



Alberta
Justice

Alberta
Seniors and
Community Supports

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

Stakeholder Consultations Summary

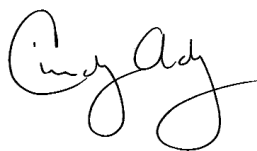
Stakeholders

- *Advocacy groups for persons with disabilities*
- *Court services*
- *Ethics organizations*
- *Financial institutions*
- *Health care providers*
- *Legal community*
- *Long-term care centres and lodges*
- *Mental health agencies*
- *Physicians*
- *Police and other government personnel*
- *Private guardians and trustees*
- *Professional organizations (e.g., nursing and social work)*

At a time when the pace of life is fast and people are busy, it takes an important issue to catch the attention of the public. In this case, the issue is an opportunity — a chance to be part of a legislative review to update the *Dependent Adult's Act* and the *Personal Directives Act*. Together, these pieces of legislation affect thousands of Albertans, some of whom are the most vulnerable of our citizens. Albertans echoed our belief that this legislative review is important by making the time to come to a public meeting or focus group, complete a survey or write a letter. We are very pleased that so many people shared their stories, concerns and ideas with us.

The legislative review process has several phases. In this phase, we asked stakeholders — the people who work with the legislation on a daily basis — for their thoughts on the proposals and ideas being considered so far. They offered a unique point of view, for they see both the success stories and the sad stories as they work in our hospitals, courts, care facilities and agencies, or provide decision-making support in their role as guardian or trustee. We had a chance to see the issues through their eyes and to gather valuable input about how the legislation could be improved to better help adults with diminished decision-making capacity and the many people in their circle of care.

I am pleased to report that 457 Albertans participated in the stakeholder consultations, and I extend my sincere appreciation to each one of them. The fact that they took time from their busy schedules to be part of this process speaks of their commitment to change.



Cindy Ady

Review Chair

Member of the Legislative Assembly of Alberta, Calgary-Shaw

INTRODUCTION

Alberta Seniors and Community Supports and Alberta Justice and Attorney General are pleased to present a summary of the stakeholder consultations for the *Dependent Adults Act* (DAA) and the *Personal Directives Act* (PDA) review. Public input helps policy-makers develop recommendations for change and is an important part of the legislative review process. Recommendations will be submitted to the Alberta Legislature for consideration in 2007.

There are several phases in the consultation process. This report captures highlights from phase three. Reports from all phases of the consultation are available online at www.seniors.gov.ab.ca or at www.justice.gov.ab.ca.

Phase One: Public Survey

- In the spring of 2005, more than 3,500 Albertans completed a survey.

Phase Two: Community Consultations

- In the fall of 2005, more than 300 people attended open public meetings.

Phase Three: Stakeholder Consultations

<i>Phase Three Consultation</i>	<i>Participants</i>
<i>43 stakeholder focus groups</i>	<i>318</i>
<i>General online questionnaire</i>	<i>88</i>
<i>Detailed online questionnaire*</i>	<i>40</i>
<i>Written submissions</i>	<i>11</i>
<i>Total</i>	<i>457</i>

** Results are published in a separate report*

- **Stakeholder Questionnaires:** In December 2005 and January 2006, we asked for input from stakeholders — people who are involved with the legislation on a daily basis. Approximately 140 people completed a survey or made a written submission. There were two surveys — a general one and a detailed one primarily about trusteeship issues.

The themes from the general questionnaire are presented in this report. The themes from the detailed survey are featured in a separate report entitled *Feedback from the Detailed Questionnaire for Stakeholders*.

- **Stakeholder Focus Groups:** In January 2006, 43 focus groups were held with lawyers, service providers in the developmental disability and mental health fields, health care and long-term care professionals, trustees, guardians, Aboriginal groups and others to explore the issues from their unique perspective. The themes are presented in this report.

Phase 4: Consultations with Dependent Adults and Self-Advocates

- In February 2006, we held 10 focus groups with dependent adults who have guardians and/or trustees (they may have private guardians/trustees or the Office of the Public Guardian/Office of the Public Trustee may be their guardian/trustee) and self-advocates (persons with developmental disabilities who are speaking on their own for changes they would like to see).

CONTENTS

Executive Summary	7
<i>Dependent Adults Act</i>	14
1.1 Guiding principles	14
1.2 Informal decision-making authority	18
1.2.1 Informal personal decision-making authority for next-of-kin	18
1.2.2 Access to funds for paying everyday living expenses	20
1.3 A non-court procedure for appointing the Public Trustee as trustee	22
1.4 Assisted or supported decision-making	23
1.5 Determining incapacity	24
1.6 Factors to consider when appointing a guardian or trustee	26
1.7 Appointing a guardian or trustee	28
1.8 Legislated areas of decision-making authority for guardians	30
1.9 Safeguards in the Act	31
1.9.1 Effective screening or prospective private guardians and trustees	31
1.9.2 Monitoring the actions/decisions of private guardians and trustees	33
1.9.3 Investigating concerns about private guardians and trustees	34
1.9.4 Granting emergency protective orders	36
1.10 Review of guardianship and trusteeship orders	37
1.11 Compulsory care orders and certificates	38
1.12 Other feedback from stakeholders	39

<i>Personal Directives Act</i>	40
2.1 Guiding principles	40
2.2 Voluntary use of a standard form for personal directives	43
2.3 Voluntary registration of personal directives	47
2.4 Personal directive made outside of Alberta	48
2.5 Assessing capacity of the maker	49
2.5.1 Who may assess capacity?	50
2.5.2 Process for assessing capacity	51
2.6 Allowing adults with capacity limitations to make personal directives	53
2.7 Re-assessing the capacity of the maker	54
2.8 Automatically revoking personal directives	56
2.9 Care of minor children	57
2.10 Temporary substitute agents	58
2.11 The Public Guardian as agent	60
2.12 Powers, duties and responsibilities of agents	60
2.13 Reviewing an agent's capacity or decisions	62
2.14 Protective safeguards	64
Next Steps	65

EXECUTIVE SUMMARY

In June 2005, the Government of Alberta announced a review of the *Dependent Adults Act* (DAA) and the *Personal Directives Act* (PDA). Both Acts deal with decision-making for adults who are unable to make decisions of their own because they have diminished decision-making capacity. To ensure this legislation meets the needs of Albertans now and in the future, the government asked the public for input.

In this phase of the consultation process, 43 focus groups were held with stakeholders across the province. Although focus groups do not provide quantitative results, they provide a rare opportunity for in-depth exploration of the issues. Each focus group consisted of a specific profession or population such as advocacy groups, lawyers and people working in long-term care centres. In addition to focus groups, stakeholders could offer their input through a survey. Some, such as the College of Physicians and Surgeons of Alberta, and the Honourable Madam Justice C. I. Johnstone and the Honourable Judge R. J. Wilkins of the Court of Queen's Bench of Alberta, chose to submit written responses. The results of the focus groups, the survey and the written responses were combined and analyzed by a third party.

Common themes

Guiding Principles: The majority of stakeholders favoured the addition of guiding principles to both the DAA and the PDA. The proposed principles strike a delicate balance between autonomy in decision-making and providing support and protection for the incapable adult. Some people preferred to see increased emphasis on protection. Some members of the legal community cautioned that guiding principles may leave too much room for interpretation.

Recognizing the abilities of the adult: The decision to appoint a guardian or trustee, or to activate a personal directive, is based on an assessment of capacity. In the past, there has been a tendency to declare an individual incompetent in all areas rather than only the areas in which they have a proven need for assistance in making decisions. The proposals to revise the DAA and the PDA recognize that the incapable adult or maker of a personal directive has the right to as much independence as possible. Stakeholders support the notion of tailoring decision-making authority.

They also favour re-assessing capacity based on a timeline that is appropriate to the situation.

Education: A theme repeated throughout the consultation was the need for more education on both the DAA and the PDA. Guardians, trustees and agents often have the best intentions, but limited awareness of the requirements and philosophy of the legislation. They need information and support to carry out an important role. Even professionals who work with the legislation, such as social workers and health care workers, said they need more education about the legislation and its application.

Members of the public also need education; they remain largely uninformed about guardianship, trusteeship and personal directives. With more information, they could be more likely to prepare for the future and identify a decision-maker they trust.

Investigations: Currently, when someone has concerns about the decisions of a guardian, a trustee or an agent, they must take their concerns to court. Many people said they find this process intimidating and costly, and they were concerned that it would make a future relationship with the guardian, trustee or agent very difficult. A consistent theme in the consultations was the need for an investigative mechanism that would be triggered by a complaint. They favoured a mediation or alternate dispute resolution process, with the courts having final word if resolution cannot be reached.

Dependent Adults Act themes

Informal decision-making authority: Some incapable adults do not have a guardian to help make personal decisions for them or a trustee to help pay their day-to-day living expenses. The proposals suggest that family, friends and other important people in the adult's life be allowed to assist. It includes a ranked list of people who should be considered such as spouse, child, parent or sibling. While most stakeholders liked the concept of informal decision-making, they were concerned that the pre-determined list of people entitled to assume the informal decision-making role may not necessarily reflect the nature of the incapable adult's

relationships or trust within the family. The list also does not take into account the capabilities or intentions of the individual and therefore requires safeguards.

Assisted or supported decision-making: Sometimes an incapable adult can make reasonable decisions if they have support and assistance. Stakeholders supported the proposal that before appointing a guardian or trustee, the court should be satisfied that the adult could not make decisions with the assistance of a support network.

Determining incapacity: There was strong stakeholder support for expanding the scope of professionals who may perform assessments, provided they have training, follow a consistent model and have updated assessment tools. Although some people suggested that physicians be required to take the training, physicians felt this was redundant.

Proposed changes to the Act recognize the fluctuating nature of capacity, but stakeholders wondered what this would look like in practice, particularly in light of the support for tailoring the declaration of incapacity to reflect the individual's competencies. Re-assessment of capacity was favoured at intervals appropriate to the individual's situation.

Appointing a guardian or trustee: The current Act sets out criteria for appointing a guardian or trustee, but stakeholders agree that the terms need to be clarified. The proposal also suggests that guardianship applicants submit a plan that outlines upcoming decisions, to establish whether they are ready to take on the responsibility of guardianship. There was mixed opinion about the value of this.

The current Act does not provide guidance for determining if an applicant is suitable for the role of guardian or trustee (e.g., criminal record check). Stakeholders agreed that screening is critical and that the Act should provide a list of matters for the court to consider. Most felt the criteria for trusteeship should no longer require residency in Alberta.

The Court of Queen's Bench decides whether to approve applications for guardianship and trusteeship. Some people find this process expensive, complex and somewhat intimidating. Many stakeholders expressed

support for a tribunal process as a forum for appointments. In addition to the reasons listed above, they thought a carefully selected and trained panel would offer a more holistic understanding of the issues surrounding guardianship and trusteeship and create an opportunity for more involvement by the adult in the process. Many members of the legal community were unconvinced that a compelling case had been made for an alternative forum.

In certain circumstances, the Public Trustee can be appointed to look after an adult's financial affairs without going to court. Unlike a court-appointed trustee, the Public Trustee does not have to present an account to the courts every two years of how the money was spent. Stakeholders wanted to retain the option of Public Trustee appointments but add an accountability process through regular reporting.

Monitoring and investigations: The Office of the Public Guardian does not monitor the quality of decisions made by private guardians, although it is often assumed by the public that this is their role. The courts deal with a complaint only if someone brings it to their attention. Stakeholders said they needed a place to go other than the courts with their concerns. They did not want monitoring to become a “watch dog” function; it should be triggered by a concern, on an as-needed basis. They stressed that the focus of monitoring be an opportunity to provide education and support for guardians.

