

NATIONAL ASSEMBLY OF QUÉBEC

FIRST SESSION

FORTY-SECOND LEGISLATURE

Bill 56

An Act to recognize and support caregivers and to amend various legislative provisions

Introduction

Introduced by Madam Marguerite Blais Minister Responsible for Seniors and Informal Caregivers

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EXPLANATORY NOTES

The purpose of this bill is to guide the Government in planning and carrying out actions aimed at fostering awareness and recognition of the contribution of caregivers and to support them in their role.

To that end, the bill provides that the Government is to adopt a national policy for caregivers. It sets out the guiding principles of the policy and establishes the key areas its policy directions are to focus on. Under the bill, a government action plan setting out the measures and actions proposed to implement the national policy is to be adopted every five years.

The bill specifies the responsibilities of the various government actors with respect to caregiving. To that end, it designates the Minister as the Government's adviser on all issues relating to caregivers, and obliges the ministers and government bodies to take into account the national policy's guiding principles and policy directions when developing, implementing and evaluating their programs, services or other measures. The bill provides for the creation, by the Minister, of the Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes, to support the Minister in the exercise of his or her responsibilities.

The bill establishes the Comité de partenaires concernés par le soutien aux personnes proches aidantes, one of whose functions is to make any recommendation to the Minister that it considers necessary regarding the national policy, the government action plan or any other matter concerning caregivers. The bill also establishes the Observatoire québécois de la proche aidance, whose purpose is to provide reliable and objective information regarding caregiving.

The bill proclaims the first week of November as National Caregivers Week.

Furthermore, the Act respecting health services and social services is amended to give the Minister of Health and Social Services a power to inspect private seniors' residences and other resources offering lodging to vulnerable clienteles determined by regulation. The bill also creates, in that Act, a reserved name for seniors homes and alternative homes.

Lastly, the bill includes transitional provisions.

LEGISLATION AMENDED BY THIS BILL:

| _ | Act respecting | health | services | and | social | services | (cha | pter (| S-4.2 | 2). |
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Bill 56

AN ACT TO RECOGNIZE AND SUPPORT CAREGIVERS AND TO AMEND VARIOUS LEGISLATIVE PROVISIONS

AS it is fundamental to recognize the considerable contribution of caregivers to Québec society and the crucial nature of their engagement;

AS the responsibilities inherent in the role of caregivers may entail significant repercussions for their quality of life;

AS it is essential for caregivers to recognize themselves and be recognized in the diversity of the realities they experience, of their life paths and of the contexts in which they assume their role;

AS all caregivers are persons in their own right who must be treated with dignity, care and consideration;

AS it is appropriate to affirm the desire of the Gouvernement du Québec and of Québec society as a whole to act in a coordinated manner and pursue a common course of action designed to foster awareness and recognition of the contribution of caregivers and to support them in their role;

THE PARLIAMENT OF QUÉBEC ENACTS AS FOLLOWS:

CHAPTER I

OBJECT AND DEFINITION

1. The purpose of this Act is to guide the Government in planning and implementing actions to foster awareness and recognition of the contribution of caregivers and to support them in their role.

To that end, the Act provides in particular that the Government must adopt a national policy for caregivers, as well as an action plan to implement it.

The Act also provides for the establishment of the Comité de partenaires concernés par le soutien aux personnes proches aidantes and the Observatoire québécois de la proche aidance.

2. For the purposes of this Act, "caregiver" means any person who continuously or occasionally provides significant support to a member of his or her immediate circle who has a temporary or permanent incapacity and with whom the person shares an emotional bond as a family member or otherwise.

The support is provided on a non-professional basis, in an informal setting and regardless of the care receiver's age or living environment or the nature of the incapacity, whether physical, mental, psychosocial or other. The support may take various forms, such as transportation, assistance with personal care and housekeeping, emotional support or the organization of care.

