



Alberta
Justice

Alberta
Seniors and
Community Supports

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

Survey Results

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□ Introduction

Alberta Seniors and Community Supports and Alberta Justice are pleased to present the results from the *Dependent Adults Act* and *Personal Directives Act* discussion guide and survey.

Albertans completed over 3,500 surveys. We are very grateful for the time that participants took to complete this survey and for their insightful comments and suggestions. These responses will help frame the public consultation sessions that will be held across Alberta during the fall of 2005 and will help the government make meaningful changes to the legislation.

This report contains the results of the survey questions and comments made by participants. The Executive Summary contains highlights from the survey results, and detailed results follow in the *Dependent Adults Act* and *Personal Directives Act* sections.

Thank you to everyone who responded to the survey questions. Your input will help ensure that the *Dependent Adults Act* and the *Personal Directives Act* will meet the need of Albertans, now and into the future.

□ Executive Summary

In June 2005, the Government of Alberta announced a review of the *Dependent Adults Act* and the *Personal Directives Act*. To make sure that these acts would meet the needs of Albertans, the government asked the public for their input.

To gather input, a discussion guide with survey questions was developed and sent to private guardians, trustees, family members and legal advisors of dependent adults, health care providers and community groups. Albertans who were interested in answering the survey questions could also find the discussion guide on government websites.

The discussion guide was divided into two sections: one for the *Dependent Adults Act* and one for the *Personal Directives Act*. Respondents were invited to respond to either section or to complete both sets of questions.

In total, 1,905 surveys were completed for the *Dependent Adults Act* and 1,596 for the *Personal Directives Act*. Eight formal written submissions were also submitted.

The *Dependent Adults Act*

Highlights from the Survey Results

- 96% of respondents agreed that someone should be appointed to make reasonable financial or personal decisions for them when they are unable because of a medical condition.
- 76% agreed that an informal process should be developed to allow family members to make some decisions without going to court.
- Of those who agreed with an informal process:
 - 87% of respondents would most prefer their spouse/partner to make decisions for them, informally, if they were unable themselves.

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- 97% would be comfortable having someone pay their daily living expenses if they were unable to make decisions themselves.
 - 96% felt that minor health care decisions could also be made on their behalf.
 - One of the most common concerns expressed by respondents related to the complexity and cost of applying for guardianship or trusteeship orders.
 - Many respondents also felt the review period for guardianship or trusteeship should be reviewed. Some felt that the review period was too short and that the relationship between the guardian and the dependent adult should be taken into consideration.
 - Many respondents commented about the personal nature of the survey and how the survey made them think seriously about their lives and future.

The Personal Directives Act ***Highlights from the survey results***

- 81% of respondents felt there should be a standard form available for the preparation of personal directives.
- 85% of respondents felt that a personal directive that was made outside Alberta should be recognized in Alberta.
- 80% felt that their physician should be the one to decide if they were no longer capable of making decisions.
- 84% thought a personal directive should include the signed consent of the agent that was named.
- 77% of respondents felt that immediate family members should be able to make decisions for them in the absence of a personal directive.
- 69% were in agreement that there should be a process to review an agent's decision by either immediate family, another agent or a monitor.
- Only 31% felt the court should be reviewing an agent's decisions.
- Some respondents commented about the importance of having a personal directive and some commented about the need to make personal directives more detailed.
- Others commented about the need for more public education and awareness about personal directives.

□ **Dependent Adults Act**

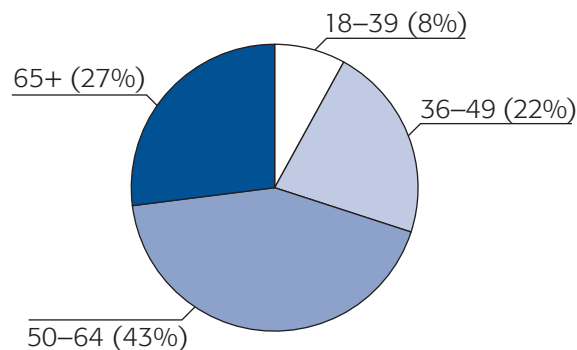
In total, 1,905 *Dependent Adults Act* surveys were completed.

Who we heard from

	# of respondents	% of respondents
I am an Alberta resident interested in the <i>Dependent Adults Act</i>	1,262	66 %
I am a private guardian or trustee	1,091	57 %
I am a relative of a dependent adult	1,055	55 %
I am a professional working to provide services to dependent adults	533	28 %

Demographic Information

(Respondents were asked to check all statements that applied to them.)



