Legislative Review of the Dependent Adults Act and the Personal Directives Act



Seniors and Community Supports

Community Consultations Summary

He drove 11 hours to attend the community consultation. His actions and his words told of his commitment to his dependent adult brother.

When you hear stories like that, it is easy to be impressed. This isn't the only one that comes to mind; there are many. Each time I saw a senior navigate the chilly streets with a walker to come to the meeting or saw a service provider who gave up their evening to attend, I stopped to think about the level of commitment that brings people out to a public consultation.

Approximately 300 people came to talk about the *Dependent Adults Act* and the *Personal Directives Act*. Each person was a symbol of how important this legislation is to Albertans. These two Acts affect the lives of thousands of people, many of whom are the most vulnerable in our society. They both deal with decision-making for adults who are unable make decisions of their own because they lack mental capacity.

Although there is not room in this report to capture the emotion and the depth of the conversation that took place in each meeting, the committee members responsible for drafting the recommended changes to the Acts were at each session. We are grateful to the people who attended for sharing their time, their stories and their unique perspective.

I am confident that the changes we recommend to the *Dependent Adults Act* and the *Personal Directives Act* will make a positive difference in the lives of Albertans, both now and in the future.

Cindy Ady

Review Chair

Member of the Legislative Assembly, Calgary-Shaw

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INTRODUCTION

In June 2005, the Government of Alberta announced a review of the *Dependent Adults Act* and the *Personal Directives Act* to make sure this legislation meets the needs of Albertans now and in the future.

This Legislative Review, led by Cindy Ady, MLA for Calgary Shaw and supported by Alberta Seniors and Community Supports and Alberta Justice and Attorney General, held community consultations. The aim of the consultations was to gather public input on this legislation dealing with decision-making for adults who are unable to make decisions on their own.

The results of the community consultations will be integrated with data gathered through the public survey, stakeholder questionnaires and stakeholder focus groups to create a framework of the legislative changes would best serve Albertans. It is anticipated that the revised Acts will be tabled in the Alberta Legislature in the spring of 2007.

The Legislative Review process includes:

Public Survey

• In the spring of 2005, Albertans were invited to complete a survey to determine how the two Acts should be changed. More than 3,500 people responded.

Community Consultations

• Open public meetings on the *Dependent Adults Act* and the *Personal Directives Act* were held in the fall of 2005. These are the meetings outlined in this report.

Stakeholder Consultations

- Stakeholder Questionnaires: In January 2006, Albertans who have some involvement or interest in the legislation are invited to complete a questionnaire to comment on proposed changes and issues that have been raised so far.
- Stakeholder Focus Groups: Focus groups will be held in January 2006. Lawyers, judges, health care professionals, trustees, guardians, dependent adults and other groups will explore the legislation and provide feedback.

You are invited to complete the stakeholder questionnaire or read the survey results and this community consultation summary at www.seniors.gov.ab.ca or at www.justice.gov.ab.ca.

EXECUTIVE SUMMARY

During the second phase of the review of the *Dependent Adults Act* and the *Personal Directives Act*, 11 community consultations were held in eight communities including Grande Prairie, Fort McMurray, St. Paul, Edmonton, Red Deer, Calgary, Lethbridge and Medicine Hat. Approximately 300 Albertans attended the meetings to share their experiences and ideas for change.

A wide variety of people attended the consultations including doctors, parents, police officers, adult children with elderly parents, lawyers, social workers, concerned friends of dependent adults and people who provide services and support to dependent adults. Although their stories varied, the concerns they raised were consistent across the province. This report highlights the main themes. Overall, the themes reflect the challenge of finding balance between supporting the independence of the dependent adult and keeping them safe.

In each community, participants indicated that the application process to become a guardian or trustee is expensive, slow and that there is too much paperwork involved. Although they want a simpler process, people who attended the consultations did not take the role of guardian or trustee lightly. They spoke with caution about the power that guardians/trustees have. They want better screening of applicants to decrease the potential for abuse and neglect and they recommend mandatory training to prepare people for these roles. They also want dependent adults to have as much decision-making power as possible.