CHAPTER II

NATIONAL POLICY FOR CAREGIVERS

- **3.** After consultation with caregivers, researchers, bodies or groups representing caregivers, as well as with the government departments and bodies concerned, the Government adopts a national policy for caregivers.
- **4.** The national policy's guiding principles are as follows:
- (1) recognize the considerable contribution of caregivers to Québec society and the importance of supporting them;
- (2) promote preservation of the health and well-being of caregivers and help them maintain a balanced life;
- (3) consider the diversity of caregiver realities in responding to their specific needs;
- (4) recognize the experience and knowledge of caregivers and of the care receiver, and consider such experience and knowledge in a partnership-based approach;
- (5) respect the wishes and capacities of caregivers as to the nature and scope of their engagement; and
- (6) facilitate government and collective coordinated action at the national, regional and local levels by involving caregivers, so as to promote responses adapted to their specific needs.
- **5.** The policy directions set out in the national policy focus on the following key areas:
- (1) recognition and self-recognition of caregivers, as well as mobilization of the Québec society stakeholders concerned by caregiving;
 - (2) information sharing and the development of knowledge and skills;
- (3) the development of health and social services intended for caregivers, in a partnership-based approach; and
- (4) the development of environments that support the social participation of caregivers.

- **6.** The policy directions related to recognition and self-recognition of caregivers and to mobilization of the stakeholders concerned must, in particular, be aimed at raising awareness within Québec society of the role and undeniable contribution of caregivers, of the diversity of their realities and of the importance of supporting them through coordinated actions relating to various spheres of their life.
- **7.** The policy directions related to information sharing and the development of knowledge and skills must, in particular, be aimed at meeting the information and training needs of caregivers and of the various stakeholders concerned, and at supporting research and the transfer of knowledge regarding caregivers.
- **8.** The policy directions related to the development of health and social services must aim to support the health and well-being of caregivers as users, taking into account their knowledge, wishes and engagement capacity and promoting a partnership-based approach.
- **9.** The policy directions related to the development of environments that support the social participation of caregivers must, in particular, be aimed at promoting balance between the caregiver role and the other spheres of caregivers' lives.

CHAPTER III

GOVERNMENT ACTION PLAN

10. Every five years, the Government adopts and makes public a government action plan setting out measures and actions to implement the national policy for caregivers.

The action plan describes the objectives to be attained, the means to be used to attain them and the available resources. It also determines the conditions, terms and schedule for implementing the actions set out in the plan, which involves identifying the stakeholders concerned and their responsibilities.

11. The Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes, the Comité de partenaires concernés par le soutien aux personnes proches aidantes and the Observatoire québécois de la proche aidance are consulted in the development and follow-up stages of the action plan.

Those committees and the observatory must meet at least once a year to discuss the follow-up to the action plan.

12. As an incentive for collective mobilization, the action plan may provide for the making of agreements between the ministers concerned and the national, regional and local partners, and for mechanisms for coordinating and periodically following up on the actions carried out within the scope of those agreements.

13. The Minister is responsible for the implementation of the action plan and coordinates its application.

The Minister submits an annual report to the Government on the activities carried out within the scope of the action plan for the preceding fiscal year. The Minister may, for that purpose, request from the other ministers concerned specific reports concerning the activities carried out in their fields of jurisdiction.

The report is published on the department's website within 60 days after it is submitted to the Government.

CHAPTER IV

RESPONSIBILITIES OF VARIOUS GOVERNMENT ACTORS

14. The Minister is, by virtue of office, the Government's adviser on all issues relating to caregivers, in particular in the development of the national policy for caregivers and the related government action plan. In that capacity, the Minister gives other ministers any opinion the Minister considers advisable to ensure implementation of the policy and the action plan, and takes part in the development of measures, policy directions and actions that could have a significant impact on caregivers. The Minister also monitors implementation of the national policy and the action plan.

It is incumbent on government departments and bodies to communicate to the Minister any information necessary for the carrying out of those responsibilities.

15. The Minister establishes a committee to monitor government action for caregiver support, called the "Comité de suivi de l'action gouvernementale pour le soutien aux personnes proches aidantes" (monitoring committee), to support the Minister in the exercise of his or her responsibilities.

The Minister designates the committee members from among the representatives of the departments, government bodies or persons appointed by the Government to hold office that are concerned by caregiver support.

- **16.** Ministers and government bodies must, in keeping with their respective missions and the Government's budgetary and fiscal policies, take into account the guiding principles of the national policy for caregivers and its policy directions when developing, implementing and evaluating any program or any other service or measure concerning caregivers.
- **17.** If a minister considers that proposals of a legislative or regulatory nature could have direct and significant impacts on caregivers, the minister reports on the impacts he or she anticipates when presenting the proposals to the Government.

