

GUIDE
TO DEVELOPING THE DRAFT DECLARATION
ON RIGHTS AND RESPONSIBILITIES
IN HEALTH AND WELL-BEING

Conseil de la santé et du bien-être
March 2005

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:

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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 : 2-550-44664-X

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INTRODUCTION

In August 2004, the Minister of Health and Social Services directed the *Conseil de la santé et du bien-être* (CSBE) to develop a **draft Declaration on rights and responsibilities in health and well-being**.

Over the past few years, several countries, such as Great Britain, New Zealand, Sweden and Germany, have adopted declarations or charters on health and well-being. Similar initiatives have also been discussed in certain Canadian provinces. New Brunswick, for example, is currently reviewing a bill in this regard.

These declarations, charters or laws are designed primarily to frame the relations between patients and health-care providers (e.g., physicians, nurses). The draft Declaration that the Conseil de la santé et du bien-être wishes to propose would be addressed to all Quebec citizens and would cover both health services and social services.

In developing this draft Declaration, the Conseil will also take into account the Québec government's desire to appoint a Health and Welfare Commissioner (Bill 38). The Commissioner's chief duties will be to assess the performance of the health and social services system, and to consult and inform citizens with a view to fostering informed decisions and public debate. The Health and Welfare Commissioner will also be mandated to issue "an advisory opinion on the most appropriate way for the Minister and health services and social services institutions to inform the public of their rights under the law with respect to health and social services and to sensitize the public to their attendant responsibilities as regards their health and their use of the services offered" (Bill 38, s. 12).

The Conseil de la santé et du bien-être will develop this draft Declaration by calling on the reflection and civic-mindedness of engaged citizens. The process advocated by the Conseil will take place in two stages during 2005. This project will first be presented to various citizens' groups and actors in the health and social sectors (professional and institutional associations, and patient rights' groups). This initial stage will pave the way for a consultation to be held in the fall of 2005 on a preliminary draft Declaration, the development of which will constitute the second stage in the process. According to this timetable, the Conseil should be in a position to propose a draft Declaration to the Minister of Health and Social Services by the end of 2005. It should also be able to present a consultation report at that time. This report will be made public.

This guide is intended to inform and stimulate reflection, and to nourish the debate on the scope and application of the Declaration as well as on its content. It presents framework that the Conseil will use in developing the preliminary draft Declaration, which will be submitted for consultation in the fall of 2005. It may also inspire those interested in participating in the consultation.

This guide is meant for the following people:

- participants attending the “Rendez-vous stratégique sur la santé,” a strategy meeting organized by the *Institut du Nouveau Monde*;
- local, regional and national representatives from various bodies in the health and social services sector;
- representatives from civil society organizations.

Meetings will be held with these people during the winter and the spring. This document will also be made available to the general public, chiefly through the Web site of the Conseil de la santé et du bien-être.

WHAT IS A DECLARATION?

In the context of this project, a Declaration is a document that sets out rights and responsibilities and promotes particular values. It is not a legal instrument but a document with political and symbolic value, and possibly with considerable instructional value for our society, as we shall see further on.

Given that it has no legal status, this Declaration will differ from other major documents that enshrine fundamental rights, such as the *Québec Charter of Human Rights and Freedoms*.

WHY SHOULD QUÉBEC ADOPT A DECLARATION ON RIGHTS AND RESPONSIBILITIES IN HEALTH AND WELL-BEING?

The health and social services system is a public good. It belongs to us all and empowers us all. Its value is rooted in our shared desire to have a high-quality, safe, reliable and accessible health-care system founded on the values of equity, solidarity, justice, freedom and respect for dignity and privacy.

The media often refer to the crisis in our health and social services system and its various problems, some of which seem insoluble (e.g., lack of resources, high cost of technological innovations). Citizens are concerned; some feel a certain sense of powerlessness, while others are cynical about this situation.

The time has therefore come for a collective discussion on our system, on the fundamental values that it must embody, and on the rights and responsibilities related to it.

The development of a Declaration on rights and responsibilities in health and well-being must follow an approach based on participation and deliberation. This approach will culminate in the creation of a text that will be unifying, useful and relevant to Québec citizens as a whole, including members of the government and the various actors in the health and social sectors, such as practitioners (e.g., physicians and nurses) and administrators (e.g., directors and CEOs of regional health and social service development agencies, and directors general of health and social service centres).

WHAT IS THE PURPOSE OF THIS DECLARATION?

