

Guardianship News

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

Fran's legacy of caring

by Pat Feindel

Some people thought it couldn't be done, but a small group of dedicated friends and supporters successfully designed and used a representation agreement for a woman with no family and very limited ability to communicate.

Frances is a woman who is supported by the Community Living Society. She lives in a home with two other women.

When Lynn Thomas of the Community Brokerage Services Society met her about a year and a half ago, Frances was ill with cancer. She had already had a serious health crisis because no one was available to consent to health care. She had difficulty understanding and communicating, and had no family members or close friends to help make health care decisions. (Group home staff are not permitted to make health care decisions for individuals.)

Lynn Thomas is a community services broker. She helps individuals figure

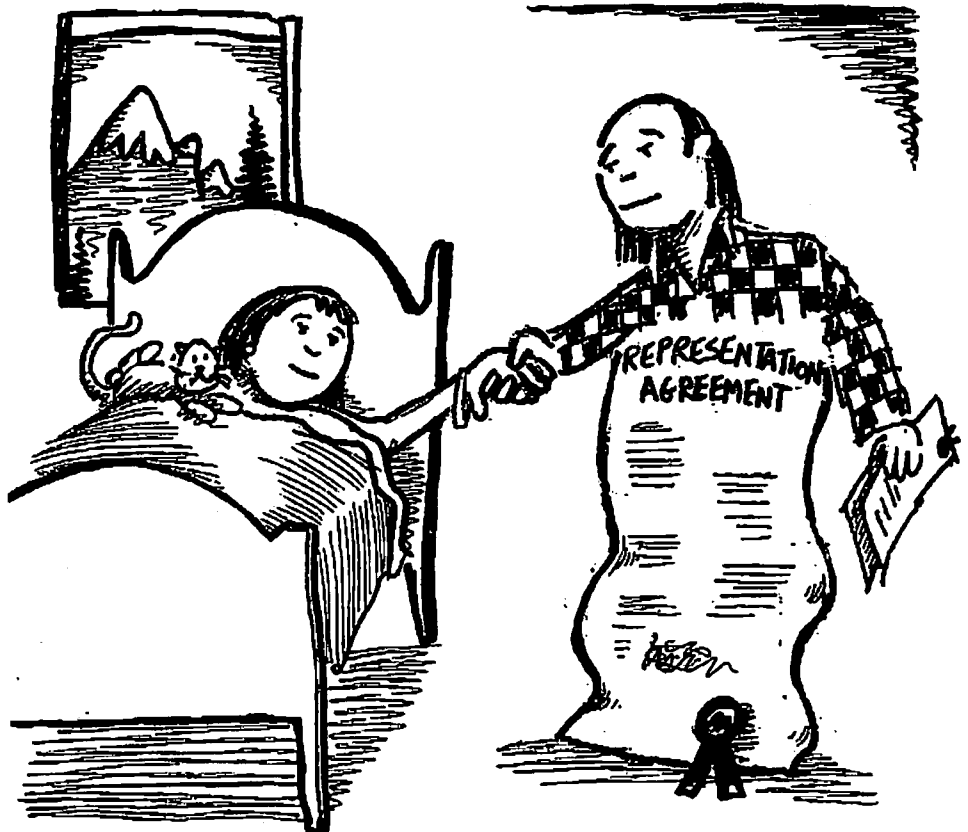
out what services they need and where to find them. Lynn realized that what Frances needed was a "personal network."

With a little searching, Lynn found two people who had known Frances for many years and were willing to become her personal

advocates. One was a childhood friend and the other was the mother of another person in Frances's home.

But both advocates were nervous about making decisions for her. How could they make decisions if

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This issue: Representation Agreements



Frances Denny

Fran's Story

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Frances couldn't understand what was happening or tell them what she wanted? It seemed like a big responsibility.

So, Lynn brought together all the people involved in Frances's care to talk about making a representation agreement. She also invited Christine Gordon and Joanne Taylor from the Community Coalition to give them more information about representation agreements. "Having this outside resource was a big, big help," said Lynn.

