

# Representation Agreements from the Ground Up: Report on Community Workshops

prepared by

Representation Agreement Task Group

of the Community Coalition for the Implementation of Adult Guardianship Legislation

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## Summary of Report on Community Workshops

The Representation Agreement Act is one of the new laws designed to reform the adult guardianship system in British Columbia. The idea of Representation Agreements began with people in the community who were deeply concerned that imposing guardianship on someone meant a loss of the individual's rights as a citizen.

Along with the other three new acts that govern adult guardianship, the Representation Agreement Act will have to be implemented before it comes into effect. It is during implementation that all of the policies, procedures and regulations are developed that will determine how Representation Agreements will actually work.

A Community Coalition, made up of the groups and individuals who are most likely to be affected by guardianship laws, was formed soon after the legislation was passed in July, 1993. The Coalition's mission is to ensure that all the opportunities of the legislation to create alternatives to public guardianship are realized.

The Community Coalition has been working to ensure that the implementation of all of the guardianship laws is built from the ground up. This means starting with people's experiences and using this knowledge to influence the development of policies, procedures, regulations and programs.

In the fall of 1993, the Representation Agreement Task Group began discussing Representation Agreements with those most affected by formal guardianship. These individuals are the experts who can best articulate their needs and concerns which all of us may at some time share.

In its efforts to find out what the community thinks about Representation Agreements, the

Task Group is using an approach based on the principles of participatory action research. Participatory action research focuses on social issues and social change. This approach engages people who are affected by the issues as essential participants in the research process. People are not seen as subjects of research conducted by an outside expert, but participants in a collaborative process of developing shared knowledge and taking collective action.

These principles guided the province-wide workshops on Representation Agreements organized by Task Group volunteers. The information from these workshops forms the body of this report.

### Highlights from the workshops

The feedback from these workshops tells us that:

- The community strongly supports the idea of Representation Agreements.
- Representation Agreements are a way of acknowledging and strengthening informal support networks.
- Representation Agreements must be accessible; that is, simple, flexible, inexpensive and responsive to a variety of needs.
- Representation Agreements must have demonstrated power and authority.
- Representation Agreements should be easy and inexpensive to change or cancel.
- The differences between "minor" and "major" health care decisions, and other kinds of decisions, are not clear cut. We need to discuss the different areas of decision-making and determine whether and how to distinguish among different areas.

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- The differences between standard and “special powers” Representation Agreements need to be reconsidered.
- People need to discuss how complex decisions are made and how these kinds of decisions can be covered in Representation Agreements.
- A registry of Representation Agreements will be helpful, but the details of its implementation, especially the issue of privacy, need further discussion.
- People who live out-of-province should be eligible to be representatives or monitors.
- The legislation’s current signing and witnessing requirement is impractical and needs to be reconsidered.
- The relationship of Representation Agreements to the Mental Health Act needs more discussion.
- Agreements, choices and plans that are in place must be recognized when the law takes effect.
- There are difficulties around foreseeing all the possible “triggering events” that would make a Representation Agreement take effect. Other ways may be needed to determine when an Agreement starts.
- The roles of representatives, alternates and monitors must allow flexibility and be guided by the responsibility to support the adult and each other.
- A variety of sources of information, support, and advocacy must be available to adults and their representatives. Information and support must be accessible and inexpensive.

- Ways of building support networks for people who currently have no one to act as a representative or monitor are a priority.

### Future action

The Representation Agreement Task Group has identified some strategies for action based on the results of the workshops:

- Organizing a Provincial Forum with key people from various regions in the province, including those who organized workshops in their communities. This forum will share information from the workshops and promote a network of community organizers to implement a province-wide action plan.
- Requesting amendments to the legislation in the areas of concern identified by those who will be affected. These areas include:
  - including instructions regarding life-prolonging health care measures in a standard agreement,
  - making changes to the role of the monitor,
  - allowing for more than one Representative to act on a particular area of decision-making so that Representatives can act together, and effectively support each other and the adult,
  - honouring (“grandfathering”) agreements made before the legislation is enacted,
  - clarifying and limiting the role of the Registry so that Representation Agreements can be used in emergency situations, but adults’ rights to privacy are respected, and
  - changing the “signing” procedure to make it more accessible.
- Supporting problem-solving with people by trying out Representation Agreements.

