

**Summary
of the study from the Alliance des femmes de la francophonie
canadienne**

**Natural caregivers
in Francophone and Acadian communities across Canada**

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SUMMARY

CONTEXT

The work and needs of natural caregivers are more and more the subject of debates and studies in Canada as well as elsewhere in the world. In 2000, the creation of the Canadian Caregiver Coalition mobilized government, community, feminist and research authorities in order to promote changes in national policies affecting working conditions of these workers.

In parallel, the awareness of the necessity to support official languages communities living in minority settings contributes to the strengthening of public services being delivered in both Canadian official languages. French-speaking communities still aspire to legitimize the fact of asking and obtaining services in French in highly minority regions that have never had access to such services and that are not in the habit or don't have the reflex of asking for them.

Spending restraints on health programs and social and community services result in women having to pick up the slack in the absence of support. More and more frequently, people of various ages with different needs are left on their own or receive minimum home care and support. In view of the lack of home care services, those who are named "natural caregivers" are often responsible for people with needs, for example their parents, spouse, children and spouse's parents.

According to Health Canada (2002), 77% of caregivers are women. A large number of them spend some years of their lives taking care of vulnerable parents, handicapped children or spouse. Besides having to give up their job, they have to meet extra costs that the government does not wish to or cannot provide anymore. For French-speaking women living in minority settings, the situation is more overwhelming, as the demand is high, services in French are limited or nonexistent and the task is heavy.

That is the context in which the Alliance des femmes de la francophonie canadienne (AFFC) explored the place occupied by French-speaking natural caregivers in different provinces. The study, titled *Natural caregivers in Francophone and Acadian communities across Canada*, was published in the fall of 2006. The current situation assumes that the demand for care will increase in the coming years. In Canada, health care and employment systems do not recognize the role of natural caregivers as health care providers. Too often, they offer care in social and professional isolation. We presume that in the future, they will have a more important role to play in the health sector because provinces have more and more difficulties meeting the needs of a growing population requiring a substantial amount of care. Social policies will necessarily need to consider their place among the health system. Here are the following objectives of the AFFC study:



- Create a socio-demographic profile of French-speaking natural caregivers in Francophone and Acadian communities
- Research the role of natural caregivers
- Establish links between their function as natural caregivers and the impact on their family and professional life
- Know the support and resource needs in French of natural caregivers to better help them fulfil their role

METHODOLOGICAL NOTE

In the eight provinces where the study was conducted, qualified interviewers (one per province) questioned 92 Francophone and Acadian caregivers in person and two over the phone. Here is the distribution of the 94 participants:

Table 1: Distribution of Participants

Province	Number of interviews
British Columbia	12
Alberta	13
Manitoba	11
Ontario	12
New Brunswick	12
Prince Edward Island	12
Nova Scotia	12
Newfoundland and Labrador	10

The limits of the study did not allow us to communicate with French-speaking natural caregivers in the Yukon, Northwest Territories and Nunavut. We left out Saskatchewan as a study is taking place on Franco-Saskatchewanian caregivers.

The AFFC developed and applied various methods in order to ensure confidentiality and validity of the data gathering process. It made sure to reach French-speaking caregivers in various rural and urban regions.

To carry out the study, interviewers used, with each participant, a 33 open question questionnaire. It is important to note that the majority of caregivers appreciated these interviews that gave them a rare occasion to share their experiences and feel like they were understood and supported.

The first section of the report presents a global analysis of the results and 33 recommendations. Results from interviews and the recommendations are assembled by province in the second section.



DATA

The study produced a mass of useful data helping to draw a socio-demographic profile of natural caregivers and assisted persons in the Francophone and Acadian communities across Canada.