After hearing the information, the group started by identifying everyone involved in Frances's life and defining each person's role in supporting her. They used a blank representation agreement form provided by the Coalition, filling it in and expanding on the basic elements.

They continually asked themselves: "If Frances were speaking to us, what would she tell us to do?" Since Frances's condition was rapidly deteriorating and the group knew her illness was terminal, they also asked: "How would Frances want to spend her last days? How can she be supported with dignity and respect?"

Talking about these questions was not always easy. "A lot of emotion happened during those meetings.... Every time we sat down to talk about it, there would be grief about Frances's illness progressing" says Lynn. "We all decided it was okay—you're going to have emotions during this process, and it's better to talk about them to clear the air."

For health reasons, Frances was not able to attend, but Lynn and the group home staff kept her informed. Lynn contacted someone with experience in non-verbal methods of communication who helped the group home supervisor develop an album. The album included photos of the people involved, and a picture script to help Frances understand as much as possible about the group's discussions.

After several drafts, the group came up with a strong agreement that they believed represents Frances's wishes. Frances's two personal advocates became joint representatives, making decisions only with the input of the larger group of support people. In addition, two of the staff were able to give health care consent in emergencies if the representatives weren't available.

Lynn believes that having so many people involved is a great advantage. "They all care about Frances and they share a common goal." The larger group acts as a safety net, and the representatives don't feel burdened by the responsibility of making decisions alone.

"It helps to anticipate situations and cover as many bases as possible ahead of time," says Lynn. The group discussed issues that would arise as Frances's health deteriorated, and planned for them in the agreement. These included palliative care,

pain management, dying at home, and a "Do Not Resuscitate" order.

The agreement also addressed the role of Frances's health care professionals. Lynn went with Frances and her staff to her medical specialist, naturopath and community health nurse, and told them about the representation agreement. The health care workers all enthusiastically agreed to cooperate with Frances and her representatives.

With so many people involved in the agreement, good communication was vital. "There has to be a clear flow of information... not just about big things, but about little details too," said Lynn.

The group nominated Lynn as monitor. Lynn doesn't participate in decision-making, but she gathers information, passes it on to everyone, and makes sure that everyone is involved according to the agreement.

"We took on a challenging situation," admits Lynn. "But the process evolved naturally as we went along." And the key that made it all possible was the committed support of a group of caring and dedicated people who wanted to assist Frances.

★ ★ ★

On September 1, 1995, Frances died peacefully in her home surrounded by people who cared about her. The representation agreement had ensured that her last wishes were carried out.

A few weeks after Frances's memorial service, her representatives and the personal supporters who assisted them came together to reflect on their experience. The process of making and living the agreement with Frances had been a powerful one. "It kept us so focussed on Fran," everyone agreed, "and it gave us the confidence and the credibility to speak up for her. The representation agreement will be her legacy."

One of Frances's representatives has volunteered to be a resource for other people developing representation agreements. If you would like to talk to her, contact the Community Coalition.

As more and more of you develop representation agreements, your experience will become a valuable tool to help others. We invite you to share your stories and experiences with us. □

A Simple (Sample) Agreement

The following is a short fictional representation agreement. A complete agreement would include additional details such as addresses and phone numbers. For full details on the elements of a representation agreement, order a copy of "Walking Through a Representation Agreement" (see back cover).

My name is Iris. I am making a representation agreement because my current health makes it difficult for me to get around and I need assistance now with managing some routine daily affairs. I also want to plan for the future if I become unable to make my own decisions.

My friends Jean and Pat, and my daughter Elly are my Representatives. My son Ron will be my Alternate Representative.

I appoint Jean and Pat to make decisions about my health and personal care and financial matters related to daily living. I appoint Elly to handle any larger financial matters and my legal affairs. Jean and Pat will make decisions together. If they disagree, they will contact Elly and I want all three of them to come to an agreement.

I want this representation agreement to begin immediately.

I have given copies of this document to my Representative and Alternate Representative. I have discussed my wishes with my doctor and my bank manager. □

Walking a new path...

Being a Representative

by Christine Gordon

The story of Frances's representation agreement brings to life the vision that inspired people to come together to talk about these agreements more than five years ago.