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Finding out about the experiences of "real" people and their situations will:

- identify problem areas and engage those involved (i.e., informal networks, formal supports and third parties) in creating solutions,
  - demonstrate the effectiveness of Representation Agreements, and
  - develop ways to ensure that the principle of self-determination and the presumption of capacity are honoured for all adults.
- Conducting further participatory action research with various groups and organizations (e.g., Alzheimer Association, Mood Disorder Association, Self-Advocacy Caucus) to explore specific issues identified in the workshops as requiring more discussion. These issues include:
    - building informal support networks with people who have limited or no informal sources of support,
    - the role of community and advocacy organizations in supporting people who are making and using Representation Agreements,
    - decision-making within Representation Agreements, and
    - triggering events.
  - Linking formally with the Community Coalition's Task Groups on Advocacy, Needs and Capacity and Abuse/Neglect, and with individuals in the community to facilitate informal support networks for people who want this assistance. These networks will build on the capacities of individuals and communities and will promote mutual trust and strong relationships.

In addition to providing a summary of workshops and future directions, this report will be a guide for the Task Group's ongoing work. We will continue to facilitate input from those most affected by guardianship legislation to ensure that Representation Agreements work for those who need them.

We will continue to use a participatory action research approach as it fits most closely with the principles of the legislation and those guiding the process of implementation, and provides us with the most meaningful analysis of concerns and solutions.

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*The Task Group wants to thank all the participants and local organizers of the workshops for their commitment, enthusiasm and efforts to provide input into making Representation Agreements work. We look forward to working on future action together.*

**This report is available in large print and on cassette tape. Contact the Community Coalition office at the address in the box above.**

# Community Workshops Report

## Background

### Representation Agreements

The Representation Agreement Act is one of the new laws designed to reform the adult guardianship system in British Columbia. A Representation Agreement offers a way for adults to choose someone they know and trust to help them now and/or in the future with making important decisions about their lives. Representation Agreements can cover decisions about health and personal care, as well as legal and financial affairs.

### The community vision

The idea of Representation Agreements began with people in the community who were deeply concerned that imposing guardianship on someone meant a loss of the individual's rights as a citizen. The community wanted to design alternatives that will ensure that a person's wishes and choices are respected and supported, and that will focus on a person's abilities rather than her disabilities.

The community, through the Project to Review Adult Guardianship, initiated and led the process of reforming the guardianship laws. In July 1993, the new laws were passed by the provincial government and we are now in the stage of implementing the new laws. This is the time when policies are written, forms are designed, and procedures are developed. It is exciting that the implementation of these new laws is being done in a new way—one that is open, public, and led by the people most affected by the legislation.

The Community Coalition for the Implemen-

tation of Adult Guardianship Legislation has been working to ensure that Representation Agreements are built from the "ground up." This means starting with people's experiences and using this knowledge to influence policies and procedures related to Representation Agreements.

In the fall of 1993, the Community Coalition, through its Representation Agreement Task Group, began discussing Representation Agreements with those most affected by formal guardianship. These individuals are the experts who can best articulate their needs and concerns which all of us may at some time share. Over the past year, volunteers from the Task Group held workshops throughout the province.

This report summarizes the ideas and concerns that community members expressed in the workshops. It also provides direction regarding the next steps we need to take in the implementation process. The report will serve as a guide for the Task Group's ongoing work, and for discussion at a Provincial Forum planned for November 1994.