Stakeholders also said that if monitoring reveals a significant issue, there should be an investigative mechanism with the power to remove a guardian or trustee and appoint a suitable replacement if necessary. They generally favoured mediation and alternate dispute resolution mechanisms, with the courts having the final word if resolution could be reached. Similarly, emergency protective orders should be issued when it is in the dependent adult's interest to freeze their assets or remove them immediately from an unsafe environment.

Review of guardianship and trusteeship orders: Although guardianship and trusteeship appointments are supposed to be reviewed every six years or upon request, many people do not apply for review. Stakeholders felt

reviews were valuable and should be retained, but that the review schedule should be linked to the nature of the disability and/or the family/guardian situation. Better education for guardians and trustees regarding their role and reporting requirements would help them prepare for review. However, those who do not apply for a review as scheduled should face a penalty.

Compulsory care orders and certificates: There was mixed opinion about whether the provision for granting compulsory care orders and certificates should be removed from the DAA. These orders are granted in rare circumstances when an incapable adult needs protection or treatment and is confined to a place of care, such as Alberta Hospital Ponoka, for up to three years. Several people mentioned that these provisions are already covered in the *Mental Health Act*.

Personal Directive Act themes

Standard Form: In Alberta, there is no standard form for personal directives. Stakeholders felt strongly that there should be guidelines and a standard form. However, they did not believe it should be mandatory to use this format.

Registry: Stakeholders generally agreed that there should be some type of registry to identify if a person had a personal directive, but it should not be mandatory. However, they felt it was essential that the maker of a personal directive be required to inform their agent that they had been named in the directive and that the agent be given a copy.

Personal directives made outside of Alberta: Stakeholders said personal directives, or other similar planning tools, from outside of the province should be considered valid as long as they meet minimum provincial standards.

Assessing capacity of the maker: A personal directive is activated when capacity is assessed and a declaration of incapacity is completed. This process can be completed by a person named in the directive in consultation with a physician or psychologist, who makes a written declaration that the maker lacks capacity. Most stakeholders supported expanding

the scope of who may assess capacity to include other health professionals, as long as they had training. They noted that many people do not have a family doctor and that increasing the scope could increase access to assessments.

Under the current PDA, the process for assessing capacity is not well defined. Stakeholders felt strongly that the process, tools and forms need to be standardized and recognize the fluctuating nature of capacity.

Stakeholders said there should be a well-defined process for re-assessment, particularly in situations where a person's condition may improve. It could be triggered not only by the agent, but also by the maker or a service provider. There should be a demonstrated need for re-assessment or a timeline established when the order is first activated.

Allowing adults with capacity limitations to make personal directives with safeguards: Most people are supportive of allowing people with decision-making capacity limitations to write a personal directive that covers all areas in which they are capable. However, there was limited support for the notion of naming someone to monitor the decisions of the agent. They questioned whether it would affect the ability of the agent to operate effectively.

Automatically revoking personal directives: The majority of stakeholders support the notion that when a spouse or partner is the sole named agent and they divorce or terminate their relationship with the maker, the personal directive should be automatically revoked. People wondered who would then act as a substitute decision-maker.

Care of minor children: Currently, the law is not clear about whether you can name a temporary guardian for minor children in a personal directive in the event that you are incapacitated, but do not die. People liked the idea of being able to plan ahead for the care and well-being of minor children.

Temporary substitute agents: Some people do not name an agent in their personal directive or the agent is unwilling or unable to take on the role. Stakeholders generally liked the idea that a temporary substitute decision-maker could be named, but were concerned about the process. The

proposal includes a pre-determined, ranked list of people who should be considered — such as spouse or partner, child, parent and sibling, — from which a service provider can choose.

The Public Guardian as agent: Under the current Act, it is not possible to name the Public Guardian as agent or alternative agent in a personal directive. Stakeholders felt this should be a last resort, but that for some people, the Office of the Public Guardian is the only viable option.

Powers, duties and responsibilities of agents: Stakeholders agreed that agents should have a copy of the personal directive and consent in writing that they would assume the role and follow the directions of the maker. However, they were concerned with the stipulation that the agent had to follow the verbal wishes of the maker if they are more recent than the written directions in the personal directive. There is no way to verify the wishes, which opens the door to potential conflict.

Reviewing an agent's capacity or decisions: There was general agreement that there should be a process to ensure an agent is capable and is making sound decisions in the adult's best interests. However, the mechanism to review an agent's decisions raised concerns. The proposal suggested that a review may be carried out by other agents named in the directive, immediate family, a monitor, a panel of community members or the court. Stakeholders felt the process should be objective, which is why they did not favour immediate family members. A mediation or tribunal process was favoured.

Protective safeguards: Most stakeholders supported the idea that a maker should have the option to name a person to monitor the decisions of the agent. However, it should not be mandatory.

PART 1

DEPENDENT ADULTS ACT

1.1 Guiding principles

Background

In many parts of Canada and overseas, legislation about dependent adults begins with principles that guide the decisions of the court and of trustees and guardians. Alberta's current *Dependent Adults Act* does not contain guiding principles.

Make sure you choose the right words in the guiding principles because they will be interpreted by judges in contentious cases and used to guide their decisions — be careful.

Focus group

My concern is that people will follow the guiding principles rather than the Act. I would rather that judges have the flexibility to apply the law according to legislation. One word could create a whole lot of problems if interpreted rigidly.

Focus group

Some suggested principles

1. Every adult should be presumed to have full capacity unless the contrary has been established.
2. Decisions or actions taken under the Act should strike a balance between the right of an adult to have the greatest possible degree of autonomy in decision-making and the adult's right to adequate and appropriate support for decision-making.
3. When making a decision, the substitute decision-maker is required to give significant consideration first to the wishes expressed by the adult while capable, second to the values and beliefs of the adult and finally to the best interests of the adult about a certain decision.
4. Decisions or actions taken under the Act should recognize the importance of preserving family relationships and cultural and linguistic environments.
5. Adults with diminished decision-making capacity are entitled to be informed about and, to the best of their ability, participate in decisions that affect them.
6. An adult with diminished decision-making capacity is entitled to receive the most effective but least restrictive and intrusive form of support, assistance or protection when they are unable to make decisions about any matter.

Feedback

There was a high level of support for including guiding principles in the Act. In general, participants liked the proposed statements and wanted to see them further defined throughout the legislation.

The exception was some members of the legal community who cautioned that guiding principles could leave too much room for interpretation and become an obstacle in court decisions. They preferred that judges have the flexibility to apply the law according to the legislation.

1. Every adult should be presumed to have full capacity unless the contrary has been established.

- There was strong support for the notion of “presumed capacity.” There were also many questions about how capacity is determined. The process is defined later in the Act, but these comments highlight concerns that diminishing and fluctuating capacity are not clearly addressed in the current Act.

2. Decisions or actions taken under the Act should strike a balance between the right of an adult to have the greatest possible degree of autonomy in decision-making and the adult’s right to adequate and appropriate support for decision-making.

- Many participants were pleased to see a statement about the balance between autonomy and support. They felt the power of the guardian and trustee should be the least intrusive possible. There were several comments that some guardians and trustees need more education about their role so they include dependent adults in decisions where appropriate.
- The guiding principles need to include an emphasis on protection to minimize the risk that adults with diminished decision-making capacity will be exploited by others.

3. When making a decision, the substitute decision-maker is required to give significant consideration first to the wishes expressed by the adult while capable, second to the values and beliefs of the adult and finally to the best interests of the adult about a certain decision.

Adequate training and informed guidance is a must to ensure success of the proposed principles.

Written submission

Tools and processes to determine capacity need to be defined clearly.

Online survey

You have to build in respect for the fact that there is a continuum of capacity — that capacity may diminish over time.

Focus group

Anything that puts the decision-making power back into the hands of the dependent adult is of vital importance, regardless of the person's capacity.

Online survey

As professionals, we need to recognize that it is a good thing for dependent adults to exercise their autonomy but sometimes decisions they make will place them at harm.

Focus group

The words 'best interests' bother me because it always depends on who's defining best interest.

Focus group

Many patients we deal with don't have family or their family may be doing more harm than good. When family is not supportive, we could encounter problems with the third guiding principle.

Focus group

- The ranked order of considerations implies priority and some participants felt that was restrictive, depending on the circumstances. They also felt the considerations should be equally weighted.
- There was concern that a guardian would be obligated to honour irrational or unsafe wishes of the dependent adult.
- Some thought this principle was operational in focus and would be more appropriate in another part of the Act.
- Terms such as “best interests” and “about a certain decision” leave too much room for interpretation to provide clear guidance for guardians and trustees and to provide protection for dependent adults.
- Given that some adults with diminished decision-making capacity were never capable, participants suggested “while capable” should be deleted from the principle.

4. Decisions or actions taken under the Act should recognize the importance of preserving family relationships and cultural and linguistic environments.

- Although some participants were pleased to see the role of the family recognized, many people noted that some adults with diminished decision-making capacity do not have family or have family that are not a consistent part of their support network. Health care and long-term care providers shared many examples of harmful family relationships.
- Given that society’s understanding of family is evolving, it was suggested in one focus group that the term “personal relationships” is a more functional and inclusive option than “family relationships.”
- Aboriginal participants liked the focus on preserving family relationships and cultural environments.

5. Adults with diminished decision-making capacity are entitled to be informed about and, to the best of their ability, participate in decisions that affect them.

- It was suggested that the adult with diminished decision-making capacity should have someone to explain what was happening at the time of an application (e.g., an advocate). Although there was a high level of support for the right of the adult to participate in decisions that affect them, a significant number of long-term health care providers mentioned that informing adults with diminished decision-making capacity about a new or renewed guardianship or trusteeship order causes undue stress and may endanger productive family relationships.

6. An adult with diminished decision-making capacity is entitled to receive the most effective but least restrictive and intrusive form of support, assistance or protection when they are unable to make decisions about any matter.

- There was very strong support for this proposed principle. It directly addresses the rights of the adult with diminished decision-making capacity to make as many decisions as possible. A strong theme in the stakeholder consultations was the concern that the rights of the adult are often removed without due consideration for degrees of capacity. It is essential that the guardianship or trusteeship order contain only those areas necessary, based on a physician's statement and a functional assessment.
- A dominant theme throughout the consultations was that if guardians and trustees were better educated about their role, they would be more likely to involve the dependent adult in the decision-making process.

We would strongly recommend that it be made clear that only those powers required by the guardian and/or trustee should be sought. In the spirit of maintaining the dignity of the proposed dependent adult it is absolutely essential that the applicant ask only for the powers that are necessary based on the physician's statement and the functional assessment. Often we find lawyers following a precedent. They include all the legislated powers particularly so in the case of a guardianship application when such powers are unnecessary or irrelevant given the age or lack of capacity of the proposed dependent adult.

Written submission

There needs to be safeguards in place to ensure that the informal guardian is not abusing the situation, and care must be taken to ensure that a guardianship order or personal directive is not already in place.

Online survey

As this may apply to a one-time situation, what happens when temporary substitute decision-makers change? Who will ensure there is continuity of care as different family members make decisions?

Online survey

I believe close personal friend needs to be added to this list.

Online survey

1.2 Informal decision-making authority

Background

Seventy-six percent of the people who completed the first public survey said that if they were no longer capable of making decisions for themselves, and no one was formally appointed to make decisions for them, they would want someone else to be able to make decisions for them informally (without going to court).

