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In-home and Caregiver Support: A Necessary Philanthropic Intervention?

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Context of in-home and caregiver support policies

Regarding in-home care, social-health programs in Quebec have had a difficult time evolving, and this, despite repeated attempts to improve in-home care, be it at the moment of the first policy in 1979, the ambulatory shift at the end of the 90s, or the 2003 *Chez soi, le premier choix* (The first choice: at home) and its specifications in 2004. It is not surprising to see, year after year, that caregivers are responsible for the greater portion of support and in-home care, estimated at 80% of total hours. In a 2008 notice, the *Conseil des Aînés* estimated the value of services offered by caregivers at five billion dollars, using the minimum wage as a reference point.

The pressures exerted on both the healthcare and caregiver systems are not exclusive to Quebec. Governments of the Western world have access to statistics which allow them to grasp the scale of caregiving as well as its different forms. This information helps in the prediction of challenges: care giver-receiver ratios; ageing of caregivers; home care information and training. French surveys bring up the fact that caregivers provide more diverse care (transport, daily tasks, treatments) than the professionals of the institutional network, particularly moral support (Soullier et Weber, 2011).

A profound collective reflection concerning the restructuring of private (family) and public (State) solidarities is required. The debate cannot be limited to “double-sided accusations of disengagement”: the number of care hours, as well as the budgetary envelopes, have increased, yet the needs continue to grow and a significant portion of family members are nearing exhaustion (Bresson & Dumais, 2017). This reflection must also consider the contributions of the third sector (home and community care associations or nonprofits) and of the private sector (in-home care or retirement homes). Grantmaking foundations have also invested in the home care and caregiving sectors and their practices deserve to be highlighted. The following short text will give an account of several observations that our ongoing research is beginning to uncover.

Recomposition of private and public solidarities

In the reconfiguration of responsibilities between “family” and “State”, the redistribution of roles requires more than financing: it encompasses the representations that we have of public solidarities (involving the State and different forms of public services) and of private solidarities (the burden carried by families,

neighbours, volunteers). Furthermore, the definition of caregiving careers is in development, with research showing to what extent they harbour an invisible side as well as certain paradoxes (Benneli et Modak, 2010). Thus, at the heart of caregiving, we find an emotional weight for family members or partners regarding what is a matter of the private sector, the personal connection or of responsibility. The strong significance of the family connection explains why family member support remains inevitable, or even irreplaceable. Their intimate knowledge of those needing care, their intense connection, as well as their latent conflicts and risks of mistreatment, indicate to what extent the role played by relatives is far from being universal or homogenous. In the end, the many consequences of daily life at home - from treatments to hygiene, to nutrition, to assistive technology, to transport, to moral and psychological support, to information and access to other services - largely surpasses the traditional image of the professional care required in our universal healthcare system.

The role of the social State remains more than necessary, but its borders and capacity for finding a solution to the challenge of in-home care on its own is questioned. Several European analysts brought to light the need to rethink the traditional forms of the Welfare State and have focused on which programs to favour in both the youth and senior sectors (Esping-Andersen *et al.*, 2002; Esping Andersen, 2008; Palier, 2014). A comparative analysis of long-term care in Europe highlighted that several States relied on the role played by families while proposing options in terms of reconciling the balance between work and family, of paid time off, or respite services, and of retirement pensions (Naiditch, 2012).

Statistics on caregivers in Quebec

Who are the caregivers and who exactly are they caring for?

Statistics Canada (Turcotte 2013; Sinha 2013)¹ reports that 28% of the Canadian population provides care or help for a family member (2012 data). Among these family caregivers, 39% were mainly helping their mother or father, 8% their spouse, 5% their child, and 48% another family member or friend. Ageing is the primary cause of caregiving (28%), before cancer (12%), in terms of hours provided. It is constant family caregivers who care for a child or a spouse who have the biggest difficulty reconciling their caregiving responsibilities with a job; it is this same group who they are often depressed by their situation and more dissatisfied with governmental financial aid.