Although guardians and trustees have legal authority to make decisions, people at the consultations spoke about their frustration when their wishes are contradicted or ignored by others, particularly service providers and health care professionals. They suggested having a non-court process to mediate or resolve their concerns. Similarly, if someone has a complaint or concern about a guardian/trustee, they do not want to have to take it to court but want it investigated and resolved by a body with authority. In emergency situations, there should be some way to act quickly to freeze accounts or remove a dependent adult from an unsafe environment.

While formal guardianship and trusteeship is important, consultation participants said there should be a recognized role for those who help the dependent adult to make decisions informally. There are many day-to-day decisions that can be made with the help of family or friends. Privacy legislation has made this increasingly difficult.

People who spoke about personal directives were often seeking information about which forms are legally acceptable and what happens if there is a dispute between family members. There is increased awareness about personal directives since the Terri Schiavo case in Florida where an incapacitated woman's husband and her family had a bitter and much-publicized dispute about ending her life. Albertans at the sessions wanted to avoid this by having a personal directive and they suggested a non-court process to mediate family disputes.

Health care professionals and long-term care administrators talked about how difficult it is to know if someone's personal directive is valid because there is no standard format, and there is no process to recognize personal directives from outside of Alberta. There was general agreement that a standard format is a good idea, but people should not be required to use it. They also thought a registry for personal directives was helpful, but that it should not be mandatory.

If there was an over-riding message at the community consultations, it was the paramount importance of respect for the rights of dependent adults. Although the *Dependent Adults Act* was state-of-the-art when it was introduced 30 years ago, this legislative review is an opportunity to bring it back in line with our societal values. The *Personal Directives Act* is only seven years old, but it has been tested by the people living and working with it. This is a chance to recommend changes to both Acts so they better reflect the needs of Albertans.

□ THEMES: Dependent Adults Act

Guardian and Trustee Application Process

What we heard

Applying for private guardianship and/or trusteeship is too complex.

• Although self-help kits and assistance are available, people still find the application process difficult to navigate without legal help.

There should be a non-court process for appointing guardians and trustees.

People consistently said that going to court is intimidating, costly
and too slow. They wanted a more accessible system for guardian
and trusteeship appointments and reviews.

Becoming a guardian/trustee should be easier for parents whose child with developmental or other mental disabilities is turning 18.

• Many parents at the consultation wondered why it is necessary to apply for guardianship and/or trusteeship when their child turns 18, as they have cared for the child their entire life and the child's condition has not changed (e.g., Down syndrome). They suggested that parents be automatically granted guardianship/trusteeship when their child turns 18. At the very least, the application process should be less formal for parents.

"Becoming a guardian and trustee for my mother ended up costing a fortune. After a neighbour got involved, my mother objected to the application and they had to go through the assessment and court process several times."

"Three to four months to obtain a guardianship order is too long."

The quotes and personal stories included in this document are actual stories submitted during the consultation process. To protect the confidentiality of the individuals, no names have been included, and in some cases, the comments have been slightly edited.

Reviewing Guardianship and Trusteeship Orders

What we heard

Guardians/trustees who are doing a good job should not automatically have to go to court every six years to have their appointment reviewed.

• At least every six years, guardian/trustee appointments are supposed to be reviewed by the court to ensure they are still necessary and that the person is doing a good job. People felt this was unnecessary if the dependent adult's condition will never improve and if the guardian/trustee is doing a good job. The cost of going to court has to be covered by the guardian/trustee if the dependent adult does not have the funds to cover it. People at the consultations suggested that reviews be a non-court process.

"Education should be mandatory for guardians. Service providers could play a role in providing that education."

Education and Resources for Private Guardians and Trustees

What we heard

Being a guardian or trustee is a position of great responsibility. There should be more preparation and support for people who take on this role.

Many guardians and trustees said they are not as clear as they
would like to be about their responsibilities. They suggested
that there should be a mandatory course for new guardians and
trustees. They also wanted the information presented in a way that
was easier to understand.