1.2.1 Informal personal decision-making authority for next-of-kin

Background

In Alberta, family members or next-of-kin do not have the right to make personal decisions for an incapable adult unless they are the guardian or the person named as agent in a personal directive. However, health care providers and the long-term care system sometimes make an exception.

Ninety-six percent of the people who completed the first public survey and who agreed with an informal process said they were comfortable with someone else making a decision for them about minor health matters. For more significant health matters, the percentage decreased, but was still high. Seventy-five percent said someone else could decide all health care matters, including consenting to surgery and deciding to put them on or take them off life support.

Proposals

- 1) The *Dependent Adults Act* should contain an informal process allowing next-of-kin on a ranked list in the Act to make a personal decision such as minor and major health care, including surgery on behalf of someone who has been declared incapable by a health care professional. It can be on a one-time basis or on a decision-specific basis.**

2) The ranked list of persons who may make a personal decision on behalf of the incapable adult should be: spouse or adult interdependent partner, child, parent, sibling, another relative, friend, doctor, the Public Guardian.

Feedback

Most participants saw the value and practical application of this proposal. They stated that it reflects the current practice that is happening across Alberta now and that formalizing it in the legislation would give legal recognition to the practice. It would also authorize the substitute decision-maker to receive more health information about the adult in order to make a health care decision. Under current privacy laws, family members cannot access the health records of the person with diminished decision-making capacity if they are not the agent under a personal directive or a legal guardian.

Concerns raised in the stakeholder consultations were primarily related to how the ranked list would be implemented and how “family” is, or would be, defined. There was concern that the ranked list does not necessarily reflect the nature of the adult’s relationships or trust within the family. There would need to be safeguards added to the Act to ensure the informal personal decision-maker is competent and trustworthy.

The wording needs to reflect the closeness of the individual to the incapable adult. If someone has not been in close contact, it is difficult for him or her to make informed decisions on the adult’s behalf. There was concern that a more able and trustworthy decision-maker could be “out ranked” by a less capable or trustworthy person on the list.

Currently, health care providers informally confer with the person who is at the bedside regularly and who is involved in the adult’s life. The ranked list will provide them with some legal protection or direction in emergency situations, but it could preclude people who are not on the list.

It was suggested the legislation would need to address and provide guidance when navigating socially challenging situations such as blended families and estranged spouses.

This (informal process) would be useful if someone does not have a personal directive and is unable to express themselves. Ultimately, though, it should be their choice.

Focus group

I agree with the principle but do not agree with the ranking. It is difficult to rank relationships, as many of my clients value friends over family or would respect the opinion of a doctor more than a family member.

Online survey

For 80 percent of the people, this would be a Godsend but for the 20 percent where the family is dysfunctional, how do we protect the dependent adult?

Focus group

Possible suggestions for change include establishing criteria for the ranked list (e.g., proximity, regular contact, asking the adult who they would like as a decision-maker), adding “primary caregiver” to the list, requiring the consent of two people on the list rather than one and consulting with health care and service providers involved with the adult’s life. These individuals generally have insight into who the adult has contact with and who would be an appropriate informal personal decision-maker. The Dependent Adults Appeals Panel focus group also suggested adding “most competent individual” to the list.

There should be a method of review or appeal available regarding the appointment of an informal personal decision-maker and their decisions on a very timely basis.

Concerns were raised that this process could circumvent the need for formal guardianship. Perhaps it should be called “interim” rather than “informal” personal decision-making. There was also concern that legitimizing this process could undermine people’s motivation to make personal directives.

1.2.2 Access to funds for paying everyday living expenses

Background

Seventy-six percent of the people who completed the first public survey said that if they could not make their own decisions and no one was formally appointed to make decisions for them, they would want someone else to be able to make decisions for them informally (without going to court). Almost all of these people were comfortable with someone else paying their daily living expenses.

Currently in Alberta, no one can draw money from the bank account of an incapable adult unless they are the trustee or they have power of attorney. This presents a challenge for incapable individuals who have no one to perform this role and therefore cannot access the funds for daily living expenses.

Question

Should the *Dependent Adults Act* provide an informal (non-court) mechanism by which family members of an incapable adult could be given access to funds of the adult in a bank account to pay for day-to-day living expenses?

Feedback

There was mixed support for including informal financial decision-making in the revised Act. Overall, the concept was well received, but there was a consistent concern about the potential for financial abuse. The legal community were the least enthusiastic and suggested that the role of informal financial administrator under AISH (Assured Income for the Severely Handicapped) and other pension programs should be expanded instead. In one focus group, it was suggested that financial institutions could be authorized to pay service-providers directly, without giving family members the ability to withdraw funds from the account.

Many people felt informal trusteeship arrangements were appropriate for emergency or temporary situations but should not continue indefinitely. A formal trusteeship appointment allows for checks and balances, which may be missing under an informal arrangement.

Unlike informal guardianship, no details are available regarding how someone would be appointed an informal trustee. Many participants suggested that Office of the Public Trustee or another body could screen informal trustees (e.g., do a criminal record and reference check) and authorize this process.

Day-to-day expenses should be further defined and there must be safeguards in place. There should be spending boundaries and accountability and monitoring process. However, the system should be relatively simple or it would add another layer of bureaucracy.

It is interesting that there exists an option for informal trusteeship without constricting legislation when this is an area where most of the abuse seems to occur.

Written submission

If we had informal trusteeship, it would be great but the safeguards have to be in place.

Focus group

Banks are concerned about being pushed into a monitoring role with families; they want to know who has authority and who doesn't.

Focus group

This opens up way too many opportunities for families to take advantage of finances. How would the informal trustee be determined? Who would ensure that funds are spent appropriately?

Online survey

This legislative review emphasizes public outcry for a proficient, efficient, low cost mechanism for guardian and trustee appointments. Why would the amended Act do away with the existing certificate of incapacity mechanism which is reliable and cost-efficient/effective? There is no precedence of abuse, the certificate process is performed by highly trained health care professionals, and it is reviewed every two years rather than six.

Online survey

1.3 A non-court procedure for appointing the Public Trustee as trustee

Background

When an adult is unable to make reasonable decisions about their finances, a trustee can be appointed through the courts. However, in specific circumstances, the Public Trustee may become an adult's trustee through a non-court process. If an adult is a resident of certain care facilities, two physicians who are satisfied that the adult is unable to make reasonable decisions about their financial affairs may issue a certificate of incapacity. This appoints the Public Trustee as the adult's trustee.

Question

Should the certificate of incapacity mechanism for appointing the Public Trustee as trustee for an adult be eliminated from the *Dependent Adults Act*, or should the mechanism be retained but modified to address concerns about due process?

Feedback

Some people saw value in the process because it is faster and less expensive than going through the courts, but several participants felt it should be eliminated or modified to better accommodate due process.

Under the current system, the Public Trustee does not have to present an account to the courts every two years of how the person's money was spent, unlike court-ordered trusteeship. Several people recommended that accountability be built into the system through regular reporting.

It should be easier to reverse the Public Trustee appointment if and when the individual regains capacity. It was recommended that a standard set of assessment tools be used to determine capacity and that it be performed by specially trained assessors.

1.4 Assisted or supported decision-making

Background

Sometimes a person with diminished decision-making capacity can make reasonable decisions if they have support and assistance. The current Act does not formally recognize this type of arrangement. Other jurisdictions offer examples of co-decision-making and decision-making with the help of a support network.

Proposal

- 1) Before appointing a trustee or guardian for an adult, the *Dependent Adults Act* should require the court to be satisfied that the adult could not make the relevant decisions even with the assistance of a support network.
- 2) The *Dependent Adults Act* should allow the court to appoint a co-decision-maker who would share authority with the adult for making decisions regarding personal matters identified in the order.

Feedback (online survey and written submissions only)

People see value in the concept of assisted or supported decision-making because this type of arrangement already exists; it just is not recognized in the legislation. The proposals recognize that most dependent adults can and should have input into day-to-day decisions.

I agree with supported decision-making. Most dependent adults can have input into their day-to-day lives.

Online survey

The Dependent Adults Act should not need to formalize it (collaborative decision-making) by designating a co-decision-maker.

Written submission

Expanding the number of professionals that can do assessments is good, but there must be specific training to do this work. I wouldn't be comfortable with other disciplines doing assessments without training.

Focus group

We don't have access to psychologists in rural Alberta. It's the nurses that know the person.

Focus group

Would those who are formally trained then be charging for the assessment? That could create a barrier.

Focus group

If you define 'capacity' as a form of psychosocial assessment, then a lot of health care professionals are restricted from working in this area. There needs to be clarity.

Focus group

1.5 Determining incapacity

Background

In Alberta, the tools for assessing incapacity are still relevant, but they need to be updated. With training and guidance, it may be possible to have a range of professionals who are qualified to assess capacity, making the process more accessible in rural areas of the province.

Proposals

- 1) *The Dependent Adults Act* should expand the current scope of who may assess capacity to include a health professional under the *Health Professions Act* who has completed recognized training in assessing capacity, provided this activity is within the scope of that profession's restricted activities.
- 2) *The Dependent Adults Act* should outline a new process to assess capacity that takes into consideration the sometimes fluctuating nature of capacity, uses both medical and functional assessment models and allows for assessment and re-assessment over a period of time.

Feedback

There was strong support for expanding who may perform assessments to include a range of other professionals, as long as there was training and a consistent assessment model.

Some people said they still preferred to have a doctor or psychologist involved in an assessment of capacity, at least in an overseeing role. There is concern that other professions may not have the background to diagnose the subtle elements of illness and capacity. In several focus groups, the suggestion was made to create a system where more complex cases would receive rigorous assessment.

If training is provided to other health professionals to expand the scope of who may do assessments, it was recommended in several focus groups that doctors be required to take the training as well. Many physicians are

General Practitioners and do not have specific expertise in capacity assessment. Physicians disagreed; to undergo additional training to perform assessments would likely be resisted by the majority of the medical profession.

There was general consensus that an ideal assessment would include more input from people who know the person well. It is critical that the assessment is not based on one meeting; knowing the individual is essential for an accurate assessment. The concept of a multi-disciplinary team was discussed in several focus groups and it was agreed that it may be difficult to achieve this in rural areas.

Concern was raised about cost of assessment to the family/adult and keeping the trained professionals updated. It was suggested that a registry be developed that lists the people who are qualified to do assessments.

Assessment tools need to be updated and a consistent approach should guide capacity assessment to yield results that are meaningful to guardianship issues. They should also be adjusted and appropriate for the disability. It is important that culture and language be considered when assessing capacity and that the assessment process not be too stressful for the dependent adult.

Depending on when the assessment is performed, the results can vary. This is especially true for people with fluctuating capacity. It was recommended that this be acknowledged and accommodated when assessments are conducted.

Although the current system provides for an assessment each time the Guardianship Order or Trusteeship Order is reviewed, the revised Act should build in flexible re-assessment options. People who are ill or hospitalized can recover (e.g., a person with a head injury, a senior in acute care). Many people suggested that a date for review of capacity be established at the time of the initial assessment and that the timeline be tailored to the individual situation.

There should be a review process other than the courts (e.g., an advocacy group) where an assessment can be challenged.

I particularly like the idea of re-assessment over a period of time. It allows for the possibility of changes or for a partial guardianship order.

Online survey

I think the issue of fluctuating capacity is more important than who does assessments.

Focus group

It is critical that the person is assessed in a familiar environment.

Focus group

Guardianship and trusteeship are two totally different things. They get muddled in people's minds. Make sure that this is clearly spelled out.