Table 2 : Socio-demographic characteristics of caregivers

Category	Description
Age	36.2% - 50 years old and more
	27.7% - 40 years old and more
	16% - 60 to 69 years old
	6.4% - 80 to 89 years old
	3.2% - - 20 to 30 years old
Social status	66% - married or common law relationship
	34% - divorced, single or widowed
Education	35.1% - university diploma
	24.5% - college diploma
	24.5% - high school diploma
	13.9% - not completed high school diploma
Employment	56.4 % - wage-earning employment
	43.6% - unpaid work
Gross annual income, personal and family	36% - annual family income of \$50,000.00 and more
	50% - annual personal income of \$30,000.00 and less
Language spoken at home	60.6% - French
	30% - French and English
	9.4% - English or other mother tongue



Table 3: Socio-demographic characteristics of assisted persons

Category	Description
Person	21.8 % - Spouse 21% - Mother 19.4% - Son 37.8% - Other family member or friend
Age	41.5% - 60 years old and more (34 assisted persons are 80 years old and more) 30.9% - Average age adult 21% - Less than 20 years old
Care received	Supportive care and attention, small tasks, business and financial management, personal care, specialized medical care
Duration of help	21% - 15 to 46 years 59% - Less than 10 years
Most frequent diseases	Cancer, diabetes, Alzheimer, Parkinson, ageing, mental health, multiple sclerosis, stroke, coronary problems, physical and/or intellectual disability, autism, trisomy, etc.
Caregiver and assisted person under the same roof	56.8% - Yes 41.5% - No

What can we conclude from these data? The profile of the natural caregivers interviewed reveals a variety of situations in urban and rural regions. However, some global characteristics suggest intervention and research courses of action for the AFFC.

Care given by caregivers is relatively for a long period, often linked to ageing or chronic diseases. In the case of caregivers aged between 80 and 89 years of age, they are taking care of children who are now adults and who suffer from intellectual or physical disabilities.

Caregivers are educated. More than half have jobs and have to juggle family, work and their role as natural caregivers. About less than half of caregivers have no jobs, as they often had to quit their jobs in order to take care of a close relative.

The natural caregivers interviewed are themselves ageing. They have family and financial responsibilities. Sometimes, they help more than one person. More than half of caregivers live under the same roof as the assisted person, in the case of a child or an average aged adult. In most cases, the assisted person is 60 years of age and older and lives in a residential complex or an apartment for the elderly. In the Atlantic region, it is interesting to note that assisted



persons of 60 years and more often live under the same roof as their caregiver. As for spoken language, natural caregivers are bilingual enough to use services in English. However, assisted persons are predominantly unilingual in French and find it hard to be looked after or assisted in English.

The assisted persons suffer from chronic diseases, have a functional limitation or need help because of their age or a particular difficulty, etc. It is not rare for someone to have more than one problem. People suffering from chronic diseases often require specialized medical care.

HIGHLIGHTS

In the study, results from the interviews conducted with 94 French-speaking caregivers from eight provinces are presented under different categories: women as caregivers; paid work and financial questions, help and services; services in French; impact of the role of caregivers on physical and mental health, and family, conjugal, personal and social life; positive aspects of being a caregiver.

Natural caregivers expressed 33 recommendations which we have grouped together in order to highlight four main challenges:

1. Recognition of natural caregivers work and definition of their status.
2. Access to health and social services in French.
3. Economic impact of natural caregivers work
4. Impact on natural caregivers quality of life

We repeat each challenge by drawing up the situation assessment that takes into account the main concerns of the interviewed caregivers. We suggest intervention and future research courses of action that the AFFC could undertake.

Other national organizations are doing studies on similar issues. The AFFC will have to explore the possibility of establishing partnerships with them. Among these "natural" partnerships, we find the following non governmental organizations: the Canadian Caregiver Coalition and its provincial chapters, where appropriate; the Assemblée des aînées et aînés francophones du Canada; the Fédération des communautés francophones et acadienne du Canada; the Société Santé en français and its 17 networks; the Consortium national de formation en santé. The AFFC also has to continue its awareness approach and efforts with the following governmental institutions: Status of Women Canada, Health Canada, Human Resources and Social Development Canada; the Centres of Excellence for Women's Health; the provincial Health, Social Services and Status of Women departments; the regional health authorities. As for research organizations, the Canadian Institutes of Health Research, and the Canadian Institute for Research on Linguistic Minorities also have to be made aware of the uniqueness of natural caregivers situation in French and Acadian communities across Canada. They have to become aware of the need to do research on their particular situations.