### Our approach

To find out what the community thinks about Representation Agreements, the Task Group chose an approach based on the principles of participatory action research. This approach says that the people who are affected by a social issue are leaders in the research process. Participatory action research is a process of developing shared knowledge and taking collective action. This means the research process evolves and changes according to the understanding and desires of the participants.

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The Task Group chose this approach because its principles fit closely with the principles in the new law and those guiding the process of putting the law into effect—that the experiences, values and beliefs of those affected should lead the process of change; that policies and procedures need to be built from the ground up; and, that the process itself can help to build strengths in communities.

### Goals of the research

The goals of the research on Representation Agreements conducted over an eight-month period by the Task Group were:

- to identify the areas of agreement among community members,
- to identify the areas where there were differences of opinions,
- to identify areas for community development, and
- to identify issues requiring further research and suggest potential research strategies to address those issues.

### Gathering information through community workshops

The Task Group combined participatory action research with popular education techniques and community development processes to design interactive workshops that would gather information on Representation Agreements from those most affected.

The Task Group volunteers held 35 workshops in various locations throughout the province. We responded to requests from groups and organizations who wanted to learn more about Representation Agreements and to provide input to the implementation process.

The Task Group reached individuals who would be likely to enter into Representation Agreements, those who would be involved in supporting people with Representation Agreements, and those who would be acting on Representation Agreements: seniors, people with disabilities, people with mental illness, family members, health professionals, advocates, notaries public, and members of different cultural groups. Professionals who attended the workshops were asked to take off their “professional hat” and participate as an individual in the community. In all, more than 600 people participated in the workshops (*a list of the groups and organizations who participated in the research process is available from the Coalition office*).

The workshops ranged in length from one to five hours, with most averaging three hours. They followed a general outline which varied depending on the interests of the participants and the amount of time available. They usually began with a brief introduction to the new guardianship laws and an outline of the key features of Representation Agreements. In small groups, participants used scenarios based on people’s experiences to discuss how Representation Agreements can work (*a sample of the scenarios used in the workshops is available from the Coalition office*). The small groups then reported back to the whole group on the major issues they discussed. The workshops finished with general discussion of what the group thought their next steps should be.

### How the information from the workshops was analyzed

Participatory action research is an evolving process that seeks the expertise of people who are most affected. As already mentioned, workshop participants were people who had an interest in Representation Agreements; the Task Group did not attempt to survey a representative

sample of the general population. Therefore, the thoughts and opinions expressed are those of the people who were involved in the research; they are not necessarily representative of any particular group or of the general public. Time limitations did not allow in-depth discussion on every aspect of the new law.

We collected information from workshop participants through written feedback forms, facilitator's notes, highlights presented to the larger group, and comments that participants provided in writing. Additional information came from a discussion among workshop facilitators.

A researcher categorized the information according to the most important themes that appeared in the information. The Task Group then reviewed and discussed the categorized information. Through the discussion, the Task Group identified what we know and what future information we need to gather.

The process, and the knowledge gained from it, have given us a deep and rich understanding of what Representation Agreements mean to community members. The rest of this report presents the summary and analysis of the information from the workshops.

## **Areas of endorsement and areas for further action**

### **Community support for Representation Agreements**

In general, participants in the workshops said that the idea of Representation Agreements is a good one. They describe it as a "courageous step," a "revolutionary idea," and "an overdue response to a need manifest in all age groups in our society."

Representation Agreements are seen as an important tool that should be part of planning for everyone, and as especially valuable for people who are most vulnerable (e.g., people who currently have no one to act as a representative or monitor).

Several aspects of Representation Agreements, as outlined in the new law, were endorsed:

- Representation Agreements are based on the assumption of capability and on honouring the wishes and values of the adult.
- A measure of accountability is built in through having the representative discuss decisions with the adult and acting on the adult's wishes and values, as well as through the involvement of others in the support network.
- Representation Agreements are based on the principle of intervening only when needed, and in the least intrusive way possible.
- Representation Agreements will give status to those closest to the adult and enable them to act with authority.
- The availability and accessibility of Representation Agreements will encourage adults to use them.
- Representation Agreements will acknowledge and strengthen the informal networks or support teams in people's lives.

