

Charting the Course Ahead

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

Representation Agreement Resource Centre (RARC)

Non-profit, registered charitable organization

411 Dunsmuir Street (411 Seniors Centre)
Vancouver, BC V6B 1X4

Tel: 604-408-7414 Fax: 604-801-5506
info@rarc.ca www.rarc.ca



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TABLE OF CONTENTS

Introduction	3
Government introduces, then withdraws Bill 32.....	3
Charting the course ahead	4
RARC's Proposal	
Amendments to Bill 32.....	5
Invest resources in community-based public and professional education	11
Establish a community-government partnership for planning, implementation and monitoring.....	12
Endnotes (legislative references for section on Amendments to Bill 32).....	14
Background.....	19

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.

An executive summary (without legislative references) of this proposal 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 19 to 20.

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.

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 (HCCCFAA)* that Representation Agreements will always supersede advance directives, whether the advance directive is made before or after the Representation Agreement is made.¹
 - ◇ RARC obtained a legal opinion that the current wording for the *HCCCFAA* in Bill 32 likely allows advance directives to override a Representation Agreement.
 - ◇ The only specific statement in Bill 32 describing the relationship between Representation Agreements and advance directives is in an amendment to the *Representation Agreement Act (RAA)*. Yet it is the *HCCCFAA* that would govern advance directives.
 - ◇ Further, the amendment to the *RAA* only refers to Representation Agreements taking precedence when an advance directive is made before the Representation Agreement is made.
- Require health care providers to inform patients/clients about Representation Agreements for health and personal care planning.
 - ◇ Protocols must be established to ensure that information and help with Representation Agreements is the first priority over advance directives.
- Amend the *Health Care Consent and Care Facility Admission Act* to place a legal duty on health care providers to search for a Representation Agreement *before* looking for or acting on an advance directive. (See next main bullet on the community-based Nidus eRegistry that makes this fast and easy to do, and at no cost to the health system.)²
 - ◇ Bill 32 as introduced says that the health care provider can follow an advance directive if they do not know there is a personal guardian (someone appointed by the court to make health care decisions) or a representative. It says the health care provider is not required to make

- more than a reasonable effort to determine if there is an advance directive or a personal guardian or representative.
- ◇ The only way to ensure health care providers ‘know’ there is a Representation Agreement is if they are required by law to search for an Agreement as their FIRST step after determining an adult is incapable. And the most practical and cost effective way to do this search is to use the Nidus eRegistry™.
 - Provide support in legislation, including the *Health Care Consent and Care Facility Admission Act* and the *Adult Guardianship Act*, 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™.
 - ◇ The Nidus eRegistry™ was developed to honour the public’s demand for a centralized registry service that would make sure a Representation Agreement is available when needed. The idea of a registry was part of the grass-roots law reform project that created the *Representation Agreement Act*.
 - ◇ Currently Nidus registers Representation Agreements and Enduring Powers of Attorney. Nidus will also register advance directives. Government should also enable Nidus to register court-appointed guardians.
 - ◇ Nidus has special protocols to facilitate quick access by health care providers in the case of emergencies.
 - ◇ Nidus is operated by the Representation Agreement Resource Centre (a non-profit, charitable community organization) in partnership with the Law Society of BC’s Juricert Program. It is private and secure.
 - ◇ Nidus does not charge publicly funded institutions (such as hospitals and government services) to access information in the Nidus eRegistry™.
 - ◇ One of the principles of the community-driven law reform and a guiding principle stated by the Ministry of Attorney General in the consultation leading up to Bill 32 is that guardianship must be the last resort. In order to avoid guardianship and to honour the choices people have made, there must be a requirement for health authorities, those applying to court and government agencies to search for people’s personal planning documents.

- Require that for an advance directive to be valid, it must be written as a refusal of a *specific* treatment for a *specific* circumstance.
 - ◇ Bill 32 amendments to the *Health Care Consent and Care Facility Amendment Act* are not clear on this point. The word *specific* is used some times and not other times.³

- Ensure the witnessing and signing requirements for a Representation Agreement are equivalent to those for an advance directive.
 - ◇ We do not know what these requirements will be for advance directives. Following are examples of issues that may need to be addressed.
 - ◇ If advance directives only require one witness, then the same must apply to Representation Agreements. This will require amendments to Bill 32.⁴
 - ◇ If health care providers will be able to witness advance directives there must also be explicit policies that health care providers will witness Representation Agreements. Currently, many institutions have policies preventing staff from being witnesses. This has been a major barrier for patients in hospitals. There must be no bias or perceived bias in this process.
 - ◇ Requirements for signing on behalf of a capable adult who cannot *physically* sign must be equivalent for both documents.