What does it mean to represent someone? At the heart of the question is the idea of what it is to be a human being. We are so similar that we can share the experience of being human, yet very different in how we each choose to express ourselves.

The ability to make choices that are uniquely our own constitutes the great struggle of our lives. Being denied the right to make those choices leads to a sense of helplessness and sometimes hopelessness. Personal decision-making is so critical that most research now identifies it as the key to health and well-being.

The new adult guardianship legislation recognizes this by stating that every adult is capable and must have the right to self-expression wherever possible. Expression can be words or gestures or patterns of behaviour. All communication is a form of self-expression. When self-

expression is not possible, then others must try to express all that they know about what the person they are representing believes, values or desires.

This idea of representing another person is very different from old ideas of guardianship. A guardian has traditionally done what they think is best for a person. This could mean applying the beliefs or wishes of the guardian to the situation of the person in care. It is usually easier to do this because our knowledge of ourselves is always surer than our knowledge of others. And it is often more comfortable to do this because a best interest decision tends to avoid risks and conforms to the middle ground or to what most people usually do.

Representatives must walk a different, more challenging course by constantly seeking to put themselves in the shoes of another person and by **speaking out the other person's values and beliefs**, no matter how different these may be from the representative's own.

How can a parent meet this challenge of being a representative? Everyone who has been a parent knows how difficult it is to let go of personal expectations and to allow children

to be themselves. Representing an adult who is your child will mean struggling with the same questions that began at birth: Is this what I want or is this what my child wants? Children who represent their parents must turn this question around and face the same critical self-examination.

What is the role of professionals who support adults who cannot express themselves? The professionals in Frances's life cared for her and respected her, but they realized that they could not represent her effectively. That is why they sought out people who were not bound by professional responsibilities but who were free to act only for Frances. When they enabled these representatives to act, the difference in Frances's life, they said, was "night to day."

Frances's experience tells us that the dream of an identity affirmed through a representation agreement can work and that everybody involved can help to make it work. This is the legacy of Frances's representation agreement and this is the opportunity of the new legislation. □

Christine Gordon is the Coordinator of the Community Coalition

Regaining control of your life

How a representation agreement can help

At the Provincial Forum on Representation Agreements held in November, 1994, participants spoke about their life experiences and how representation agreements could fit their needs. One person told the story of her son and what he did to take control of his life.

Mark is a young man who has experienced episodes of mood disorder. Each episode created great disruption in his life. Not only did Mark have to struggle to get treatment, but he also suffered unpredictable consequences. Sometimes his bank account was overdrawn, or he lost his job or housing.

Mark's doctor gave him a sample Ulysses Agreement published by the Project to

Review Adult Guardianship (the forerunner of the Community Coalition). This type of agreement lets individuals plan for episodes of mental illness that may leave them temporarily unable to make decisions on their own. Mark thought about this idea for several months and then decided to try it out.

He asked four members of his extended family to act as his Representatives. He simplified the sample agreement and divided the Representatives' responsibilities into three major areas: health care, financial affairs, and employment. He described very clearly the circumstances that would signal his Representatives to act on his behalf. He also indicated what he wanted them to do. His doctor

agreed to play a supporting role.

Mark and his family members signed the agreement and then they took it to a notary public to verify their signatures.

Mark's Representatives have acted on the agreement several times in the past three years. They've used it to freeze bank accounts and credit card accounts, to help Mark to obtain treatment, and to manage his personal affairs. The agreement has been honoured by the financial institutions and professionals who have been called upon by the Representatives.

Mark says that the agreement has "saved his life." He no longer has to pick up the pieces and start over after an illness. □

Advocacy Award

Congratulations to **Helen Connolly** and **John Sheckleton** who were named as the winners of the 1995 second annual B.C. Mental Health Society Advocacy Award.

Helen and John are both members of the Community Coalition and long time advocates.

They'll receive their award formally on December 12 at a special dinner to be held at the Hotel Vancouver.



Seniors at a Representation Agreements workshop

What you wanted to know:

Following are some of the questions frequently raised at presentations on representation agreements.

