissement*, 26(S1), 77-89. https://doi.org/10.3138/cja.26.suppl\_1.077
  - Larkin, M. et Milne, A. (2014). Carers and empowerment in the UK: A critical reflection. *Social policy and society*, 13(1), 25-38.
  - Colombo, F. et al. (2011). Policies to support family carers. In Help Wanted? Providing and Paying for Long-Term Care (pp. 121-158), OECD Health Policy Studies. Paris: OECD Publishing.
  - Ottmann, G., Allen, J. et Feldman, P. (2013). A systematic narrative review of consumer-directed care for older people: Implications for model development. *Health & social care in the community*, 21(6), 563-581. Da Roit, Barbara, Blanche Le Bihan, and August Österle, 'Cash-for-care benefits', in Cristiano Gori, Jose-Luis Fernandez, and Raphael Wittenberg (eds), *Long-Term Care Reforms in OECD Countries* (Bristol, 2015; online edn, Policy Press Scholarship Online, 19 Jan. 2017), <a href="https://doi.org/10.1332/policypress/9781447305057.003.0007">https://doi.org/10.1332/policypress/9781447305057.003.0007</a>
- 29 Aggar, C. et Broady, T. (2017). Carer legislation, policy support initiatives and future implications. *Journal of the Australasian rehabilitation nurses association*, 20(1), 26.
  Bouget, D., Saraceno, C. and Spasova, S. (2017). Towards new work-life balance policies for those caring for dependent relatives? Social policy in the European Union: state of play 2017.
- 30 Laroque, M. (2016). La prise en charge de la dépendance en France et en Allemagne. *Vie sociale,* 15(3), 175-186.
  - Rummery, K. (2011). A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment. Ethics and Social Welfare, 5(2), 138–152. https://doi.org/10.1080/17496535.2011.571064

- 31 MSSS. (2008). If you are receiving assistance: home care services and the service employment paycheque. Online: <a href="https://publications.msss.gouv.qc.ca/msss/en/document-000865/">https://publications.msss.gouv.qc.ca/msss/en/document-000865/</a>
  Rummery, K. (2011). A Comparative Analysis of Personalisation: Balancing an Ethic of Care with User Empowerment. Ethics and Social Welfare, 5(2), 138-152. <a href="https://doi.org/10.1080/17496535.2011.571064">https://doi.org/10.1080/17496535.2011.571064</a>
- 32 Association des retraitées et retraités de l'éducation et des autres services publics du Québec. (2014). Commentaires présentés à la Commission d'examen sur la fiscalité québécoise. <a href="http://www.groupes.finances.gouv.qc.ca/examenfiscalite/fileadmin/user\_upload/memoires/areq\_csq.pdf">http://www.groupes.finances.gouv.qc.ca/examenfiscalite/fileadmin/user\_upload/memoires/areq\_csq.pdf</a>

Bélanger, É. et Tremblay, M.-E. (2017). Vers une simplification du système fiscal ? *Revue Organisations et territoires*, 26(1-2), 225-237.

Fleming, P., McGilloway, S. et Barry, S. (2016). The successes and challenges of implementing individualised funding and supports for disabled people: An Irish perspective. *Disability & Society*, 31(10), 1369–1384. Laragy, C., Sanders, F. et Brophy, L. (2015). Implications for family carers when people with psychosocial disability have individualised funding packages – literature review. <a href="https://citizen-network.org/uploads/attachment/512/individualised-funding-implications-for-family-carers.pdf">https://citizen-network.org/uploads/attachment/512/individualised-funding-implications-for-family-carers.pdf</a>

Larkin, M.et Milne, A. (2014). Carers and empowerment in the UK: A critical reflection. *Social policy and society*, 13(1), 25–38.

Ragnat, A., Parsons, J.et Radhakrishnan, R. (2018). The barriers determining the use of the carer support subsidy in the Northland region of New Zealand—A qualitative study. *Journal of geriatric care and research*, 5(1), 28–35.