"I told the hospital that I didn't want my husband to have psychotropic drugs. Even though I am his legal guardian, they didn't listen."

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Standing Behind the Guardians' Decisions

What we heard

There should be a non-court process where guardians can take their concerns when their decisions regarding the dependent adult are not adhered to by others.

• Guardians often spoke of their frustration about health care professionals and other service providers not abiding by their decisions. They felt they had nowhere to go with their concerns, aside from court, which is lengthy, adversarial and costly.

"We need to identify older persons in care who haven't been assessed but if they are very ill or new to the environment, it won't be an accurate assessment."

Assessing Capacity

What we heard

The way capacity is assessed should take into consideration that sometimes people are able to make decisions at certain times and not at others.

• The current Act has no middle ground on this issue; you are either wholly incapacitated or not.

There is some confusion about who is qualified to do assessments and whether the process is reliable.

• People are nervous about the idea that someone has the ability to declare them capable or incapable. There were many questions about who is qualified to do this. They want the process to be consistent, well-defined and predictable. Currently in Alberta, the decision is based on a medial assessment and a functional assessment. These tools need to be updated and expanded. "It appears to be easier to declare someone incompetent in all areas rather than just some."

"What do we do with someone stuck in a hospital who should be in a lodge? It costs money but there is no one available to write cheques. We need better informal trustee processes."

Informal Decision-Making and Trusteeship

What we heard

A parent, sibling or close friend should be able to make personal decisions on behalf of a dependent adult informally, even if they are not guardians.

• In Alberta, family members or anyone else cannot make personal decisions for a dependent adult unless they are their legal guardian. That means, for example, that a doctor cannot ask a parent to make health-care decisions on behalf of their adult dependent child.

There should be some way to access a dependent adult's bank account to pay for day-to-day living expenses informally.

• Many service providers said they were very frustrated that they were unable to help clients who did not have a trustee (because they did not have a large estate) to access their funds for day-to-day expenses. Banks used to allow them to help on an informal basis, but this arrangement is unusual now.

"My sister has a history of taking advantage of people and now she is Dad's guardian and trustee. Is there not a screening process for guardians? Is there someplace I can register a complaint without going to court? That would end any contact with Dad for sure."

Abuse by Guardians and Trustees

What we heard

There should be better initial screening of people who apply to be a guardian or trustee.

Although most guardians and trustees have good intentions, some
do not. People were very concerned about the potential for abuse
and neglect of dependent adults by their guardian or trustee. They
wanted applicants to be screened. Presently, the *Dependent Adults*Act does not give any guidance for determining if an applicant is
suitable.

"As a police officer, I see many elderly people being taken advantage of by their families. It's not uncommon for an adult child with a gambling addiction to convince an aging parent that they need a trustee to look after their money. It takes months before you can get a court date to stop the drain on the account. By that time there's nothing left."

There should be a non-court process to monitor and investigate concerns about guardians and trustees.

 Many people at the community consultations attended with the hope that they could find help to address their concerns about potential abuse or neglect of friends, loved ones or clients. They said they would not take their concerns to court because it is intimidating, costly and would almost certainly negatively affect relationships.

It should be possible to freeze a dependent adult's assets or remove the adult immediately from an unsafe environment if necessary.

• People talked about how powerless they feel when a guardian or trustee is abusing or neglecting the person they are supposed to help. Legally, they cannot act against the guardian/trustee's decisions, and it takes too long to challenge them in court when time is of the essence.

"The guardian of a vulnerable person holds a lot of power, but there is no screening. Even Uncles at Large has extensive screening."

☐ THEMES: Personal Directives Act

Education about Personal Directives

What we heard

The public needs more awareness about the importance of personal directives and the consequences of not having one.

Many people said they are surprised by the number of people
who do not know about personal directives and who assume their
family has the legal right to make decisions on their behalf if they
become incapacitated. They suggested that an awareness campaign
would help inform the public.

"My wife had a stroke at age 30. It was really difficult on the family. People think personal directives are only for seniors, but that's not true."

Information about personal directives should be easier to understand.

