

**Declaration
on rights and responsibilities
in health and well-being
(Draft)**

The Conseil de la santé et du bien-être was established by law in May 1992. Its mission is to contribute to the enhancement of Quebecers' health and well-being by advising the Minister of Health and Social Services, informing the public, fostering debate and establishing partnerships. The CSBE's initiatives revolve around these four objectives and are aimed at finding the best means to achieve its goal.

The CSBE is composed of 23 members representing users of health and social services, community agencies, actors, researchers and administrators involved in health and social services or in sectors that have an impact on public health and well-being.

This publication was produced by:

Conseil de la santé et du bien-être
1020, route de l'Église, bureau 700
Sainte-Foy (Québec) G1V 3V9
Telephone: (418) 643-3040
Fax: (418) 644-0654
E-mail: csbe@csbe.gouv.qc.ca

This publication is available in the Publications section of the Web site of the Conseil de la santé et du bien-être: www.csbe.gouv.qc.ca

Legal deposit
Bibliothèque nationale du Québec, 2005
National Library of Canada, 2005
ISBN: 2-550-45246-1

© Gouvernement du Québec

CSBE Board Members

Hélène Morais, President
André Archambault
Christophe Auger
Linda Beauchamp Provencher
François Béland
Luc Boileau
Gylaine Boucher
Yvon Caouette
Paul-André Comeau
Jocelyne Dagenais
Gisèle Dubé
Jacques Fiset
Michel Hamelin
Yolette Lévy
Louise-Andrée Moisan
Marie Soleil Renaud
Marielle Tremblay
Stanley Vollant

Working committee

Linda Beauchamp Provencher
Yvon Caouette
Paul-André Comeau
Gisèle Dubé
Hélène Morais

Research and writing

Jean Rousseau
Marie-Rose Sénéchal

Technical support

France Darveau
Ginette Langlois
Céline Vaillancourt

Coordination and editing

Anne Marcoux

Design and illustrations

Rouleau-Paquin design communication

FOREWORD

A Declaration on Rights and Responsibilities in Health and Well-being will be a solid reference and dynamic tool for citizens in Québec.

Following a mandate from the Minister of Health and Social Services, the Honourable Philippe Couillard, to draft such a Declaration, we opted to follow a democratic approach. We began by distributing a guide designed to inform, stimulate and nourish reflection on the scope, application and content of the Declaration. We then met with roughly 400 people all across Québec who had agreed to discuss the issues presented in it.

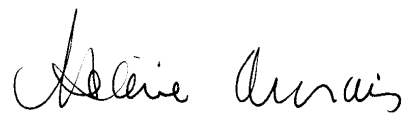
Bearing in mind their allegiances, concerns and proposals, the *Conseil de la santé et du bien-être* prepared a draft Declaration presented to the Minister of Health and Social Services.

I am honoured on behalf of the CSBE to propose this draft Declaration on Rights and Responsibilities in Health and Well-being.

The values, rights and responsibilities stated in this document transmit an abiding concern for the public good and a firm determination to call upon all citizens to discuss and decide on this issue, and to take action in favour of health and well-being.

The statements presented here are inspired by the foundations of our acquired legal rights and public institutions. They associate health and well-being with the on-going development of a democratic and progressive society.

I would like to thank all those who so generously contributed to this project, which will be submitted to the Health and Welfare Commissioner. I invite all of you to pursue the debate on our collective values, rights and responsibilities.