This Declaration will be a tool serving to inform all citizens of their rights and responsibilities. It will help raise their awareness of the importance of exercising their rights and meeting their responsibilities. It will also serve as a reference for directing, managing and using our system, and for defending and advancing commonly agreed social values.

Through its elaboration process and the rights and responsibilities that it will recognize, this Declaration will also contribute to strengthening our common commitment to the system and to consolidating democratic life in Québec.

WHOM WILL THE DECLARATION ADDRESS?

This Declaration will address all Québec citizens, not only users of the health and social services system. The values, rights and responsibilities set out in this Declaration will be matters of concern to government members, to various actors in the health and social sectors (e.g., administrators and practitioners) and to citizens as a whole.

WHO WILL ENFORCE THIS DECLARATION AND HOW WILL IT BE ENFORCED?

Respecting the terms of this Declaration should be a collective responsibility shared equally by government members and various actors in the health and social sectors, and by all Québec citizens. The Declaration will not contain legally enforceable measures. Mechanisms designed to protect individual rights in health and well-being already exist in Québec legislation.

It is nevertheless apparent that promoting and applying the Declaration will require moral leadership. The Minister of Health and Social Services or the Health and Welfare Commissioner could shoulder this responsibility.

For the Commissioner, this leadership role could be part of the assessment, information and consultation duties attached to this function. The Commissioner could, for example, promote the establishment of mechanisms sustaining the rights and responsibilities set out in the Declaration. The Commissioner's term of office is set for five years. During that time, the Commissioner could evaluate the relevance and effectiveness of the Declaration, and then update its content. The scope and application, social values, and rights and responsibilities in health and well-being specified in the Declaration could be reviewed and amended accordingly.

- **Who should assume leadership in promoting and applying the Declaration?**
- **Is it appropriate for the Health and Welfare Commissioner to assume this role with regard to the Declaration, as described above? Should some aspects be modified, added or excluded?**
- **Should the Declaration include a clause providing for regular amendments? If so, who should amend it** (e.g., the government, the National Assembly, the Minister of Health and Social Services or the Health and Welfare Commissioner)?

WHAT SHOULD THE DECLARATION COVER?

The Declaration could be divided into five parts: a preamble, followed by sections bearing on its scope and application, on the system's core values, and on rights and responsibilities in health and well-being.

1. Preamble of the Declaration

The preamble could first present statements underpinning both the nature and the scope of the Declaration. The messages conveyed in this section could serve to highlight the collective dimension of the Declaration.

The preamble could contain the following elements:

- The health and social services system is a **public good** that belongs to the community that creates, finances, transforms, evaluates and uses it as a tool for ensuring its health and well-being.
- Québec citizens share social **values** that guide their relations with the government and their fellow citizens as a whole. These values are the cornerstones of the health and social services system.
- Quebecers have health and well-being **rights**, which are recognized and protected by law.
- Recognition of these health and well-being rights contributes to consolidating a **community** that actively defends the common good.
- Citizens, actors in the health and social services sectors and government members have **responsibilities** with regard to the health and social services system.
- The politico-social context shaping the definition of health and well-being policies and issues includes the **standards** and **legal instruments adopted in the international arena**.

- The Declaration is a tool made available to citizens and decision makers in the health and social services system. It is designed to **inform all citizens of their rights and responsibilities**, to **guide the direction, management and use of the system**, and to **defend and advance commonly agreed social values**.
- Consequently, this Declaration spells out the core values and rights and responsibilities in health and well-being that all Quebecers, the government and actors in the health and social services sectors will work toward respecting in order to **sustain our community's commitment towards the health and social services system**.
 - **Should the preamble include all these proposed statements? If not, which should be removed? Which should be added, if any?**
 - **Do you agree with the scope of the Declaration, as presented in the next-to-last paragraph in the preamble?** (a tool to inform all citizens of their rights and responsibilities, to guide the direction, management and use of the system, and to defend and advance commonly agreed social values)

2. Scope and application of the Declaration

Section 1 of the *Act respecting health services and social services* stipulates that “the health services and social services plan established by this Act aims to maintain and improve the physical, mental and social capacity of persons to act in their community and to carry out the roles they intend to assume in a manner which is acceptable to themselves and to the groups to which they belong.”

The objectives and action strategies set out in the *The Policy on Health and Well-being* are, for their part, based on three convictions: health and well-being are conditions arising from ongoing interaction between individuals and their environment; the maintenance and improvement of health and well-being depend on a balanced share of responsibilities among individuals, families, communities, public authorities, society as a whole; public health and well-being is a fundamental investment for society.