Age of respondents

	# of respondents	% of respondents
I live in Northern Alberta (not in the Edmonton Area)	176	9 %
I live in the Edmonton Area	710	38 %
I live in Central Alberta (including Red Deer)	238	13 %
I live in the Calgary Area	471	25 %
I live in Southern Alberta (not in the Calgary Area)	279	15 %

Where respondents live

Details of what we heard about the *Dependent Adults Act*

Question 1

At what point should someone be appointed to make personal or financial decisions for you?

(Respondents were asked to choose all options they felt were applicable.)

	Yes		No		Unsure/ No opinion	
	#	%	#	%	#	%
When, in the opinion of others, I am making decisions that are not in my best interests	880	54	378	23	374	23
If other people are taking advantage of me	1,280	73	183	11	266	16
If, as a result of a medical condition, I am repeatedly unable to make reasonable financial or personal decisions	1,761	96	13	1	51	3
When I am in a coma, and I cannot make personal and/or financial decisions for myself	1,627	93	50	3	63	4

Comments

“This review is double-edged for me as a guardian for my two dependent children but the question of myself and my age makes me look at what decisions I need to make should I become incapacitated. For my children – total decision making – but for me many questions are still in my mind.”

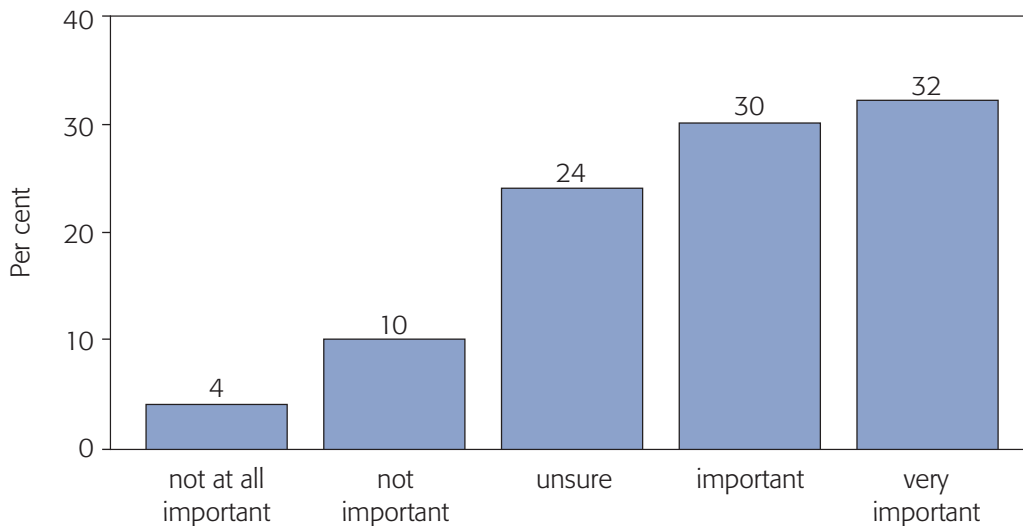
“Hardest questionnaire I’ve ever filled out. It seems to me guardianship for a mentally challenged person from birth is just sensible. But when I have to relate it to myself and the fact that I’m aging... WELL it’s a totally different thought process. Not as clear as to who decides I’m incompetent or whatever and to what degree.”

“Determination of incapacity is a grey and difficult matter to manage.”

“There needs to be a clear process for determining capacity and a process to re-evaluate it. Capacity is fluid and changes depending on the decision.”

Question 2a

If you were to become less capable of making decisions, how much value would you place on your personal freedom and autonomy to continue to make decisions on your own without a substitute decision-maker?



How much value would you place on your personal freedom and autonomy to continue to make decisions on your own?