Hélène Morais, President

CONTENTS

Preamble 5

Values 6

Rights 7

Responsibilities 9

**Implementation of the Declaration on Rights and
Responsibilities in Health and Well-being 11**

**DECLARATION
ON RIGHTS AND RESPONSIBILITIES
IN HEALTH AND WELL-BEING
PRELIMINARY DRAFT**

PREAMBLE

- **Whereas** health and well-being in Québec play an instrumental role in building a democratic, free, egalitarian and united society;
- **Whereas** health and well-being are rooted in people's physical, mental and social capacities to act within their communities and to carry out their assumed roles;
- **Whereas** health and well-being are linked to a set of factors that society is able to influence, such as lifestyle, education, housing, income, work, living environment, the natural environment and the health and social services system;
- **Whereas** the health and social services system is a public good belonging to the Québec society that creates, finances, uses, transforms and evaluates it;
- **Whereas** social and ethical issues related to health and well-being are complex, have individual and collective dimensions, are the expression of multiple, often conflicting, interests, generate discussions on the meaning and consequences of actions, and may shift the balance of our core social values;
- **Whereas** the public possesses specific knowledge that complements administrative and expert knowledge;
- **Whereas** health and well-being are a collective responsibility that calls into play the state and numerous social actors, including individuals, families, local communities, municipalities, regions, private enterprise, actors in the health and social services system as well as those working in various fields, such as education, labour, socio-economic development and the environment;
- **Whereas** there is a need to share a common reference that spells out values, rights and responsibilities in health and well-being in order to promote informed public debate and decision making, and to support the authorities responsible for protecting our rights;

Therefore, this Declaration states the values, rights and responsibilities in health and well-being that contribute to strengthening a community of citizens committed to defending the public good. It invites all citizens, without exception, to speak out, to exercise their critical judgement, to claim their rights and to take action in favour of health and well-being.

VALUES

Québec's collective commitment to health and well-being rests on the fact that we share a certain number of core social values that lie at the heart of democratic life. Public deliberation allows Québec citizens to give meaning to these values, to determine their importance according to the issues at stake and to influence collective choices in the area of health and well-being. This set of values is as follows:

- **Human dignity** consists of respect for life, personal inviolability and integrity, and the refusal to countenance any form whatsoever of humiliating or degrading treatment. It governs not only the relationship between the state and its citizens but also their respective interrelationships. It is also tied to self-esteem, decent living conditions and access to high-quality and appropriate health and social services. Human dignity underlies the requirement to humanize care and services;
- **Freedom** stems from the recognition of people's autonomy, capacity for self-development and ability to make choices. It gives rise to the requirement of informed consent and its corollary, the refusal of treatment. It is the basis for respecting people's privacy and the confidentiality of their personal information. Freedom entitles social actors to assemble, to protest, and to debate social and political options;
- **Equality** confers the same value upon all citizens as human beings. It allows for the recognition and exercise of rights without unjustified distinction, exclusion or preference. It protects against discrimination and arbitrariness. Equality enables all citizens to participate in public life, to be fully part of health services and care, and to lodge complaints, if need be.
- **Solidarity** characterizes the relations between citizens who care about the welfare of others and who feel mutually responsible within a society. It influences the choice and scope of the public good that protects collective interests. Solidarity implies redistributing resources, reducing inequities in health and well-being, establishing a universal public system and providing equitable access to that system.

These values are the underlying basis for the rights and responsibilities in health and well-being.

RIGHTS

Rights in health and well-being are sustained by a vast body of legislation.¹ These rights have both individual and collective dimensions. The exercise of these rights gives concrete shape to recognized core values, protects individuals and contributes to defining Québec society. Inseparable from the rights and freedoms of others, these rights are exercised in conjunction with respect for democratic values, public order and the general well-being of the Québec citizens.

Some of the fundamental rights that are closely linked to health and well-being are:

- The **right to life, integrity and assistance**²;
- The **right to personal inviolability and autonomy**³;
- The **right to respect and dignity**⁴;
- The **right to privacy**⁵ and the **right to professional secrecy**⁶;
- The **right to freedom**, freedom of conscience, freedom of religion, freedom of opinion, freedom of expression, freedom of peaceful assembly and freedom of association⁷;
- The **right to equality** in the recognition and exercise of rights and freedoms.⁸

Stemming from these fundamental rights are the following specific rights:

- The **right to receive adequate services** that are scientifically, humanly and socially appropriate and that are offered with continuity and in a personalized and safe manner⁹; and the right to choose a health professional and a health-care institution.¹⁰ These rights are exercised in accordance with the legislative and regulatory provisions related to the organizational and operational structure of each institution and within the limits of the human, material and financial resources at its disposal.¹¹

1. This body of legislation includes the Canadian Charter of Rights and Freedoms (“Canadian Charter”); the Québec Charter of Human Rights and Freedoms (“Québec Charter”); the Civil Code of Québec (C.C.Q.); the Act respecting Health Services and Social Services (A.H.S.S.S.); the Act respecting the Health and Social Services Ombudsman; the Youth Protection Act; the Act respecting the Protection of Persons Whose Mental State Presents a Danger to Themselves or to Others; the Public Health Act; the Public Protector Act; the Public Trustee Act; the Act respecting Access to Documents Held by Public Bodies and the Protection of Personal Information; the Professional Code and its associated regulations; the Act to Combat Poverty and Social Exclusion; and the Canada Health Act.