This highly open-ended view of health and well-being could lead to a very broad definition of the scope and application of the Declaration. This is a matter of responsibility for the government as a whole and requires that action be taken in several sectors, in addition to health and social services, which include education, employment and the environment.

In view of the significance of the issues at stake in this sector and to ensure that the application of the Declaration can be followed up more effectively, consideration should nevertheless be given to the option of limiting its scope of application to the area under the direct authority of the Minister of Health and Social Services, which includes health and social services, as well as public health.

- **Should the scope and application of the Declaration be consistent with a very broad view of health and well-being, or should it be related to the area of responsibility of the Minister of Health and Social Services?**
- **What would be the pros and cons of each approach?**

3. Core values of Québec's health and social services system

A third element that could appear in the Declaration is a statement identifying the core values considered to be socially and politically relevant for guiding the health and social services system.

As defined in the 1960s, Québec's health and social services system is a public and universal system. This implies access to quality services for all citizens, regardless of their income, geographic location, sex, sexual orientation, ethnic origins, religious beliefs or age. This system is founded on a set of values that are of particular importance to Québec citizens. These values include **solidarity**, **equity** and **social justice** (which imply equitable resource reallocation), citizens' **equality** before the system, the **refusal to countenance any form whatsoever of unjustifiable discrimination**, **freedom** (understood as individual freedom of choice, freedom of action, freedom of expression, and the freedom to challenge that underpins the right to lodge complaints), **respect for dignity**, **respect for privacy**, **civic-mindedness** and **concern for others**, and citizens' **safety and security**.

It should be borne in mind that no one of these values is in itself absolute. Furthermore, the meaning assigned to our core values, along with their political import, needs to be continually clarified, given that society is constantly changing. New social values may also come to be recognized. Current charters of rights and freedoms, along with the laws and standards adopted by governments, contribute to defining these values and to making some of them higher priorities. These decisions reflect the political and ethical choices made by governments. Nevertheless, the struggles waged by citizens and their public involvement mean that these definitions are not static and are part of democratic dynamics that must be recognized and sustained.

The health and social services system is facing several ethical issues that challenge some of our values. For example, the ethical issues surrounding research and technological innovations that lead to interventions earlier in life or that prolong it, sometimes at any cost, as well as the ethical issues surrounding the development of predictive medicine, raise questions not only about respect and the redefinition of dignity, equity and privacy, but also about the system's ultimate purpose and about our conception of what it is to be a human being.

Remember that Québec's health and social services system is also founded on a set of principles set out in the *Canada Health Act*, namely, public administration, comprehensiveness, universality, portability and accessibility.

- **Should the values cited above continue to serve, in whole or in part, as the foundation of Québec's health and social services system? Should some be added, modified or clarified?**
- **Should we give preference to certain values? If so, which ones and why?**

4. Citizens' rights in health and well-being

A fourth element that could be included in the draft Declaration would be a statement on citizens' rights in health and well-being. Recognition of these rights is not intended solely to protect citizens' individual rights. This recognition also covers collective interests, stemming from the fact that health and well-being constitute a common good that must be protected by the government's commitment and concrete actions, such as the allocation of financial, material and human resources. Health and well-being rights are an integral part of the desire to build a healthy, democratic, just, egalitarian and solidaritarian society.

Québec citizens enjoy a number of rights applied within the health and social services system.

- *The major laws spelling out individual rights in health and well-being in Québec include:*
 - *The Act respecting health services and social services;*
 - *The Civil Code of Québec;*
 - *The Charter of Human Rights and Freedoms;*
 - *The Canadian Charter of Rights and Freedoms;*
 - *The Youth Protection Act;*
 - *The Act respecting access to documents held by public bodies and the protection of personal information;*
 - *The Public Health Act;*
 - *The Act to combat poverty and social exclusion.*

- The major individual rights recognized and cited in the *Act respecting health services and social services* include the following rights for users:
 - The right to be informed of the existence of health and social services and resources available in the community and of the conditions governing access to such services and resources;
 - The right to receive, with continuity and in a personalized and safe manner, health services and social services which are scientifically, humanly and socially appropriate;
 - The right to choose the professional or the institution from whom or which he wishes to receive health services or social services, taking into account the institution's service organization and the availability of its resources;
 - The right to be informed of his state of health and welfare and to be acquainted with the various options open to him and the risks and consequences generally associated with each option;
 - The right to consent to treatment;
 - The right to participate in any decision affecting his state of health or welfare;
 - The right to receive emergency care;
 - The right to be accompanied and assisted by the person of his choice when he wishes to obtain information or to file a complaint;
 - The right of access to users' records;
 - The right to the confidentiality of users' records;
 - The right for English-speaking people to receive services in their language, in accordance with the access program established for the region;
 - The right to lodge a complaint against the services received or that should have been received.