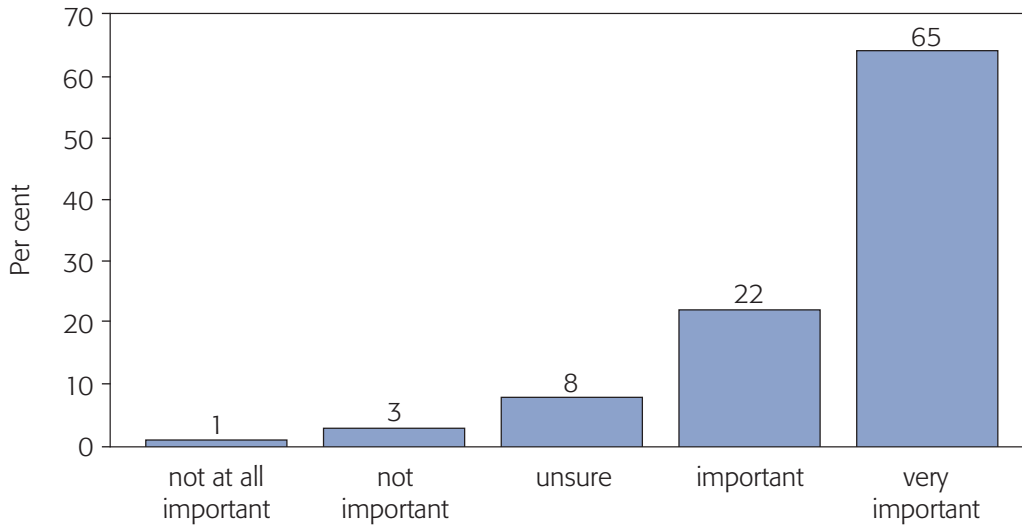
Comments

“I have a strong belief that decision makers need to act in a manner that respects the spirit in which the individual would have made a decision when they were capable of doing so. I also believe that decision-making should respect the principles of autonomy of the individual requiring the service; namely that anyone with a guardian/decision-maker should be permitted to make all decisions in which they are capable and have support for the others.”

“Having choices and being involved in making choices is very important to me. The person that I trust and know very well should be able to make and help to make these decisions should I not be able to.”

Question 2b

If you were to become less capable of making decisions, how much value would you place on protecting your personal or financial interests?



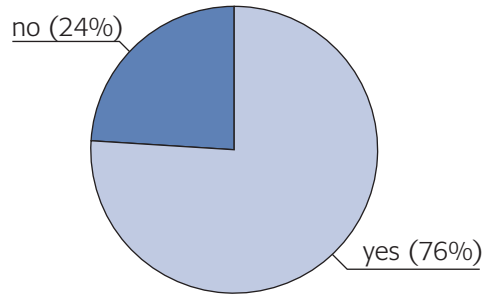
How much value would you place on protecting your personal and financial interests?

Comments

“The system is rightfully set-up to protect the person who cannot always make good decisions regarding finances, personal safety, health, etc. but it leaves little room for some minor choices that the individual is capable of making (e.g. purchasing small gifts).”

Question 3a

If no one was formally appointed as your substitute decision-maker and you were no longer capable of making decisions yourself:



Would you want someone else to make decisions for you informally?

Comments

“As a parent of a dependent adult who was born mentally disabled it should be easier to be appointed guardian and trustee of your own child. This should be done without having to retain a lawyer and going through court.”

“Immediate family should be used as they love and care about and know a person best.”

Question 3b

Who would you want to make decisions for you informally?

(Respondents were asked to rank their preferences.)

- Most Preferred** →
1. Spouse or Partner
 2. Children
 3. Parent
 4. Brother or Sister
 5. Another relative
 6. Friend
 7. Doctor
- Least Preferred** →
8. Government

Comments

“Being a guardian and trustee for my spouse I would like to be free to make decisions without court intervention. It is very costly and time consuming to have to prepare accounts and renew guardianship orders. I firmly believe spouses in particular should not be regulated in this way.”

“I would like my children who live closest to me to be my decision makers. I know they would consult my other children.”

Question 4

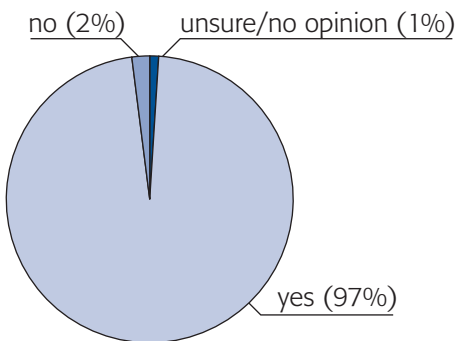
If you were no longer capable of making decisions on your own, what kinds of decisions would you feel comfortable having someone else make informally for you?

(Respondents were asked to choose all options they felt were applicable.)