- Change the requirement that for a Representation Agreement to be in effect it must be signed by all representatives and alternates. Allow Agreements for health and personal care to be in effect if at least one authorized representative has signed. This change must be retroactive.⁵
 - ◇ There must also be flexibility in the ways a representative can sign, for example, by counterpart, by fax and other means that will facilitate the Agreement being in effect as quickly as a situation may require.
 - ◇ These changes are necessary particularly in cases where an urgent health or personal care situation arises.
 - ◇ These changes must be retroactive for all Agreements that include health and personal care matters. Since 2000, many adults, especially seniors, have made and are making Agreements with standard powers, under Section 7, because additional health and personal care powers, under Section 9, are not accessible due to the requirement for legal consultation.

- Provide wording in the *Representation Agreement Act* 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.⁶

- ◇ Because there is no simple, general and comprehensive authority for health and personal care matters, a Representation Agreement is made considerably longer because it lists all the separate powers from the Act. It may be necessary to amend definitions in the *HCCCFAA* to enable this provision.
 - ◇ Many people want to give their representative (often a spouse) broad and unrestricted authority to make all necessary health and personal care decisions on their behalf in any circumstances.
 - ◇ A list of separate powers should be retained for those who want to make a SPECIFIC or limited Agreement.
- 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.⁷
 - ◇ People communicate in a variety of ways. A health care provider may not understand your type of communication but it does not mean you are incapable.
 - ◇ You may be capable but have difficulty communicating due to pain, a medical procedure or a device (for example having a tube down your throat).
 - ◇ Deciding you are incapable because you cannot communicate is likely to be based on the particular health care provider's opinion.
- 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.⁸
 - ◇ 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.
 - ◇ In part, the difficulty is in introducing a new term, close relative, instead of amending the existing term, near relative, which is already found in the definitions section of the *RAA*.
- 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.⁹
 - ◇ Bill 32 amendments to the *Adult Guardianship Act* allow the court to appoint a 'personal guardian' for an adult who is incapable of making a decision and where a decision about the adult's health or personal care needs to be made. The court can appoint the personal guardian for a

- specific matter only, such as deciding where the adult will live and with whom.
- ◇ If the court appoints a personal guardian only to decide where the adult will live and with whom, this should not affect an adult's Representation Agreement which, for example, gives his or her representative the authority to make all health care decisions if the adult becomes incapable. Bill 32 wording is not clear on this: "If a personal guardian is appointed for an adult, any provisions respecting personal care or health care within a representation agreement ... made by the adult are ended."
 - 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 must stop.¹⁰
 - ◇ It is common practice for care institutions to ask a spouse, family members or representatives to sign degrees of intervention or levels of care forms on behalf of the person in care. There is no legislation to support this practice or to protect those who sign on the person's behalf.
 - ◇ Often these forms are presented as part of the 'routine' paperwork at the time of admission. Some families feel that signing the form is required or the person will not be admitted.
 - Recognize legal documents made in other provinces or countries that name a person to make health and personal care decisions on the adult's behalf (a proxy). The proxy would be recognized as a representative.
 - ◇ For example, if someone made a Power of Attorney for Personal Care under Ontario's legislation and they move to British Columbia but are now incapable, their Ontario legal document should be treated as a Representation Agreement. This would also apply if someone made a Personal Directive in Alberta naming an agent for health and/or personal care decisions. The agent would act as the adult's representative.
 - ◇ Bill 32 proposes to recognize certain Powers of Attorney made in certain jurisdictions. Bill 32 also provides for recognition of guardianship orders made in other provinces or countries.
 - ◇ Given that advance directives in BC will have very specific requirements and will use a mandatory form, written instructions from other jurisdictions should not be treated as an advance directive in non-emergencies but would serve as the adult's pre-expressed wishes for a personal guardian, representative or temporary substitute decision-maker to follow.

- 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.¹¹
 - ◇ Currently the Regulations use eight different terms, including contact person, next of kin and sponsor, to refer to various people involved in the life of an adult in care. There is no mention of a representative named under the *Representation Agreement Act*.
 - ◇ The current wording is incomplete and is confusing not only to the public but also to staff who must follow the legislation.
 - ◇ The Regulations also need to define the terms used and list them in order, according to legal authority to make decisions.
 - ◇ The term substitute decision-maker is not sufficiently defined. If this is meant to refer to or include the term ‘temporary substitute decision-maker’ under the *HCCCFAA*, it must be made clear that the authority of a TSDM is only with respect to health care decisions.

