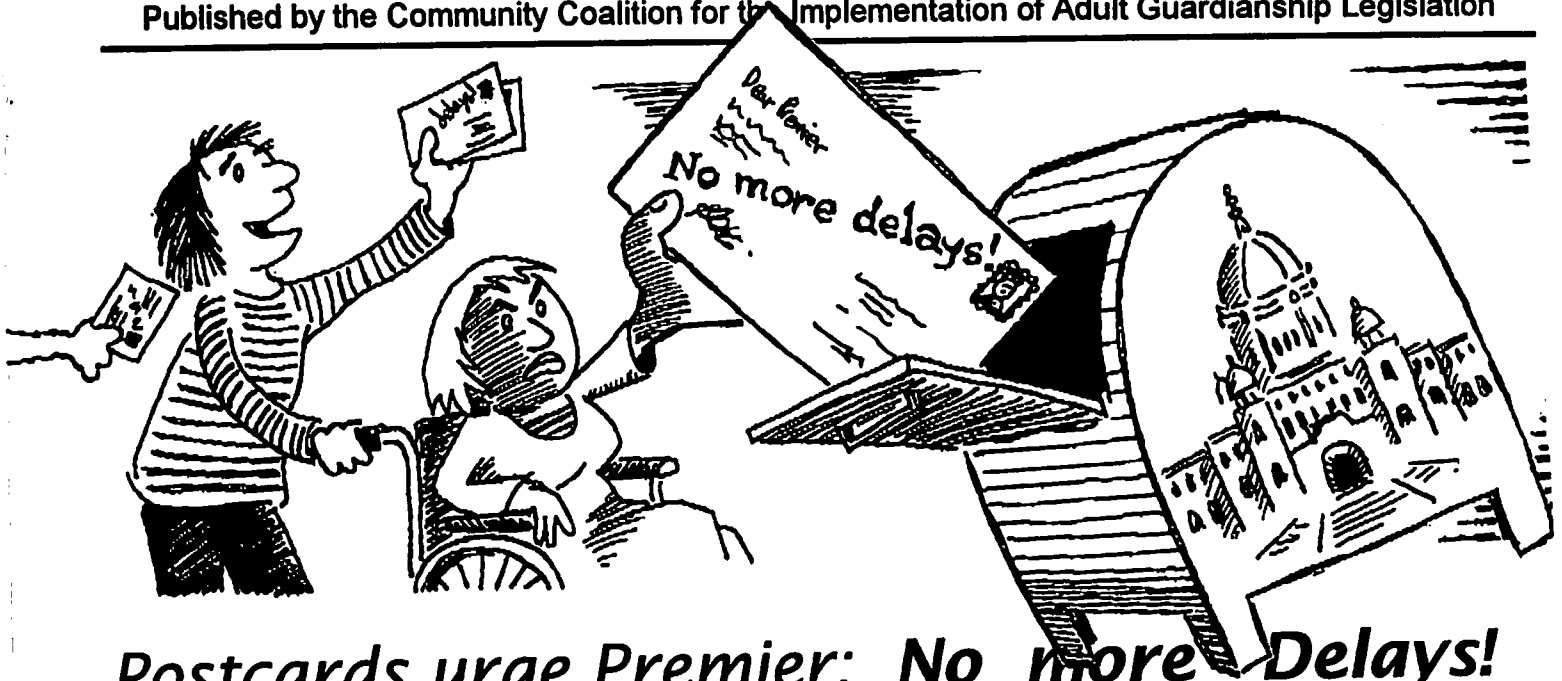


# Guardianship News

Published by the Community Coalition for the Implementation of Adult Guardianship Legislation



## Postcards urge Premier: No more Delays!

Under the leadership of the Steering Committee of the Community Coalition, and with the financial support of several community organizations, a "No More Delays!" postcard campaign is currently underway around the province.

After almost ten years of waiting for a new way to plan for assisted or substitute decision-making in health care, personal care, legal and financial matters, many British Columbians are signing postcards asking Premier Glen Clark to proclaim the Representation Agreement Act now.