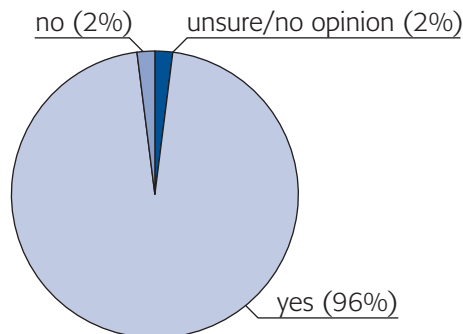
	Yes		No		Unsure/ No opinion	
	#	%	#	%	#	%
Paying my daily living expenses	1,319	97	24	2	17	1
Deciding what kind of social or recreational activities I would participate in	912	71	203	16	161	13
Deciding where I would live	1,013	78	173	13	108	8
Deciding how to invest my money	814	65	304	24	129	10
Deciding to sell my property	707	58	348	28	157	13
Deciding on minor health care matters, such as going to the doctor, taking medication, having dental treatment	1,275	96	32	2	28	2
Deciding on all health care matters including consenting to surgery, putting me on/taking me off life support	949	75	213	17	110	9

Decisions respondents are most comfortable making informally:

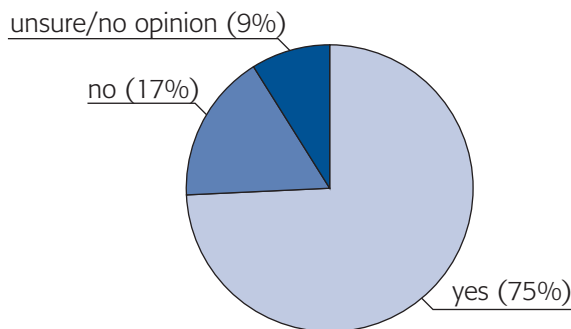
- Most Comfortable**
- ➔ 1. Paying my daily living expenses
 - ➔ 2. Deciding on minor health care matters, such as going to the doctor, taking medication, having dental treatment
 - ➔ 3. Deciding where I would live
 - ➔ 4. Deciding on all health care matters including consenting to surgery, putting me on/taking me off life support
 - ➔ 5. Deciding what kind of social or recreational activities I would participate in
 - ➔ 6. Deciding how to invest my money
- Least Comfortable**
- ➔ 7. Deciding to sell my property



Paying my daily living expenses



Deciding on minor health care matters such as going to the doctor, taking medications, having dental treatment



Deciding on all health care matters including consent to surgery, putting me on/taking me off life support

Comments

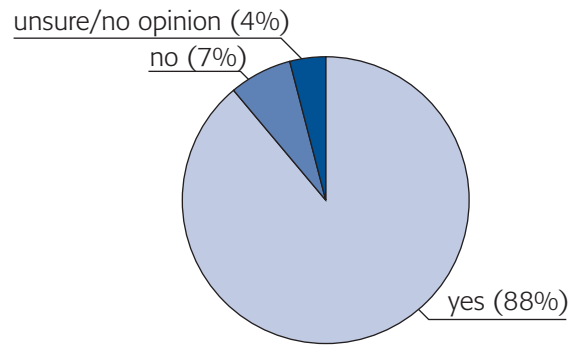
“The decision maker should be selected by the individual, close relative, if any close friends who may know the individual family members. Personal greed and decision motivations must be monitored.”

Question 5:

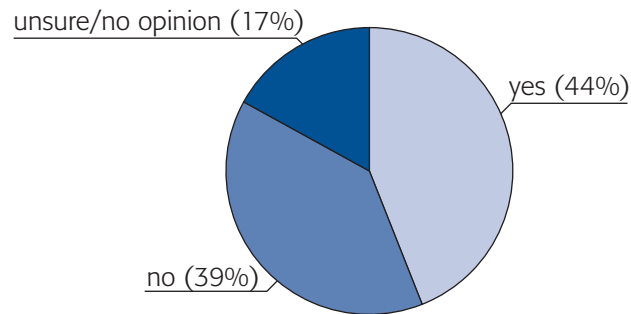
How should someone become a decision-maker for you if you were no longer capable of making decisions on your own?

(Respondents were asked to choose all options they felt were applicable.)