Workshop participants also expressed appreciation for several features of Representation Agreements, such as the flexibility to have more than one Representative, the comprehensive coverage of all areas of the adult's life, and the ability to change or cancel the Agreement.

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### Designing Representation Agreements that work—areas for future action

#### Need for simplicity and clout

It is clear from the workshops that Representation Agreements must be accessible; that is, simple, flexible, inexpensive and responsive to a variety of individual needs. This is especially true if Representation Agreements are to work for those who are most vulnerable.

At the same time, Representation Agreements must cover a variety of issues and circumstances, some of which can be extremely complex. Representation Agreements must also have demonstrated power—the authority given to representatives must be recognized and respected by third parties, including government. Some community members felt that they are so “labelled” that any Representation Agreement they draw up will not be respected.

#### Entering into a Representation Agreement

Most workshop participants said they would use a Representation Agreement. They see them as a way to clarify specific wishes and prevent disagreements within families.

Some participants are so enthusiastic about Representation Agreements that they want to start developing and using them now, even before the law takes effect.

However, there is concern that the process for making, registering and using Representation Agreements might become too difficult or too bureaucratic. There is also some concern that the process of “formalizing” informal relationships and agreements may jeopardize the trusting relationship between the adult and her supporters.

Some participants expressed concerns about acting as a representative because of: the

possibility that the responsibility might become too demanding and burdensome; possible legal liability; uncertainty about whether the person's wishes could be expressed clearly enough to guide decision-making; and, potential conflicts with other people in the adult's life.

People said that those who act as representatives will need support, information and advice when deciding to become a representative and when acting as a representative. Participants indicated that, when acting as a representative, they will look to community-based organizations that have experience and skill in encouraging self-advocacy and community advocacy as sources of information and support.

#### Roles and responsibilities

It is clear from the workshops that participants see Representation Agreements as a way to recognize and clarify the way they already make decisions, and to strengthen the authority of their informal support networks. Representation Agreements must reflect the interdependence that exists in people's relationships and in their decision-making.

Although the law describes different roles and responsibilities for representatives, alternates, and monitors, participants want the people in these roles to work as a team and to build consensus around their decision-making. Many participants felt that “two heads are better than one”, especially when it comes to making complex decisions.

The need for effective communication among all those who are involved in the adult's life will be important. Professionals involved in the adult's life (e.g., physicians, Long Term Care staff) will need to share information and be accessible to representatives as resources.

The workshops also showed that different areas of life (such as health care and finances) are interdependent and decision-making can



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sometimes be complex. More exploration is needed of the actual and potential roles of informal and formal supports, as well as how complex decisions can best be made.

### The role of the monitor

Some workshop participants expressed concerns about monitors. On the one hand, participants felt that appointing a monitor may be seen as indicating a lack of trust in one's representatives. Participants predicted that choosing a family member as a monitor to oversee other family members who are acting as representatives may cause conflicts. On the other hand, the monitor may be a positive way to provide additional support to the adult and the representative, and ensure that the adult's wishes are respected. Participants suggested that choosing a family member as a monitor who is somewhat removed from the adult's immediate situation might prevent conflicts.

Participants also saw the presence of a monitor as a way to involve more supporters in a meaningful way. Some other important questions around the role of monitors were raised:

- How can the relationship between the representative and the monitor be defined so that the adult is supported?
- Is it desirable to choose different monitors for different areas of one's life, just as you can choose different representatives?