? When will the Representation Agreement Act be proclaimed?

Laws are proclaimed (take effect) when all the regulations, policies, and programs to support them are in place. This is called the "implementation" period for representation agreements. During this time people are trying out and using representation agreements. We are learning a lot from their experiences.

The government is working towards proclamation in 1996.

? What if there's a change of government?

This legislation is non-partisan and has received support from members of all provincial parties. The law reform process started under the Social Credit government and the new laws were passed during an NDP government.

? What if I don't make a representation agreement?

You are **not required** to make a representation agreement. It's your choice, and you may not want or need one.

A representation agreement lets you express your wishes and to name the person you want to assist you to make decisions or make decisions for you if you are unable to speak for yourself.

If you don't have a representation agreement, it does **not** mean that your affairs will automatically be taken over by the Public Guardian and Trustee.

? How will my Power of Attorney or Living Will be affected by representation agreements?

The Coalition believes that all pre-planning documents which people have already made should be recognized and accepted after the *Representation Agreement Act* goes into effect.

These would include living wills, advanced directives or health care authorizations (which name someone to make decisions), enduring powers of attorney, Ulysses agreements and existing representation agreements. The government is aware of our concern.

Some people will want to make a representation agreement as well or instead of other documents. A representation agreement can include the same authority as an enduring power of attorney, living will or Ulysses agreement.

? How much will it cost to make a representation agreement?

It should cost very little. Most people will be able to draw up a standard agreement with the help of friends, family or community volunteers. There will be a modest fee to register the agreement.

If you want to give broad powers to your Representative, such as the authority to consent to withdraw life support, or to arrange temporary care of children, you will need to meet with a consultant.

Lawyers will be consultants. The government is deciding now who else will be authorized to act as consultants for representation agreements. We hope consultants will include notaries public, peer counsellors, and community advocates.

Answers to your questions

? If I choose my friend to be my Representative, can my family automatically overrule the Representative's decisions?

No. Nobody can automatically overrule your representation agreement. However, anyone can challenge your agreement if they believe that your Representative is not following your wishes or that you were forced to make the agreement.

Objections must be made in writing to the Public Guardian and Trustee, and copies must be sent to you, your Representative, Alternate, and Monitor.

When a Representative is helping you make a decision, or making a decision for you, he or she must always talk to you first. If you cannot communicate what you want, the Representative must decide according to **your** values and **your** beliefs. It's what **you** want that's important.

To prevent conflict, it's a good idea to tell family members about your representation agreement, and to outline your wishes clearly in the agreement.

? If my Representative dies or moves, can my Monitor take over?

No. A Monitor cannot take over the job of Representative. The Monitor's job is to make sure that your Representative is following the agreement and carrying out your wishes.

It is important to name someone in your representation agreement to be an **Alternate** Representative. You can say in your agreement that this person will take over if the Representative is no longer able to do the job.

? Can I use a representation agreement to say who will care for my children?

Yes. You can authorize your Representative to arrange temporary care of your children.

? Can my group home support worker be my Representative?

Many individuals and organizations in the community believe that it is a conflict of interest for someone who is paid to provide support to also become a Representative. Your Representative must be free to assist you or act for you according to your wishes and values, no matter what the rules and policies of a group home, government agency or institution might be.

However, your support worker, doctor, and mental health worker are important sources of information, and your Representative will want to talk with them when making decisions.

? What if I don't have anyone to be a Representative?

The most important and challenging part of making representation agreements accessible to everyone is to create and promote ways for people who don't have family and friends in their lives to have a Representative. Individuals and organizations in the community are exploring ways to do this.

Even people who might not seem to have an obvious choice for a Representative, may have supporters who can act for them. See Fran's story on page 1. □

Update on RATG activities

by Joanne Taylor

Many exciting activities on representation agreements are being initiated by people in communities around B.C. This article focuses on the work of the Representation Agreement Task Group (RATG).

The RATG held a provincial forum in November, 1994 in Vancouver. At that forum over 90 people from around the province outlined a plan for community action on representation agreements.