Various organizations have been created to ensure that these rights are respected and protected.

- The major organizations ensuring that individuals' rights in health and well-being are protected and respected include:
 - The Health and Social Services Ombudsman;
 - Local service quality commissioners;
 - Regional service quality commissioners;
 - The *Centres d'assistance et d'accompagnement aux plaintes* (CAAP).

- The Quebec Ombudsman;
- Users' committees;
- The *Commission d'accès à l'information*;
- The *Commission des droits de la personne et des droits de la jeunesse*;
- Professional orders and corporations;
- Ethics committees and research committees;
- The *Conseil pour la protection des malades*.

Nevertheless, these rights and their assigned meanings may need to be reviewed, given the changes that are currently taking place both within and around Québec society. Certain gaps have also emerged in recent years, especially with respect to recognizing and protecting the individual rights of people taking part in research projects, and to regulating ethics committees. The same holds true for the recognition of the rights of caregivers and vulnerable members of society (people with decreased autonomy, mental illnesses or substance-abuse problems) who live alone or in unregulated centres.

In a different vein, it would also be important to highlight certain rights in health and well-being, the recognition of which reflects the importance that Québec society as a whole attaches to the health and social services system. These rights, which require government intervention, shed light on the particular role that the future Health and Welfare Commissioner could play, given that they are tied to the Commissioner's assessment, information and consultation duties.

The following three rights could be included in the Declaration:

- The **right to a quality health and social services system**. This refers to accessibility, continuity of care, respect for persons, security, equity, effectiveness and efficiency, among other characteristics. Other factors that are indispensable for maintaining a high-quality system include common policy directions, shared information, co-ordinated actions, accountability on the part of decision makers and practitioners, and citizen involvement in evaluating the system's outcomes;
- The **right** to reliable, relevant and instructive **information** on the health and social services system. That information should enable citizens to gain a clearer understanding of how the system works, to judge whether it is fulfilling its ultimate purpose and to decide if it is being driven in a direction that corresponds to our commonly agreed social values;
- Citizens' **right to participate** in the debates on the issues raised by the health and social services system and to participate in the administration of the system's institutions. This right implies that citizens are able to engage in informed participation and to influence decision makers, chiefly on policies or major programs

liable to trigger profound changes in some aspects of the system. It also implies valuing citizens' particular knowledge, that is, knowledge related to their social and political contexts and to the practices they engage in by choice or by reason of their identity, and the knowledge they have acquired through experience and achievement.

Citizens could also turn to the Health and Welfare Commissioner to remind the government of these rights and of its commitment to them.

Depending on the choice made concerning its scope and application, the Declaration could also include the **right to health**. This right, which is based on a broader conception of health and well-being, is being widely discussed as part of the work underway in different international organizations, such as the World Health Organization. In Québec, the *Commission des droits de la personne et des droits de la jeunesse* believes that the right to health should be enshrined in the *Québec Charter of Human Rights and Freedoms*. The Commission rests its case on the work of the United Nations Committee on Economic, Social and Cultural Rights, which defines the right to health as the "right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health" (CESCR, General Comment 14, UN Doc. E/C.12/2000/4).

This right brings to mind governments' primary responsibility in the area of health and well-being, not only in terms of the programs, goods, services and facilities that they must provide to improve citizens' health but also in terms of the socio-economic factors that promote the conditions enabling citizens to lead healthy lives (food and nutrition, housing, access to potable water, healthy working conditions, and a healthy environment).

- **Should the Declaration revisit all the rights in health and well-being that are protected by Québec legislation? Should certain rights be given preference? If so, which ones?**
- **Should certain rights be clarified? If so, which ones?**
- **Should the Declaration recall the organizations and associations mandated to ensure that rights in health and well-being are respected and protected?**
- **Should the Declaration highlight, as we have just done, the right to a quality health and social services system, the right to information and the right to participation?**
- **Should the Declaration recognize the right to health?**

5. Responsibilities in health and well-being

A fifth element in the Declaration could be a statement identifying responsibilities in health and well-being, both those of the government and those of Québec citizens as a whole.