The Representation Agreement Act is the centrepiece of B.C.'s as yet unproclaimed new adult guardianship legislation. It is an Act that was made in B.C. and is unique in the world in the way that it enables people to choose others that they trust to support them in decision-

making. It was conceived by a community consensus that there must be strong alternatives to guardianship that are rooted in self-determination and the idea that people are capable through the support of others.

The Community Coalition for the Implementation of Adult Guardianship Legislation has worked over the five years of implementation to keep the dream

*Continued on page 6...*

## Attorney General fails to act

The Attorney General has failed to act on the recommendation of MLA Tim Stevenson's report to proclaim B.C.'s package of adult guardianship legislation. Mr. Stevenson's review of the five year implementation process was sparked by a call from more than 20 community organizations for more public accountability on both the costs and the regulations to the four Acts, especially the Representation Agreement

Act, the centrepiece of the reform.

Mr. Stevenson's report, submitted to Attorney General Ujjal Dosanjh in the summer of 1997, has never been made public, but it is believed to recommend a phased-in proclamation of the package beginning in January 1998 at a total cost of \$1.5 million (down from an estimated \$12 million).

*Continued on page 3...*



## Representation Agreement Resource Centre

# Coalition launches Resource Centre

**Building on our five years of community development work around the province, the Community Coalition has created the Representation Agreement Resource Centre.**

This new non-profit, charitable society will coordinate information and provide volunteer-based assistance on making and using representation agreements.

In travelling throughout BC, Coalition volunteers repeatedly heard that people want representation agreements that are private, affordable, accessible and simple to make, so that personal decision-making remains with trusted family and friends. The Representation Agreement Resource Centre will respond to this need by providing a focus for community-based support and assistance with decision-making.

The Resource Centre has been endowed with resource

material developed during the Coalition's five years of work on representation agreements. One of the most important of these resources is the "Guide Book" to representation agreements—a detailed manual for community advocates and others who are helping other people to make agreements. The Guide Book was the brainchild of the Network of Burnaby Seniors (NOBS) and was partially funded by the Seniors Health Promotion Network.

"This is about average people helping other average people," said Tom Klopp of NOBS, who worked on the Guide Book project for three years. He pointed out that the Guide Book was written by community



**Resource Centre Opening:** Tom Beddows, Judy Carter-Smith, Al Etmanski, Christine Gordon, Margaret Birrell, Zara McLeod

volunteers, not government, and is based on people's real life experiences.

"We want to make sure that representation agreements are simple, inexpensive and easy to make so that average people can use them," said Klopp.

The Resource Centre is a volunteer-managed non-profit society and a registered charity. It is in operation now with volunteers providing workshops and personal assistance.

For more information write the Resource Centre at #204 - 456 W. Broadway, Vancouver, BC V5Y 1R3 or call (604) 875-0188 or fax (604) 875-9227. □

**Guide Book Launch:** MLA Fred Randall, MLA Graeme Bouwrick, Tom Klopp of NOBS, MLA Christie Clark, MLA Joan Sawicki



## Advance directive policy ignores rep agreements

Three member groups of the Community Coalition—the Alzheimer Society, the BC Association for Community Living (BCACL), and the BC Coalition of People with Disabilities (BCCPD)—have expressed their concern about the Ministry of Health's advance directive policy. In a joint letter to the Ministry they said:

"Even with the best of intentions, advance directives that are administered through health care providers or health care facilities jeopardize people's ability to privately plan for end-

of-life care. Health care providers need to be consulted, but they should not be the initiators of end-of-life planning in order to avoid even the semblance of conflict of interest or values in the most important personal decision of an individual's life."

"Representation agreements offer a better way to provide health care providers with instructions as well as representatives who can be trusted to speak on behalf of the patient."

However since 1997, despite the offer by Community Coalition member groups to collabor-

ate on implementing representation agreements as the best kind of advance directive, the Ministry of Health has proceeded to develop its own policy on advance directives. The Ministry is currently conducting workshops to introduce the "Let Me Decide" format to health care providers and service providers for people with disabilities.