In Quebec, 35% of the population claim to be caregivers (1,7 million people), the lowest proportion in Canada (Lecours, 2015). A larger proportion of women than men claim to be caregivers (29% vs. 21%). It is in the 45-64 year old range that we find the largest proportion of caregivers: 40% of women and 30% of men of this age claim to be caregivers. In the over 65 age range, the proportions are 18% vs. 17%. The type of care and the volume of hours is different for the sexes. For example, 80% of caregivers between the ages of 45 and 64, as much women as men, claim to have provided help for transport (half doing it at least once a week). Twice as many women contribute to personal grooming (43% vs. 22%). More women help with domestic work (61% vs. 43%), give treatments (34% vs. 25%) or plan them (48% vs. 34%), but more men work on the maintenance of the house (57% vs. 38%). Half of all caregivers report needing to reduce the time spent with their spouse, but 95% declare facing their responsibilities as caregivers “very

¹ Statistics Canada defines ‘family caregivers’ as being the population over the age of 15 who, throughout the year, provide help or care to a family member with a long term health problem, an incapacity or problems linked with age.

well or generally well². While 70% of caregivers consider their relationship with the person they care for has grown stronger, 20% their responsibilities to be little or not rewarding at all.

Quebec has 1,5 million individuals over the age of 65 and it is predicted that they will make up over 20% of the population in 2026. In Montreal alone, there are 150 000 people over the age of 75 and 50 000 over the age of 85 (2016 data). Approximately 40 000 spaces in nursing homes and 10 000 in non-institutional housing resources are allocated to seniors or handicapped persons in situations of severe loss of autonomy, which take up 80% of the MSSS (Minister of Health and Social Services) budget for seniors. This means there are little public resources remaining for in-home care or help. However, one-third of seniors present moderate or serious incapacities. Let us be reminded here that nearly a fourth of the senior population volunteer, especially in early retirement.

Others, youth or adults, need in-home care and very much depend on their family members: children with multiple disabilities and adults suffering from chronic illness or certain types of cancer require, of their family members, very intense duties: as much in the number of hours as the moral and psychological support to provide. Aging handicapped adults with little autonomy will lose their parents and depend on their siblings. How can we guarantee to all of these people that they will be able to remain in their homes, if that be their choice, as public policies have been advocating for 20 years?

Quebec foundations regarding home and caregiver support

We will present several of the elements that our research (financed by UQAM and CRSH - Développement Savoir)² allowed us to reveal facts on the space occupied by grantmaking foundations as well as some of their practices. We demonstrate how their role must be better understood and documented in relation to that of the social State and to the particular needs of in-home care and of caregivers.

It has been said many times that Quebec's philanthropic network was a "system" that was not very unified and quite heterogeneous (Fontan, Elson et Lefèvre 2017; Institut Mallet 2016). There are 10 000 foundations in Canada, and 2000 in Quebec (800 of them being private foundations), varying in size (large, medium, small), and can be either public or private. They finance a diversity of organizations or conduct their own philanthropic operations. As a form of unity, they develop a discourse of legitimacy, with two significant axes being that of complementarity with the State and impact research within communities. While seeking ways to achieve this, other than traditional financial help, it is mainly concerning their own strategies that a number of foundations raise questions, as much about fundraising (for non-capitalized foundations) as about the distribution of said funds (from the perspective of grantmaking foundations).

These strategies are what interest us and deserve to be examined regarding in-home care and caregiving. The action methods can vary from one foundation to another, hence the interest in seeing if they converge or diverge significantly according to their size, area of activity, strategies and management, or the partners or donors with whom they are in contact.

In order to have an idea of the actions that are led in the home care and caregiving sectors, Canada Revenue Agency's recent data gives us only a superficial portrait. The Agency's database is quite general: the

² Research under the direction of Lucie Dumais (UQAM), with Christian Jetté (Université de Montréal), Sylvain Lefèvre (UQAM), Patricia Gazzoli (UQAM) as co-researchers, and Stéphanie René (UQAM) as research assistant.

“wellbeing” category groups together half of the existing foundations (Lefèvre et Khovrenkov, 2017). Many of the indexed foundations have broad missions in which senior aid is but one of their areas of intervention. Research must thus find other ways to explore the universe of foundations and their ways of positioning themselves in this field of social action.

A few well-known grantmaking foundations, public or private, intervene essentially in the more specific domains of senior aid or caregiving. Let us note three medium-sized foundations³. For seniors, we can mention the following private foundations: *Berthiaume du Tremblay* (founded in 1967) and *Oeuvre Léger* (founded in the same period, but whose sister organization *Secours aux Aînés* was created in 1986). Regarding the public foundation *Fédération des médecins spécialistes*, founded in 2012, they gave themselves the mission of supporting caregivers of both handicapped persons and seniors.