Focus group

I think anybody that can't write a guardianship plan shouldn't be a guardian.

Focus group

We don't have a plan for ourselves. Why would we expect a substitute decision-maker to have a plan?

Focus group

We need proactive education for guardians — they should have to take the course prior to/during the application process.

Focus group

The assessment process takes time. There needs to be an emergency decision-maker for crisis or acute situations when the adult becomes incapacitated and does not have a personal directive.

1.6 Factors to consider when appointing a guardian or trustee

Background

The current Act sets out specific criteria for appointing a guardian or trustee, but it includes terms such as “best interest” or “substantial benefit,” which are open to interpretation. There is concern that the criteria need to be clarified and whether the same criteria should be applied for both guardianship and trusteeship, which is currently different for each. Some jurisdictions ask the applicant to include a plan that outlines upcoming decisions, to help establish whether they are ready to take on the responsibility.

Proposals

- 1) The *Dependent Adults Act* should clarify the criteria or factors that must be considered in determining whether a guardian or trustee should be appointed.**
- 2) The Act should require a guardianship plan to be developed at the time of an application for an order.**

Feedback

There was strong agreement that the criteria used to determine whether to appoint a guardian or trustee are open to interpretation and need to be clarified. Expanding the criteria to clarify when there is a need for a guardian or trustee is a good idea if it helps promote better communication and rationale for moving forward with the application. The system of checks and balances need to favour protection of the dependent adult and to ensure they maintain as many rights as possible.

There was mixed feedback regarding whether the criteria for guardians and trustees should be the same. However, there was consensus that the two responsibilities are significantly different, and a dependent adult may need one but not the other.

There was varied opinion about the benefit of requiring an applicant to have a plan. On one hand, it acknowledges that guardianship is a serious responsibility and should be carefully considered. It could be used to encourage a dialogue between the dependent adult and the guardianship applicant about wishes. On the other hand, it raises questions about who will monitor the plan to ensure follow-through and whether a new plan would be required as the dependent adult's situation changes. It may also discourage people from applying because the paperwork is overwhelming, their first language is not English or they have low literacy skills. The application process is already cumbersome for many people.

If a plan is required, there should be templates available to help people create one. Most importantly, the plan should be an opportunity for more education about guardianship, which is a critical need. Many guardians and trustees assume the responsibility without a full understanding of reporting requirements, limits of their authority or other responsibilities.

If the tribunal makes the process simpler for families and it reduces costs, then it is a good idea.

Focus group

I think a tribunal would deal with the majority of cases, but if it was complex or contentious, it could go to court.

Focus group

We want diversity of perspective on the tribunal and for them to have some practical experience with the Act.

Focus group

My concern with some of these panels is what authority they will have. I am not against it, but in my experience it is difficult to implement in practice.

Focus group

1.7 Appointing a guardian or trustee

Background

The process of applying for guardianship or trusteeship can be expensive and complex. Under the current system, the courts make a decision. Australia uses a special-purpose tribunal for appointment decisions. Three options for formally appointing guardians and trustees are featured below.

Options

- 1) **Keep the existing court process for appointing guardians and trustees but simplify the process, where possible.**
- 2) **Change the process so that a special-purpose tribunal (similar to the Australian approach) would appoint guardians and trustees and review their actions.**
- 3) **Consider an approach that utilizes both courts and tribunals for different purposes.**

Feedback

Participants acknowledged that the current court-based process presents challenges. There was very strong support for tribunals as the forum for appointments. They perceived the tribunal process would provide an opportunity for more involvement by the dependent adult, which is missing in the desktop application process where the judge does not meet with the dependent adult.

They were also enthusiastic about the idea of a tribunal because they thought it would be less costly, faster and less formal, which might encourage more people to apply. They thought a variety of people on the panel would offer different perspectives and perhaps a more holistic understanding of the issues surrounding a guardianship or trusteeship decision.

Most people favoured option number three, a combination of court and tribunal formats. The most popular suggestions were that:

-
- 1) Straightforward applications be heard by a tribunal and complex or contentious applications go to court;
 - 2) First-time applications be heard in court and that the tribunal be responsible for reviews; and
 - 3) Tribunal appeals be heard in court.

Tribunals should be comprised of more than one person, except perhaps in an emergency situation, and members should be carefully selected. It was suggested that the panel include a client advocate and community members at large to keep a balanced perspective. Training was essential for all members to ensure fairness and consistency.

Some members of the Aboriginal community suggested that processes such as the Métis Settlement Appeal Tribunal could serve as a tribunal model, and should be examined in addition to the Australian system. They suggested caution when looking to Australia for guidance around how to include Aboriginal people.

Many members of the legal community were unconvinced that a compelling case has been made for an alternative forum. Lawyers who participated in focus groups questioned the value of creating another entity when the current system was workable and they cited examples of other panels that had significant implementation issues.

I would prefer to keep everything within the court system. I have seen so many abuses, that it is imperative we keep things within the realm of the court. Our judges do an excellent job.

Online survey

The process of both appointment and review should be simplified within the existing court-framework. We would strongly endorse the streamlining of the dependent adult applications so they are more user-friendly. We are not convinced that a special tribunal would eliminate the expense of the current process.

Written submission

1.8 Legislated areas of decision-making authority for guardians

Background

When a guardian is appointed, the court determines the areas in which they have decision-making authority. It may include any or all of the following areas: residential arrangements, personal contacts, social activities, employment, education and training, licenses and permits, legal matters (excluding financial matters), health care and daily living routines. A judge can add to this list at their discretion.

When deciding upon areas of decision-making authority, the court looks at what the dependent adult needs and what they are capable of doing themselves. In theory, the guardian is only given decision-making authority in areas that are necessary. In practice, guardians are often given decision-making authority in all areas to avoid having to return to court later, which can be an expensive and lengthy process.

Proposals

- 1) The areas of authority for guardians in the *Dependent Adults Act* should be reduced to making decisions about health care, residential arrangements (where to live), personal contacts, participation in social activities and non-financial legal matters. It should no longer include employment, education and training, and licenses and permits.
- 2) The Act should require the court to be satisfied that each area of decision-making authority or power granted is necessary, based on a functional assessment of the adult's capacity and on a guardianship plan developed by the prospective guardian.
- 3) The Act should require the court to be satisfied that the guardian's authority is no more intrusive or extensive than is necessary to effectively provide the adult with the assistance that he or she requires.
- 4) The Act should include the power of the court to enforce a decision of a guardian when the dependent adult is not compliant and there are significant safety concerns.

Feedback (online survey and written submissions only)

Throughout the consultations, a dominant theme has been that dependent adults should retain as much control over their lives as possible. However, when asked if areas of decision-making authority by guardians should be restricted and no longer include activities such as employment and dress, there was negative feedback. People were hesitant to curtail a guardian's ability to make decisions related to daily living. They believed that many dependent adults were incapable of making these decisions themselves.

There was widespread support for tailoring the authority of guardians based on a functional assessment. It supports both dependent adult and guardian by providing an objective perspective. There was, however, less support for requiring prospective guardians to file a plan. There is no mechanism to monitor follow-through and situations change so quickly that the plan can be outdated before it is enacted.

There was general agreement for enforcing guardian's decisions, but only when there are significant safety concerns.

1.9 Safeguards in the Act

1.9.1 Effective screening of prospective private guardians and trustees

Background

Any adult may act as a trustee or guardian if they agree to the responsibility and if the court is satisfied that they meet certain criteria. For example, a proposed trustee must be a resident of Alberta. However, the current Act does not provide guidance for determining if the proposed guardian or trustee is suitable (e.g., if they have a relationship with the dependent adult, whether they have a criminal record, etc.).

I do not agree with the first proposal. It should stay as it is to cover all decisions.

Written submission

Areas of authority should stay the same, provided that the need for supervision of these areas is proven.

Online survey

Some screening might not be a bad thing. Not all individuals are well-intentioned when it comes to the well-being of others.

Online survey

Screening might result in people declining to become trustees or guardians simply because it is too much of a hassle.

Online survey

Proposals

- 1) **The *Dependent Adults Act* should require some person or agency to screen the suitability of private guardian and private trustee applicants.**
- 2) **The Act should provide a list of matters for the court to consider in deciding whether someone will be a suitable guardian or trustee.**

Feedback (online survey and written submissions only)

Although focus group participants were not asked directly to address the topic of screening, many emphasized the importance of the trustee or guardian's suitability in their responses to other questions. Their comments echoed those of online survey respondents. Screening is critical. Criminal background checks should be standard procedure. The applicant's relationship with the dependent adult should be closely examined to ensure there is no conflict of interest and that the applicant is acting in the best interests of the dependent adult.

A few individuals cautioned that the application process was already complex and that this extra layer of bureaucracy would discourage applicants and add additional costs to the process.

In terms of trusteeship criteria, most people felt it was no longer realistic to limit residency. We live in a mobile society and technology can facilitate financial transactions from a distance. With safeguards, they felt it was acceptable for a trustee to live outside of the province. However, they also commented that the relationship between trustee and the dependent adult is critical to fulfilling the role of trustee effectively. A trustee who does not see the dependent adult often may not have a full understanding of their needs.

When asked whether a bond was necessary for trustees, most people felt this was appropriate only in situations where the trustee resides outside of Alberta. However, there was not consensus that this should be routinely required.

1.9.2 Monitoring the actions/decisions of private guardians and trustees

Background

The Office of the Public Guardian does not traditionally monitor the quality of decisions made by private guardians, although it is often assumed by the public that this is their role. The courts will deal with a complaint only if someone follows specific procedures to bring the complaint to the court's attention and ask for an appropriate remedy.

Proposals

- 1) The Act should require a person or agency to monitor private guardians' actions at the time of the review of the guardianship order, when a complaint is filed and/or on a continuous basis when a guardian is reported as lacking involvement with the dependent adult. The Act would clarify when and how monitoring would occur and could include the requirement for mediation and consultation prior to formal court intervention.
- 2) The Act should specify that private guardians and trustees be fully informed regarding their responsibilities and obligations.

Feedback

People generally agreed that monitoring on an as-required, complaint basis, was a good idea. They did not want monitoring to become a "watch dog" function, but they needed a place to go with concerns other than the courts. They also wanted a place for guardians and trustees to go for support and for answers to their questions.

Some expressed concerns that the costs and bureaucracy associated with a broad monitoring activity would be prohibitive, particularly as our population is aging and more guardianship and trusteeship arrangements will be required. The focus was on someone with authority who could receive concerns and check out a dependent adult's situation to make sure the person was not being harmed.

On one hand, you are trying to make it (guardianship) easier but monitoring would make it cumbersome. It is a resource issue as well.

Focus group

There should be someone overseeing the actions of private guardians and trustees. A monitoring system is a good idea.

Written submission

If you are looking at monitoring as working with the family, then yes – it would be a help and a resource. If families see it as being "checked up on" it could become intimidating and they would be less likely to discuss issues they are worried about.

Focus group

They also worried that monitoring would discourage people from applying. Rather than package it as an overseer function, monitoring should be an opportunity to provide education and support to guardians. They suggested that monitoring be mandatory in the first year and taper off if there were no problems. They also suggested that better screening and front-end education for applicants could curtail some of the need for monitoring.

The second proposal, which states that private guardians and trustees be fully informed of their responsibilities and obligations, was met with widespread enthusiasm. Private guardians and trustees, and members of the dependent adult's family, need better education about their role. This theme was echoed throughout other elements of the consultation process and transcends the issue of monitoring.

It's a question of timeliness. If you suspect there is an abuse of funds, it must be investigated before all the funds are gone. We need a more timely process of investigation.