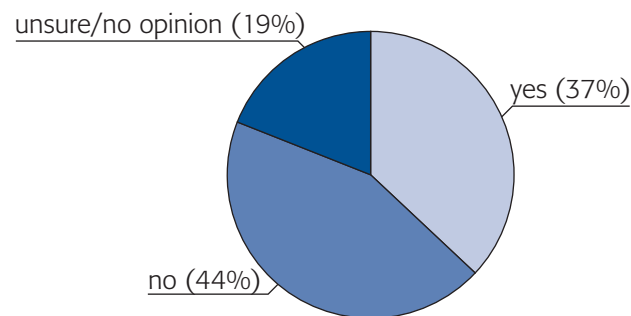
	Yes		No		Unsure/ No opinion	
	#	%	#	%	#	%
Certain people should be automatically designated in the <i>Dependent Adults Act</i> as being able to make a decision for me in certain circumstances (for example, immediate family could make a health care decision for me)	1,576	88	131	7	81	4
A panel of appointed community members, including experts, would appoint a decision-maker for me	424	26	900	56	284	18
A judge would appoint a decision-maker for me	744	44	649	39	287	17
A government official, such as a Public Guardian or the Public Trustee, would appoint a decision-maker for me	608	37	728	44	311	19
A physician or psychologist would issue a certificate appointing a government official to be my decision-maker	461	28	874	54	287	18



Certain people should be automatically designated in the Dependent Adults Act



A judge would appoint a decision-maker for me



A government official would appoint a decision-maker for me

Question 6

If you were no longer capable of making decisions on your own, how should your substitute decision-maker make decisions about your *personal matters* for you, (for example, decisions about health care or where you would live)?

(Respondents were asked to rank their preferences.)

- Most Preferred** →
- Based on what my decision-maker knows of my past preferences
 - Based on a discussion with me at the time a decision needs to be made
 - Based on what my decision-maker thinks is in my best interest
- Least Preferred** →
- Based on previous conversations with relatives and friends

1 = most preferred; 4 = least preferred

	1		2		3		4	
	#	%	#	%	#	%	#	%
Based on a discussion with me at the time a decision needs to be made	803	43	256	14	290	16	497	27
Based on what my decision-maker knows of my past preferences	861	47	674	37	232	12	82	4
Based on what my decision-maker thinks is in my best interest	478	26	455	25	500	27	414	22
Based on previous conversations with relatives and friends	340	18	363	20	513	28	619	34

Question 7

If you were no longer capable of making your own decisions, how should your substitute decision-maker make decisions about *financial matters* for you (for example, managing your investments or selling your house)?

(Respondents were asked to rank their preferences.)

- Most Preferred**
- Based on what my decision-maker knows of my past preferences
 - Based on a discussion with me at the time a decision needs to be made
 - Based on what my decision-maker thinks is in my best interest
- Least Preferred**
- Based on previous conversations with relatives and friends

1 = most preferred; 4 = least preferred

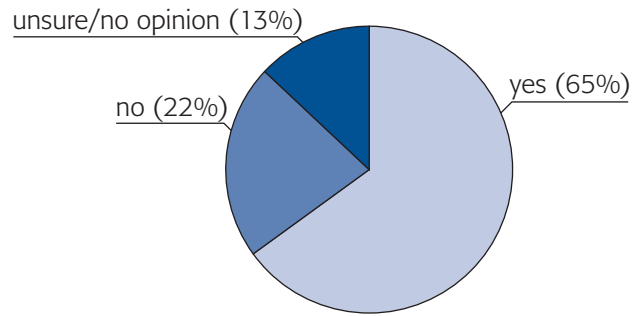
	1		2		3		4	
	#	%	#	%	#	%	#	%
Based on a discussion with me at the time a decision needs to be made	760	41	226	12	311	17	546	30
Based on what my decision-maker knows of my past preferences	823	45	683	37	262	14	72	4
Based on what my decision-maker thinks is in my best interest	547	30	498	27	471	26	325	18
Based on previous conversations with relatives and friends	308	17	331	18	508	28	681	37

Question 8

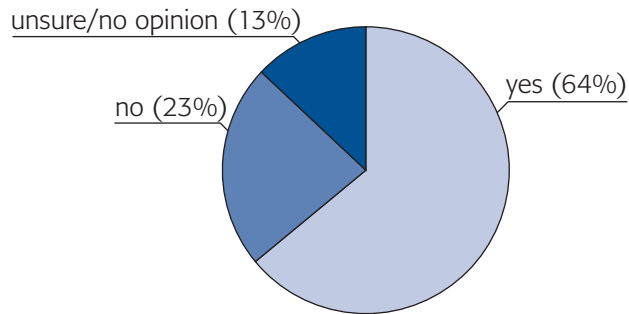
If you were no longer capable of making decisions on your own, what steps should be taken to ensure that your substitute decision-maker acts in your best interests?

(Respondents were asked to choose all options they felt were applicable.)