CHAPTER V

COMITÉ DE PARTENAIRES CONCERNÉS PAR LE SOUTIEN AUX PERSONNES PROCHES AIDANTES

DIVISION I

ESTABLISHMENT AND ORGANIZATION

- **18.** A committee of partners concerned by caregiver support, called the "Comité de partenaires concernés par le soutien aux personnes proches aidantes" (partners committee), is established.
- **19.** The partners committee is composed of at least 8 and not more than 15 members appointed by the Minister, as follows:
- (1) at least two members appointed after consultation with the nongovernment bodies concerned by caregiver support determined by the Minister;
 - (2) at least two caregivers appointed after a public invitation for applications;
- (3) at least two researchers appointed after consultation with the integrated university health network coordination panel established under section 436.8 of the Act respecting health services and social services (chapter S-4.2); and
- (4) one member from the Observatoire québécois de la proche aidance, appointed after consultation with the latter.

The Minister designates an observer within the partners committee. The observer participates in committee meetings, but is not entitled to vote.

20. The members are appointed for a term of not more than five years.

On the expiry of their terms, the members remain in office until reappointed or replaced.

- **21.** Any vacancy among the members of the partners committee is filled in accordance with the rules of appointment to the committee.
- **22.** The members of the partners committee receive no remuneration, except in the cases, on the conditions and to the extent that may be determined by the Government. They are, however, entitled to the reimbursement of expenses incurred in the exercise of their functions, on the conditions and to the extent determined by the Government.
- **23.** The Minister designates the chair and the vice-chair from among the members of the partners committee.

DIVISION II

FUNCTIONS AND POWERS

- **24.** The partners committee's functions are
- (1) to make any recommendation to the Minister that it considers necessary regarding the national policy for caregivers, the government action plan or any other matter relating to caregivers;
- (2) to support the Minister and the monitoring committee in implementing the national policy for caregivers and the government action plan; and
- (3) to give the Minister its opinion on any matter referred to it by the Minister regarding caregiving.
- **25.** In the exercise of its functions, the partners committee may recommend to the Minister to consult with, solicit opinions from, or receive or hear requests and suggestions from persons, bodies or associations regarding caregiving. The partners committee may also seek the contribution of the Observatoire québécois de la proche aidance.

DIVISION III

REPORT

26. The partners committee must, within six months after the end of the fiscal year, send the Minister a report on its activities for that year.

CHAPTER VI

OBSERVATOIRE QUÉBÉCOIS DE LA PROCHE AIDANCE

DIVISION I

ESTABLISHMENT AND ORGANIZATION

- **27.** An observatory on caregiving, called the "Observatoire québécois de la proche aidance" (observatory), is established.
- **28.** The observatory is managed by a managing committee composed of the following 11 members, appointed by the Minister:
- (1) two members representing the departments concerned by caregiver support, including one member representing the Ministère de la Santé et des Services sociaux, appointed after consultation with the ministers concerned;
 - (2) the observatory's scientific director;

- (3) one member representing the institution or body responsible for the observatory's organization and administrative support;
- (4) four researchers appointed after consultation with the integrated university health network coordination panel;
- (5) two members appointed after consultation with the non-government bodies concerned by caregiver support determined by the Minister; and
 - (6) one caregiver, appointed after a public invitation for applications.

The Minister designates the chair and the vice-chair from among the members of the managing committee.

29. The observatory's managing committee determines the observatory's scientific directions, general objectives and policies, as well as the annual activities it intends to carry out, and sends that information to the Minister.

It also evaluates the relevance, priority status and scientific quality of the observatory's programs and activities.

30. The members of the observatory's managing committee are appointed for a term of not more than three years.

On the expiry of their terms, the members remain in office until reappointed or replaced.

- **31.** Any vacancy among the members of the managing committee is filled in accordance with the rules of appointment to the committee.
- **32.** The members of the observatory's managing committee receive no remuneration, except in the cases, on the conditions and to the extent that may be determined by the Government. They are, however, entitled to the reimbursement of expenses incurred in the exercise of their functions, on the conditions and to the extent determined by the Government.
- **33.** The Minister entrusts, by agreement, the observatory's organization and administrative support to an institution within the meaning of the Act respecting health services and social services or to any other body.

