

2018



*Empower and support
caregivers, these
essential allies for a
fair province of
Quebec.*

To contact us:

Mélanie Perroux, general coordinator

coordination@ranq.qc.ca

514 524-1959

www.ranq.qc.ca

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This document was produced by the social and political action committee of the RANQ. Those who participated in producing the document are:

- **Johanne Audet**, Regroupement des proches aidants de Bellechasse.
- **France Boisclair**, Association Lavalloise des Personnes Aidantes.
- **Linda Bouchard**, Association des proches aidants Arthabaska Érable.
- **Luc Chulak**, Groupe des aidants du Sud-Ouest (Montréal).
- **Guillaume Côté Philibert**, Centre d'aide aux proches aidants des Basques.
- **Marie-Claude Guay**, Regroupement des personnes aidantes de Lotbinière.
- **Véronique Mergeay**, Association des personnes proches aidantes de Bécancour-Nicolet-Yamaska.
- **Sonia Nadeau**, Société Alzheimer Chaudière-Appalaches.
- **Carole Sirois**, Association Aidants Naturels de la Côte-Nord.
- **Mélanie Perroux**, Regroupement des Aidants Naturels du Québec.

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Highlights

Created in 2000, the *Regroupement des Aidants Naturels du Québec* (RANQ) has 75 members and represents more than 20,000 caregivers throughout Québec. The RANQ has acquired an expertise by working with caregivers and has developed an inclusive national strategy to support caregivers.

According to our short definition, caregivers are people who voluntarily provide care and assistance, without being paid, to one of more family members, friends, neighbours or others who have a temporary or permanent disability (accident, impairment, illness, aging, etc.) and with whom they have an emotional connection (father, mother, spouse, child, brother, sister, neighbor, friend, etc.). This national strategy also provides a more thorough definition that explains the nature of this extra role and its challenges.

The most detailed statistics indicate that one quarter of the province of Québec's population are caregivers. More than a third of these caregivers spend more than five hours per week providing care for over four years. Fifty-seven percent of them combine this occupation with paid employment. The Québec government would have to spend between four and 10 billion dollars per year to replace the millions of hours allotted by caregivers, as caregivers provide essential services which complement those provided by the health and social services system. Since caregivers must reduce their paid work hours, assessments suggest that the cost for the government in lost annual revenues and last-resort social benefit payments would be in the millions of dollars. In short, the current status quo is detrimental to all.

For many years, community organizations have noticed several systemic factors that contribute to the exhaustion of caregivers and that are linked to the invisibility of caregivers' daily activities: a lack of funds and services, difficulties in obtaining homecare services, the fragmentation of care services, frequent changes in healthcare professionals, etc. Although being a caregiver can be morally rewarding, **the level of exhaustion of caregivers suggests there is urgency to act to prevent psychological distress.**

Therefore, the RANQ is **requesting the creation of an interdepartmental committee which would involve the various actors and community organizations** tied to caregivers to establish the operational and financial parameters of a national support strategy for caregivers. This commission must be based on **an inclusive vision of caregivers**, which means that it should take into consideration all situations and conditions of persons being cared for. It should also be based on the following five approaches:

1. **The free, informed and revocable choice** based on the right to be able to change one's commitment as a caregiver over time, the right to quality information, and the right to receive appropriate, customized support and respite services.
2. **The recognition of the expertise of caregivers**, who often provide and coordinate care and services for the person being helped. This recognition will enhance trust between caregivers and professionals, empower caregivers and make care services more adapted.
3. **An annual, comprehensive assessment of the needs of caregivers**. Stressing the distinction between the caregiver and the person being helped is crucial as it enables an assessment of the different, but interrelated needs of each. Processes for early identification of caregivers as well as continuous and regular evaluation, based on human approaches, would prevent the deterioration of caregivers' conditions and health during major changes in their lives (e.g., job loss, birth of a child, illness) or in the life of the person they help (e.g., deterioration of health condition, death, residential changes). In our national strategy, we describe the basic services needed by the people being helped to reduce the responsibilities of caregivers (care continuity, additional residential facilities for people with disabilities, improvement of home care services, etc.), but also the services needed by caregivers to be supported in this extra role (psychosocial services, better care experience regarding elements such as appointment scheduling, transportation or parking, information and awareness-building, safety technologies, access to complementary services, etc.)
4. **The fight against the impoverishment of caregivers**, which is due to increased direct costs (housing adjustments, travel expenses, etc.) and reduced employment income. We recommend the introduction of allowances for caregivers, improved tax measures and subsidies, as well as improved and more flexible labor standards and higher education regulations in order to allow a better family-caregiving-work-study reconciliation.
5. **Expertise development**, through research on the psychosocial and economic dimensions of caregivers' lives, but also through better synergy between community organizations and the academic world. To do so, it is essential to recognize that community organizations, such as the RANQ, are key players. Therefore, they should be supported financially for their mission, and be involved in prior consultation processes as well as in the implementation of measures developed for all caregivers.

A national strategy is a strong political signal that would position the province of Quebec among the leaders, by providing a legal status to citizens voluntarily playing a caregiving role while upholding their right not to take on the full responsibility to provide all care and services that the person being helped requires.

Background

Currently, more than a quarter of Quebec's population over the age of 15 plays a caregiving role for one or more members of their social or family circle (Gouvernement du Canada, 2013). This proportion keeps increasing (Fast, 2015). More than a third of caregivers (35%) spend more than five hours per week providing care and support, and 10% of them provide more than 20 hours. The public health and social services system faces significant challenges (demographic changes, reduction in the tax base, etc.) and caregivers provide, without being paid, essential care and services that health and social services professionals should otherwise offer.

A study conducted by the Centre de recherche et de partage des savoirs InterActions (Kempeneers, Battaglini, & Van Pevenage, 2015) demonstrates that the Quebec government would have to spend between \$ 4 and \$ 10 billion a year to replace the millions of hours allotted by caregivers to support people in need. In Canada, 1.2 million full-time

Quebec's population would benefit from a national strategy to support people who voluntarily take on a caregiving role.

professionals should be hired to provide care and services currently offered by caregivers (Fast, 2015).

However, there is no reliable assessment of the economic, individual and social loss occasioned by caregivers' burnout. For example, assessments suggest that the cost to the government in lost income tax revenues and additional social benefit payments is of \$ 641 million (Fast, 2015), but these calculations neither include caregivers that devote limited numbers of hours to care and services nor take into account the cost of services generated by the burnout of caregivers (Fast, 2015). That is why Quebec's population would benefit from a national strategy to support people who voluntarily take on a caregiving role.

This national strategy should be consistent and inclusive. By inclusive, we mean that it should take into account all caregivers and their specific needs, regardless of the age of the person being helped (senior, adult, child), his or her condition (temporary or permanent disability, illness, aging, etc.) and his or her residential situation (home, residential institution, etc.). By consistent, we refer to the necessity of harmonizing various existing measures, not only between the federal and provincial levels, but also between provincial Ministries, such as the Ministry of Health and Social Services, the Ministry of Family and Seniors, the Ministry of Labor, and the Ministry of Finance/Revenu Québec. The aim is to reduce the fragmentation of funds and services. In fact, support measures for caregivers currently fall under different Ministries'

authority, which means that existing programs are complex, changing and unequal (Fast, 2015).

According to us, a national strategy is a strong political signal that would provide formal recognition to citizens voluntarily playing an extra caregiving role while upholding their right not to take on the full responsibility to provide all care and services that the person being helped requires. The various measures proposed in this national strategy to support the role of caregivers would place the province of Quebec among the leading nations that are working towards a fairer and more equitable society. This strategy is based on the recommendations that a Canadian research team submitted to the UK Parliament (Fast, 2015) and presents a comprehensive policy framework divided into several crucial and inseparable parts: 1) caregivers' recognition and rights; 2) health care and services for caregivers and the people they help; 3) work-caregiving role balance, and 4) financial security.