Advance directives are a list of instructions that document personal wishes for health care in the event that individuals are unable to state their wishes.

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## Proclamation delay: Inaction undermines community effort

*Continued from Page 1*

Since receiving the report last year, the Attorney General has been silent on the government's plans for the legislation. This is despite frequent efforts by a range of community groups to contact his office and to press for his response.

In questioning by Liberal MLA Geoff Plant during the Estimates debates for the Attorney General's Ministry on April 27, 1998, Mr. Dosanjh cited "fiscal constraints" as the major hurdle to proclamation.

The work to develop B.C.'s package of adult guardianship laws began in the community in 1989. After four years of extensive community participation under the leadership of the Project to Review Adult Guardianship (PRAG), a unique partnership agreement was made between PRAG and the Office of the Attorney General. This

partnership led to passage of the four Acts by the B.C. Legislature in July, 1993.

In September, 1993 with joint community-government conference was held to identify key implementation issues. The formation of the **Community Coalition for the Implementation of Adult Guardianship Legislation** came from the conference's major recommendation to have strong representation from the people whose lives would be most affected by the legislation: seniors, people with disabilities, and their personal supporters.

Volunteer representatives of the Community Coalition have been working consistently since 1993 to bring the consumer's voice to all aspects of the implementation process and to play a leadership role in the community development and public education for the

Representation Agreement Act.

PRAG's four years of groundbreaking work (the Project's documents are now housed in B.C.'s Legislative Archives) was followed by five years of volunteer work by the Community Coalition. The Coalition's publication list stretches over two pages and during 1997 alone it held more than 100 workshops throughout B.C. Other community groups have also been involved in the government committees that have been struck over the years. All this adds up to an unprecedented and extraordinarily long-running community contribution.

The Attorney General's failure to act on the Stevenson Report appears to devalue this contribution and the needs of the people who are seeking through these new laws dignified community-based alternatives to public guardianship. □

## Why Seniors need Representation Agreements

**For this issue we interviewed three seniors on their views about why representation agreements are important for seniors.**

**Tom Klopp** is a founding member of the Network of Burnaby Seniors. He joined the Burnaby Caregivers support group a number of years ago because his wife had Parkinsons Disease. Tom has been involved with the adult guardianship legislation since the early days of the Project to Review Adult Guardianship—about eight years.

**Don Beddows** retired ten years ago and joined the BCGEU Retirees New Westminster chapter. He was appointed as a delegate to the Council of

Senior Citizens Organizations of BC, and is now Treasurer. He joined the Community Coalition just after the new legislation was passed in 1993.

**Patricia Fulton** has been involved with seniors groups since 1973. She served as Executive Director for the Federal New Horizons program, was a founding member of the Seniors Resources and Research Society, Chairs the Seniors Health Committee of the Social Planning and Research Council of BC, is a member of the Board of Directors of the Seniors Foundation, and sits on the Seniors Public Health Advisory Committee of the Vancouver/Richmond Health Board. Pat joined the Community Coalition in 1993.



**Pat Fulton**



**Tom Klopp**

**Why are representation agreements important for seniors?**

**Don:** I used to be immortal and invulnerable. But once you get past 70 life gets to be quite dangerous. It is vital to be able to pre-plan not just wills and funerals, but the sorts of care we need and sorts of decisions that might have to be made on our behalf. This is not available except through a representation agreement.

My wife and I have reciprocal powers of attorney but they're limited and they don't cover areas into which we really want to go. The representation agreement has the underpinning of legal authority, and that's a very comforting thing.

Seniors tend to look ahead and it's likely to be more important for them than to young people.

**Pat:** Representation agreements make provision for people to assist their peers and relatives in a humane, truly charitable fashion. I am particularly interested in how they will

facilitate setting up support networks for isolated seniors

**Tom:** It allows a person to pre-appoint somebody to speak for them when they are not able to speak for themselves, or have difficulty making themselves heard.

