

Charting the Course Ahead

Proposal to Enable British Columbians to Engage in Meaningful and Effective Planning for Future Care

EXECUTIVE SUMMARY

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This proposal is being circulated to community groups who were involved in the recent campaign to say “No to advance directive legislation.” After receiving input from the community this proposal will be presented to the Attorney General and the Minister of Health.

The complete version of this proposal includes legislative references and more detailed explanation and examples. It is available at www.rarc.ca

To discuss any aspects of this proposal, please contact Joanne Taylor, Executive Director, Representation Agreement Resource Centre, at 604-408-7414 or jtaylor@rarc.ca

If you are not familiar with the terms Representation Agreements and advance directives or the community’s concerns on this issue, please see pages 8 to 9.

INTRODUCTION

In 2000, the *Representation Agreement Act* was proclaimed with all-party support. This Act provides British Columbians with a meaningful and effective way to plan for the future. For the first time, BC citizens have a legal tool for health and personal care planning.

The *Representation Agreement Act* was the result of a community-government partnership and a consensus-based, grass-roots law reform process. During law reform, advance directive legislation was rejected in favour of Representation Agreements, which are more comprehensive, safer and offer more benefits than advance directives alone.

During the development of the *Representation Agreement Act* and since, some health care providers, health authorities and staff within the Ministry of Health have continued to lobby for advance directive legislation.

Along with lobbying for legislation, some health authorities have been promoting and helping people to complete advance directives. This has given advance directives special status in the minds of many health care providers. Representation Agreements, although law for six years, have not received this kind of support from health authorities or the Ministry of Health and so they are not well known or promoted. Health care providers often do not even ask if someone has a Representation Agreement. This unequal status must be corrected.

Government introduces, then withdraws Bill 32

On December 22, 2005, the Ministry of Attorney General announced a consultation on proposed amendments to four statutes that govern personal planning and adult guardianship in the province of British Columbia. These are: *Representation Agreement Act*, *Power of Attorney Act*, *Adult Guardianship Act* and *Health Care Consent and Care Facility Admission Act*.

The community was taken aback to read that the government proposal included advance directive legislation.

In response to the government consultation on proposed amendments, over 200 community groups said NO to advance directive legislation.

Community groups were therefore very alarmed when advance directive legislation appeared in Bill 32, *Adult Guardianship and Personal Planning Statutes Amendment Act*, which was introduced in the legislature by the Attorney General on April 27, 2006.

The community continued its protest in a wider, public campaign. The result was, that in May, the government decided not to proceed with Bill 32 in the spring session in order to allow for more discussion.

Charting the course ahead

After consulting legal opinion and making careful study of Bill 32, RARC proposes a plan to address the community's concerns and to clarify the place of advance directive legislation in relation to Representation Agreements. It offers British Columbians the opportunity to make a meaningful and informed choice.

Meaningful choice calls for a level playing field for Representation Agreements using a three-pronged approach of legislation, professional and community education and a transparent cooperative planning and implementation process. This means:

- 1) Bill 32 must be amended to further streamline the Representation Agreement process, to enact supporting legislation and policies and to ensure that Representation Agreements supersede advance directives.
- 2) Resources must be invested in community-based public and professional education that will enable Representation Agreements to be well known and easily accessible.
- 3) A community-government partnership must be established with the goal of planning, implementing and monitoring the legislative and policy framework for personal planning.

The following pages provide detail of RARC's proposal for each of the above points. For comprehensive legislative references with respect to the needed improvements to Bill 32, please consult the full proposal at www.rarc.ca

The government of British Columbia introduced Bill 32 in order to give citizens a choice. This proposal lays out the course that must be followed if there is to be a real choice for British Columbians. Every aspect of this proposal is crucial to this goal. Consequently it must be adopted as a package. A piece meal approach will not be acceptable.