For the RANQ, formalizing an inclusive definition of caregivers is a prerequisite for any supportive policy, to make sure that all situations experienced by caregivers are considered, without discrimination, and regardless of the state of the person being helped. Such a definition would thus bring dual recognition: the society's recognition towards caregivers, and caregivers' own recognition of the indispensable role they play to support the person in need.

An inclusive definition of caregivers¹

Caregivers²

Caregivers voluntarily provide care and assistance, without being paid, to one or more family member, friend, neighbour or other who has a temporary or permanent disability (accident, impairment, illness, aging, etc.) and with whom they have an emotional connection (father, mother, spouse, child, brother, sister, neighbor, friend, etc.). On this basis, caregivers:

- Provide emotional support, care, or try to meet the needs of the person being helped, which vary according to each specific situation (e.g. errands, transportation, appointments with specialists, meals, housework, etc.). They do so in addition to the services provided by the public health and social services system.
- Support the person receiving help on an occasional or continuous basis, in the short or long term, according to the changes in the situation of the person being helped.
- Fulfill their caregiving role in their own home, at the home of the person being helped or in residential institutions (specialized care facilities, residential and long-term care centres (CHSLD), intermediate resources, etc.).
- Offer their support voluntarily, according to their own life situation and abilities, and can decide to decrease or end their involvement with the person being helped at any time.

Parents of children with disabilities, regardless of the children's age, and relatives or friends of an adult who is not an elder are also caregivers. It is therefore an additional role to that of being a parent, a spouse, a worker, etc.

Caregiving is an extra role that redefines the emotional relationship with the person being helped. However, a person's identity and role as a caregiver should not be confused, which is why caregivers should be able to access respite

services in order to have time for themselves, for their hobbies and for the maintenance of their other social and familial relationships.

In 2012, 64% of caregivers reported that they had decreased their social and relaxation activities; almost half of them reduced the time spent with their own spouse, and 34.5%

¹ This definition complements that of the Quebec Ministry of Health and Social Services in its home care policy "Chez soi : le premier choix." The policy defines caregivers as anyone in the social circle of the person needing assistance who provides significant support, continuously or occasionally, and not as a professional occupation, to a person with a disability. Caregivers can be family members or friends.

² In this document, we mostly use "caregivers" in its plural form because many of those needing assistance are supported by several caregivers, one of whom takes on a leading role.

of them changed, canceled or stopped taking their holidays (Institut de la Statistique du Québec, 2014). In order to fully take on their caregiving role without jeopardizing their physical and mental well-being, caregivers themselves have the right to receive support according to their own needs (Nuffield Council on Bioethics, 2009).

Comprehensive data on caregivers is scarce. First, most studies focus exclusively on caregivers providing help to senior citizens. Second, many caregivers do not identify themselves as such and are consequently not included in studies. They feel that what they do is “normal.” Surveys carried out in Europe in 2010 – 2011 (mainly in Belgium (Thibaut & Vogels, 2011)) that focus on caregivers’ opinions argue that it is usually only after several years of performing caregiving tasks that a caregiver starts considering himself as such and not merely as a parent fulfilling his or her duty as a mother, a father or a child taking care of his or her parents.

Most caregivers (57%) are employed and struggle to find ways, each day, to reconcile their work, family, caregiving engagements and personal lives. However, these figures are underestimated since this survey only considered caregivers providing help to senior citizens, even though in 2012 a fifth of the care recipients were under 55 years of age (Institut de la Statistique du Québec, 2015a). Thus, these statistics do not take into account all these other caregivers who identify themselves even less as such.

Caregivers, who are often experts in understanding the needs and condition of the person they help, perform essential tasks. They are primary actors of the support and care the person in need receives. With the increased life expectancy of care recipients – whether seniors or persons living with a disability – available services become more and more inadequate. In addition, caregivers are also aging due to the growing period through which they have to provide support. As a result, they are more at risk of experiencing burnout. They are not always aware of the (limited) resources available. They are often left alone, while trying to maintain a personal and family life balance.

A person with an intellectual disability (ID) lives at home with her parents. When she reaches 55, her parents, themselves aging, are no longer able to support her regularly because of her deteriorating health condition. Consequently, she must be transferred to a residential and long-term care centre (CHSLD) not specialized in DI, which can lead to a loss of the abilities she gained.

Caregivers: cornerstones of the health care and services system

The help provided by caregivers fulfills essential physical, psychological and emotional needs. For example, in 2013, the Health and Social Services Minister acknowledged that caregivers provided 85% of the total help for senior citizens. More generally, more than 414,400 caregivers provide personal care and/or participate in medical treatments and/or organize care services (Institut de la Statistique du Québec, 2015b). Engaged and

generous, many caregivers keep supporting the people being helped even after their transition from home to a residential care centre or a specialized resource.

Caregivers are too often considered as complementary support and care providers rather than as actual people who also have needs.

Currently, there are few services specifically available to caregivers in the province of Quebec. In general, home-based services primarily address the needs of people with physical or cognitive problems. While relying on caregivers' commitment, the health and social services system largely neglects their needs. Caregivers are too often considered as complementary support and care providers rather than as actual people who also have needs. This perspective minimizes their role and prevents us from grasping the scope of their work as well as the precarious social and financial conditions in which they perform these caregiving tasks that are essential to collective life (RANQ, 2017b).

The programs and services currently available to caregivers are categorized according to the care recipient's age or specific condition. This fragmentation of services directly influences access to services and can potentially increase a caregiver's burden and exclusion (Quesnel-Vallée & Taylor, 2017). For instance, current policies often mention caregivers for elders. This terminology excludes some caregivers who might be senior citizens themselves. For example, a senior caregiver may take care of his or her adult child who lives with a disability. In addition, 25.7% of caregivers actually take care of two people and 10.5% of them provide support to three or more people (Institut de la Statistique du Québec, 2015b). These care recipients do not necessarily share a single situation or condition: for example, a woman who cares for her child who has a disability could also take care of her own mother who has Alzheimer's disease. Failing to acknowledge the challenges that all caregivers face, and providing scattered services based on constraining criteria might curb possibilities of collaboration and of improving caregivers' quality of life.

The challenge of home support services

Most people requiring assistance prefer staying at home as long as they can. This is consistent with best practices and the “Chez soi: le premier choix” policy (Ministère de la Santé et des Services Sociaux, 2003). Generally, caregivers also want to take care of their loved ones at home, whether in their own home or in the home of the person they help. However, this preference does not reduce the need to implement support measures for these caregivers and to provide home-based services, for both the loved ones and the caregivers. Currently, home support services clearly do not satisfy the essential quantity and quality ³ requirements for adequate services. For caregivers, this situation has a twofold effect: first, they do not receive the ongoing services needed for the maintenance of their loved ones at home, and must consequently provide them, at the expense of their professional and family life, and, sometimes, of their own health. Second, when the care recipient starts needing temporary or permanent accommodation, waiting times due to poor accessibility and a lack of continuity between services again place caregivers in a difficult situation. The objective is not to blame healthcare professionals who already accomplish tremendous work within a complicated organizational system. Instead, we must admit that increasing funds for home support services and improving integration and organization between structures and professionals is a pressing need to be able to support all caregivers in their role, regardless of the age and situation of the person being helped.