- 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.¹²
 - ◇ The term next-of-kin made sense in the past. However, in February 2000, the *Representation Agreement Act* and the *Health Care Consent and Care Facility Admission Act* were passed. These Acts spell out who can make health care decisions on behalf of an adult if the adult is or becomes incapable. In the case of Representation Agreements, the adult also has authority to assist the adult to make decisions.
 - ◇ Hospital forms must provide specific space to list representatives and at intake or admission, personnel must ask the question – do you have a Representation Agreement?
 - ◇ This is not only an issue of legal decision-making authority; it is also about privacy and confidentiality. That is, who can the institution share personal information with about a patient or client?

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

Representation Agreements are British Columbia's best-kept secret. Yet given the province's aging population it is important that future planning become common practice and routine. Education of the public and professionals is key.

In his proposals for modernizing guardianship legislation, the Public Guardian and Trustee recommended that government support an education initiative to increase awareness of adult guardianship legislation. In the case of Representation Agreements – the alternative to guardianship – support for education is long overdue and must be government's first priority.

- 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.
 - ◇ RARC is the community expert on Representation Agreements.
 - ◇ RARC was established by citizens and community organizations who were involved in the reform of adult guardianship legislation as a dedicated and hands-on provincial resource for Representation Agreements and Enduring Powers of Attorney with a focus on alternatives to guardianship.
 - ◇ RARC can build on its partnerships with other community groups and professional expertise to provide education and training.

- Government must invest resources in public education and training of professionals about Representation Agreements and the Nidus eRegistry™.
 - ◇ Some health professionals still refer to the Power of Attorney as a tool for substitute health care decision-making. (Power of Attorney cannot authorize anyone to make health care decisions.)
 - ◇ Professionals have also told us that some health care providers do not know the status of Representation Agreements. For example, a health care provider in acute care said, “we only accept what's on health authority letterhead.”
 - ◇ The public who do make contact with RARC, consistently report that they had great difficulty finding out about Representation Agreements and were often told erroneous information. They did not know there was a Resource Centre where they could get information and help and they don't understand why they were not informed about Representation Agreements and RARC by the health system and other government services. Professional education reinforces public education efforts.

- ◇ Education must be available in a variety of formats to be accessible to the public – video, large print, multi-lingual etc. Professional education also needs to be easily available such as through teleconferencing.
- Education of the public and training of professionals must be community-based.
 - ◇ Because the legislation was developed from the ‘ground-up,’ education and training must be rooted in the community’s knowledge of the intent of the legislation and hands-on experience with putting it into practice.

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.
 - ◇ The law reform process that created Representation Agreements was intended to enable all British Columbians to be self-reliant and to make their own arrangements for future care needs. As such, it was not just a tinkering with the status quo or harmonizing our law with other provinces. It is a made-in-BC solution guided by people’s real life experiences. Engaging the public and community in the legislative process builds community capacity and leads directly to a far-reaching ripple effect of public awareness.
 - ◇ We have indeed seen that the ‘aware’ public, with community-based support, has embraced Representation Agreements. Given the demographics and a social policy emphasis on consent and privacy, this is good news. However, the lack of a cooperative community-government partnership and leadership has made future planning and access to information about and assistance with Representation Agreements increasingly difficult and confusing for the majority of British Columbians. Time and capacity has been wasted.
- 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.
For example:
 - ◇ Forms used in health care settings need to record whether the patient/client has a Representation Agreement.
 - ◇ Some municipalities (City of Vancouver, City of Burnaby) include reference to Representation Agreements on information about property taxes and the homeowner grant; other municipalities do not. The Ministry of Small Business and Revenue which administers the Home Owner

Grand Program does not mention Representation Agreements in its frequently asked questions or on the forms on its website. It does however mention Power of Attorney and provides for a general Power of Attorney on-line form.

- 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.
- ◇ It is vital that everyone stays on the same page. Health authorities, for example, must work within the legislative/policy framework. It will be important to monitor that the advance directive forms are not reproduced with health authority logos or packaged as the 'hospital-approved' form.

Endnotes

¹ **Bill 32, Section 21**, amends the *Health Care Consent and Care Facility Admission Act* to introduce advance directives in Section 9.1. The current wording does not make explicit that Representation Agreements will supersede an advance directive in all circumstances.