The intervention and research courses of action are ambitious. They call out the AFFC and its "natural" partners to encourage them to partner up and put into action new interventions and



research in order to improve the situation of natural caregivers in the French and Acadian communities across Canada.

THE FOUR MAIN CHALLENGES

1. Recognition of natural caregivers work and definition of their status

As emphasized by the Canadian Caregiver Coalition, the terminology used to designate a "natural caregiver"¹ restricts his/her work to the volunteer and informal sectors. This description is heavy with economic consequences for the society, natural caregivers and assisted persons. Being a caregiver is not natural²; it is a choice, but is it really a choice for every caregiver who took part in this study? More often than not, family members and society expect that women will take care of their close relatives, sometimes pressuring them into this choice.

In addition, natural caregivers often offer personal or specialized medical or care that go way beyond their role of mother, daughter or spouse. And yet, this type of care is neither paid nor officially recognized by governments, membership communities, main social actors or health professionals. Furthermore, natural caregivers have not received any training to offer the care that often requires very specific interventions.

It is necessary to create a sense of awareness so that society, governments and health professionals may change their perceptions. We need to mention the fundamental contribution of natural caregivers to the well-being of Francophone communities in minority settings. We have to highlight the added value of their work and offer them the support they demand. The awareness process could be part of the efforts put together by other organizations such as the Canadian Caregiver Coalition.

Intervention and research courses of action

- a) Draw up an inventory of care offered by caregivers in French communities in minority settings, and conduct a comparative analysis with comparable services offered by health and social services professionals, residential services for the elderly or people suffering from an intellectual handicap, and the private sector. This inventory would allow the recognition of the compensation allocated for similar work, and required qualifications and diplomas to offer this type of care (see 2.b).
- b) According to the results from a), examine the used terminology to designate French-speaking natural caregivers and their work; describe the different categories of natural caregivers according to the types of care offered, the duration (extended or acute), the frequency and the intensity of care.
- c) Organize a targeted awareness campaign and elaborate, according to the results from a) and b), appropriate tools for social actors (communities, municipalities, community and

¹According to the Canadian Caregiver Coalition, natural caregivers offer unpaid care and help to members of their family, and friends who need support considering their physical or cognitive state or their mental health.

²The natural caregivers who took part in the AFFC study recommended that we stop using the adjective "natural" in the designation of caregiver. We are nevertheless using it in this summary.



social services), federal and provincial governments, and health professionals. The campaign would be aimed at positioning natural caregivers in the health and social services system and mentioning their contribution to the well-being of French communities in minority settings.

- d) Organize provincial and regional forums in order to discuss terms of support that meet the needs of natural caregivers in French communities in minority situation; develop support teams and medical or psychological consultation services in French.
- e) In the light of results from a) and b), explore formal and informal training options for natural caregivers and create a resource guide to support them.

2. Access to health and social services in French

The lack of community and public support services heightens the social isolation faced by natural caregivers in Francophone and Acadian communities, especially in rural regions. The sharing of responsibilities between provinces and the federal government in the health sector makes it more difficult for natural caregivers to find services meeting the assisted persons needs. Services in French are even rarer in Francophone communities in minority settings still aspiring to legitimize the asking and obtaining of services in French in highly minority regions. Information on available services and programs is hard to find as it varies a lot according to the region. The complexity and slowness of the administrative process, restrictive eligibility criteria and multiple assessments of the assisted person's file often take over.

The AFFC study demonstrated that caregivers mainly use two types of services in French and English: mental and physical health services, and social, community and municipal services.

Mental and physical health services in French

Numerous studies have looked at the importance of health services in French for Francophone communities in minority settings. They have confirmed that access to health services in one's mother tongue is an essential element for improving health conditions and the appropriation of health by the population.