2. Canadian Charter, s. 7; Québec Charter, ss. 1 and 2; A.H.S.S.S., s. 7; C.C.Q., arts 3, 7 and 13.

3. C.C.Q., ss. 3, 10, 11 and 13; A.H.S.S.S., s. 3(3) and 9.

4. Québec Charter, Preamble, ss. 3 and 4; A.H.S.S.S., ss. 3(2) and (3), 5 and 100.

5. Québec Charter, s. 5; C.C.Q. arts 3 and 35.

6. Québec Charter, s. 9.

7. Canadian Charter, s. 7; Québec Charter, ss. 1 and 3.

8. Canadian Charter, s. 15; Québec Charter, s. 10 and subsecs.

9. A.H.S.S.S., ss. 5, 100 and 101.

10. A.H.S.S.S., ss. 6 and 80.

11. A.H.S.S.S., s. 13.

Service users are entitled to be informed, as soon as possible, of any accident having occurred during the provision of health services.¹² They are entitled to lodging services necessitated by their state of health.¹³ English-speaking users are also entitled to receive services in English, in accordance with available resources and the government access program¹⁴;

- The **right to participate in decisions** related to their health and well-being¹⁵ and the right to consent to treatment.¹⁶ Given that consent must be free and informed,¹⁷ the corollary of these rights is the right for individuals to be informed of services, of the usefulness of the treatment, and of their state of health and possible options¹⁸; the right to access their medical records and to the confidentiality of these records¹⁹;
- The **right to be accompanied and assisted** when seeking information or taking steps to obtain a service,²⁰ the **right to be represented** in the exercise of all recognized rights²¹;
- The **right to seek remedy**, to file a complaint, to be informed of the complaint procedure and to be accompanied and assisted in any such actions.²²

A universal public health and well-being system serving to build a democratic, free, egalitarian and united society is also founded on the recognition of the following rights:

- The **right to reliable, relevant and instructive information** on health and social issues, including the health and social services system;
- The **intrinsic right** of all citizens in a democracy to **initiate and take part in** debates;
- The **right to participate in the choices and decisions** concerning the policies and procedures promoting health and well-being, and those related to the health and social services system;
- The **right to a quality health and social services system** that keeps pace with evolving social values and choices.

12. A.H.S.S.S., s. 8(2).

13. A.H.S.S.S., s. 14.

14. A.H.S.S.S., s. 2(7) and s. 15.

15. A.H.S.S.S., ss. 3(4), 10, and 102–104.

16. A.H.S.S.S., s. 9; C.C.Q., arts 11 and 13.

17. C.C.Q., arts 10(2) and 1399.

18. A.H.S.S.S., ss. 4 and 8; C.C.Q., art. 13(2).

19. A.H.S.S.S., ss. 17, 19, and 24–26, C.C.Q., art. 37 and subsecs.

20. A.H.S.S.S., ss. 11, 12, 33(3), 66(3), 76.6 and 212(4).

21. A.H.S.S.S., s. 12; C.C.Q. arts 12, 14 and 15.

22. A.H.S.S.S., ss. 11, 12, 16, 33(2) and (3), 34, 42 and subsecs, 53, 60, 66(3), 76.6, 211 and 212(4); Public Protector Act, s. 8; Codes of Ethics; C.C.Q., arts 1457 and 1458 (general civil liability).

RESPONSIBILITIES

Health and well-being require an ongoing collective commitment. The values, laws and standards in this area give rise to numerous responsibilities aimed at protecting the public interest. These responsibilities are complementary and bring into play different action levers. Their exercise contributes to sustaining an active community that is built upon each and everyone's willingness and capacity to act.