Section 9.1

(2) A health care provider must not provide health care to an adult if the adult has refused consent to the health care in the adult's advance directive.

Although Section 9.1(1)(c)(i) says Section 9.1 applies when the health care provider does not know of any personal guardian or representative for the adult, there is no wording to specifically allow for a preexisting Representation Agreement to govern. While this may have been the intent, it must be made explicit in the *HCCCFAA*.

Bill 32, Section 54 (b), amends Section 39 of the *Representation Agreement Act* by adding the following subsection (2). This wording must also be explicit in the *HCCCFAA*.

(2) On the making of a representation agreement, an advance directive, as defined in the *Health Care (Consent) and Care Facility (Admission) Act*, made by the adult is ended and is to be treated as the adult's pre-expressed wishes.

² **Bill 32, Section 21**, amends the *HCCCFAA*. The following provisions refer to the effort required to locate a Representation Agreement. The requirements are weak. There must be a duty to search.

9.1 (1)... this section [about acting on an advance directive] applies when

(c) the health care provider

(i) does not know of any personal guardian or representative for the adult, and

(ii) is aware that the adult has an advance directive that is relevant to the proposed health care.

(5) A health care provider is not required to make more than a reasonable effort in the circumstances to determine whether the adult has an advance directive or a personal guardian or representative.

³ **Bill 32, Section 21**, amends the *Health Care Consent and Care Facility Admission Act*. Section 9.2 (a) refers to “**specific** health care”, however Section 9.1 does not use this terminology. Also, in Section 1, the definition of advance directive refers to “**particular** kinds of health care.” Section 35.1 also refers to “**particular** kinds of health care.” The language needs to be consistent and amendments should make clear that an advance directive must be refusal of a ‘specific’ treatment for a ‘specific circumstance.’

⁴ **Bill 32, Section 46**, amends Section 13 of the *Representation Agreement Act* regarding witnessing. Further amendments may be required to ensure signing and witnessing requirements are equivalent to those for advance directives. For example, if only one witness is required for advance directives, subsection 3.01 must be amended and subsection 3.02 must then be deleted. For example (underline is new wording):

(3.01) ~~Subject to subsection (3.02),~~ For representation agreements under Section 9, the adult's signature must be witnessed by 2 one witness ~~each of whom~~ who must sign the representation agreement.

(3.02) ~~Only one witness is required if that witness is a practising member of the Law Society of British Columbia or a member of the Society of Notaries Public of British Columbia.~~

Other amendments may be required to ensure equivalent provisions for witnessing and signing including the provision for someone to sign on behalf of the adult if the adult is physically unable to sign.

⁵ **Bill 32 Section 46** amends Section 13 of the *Representation Agreement Act (RAA)*. Additional amendments are needed to allow for further streamlining of execution requirements.

Currently, the RAA says:

13 (1.1) For the purposes of this Act, a representation agreement is executed when the following requirements are met:

- (a) the agreement is signed and witnessed in accordance with this section; ...
- (2) A representation agreement must be signed by the adult and by each representative and each alternate representative named in the agreement.

Subsection (2) needs to be amended to enable the following:

In the case of a Representation Agreement which includes health and personal care matters, these authorities are in effect if the Agreement is signed by the adult and witness(es) and by at least one representative unless more than one representative is named and the Agreement does not permit them to act independently in the exercise of their authority. Each representative/alternate representative named in the agreement must sign the Representation Agreement before they may exercise their authority. If a person named as a representative/alternate does not sign the Representation Agreement, the authority of any other representative/alternate is not affected, unless the Agreement states otherwise.

The above must also apply retroactively to all Agreements which include health and personal care powers and which were made since proclamation.

Section 13 (3) which says that those referred to in subsection (2) do not have to sign at the same time and may sign in counterpart needs further amendment in the context of the above. Representatives/alternates must be able to sign by means of fax, e-mail (scanned), etc.

⁶ **Bill 32, Section 43** amends Section 9 of the *Representation Agreement Act*. These amendments do not make Representation Agreements simple enough for adults who want to plan for future care. As noted, Section 9 (1) lists six or more* specific authorities with respect to health and personal care matters (see list below).

There must be provision for the giving of a simple, comprehensive GENERAL authority such as “I authorize my representative to assist me or to act on my behalf to give, refuse or withdraw consent for all health and personal care matters in all circumstances.” There needs to be careful review of definitions for health and personal care in this context to ensure they are all-inclusive. For example, what about alternative and complimentary health care matters, consent to admission to a care facility despite objection?