The service-employment paycheque system is unevenly used in Quebec. This measure is not well known, even among some healthcare workers, and it is relatively unstructured, which gives rise to differential interpretations of its eligibility criteria and implementation rules. The measure gets implemented in different ways due to these ambiguities. For

A few problematic examples :

- People whose condition has become stable but who are sent home by the emergency services because spaces are not available in residential and long-term care centres (CHSLDs). This poor access, coupled with limited home care service provision and lack of coordination, leads to the “revolving door” syndrome, with readmissions increasing.
- A caregiver who wishes to take care of the person needing assistance in her own home, located in a different administrative region than that of the person being helped. If the home is in the location of a different integrated university health and social services centre (CIUSSS), all assessments have to be done again and the services received might differ from those received before, depending on local resources.
- A person needs support for taking a bath at home, but a new helper comes in each week. Consequently, all procedures must be reexplained and a trusting relationship, essential to such intimate acts, must be rebuilt. Tired, the person being helped refuses this external care and the responsibility to perform this act falls on the caregiver, who does not necessarily feel equipped or comfortable to do so.

³ By quality, we mean the technical quality of the services provided, but also their relevance, their continuity to avoid fragmentation, and their inclusion of all needs.

instance, there are a lot of administrative tasks associated with receiving the paycheque, which makes it less interesting for some senior citizens. Moreover, in cases where the person being helped is not able to manage the service-employment paycheque alone, the employee-employer relationship that is created between the caregiver and healthcare workers – with their multifarious professional training – can place caregivers and those they help in vulnerable situations (poor quality care practices, extortion, lack of continuity, etc.). Caregivers then turn to community-based organizations or Domestic Help Social Economy Businesses (EESAD) that have service agreements with integrated health and social services centres and integrated university health and social services centres (CISSS-CIUSSS) to avail themselves of the service-employment paycheque program. However, EESADs, like community-based organizations, have limited resources and frequent staff turnover. They have few resources to train their employees and do not have much leverage to ensure the provision of quality services. The paycheque program, which has existed since the early 2000s, should thus be reexamined and better explained.

Given its expertise, acquired by working with all types of caregivers over the years, the Regroupement des aidants naturels du Québec (RANQ) asks for the creation of an interdepartmental committee involving the various community organizations and actors related to caregivers, including the RANQ, in order to establish the operational and financial parameters of a national support strategy for caregivers. This committee should base its work on the five guiding principles described below and on the recommendations that go along with them:

1. The free, informed and revocable choice to be a caregiver
2. The recognition of the expertise of caregivers
3. The comprehensive, systematic, ongoing and discrete assessment of the needs of caregivers to provide appropriate and ongoing services
4. The fight against caregivers' impoverishment
5. The knowledge development of organizations for caregivers and support of their expertise and leadership

The five principles of a national strategy to support caregivers

Principle 1: A free, informed and revocable choice

This principle put forward in the Government of Quebec's home support policy "Chez soi: le premier choix" must apply to all caregivers, regardless of the condition of the person being helped. The policy specifies that a caregiver's commitment is voluntary, and results from a free and informed choice. It also states that all caregivers must have the possibility to re-evaluate the nature and extent of their commitment at any time (Government of Quebec, 2003: 6).

In 2012, more than 679,000 people, which represents 61% of the caregivers helping elder people in Quebec, stated that they had no choice but to take on this responsibility.

access to home support services and public housing services due to underfunding, which compel many people to take on caregiving responsibilities in the absence of better solutions? Over the course of several months and years, caregivers' responsibilities can change, accumulate, and become heavier and more complex. For example, in France, caregiving responsibilities last for an average of 4.1 years and exceed five years for 26% of caregivers (IFOP & MACIF, 2008). Considering the experiences of our organizations, we can assume that these statistics also apply to the Quebec context. In addition, this time frame tends to increase as a result of an aging population.

Often, caregivers bear the weight of social judgement if they decide to no longer fulfill their caregiving role or reduce their involvement, no

Currently, many systemic obstacles limit the application of this principle, since having a choice is only possible if different options are available. Indeed, how can we speak of real choices if we take into account the problems of

Some problematic examples illustrating the lack of choice:

- A caregiver who is forced to lift her spouse up by herself because there are no home care services available on weekends or in remote areas, or because the orderly has canceled the service without being replaced.
- Since there are not enough accommodation resources, parents of children with disabilities are being told that they will be assisted in their caregiving role. However, occasional and intermittent services, provided by a different healthcare worker during each episode of care leads wealthier families to resort more to private services.
- Having to keep a spouse needing assistance at home while waiting for an available space in a palliative or end-of-life care institution.
- Parents of children with Autism Spectrum Disorder (ASD) who need to keep their child at home on days when school support services are not available.

matter their reasons (burnout, illness, work overload, worsening of disabilities, etc.). This can increase caregivers' own feelings of guilt.

Currently, several factors pressure caregivers to consider their situation as “normal,” and caregiving is too often described as a “natural” task. Indeed, the insistence on prioritizing home care, even though it can sometimes put caregivers and the people they help at risk, justifies a lack of investment in home care services and proximate residential services. In addition, the exclusion of caregivers' output in planning the health system's organization, as well as in the specific intervention plan of the person being helped, results in taking caregiving roles for granted. For caregivers, refusing to perform certain caregiving tasks for their loved ones, acknowledging their personal limits and/or exhaustion level, or agreeing to the institutionalization of the person they are helping are delicate steps. Yet, on the one hand their decision is seldom followed, and, on the other hand, caregivers are too often left on their own if the person being helped refuses out-of-home care services. In summary, 40% of caregivers did not feel they had the choice to take on their caregiving role, regardless of the reason (Institut de la Statistique du Québec, 2014).

Home care services also do not cover all of the needs of caregivers and the people they help, whether it is for those waiting for a place in a residential facility or for those who have the option of staying home. Respite services are limited; they are not always affordable, offered in a nearby location, or by a stable staff. This complicates caregivers' choices and often prevents them from drawing their own limits or modifying their caregiving commitment. Overall, between 27.1% and 45% of caregivers – this rate varies according to the type of help (transport, home maintenance, personal care, banking, etc.) – believe that the person needing assistance can only turn to them for help (Institut de la Statistique du Québec, 2015c).

The notion of choice must include the possibility for caregivers to modify their decision according to changes in their situation or that of the person receiving help. For this to happen, it is crucial to assess the needs of caregivers on an ongoing basis. We cannot ask them to bear this weight alone, the entire community should share caregiving responsibilities, so that those who have loved ones needing assistance can make a free, informed and revocable choice to provide help. The prerequisite for this choice is external support.

Recommendations

- To be able to play their full- or part-time caregiving role without putting their own health at risk, **caregivers are entitled to respite/replacement services⁴** that can, for example, help them perform caregiving tasks only 6 days a week, or take a holiday, if they wish. More flexible, universal and stable respite services that are adapted to the real needs of caregivers must be implemented. By universal, we mean services that are accessible to all, regardless of one's income or of where the person receiving help lives.
- For caregivers to maintain their caregiving capacity, **the services they receive from healthcare professionals should be adapted to the needs of the person receiving care as well as to their own needs.** This health service package must be optimized, broadened (home care, institutional access, etc.) and delivered in a timely manner: caregivers should not have to bear the full responsibility for care. Caregivers should be able to choose what kind of caregiving tasks they are comfortable fulfilling. When asking for a caregiver's cooperation, it is important for health professionals to consider the caregiver's investment capacity and physical and psychological state, instead of only taking into account the preference of the person needing help with regard to receiving services from people outside of his or her social and familial circle.
- To exercise their freedom of choice, **caregivers must be able to put an end to their commitment at any time.** To do so, caregivers must be informed, right from the beginning of their engagement, of their right to quit their caregiving role at any time and without justification if they deem it necessary to maintain their own physical and psychological health.
- To exercise their free and informed choice, **caregivers must have access to accurate and complete information at the outset of and throughout the whole caregiving period.** For example, they should be informed about existing financial measures, available support services, and the working conditions to which they are entitled. All

⁴ Respite services are provided to caregivers so that they can take some relaxation and renewal time (holidays, weekends, social activities, etc.) to mitigate the additional stress caused by the continuous presence of a person with special needs. Respite services also include replacement services. The latter correspond to services provided to fulfill the caregiver's tasks when the caregiver is absent or unavailable (sickness, holidays, etc.). Replacement services are provided with the help of one or more external person, and whether or not the caregiver lives with the person receiving care. These services must address caregivers' needs as much as those of the person being helped.

information, which is often provided by community organizations, must be standardized and accessible. It must enable caregivers to assess the social, familial, professional, economic and psychological repercussions of their commitment, throughout the entirety of the caregiving period.