Since 2004, the efforts of the Société Santé en français (SSF) and its 17 networks have identified French health resources and increased access to primary health care in French in minority communities. These initiatives were carried out with a real involvement from different stakeholders groups and an important participation from provinces and territories. The SSF networks thus represent an invaluable resource for natural caregivers. The AFFC must build a dialogue with the SSF and its networks to explore possible partnerships.

Social, community and municipal services in French

All interviewed natural caregivers felt that they should benefit from additional home care services for housework, medical and personal care and respites. They would like to see more possibilities, flexibility and hours of respite in French, including nights and weekends. Caregivers would like to use this time as they see fit. They wish for more educational or recreational services in day centres, and better residential services for the elderly or people with functional limitations. The lack of services in French aggravates already difficult circumstances in which caregivers offer care. It affects the caregiver's health and quality of life, and also has a negative impact on the assisted person.



Intervention and research courses of action

Governments, health care professionals, service providers, community groups, municipalities and natural caregivers must establish closer partnerships. They have to create networks to facilitate information exchange and a more consistent support system for natural caregivers in the French and Acadian communities.

- a) Analyse the capacity of medical, social, community and municipal infrastructures in French communities in minority settings in order to better plan and coordinate services in French for natural caregivers.
- b) Draw up an inventory, in each province, of physical and mental health services, and of social, community and municipal services; determine the languages in which they are offered, their accessibility criteria and their availability (see 1.a) The AFFC could complete this inventory by conducting a similar exercise about services offered by organizations whose mission is to help people suffering from chronic diseases, and list information on diseases or problems of assisted persons.
- c) Centralize inventory information in a French resources centre about available services and programs under the aegis, for example, of regional health boards or SSF networks.
- d) Explore possible partnerships with the Société Santé en français and its 17 networks; get informed on their available resources and seek their advice on means to reach different provincial stakeholders in the sector of health, and even in the social services sector.
- e) Make this information available through various means: Internet site, leaflets, etc.

3. Economic impact of natural caregivers work

Natural caregivers' contribution to the economy

Natural caregivers offer care to their close relatives with intellectual or physical handicaps, chronic diseases or who are ageing. They do so with very little financial support from the government (respite services, financial compensation, unpaid work, paid leaves, home care and services, medication costs, flexibility of worked hours, etc.)

In Canada, if the care offered by natural caregivers was offered by a paid work force, the costs would be of over 5 billion dollars a year (Fast, Eales and Keating, 2001). This represents a significant contribution to the health system. Natural caregivers interviewed in Francophone communities in minority settings thus ask that the government use a section of this economy to create services to reduce their unpaid work.

Financial security of caregivers in jeopardy

The AFFC study highlights the fact that several natural caregivers in Francophone and Acadian communities have left their jobs in order to take care of an assisted person. This is probably why 43.6% of interviewed caregivers were without a job. This loss of income comes with important expenses that neither the government nor the medical insurances reimburses.

If a caregiver leaves her job or reduces her working hours to take care of an assisted person, she suffers a negative impact on the pension plan, whether private or public. Natural caregivers have no job security during their unpaid leave from the labour market. Since their work as caregivers is not being paid, after a certain period of time, they do not qualify for



employment insurance. Care given is often over a long period of time and this jeopardizes the caregivers' financial security. Solutions need to be considered in order to offer a compensation of salary to caregivers.

In Canada, the question of caregivers' compensation needs to take into account their heterogeneity. As for Francophone communities in minority settings, results of proposed research (1.a and 2.b) will provide solution elements that should not be limited to tax relief.