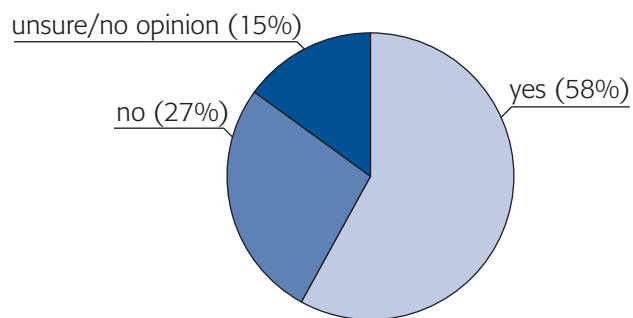
	Yes		No		Unsure/ No opinion	
	#	%	#	%	#	%
My decision-maker should have to account to me with a record of decisions made	1,156	65	384	22	230	13
My decision-maker should have to account to a person the court has appointed to monitor my decision-maker	1,129	64	406	23	236	13
My decision-maker should have to account to a government official such as the Public Guardian or the Public Trustee	1,005	58	472	27	260	15
My decision-maker should have to account to the court	919	54	513	30	283	16
For financial decisions, my decision-maker should have to post a bond before being appointed	410	25	811	49	430	26



My decision-maker should have to account to me with a record of decisions made



My decision-maker should have to account to the person the court has appointed to monitor my decision-maker



My decision-maker should have to account to a government official such as the Public Guardian or the Public Trustee

Do you have any other comments or issues you wish to raise about the *Dependent Adults Act*?

The government received 1905 completed surveys for the *Dependent Adults Act*. All the comments from respondents were recorded. The following is reflective of these comments.

Respondents expressed concern about the complexity and cost of applying for guardianship or trusteeship orders:

“I feel that having to apply to the court every six years for a new order re: guardianship and trusteeship, is an onerous expense. The legal fees for such application are generally around \$3,500 and such amount of money could better be spent for the care of my daughter.”

“The application process for guardianship/trusteeship is expensive, complicated and time consuming. Individuals who cannot afford to hire a lawyer are at a clear disadvantage.”

“Legal fees, court costs and a slow, complex process make the current court-based system frustrating to work through. Any new system should be reliable, efficient and low-cost.”

“The Government should cover the costs of bookkeeping, legal and all related costs/expenses to prepare/submit required documents, reports, etc.”

“I paid in excess of \$4,600 in legal fees to have a review of guardianship and trusteeship and a review of all financial matters on behalf of my sister who is a dependent adult. The legal fees represented her AISH income for five and a half months.”

Some respondents stated that guardianship or trusteeship orders for dependent adults whose condition would not change should not have to be renewed every six years. Some suggested that renewals could occur every 10 years and some suggested that appointments should be for the lifetime of the guardian or trustee:

“Once a trustee and/or guardian has been appointed and there are no further changes to the dependent adult’s circumstances it should not be necessary to file further court documents which cost the dependent adult (legal fees).”

“When the guardians are the dependent adult’s parents who have raised and cared for this child since day one, I do not think it is necessary to review the guardianship and trusteeship every six years. It could be extended to 10 years unless there is a death of the caregivers or other major change.”

However, some expressed caution about longer appointments:

“Family members/relatives should not be granted guardianship/trusteeship unless they can prove they will act in the best interests of the dependent adult. Guardianship orders should not remain in force past six years. Upon application for renewal, the guardian should be required to demonstrate how they have acted in the person’s best interests over the past six years.”

“Review should be mandated more often than every six years.”

Some respondents felt that an individual residing outside of Alberta should be able to be appointed trustee, as is now the case for guardianship:

“We need the same agreement for trusteeship arrangements, so the guardian can also be the trustee for the family member. I live in B.C. and am the guardian for my sister in Edmonton, but can’t be her trustee. Perhaps this could be worked on and improved/updated.”

“Financial management can be handled from anywhere in this age of technology with telephone, fax, e-mail and electronic banking. Why is it necessary that the trustee be a resident of Alberta?”

“In regard to trusteeship, I believe that the residency requirement to be a trustee should be altered, so that the trustee may reside in another province. Provisos as to how many times per year the trustee must meet with the dependent adult should be included to ensure that the trustee is currently aware of what is happening to his/her ward.”

Some respondents felt that family members should always be the preferred choice for guardianship or trusteeship appointments:

“On the whole, family members would have the best interests of the individual at heart.”

“A spouse and/or family know you better than any stranger and would know what you would be most comfortable with.”