Spreading the word

Participants in the forum wanted to go back to their communities and begin spreading the word about the new laws. In order to do this, they needed information and presentation tools. The RATG put together a kit that community organizers

can use to conduct presentations on representation agreements. (See the back page of this newsletter on how to order a copy.)

As people began using the kit, they adapted it and added to it. For example, in Comox, **Russ Hammond** incorporates a video on living wills in his presentations. To borrow a copy, call our office. **Bill Anhorn** of Kamloops uses 'what if...' scenarios to get seniors talking about and doing pre-planning in their own lives.

Another creative approach comes from **Penticton** senior **Murial Quiring** who made up her own agreement, then handed it out to people and used it as a model for discussion. She also made up a short play about being a person whose family thought she could no longer manage decision-making. This leads to discussion about how to deal with your family when they think you need help.

Kela Guincher, a RATG member, is focusing on multicultural communities. She's currently preparing materials in Spanish for a meeting in December with a Hispano-American seniors' group.

John Sheckleton, also a RATG member, is talking with consumers of mental health services about ways to provide information and support to consumers who

want to make representation agreements. A meeting is planned for January, 1996.

Helping individuals

Supporting individuals to make representation agreements is another priority of the plan developed at the forum. Some communities have formed **Resource Groups** made up of volunteers including consumers, advocates, seniors, peer counsellors, lawyers, notaries, agency staff, parents, and others. Resource groups are active in **Powell River**, **Kamloops** and **Nanaimo/Parksville**.

In response to requests from people who want to make representation agreements now, the RATG has produced a **Guide for Individuals**. The Guide is based on what we've learned from individuals who have made and used agreements. It includes a description of the key elements of a representation agreement, a sample form, and information on the responsibilities of representatives. (See back cover of this newsletter.)

Thanks to the initiative and *very* hard work of **Tom Klopp** and the **Network of Burnaby Seniors**, the **Guide Book for Facilitators** is in its second draft. The first draft was field tested with seniors and caregivers, and their suggestions are being



Clearwater senior Bill Morse

incorporated in the current edition. The Guide Book will provide community leaders and organizers with information and guidance so they can help others to make representation agreements. The Guide Book should be available in the early spring of 1996.

Thanks to the Law Foundation of B.C. for providing funds for this production.

Regulatory and policy issues

At the provincial forum, the RATG was directed to address issues arising from our participatory action research by making recommendations for regulations and policy. We formed a **Legislative Sub-committee**, chaired by **Stan Nicol** of the Society of Notaries Public, which met from January to June, 1995. The committee's recommendations were described in a 47 page report that was submitted to government. (See page 11.)

Lobbying MLA's

The Legislative Sub-committee recommended amendments to the legislation. Although these proposed amendments are modest, they are crucial to ensuring that representation agreements are accessible and workable. We also believe they must be in place when the legislation is proclaimed. Consequently, RATG members are now lobbying MLA's

of all parties about the need for amendments to the Act. If you are interested in assisting with our efforts, please call the Community Coalition for a Lobby Kit.

Communication

The next meeting of the RATG will be devoted to discussing consumer-led communication about representation agreements. We will look at the possibility of a partnership with government to develop a comprehensive communication/information plan.

A few last words

These are only some of the activities on representation agreements taking place right now. If you need information or assistance to get involved in your community, please contact us.

I'd like to take this opportunity to thank the members (all volunteers) of the Task Group. They have worked tirelessly, continuously and creatively over the past two and a half years. Most recently, members of the Legislative Sub-committee have attended numerous meetings with government over a short period of time to present our recommendations on regulatory and policy issues.

Thank you also to the staff of the Community Legal Assistance Society for providing us with meeting space and a warm welcome.



Joanne Taylor

I also express my gratitude to the Law Foundation and the Van Dusen Foundation for their financial support and to the Society of Notaries Public and the Notary Foundation for their in-kind and financial contributions.

Finally, on behalf of the Task Group, I wish to thank Christine Gordon for her ongoing dedication, inspiration and support, and Donna McMahon whose invaluable editing and formatting skills make us look good!

Stay in touch!