Focus group

I am concerned about the time factor if courts have to be involved. Abuse can become so dangerous so quickly.

Online survey

The complaint needs to be able to go to some independent body for investigation; it has to be a government body with the authority and resources to deal with it.

Focus group

1.9.3 Investigating concerns about private guardians and trustees

Background

Although most people do an outstanding job, the potential exists for neglect and abuse of dependent adults by their guardian or trustee. Some people have said that Office of the Public Guardian or the Office of the Public Trustee should expand their role to investigate concerns. Others have suggested that an alternate non-court process be established to deal with these types of concerns.

Proposals

- 1) The Act should clearly define the role and powers of a person or agency in receiving, investigating and taking action on complaints about or against private guardians and trustees, including the power to ask the court for directions.**
- 2) The Act should establish an alternate dispute resolution process (such as mediation) to help resolve a dispute prior to having to take the matter to court.**

-
- 3) The Act should clarify that the court may remove a guardian or trustee and appoint a suitable replacement if an investigation shows that the guardian or trustee is not capable of making reasonable decisions or is taking advantage of or abusing the dependent adult.

Feedback

All stakeholders agreed that if monitoring revealed a significant issue, there should be an investigative mechanism with the power to remove a guardian or trustee and appoint a suitable replacement if necessary. Investigations should be handled quickly so the safety of the dependent adult is assured. There should be a way for people to make anonymous complaints and a mechanism to screen out frivolous issues.

There was clear direction that mediation and alternate dispute resolution mechanisms were favoured, with the courts having the final word if resolution cannot be reached. Many people saw the Office of the Public Guardian or an associated entity fulfilling this role.

These two proposals are valuable. Once this process is clarified, it could be just as useful as the Child Protection Act or the Protection of Persons in Care Act is now.

Online survey

Intervention should occur only when an adult is in imminent danger of harm to herself or others, which is what the Mental Health Act covers. Alberta seniors need to be protected from overly protective professional do-gooders.

Online survey

In abuse situations, it would be nice if the Office of the Public Guardian or Office of the Public Trustee provided support for investigations and it should be their role to investigate. They should be given temporary guardianship in these situations.

Focus group

1.9.4 Granting emergency protective orders

Background

When there is abuse or neglect, it may be in the dependent adult's best interests to freeze their assets or remove them immediately from an unsafe environment. The court needs to have the authority to grant a protective or emergency order in situations where time is of the essence.

Proposals

- 1) The Act should clarify the court process for granting a temporary, emergency protective order and outline a more timely process for obtaining such orders.
- 2) The authority to grant protective orders should be an option when there is no guardianship or trusteeship order or when there is a guardianship or trusteeship order, but there is a need for protective measures to be taken.

Feedback (online survey and written submissions only)

There was widespread support for granting emergency protective orders where necessary. This addresses concerns expressed throughout the consultation that there is no process to remove dependent adults from situations of critical abuse or neglect.

The intent to protect dependent adults must also be balanced with respect for the individual's rights. Overzealous "protection" could translate into oppression.

1.10 Review of guardianship and trusteeship orders

Background

According to the legislation, guardianship and trusteeship appointments are reviewed every six years or at any time upon request. In practice, however, many guardians and trustees do not apply for review. The Act is unclear about what happens in this situation. Some people believe that in situations where a dependent adult's condition will not change over time, the review time period should be extended.

Questions

- 1) Rather than automatically requiring trusteeship and guardianship orders to be reviewed within a certain period, should the *Dependent Adults Act* leave it to the discretion of the court? Should the court decide whether a review should be required or not and if so, when that review should occur?
- 2) Should the Act require a guardian or trustee to apply for a review, at a minimum, when there is a material change in the condition or circumstances of the dependent adult?
- 3) What should be done to make the review process simpler and less expensive?
- 4) What should happen when a guardian or trustee fails to apply for a review when required to do so?

Feedback

There was general consensus that reviews are important and should be retained. The majority of people wanted review dates to be pragmatic - linked to the nature of disability and/or family/guardian situation. For example, someone with a condition unlikely to change would have a longer review period than someone whose need for guardianship could decrease over time. Some people even suggested that no review was necessary if there was clear evidence that the adult's condition would not improve. However, a shortened review period might be appropriate if

Speaking as a parent, life is quite busy and it's hard to go back into the files. In the end, (the review) was an expense but it was good. I liked to see that there was progress and that someone was paying attention to us and what was happening in my daughter's life.

Focus group

To make the process simpler, cut out the lawyers and give the trustees more leeway with keeping track of the petty cash. There should be guidelines for expenditures (e.g., phone bills, entertainment).

Written submission

At the time guardianship is granted, a review date should be set depending on the family. Three years is a lot different between functional and dysfunctional families.

Focus group

We strongly recommend that this matter be seriously reviewed and that you consider putting "teeth" in the legislation to make these individuals accountable to the court as directed by the court.

Written Submission

This could be deleted from the Act, as many of these situations are covered under the Mental Health Act for emergencies.

Online survey

Do not remove provisions for granting compulsory care orders and compulsory care certificates. Just speak to Assertive Community Treatment teams or family members of severely mentally ill people and you will hear horror stories of what happens when they are significantly ill, released to communities and often become homeless on the streets.

Online survey

there are questions about the capability of the guardian/trustee. When asked if the standard six-year review period should be extended to 10 years, many people felt that was too long.

Better education of guardians and trustees regarding their role and responsibilities could make the review process less onerous. They should have a clear idea of what information is required for the review so they can meet the requirements. Although it is acknowledged that sometimes people choose not to apply for review because of the cost, many people said that those who do not apply for review should face a penalty. It was implied frequently in the focus groups that if tribunals handled reviews, it would be less intimidating and costly.

1.11 Compulsory care orders and certificates

Background

In rare circumstances, an incapable adult who needs treatment or protection can be confined to a place of care such as Alberta Hospital Ponoka for up to three years. This provision was part of the Act when it was created 28 years ago.

Proposals

- 1) Remove the provisions for granting compulsory care orders and compulsory care certificates from the *Dependent Adults Act*.**
- 2) The Act should contain transitional provisions to deal with existing orders and certificates.**

Feedback (online survey and written submissions only)

A significant number of people stated that they did not know enough about these options to comment. Among those who did comment, opinion was divided. Although approximately half agreed with the proposals, the other half felt there was value in retaining them. They liked having some mechanism available to protect the incapable adult from harming themselves or others in extreme circumstances.

Several people indicated that these provisions were already covered in the *Mental Health Act* and were therefore redundant.

1.12 Other feedback from stakeholders

Background

Unlike other sections of this report in which stakeholders responded to specific questions in the Discussion Guide and General Questionnaire for Stakeholders, this section captures other feedback. Stakeholders were asked for their input on accounting requirements related to the DAA.

Feedback (focus groups only)

Currently, trustees must go to court every two years to review how the dependent adult's account has been managed. Stakeholders were in widespread agreement that this is an accounting exercise and not a legal issue, and the courts should not be responsible for this activity. Another entity should review accounts on a regular basis. They suggested that the Office of the Public Trustee or a tribunal be given this responsibility, with the authority to refer contentious situations to the courts.

There should be consequences for not submitting accounts regularly. In situations where the trustee is non-compliant, stakeholders suggested that the Office of the Public Trustee apply to become the adult's trustee. However, it was suggested in one focus group that there should be some flexibility in situations where a spouse is acting as trustee and they share an account with the dependent adult. In this situation, perhaps a review every two years is excessive.

There was general agreement that trustees should continue to be allowed to charge for their work, even though many do not. It is a time-consuming process that takes a certain level of skill. However, to prevent financial abuse, it was strongly suggested that a schedule of fees be developed. It could feature a sliding scale to take into account the complexity of the estate and ensure that minimal accounts are not depleted by management and legal fees. The suggestion was raised in several focus groups that perhaps guardians should be paid for their time as well. A frequent comment was that there needs to be better education for trustees so they are prepared for review.

I don't think accounting is something the court should be dealing with.

Focus group

There should be a sliding scale to account for the complexity of various estates.

Focus group

I think a lot boils down to education of trustees.

Focus group

PART 2

PERSONAL DIRECTIVES ACT

2.1 Guiding principles

Background

The *Personal Directives Act* contains a preamble that says that Albertans should be able to plan ahead for a time when they might need someone else to make personal decisions for them. However, the Act does not contain any principles to guide those who are interpreting and applying the Act, such as service providers or the agent (the person selected to make decisions on behalf of the dependent adult). Some other Canadian and overseas jurisdictions begin similar legislation with a statement of general principles that apply to decisions under the Act.

Proposal

The following are some suggested guiding principles:

- 1. An adult has the right to autonomy and to plan for the making of future personal decisions.**
- 2. An adult cannot be compelled to make a personal directive or to be an agent.**
- 3. An adult is presumed to be capable of making a decision in the absence of evidence to the contrary.**
- 4. Capacity can fluctuate and an adult may be capable of making a decision at one time but not at another.**
- 5. The inability to communicate does not necessarily mean the adult is incapable of making a decision.**
- 6. Once a personal directive has been activated, the person who wrote it (the maker) has the right to be consulted with and informed about**

decisions made by an agent or substitute agent.

7. The decisions of an agent must be based on the known values, beliefs and previously expressed preferences of the maker, while capable.

Feedback

There was nearly unanimous agreement that the principles would be useful to makers, agents and service providers and should be included in the Act. People felt they accurately reflected the values and spirit of the Act, with some minor changes. Some participants suggested that these guiding principles be part of public education campaigns and processes.

The following comments correspond to the bullets listed in the proposal.

1. **An adult has the right to autonomy and to plan for the making of future personal decisions.**
 - There was general support for this principle and it generated few questions or comments. It was suggested that it be combined with the second bullet.
2. **An adult cannot be compelled to make a personal directive or to be an agent.**
 - This bullet struck a chord with health care and service providers who talked about the challenges of providing care when a personal directive is not in place. Although an individual cannot be compelled to write one, they strongly encourage it, particularly in long-term care settings. Despite this, most people still valued the individual's right to choose.
3. **An adult is presumed to be capable of making a decision in the absence of evidence to the contrary.**
 - Although people like the spirit of this principle and agreed that people should be presumed to have the ability to make decisions, they raised questions about the definition of "evidence to the contrary."
 - This principle was also interpreted to mean that someone should be presumed to be capable of making a personal directive unless there was evidence to the contrary. There were many observations that in health care settings, people are writing personal directives and activating them only days later, which raises the question of whether they were truly capable at the time the personal directive

The principles do emphasize the individual's right to choose and participate in personal decision-making and are acceptable.

Online survey

Acceptance into a long-term care facility is often dependent upon the whether someone has a personal directive. It's an unspoken expectation.

Focus group

If he or she has fluctuating capacity, how good or valid are the decisions given to the agent?

Focus group

What does inability to communicate mean? Verbal communication is not the test - the ability to give instruction is the essence here.

Focus group

The acceptance of fluctuating capacity has the potential to create too many gray zones and too much follow-up in determining the health and safety at any given fluctuation period. Truly a person is either capable of attending to their health and safety or they require assistance.

Online survey

In number six, an agent may not know what capacity is. We need guidelines.

Focus group

The seventh point is critical. It is a good reminder to both maker and agent that decisions are based on the maker's preferences and not on common practices or norms.

Focus group

was authored.

4. Capacity can fluctuate and an adult may be capable of making a decision at one time but not at another.

- While many people were pleased to see the principles recognize fluctuating capacity, a consistent concern was how this principle would translate into practice. Would this be a formal or informal process? Would the agent be responsible to determine the degree of decision-making capacity of the maker?