Certain charters or declarations in effect around the world refer specifically to individual responsibilities in health and well-being. For example, New Brunswick's proposed *Health Charter of Rights and Responsibilities Act*, which is currently being reviewed by the Legislative Assembly, proposes recognizing the following individual responsibilities:

- the responsibility to use health care services in a reasonable manner;
- the responsibility to learn about and to make healthy lifestyle choices;
- the responsibility to share appropriate health information with health care providers;
- the responsibility to inform health care providers of any special communication requirements;
- the responsibility to participate actively in health care decisions;
- the responsibility to communicate health care decisions;
- the responsibility to treat others with courtesy and consideration;
- the responsibility to use complaints mechanisms appropriately and co-operatively.

The increasingly common trend of balancing “rights” and “individual responsibilities” reveals society's uneasiness about the significance attached to personal rights, as if the scope of these rights should somehow be qualified or contained by making people aware of certain responsibilities stemming from these rights. Keep in mind that some federal and provincial laws recognize that certain individual rights are inevitably limited by the human, material and financial resources available (e.g., section 13 of Québec's *Act respecting health services and social services*). Moreover, individual rights must always be interpreted in light of other citizens' rights, public order and recognized democratic values. In this regard, the Québec Charter states that “the rights and freedoms of the human person are inseparable from the rights and freedoms of other and from the common well-being”.

Granted, it may be beneficial to remind citizens of what constitutes a healthy lifestyle. But is it appropriate to include this in a Declaration on rights and responsibilities? The specific identification of obligations and behaviour desired by government is liable to make them prerequisites for receiving services. In that light, those who fail to comply with these standards could be refused services, which would limit their rights.

It should also be stressed that Québec's *Act respecting health services and social services* obliges every institution to adopt a code of ethics that sets out users' rights as well as the practices and conduct toward users that are expected of employees, trainees and interns, including medical residents, and professionals practising in a centre run by that institution. From that perspective, certain codes of ethics already spell out citizens' individual responsibilities. For example, the code of ethics adopted by the CLSC-CHSLD Basse-ville–Limoilou–Vanier specifies what is expected of users. Among other aspects, it covers their responsibility to make appropriate use of the services offered by the institution, that is, to avoid overusing the system, to play an active role, commensurate with their abilities, in the care, services and other activities that concern them, to comply with established standards in order to ensure that all users benefit from high-quality and equitable services, and to follow the rules of good citizenship and courtesy.

How are collective responsibilities dealt with? The government has a fundamental responsibility to ensure the quality, accessibility and continuity of care offered to all citizens. This dates back to the 1960s, when the health and social services system, having become a public good, fell subject to provincial standards and began to be administered by elected political officials. Their accountability to citizens, especially through public reporting, is an integral part of respect for citizens' rights.

To recall that fact, the Declaration should spell out the collective responsibilities of governments and citizens, including administrators and practitioners in the health and social services sectors.

By naming these responsibilities, the Declaration reminds us that it is intended above all for citizens who are actively engaged in and concerned about their community, and not only for those who use the services. Responsible citizenship requires access to appropriate and clear information, the recognition of citizens' particular knowledge and the power to influence decision makers. The government has a decisive role to play both in promoting collective responsibilities and in creating the conditions enabling all concerned to fulfill them.

The Declaration could state that the government and actors of the health and social services sectors are committed to ensuring:

- an adequate **match** between the way in which the health and social services system functions and the standards and social values recognized by citizens as a whole;
- appropriate **funding** for the health and social services system in order to respect its public nature, and to maintain and improve citizens' health and welfare;
- the **quality** of the health and social services system, which brings us back to the accessibility, effectiveness, efficiency and continuity of health-care services, and to a system that is accountable, open to scrutiny and democratic;

- the flow of available, relevant and reliable **information** on the health and social services system to foster informed public debate on health and well-being;
- **democratic debates** on health and well-being issues, primarily on policies and major projects liable to trigger profound changes in certain aspects of the system;
- citizens' informed **participation** within the different administrative and political levels;
- consideration of citizens' particular **knowledge**;
- citizens' ability to **exercise the rights** that are protected under Québec's health and welfare legislation and recognized in this Declaration.
 - **Should the Declaration include individual responsibilities? If so, which ones?**
 - **Should the Declaration spell out collective responsibilities? If so, which ones?**
Should it give priority to certain responsibilities? If so, which ones?

CONCLUSION

This guide is designed to inform and stimulate reflection and to nourish debate in preparation for a consultation that could be held in the fall of 2005 on a preliminary draft Declaration on rights and responsibilities in health and well-being to be developed by the members of the *Conseil de la santé et du bien-être*.

We hope that you will find this guide useful and we remain available to answer any questions that you may have.