Principle 2: Caregivers must be recognized as experts of their own situation

Caregivers must be considered experts of their own situation since they take part in the everyday life of the person needing assistance. They witness the changes in their situation and/or in the person's disability and its effects. Moreover, they often act as coordinators of care since they have information on test results, medication lists and the stages of the intervention plan (Bunn et al., 2017). Caregivers are also particularly knowledgeable regarding all relationship dynamics with the person being helped, which are, incidentally, a very important dimension of home care. Caregivers know well the challenges faced by the person needing assistance and develop technical skills as part of their caregiving role.

By placing expert caregivers at the core of interventions and asking for their views on the organization of services, the efficiency of the health system, and especially of home care, would be greatly improved.

Therefore, a national policy to support caregivers should consider caregivers as true partners, be it for the establishment of intervention plans for the person being helped, or for the organization of care. Various experiences in Quebec (Direction du

programme de soutien à l'autonomie des personnes âgées, 2017) have demonstrated the effectiveness of this approach, which is also developed with families of people with mental disorders. Moreover, during the two forums on best practices organized by the Minister of Health (Ministère de la Santé et des Services Sociaux, 2016, 2017), the importance of considering the caregiver as a true partner, a statement already part of the "Chez soi : le premier choix" policy, was reiterated. Now, the important step is to make sure that this recognition gets implemented, for all caregivers, regardless of the condition and age of the person being helped.

We are convinced that by placing expert caregivers at the core of interventions and asking for their views on the organization of services, the efficiency of the health system, and especially of home care, would be greatly improved. Moreover, being recognized as care partners would help caregivers legitimize their own needs and not feel as if they were solely responsible for the person needing assistance (Nuffield Council on Bioethics, 2009).

Recommendations

- **A relationship of trust must be created so that caregivers and healthcare professionals may work as equals.** Real, mutual trust will encourage information sharing and highlight the expertise of caregivers. However, professionals should have the time and resources needed to create this trusting relationship and to acknowledge the specific expertise of caregivers. Training programs have to be developed. If professionals and caregivers form a strong team, the person needing assistance will greatly benefit from it. Overall, the services provided will be much better adapted to the actual needs of the person. The person's health condition will be more carefully monitored, which will enable quicker responses in cases of significant changes (e.g. when a new medication is prescribed, the caregiver is often best placed to notice any side effects and warn professionals). If they feel valued, caregivers will be more comfortable sharing their opinion. In addition, the helper/helped dyad will be strengthened if their care experience is based on close and warm relationships with professionals. Ultimately, caregivers will feel listened to and valued.
- **To take into account their expertise, caregivers must be involved in developing, following and evaluating the care and support plans implemented by health and social services professionals.** To the extent of their availability, expert caregivers play a real decision-making role regarding the definition and planning of services received, in accordance with the empowerment principle enshrined in the Ottawa Charter for Health Promotion. If caregivers feel they are being trusted, they will be more involved and more aware of their role. This will help reduce the helplessness that caregivers often experience, which leads to stress and burnout.
- **Prioritizing caregivers' analysis of the situation in cases of disagreements with the person being helped.** When the person being helped has all of his or her cognitive abilities, the helper/helped dyad must participate in decisions related to the provision of care. However, when the person receiving assistance refuses external care, the analysis, skills, needs and wishes of the expert caregiver should be prioritized. Sometimes, individuals who are being helped are focused on their own needs (which is normal) and refuse care provided by professionals who are not part of their immediate circle because they do not notice the limitations of the caregiver they are familiar with and assume that he or she is all-powerful. On the other hand, caregivers feel guilty considering about their own needs while those of the person they help are so great. Too often, the provision of external services is prevented due

to the refusal of the person needing assistance to receive help from outside. Professionals must support the helper/helped dyad in finding a solution that allows services to be delivered while respecting the caregivers' limits (time, abilities, willingness, proximity, etc.). To this end, community organizations that specialize in assisting the helper/helped dyad in care acceptance processes should be involved as communication facilitators.

This prioritization principle applies to the residential choices of the person needing assistance as well. In fact, the caregiving role does not end when the person needing assistance leaves home, but often continues in residential or long-term care centres. It is often professionals who suggest the residential option, without real consultation with caregivers. Their decision is based on organizational constraints or on access restrictions to different types of accommodation, especially in cases of public resources such as residential centres and foster care, or in the case of remote locations. Accommodation options should be increased, regardless of the condition or the age of the person being helped. Currently, some people might find themselves in remote or ill-adapted locations, forcing caregivers to compensate for missing services. Long distance travels can also weigh on the shoulders of the people close to the person needing help. Better communication with caregivers could help find the place that best fits the needs of the person being helped. The decision should also take into account the situation of caregivers and their willingness to assume the responsibilities related to the new accommodation choice.

- **Train and mentor health professionals to acknowledge caregivers' expertise.** Health professionals' viewpoints and practices are not easily changeable. Education and awareness-raising are needed for a shift to occur. We must convince health professionals of the benefits of considering caregivers as experts. Like the patient-as-partner approach developed in recent years, these trainings on how to work with and support caregivers should be available as continuing education options and should become a mandatory part of the initial curriculum followed by health and social services professionals.

Principle 3: The comprehensive, systematic, ongoing and discrete assessment of the needs of caregivers to provide appropriate and ongoing services

First of all, it is important to acknowledge that caregivers and the people being helped are separate individuals who are thus distinct health and social services system users. The goal of making this distinction is to recognize a caregiver's right to receive services in order to fully assume their role and prevent possible psychological distress.

To obtain these services, trained healthcare workers or the health professional in charge of the initial diagnosis of the person receiving care should be able to open a file for caregivers and link it to that of the person being helped. Opening a caregiver file facilitates identification processes and systematically leads to a complete assessment of the situation, needs and wishes of caregivers (Direction du programme de soutien à l'autonomie des personnes âgées, 2017). During this initial assessment, information on support and other services available to caregivers must be provided, along with the contact information of relevant community organizations. In fact, several studies show that early, proactive support improves the ability of the family member, friend or neighbour to adapt to his or her new caregiving role (Carpentier, Bernard, Grenier, & Guberman, 2010; Direction du programme de soutien à l'autonomie des personnes âgées, 2017; Pozet et al., 2016). Overall, a human approach to evaluation should be preferred to the standardized views of assessment scales and complex surveys. Evaluation is the first step towards establishing the trusting relationship needed between professionals, caregivers and the person being helped. Because of this listening space, needs can be expressed and there is less risk to misread them.

Caregivers are a changing clientele because the health conditions of the people they help as well as their personal involvement capacities fluctuate. Their needs should be assessed annually or whenever there is a major change in their lives or that of the person they help (relocation, birth of a child, departure of a caregiver, change in the work situation, etc.) (MacCourt et al., 2013; Pozet et al., 2016). Too often, caregivers' needs assessments are not done proactively. Therefore, when assessments are made, caregivers are already exhausted, impoverished, and short on resources. As a result, they have immediate assistance requirements while wait times before a first assessment meeting can exceed 3 months.