Thank you for your letters of support, donations, and all you have done to create and promote alternatives to public guardianship within your family, with your friends, and in your community. Please keep sharing your experiences and ideas with us! □

Joanne Taylor is the Chair of the Representation Agreement Task Group

Making policy that works

In January, 1995, the Representation Agreement Task Group (RATG) formed a Legislative Sub-committee to address the concerns voiced by people who participated in the Task Group's community research on representation agreements in 1993-94.

The Sub-committee members studied the wording of the *Representation Agreement Act* and discussed the intent of the legislation to see if the wording itself was a problem. In many cases, concerns could be solved by developing regulations and policy. When those solutions did not appear adequate, amendments to the legislation were recommended.

In its report, the Sub-committee made 45 specific recommendations, including six minor amendments to the legislation. Recommendations focus on:

- ◆ Protecting citizens' privacy by limiting the information held by the representation agreement Registry
- ◆ Ensuring that Representatives have legal access to confidential information that they need to fulfill their responsibilities
- ◆ Making sure that agreements are accessible and inexpensive to make by allowing a wide range of consultants to help people make agreements
- ◆ Allowing individuals to

make widely differing kinds of agreements, according to their needs

- ◆ Honouring existing pre-planning documents that people have already made
- ◆ Making the roles of Representatives and Monitors more flexible
- ◆ Broadening the powers of a standard representation agreement to make them more useful to seniors
- ◆ Making the signing and witnessing procedures simpler and more practical
- ◆ Making it easier to change or cancel an agreement
- ◆ Developing more community sources of support and assistance for Representatives and Grantors.

The Sub-committee presented their report to government in July, 1995. It was described by the Public Trustee, Dot Ewen, as excellent. Dr. Stan Remple, special consultant to the Office of the Public Trustee, said: "I have been most impressed with the quality of the analysis and the discussion of issues related to the new guardianship and trustee legislation. It is not often that a group of volunteer advocates do such high quality work."

In the last few months, members of the Sub-committee have spent many hours meeting with the Public Trustee and her staff

to discuss how to implement the report's recommendations. Their volunteer contribution has been enormous and invaluable and they have been loyal to the direction given by the Task Group's research.

Members of the RATG are now lobbying Members of the Legislative Assembly for the six amendments that the Sub-committee recommended be made when the Act is proclaimed. This lobbying effort has been received positively by all of the MLA's who have been contacted.

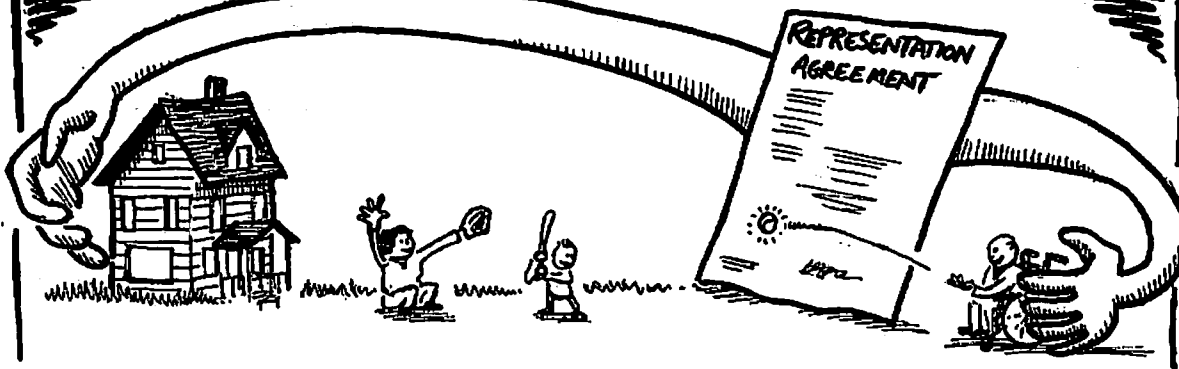
For a copy of the RATG Sub-committee report, contact the Coalition office. □