### "Major" and "minor" decisions

The law makes a distinction between major health care decisions and minor health care decisions. Some participants in the workshops felt that the differences between major and minor health care decisions are not clear cut or easy to define. Questions were also raised about where mental health issues fit into this division (e.g., decisions about consent to psychiatric treatment or the prescription of certain kinds of medica-

tion). Participants had similar concerns about where and if a line should be drawn between minor and major financial decisions.

The workshops also identified a lack of clarity around the differences between standard Representation Agreements and ones conveying "special" powers to representatives. Participants felt that some of the decisions currently classified under "special powers" (e.g., directives regarding some kinds of institutional care, end-of-life instructions) should be included in the standard agreement. In this way, issues that are of concern to large numbers of people can be covered without the need for expensive legal help.

### Out-of-province support

Participants want to be sure they can choose representatives and monitors who may live outside of British Columbia. This question is particularly important for seniors whose adult children live in other provinces or in the United States. People also want to explore ways that Representation Agreements may be effective when they are travelling, if they move, or if they live part of the year elsewhere.

### When the Representation Agreement starts

Participants saw that defining "triggering events" in Representation Agreements is problematic. It will be very difficult to predict all of the possible events that could make a Representation Agreement take effect and this may limit the Agreement's power. Rather than trying to foresee all possible triggering events, participants suggested that their representatives, monitors or others close to them, could, in discussion with each other and the adult, determine when the Agreement may take effect. People in the adult's network would be most likely to see changes in the adult's condition and provide support as soon as it is needed. More discussion is needed around how and when the Representation Agreement will start.

### Signing procedure

The law requires that the adult, the representative(s), and the alternate(s) all sign the Representation Agreement at the same time in the presence of two witnesses. Participants felt that this requirement was impractical and unnecessary.

### Changing a Representation Agreement

While workshop participants appreciated the fact that the legislation allows adults to change or cancel Representation Agreements, they had questions about how difficult it will be to do so. People want the procedure for changing or cancelling Representation Agreements to be easy and inexpensive. Participants also suggested that people be encouraged to review their Representation Agreements on a regular basis, perhaps annually.

### Representation Agreement forms

Participants want all the forms that are developed for use in Representation Agreements to be accessible and simple to understand.

### The registry

While participants felt a registry containing information about Representation Agreements was potentially helpful, they raised questions about how to balance the need for access to information (e.g., in health emergencies) with the need to protect people's privacy. Participants felt the registry should contain the minimum amount of information needed to quickly verify and find the adult's support group. They also felt that it should be a simple, inexpensive and non-bureaucratic process to register a Representation Agreement and to access the information from the registry. Some participants suggested exploring options for a community-based registry.

### Payment for representatives and monitors

The question of whether representatives or monitors should be paid a fee (in addition to out-of-pocket expenses) is a controversial one. Many workshop participants felt strongly that representatives and monitors should not be paid, that Representation Agreements are not business arrangements, but personal commitments based on relationships of mutual trust and caring.

Others felt that some payment for representatives might help to reduce the burden on representatives (especially in cases where representatives are not close family or friends) and help to formally recognize the representative's commitment. However, they were also concerned that any payment must not jeopardize the adult's quality of life. Participants suggested that any payment written into the agreement should be reviewed to determine the adult's ability to continue to pay it. For some, the question of payment is not an issue because their representatives will be beneficiaries of their estates. When participants were asked if they would want payment for acting as someone's representative or monitor, they answered with a resounding "no".

### Building informal support networks

The question of how to enable adults who don't have informal support networks to use Representation Agreements is important to community members. Situations where people have no family or friends to act as representatives or monitors present a significant challenge, since such people are often the most vulnerable.

In some cases, people without informal supports are closest to health or social service professionals or other service providers in their lives. However, participants had serious concerns about professionals acting as representa-

tives because of potential conflicts of interest and because of the differences in power between individuals and professionals. There is an eagerness in the community to explore this issue and look for innovative ways of building support networks for people who are currently without informal sources of support.