Some very large foundations financially support senior aid organizations. The private De Sève foundation, founded in 1976, is a long-time supporter of the *Petits Frères des Pauvres*, an organization dedicated to breaking isolation among seniors. Another important philanthropic actor, *Appui*, directs their services to caregivers of seniors with severe incapacities. It isn't a foundation per se, but a fund created in 2009 as a partnership between members of the Chagnon family and the Quebec State for a period of 10 years. This public-philanthropic partnership nevertheless represents a significant force of action and influence for caregiving as they have distributed 35 million dollars to 600 organizations across Quebec in only five years. They have supported some organizations with 1 million dollar gifts. In comparison, smaller foundations offer a few thousand dollars or dozens of thousands, rarely more. Nonetheless, whatever their size, every foundation seems to be repositioning themselves to encourage organizational development or to support activities deemed to be structuring or innovative, as they lack the capacity to significantly impact the volume of services or their perpetuation.

A few activity sectors to observe

Within our research, we examine how the practices of small and large foundations have evolved and, if they merge, why? We also want to grasp what effects they've had on recipient organizations. We were led to explore diverse fields of social activities related to in-home care and caregiving, that we will present here quickly.

Social action missions such as Meals on Wheels, home visits and maintenance help within senior communities have been led by volunteer centers for a long time. These centers received their share of philanthropic financing. Below is how the respondent of a medium-sized private foundation speaks of his role regarding such missions:

Here at the Foundation, we finance punctual projects for capital, rental improvements, equipment. This has helped start-up Meals on Wheels initiatives, Community Centers for seniors who were starting off and, throughout the years, Alzheimer organizations as well. (...) We helped finance minibuses that would transport seniors to the Center during the day. Afterwards,

³ Lefèvre and Khovrenkov make the distinction between four categories of assets from CRA's repertoire: under 25 000\$ CAD (27% of foundations); up to 1 million (46%); between 1 and 100 million (26%); over 100 million (0.5%). The smaller ones have little or no paid staff. The biggest 150 hold 44% of the assets of all the private and public foundations but together, and give approximately 1.1 billion\$ per year (2013 data).

we thought “that’s the Minister’s job”, he should take over. Foundations play the role of innovators or of substitution, then, the responsibility goes to the State.

Meals on Wheels can be considered as a niche service that was implemented in part thanks to foundations. We can hypothesize that Quebec’s State cleared themselves of the responsibility of meal help services as it is a domain requiring volunteers, without the input of professional services. Within this niche, senior volunteering is very common.

Transport and accompaniment is an important marker of caregiving. It is often in this way that people start helping a senior parent or grandparent in loss of autonomy. Public or adapted transport, especially if required for medical treatment, is provided in large cities. In the country, nonprofits and volunteer centers have taken over the responsibility of this service. However, it is important to note that the frequency of trips and the distance covered by volunteers are increasing, while the opportunities for recreation outings are limited, with priority given to medical visits.

In the past twenty years, the prevalence of Alzheimer's has started a wave of shock. Home visits, information, psychosocial help as well as respite for caregivers are becoming increasingly necessary. In our research, we have found it useful to document how foundations followed or even stimulated, the rise of Alzheimer organizations across Canada and Quebec. Coffee Shop meetups for caregivers were also developed in the *Regroupements d'aidants naturels du Québec* across the province as they allow for individuals to escape isolation and to counter certain feelings of guilt. These activities are currently supported by the Minister of Health and Social Services, but also by philanthropy. For example, when we examine the sources of financing of either Alzheimer organizations or local caregiver associations, *Appui* and *Centraide* cover between 10 and 20% of recipient organizations’ expenditures. On their end, small foundations contribute in the planning of new projects and services. The *Baluchon Alzheimer* is an example: they are supported by *Oeuvre Léger* for the development of a strategic plan and in the support of their activities. The *Baluchon*, created 20 years ago, is innovative in the field of respite and employs around 25 ‘*baluchonneuses*’ today. Their funding is divided, with 15% coming from philanthropic sources (including the *Baluchon Foundation* itself) and 85% stemming from agreements with the Minister and of the *programme de soutien aux organismes communautaires (PSOC)*. The evolution of *Baluchon* evokes a cautious relationship between their managers and large foundations as, in their eyes, the continuity of their services depends first and foremost on public financing.

Homecare companies took on the respite challenge with determination. Twenty years after the State established the financial exoneration program to financially support their development for in-home care services, many of these companies launched themselves into new in-home services. We have observed that the *Appui*’s funding contributed to many of these companies offering respite services.

In caregiver support, the choice of staying in one's home is also the choice of leaving when the time is right. However, adequate housing resources are lacking for seniors and handicapped persons. The creation of palliative care homes is another facet to be considered. Several foundations partnered with public establishments and other organizations in the field in order to open non-institutional homes. For example, foundations such as Yvon Lamarre (public) or Maxwell Cummings (private) have supported the development of homes for a long time, with the goal of helping families who took on the responsibility for the care of a child, a parent, or a spouse at home.