5. The inability to communicate does not necessarily mean the adult is incapable of making a decision.

- This principle raised the most questions. “The inability to communicate” must be further defined and should include methods of communication other than verbal delivery.

6. Once a personal directive has been activated, the person who wrote it (the maker) has the right to be consulted with and informed about decisions made by an agent or substitute agent.

- This principle resonated with people because it acknowledges the right of the maker to be part of the decision-making process where possible. However, most of the focus groups also raised questions about implementation. How would you consult with someone who cannot communicate? Do all decisions need to be made in collaboration with the maker? Why would it be necessary to consult if the maker lacks capacity to make decisions? There was a general feeling that this principle could complicate and increase the work of the agent.
- Physicians commented that although it makes sense that the maker is consulted with and informed about decisions, it must be recognized that once the directive has been activated, the agent has the authority to make decisions irrespective of the discussions at that time with the maker.

7. The decisions of an agent must be based on the known values, beliefs and previously expressed preferences of the maker, while capable.

- This principle is possible if the agent is aware of the values, beliefs and preferences of the maker. This is not always the case and it points to the need for better communication between the maker and the agent. Many people also raised the issue of agents imposing their own or societal values upon the dependent adult. This principle would serve as a reminder that the rights of the individual are paramount. Physicians suggested that there should be a hierarchy of principles — written instructions (unless subsequently rescinded verbally by the maker), known wishes of the maker, and the values, beliefs and previously expressed principles of the maker.

2.2 Voluntary use of a standard form for personal directives

Background

In Alberta, there is no standard form for a personal directive. It can be a formal document drafted by a legal professional or a handwritten note crafted at the dinner table. Most members of the public believe that there should be a standard form, but that it should not be mandatory.

Proposal

The *Personal Directives Act* should include a standard form that may be used for personal directives. The form should contain the following information and instructions, at a minimum:

1. It should state that all previous personal directives granted by the maker are revoked;
2. It should name a primary and alternate agent(s), if any;
3. It should grant authority to the agent to make decisions for all or only certain specified personal (non-financial) matters;

-
4. It should require the agent to follow specific instructions (e.g., residential, end of life, medical, day to day preferences, if any);
 5. It should designate someone or any one of the named agents to be the person, in consultation with an assessor (see 2.5.1), who determines whether the maker is capable of making a personal decision;
 6. It should direct the agent to notify certain persons when the directive comes into effect (e.g., children);
 7. It should name a person to monitor the decisions of an agent or directing the decisions of the agent to be reviewed by certain persons, at certain periods of time or upon a specific event; and
 8. It should allow an agent to be reimbursed for reasonable expenses incurred while carrying out his/her duties and responsibilities under the personal directive.

Feedback

There was widespread consensus that a standard form should be created as a template for people to follow if they wish. However, it should not be mandatory.

Stakeholders also felt personal directives should contain specific information, but that it be optional and not mandatory. It was recommended that the word “should” be changed to “could” in the proposal. Better education and tools could help people recognize, consider and include the important elements. It could also facilitate communication between the maker and the agent.

People felt strongly that the information should be simple, easy to understand and available online. A variety of issues (e.g., place of residence and quality of life) and options (e.g., end of life and medical life saving procedures) could be included in a standard form, triggering discussions and planning between the maker and agent(s) while, at the same time, serving as an educational tool.

1. It should state that all previous personal directives granted by the maker are revoked.

- This item generated few comments; it appeared to be clear that the most recent personal directive replaces previous ones.

Having a standard form without involving a lawyer would be extremely helpful.

Focus group

2. It should name a primary and alternate agent(s), if any.

- Some people do not name an agent and should not be forced to do so. Naming an alternate agent is a good idea, especially as spouses often name each other as agents. By the time the personal directive is enacted, the spouse may be unable to do the job.

Making it easier to complete may increase the completion rate of personal directives.

3. It should grant authority to the agent to make decisions for all or only certain specified personal (non-financial) matters.

- No direct comments were offered about agents making decisions for all or only certain specified personal matters. However, consultations on the *Personal Directives Act* and the *Dependent Adults Act* demonstrated strong support for the autonomy and rights of the dependent adult and for allowing them to make as many decisions on his or her own behalf as possible.

Focus group

Ninety percent of the personal directives I've seen from seniors simply state that a specific agent will make all their decisions. Not a lot of details are included. Seniors may not be aware that they can actually include a lot of details.

4. It should require the agent to follow specific instructions (e.g., residential, end of life, medical, day to day preferences, if any).

- It was suggested that this bullet be reworked to better reflect its intent — that the agent should follow the instructions of the maker. It currently implies that the maker needs to provide specific instructions.

Focus group

5. It should designate someone or any one of the named agents to be the person, in consultation with an assessor (see 2.5.1), who determines whether the maker is capable of making a personal decision.

- There were few comments about whether someone should be named to determine incapacity in conjunction with an assessor. There was general support for the idea that the agent alone should not decide when the directive comes into effect.

Including very specific instructions in personal directive without in-depth knowledge of certain medical procedures may be contentious and dangerous.

Focus group

An agent should be reimbursed for reasonable expenses while carrying out duties. The job is thankless enough. I would even go so far as to say that the guardian should be compensated. If I'm unable to care for myself, I would probably rather see my guardian paid than the person looking after my money, which is the opposite of the way it works now.

Online survey

Naming a monitor would send a message that the maker does not trust the agent.

Focus group

6. **It should direct the agent to notify certain persons when the directive comes into effect (e.g., children).**
 - The maker could include the names of the people they wish to be notified when the personal directive comes into effect.
7. **It should name a person to monitor the decisions of an agent or directing the decisions of the agent to be reviewed by certain persons, at certain periods of time or upon a specific event.**
 - This point generated significant debate. Naming a monitor — someone chosen by the maker to review the decisions of the agent — is a new concept, created as a safeguard. There was strong agreement that there needs to be some sort of accountability process so abusive situations can be uncovered and addressed. People who work with seniors were the most likely to support this idea because many seniors name their spouse as agent. They, too, may face diminishing decision-making capacity. However, most people were concerned that naming a monitor could create conflict among families. They felt it should be an option and not a requirement. Physicians felt that the naming of a monitor is not only impractical, but invalidates the trust implicit in the naming of an agent.
8. **It should allow an agent to be reimbursed for reasonable expenses incurred while carrying out his/her duties and responsibilities under the personal directive.**
 - Many people raised concerns about reimbursing agents for reasonable expenses. “Reasonable expenses” is difficult to quantify and could lead to abuse. A schedule of acceptable expenses would be helpful. The core issue, however, was whether the agent should be paid for their time or for making decisions on behalf of the maker. While it was acknowledged that agents often incur expenses (e.g., time off work), there was concern that this provision could deter lower income people from writing a personal directive and naming an agent to act on their behalf.

2.3 Voluntary registration of personal directives

Background

Under the current Act, you do not have to give a copy of your personal directive to the person you named as your agent, to family members or to service providers such as your doctor. During the community consultation, health care providers said they sometimes have no way of knowing if someone has a personal directive, particularly in an emergency situation. However, public opinion was divided on whether there should be a central registry and whether filing should be mandatory. Forty-three percent of survey respondents agreed that the personal directive should be filed in a central registry, but 55 percent felt that filing a personal directive in any kind of registry should be voluntary.

Proposals

- 1) **The *Personal Directives Act* should require you to give a copy of your personal directive to the person(s) you selected as your agent(s).**
- 2) **You should be allowed, but not required, to register a personal directive by having it connected or added to your electronic health record and/or identified on your driver's licence or Alberta Health Care card. The registration information could include the fact that you have a personal directive, its location and contact information for the agent(s).**

Feedback

There was almost unanimous support for the maker informing the agent that they are named in a personal directive. There was also strong agreement that makers should discuss their wishes candidly with the agent at the time the personal directive is written and give them a copy. A small minority did not feel it was necessary to do this. Like a will, they considered the information to be private. They preferred to avoid uncomfortable conversations or be swayed by the wishes of others who question their preferences.

It is important for the agent to sign off on the personal directive. We often hear of children who are named as agents but have no knowledge of their parents' personal directives.

Focus group

Care providers are at a loss to know if a personal directive exists or not, as there is no central registry. I would agree that some form of identification needs to be placed on a driver's licence and/or health care card.

Online survey

I don't see a reason for having this information listed on health records or driver's licence. Personal directives should be considered along the same lines as a will and kept in similar places.

Online survey

Registry makes sense but who has access? Keep in mind that group homes and lodges, not just nursing homes, need this information.

Focus group

We support the registration of personal directives. Indeed, there is little value to having a personal directive unless one's family, agent and caregivers are aware of its existence. We support...the requirement that the agent be given a copy of the directive. We would prefer mandatory registration of personal directives.

Written submission

Unlike the general public who were divided on the concept of whether registering a personal directive should be mandatory, stakeholders were generally in favour of the idea. They were more likely to be health care or service providers who encounter situations where knowledge of a personal directive is not only helpful, but essential. They offered many examples of crisis situations where they had no way to know if there was a personal directive and therefore did not have access to the agent.

Stakeholders considered whether personal directives should be attached to other government documents, such as a driver's license or health care card, or to existing electronic systems such as the new electronic health record. However, they were concerned that some unauthorized people would have access to sensitive and personal information. They preferred that the information indicate only that they have a personal directive or that specific parties (e.g., doctors) have access only to relevant information (e.g., medical decisions and not other personal decisions).

2.4 Personal directive made outside of Alberta

Background

In today's highly mobile society, it would not be unusual to make a personal directive while living in another province or territory and to be in Alberta when it comes into effect. The current Act does not recognize personal directives or other similar advance-planning documents made outside Alberta.

In Manitoba, any personal directive that meets the requirements of their *Health Care Directives Act* is acceptable. Other parts of Canada have similar legislation.

Proposals

- 1) The *Personal Directives Act* should recognize personal directives or other similar advance-planning documents for personal decision-making, provided they comply with the requirements of Alberta's Act.
- 2) A process should be developed to determine whether a document meets the requirements for being a valid personal directive under Alberta's Act.

We should recognize all personal directives regardless of what they do or don't comply with. These documents are as important to the individuals writing them as their wills are.

Online survey

Feedback (online survey and written submissions only)

There was strong agreement that personal directives or other similar planning tools prepared outside Alberta should be considered valid as long as they meet minimum provincial standards. It is essential that these standards be clear so service providers can evaluate documents easily. A checklist would be helpful. There was also discussion about whether personal directives written in Alberta would be recognized elsewhere. There is a national committee currently examining this issue.

Personal/advance directives done in other jurisdictions should be valid in Alberta provided they meet our own minimal requirements.

Online survey

2.5 Assessing capacity of the maker

Background

“Capacity” is defined in the Act as “the ability to understand the information that is relevant to the making of a personal decision and the ability to appreciate the reasonably foreseeable consequences of the decision.”

A personal directive is brought into effect (activated) when capacity is assessed and a form called a declaration of incapacity is completed. This process can be completed by a person named in the directive, after consulting with a physician or psychologist or by two service providers, at least one of whom is a physician or psychologist. In either case, the physician or psychologist must make a written declaration that the maker lacks capacity.

The difficulty is that in some long-term care facilities, physicians are there only once a month.

Focus group

Not everyone has a family physician.

Focus group

The issue is not only ease of access. It's also about who has the training to do this.

Focus group

The assessment process would be speeded up if other professions were allowed to perform these assessments.