The Canadian Caregiver Coalition is developing a policy on financial security for caregivers and is considering implementing governmental programs for that purpose. To alleviate Canadian natural caregivers' financial burden, including those in Francophone and Acadian communities, the Coalition wants the federal government to put the following four concrete measures into action:

- i) Expand the Canada pension plan (CPP) in order to allow caregivers who leave their jobs or reduce their work week to maintain their contributions, including the federal government ones.
- ii) Amend the Canada Labour Code in order to grant a leave to caregivers who must leave their jobs to take care of a person with a handicap or a medical condition, or an elderly person.
- iii) Amend the employment insurance to offer six paid weeks to caregivers who must temporarily leave their jobs to take care of a person, beyond the limits of the compassionate leave for dying or seriously ill persons.
- iv) Institute a substantial tax credit for caregivers.

In addition, the National Conference on Caregiving (held in Gatineau, on October 17 and 18, 2005) highlighted priorities to ensure the economic security of caregivers, notably a financial compensation for the work done that is linked to the type of care offered (see 1.a and 2.b). There was also a recommendation of revamping existing financial support for caregivers, and employment and work place support to facilitate the conciliation of professional and caregivers' responsibilities. There was also talk of creating a dedicated respite fund that would work under the following principles: choice of the caregivers, accessibility, quality and continuity of care.

Intervention courses of action

All actions and recommendations mentioned are pertinent for natural caregivers in Francophone communities in minority settings. The AFFC must join this movement and work in partnership with organizations already looking at compensation and tax relief issues. First, the AFFC will distribute results of this study to these organizations to make them aware of the caregivers and assisted persons' situations and needs in Francophone communities in minority settings.

4. Impact on natural caregivers' quality of life

The previous three challenges all have harmful impacts on the family and social life of natural caregivers who took part in this AFFC study. They also affect their mental and physical



health. The insufficiency of resources and health support services, governmental help, work flexibility and respite options isolate caregivers, thus accentuating their despair and exhaustion. The situation is alarming considering the ageing of the population and the average age (50 years old) of natural caregivers in Francophone communities in minority settings. The exodus of young Francophones to urban centres also seriously jeopardizes the future, as only 3.2% of caregivers who took part in the study were between 20 and 30 years old.

Caregivers' mental and physical health warrants a particular attention in the policies and programs developed for them. They have as many rights as the assisted persons. Their needs and quality of life need to be taken into account during the development of strategies so that their work is supported and the well-being of assisted persons is guaranteed.

The majority of caregivers who took part in this study suffer from isolation, exhaustion, depression, and chronic fatigue. Their family, personal and intimate life are greatly disrupted. All have requested a psychological support in French in order to deal with the difficult conditions of the caregivers' role and the emotional demands which overburden them.

Intervention courses of action

If we are able to better determine the place and role of natural caregivers in the delivery of health services, if we can better coordinate services that they need, if we can offer them the financial resources they require and have a right to, the AFFC will be better equipped to continue its awareness work. It will be able to highlight to the government authorities the natural caregivers' contribution to the well-being of Francophone communities in minority settings, and emphasize the urgency of implementing mechanisms to facilitate their tasks and allowing them to find a balance and a better quality of life.

Meanwhile, the AFFC will keep contact with the natural caregivers who took part in this study by creating discussion forums and offering networking possibilities between caregivers living in a same region or province, in order to break the isolation. This will also allow for a reduction in their daily and financial stress.



CONCLUSION

The AFFC study allowed the drawing up of a profile of natural caregivers in Francophone communities in minority settings, and helped to better understand their role towards assisted people and need for support and services.

In addition, the study on natural caregivers in Saskatchewan will without a doubt complement the results of this study. It would also be appropriate to draw territorial profiles for the Yukon, Northwest Territories and Nunavut and for immigrant French caregivers in minority settings. The financial security of natural caregivers being in jeopardy, the AFFC could also examine the links between the poverty of French-speaking women and the situation of caregivers in minority settings.

The AFFC will develop an intervention and research strategy in the form of a 4 or 5-year action plan drawn from suggested intervention and research courses of action. This action plan will allow the AFFC to target its awareness efforts towards its "natural" partners who share common objectives in this respect on specific challenges and needs of natural caregivers in Francophone and Acadian communities through Canada.