Conclusion

What practices do foundations develop in the in-home care and caregiving sectors? What effect do foundations have on recipient organizations in this social action domain? What relationships do they establish with the State and with families? In this perspective, one of our ongoing research projects explores two foundations in particular, in several regions of Quebec.⁴ In our opinion, understanding foundations' action methods, and if these methods converge amongst them, will allow for the documentation of the development of philanthropy in this field in Quebec and, ultimately, to analyze its structuring effect on this key domain of social action.

Interesting references to go further

Alberio, Marco (2018). Supporting carers in a remote region of Quebec, Canada : how much space for social innovation ? *Intl J of Care and Caring*, vol. 2, no. 2: 197-214.

Benneli, N. et M. Modak (2010). « Analyser un objet invisible : le travail de care », *Revue française de sociologie*, vol. 51, p39-60.

CONSEIL DES AÎNÉS (2008). *Pour un équilibre vital : des responsabilités équitables. Avis sur l'état de situation des proches aidants auprès des personnes âgées en perte d'autonomie*, Québec, Gouvernement du Québec, 15 p.

L'APPUI - Léger Recherche-Stratégie-Conseil (2107a). *Rapport d'analyse d'entrevues en profondeur menées auprès de représentants de ministères et d'acteurs au niveau national*, Québec, décembre 2017, 40 p.

L'APPUI - Léger Recherche-Stratégie-Conseil (2107b). *Rapport d'analyse d'un sondage Web mené auprès de divers acteurs au niveau régional*, Québec, décembre 2017, 60 p.

Bresson, Maryse et Lucie Dumais (2017). Les paradoxes du recours aux aidants familiaux. L'exemple des politiques de soutien à domicile dans le champ du handicap en France et au Québec, *Revue des politiques sociales et familiales*, No. 124, 1^{er} et 2^e trimestres, p. 43-52.

Ennuyer, Bernard (2007). « 1962-2007 : regards sur les politiques du maintien à domicile et sur la notion de libre choix de son mode de vie », *Gérontologie et société*, n° 123, p153-167.

Esping-Andersen, Gosta, Duncan Gallie, John Myles et Anton Hemerijck (2002). *Why We Need a New Welfare State*, Oxford University Press, 232 p.

Esping-Andersen, Gosta avec B. Palier. (2008). *Trois leçons sur l'État-providence*, France, Seuil / République des idées, 135 p.

Fontan, Jean-Marc, Peter Elson et Sylvain Lefèvre (2017). *Les fondations philanthropiques. De nouveaux acteurs politiques ?* Québec, Presses de l'Université du Québec, 351 p.

⁴ Our research will continue until the end of 2019. Our quote takes on the 2-3-15 form: study of two foundations of different sizes, through their actions in three of Quebec's regions as well as their evolution over the past fifteen years.