RARC'S PROPOSAL

1) Amendments to Bill 32

In Bill 32, as introduced, the government provides changes to the Representation Agreement Act to make Representation Agreements simpler and more affordable. For example, the requirement to consult a lawyer will be removed and signing requirements will be simpler by the elimination of most of the prescribed Certificates. These changes are welcome and necessary.

But further changes are still needed to make Representation Agreements for health and personal care planning, truly accessible to British Columbians and to ensure they have priority over advance directives.

- Make explicit in the *Health Care Consent and Care Facility Admission Act* that Representation Agreements will always supersede advance directives whether the advance directive is made before or after the Representation Agreement is made.
- Require health care providers to inform patients/clients about Representation Agreements for health and personal care planning.
- Place a legal duty on health care providers to search for a Representation Agreement *before* looking for or acting on an advance directive. (The community-based Nidus eRegistry™ is a centralized registry that makes searching for a Representation Agreement and representative quick and simple to do, and at no cost to the health system.)
- Provide support in legislation for health authorities and government agencies to use the Nidus eRegistry™, and to provide that health care providers have fulfilled their duty to search for a Representation Agreement by using the Nidus eRegistry™.
- Require that for an advance directive to be valid, it must be written as a refusal of a *specific* treatment in a *specific* circumstance.
- Ensure the witnessing and signing requirements for a Representation Agreement are equivalent to those for an advance directive.
- Change the requirement that for a Representation Agreement to be in effect, it must be signed by all representatives and alternates. Allow the Agreement to be in effect if at least one authorized representative has signed. This change must be retroactive.
- Provide wording to enable comprehensive coverage of all health and personal care matters within a single GENERAL statement, instead of having to list several SPECIFIC powers and circumstances to try to cover all needs.

- Delete Bill 32 wording related to advance directives which suggests that being incapable of *communicating* a decision is the same as being incapable of giving or refusing consent for health care. Problems communicating do not automatically mean you are incapable.
- Clarify the definition of close relative in Bill 32 to ensure that it includes any adult relative by birth or adoption and his or her spouse. Bill 32 amends the *Representation Agreement Act* to say that people who are paid to provide personal and or health care services to you cannot be named as a representative. This limitation does not apply if the person who is paid is your spouse or close relative. However, the definition used for close relative may not be broad enough and may, for example, exclude an adult grandchild and his or her spouse.
- Clarify that all health and personal care powers in a Representation Agreement are not automatically ended if the court appoints a personal guardian to deal only with a specific matter.
- Give clear direction to care providers and care institutions, such as group homes and care facilities, that an advance directive, including degrees of intervention and levels of care, can only be signed by the adult for him/herself and only if the adult is capable. The practice of requesting or requiring these forms to be signed by anyone else (eg. a representative, spouse or family member) must stop.
- Recognize legal documents made in other provinces or countries that name a person (proxy) to make health and personal care decisions on the adult's behalf. The proxy would be recognized as a representative.
- Update the Community Care and Assisted Living Act – Adult Care Regulations to include Representation Agreements and to clarify the status of representatives in relation to others listed in the Regulations such as next-of-kin and contact person.
- Update the *Hospital Act* and other relevant legislation to require admitting and intake forms and procedures that list next-of-kin to list a patient's or client's Representation Agreement and representative and ensure the categories of people listed are ranked according to legal authority.

2) Invest resources in community-based public and professional education

- Government (Ministry of Attorney General and Ministry of Health) and RARC must begin work immediately on developing community-based promotion, education and training plans to ensure British Columbians have access to information and assistance with making, registering and using Representation Agreements.

- Government must invest resources in public education and training of professionals about Representation Agreements and the Nidus eRegistry™.
- Education of the public and training of professionals must be community-based.