In many cases long term care and other personnel have the idea that they know what is best for a person, and that person may be unable to express themselves so that somebody will listen to them. A Representative can ensure that their voice will be heard.

It's particularly important that this representation continue after admission to a facility. Institutions often do not listen. Representatives can be there to support the individual.

**Some people are worried that representation agreements may be used as a tool of abuse. How do you feel about that?**

**Pat:** I think it's a very jaundiced view of society. The majority of

older people are going to the greatest lengths they can to assist their peers.

**Tom:** There will always be people who abuse the system. But to legislate for that very small minority is very wrong. The vast majority of people will be able to use representation agreements. They know who they can trust to appoint.

**Don:** Why would I fear abuse with a new tool that has more safeguards than anything available now?

It doesn't matter what protections you put in place, some people will abuse them. If broom handles are used to beat people, you can't take broom handles out of every home. What instrument would be totally proof from abuse?

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**Can you give some examples of situations where a representation agreement would have made a difference?**

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**Pat:** Years ago an employee of mine became seriously ill. We set up a care team of seven people so that she could die at home. These people, this group, were really a sort of representation agreement, without the legal document. We represented and supported her.

Representation agreements are a way of formalizing groups that surround people who are in need of assistance.

**Don:** I know of a case involving an elderly lady in an institution. Her daughter applied for committee through the court and got it without her knowledge. The family doctor didn't inform the mother about the application because "it might upset her." Nobody asked her what she wanted.

If she had made a representation agreement, she would have appointed another relative as her Representative, not her daughter, and nothing could have been done without first consulting her.



**Don Beddows**

**Tom:** In the case of my wife, the care home would not listen to me about what she needed. I called in my entire family for support and the home said they were listening, but they didn't.

I ended up starting the committee process for my wife because everybody "knew best" and didn't listen to us. If we'd have had a representation agreement with legal clout it would have made a difference.

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## *On resisting temptation to give people advice*

One of the things that Coalition member Don Beddows talks about when he goes out to give workshops on representation agreements, is "the dangers of giving people advice."

Beddows and other Coalition members have been training volunteers to assist other people with making representation agreements. One of the keys to doing this, he says, is **learning to help people reach conclusions without influencing them.**

"It's tempting to offer personal opinions—and some people will even ask you to make a decision for them," said Beddows. "But we have no right to influence anyone. We only present the options clearly and let the other person decide."

A good way to learn this is by holding role-playing sessions in which new volunteers "practice" helping someone make an agreement. "Avoid saying things like 'If I were you...'," said Beddows.

Beddows also urges volunteers not to rush people, or to try to cram too much into one session.

"You may have to see a person two or three times," said Beddows, "and let them think about it in between and perhaps discuss issues with family members or others concerned."

People who are interested in helping others make representation agreements should contact the Representation Agreement Resource Centre. □

## Advance Directives: Ministry turns clock back 8 years

Continued from Page 3

There are currently many different types of directives being used for health care decision-making. Many hospitals use Do Not Resuscitate (DNR) directives that are supposed to be offered as an option to patients. However, there are reports that DNR orders are sometimes entered into patients' charts by health care providers without adequate discussion with patients or their families.

Many long term care facilities are using Degrees of Intervention directives that outline how much care will be provided in given medical situations. New residents or their families are often compelled to check off these selected options as a prerequisite to admission to the facility.

Living wills are another kind of directive which emphasize a statement of personal beliefs and values about how end-of-

life decisions should be made.

The advance directives model promoted by the Ministry of Health is based upon the "Let Me Decide" Health Care Directive developed by Ontario physician William Molloy. Molloy's format combines the degrees of intervention approach with the living will statement of beliefs and values. The "Let Me Decide" directive also includes the naming of a proxy or substitute decision-maker.