“Where families can be responsible for the dependent adult they should be and also be accountable to each other making sure the dependent’s best interests are taken care of.”

“It is my opinion that, whenever possible, spouses/close family members should make decisions for individuals who lose capacity. Legislation should cut through the “red tape” that would allow for.”

“I strongly believe that as long as there is any member of the family of a dependent adult willing to be guardian/trustee they should be granted this without going through the courts.”

“When a person has a life-long history of not being mentally capable of looking after themselves and this is recognized by all physicians - the appointment of their parents as guardians should be automatic - guardianship should not have to be applied for.”

Others expressed concern about family members being appointed:

“Under no circumstances should there be legislation appointing an automatic decision-maker based on degree of kinship. We have encountered too many cases where the next of kin is estranged or had some sort of grudge against the incompetent person. I have encountered other cases where the decisions of the family would clearly not be in the person’s best interests, due to the fact that there are financial considerations which clearly are driving the family, not the patient’s best interests.”

“My concern with family members looking after finances is that they are sometimes more concerned with maintaining their inheritance than they are with providing appropriate and necessary items to help clients with their quality of life.”

“People with developmental disabilities often have their parents as guardians. This is not always in their best interests. Sometimes, the parents do not consult with the client or make decisions that are not in the best interests of the client. I have seen many cases of financial abuse by family members with no recourse.”

Some respondents felt that government and the courts should have less or no involvement in the lives of dependent adults:

“Unless a parent has shown disregard for the child (adult) he should be allowed to continue making decisions for the child without interference from government bureaucracy.”

“If a family member is the decision maker for a dependent adult then the courts should not be involved.”

“Any court sanction is both costly and complicated. As our population ages, there will be increasing pressure on our loved ones. I believe that for the most part, the elderly will be well served by family members without the need for court intervention.”

“I do not want the government or the courts responsible for these private decisions in my life.”

Others suggested greater court and government involvement:

“The Public Guardian’s office should be expanded so more people who have no appropriate supports can have an advocate for them.”

“I would like to see a regulatory body be established. I would prefer that this regulatory body have some links to government (municipal and provincial). A regulatory body should have some powers of authority such as investigators, who are able to access critical and personal information of the person who is making decisions for another. Powers of enforcement as well.”

“The Office of the Public Guardian should be required to investigate allegations of abuse/neglect of dependent or vulnerable adults. In other words this should become protective legislation and the office should be adequately staffed to investigate allegations and to provide protective services where there is not an agent in a personal directive available.”

“I would like to see an expanded role for an office such as the Public Guardian/Trustee in averting and preventing abuse or neglect, and having the ability to intervene in toxic family situations to ensure that the person’s best interests are being served.”

“Appoint and fund a position that would assist seniors and general public go through this process on their own.”

Some respondents commented about the survey itself. For example:

“Found some of the questions confusing.”

“As a legal guardian I was very happy with this survey. There are things I didn’t know.”

“This has been quite comprehensive.”

“This has been quite a thought provoking exercise.”

Some respondents commented about the need for more public education/awareness of the *Dependent Adults Act*. For example:

“Need to have a good public education system in place so that a substitute decision maker is chosen well in advance of being incapable.”

“I work in long-term care and feel the doctors need education on the *Dependent Adults Act*; most are not aware of what they can legally do or how they can legally act.”

“People should really be informed of the importance of preparing – and updating – wills, personal directives and enduring power of attorney from an early or responsible age.”

“More awareness should be made during major changes in their life-marriage, starting a family etc. as accidents can/do happen at any age.”

□ **Personal Directives Act**

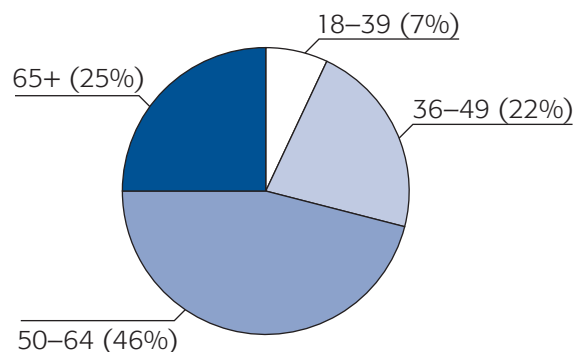
In total, 1,596 *Personal Directives Act* surveys were completed.