3) Establish a community-government partnership for planning, implementation and monitoring

- Leadership by a community-government partnership is crucial to successful and widespread utilization of future planning and is cost-effective.
- Government must immediately ensure all existing services, policies, forms and promotional vehicles include information about Representation Agreements, the Nidus eRegistry™ and sources of community-based support.
- Implementation and proclamation of amendments in support of Representation Agreements, as outlined here, must have priority over other personal planning and adult guardianship legislative amendments. Amendments in support of Representation Agreements are long overdue. (The community first presented recommendations to government to make Representation Agreements more accessible in 1995.)
- It is essential that health authorities support and refer to community-based public education on Representation Agreements.
- Any programs developed by health authorities or other government departments must be linked to and coordinated with the government-RARC implementation plan and community-based education. For example, discussions about health care wishes including end-of-life care are integral to the process of making a Representation Agreement. When health authorities develop separate programs for health care planning this creates confusion for the public and potential problems for professionals regarding their legal responsibilities.

BACKGROUND

Representation Agreements

A Representation Agreement is a legal document that appoints the person or people you trust to make decisions for you when you cannot speak for yourself because of an illness, accident or disability.

A Representation Agreement covers personal care matters (living arrangements, diet, exercise) as well as health care matters. It can also cover routine financial and legal matters.

Your representative must make decisions according to your wishes. You can express your wishes in the Agreement, in a separate form such as a living will or an *advance directive*, or verbally.

Having a representative ensures your wishes are applied to the correct circumstances. The doctor must explain your situation to your representative and your representative will give consent, refuse consent or withdraw consent according to your wishes for that situation. This dialogue is an important safeguard for you when you cannot speak to the doctor yourself.

Representation Agreements are more comprehensive (they cover more types of decisions and more areas than just health care), are safer and offer more benefits than advance directives alone.

Advance directives

An advance directive is a written document that lists health care treatments you do not want. You sign the directive when you are capable. If, in future, you are incapable of making health care decisions, the advance directive says what treatments you refuse.

There are serious flaws with advance directives. Here are a few examples:

- Directives may have been written some time before being used and may contain out-of-date instructions or may not include more recent wishes you want followed.
- Directives may be based on old medical knowledge and cannot address new treatment options you may or may not want.
- If they are used alone, they will be interpreted in almost all cases by a health care provider who does not know you and will not know what situation you had in mind when you signed the form or if your views have changed.
- It is impossible to give instructions for every potential future situation. There will be situations not covered by the advance directive.

- People come into contact with the health system when they are at their most vulnerable. There is great risk that patients will feel pressured to sign advance directive forms because they want access to care – not because they fully understand the directive or that it reflects their wishes.
- There is a serious ethical conflict when those responsible for providing health services (Ministry of Health and health authorities) are also behind the promotion and facilitation of advance directives. There must be several arms lengths between the service provider and advance directives or it will be seen to be a method of rationing health care services.

The failure of the advance directive approach has also been documented by scientific research.

During the development of the *Representation Agreement Act* and since, community groups have spoken against legislation that would allow health care providers to act on advance directives alone, except in emergencies.

The current law in BC says that health care providers must get consent before treating you. If you cannot give or refuse consent then they must go to your representative. If you did not make a Representation Agreement, they must go to your spouse, a family member or friend (these people must be selected in a particular order). The point is that the health care provider *must* talk with someone who knows you and your wishes. If you have an advance directive, your representative or the selected decision-maker must follow it if it applies to your present situation.

Advance directive legislation in BC

The law already recognizes the use of advance directives alone in *emergency* situations. If the health care provider knows you do not want a specific treatment they must not give it to you.

Bill 32 proposes that health care providers can act on advance directives alone in *non-emergency* situations. The health care provider does not have to involve anyone else in the decision – not your spouse, family member or friend.

Of great concern with Bill 32 is that advance directives could override Representation Agreements. Bill 32 must be amended to clarify that Representation Agreements will supersede advance directives and to ensure a level playing field for Representation Agreements through enacting of supporting legislation and policies as well as enabling community-based education for the public and professionals.