Focus group

Is there a simple, standardized assessment tool to achieve this goal? If no, expanding the assessor list should be taken with much caution.

Online survey

2.5.1 Who may assess capacity?

Background

When asked who should decide when and if they were no longer capable of making personal decisions, survey respondents' first choice was their physician (80 percent), followed by the person they had appointed as agent (64 percent), or a member of their immediate family member or friend (55 percent).

Proposal

The *Personal Directives Act* should expand the current scope of who may assess capacity to include a health professional under the *Health Professions Act* who has completed recognized training in assessing capacity, provided this activity is within the scope of that profession's restricted activities.

Feedback

A very small percentage of people prefer to restrict assessments to physicians, primarily because it is assumed the physician and maker have a long-term relationship and because some medical conditions are complex. However, the majority supported expanding the scope of who may perform assessments. They noted that many people do not have a family doctor or that their relationship with the doctor is not strong. Access to doctors and psychologists is particularly challenging in rural areas. In many cases, physicians already rely upon other professionals to assist with the assessment process.

Health care providers who work with seniors commented that expanding the scope of professionals qualified to do assessments could also increase access by seniors who are house bound. Few doctors perform house calls, but other professionals such as social workers do. Other professionals may also have more time to devote to the assessment process than a doctor and they may already have an established relationship with the senior.

All professionals who perform capacity assessments must be well trained, as the outcome has serious implications. Some people even stipulated that they should be certified. Questions were raised regarding who pays for the training.

Physicians felt that they already had the training and experience to assess capacity. Asking them to undergo “recognized training” in order to do capacity assessments would be a huge burden and one that would be resisted by the majority of the medical profession. They also commented that the wording about who can do assessments was too broad — a health professional under the *Health Professions Act* who has completed recognized training in assessing capacity, provided this activity is within the scope of that profession’s restricted activities. Based on their knowledge of registered activities, they were concerned that this could be interpreted to include any health professional, which they would not support.

To require physicians to undergo 'recognized training' in order to do capacity assessments would be a huge burden and one that would likely be resisted by the majority of the medical profession.

Written submission

2.5.2 Process for assessing capacity

Background

A number of concerns about the assessment process have been raised by service providers, as well as participants in the survey and community consultations. These include the kind of assessment test(s) or model(s) that should be used, the level of assessment needed depending on the condition of the adult, whether the assessment should be based more on clinical or functional tests, or both, and what the declaration of incapacity form should look like.

The issue was raised that an individual’s capacity can fluctuate depending on their state of health, the nature of their condition and other factors. Currently the Act does not take this into account. Someone is either considered capable or incapable.

Right now, some doctors write on their scratch pad that someone is mentally incapable. This is a bit scary. Are there plans to make declaration forms mandatory?

Focus group

If the maker has a functional assessment and is deemed to be capable in two of four areas, would that be used to determine the level of decision-making for agents?

Focus group

What are the costs of a complex system of assessment and re-assessment? There may be situations where frequent assessments are necessary (e.g., brain injury cases) and not others (e.g., Alzheimer disease).

Focus group

Proposal

The *Personal Directives Act* should outline a new process to assess capacity that takes into consideration the fluctuating nature of capacity, uses both medical and functional assessment models and allows for assessment and re-assessment over a period of time.

Feedback

There was strong support for modifying the assessment process. Unlike the *Dependent Adults Act*, assessment of capacity is not well-defined in the current *Personal Directives Act*. The process, tools and forms need to be standardized and consistent.

A number of people noted that the process for assessing capacity should be similar in both Acts because the goal is the same — to determine the degree to which someone is incapable of making decisions for his or herself. Focus group participants were informed that a sub-committee was examining the assessment process in detail.

Rather than declare someone incapable in all areas because it is convenient for the agent or it is standard practice, there was strong support for tailoring the declaration of incapacity to the individual so areas of competency are recognized and respected.

People were pleased to see fluctuating capacity addressed directly in the proposal. While family members and agents gage capacity on an informal basis each day (e.g., they know when “mom” is having a good week and when it’s appropriate to ask for input on decisions), people wondered what this would look like if it became formalized in the Act.

It was generally acknowledged that it is difficult to revoke a declaration of incapacity. The Act does not outline an established process for re-assessment and people felt strongly that this is critical, particularly in situations where the maker’s capacity may improve over time (e.g., following a stroke). This raised many questions regarding logistics. People wondered what would trigger a re-assessment — whether there would be a standard timeframe or whether it would vary by situation. One suggestion was that the Act outline key indicators of change in the maker’s condition that

would prompt a re-assessment. Several focus groups suggested that the maker could request a re-assessment of capacity upon recovery. Overall, their comments did not offer clear direction regarding preferences but a consistent theme was concern about the cost of repeated re-assessments. Perhaps a partial assessment would suffice. Expanding the scope of professionals qualified to perform assessments could reduce costs to the overall healthcare system, while increasing access.

We should allow for re-assessment upon request by the dependent adult, where another professional having the authority to assess that adult concurs.

Online survey

2.6 Allowing adults with capacity limitations to make personal directives with safeguards

Background

As long as you are at least 18 years old, it is presumed that you are capable of making a personal directive. If you are dependent adult with a guardian, your personal directive cannot include matters over which your guardian has authority. In Alberta, many guardians are automatically given authority over all personal matters.

Eight-eight percent of the people who filled out the survey said that if they were an adult who had trouble making personal decisions and their capacity was questioned, they would want to be able to make a personal directive, provided there were safeguards in place for their protection.

Proposals

- 1) The *Personal Directives Act* should allow an adult with capacity limitations to make a personal directive in every area in which the adult is capable of expressing his/her choices and preferences and understands the consequences of those choices or preferences.**
- 2) The personal directive of an adult with capacity limitations must include the name of a person who will monitor the decisions of the named agent(s), but cannot substitute his/her decision for that of the agent. The duties of the monitor would include visiting or speaking with the maker, requiring the agent to account for his/her decisions and, if necessary, having the decision(s) of the agent reviewed (under the Act's review provisions).**

I agree that the basic principle is "personal" directive and that an individual with a guardian can make a directive as long as there are safeguards in place.

Online survey

These proposals do not represent a clear understanding of the nature of reduced capacity. A personal directive or any document giving decision-making ability to another person requires the maker to have a broad sense of power and responsibilities involved. Most individuals with reduced capacity do not have this insight and could be subject to coercion. This is not in the individual's best interests.

Online survey

Feedback (online survey and written submissions only)

Most online survey respondents were supportive of the first proposal in which a person with capacity limitations is able to write a personal directive. They cautioned that the individual should have assistance drafting and understanding the document. A small number took a more polarized view and expressed concern that an individual with diminished decision-making capacity does not have the ability to fully comprehend the significance of the document and could be subject to coercion.

The second proposal suggests that a monitor could be named to review decisions by the agent, as a safeguard. It raised many questions.

People also wondered if the monitoring process would be too onerous to be of significant value. It could be hard to find someone willing to act as monitor and it could negatively affect the ability of the agent to operate effectively. They suggested that monitors be optional and that they could be appointed (by a court or tribunal process) as necessary.

2.7 Re-assessing the capacity of the maker

Background

Because the capacity of an adult may change from day to day or hour to hour depending on his/her medical condition (“fluctuating” capacity), a number of survey and community consultation participants raised the issue of re-assessing capacity. They asked at what point capacity should be re-assessed in situations where the maker suffers from a recoverable medical condition. Currently, the Act requires the service provider to make a reasonable effort to determine if the maker continues to lack capacity and to notify the agent if the maker has regained capacity.

Proposals

- 1) The *Personal Directives Act* should provide that an agent who believes the maker has regained capacity to make a personal decision, after consulting with the maker and the service provider, must complete a written declaration of capacity, declaring that the personal directive is no longer wholly or partially in effect.
- 2) If there is a disagreement between the agent, maker and/or service provider about a significant or material change in the maker's capacity, the capacity of the maker must be re-assessed.

Feedback

There was strong support for defining a process to re-assess capacity. Currently, there is no uniform approach in place. People wanted standardized tools and a process for re-assessment that is not too complex, with safeguards in place to protect the maker, especially in situations where there is the potential for abuse.

Although it was agreed that someone close to the maker should trigger the re-assessment, some people were concerned about placing the authority on the shoulders of the agent. While most agents do a good job and are acting in the best interest of the maker, some are not. An agent who is neglectful, abusive, exhausted or who benefits by retaining control is not in a position to make such a decision. Also, some people do not name an agent in their personal directive. Many stakeholders suggested that the proposal be expanded to read that the maker, service provider or the agent could trigger a reassessment.

Assessments can be time-consuming and costly, and there was consensus that re-assessment was not value-added for people whose conditions were unlikely to change. There should be demonstrated need for re-assessment and it may be possible to identify this at the time of the initial assessment.

In terms of who has the authority to re-assess capacity of the maker, many people suggested that it be professionals trained to perform the task or, at the least, the same type of professional who did the initial assessment. There was concern that the term "service provider" should be further defined. Either way, a third party without vested interest should be part of the re-assessment process.

I believe this should be proactive and re-assessment should happen on a "stated time" basis. This could vary from once a week to once a year. Anyone who is in a position to personally benefit from the incapacity of another should not have the ability to decide when re-assessment should occur.

Online survey

The agent shouldn't be the only one that can trigger a re-assessment. There are some bad apples in the barrel.

Focus group

If the maker has the ability to request a re-assessment, this may become a nuisance if requested on a frequent basis.

Focus group

The same professionals who are qualified to declare incapacity should be declaring regained capacity to ensure that capacity has truly been restored.

Online survey

I agree. Even in cases of an amiable divorce the process should begin again. If the spouse is again considered to be the best agent and there are no other persons available, a new personal directive should be signed.

Online survey

Relationship can deteriorate and affect decision-making even before divorce. Who is to define the meaning of “termination of relationship?”

Online survey

2.8 Automatically revoking personal directives

Background

There are circumstances in which a personal directive can be revoked. In some Canadian jurisdictions, divorce or ending an adult interdependent relationship will revoke a personal directive if the ex-spouse or partner was the only agent named in the personal directive. Also, in some jurisdictions, the revocation is not effective until certain persons are notified.

In Alberta, there continues to be some confusion, especially among service providers, over when and how a personal directive should be revoked, especially if the capacity of the maker is in question.

Proposals

- 1) **The *Personal Directives Act* should, in addition to the current circumstances for revoking a personal directive, require the authority of an agent to be automatically revoked upon the divorce or termination of an adult interdependent relationship when the spouse or partner is the sole named agent.**
- 2) **Any agent or alternate agent named in the personal directive should be given written notice of the revocation.**

Feedback (online survey and written submissions only)

The majority of the people who responded to the online survey support the notion that when a spouse or partner is the sole named agent and they divorce or terminate their relationship with the maker, the personal directive should be automatically revoked.

Currently, it is unclear whether the maker can simply name a new agent or whether they must write a new directive. People wondered who would act as a substitute decision-maker during the transition.

The question also was raised several times about when to draw the line; at what point is the relationship considered unsupportive? This can happen long before a relationship is terminated legally.

Conversely, sometimes ex-spouses maintain good relationships and can be counted on for continued support as an agent. Some session participants felt that automatic revocation of personal directives upon divorce is too harsh and proposed that instead there should be an automatic review process. For example, some senior couples are “forced” to divorce when spouse is admitted to a long-term care facility in order to qualify for maximum federal government financial assistance.

People generally supported the second proposal, which stipulates that the agent or alternate agent be notified in writing that the personal directive has been revoked. No additional comments were offered.