Those who want to give specific or limited powers can choose from a list of specific authorities. Here is the current wording with Bill 32 amendments ((d) and (e.1)):

9 (1) In a representation agreement, an adult may authorize his or her representative to do any or all of the following:

- (a) physically restrain, move or manage the adult, or have the adult physically restrained, moved or managed, when necessary and despite the objections of the adult;
- (b) give consent, in the circumstances specified in the agreement, to specified kinds of health care, even though the adult is refusing to give consent at the time the health care is provided;
- (c) refuse consent to specified kinds of health care, including life-supporting care or treatment;
- (d) make decisions about major health care and minor health care, as defined in the *Health Care (Consent) and Care Facility (Admission) Act*, and give consent to specified kinds of health care, including one or more of the types of health care prescribed under section 34 (2) (f) of that Act;
- (e) accept a facility care proposal under the *Health Care (Consent) and Care Facility (Admission) Act* for the adult's admission to any kind of care facility;
- (e.1) make decisions about the adult's personal care, including, for example, where and with whom the adult is to reside;

Note: (d) which is a Bill 32 amendment is itself a combination of authorities. If the above is a list of specific authorities to choose from, it may make sense to separate the powers in (d) into (d)...minor and major health care... and (d.1)...consent to specified kinds of health care.....

⁷ **Bill 32 Section 21** amends the *Health Care Consent and Care Facility Admission Act (HCCCFAA)* with respect to advance directives:

- 9.1 (1) Subject to subsection (3), this section applies when
- (a) in the opinion of a health care provider, an adult requires health care,
 - (b) **the adult is incapable of**
 - (i) giving or refusing consent to the health care, **or**
 - (ii) **communicating the adult's decision about the health care,**

The references in bold are inconsistent with the principles of law reform and with Section 3 of the *HCCCFAA*, which says “An adult’s way of communicating with others is not, by itself, grounds for deciding that he or she is incapable of understanding [giving, refusing or revoking consent to health care...]”

⁸ **Bill 32, Section 40** amends Section 5 of the *Representation Agreement Act* which deals with who can be a representative. Bill 32 introduces a limitation. An adult cannot name “an individual who provides personal care or health care services to the adult for compensation.” However, “a spouse or close relative of the adult who receives compensation for providing personal care or health care services to the adult for compensation may be named as a representative.”

Why the use of the term ‘close relative?’ This term is not defined in the *RAA*. Amendments to the *Power of Attorney Act (POAA)* (see Bill 32 Section 35) use the term ‘close relative’, which is likely why it appears in Section 40.

"close relative" means a child, a parent, a grandparent, a sibling, an uncle, an aunt, a nephew, a niece, and a person who is married to, or in a marriage-like relationship with, one of these people;

The *RAA* uses the term near relative:

"near relative" means a spouse, adult child, parent, adult brother or sister or other adult relation by birth or adoption;

The *POAA* definition does not include “other adult relation by birth or adoption” which would most notably exclude an adult grandchild. RARC knows of a number of seniors who have named a grandchild as a representative or alternate.

The best approach for the Bill 32 amendment with respect to Section 5 of the *RAA* is to amend the existing term ‘near relative’ rather than introduce a new term. And the amendment should be similar to the definition of ‘close relative’ from the *POAA* while retaining the *RAA*’s broader definition of relative.

Therefore, Section 1(definitions) of the *RAA* would be amended to read something like (underline is new wording):

"near relative" for the purposes of Section 5(1.1), means an spouse, adult child, parent, adult brother or sister or other adult relation by birth or adoption, and a person who is married to, or in a marriage-like relationship with, one of these people;

And **Bill 32 Section 40** re Section 5 of the *Representation Agreement Act* would be amended by deleting the term close relative and substituting near relative in the following subsection:

(1.1) Despite subsection (1) (a), a spouse or ~~close relative~~ near relative of the adult who receives compensation for providing personal care or health care services to the adult for compensation may be named as a representative.

⁹ **Bill 32 Section 4** amends the *Adult Guardianship Act (AGA)*, Part 2 – Court Appointed Guardians, Division 1 – Appointment Procedures, Section 12 on the effect of appointing a guardian on other instruments. Wording as follows:

Section 12 (1) If a personal guardian is appointed for an adult, any provisions respecting personal care or health care within a representation agreement or an advance directive made by the adult are ended, and are to be treated as the adult's pre-expressed wishes under section 20.