### **Agreements made before the law takes effect**

Many people are eager to start developing a Representation Agreement without waiting for the law to take effect and some are already using agreements they have developed on their own. Seniors are concerned that their capacity might become limited before Representation Agreements are officially available. Participants felt strongly that agreements, choices and plans (for example, living wills) currently in place must be honoured when the law takes effect. Also, participants felt that agreements, such as enduring power of attorney, which designate someone as a representative for financial or legal affairs, should be extended to authorize health and personal care decision-making when the law takes effect.

### **Representation Agreements for emergencies**

Participants see Representation Agreements being used for emergency health care decisions. For example, if an adult gave her representative specific instructions regarding emergency care (e.g., instructions to refuse resuscitation efforts), health care providers must be alerted to the fact that a Representation Agreement exists and must have quick access to the representative.

Participants suggested that professionals could be alerted to Representation Agreements by medic-alert-type bracelets or by some kind of code or sticker on an adult's Care Card.

### **The relationship of Representation Agreements to the Mental Health Act**

The fact that some sections of the Mental Health Act override the Representation Agreement Act was a concern for some participants. Groups in the community are continuing to explore ways to balance the need for safety with the opportunity for honouring self-determination.

### **Concerns about abuse**

The new law represents a shift in the power relationships among professionals, adults, and their support networks. Professionals will be sharing power in new ways and adults who may not be used to having their choices respected will become powerful agents in their own lives. Because of these changes, participants were concerned that adults may be taken advantage of or may meet resistance among those whose relationship to them is changing. As discussion of these issues continues, caution will be needed to ensure that concerns about the potential for abuse are not used to limit the opportunities that the new law offers.

### **Advice, support and education**

The workshop participants felt that many people will need to talk to someone knowledgeable about Representation Agreements to discuss questions such as:

- Who should I choose as my representative(s)?
- Do I need a monitor?
- What kinds of instructions should I write into my Representation Agreement?
- How can I ensure that my representative is supported?
- What problem-solving assistance will be available for my representatives and monitors?

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- What should I do if I have difficulty getting people in authority to take the Representation Agreement seriously?

A wide variety of individuals and organizations are seen as appropriate sources of information, advice, and support. People want advice from others who understand their situation and who can help them to create an agreement that will be effective.

Participants felt strongly that information and support must be available from community-based or self-help organizations, such as seniors centres, community centres, agencies serving ethnic communities, or advocacy organizations.

Many people said they would consult lawyers or notaries public for technical information about the legalities of their Representation Agreement, and other professionals for information about financial and health care matters. Others mentioned government resources such as public health units, the Office of the Public Trustee, or the library.

Participants suggested other resources that might be helpful, including a "do-it-yourself kit", a toll-free information line, a computer data base or bulletin board, and instructional videos. A guidebook, designed by those who would use Representation Agreements, was also suggested to assist people wanting to enter into an agreement and people who will be acting as representatives, alternates and monitors.

Participants felt that public education is crucial to support people involved in Representation Agreements. Seminars and workshops at community centres, regional colleges, schools, health care agencies, and seniors centres were recommended. Participants emphasized the need to educate professionals as well as the general public.

Participants also pointed out that education efforts and other efforts designed to provide

support and assistance will need to be multi-faceted and targeted to address the needs of different groups, such as people with disabilities, seniors, people in different cultural groups, people with mental illnesses, people with limited literacy skills, people who rely on alternative forms of communication, and people who are socially isolated. Again, such efforts need to be developed from the perspective of those using Representation Agreements—from the ground up.

## Conclusion

It is clear from the workshops that the community supports the idea of Representation Agreements. However, if they are to be used, they need to be accessible; that is, simple, flexible, inexpensive and responsive to a variety of individual needs.

The new law emphasizes the importance of self-determination, supported decision-making and the least intrusive means of support. The workshop participants felt strongly that these principles should continue to guide future discussion of unresolved issues and the implementation process.

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