More News

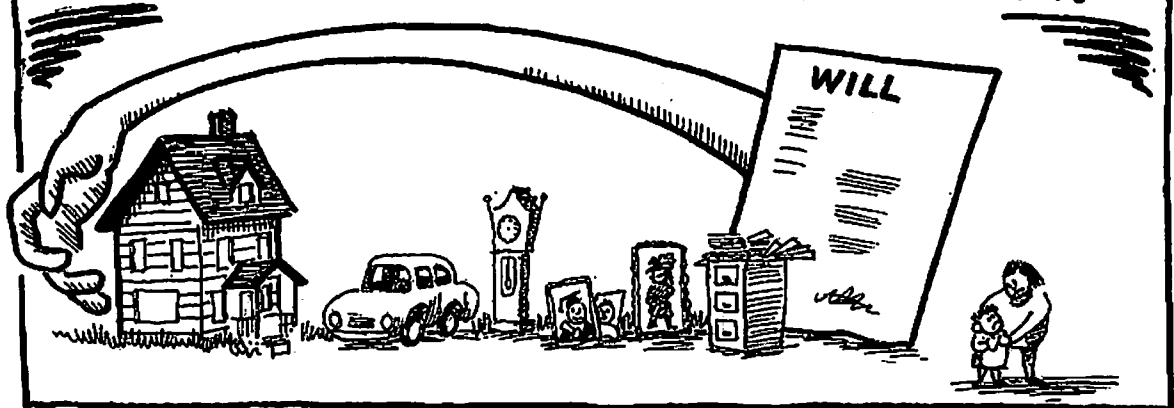
Kamloops builds a community response

In the spring of 1995, the Coalition sponsored a series of workshops, small group meetings, and one-on-one interviews in the Kamloops area with people who are most likely to be affected by the new adult guardianship laws. More than 150 people participated from Chase, Kamloops, Vavenby, Clearwater and Barrier, sharing ideas and concerns about their community's response to cases of abuse, neglect and self-neglect.

REPRESENTATION AGREEMENTS SPEAK FOR YOU WHILE YOU ARE LIVING...



WILLS SPEAK FOR YOU AFTER YOUR DEATH.



Their ideas formed the basis for a second phase of community organizing. With funding from the Office of the Public Trustee, people are now planning a community response network that will honour people's choices while keeping them safe. □

Understanding health care consent law

The Community Coalition's Advocacy Task Group is coordinating a series of workshops to help people understand their rights under the new *Health Care (Consent) and Care Facility (Admission) Act*. The workshops use plain language guides (*Making Decisions*

About Your Health Care and Going into a Care Facility).

Coordinators are organizing workshops this winter in the Lower Mainland, Victoria, Duncan, Parksville, Dawson Creek, Prince Rupert, Prince George, Kamloops, Penticton, and the East and West Kootenays. If you're interested, please contact the Coalition office. □

Nanaimo sponsors capability project

The new *Adult Guardianship Act* promotes support and assistance for adults as a first resort, rather than assessing capability. Capability assessments, if they are necessary, should involve

everyone who can contribute useful information. This is a different way of doing things than the "medical approach" that is currently being used, which focuses only on the adult being assessed, not the people who know and assist them.

In Nanaimo, a group of citizens (both professionals and laypeople) are sponsoring a community-based project that combines new ideas about what it means to be capable with the experience of advocates and professionals.

Please contact the Coalition or Robert Pepper-Smith at 753-3245, local 2411 for more information. □

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.

Join Us!

The Community Coalition is made up of:

- **Provincial Organizations** - like Seniors Resources and Research, BCACL, the Alzheimer Society, BCCPD, the West Coast Mental Health Network, the Council of Senior Citizens Organizations;
- **Local Groups** - like the Network of Burnaby Seniors, Family Link, ACE, Self-Advocates on the Move, Kamloops Seniors Liaison Council;
- and more than 3000 **individuals**.

To become a member, write, phone or fax us at the address below.

Materials available from our office:

- "Walking Through a Representation Agreement" - A Guide for Individuals (November, 1995)
- Presenters Kit: Organizing Workshops on Representation Agreements in Your Community (January, 1996)
- The Provincial Advocacy Directory (January, 1995)
- A Practical Guide to Discussions with Consumers about Abuse/Neglect and Self-Neglect (April, 1995)

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