Several fundamental principles must be kept in mind regarding service provision (RANQ, 2017b):

1. The universality principle enshrined in the Canada Health Act. This means that all caregivers must have access to public, adequately funded, and uniformly available services across the province, regardless of their income, their level of involvement with the person receiving help, or the place of residence of the latter (at home or in a residential institution).
2. Service continuity and integration between institutional and community organizations, according to the expertise of each. This enables immediate and fluid referencing, whether the needs assessment was done by a community organization or a health and social services system professional. The aim here is to develop communication tools to transmit information about the caregiver, with his or her consent, between the various organizations or multidisciplinary teams delivering services (health and social services system, community organizations, referencing phone line, etc.).
3. User-centered care and services which include the person being helped as well as caregivers. The health system functions via programs whose inclusion criteria neither represent the life situation of caregivers nor that of the person being helped (Direction du programme de soutien à l'autonomie des personnes âgées, 2017). Caregivers thus have to negotiate with their employers to obtain holidays, seek the help of their family or friend circle to perform certain care tasks in the evenings or weekends, or move constantly from one institution to another to obtain the care and services required.
4. Support for caregivers should be planned according to the situation of the person needing assistance but also according to caregivers' capacities and willingness to be involved (a choice that can always be changed). This means that health care professionals and community organizations will have to pay specific attention to transition periods (residential location change, transition to adulthood, or any other transformations in the lives of the caregiver and the person they help), in order to best support caregivers in their adaptation.

The work that caregivers accomplish is unfortunately invisible. One of the reasons for this is that a very small proportion of caregivers identify themselves as such. Consequently, caregivers rarely ask for support. Caregivers' experiences must be brought to light to help many other people identify themselves as caregivers and to help raise the awareness of those around them (family, friends but also employer) regarding their situation.

Recommendations

- **Review and standardize regional and provincial assistance programs for caregivers** (benefits, service-employment paycheques, respite services) to be consistent and equitable. Develop an inclusive identification and reference system for all caregivers, regardless of the situation of the person being helped.
- **Develop and standardize the access to quality replacement services, adjusted to the needs of the person being helped and of the caregiver, and available in all regions.** Access to replacement services can be temporary or regular, planned or urgently required within 24 hours since they can compensate for the absence of a caregiver due to illness. Respite can be offered at home or in residential facilities, since caregivers can also provide services that are essential to the quality of life of the person being helped in these facilities. Depending on the services required, replacement services must be of high quality and delivered by stable, qualified people. Finally, these services must be financially accessible, through minimal contribution or a financial support.
- **Develop and standardize access to quality respite services adjusted to the needs of the person being helped and of the caregiver.** Services may include temporary accommodation options for the person being helped, or home support, for any duration. Although the main objective of respite services is to offer caregivers an opportunity to take a break and retake control of their own homes, it is also important to improve respite care services for caregivers who would prefer taking time for themselves outside their homes. Whether at home or outside, caregivers should be able to use this time as they see fit. Several measures need to be developed to enable this, such as tax credits, an annual direct benefit for caregivers, and the creation of accommodation and respite facilities with preferential rates and specific services for caregivers. Respite facilities hosting the person being helped must also provide stimulation activities.
- **Develop psychosocial support services for caregivers, throughout their journey.** These can consist of support, listening and group, family, or individual psychosocial counselling. These services must be coordinated between integrated health and social services centres/integrated university health and social services centres (CISSS-CIUSSS) and community organizations. They must also be maintained after the death of the person who was receiving assistance. Indeed, after

the death of the person they were helping, caregivers can be very disorganized because their time was structured around the needs of that person. Support for caregivers is necessary in this transitional period, to help them maintain their health and, in certain cases, get re-accustomed to a social or professional life.

- **Develop temporary accommodation services for caregivers supporting a person in need during an episode of care.** These services exist for parents of ill children living more than 55 km away from a healthcare facility. These services must be strengthened and extended to all caregivers, regardless of the situation of the person being helped (temporary stay in a rehabilitation centre following a brain injury, transition of a spouse having cancer to palliative care, etc.). Alongside accommodation, these facilities should always set up a range of services for caregivers, such as psychosocial support and information provision.
- **Support the development of caregivers' skills and expertise.** Training courses, conferences or educational workshops should be available on issues such as disabilities and the condition of the person being helped, support services and residential facilities, end-of-life care, self-care, nutrition, etc. The RANQ's expertise shows that community organizations have gained real knowledge in this field and should thus receive better support to disseminate it.
- **Strengthen local care and support services for the person being helped.** In 2012, 26.6% of caregivers provided care to a person in need, and 69% of them did so at least once a week (Institut de la Statistique du Québec, 2015c, 2015d). In France, estimates indicate that caregivers devote an average of 5.18 hours per week to perform 3.5 care tasks for the person receiving assistance (IFOP & MACIF, 2008). A basic minimum number of services (assistance with bathing, clothing, getting in and out of bed) should be available to any caregiver requesting them. These services should be available outside of regular work hours as well, to provide support in the evening and/or during the week. The professionals providing this support should be trained and stable enough to maintain continuity in the relationship, regardless of where the person being helped is located.
- **Develop a housework service package (housekeeping, meals...).** In 2012, 53.5% of caregivers were handling housework and 46.3% were maintaining the home of at least one person needing assistance, more than once a week for the majority of them (Institut de la Statistique du Québec, 2015c, 2015d). To take care of house chores – if

possible in collaboration with the person being helped to support their independence – caregivers need support, be it regular or temporary, at home or through external services (frozen meals, community meals, collective kitchens, meals-on-wheels and assistance for preparation of meals). These housework support services should be improved and made available everywhere, regardless of the place of residence of the person being helped. They should also cover the tasks that caregivers cannot fulfill because of their other responsibilities towards the person being helped. For example, the time caregivers devote to providing care to a person needing assistance, even to those living in institutional residential facilities, is time and energy that they cannot put in the management of their own housework needs. Currently, such services are only available in certain regions of Quebec, based on caregivers' income. However, admissibility criteria should be based on the intensity of the caregiving role, regardless of caregivers' employment status and annual income, because all caregivers are short on time and have, as a result, reduced personal time.

- **Improve public and para- transit services.** Paratransit services must be simple and flexible when it comes to reservation and shifts between types of transport. More than two-thirds of caregivers are in charge of transportation for at least one person needing assistance, and the majority of them perform this task at least once a week (Institut de la Statistique du Québec, 2015c, 2015d). In many cases, they do not use their own vehicle. In addition, paratransit services should be available with or without personal assistance and eligibility criteria should be extended to people with less serious health conditions. In the case of public transport, those accompanying people needing assistance should have access to a special transit fare. Likewise, the parking sites of healthcare facilities should offer a reduced parking permit fare or free admission to those who have to regularly come for consultations. Caregivers and those being helped should be able to participate in the development of transport services so that their needs are taken into account. Similarly, transportation organizations should clarify procedures for filing a complaint and be accountable regarding their inclusion strategy in order to improve access and quality of services (Confédération des organismes de personnes handicapées du Québec, 2017).
- **Develop information on and access to services and safety technologies.** There are several types of services, some private and others community-based. Some of

these are safety calls (e.g. the Pair program⁵), safety accessories (bracelet, pendant, button, and others), and abuse and ill-treatment prevention services (*Abus Aînés* (Elder Mistreatment Helpline), *Tel-Jeunes* helpline). These services are not well known at the moment. Awareness-raising and support programs are necessary so that caregivers who are less familiar with these services can start using them. There should also be measures to ensure that these services are financially accessible.