- Association des retraitées et retraités de l'éducation et des autres services publics du Québec. (2014). Commentaires présentés à la Commission d'examen sur la fiscalité québécoise. <a href="http://www.groupes.finances.gouv.qc.ca/examenfiscalite/fileadmin/user\_upload/memoires/areq\_csq.pdf">http://www.groupes.finances.gouv.qc.ca/examenfiscalite/fileadmin/user\_upload/memoires/areq\_csq.pdf</a>
  - Bélanger, É., et Tremblay, M.-E. (2017). Vers une simplification du système fiscal ? *Revue Organisations et territoires*, 26(1-2), 225-237.
  - Ragnat, A., Parsons, J. et Radhakrishnan, R. (2018). The barriers determining the use of the carer support subsidy in the Northland region of New Zealand—A qualitative study. *Journal of geriatric care and research*, 5(1), 28–35.
  - Sinha, S., Dunning, J., Wong I. et Nicin, M. (2018). Why Canada needs to better care for its working caregiver. National Institute on Aging: Ryerson University. <a href="https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de40b6f82867f0a4729e1/1570628621053/working-caregivers.pdf">https://static1.squarespace.com/static/5c2fa7b03917eed9b5a436d8/t/5d9de40b6f82867f0a4729e1/1570628621053/working-caregivers.pdf</a>
- Purcal, C., Fisher, K. R. et Laragy, C. (2014). Analysing choice in Australian individual funding disability policies. *Australian journal of public administration*, 73(1), 88–102.

  Ragnat, A., Parsons, J. et Radhakrishnan, R. (2018). The barriers determining the use of the carer support
  - subsidy in the Northland region of New Zealand—A qualitative study. *Journal of geriatric care and research*, 5(1), 28–35.
- 35 Conseil du statut de la femme. (2018). Portrait les proches aidantes et les proches aidants au Québec Analyse différenciée selon les sexes.
  - Hamel, P. J., Sénécal, G. and Vachon, N. (2018). Une place après 21 ans pour les jeunes adultes polyhandicapés. Institut national de recherche scientifique: Centre urbanisation, culture et société. <a href="https://espace.inrs.ca/id/eprint/7605/1/Une-place-21ans-rapportINRS-final2.pdf">https://espace.inrs.ca/id/eprint/7605/1/Une-place-21ans-rapportINRS-final2.pdf</a>
  - United Nations Research Institute for Social Development. (2017). Care policies: Realizing their transformative potential. In *Policy Innovations for Transformative Change: Implementing the 2030 Agenda for Sustainable Development* (pp. 87-114).
- 36 Jankowski, J. (2011). Caregiver credits in France, Germany, and Sweden: Lessons for the United States. *Social security bulletin,* 71(4).
  - Simpson, M., McKeever, G. et Gray, A.-M. (2017). Social security systems based on dignity and respect. <a href="https://www.equalityhumanrights.com/sites/default/files/social\_security\_systems\_based\_on\_dignity\_and\_respect.pdf">https://www.equalityhumanrights.com/sites/default/files/social\_security\_systems\_based\_on\_dignity\_and\_respect.pdf</a>
- 37 Jankowski, J. (2011). Caregiver Credits in France, Germany, and Sweden: Lessons for the United States. Social Security Bulletin, 71(4).

- 38 Keefe, J., Glendinning, C. et Fancey, P. (2008). Financial payments for family carers: Policy approaches and debates. Dans A. Martin-Matthews et J. Philips (Eds.), Ageing at the intersection of work and home life: Blurring the boundaries (p. 185-206). Lawrence Eribaum.
- 39 Keefe, J.et Rajnovich, B. (2007). To pay or not to pay: Examining underlying principles in the debate on financial support for family caregivers. Canadian journal on aging / Revue canadianne du vieillissement, 26(S1), 77-89. <a href="https://doi.org/10.3138/cja.26.suppl\_1.077">https://doi.org/10.3138/cja.26.suppl\_1.077</a>
  Colombo, F. et al. (2011). Policies to support family carers. In Help Wanted? Providing and Paying for Long-Term Care (pp. 121-158), OECD Health Policy Studies. Paris: OECD Publishing.
- 40 Le Bihan, B. (2012). The redefinition of the familialist home care model in France: The complex formalization of care through cash payment. *Health & social care in the community*, 20(3), 238–246.