2.9 Care of minor children

Background

Under Alberta law, you can name a guardian for minor children in your Will. However, the law is not clear about whether, in your personal directive, you can name a temporary guardian for minor children in the event that you do not die but are incapacitated.

In Ontario’s *Representation Agreements Act* (similar to Alberta’s *Personal Directives Act*), you can name someone to make arrangements for the temporary care, education and financial support of your minor children and any other persons you care for or support if you become incapacitated.

Proposal

The *Personal Directives Act* should contain a new provision to allow the contents of a personal directive to include the name of (a) person(s) who may make arrangements for the temporary care, education and financial support of the maker’s minor child(ren) and any other persons who are cared for or supported by the maker until a guardianship order is made under the *Family Law Act* or the maker regains capacity.

This proposal should be enacted to ensure minimal disruption in the lives of minor children in the event that their guardian/parent is incapacitated.

Online survey

Feedback (online survey and written submissions only)

Feedback to this proposal was almost unanimously positive. People liked the idea of being able to plan ahead for the care and well-being of their loved ones. A few people wondered if this information should be part of a Will rather than a personal directive.

2.10 Temporary substitute agents

Some people do not name an agent in their personal directive or the agent is unable or unwilling to take on the role. In the current legislation, it is not clear how an agent should be selected if one is not named or is not available.

In the survey, we asked people who they would want to make decisions for them if they had not appointed anyone and they were no longer able to make decisions themselves. Their preference, in ranked order, was spouse or partner, child(ren), parent, sibling, another relative, friend, doctor and Public Guardian.

In B.C.'s *Health Care Consent Act*, temporary substitute decision-makers, such as family members, are listed in a preferred order. They must also meet certain criteria before they can make health care decisions.

Proposals

- 1) **The *Personal Directives Act* should provide that where no agent is named in a personal directive or the named agent is unavailable, unable or unwilling to act, a service provider may choose the first in a listed order of persons who are available and qualified under the Act to make a decision on behalf of the maker. The list, in order of preference (based on the survey results) would be: spouse or partner, child, parent, sibling, another relative, friend, doctor and Public Guardian.**

-
- 2) A temporary substitute agent should be 18 years of age or older, capable of making personal decisions, have had contact with the maker in the last 12 months, have no current dispute or conflict of interest with the maker on personal matters, be willing to comply with the instructions or wishes the maker expressed while the maker was capable, and be willing to comply with the principles and guidelines for agents in the Act.

Feedback (online survey and written submissions only)

People generally liked the idea that a temporary substitute decision-maker could be named in the absence of a named agent. It formalizes a process already happening between health care workers and families in the absence of a named agent or a guardian.

If this proposal is implemented, service providers need a clear set of expectations regarding how long they are expected to wait for an answer before moving to the next person on the list, how extensively they are expected to search and screen candidates. This assessment often has to happen quickly. There is also a minor concern that service providers will “shop” the list for a party who is amenable to their perspective.

The idea of a pre-determined ranked list raised some concerns because it is based on the premise that all families are supportive and functional. This is not always the case. For example, a temporary substitute decision-maker may not disclose a conflict of interest. It was suggested that perhaps an independent review process could be used to review the appointment.

There should be some direction in the Act that indicates the service provider cannot go shopping down the list of proposed agents. For example, if the spouse is not willing, the service provider should go directly to the Public Guardian.

Online survey

I absolutely disagree with automatically appointing family members in the absence of a personal directive and would hope that there is a more appropriate solution to ensure that we are not putting vulnerable individuals at further risk. A dispute between parties may not be known.

Online survey

Yes, provided the Public Guardian is given adequate resources to do the job.

Online survey

Yes. We have many disjointed families and the Public Guardian would be in a balanced position to assist the individual.

Online survey

2.11 The Public Guardian as agent

Background

Not everyone has family or friends they would name as an agent to make decisions on their behalf if they became incapacitated. A number of people who responded to the survey or attended the community consultations wanted the option to name the Public Guardian as their agent or alternate agent in their personal directive. This is not currently possible under the Act.

Proposal

The *Personal Directives Act* should allow the Public Guardian to be named as the agent or alternate agent in a personal directive if the Public Guardian has consented to this role and is given a copy of the directive.

Feedback (online survey and written submission only)

Feedback was unanimously positive to this proposal. People said the Office of the Public Guardian should be a last resort but acknowledged that it is the only viable option for some people.

2.12 Powers, duties and responsibilities of agents

Background

In Alberta, you are not legally required to tell someone that you have named him or her as your agent in your personal directive. The agent also does not have to consent to being named.

Proposal

The *Personal Directives Act* should have a new section on powers, duties and responsibilities of agents including the following provisions:

- An agent must be given a copy of the maker's personal directive;
- An agent must consent in writing to be the agent and to follow the instructions of the maker in the personal directive;
- An agent must agree to comply with the guiding principles and the duties and responsibilities of agents under the Act;
- An agent may resign as agent at any time but must do so in writing. If the agent is incapable of resigning, a health professional under the *Health Professions Act* who has the authority to assess capacity may sign a written declaration that the agent is no longer capable of acting as agent; and

An agent may follow the verbal wishes of a maker that are more recent than the written instructions in a personal directive if:

- The wishes relate to the same kind of personal matter the agent must make a decision about;
- The wishes were expressed when the maker was capable and the agent is aware of them; and
- The agent believes that the maker would still act upon those wishes if he/she was capable.

Feedback (online survey and written submission only)

There is a high degree of support for most of the proposals outlined. People agreed that agents should be required to consent in writing, as there is no process currently in place to ensure they know they have been named as an agent or that they are willing to assume the responsibility. They should be fully apprised of all that this entails. Equally important, this was seen as a catalyst for better communication between the maker and their agent.

The inclusion of recent verbal wishes is most definitely not acceptable as it would be impossible to verify any claims made by an agent and would violate the maker's stated wishes. Such a clause would reap havoc in every emergency room, intensive care unit and continuing care facility in the province.

Online survey

If there is a verbal wish by the maker, then it seems to be a simple matter to write a codicil to the original and have your signatures witnessed by a third party. An oral change would seem to cause a grey area. Was this oral off-hand remark of Terri (Shiavo's) real or did her husband make it up? Look at the trouble that caused her family

Written submission

The ability to follow verbal wishes is important. When death nears or some health crisis occurs, makers and agents engage in specific, candid discussions regarding the maker's wishes.

Online survey

It was agreed that agents should have a copy of the maker's personal directive. There were few comments regarding whether or not an agent should have to submit their resignation in writing. At a Red Deer focus group, participants suggested that there be a standardized process and that perhaps the agent could be required to sign a "refusal form."

The last section of the proposal elicited concerns. Several people commented that the verbal wishes of a maker cannot be verified. If those wishes are in conflict with what is written in the personal directive, it places service providers in a difficult situation.

2.13 Reviewing an agent's capacity or decisions

Background

While most personal directives are carried out without problems, sometimes questions are raised about whether the agent is acting in the best interests of the maker and whether they are capable of doing the job. Members of the public favour a non-court process, such as mediation, to help resolve disputes over personal directives.

Currently under the Act, anyone can apply to the court to review the actions of the agent at any time. However, the Court of Queen's Bench is the only body that can conduct the review.

Proposals

- 1) **The *Personal Directives Act* should provide for the review of an agent's capacity or decisions when either has been questioned.**

2) The review may be carried out by:

- any or all other agents named in the directive who are capable and willing;
- immediate family members;
- a monitor named in the personal directive;
- a panel of community members, including experts, who may use an alternate dispute resolution process such as mediation; or
- the court, with the power to order an assessment of the agent's capacity

Feedback

There was general agreement that there should be a process to ensure the agent is capable and is making sound decisions on the agent's behalf.

However, the mechanism to review an agent's decisions raised concerns and questions. It was agreed that the process must be objective, which is why immediate family members were not a favoured choice to carry out the review. While it is understandable that the maker would trust family, the issues are often sensitive. Family dynamics are complex, especially in times of crisis or conflict.

A key concern was that the review process be accessible, cost effective and timely. For example, there should be flexibility in allowing review processes to take place or be fast-tracked, especially in situations of potential abuse. A mediation process or a tribunal was suggested and supported by many. It was hoped that many disputes could be resolved before they ended up in court, which was seen as a last resort.

The point was raised in several focus groups and submissions that most agents are well-intentioned, but the source of their inappropriate actions is often misinformation or missing information about their role and the true intentions of the Act. Better education of agents is important.

How do we control frivolous complaints?

Focus group

There needs to be a non-court process to handle these cases.

Online survey

Costs of an agent's representation are serious. What is the likelihood that they can recover their costs?

Focus group

We disagree with the concept of a monitoring process but accept the potential for there to be, at times, legitimate questions about the agent's decisions. We could support the Court having power to order an assessment of the agent's capacity.

Written submission

The monitor needs to be unbiased or it has no validity. For example, mom is guardian but makes poor decisions. Dad is monitor but does whatever mom says.

Online survey

I agree with this proposal. However, it could cause huge family problems as one brother monitors another, or a son monitors a mother, etc.

Online survey

2.14 Protective safeguards

Background

In the survey, 59 percent of respondents agreed that their agent's decisions should be reviewed by a monitor named in their personal directive. Under the current *Personal Directives Act*, there is no provision for a monitor. Legislation in some Canadian jurisdictions allows, or in some cases requires, a monitor to be named or appointed in a personal directive. A monitor's role is to watch over and check on the actions of the agent.

Proposals

- 1) **The *Personal Directives Act* should have a new protective safeguard that allows a maker to name a person to monitor the decisions of the agent. The monitor could be a family member, another agent or other person.**
- 2) **If an adult with diminished decision-making capacity makes a personal directive, the maker must name a person to act as a monitor.**
- 3) **If the monitor questions the actions or decisions of the agent, the matter may be reviewed through the courts or through a non-court process set out in the Act, including an alternate dispute resolution process.**

Feedback (online survey and written submission only)

The majority of people favoured the idea that a maker should have the opportunity to name a monitor. However, they believe it should not be mandatory.

Although it is a likely scenario that a family member be named as monitor, many people cautioned against this. They recommended that the monitor be unbiased.

An alternate dispute resolution process was favoured over traditional court processes.

Physicians did not support the idea of naming a monitor. They felt it defeated the purpose of naming an agent, who is supposed to be acting on the maker's behalf. Instead, they suggested that more emphasis needs to be placed on ensuring the right person is selected as the agent and that there be a high level of trust between that person and the maker.

NEXT STEPS

The results of this report will be analyzed with the data gathered in the other three phases of the consultation process. You can view and download all of the consultation reports online at www.seniors.gov.ab.ca or www.justice.gov.ab.ca.

- Legislative Review Survey Results Report (Phase One)
- Community Consultations Summary (Phase Two)
- Stakeholder Consultations Summary (Phase Three)
- Dependent Adults and Self-Advocates Consultations Summary (Phase Four)

Recommended changes to the *Dependent Adults Act* and the *Personal Directives Act* will be submitted for government consideration. This will launch an extensive process of internal review. It is anticipated that the revised Acts will be introduced in the Alberta Legislature in the spring of 2007.

The new legislation will capture the ideas and opinions of the many Albertans who participated in the consultation process. While their individual points of view were unique, there was strong consensus about what needs to change and what should remain the same in the two Acts. Their input was a very important and valued part of the legislative change process.

You may direct further inquiries to the Office of the Public Guardian at (780) 422-1868 or the Office of the Public Trustee at (780) 427-2744. To be connected toll-free in Alberta, dial 310-0000 followed by the area code and the phone number.