DIVISION II

FUNCTIONS AND POWERS

34. The purpose of the observatory is to provide reliable and objective information regarding caregiving through observation, monitoring, analysis and knowledge sharing.

More specifically, the observatory's functions are

- (1) to collect, integrate, compile, analyze and disseminate information, in particular of a statistical nature, on caregiving;
- (2) to monitor the evolution of caregivers' needs and of efficient practices, measures and actions to support them;
- (3) to facilitate the transfer of knowledge for the benefit of the various actors involved in caregiving; and
- (4) to facilitate collaborations regarding caregiving, in particular with university institutions, research centres, other observatories or the government bodies participating in research activities or activities to promote clinical excellence and efficient use of resources in health and social services.

In the exercise of its functions, the observatory may consult experts or other actors from the caregiving sector and entrust them with any mandate it deems necessary.

- **35.** The observatory enlightens the Minister by finding and reporting on current knowledge and trends, or those to be developed, concerning evaluation approaches and indicators to measure the quality of life, health and well-being of caregivers, and to measure the impact of the policy directions, measures and actions set out in the national policy for caregivers and the government action plan. To that end, the observatory enhances the value of existing information and data and promotes knowledge transfer and sharing.
- **36.** Within the scope of its work, the observatory must cooperate with the monitoring committee and the partners committee.

DIVISION III

REPORT

37. The observatory's managing committee must, within six months after the end of the fiscal year, send the Minister a report on its activities for that year.

CHAPTER VII

NATIONAL CAREGIVERS WEEK

38. The first week of November is proclaimed National Caregivers Week.

CHAPTER VIII

REPORT

39. The Minister must, not later than (*insert the date that is five years after the date of assent to this Act*), report to the Government on the implementation of this Act.

After that, the Minister must report to the Government on the carrying out of this Act every five years. The report is prepared in coordination with the other ministers concerned. It must take into account the opinions received from the partners committee as well as the evaluation approaches and indicators proposed by the observatory that have been selected by the Minister. The report must also state the results obtained in implementing the national policy for caregivers and include a status report on the progress of Québec society toward achieving the goals pursued by the policy.

Any report referred to in this section is tabled by the Minister in the National Assembly within 30 days after it is presented to the Government or, if the Assembly is not sitting, within 30 days of resumption.

CHAPTER IX

AMENDING PROVISIONS

ACT RESPECTING HEALTH SERVICES AND SOCIAL SERVICES

- **40.** Section 438 of the Act respecting health services and social services (chapter S-4.2) is amended
- (1) by inserting "seniors home, "alternative home," after "health and social services centre," in the first paragraph;
 - (2) in the second paragraph,
- (a) by replacing "Nothing in the first paragraph shall" by "The first paragraph does not":
- (b) by adding the following sentence at the end: "Nor does it prevent the use of the words listed in it in the name of a person or partnership whose activities are not likely to be confused with the activities inherent in the mission of a centre operated by an institution, provided that the Minister's authorization has been obtained."

- **41.** The Act is amended by inserting the following section after section 489:
- "**489.0.1.** The Minister has the inspection power provided for in section 346.0.8 in respect of a private seniors' residence and any other resource or category of resource offering lodging determined by government regulation under the first paragraph of section 346.0.21. The provisions of section 346.0.9 apply to a person authorized by the Minister to carry out such an inspection."

CHAPTER X

TRANSITIONAL AND FINAL PROVISIONS

- **42.** The Government adopts and makes public the first government action plan not later than 12 months after the adoption of the national policy for caregivers.
- **43.** The first government action plan must contain measures and actions concerning assessment of needs, planning and delivery of the services provided to caregivers by the institutions concerned in the health and social services network.
- **44.** The Minister must, before (*insert the date that is six months after the date of assent to this Act*), appoint the members of the observatory's managing committee.
- **45.** Section 438 of the Act respecting health services and social services (chapter S-4.2), as amended by section 40, does not prevent persons or partnerships that, on (*insert the date of introduction of this bill*), carry on their activities under a name that includes the words "seniors home" or "alternative home" and appears in the registration declaration filed under the Act respecting the legal publicity of enterprises (chapter P-44.1) from continuing to use those words in their name.
- **46.** The Minister Responsible for Seniors is responsible for the administration of this Act.
- **47.** This Act comes into force on (*insert the date of assent to this Act*).