However, Section 16 allows the court to appoint a personal guardian to do “one or more things.” If the court appoints a personal guardian to do ‘one’ thing listed, such as decide where the adult lives and with whom, why would ‘any’ personal or health care provisions within a representation agreement end? Is the intent that ‘any’ refers only to the specific authority authorized by the court?

The wording of Section 12 (1) is confusing. Is there confusion about the policy intent? During law reform and development of the *AGA*, there was consensus to move away from ‘plenary’ powers and to instead focus on specific powers as related to the particular and current need.

10 The BC Association for Community Living (BCACL) discusses this issue in its policy on Advanced Health Care Directives. In its paper, BCACL discusses the concept of anticipatory planning, which says that decisions and planning must arise from the adult’s *current* condition. To read more, go to their web site at www.bcacl.org and select Social Policy Positions from the left side of the home page.

11 The Community Care and Assisted Living Act – Adult Care Regulations do not include the term representative under the *Representation Agreement Act* in the definitions nor in sections where they would clearly have authority – for example, Section 4 (5)(c)(ii)

The Regulations need to be updated to be consistent with not only the *Representation Agreement Act* but also with the *Health Care Consent and Care Facility Admission Act* and changes to the *Adult Guardianship Act*.

The **terms** (in bold) are found in the following Sections of the current Regulations:

Section 1 - Definitions

"contact person" means an individual who is willing to assist in making application for care or is willing to maintain contact in the interest of the applicant’s general welfare;

"financial abuse" means

- (a) the misuse of the funds and assets of a person in care by a person not in care, or
- (b) the obtaining of the property and funds of a person in care by a person not in care without the knowledge and full consent of the person in care or their **substitute decision maker**;

"substitute decision maker" means a person who is authorized to make decisions on behalf of a person in care.

Section 4

(2) The licensee shall maintain in safe keeping a separate and confidential record of each person accommodated which shall show

- (c) the name and telephone number of the person's **sponsor, contact person or next of kin**,
 - (d) the name and telephone number of **a person or agency** to contact in the event of accident or illness,
 - (g) any medical disabilities or pertinent information made known to the licensee by the person, the person's medical practitioner, the **next of kin or sponsor, or the contact person**,
- (3) The licensee shall
- (e) keep a record of all effects, monies and valuables returned to the person in care, **next of kin, sponsor or legal representative** at time of discharge or death, and
- (5) The licensee shall not
- (c) other than in an emergency
 - (i) send a person in care to a hospital except on the direction of the person in care's medical practitioner, and
 - (ii) transfer a person in care to another community care facility without the prior consent of the person in care or the prior approval of the **next of kin or sponsor**.

Section 10.9

- (2) A restraint may be used if all of the following apply:
- (a) all alternatives to the use of a restraint have been exhausted;
 - (b) the restraint is as minimal as possible;

(c) the restraint has been approved by the person in care or, if the person in care is incapable of giving approval, by the person in care's medical practitioner and the person in care's **substitute decision maker**;

Section 10.14

The licensee must ensure that

- (a) a fair, prompt and effective process is established for persons in care and their **families or substitute decision maker** to express a concern, make a complaint or resolve a dispute,
- (b) there is no retaliation as a result of a person in care, **family member or substitute decision maker** expressing a concern or making a complaint,

Section 11.3

(1) A licensee must facilitate a forum for persons in care and for **family members and substitute decision makers**, to meet in order to promote the collective and individual interests of persons in care and the involvement of persons in care in decision making on matters and concerns which affect their day to day living.

(2) The forum referred to in subsection (1) may consist of a person in care council or a person in care/family council.

(3) If no person in care council or person in care/family council is established, a licensee must provide an opportunity, at least annually, for persons in care, **family members or contact persons**, or all of them together, to establish a council or similar organization.

The Regulations may also need to be reviewed for consistency with the *HCCCFAA* regarding plans for minor health care and consent for immunizations.

12 Patients have reported that when admitted to hospital they have tried to give the name of their representative but the admitting clerk has responded with a blank stare and said there is not space on the form for this information. While a representative's name can be listed under next of kin or emergency contact that is not the point. The representative's status is the crucial issue. If a patient cannot give or refuse consent for health care when s/he is admitted or during his or her stay, the representative is the contact for emergencies and non-emergencies. Representatives are also authorized to assist the adult with decision-making.

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.