Individuals and families, whose willingness and capacity to act are related to their particular socio-economic, political, environmental and cultural situations, must be sensitized to the following responsibilities:

- To strive to maintain and improve their health and well-being;
- To speak out, to take part in public debates and in the different stages of the decision process, and to remain vigilant to the social and ethical consequences of proposed actions in the area of health and well-being;
- To participate as fully as possible in the care and services concerning them and to make reasonable use of the services on the basis of appropriate and accessible information.²³

Local communities, together with municipal and regional governments, are the places for anchoring and developing public health and well-being. They have the following responsibilities:

- To establish conditions that foster public participation;
- To encourage co-operation among the various social actors in order to improve living conditions and to provide complementary programs and services tailored to community needs.

Private enterprise occupies a special place through its involvement within the system and their impact on the determinants of health and well-being. It must assume the following responsibilities:

- To take into account the impact of their activities, especially in terms of working conditions, human-rights protection, environmental protection, local and regional socio-economic development and respect for Québec's recognized public good.
- To reconcile their interests with the imperatives of a universal public system.

The **actors involved in the health and social services system**, including administrators, board members, health professionals and other practitioners, specifically assume the following responsibilities:

- To guarantee the quality of the care and services offered and to inform citizens of available services and how to access them;

23. A.H.S.S.S., s. 3(4) and (5).

- To promote a humanistic approach through interventions that take into account people's mental, physiological, spiritual and social dimensions and that incorporate the values of dignity, freedom, equality and solidarity. To establish educational and support mechanisms and measures that are consistent with this approach;
- To ensure that reasonable use is made of the system's resources while respecting the pursuit of the public good, especially in their dealings with the private sector;
- To facilitate public participation in the choices and decisions to be made.

The **state** plays various roles and controls the levers with regard to interventions in health and well-being as guardian of social values, legislator and protector of human rights, administrator of public finances, redistributors of public wealth and arbitrator of conflicts of interest and emerging ethical issues.

Given the importance of the dissemination of knowledge, the democratization of the debates and decision-making process, and of taking into account knowledge of its citizens, the state has the following responsibilities:

- To guarantee the flow of accessible, relevant and reliable information;
- To initiate and foster democratic debates, especially on emerging issues, public policies and projects that could potentially trigger profound changes in certain aspects of the system;
- To establish conditions favourable to citizens' informed participation within their communities and within the different administrative and political levels of government;
- To take into consideration both public knowledge and expert knowledge in the decision process.

As protector of health and well-being, and as provider and regulator of health and social services, the state has the following additional responsibilities:

- To ensure that the health and social services system is of high quality, which implies, among other aspects, the accessibility, relevance, effectiveness, cost efficiency and continuity of health-care services; respect for people; fairness, transparency and accountability on the part of decision makers, administrators and practitioners; and public participation in shaping policy directions, making choices and evaluating the system;
- To guarantee adequate funding for the health and social services system as well as the ready availability of the human resources required to offer these services;
- To take positive action on the socio-economic and environmental factors liable to promote conditions favourable to health and well-being, and to ensure that public policies and interventions are harmonized accordingly;
- To ensure that the outcomes emerging from the conclusion of partnerships and service agreements, particularly with the private sector, adhere to the principles underlying the public system and guarantee its sustainability;
- To ensure that the negotiation of international agreements does not have a negative impact either on public health and well-being or on the public system.

IMPLEMENTATION OF THE DECLARATION ON RIGHTS AND RESPONSIBILITIES IN HEALTH AND WELL-BEING

Compliance with the Declaration on Rights and Responsibilities in Health and Well-being is a collective responsibility shared by all Québec citizens, the government and the various social actors.

Many organizations contribute to protecting and enforcing several of the rights stated in this Declaration. These include the Health and Social Services Ombudsman; local service quality commissioners; regional service quality commissioners; users' committees; advocacy groups working to defend the rights of people with psychiatric disabilities; the *Centres d'assistance et d'accompagnement aux plaintes* (CAAP); the Québec Ombudsman; the *Commission des droits de la personne et des droits de la jeunesse*; the Public Curator; the *Commission d'accès à l'information*; professional corporations and associations; ethics committees and research committees; organizations such as the Civil Liberties Union and the *Conseil pour la protection des malades*; and other non-profit organizations for service users or their representatives.

The task of ensuring that the Declaration is recognized, applied and amended, as need be, should fall under the leadership of a formal body composed of Québec citizens. This body could be led by the Health and Welfare Commissioner, in accordance with the Commissioner's duties and powers of assessment, information and consultation, and through the establishment of a Consultative forum.