The position of the Coalition's member groups is supported by research at the Centre for Bio-ethics at the University of Toronto. In an article in the *Journal of Health Law in Canada* (Aug./95, Vol.16, No.1) entitled "Advance Directive Fallacies," Dr. Peter Singer, the Centre's Associate Director stated that in their research:

*"people viewed their advance care planning as a private matter that belongs in the context of their family and close relation-*

*ships. So advance care planning, a social process, does not primarily unfold in hospital rooms and doctors' offices. It unfolds in people's living rooms and around their kitchen tables in the context of their families and loved ones. The goal of social policy... should be to support these discussions between people and their family or loved ones."*

In letters to the Minister of Health and the Attorney General, the Alzheimer Society, BCACL and BCCPD expressed shock that the Ministry of Health has turned the clock back a full eight years by ignoring all of the work that has been done to develop the representation agreement. They have urgently requested that the Advance Directive policy be shelved and that the Ministry of Health work with the community to make the representation agreement the standard for ethical end-of-life decision-making. □

## Postcards

Continued from Page 1

of representation agreements alive. The Coalition wants representation agreements to be accessible to every British Columbian. They must be private, affordable, and simple to make. This is not an easy mission, but it is essential if the whole package of adult guardianship legislation is to remain true to its principles: that representation agreements be a people's tool and not a bureaucratic nightmare.

People who need or may soon need representation agreements cannot afford to wait any longer for these agreements to have legal effect. Although many people are making and successfully using representation agreements now, many others are waiting until the Act is proclaimed because they are worried that their agreements might not be respected without the "force of law" that proclamation of the Act will bring.

The postcard campaign's message is "No More Delays!" and it is addressed to the Prem-

ier. It asks for his leadership in ensuring that the proclamation of the made-in-B.C. representation agreement is given the same place of pride as Forest Renewal BC, the BC Film Industry, and the BC Fishing Industry. The proclamation of the Representation Agreement Act can be the first step in the government's new initiative to cut red tape and give people a tool to support private decision-making.

All British Columbians need the opportunity to make representation agreements and the security to use them. □

# Top 9 Reasons to make a Representation Agreement

**Voice**

Your representative will ensure you have a voice at a time when you can't speak for yourself.

**Strong Relationships**

The process of making an agreement gives your friends and family an opportunity to get to know you better. It strengthens your relationships with those you trust.

**No Guessing**

Your friends and family don't have to try and guess what you want, especially in an emergency. It helps prevent arguments and confusion and makes decision-making quicker.

**Protection**

It is the best chance for your wishes, values & beliefs to be honoured. It prevents someone from making a decision about you that is based on his or her priorities rather than yours.

**Credibility**

Having a legal document gives your representatives confidence and credibility. Those who care about you the most will not be ignored or treated with suspicion.

**Privacy**

It keeps your personal and private life out of the hands of government bureaucracy. It helps prevent you from being treated like just a number or a case.

**All-in-One**

An agreement can cover all your

affairs: financial, legal, health and personal care.

**Simplicity**

Almost everyone can make a simple agreement easily and inexpensively. You don't have to get an assessment or be scrutinized beforehand.

**Flexibility**

Your Representatives, Alternates and (if you wish) Monitor will make sure the agreement keeps working for you even if circumstances change.

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## Purposes of the Community Coalition

1. To provide a way for people who are immediately and critically affected by guardianship laws to speak with one voice.
  2. To promote the community's work of keeping people safe and honouring their choices.
  3. To build on community strengths when putting the adult guardianship laws into effect.
  4. To promote community alternatives to public guardianship.
- 

### Representation Agreements

allow B.C. citizens to choose people we trust to speak for us if we are unable to speak for ourselves.

Representatives protect our beliefs, wishes and values, and can make decisions about:

- health care
- legal matters
- finances
- personal care

No other legal document offers private citizens this kind of broad protection.

The *Representation Agreement Act* was passed in 1993 and is STILL not in effect.

Community members have been working on its implementation for 5 years. British Columbians want representation agreements made legally enforceable NOW!