Many studies are developing tools or applications to help aging people or people with autism spectrum disorder and their caregivers. However, these studies are carried out in silos, following specific themes, and there are few cross-cutting knowledge transfer mechanisms, even though what might be useful for the caregiver of an aging person can be just as useful for the parent of a child with a disability. We recommend the creation of a technological tools and services directory, and the development of cross-sector collaborations through studies, conferences or fairs on cross-cutting themes.

Finally, caregivers are part of a community that, like in the case of suicide prevention, could be involved in detecting other caregivers' signs of exhaustion or emotional distress. The *Sentinelle* project for suicide prevention has produced interesting outcomes (Institut national de santé publique du Québec, Julien, Laverdure, Institut national de santé publique du Québec, & Direction du développement des individus et des communautés, 2004), and could be adjusted to detect signs of exhaustion among caregivers. There are already tools (short-form Zarit scale) that, once adjusted, would be useful to assess caregivers' strain (Direction du programme de soutien à l'autonomie des personnes âgées, 2017).

- **Strengthen and facilitate access to specialized and supplementary services.** The needs of caregivers go beyond the scope of the health and social services system. Among other things, there are tax measures (tax credit, tax return, involuntary separation) and support services for adjusting (technical assistance, home and vehicle adjustment, specialized education resources). In addition, caregivers must undertake complex procedures for funeral services, the recognition of their rights and those of the person being helped (insurances, lease, tutorship, protection mandate, power of attorney, will) and filing complaints. These administrative procedures are scattered

⁵ <https://www.programmepair.com/>. These calls can be for *safety* purposes, with an alert launched if the subscriber does not answer after three attempts, or serve as *reminders* to take medication, check the blood sugar level, eat, etc.

among several organizations or ministries, and many caregivers might find their digitization challenging. Moreover, it is not always easy to assess whether one's situation meets the eligibility criteria to access certain support services. In certain regions, there is a contact person in charge of explaining and accompanying the caregivers in these procedures involving various organizations. Such positions should be consolidated, extended to the whole province, and benefit all caregivers, regardless of the age or the condition of the person being helped.

- **Improve access to information and raise awareness.** The objective here is to make the experiences of caregivers visible to the population and healthcare professionals, but also to inform caregivers of the services to which they are entitled. To this end, the RANQ launched the National Week of Caregivers in 2008, an event which has since been closely followed by community organizations. However, with more substantial official support, the National Week could gain greater media attention and develop original and relevant outreach activities to better raise awareness on the caregiving experience.

Caregivers face the challenge of fragmented support and service spaces. Currently, no common platform, neither governmental nor community-based, gathers all of the information related to caregiving that caregivers would need, regardless of the condition of the person being helped (information on financial support, psychological support, respite or accommodation facilities, family-work reconciliation, etc.). A single platform, accessible to caregivers and professionals, would help develop synergy, greater access to information and support, and bring more cost advantages than the multiplication of information sites focused on specific themes (age of the person being helped, geographical location, etc.). Given the heterogeneity of caregivers' profiles, this common platform has to be multimodal: digital (web, applications) as well as phone-based. Finally, the number of information dissemination sites should be increased to reach out to the largest number of caregivers, especially those who do not identify themselves as such. Spaces such as drug stores, businesses and service fairs could be considered for this purpose.

Principe 4: Breaking caregivers' cycle of impoverishment

Even now, supporting a person increases caregivers' impoverishment because of two simultaneous dynamics: a rise in additional costs (travel expenses, service fees, respite care fees, etc.) and a loss in caregivers' income and benefits (unpaid leave, loss of employment ties, suspension of retirement pension contributions and group health benefit plans, etc.).⁶ For people taking care of someone with high levels of needs, estimates indicate that the average Canadian annual expenditure is approximately \$7,600, with some spending more than \$120,000 (Fast, 2015). The same study points to an inequality, with people earning lower incomes (below \$30,000) spending as much as those in a better financial situation. Nearly 20% of caregivers live in a situation of financial insecurity, forcing them to reduce their own spending on transport or healthcare, and even to take on new debt (Fast, 2015).

A few problematic examples demonstrating the cycle of impoverishment:

- A caregiver must accompany her spouse with kidney disease for hemodialysis twice a week. To cover parking fees, she had to buy the \$300 annual pass. She also reduced her working time to four days a week. With her median income, this represents an annual loss of \$8,316.
- A caregiver supports both his parents who experience a loss of autonomy for more than 25 hours a week. For this reason, he cannot take up a new job. Nevertheless, he constantly has to prove that he is actively searching for employment.

Many countries, mostly in Europe, have started providing benefits directly to caregivers, in the form of monthly or biweekly payments or fee reimbursements. Again, the amounts given are most often too low to represent a salary, but they constitute a contribution for this extra caregiving role, which help caregivers mitigate financial insecurity and reduce the risk of establishing an uneven relationship of dependence between them and the person being helped.

Compensation for direct costs

There are a few measures to compensate caregivers for additional expenditures and some financial assistance for home adaptation, but many of these measures remain taxable and are not available for all health conditions (loss of autonomy, disability, etc.) (RANQ, 2017a). Most tax compensation measures for direct costs (deductions, non-refundable and refundable tax credits) neither apply to people who already have low, and thus non-taxable, incomes, nor in cases where the person being helped lives in a residential center

⁶ This chapter comes from the RANQ's Recommendation Statement submitted to Quebec's Labour Minister in 2017.

but periodically stays at the caregiver's home (weekends, holidays). Moreover, these measures generally have time limitations or are only available in cases of imminent death, which leave caregivers of people with disabilities or with chronic health conditions and significant care needs without any support.

Two types of financial benefits are available: those granted to the person being helped, and those given directly to caregivers. Benefits granted directly to the person being helped can create situations of dependency for caregivers who do not have their own source of income and rely on the willingness of the person being helped to be paid. In addition, benefits are rarely sufficient to offset actual costs and home care expenditures. Finally, such measures do not acknowledge caregivers' full contribution.

Regardless of the type of benefits, it is important to stress that this compensation should

Regardless of the type of benefits, it is important to stress that this compensation should not reduce the quantity and quality of public services, which would lead to a form of privatization of care within the family.

not reduce the quantity and quality of public services, which would lead to a form of privatization of care within the family. Compensations should help the informed and voluntary choice of caregivers and reduce

burnout risks. Nevertheless, several questions remain on the best ways to operationalize this type of support: how to make sure that these benefits would not socially and professionally exclude caregivers? Which amount and duration would be adequate and representative of the actual work caregivers accomplish, without leaning towards the professionalization of caregivers? How to limit the risk of tense relationships, of abuse or of maintaining dependency between caregivers and the people they help?

Recommendations

- **Create a caregiver insurance benefit** to compensate people performing caregiving tasks for more than 10 hours a week who have low or no income. Decisions regarding how to use this benefit should be left to the caregiver's discretion and the compensation should be reassessed periodically, as circumstances change. Unemployed caregivers (beneficiaries of social assistance or employment insurance benefits) should be considered unavailable to avoid subjecting them to harassment.
- **Maintain contributions to the Régie des rentes du Québec (Quebec Pension Plan) for caregivers who have left their jobs or reduced their work hours**, in order to durably break the circle of impoverishment. Employers should also allow the

maintenance of group insurance and pension plans for employees who have reduced their work hours because of their caregiving responsibilities.