- Fortin, Maxim (2018). Impact du financement des fondations privées sur l'action communautaire, Note socioéconomique de l'IRIS, Montréal, mars 2018, 9 p.
- Fustier P. (2012). « Le lien d'accompagnement : un métissage entre échange par le don et échange contractualisé. », *Informations sociales*, n° 169, p91-98.
- Institut Mallet (2016). *Ecosystème philanthropique : perspectives, perceptions et échanges*. Actes du Sommet 2015 sur la culture philanthropique, Montréal. 204 p.
- Gravel, Marie-Andrée (2017). « Le bénévolat au Québec, de 2004 à 2013 », Coup d'œil sociodémographique, 52, Institut de la statistique du Québec, [En ligne].
- Hennion Antoine, Pierre Vidal-Nacquet (2015). « La contrainte est-elle compatible avec le *care* ? Le cas de l'aide et du soin à domicile », *Alter, Revue européenne de recherche sur le handicap*, v. 9, n° 3, juillet-sept., p207–221.
- Jany-Catrice, Florence et Emmanuelle Puissant (2010). « L'aide à domicile face aux services à la personne et registres d'action contradictoires : des politiques aux organisations », *Revue de l'ITRES*, n° 64, p121-47.
- Jetté, Christian, Catherine Lenzi, Lucie Dumais et Yves Vaillancourt (2016). Le rôle des milieux associatifs dans l'intervention à domicile auprès des aînés. Une mise en perspective France-Québec, *Revue TEF Travail emploi formation*, n° 14 : p23-41.
- Lefèvre, Sylvain et Iryna Khovrenkov (2017). Regards croisés sur la classification des fondations, chap. 4 dans J.M. Fontan, P. Elson, S. Lefèvre, *Les fondations philanthropiques. De nouveaux acteurs politiques ?* Québec, Presses de l'Université du Québec, p88-119.
- Lefèvre, Sylvain et Annabelle Berthiaume (2017). Les partenariats entre secteur public et fondations philanthropiques au Québec : genèse, contestation et épilogue d'une réforme de l'action publique, *Revue française d'administration publique*, no 173, p483-506.
- Lecours, Chantale (2015). « Portrait des proches aidants et les conséquences de leurs responsabilités d'aidant », Coup d'œil sociodémographique, 43, Institut de la statistique du Québec. [En ligne]
- Loirdighi, N., A. N'Dengeyingoma, E. Lebeau, G. Couture (2018). CIUSSS MCQ. *Le profil de santé physique des personnes âgées présentant une déficience intellectuelle (PADI)*. Trois-Rivières (Canada), Collections de l'Institut universitaire en déficience intellectuelle et en trouble du spectre de l'autisme, 48 p.
- Naiditch Michael (2012). « Protecting an Endangered Resource ? Lessons from a European Cross-Country Comparison of Support Policies for Informal Carers of Elderly Dependent Persons », *IRDES - Questions d'économie de la Santé*, n° 176, may, 8 p.
- Palier, Bruno (2014). *La stratégie d'investissement social*, Étude du Conseil économique, social et environnemental, Journal officiel de la République française, HAL Archives-ouvertes.fr, 19-40. HAL Id: hal-01064753 <<https://hal-sciencespo.archives-ouvertes.fr/hal-01064753>>
- Pennec, Simone (2006). « L'attachement au domicile entre désir et contraintes », *Les Cahiers de l'Actif*, n° 364/365 (sept-oct), p11-32

Protecteur du citoyen du Québec. (2014). « La réponse aux besoins de soutien à domicile et d'hébergement fournie aux aînés en perte d'autonomie et aux personnes handicapées : problématique, enjeux et défis », 13^e Congrès annuel du Conseil pour la protection des malades, Laval, 2 juin.

Reguer, Daniel et Michèle Charpentier (2008). «Regard critique sur les politiques de maintien à domicile des personnes âgées en France et au Québec», *Revue canadienne de politique sociale*, n° 60-61, p39-51.

Sinha, Maire (2013). « Portrait des aidants familiaux, 2012 », Statistique Canada, no89-652-X au catalogue, sept. 2013. [En ligne]

Soullier Noémie (2012). « Aider un proche âgée à domicile : la charge ressentie », *Études et résultats*, Direction de la recherche, des études, de l'évaluation et des statistiques (DREES), France, n° 799, mars, 8 p.

Soullier Noémie, avec la participation d'A. Weber (2011). « L'implication de l'entourage et des professionnels auprès des personnes âgées à domicile », *Études et résultats*, DREES, n° 771, août, 8 p.

Tables de concertation des aînés de l'Île de Montréal (TCAIM). (ca 2017) Portrait des besoins des citoyens aînés de l'île de Montréal, 58 p.

Théry, Irène (2011). « Transformations de la famille et 'solidarités familiales' : questions sur un concept », in Paugam S. (dir.), *Repenser la solidarité*, Paris, Quadrige /PUF, p149-168.

Turcotte, Martin (2013). « Être aidant familial : quelles sont les conséquences? », Statistique Canada, no75-006-X au catalogue, septembre 2013. [En ligne]

Vaillancourt, Yves, François Aubry et Christian Jetté (2003). « La politique de soutien à domicile au Québec, un perpétuel recommencement », in *L'économie sociale dans les services à domicile*, Sainte-Foy, Presses de l'Université du Québec, 47-112.

Vidal-Nacquet, Pierre (2014). « Le travail de care : tact, ruse et fiction » in Brodiez A., von Bueltingsloewen I., Eyraud B., et al. (dir.) *Vulnérabilités sociales et sanitaires. Approches sociologiques et historiques*, Presses Universitaires de Rennes, p137-152.

Weber, Amandine (2015). « Des enquêtes nationales pour connaître l'aide apportée par les proches en raison d'un handicap ou d'un problème de santé », *Informations sociales*, v. 2, n° 188, p42-52.

Weber, Florence (2010). « Les aidants familiaux : une réalité contrastée », in Halpern C. (dir.), *La Santé, un enjeu de société*, Éditions Sciences humaines, p140-147.