**Postcard to the Premier**

**Mail this!**

Clip & send in an envelope or contact the Coalition for postcards. (see next page for our address)

**Join us!**

The Community Coalition is:

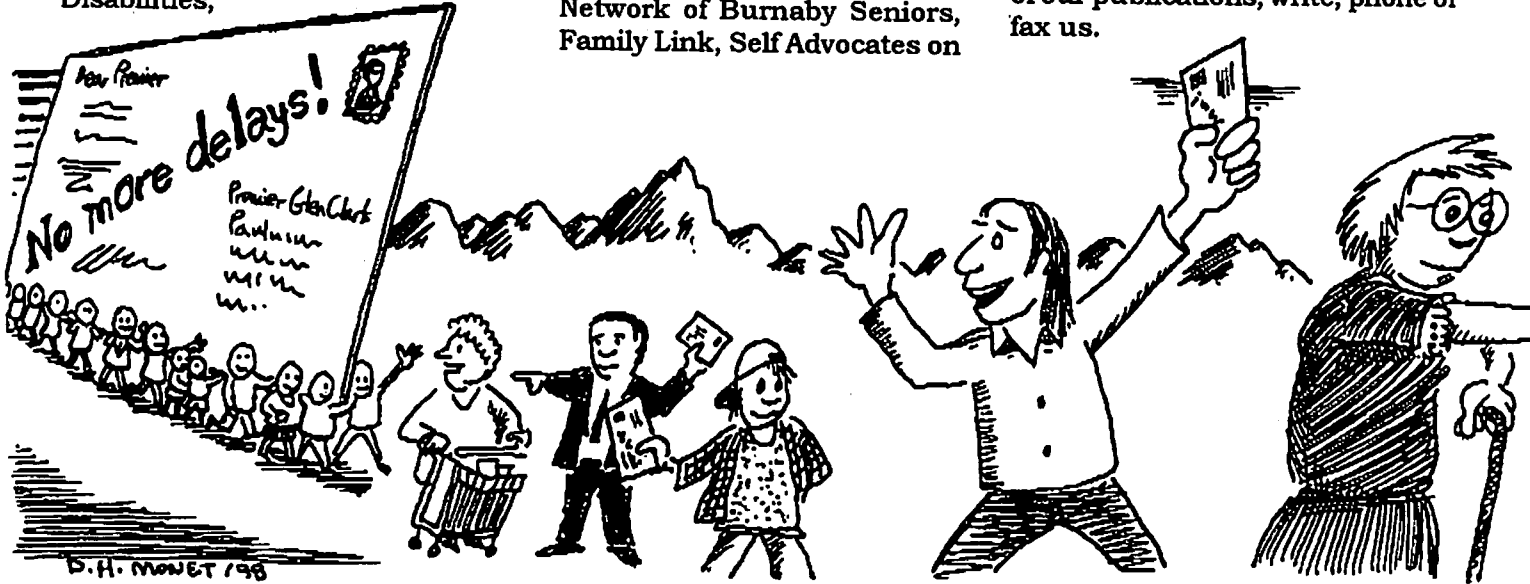
- ◆ **Provincial Organizations** - like BC Coalition of People with Disabilities,

the BC Association for Community Living, the Alzheimer Society, and the Council of Senior Citizens Organizations

- ◆ **Local Groups** - like the Network of Burnaby Seniors, Family Link, Self Advocates on

the Move, and the Kamloops Seniors Liaison Council

- ◆ and over 3000 **individuals**
- To become a member or to get any of our publications, write, phone or fax us.



**About this issue of Guardianship News**

This newsletter was produced by the Community Coalition for the Implementation of Adult Guardianship Legislation, #204 - 456 West Broadway, Vancouver, BC V5Y 1R3

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**Postcard to the Premier**

**Mail this!**

Clip & send in an envelope or contact the Coalition for postcards. (see address above)

Dear Premier,

The *Representation Agreement Act* was passed in 1993 and is STILL not in effect.

Community members have been working on its implementation for 5 years. British Columbians want representation agreements **NOW!**

Signature \_\_\_\_\_

Address \_\_\_\_\_

Postal Code \_\_\_\_\_

**No more delays!**

attach stamp here

Premier Glen Clark  
 Parliament Buildings  
 Victoria, B.C.  
 V8V 1X4

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