• Although the Office of the Public Guardian has pamphlets and offers other information about personal directives, people said they need information that is easier to understand.

There should be training for agents.

 Most people are unaware of what being an agent entails. People at the consultations suggested that training be developed for agents and that it be mandatory (as they also suggested for guardians and trustees).

Personal Directive Registry

What we heard

It is a good idea for the person you name as your agent, your family or health care providers to know that you have a personal directive.

• Currently in Alberta, you do not have to give a copy of your personal directive to the person you chose to be your agent, to your family or to your doctor. Many health care professionals at the consultations said it is often impossible to know if you have a personal directive if you cannot communicate or if there is an emergency situation and they have to make a decision quickly.

"Emergency medical technicians and first responders are in no man's land. They have to do everything possible to keep a person alive but then they get to the hospital and find out there is a no resuscitation order."

A registry for personal directives is a good idea, but it should not be mandatory.

 Participants made several suggestions on registering a personal directive such as linking it electronically to a driver's license or an Alberta Health Care Insurance card. It would let people know you have a personal directive, where it is and who your agent is (if you have one).

Personal Directive Form

What we heard

There should be a recommended form for personal directives in Alberta, but people should not be required to use it.

• In Alberta, there is no standard form for a personal directive. It can be a document drafted by a lawyer or something handwritten at the dinner table. Health care and other service providers said it is very difficult to know if a personal directive is valid because the format can vary so much.

"I help seniors with dementia make a new home in a care facility. Many come in with a personal directive naming someone to make their decisions. But how do I know it's valid or if the senior was even capable of making the personal directive when they wrote it?"

Personal Directives From Outside of Alberta

What we heard

Personal directives from outside of Alberta should be recognized here.

• Currently, there is no process to recognize personal directives from outside of Alberta. This is a problem for people who move here and do not update their personal directive (or similar tool) or for people who are traveling here when they become incapacitated.

Naming the Public Guardian as Agent in a Personal Directive

What we heard

People should be allowed to name the Office of the Public Guardian as their agent in a personal directive.

• Not everyone has family or friends they would name as an agent to make decisions on their behalf if they become incapacitated. Several people at the community consultations said they wanted the option to name the Office of the Pubic Guardian as agent in their personal directive. Currently, this is not possible.

daughter with Down syndrome. We are her guardians but are getting on. Who will take care of her when we are gone? It's a big responsibility, and we are not sure we can ask our family members to do it."

"We worry about our

Mediation of Disputes

What we heard

We need a non-court process, such as mediation, to help resolve disputes over personal directives, particularly in situations of alleged abuse or neglect.

• People are worried that if their family members cannot agree on decisions about their care or their finances, it will tear the family apart. Also, health care workers are concerned that they have no choice but to follow the decisions of an agent, even if they believe decisions are not being made in the best interests of the patient. "I had a stroke and was incapacitated for seven months. Without a personal directive, my new wife and the children from my first marriage struggled to agree on my care and about what to do with the farm. I recovered but the relationships within my family did not."

DEFINITIONS

Agent is the person you name in your personal directive to make personal decisions for you if you become incapacitated.

Capacity is the ability to understand the information you need to make a decision and the ability to understand the consequences of your decision.

Enduring Power of Attorney is a type of power of attorney which remains in effect even if the person who gave the authority subsequently becomes mentally incapable of managing his or her own financial affairs.

Guardian is someone who is legally responsible to make or help make personal decisions for a dependent adult.

Monitor is a person you name in your personal directive to watch over or check the decisions of your agent (the person making decisions on your behalf).

Power of Attorney is a document in which one person gives another person authority to act on their behalf regarding financial matters.

Public Guardian is an official who works for the Office of the Public Guardian. They can act as guardian for a dependent adult. There are five Public Guardians in Alberta.

Public Trustee is an official appointed under the *Public Trustee Act* who may act as a trustee under the *Dependent Adults Act*.

Service Provider is a person in a business or profession who provides a personal service to you (e.g. an employment counsellor or a hairdresser).

Trustee is someone who is legally responsible to make or help make financial decisions for a dependent adult.