- **Make caregivers who do not have employment ties eligible for compensation for work-related accidents** in cases of injuries incurred while providing care to a loved one.
- **Create a revision committee formed by the Ministry of Revenue, community organizations supporting caregivers, professionals (lawyers, tax specialists, etc.) and researchers to revise tax credits and other tax measures to support caregivers.** Solutions could include increasing tax exemptions, creating more flexible eligibility criteria for caregivers (relationship with the person being helped, location of the person being helped, age of the helper-helped dyad, etc.), and applying criteria based on the caregiver's life circumstances and not on those of the person being helped. Other options would be to not tax service-employment paycheques granted for respite, benefits granted for home adaptation, etc. Caregivers want simple, understandable and unfragmented measures, regardless of their situation or that of the person being helped (age, type of disability). A single window access would greatly contribute to this integration.
- **Strengthen and broaden the criteria and expedite access to financial assistance for adapting living spaces.** It would also be necessary to involve other levels of government, such as the municipal level, to compensate for current service gaps.
- **Maintain, improve and coordinate the various benefits and allowances for children with disabilities.** Currently, the eligibility criteria of these benefits are too restrictive and do not adequately help parents offset the costs of caring for their children. In addition, policies are not consistent across various levels of government. At the federal level, the child disability benefit is granted only if the child lives with the parents, whereas in Quebec, the law requires these same parents to pay for the external accommodation costs of their child. Parents often find themselves without financial support, even when external accommodation is needed given the child's condition (Lavallée, 2017).

The challenges of work-study-caregiving reconciliation

According to the Institut de la statistique du Québec (ISQ), 57% of caregivers were employed in 2012, which represents more than 30% of the Canadian work force (Fast, 2015). Thus, close to 750,000 workers have to reconcile their work, family and caregiving responsibilities each week. This commitment, averaging between five and 20 hours per week, can be very demanding, but the vast majority of studies state that caregivers, especially women, underestimate the amount of time and care provided to a loved one. About 44% of active caregivers had to miss between eight and nine days of work per year because of their caregiving responsibilities (Fast, 2015).

To facilitate work-family life balance, the Act respecting labour standards allows a *leave for family or parental matters*. However, caregivers do not feel included because their situation is not specified in the Act. The same goes for community organizations or the public services that support them. They are not familiar with the scope of this leave because the Act does not specifically address the concept of a “caregiver.” In addition, this option is meant for immediate family members rather than for all relatives, friends or neighbours. In this respect, leaves of absence are not well adapted to the various possible family configurations or to the need to acknowledge friends’ and neighbors’ support, which often makes up for the small size of many families and/or their geographic dispersion.

We should also add that current leave options are unpaid and can hardly be used for an absence of a few hours or half a day, since the employer has to consent to the leave. As a result, caregivers often have to miss a whole day of work just to accompany a loved one to a medical appointment, and they then have to bear the full financial loss of this leave.

Including caregivers in the Act Respecting Labour Standards and in policies and measures related to work-family reconciliation costs almost nothing, whereas the wage losses of employed caregivers and of the businesses that hire them are massive.

Nevertheless, caregivers, who are mostly women, miss work and lose employment income to perform these support tasks. Researcher Diane-Gabrielle Tremblay (2016) has calculated that wage losses of employees who provided care to a loved one in Quebec between 2005 and 2008 amounted to \$336 million. Other studies present a wide range of situations, and indicate greater wage losses (more than \$16,000 per year) for caregivers helping non-seniors (Fast, 2015). As for employers, a federal government report has calculated that Canadian businesses were losing 2.2 million hours of work per week and approximately \$ 1.3 billion in reduced productivity per year (Bernier, 2015). The Conference Board of Canada estimates that turnover among caregivers aged 45 years and

over costs employers \$355 million (replacement, hiring, vacation pay, etc.) (Fast, 2015). Thus, the labor market must adapt to the realities of caregivers. Workers who have additional caregiving responsibilities should not have to bear the burden of negotiating piecemeal work arrangements with their employer. Even if present, the compassion and goodwill of many employers is not enough.

Acknowledging these challenges, the federal government launched the Canadian Employers for Caregivers Plan (CECP)⁷ in 2014, which proposes different strategies to help workers who are also caregivers maintain their participation in the labor market. We suggest that the Quebec government should draw from this initiative and go further by considering work-caregiving reconciliation as an issue that needs to be addressed.

Recommendations

- **Adapt the Act Respecting Labour Standards to the realities of caregivers.** The prerequisite would be to specifically identify caregivers in the Act. For example, the title of section V.1 of the Act could read “Leave and absences for family, parental or caregiving purposes.” In terms of leave (articles 79.7 and 79.8), every caregiver should be able to take 10 days off work each year, which would include two paid days, to provide care or support to a loved one, whether the person is a member of their immediate family or not. These days should be dividable into half-days or hours, according to the caregiver’s needs. Consistent with the new federal employment insurance benefit for caregivers, the period for which an employee who acts as a caregiver can be absent from work due to the illness or serious injury of a loved one should be increased to 16 weeks. Finally, like for compassionate care benefits, employees who act as caregivers should be allowed to take a leave of absence of up to 26 weeks, if serious death risks are associated to the illness or the injury. Additionally, we recommend that the work-family balance standards set by the Bureau de normalisation du Québec (BNQ) be expanded to specify better what work-caregiving balance best practices should be. Currently, work-family balance standards include very few criteria on this matter.

Other working time arrangements would also facilitate work-caregiving time balance (Fast, 2015), such as teleworking or, like a measure implemented in France in 2017, allowing colleagues to give each other leaves for family obligations (Agence France

⁷ <https://www.canada.ca/en/news/archive/2014/06/harper-government-launches-canadian-employers-caregivers-plan.html>

Presse, 2017). We support the measures proposed in the platform of the Coalition Famille-Travail-Études (Family-Work-Study Coalition), of which we are members:

- The right to know your work schedule in advance;
 - The right to refuse to work overtime;
 - The right to have real breaks and time for meals;
 - Better leaves for parental or family obligations;
 - Having paid sick leaves;
 - Having a higher number of annual holidays or vacations;
 - Increased remuneration for public holidays.
- **Help raise the awareness of employers and employees who also act as caregivers.** We recommend that the Ministry of Labor, Employment and Social Solidarity undertake a campaign with both public and private sector employers to raise their awareness regarding the experiences of caregivers in employment. The Commission des partenaires du marché du travail could be asked to:
 - form an advisory committee on support measures for caregivers in employment;
 - Start raising awareness among Sectoral Workforce Committees (Comités sectoriels de main d’oeuvre) and regional Labour Market Partner Councils (Conseils régionaux des partenaires du marché de l’emploi), with the RANQ’s assistance;
 - prepare tools (information packages) for employers.
 - **Help raise the awareness of training and higher education institutions for student-caregivers and support the implementation of support and accommodation structures.** Currently, several support measures are available, but only for full-time students. However, given their responsibilities toward the person being helped, student-caregivers can hardly reconcile their class schedule and workload, which leads to burnout, impoverishment and, ultimately, dropping their studies (Bélanger, Landry, Ndiaye, & Caouette, 2017).
 - **At the Ministry of Labor, Employment and Social Solidarity, create an employment reintegration program specifically taking into account the expertise developed by caregivers.** There is a life after caring for a loved one, but caregivers have often lost their employment relationships and reintegration into work is difficult. Creating a program that recognizes prior learning and offers support for job search or returning to studies would help caregivers be less worried about their

future. It would also reassure them about their role, which they would thus assume more efficiently.

Once the amendments to the Act Respecting Labour Standards are adopted, we would also recommend an advertising campaign (televised clips and flyers) targeting caregivers to disseminate information regarding programs and protections available to them. We reiterate that caregivers are not well informed.

Principle 5: Develop the knowledge of organizations for caregivers and support their expertise and leadership

As specified in the introduction, caregivers' life conditions, the issues they face, as well as the possible solutions to their problems have been either rarely studied in Quebec or studied in the context of very specific situations (elderly caregivers, etc.). Thus, it is time to document and evaluate all aspects of caregivers' experience: impoverishment, health,

It would be interesting to know more about caregivers' mental health, about how caregiving affects people fulfilling this role, about cases of abuse from the people being helped on caregivers, as well as about caregiver's financial contribution.

work-study balance, financial contribution and cost, etc. In the coming years, better collaboration between community organizations, health and social services professionals and the academic research sector should be fostered in order to develop best practices. For instance, given their expertise on

the ground, community organizations notice rising issues and can guide research topics. There is no shortage of research subjects: for example, it would be interesting to know more about caregivers' mental health (suicidal risks), about how caregiving affects people fulfilling this role, as well as about cases of abuse towards caregivers by people being helped, by family and social circle members or by healthcare professionals. It is also essential to more thoroughly assess caregivers' social and economic contributions, and which measures should be put in place to compensate for their impoverishment. It is equally necessary to evaluate the quality of the services offered to them.

We also believe that these studies should develop concrete tools that could be used by organizations in practice. To achieve this goal, efforts should be combined to develop knowledge transfer systems that equally target caregivers, health and social services professionals, community organizations and the general population.

The Regroupement des aidants naturels du Québec, with its 75 members across the province of Quebec, and the expertise it has acquired over the years, is a key player to guide practices that could improve caregivers' life conditions. We believe that the needs of caregivers should be assessed in a cross-cutting manner, not only according to the age of the person being helped or the nature of their illness or disability.

The RANQ is a key player with a cross-cutting expertise that can help guide practices that could improve all caregivers' life conditions.

Therefore, we request that the national strategy be applied to all caregivers, and not only to caregivers of seniors.

To fulfill this mission, the RANQ needs proper financial autonomy. The RANQ's role has to include the development of further thinking, expertise sharing (forum on new issues and research result dissemination, information packages, etc.), specific training provision, as well as consulting and advising work on service development for caregivers across Québec and their access to information (reference websites, centralized phoneline for caregivers following the SOS Domestic violence line model, etc.).

The RANQ and community organizations are “watchdogs” when it comes to really acknowledging caregivers, their role, their expertise, their needs, as well as the services they receive.

Community organizations that support caregivers are key players. To help, support and inform caregivers, they have developed expertise based on a variety of practices that are innovative and adapted to realities on the ground. Community organizations want to develop a real partnership with the public system because they complement it. However, they need proper funding to do so. This funding would enable them to develop all of the services needed by caregivers across the province of Québec and facilitate cooperation, with the ongoing goal of improving the service package for caregivers.

Recommendations

- **Consult and involve as real partners** associations regrouping community organizations such as the RANQ and their members, right from the first planning stages of public policies that affect caregivers.
- **Increase funding to support the mission of community organizations and advocacy organizations** so that they can develop and maintain their capacity to act in the long-term.
- **Promote research and expertise sharing** between all the actors involved with caregivers, including caregivers themselves, while respecting each other's mission, availability and expertise.

Conclusion

Caregivers are a vital force that provides quality care and services to a vulnerable population. In that regard, they help create significant savings for Quebec society. However, it is important to remember that caregiving is a role that adds to people's other roles, which too often leads to exhaustion and creates financial burden. These consequences have significant social, economic and personal costs. **Without caregivers, these essential allies for a fair province, offering quality and accessible care to the Quebec population is a utopian task.**

By caring about caregivers' needs, valuing them and supporting them in their responsibilities, we will be more proactive. Confronted with caregivers' exhaustion, community organizations such as the RANQ stress the urgent need to act on the systemic factors contributing to the health and well-being of caregivers and, in turn, of the people they support. To do so, we have identified five principles for action that can improve the situation of all caregivers, without discrimination, regardless of the condition of the person being helped.

This strategy is a first step in the RANQ's desire to team-up with the government and others to develop, within an interdepartmental working committee, the priorities, mechanisms and funding of a national support strategy.

By implementing an inclusive and cross-cutting strategy such as this one, the province of Quebec would become a leader in the field, at the Canadian and global levels, and would prove its commitment to forms of social progress that improve the population's well-being.

The future of care services provided to Quebecers depends on this.



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Appendix : Liste of RANQ members

1. À fleur d'espoir
2. Action-services aux proches aidants de Longueuil
3. Aide communautaire de Lennoxville et des environs
4. Albatros Québec
5. Association bénévole Beauce-Sartigan
6. Association bénévole de Charlevoix
7. Association de l'action volontaire Appalaches
8. Association des aidants naturels de la Côte-Nord
9. Association des aidants(es) naturels du Bassin de Maskinongé "Mains tendres"
10. Association des aidants(es) naturels(les) du Bas-Richelieu
11. Association des personnes proches aidantes Drummond
12. Association des personnes proches aidantes de Bécancour–Nicolet–Yamaska
13. Association des proches aidants Arthabaska–Érable
14. Association des proches aidants de la Capitale-nationale
15. Association lavalloise des personnes aidantes
16. Association québécoise des personnes aphasiques
17. Association des personnes aidantes de la Vallée de la Bastican
18. Carrefour des proches aidants de Québec
19. Centre action générations des aînés de la Vallée-de-la-Lièvre
20. Centre d'action bénévole Accès
21. Centre d'action bénévole association solidarité d'Argenteuil
22. Centre d'action bénévole Beauce-Etchemin
23. Centre d'action bénévole de Boucherville
24. Centre d'action bénévole Concert'Action
25. Centre d'action bénévole de la MRC de Bécancour
26. Centre d'action Bénévole de Montcalm
27. Centre d'action bénévole de Valleyfield
28. Centre d'action bénévole des Seigneuries
29. Centre d'action bénévole du Grand Chateauguay
30. Centre d'action bénévole du Lac
31. Centre d'action bénévole Région Témis
32. Centre d'aide aux proches aidants des Basques
33. Centre d'entraide aux aînés
34. Centre d'entraide bénévole de St-Amable
35. Centre de bénévolat de St-Hyacinthe
36. Centre de soutien entr'aidants
37. Centre des femmes du Ô Pays
38. Centre des femmes du Témiscouata
39. Coop SORE, Solidarité, Répit, Entraide pour les Proches Aidants des Pays-d'en-Haut
40. Corporation de développement de la communauté d'expression anglaise de Mégantic
41. Groupe des Aidants du Sud-Ouest
42. Inter-association des personnes handicapées du Saguenay
43. L'Ancre de l'Isle-aux-Coudes

44. L'APPUI Lanaudière
45. L'APPUI Laurentides pour les proches aidants d'ânés
46. La Maison Écho du Coeur
47. Le Maillon inc.
48. Le Réseau des aidants naturels d'Autray
49. Les aidants naturels du Haut-St-Laurent
50. Les cercles de fermières du Québec
51. Les proches aidants de Shawinigan
52. Lien-Partage
53. Lumi-Vie
54. Maison des familles de La Matapédia
55. Maison soutien aux aidants
56. Nouvel Essor
57. Palli-Aide
58. Parrainage civique de Vaudreuil-Soulanges
59. Proches Aidants des Chenaux
60. Regroupement des aidantes et aidants naturels (RAAN) - Un service du Réseau d'Amis de Sherbrooke
61. Regroupement des aidantes et aidants naturels de Montréal
62. Regroupement des aidants naturels de la Mauricie Inc.
63. Regroupement des aidants naturels du comté de l'Assomption
64. Regroupement des organismes montréalais d'aidants naturels
65. Regroupement des personnes aidantes de Lotbinière
66. Regroupement des proches aidants de Bellechasse
67. Réseau des Proches Aidants Les Moulins
68. Société Alzheimer Chaudière-Appalaches
69. Société Alzheimer de Granby et région Inc.
70. Société Alzheimer de l'Estrie
71. Société Alzheimer de Lanaudière
72. Société Alzheimer des Laurentides
73. Table de concertation des aînés de la MRC de Memphrémagog
74. Tel-Écoute
75. Voix et solidarité des aidants naturels de la Vallée-de-la-Gatineau