Who we heard from

	# of respondents	% of respondents
I am an Alberta resident interested in personal directives	1,253	78 %
I currently have a personal directive	506	32 %
I have been named as an agent in someone else's personal directive	459	29 %
I am a professional working with Albertans who have personal directives	406	25 %

Demographic Information

(Respondents were asked to check all statements that applied to them.)



Age of respondents

	# of respondents	% of respondents
I live in Northern Alberta (not in the Edmonton Area)	152	10 %
I live in the Edmonton Area	607	38 %
I live in Central Alberta (including Red Deer)	187	12 %
I live in the Calgary Area	400	25 %
I live in Southern Alberta (not in the Calgary Area)	236	15 %

Where respondents live

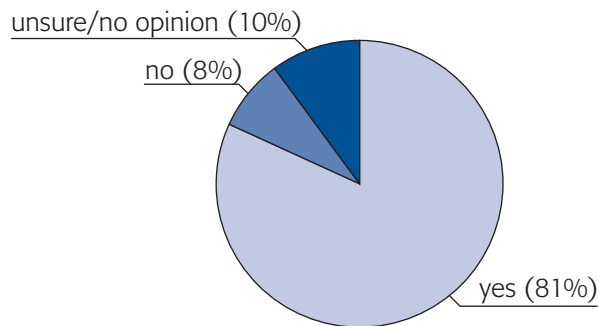
What we heard about the *Personal Directives Act*

Question 1

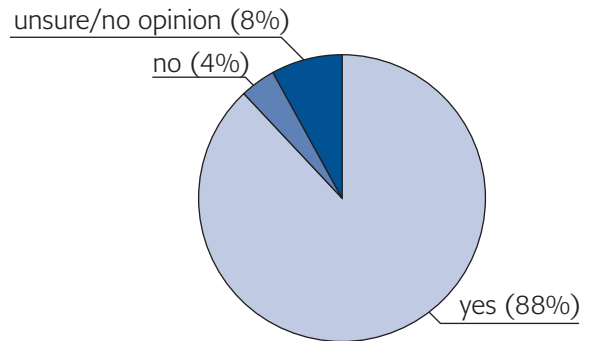
How would you like personal directives to work?

(Respondents were asked to comment on all options.)

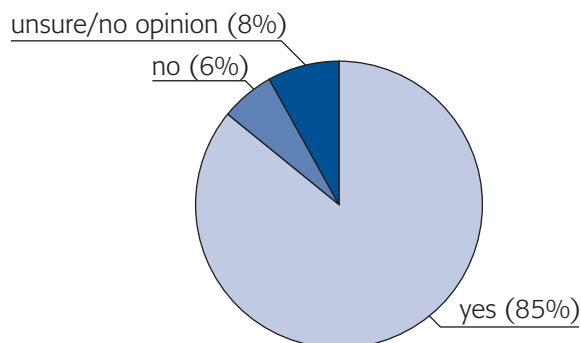
	Yes		No		Unsure/ No Opinion	
	#	%	#	%	#	%
There should be a standard form available for personal directives	1,260	81	105	8	158	10
If I were an adult who had trouble making personal decisions and my capacity was questioned, I would like the <i>Personal Directives Act</i> to allow me to make a personal directive that has safeguards built in for my protection	1,352	88	65	4	119	8
A personal directive that was made by me or by a family member outside Alberta (that is, in another province or country) should be recognized in Alberta	1,323	85	93	6	132	8
If I do not have a personal directive, my immediate family should be able to make the kinds of personal decisions for me covered by a personal directive	1,225	78	164	10	176	11



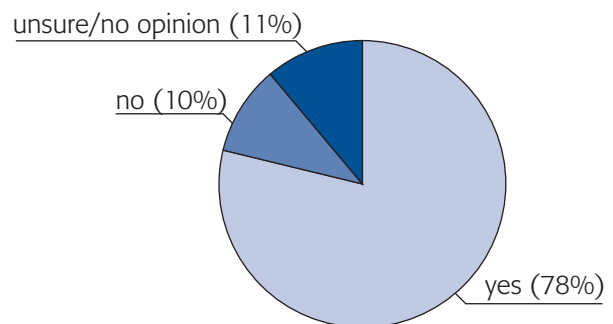
There should be a standard form available for personal directives



Allow me to make a personal directive that has safeguards built in for my protection



A personal directive made outside Alberta should be recognized in Alberta



My immediate family should be able to make the kinds of decisions covered by a personal directive

Comments

“Make sure family is aware of what you want. Find most personal directives are very generic i.e. “don’t wish life support if no chance of quality life” – often don’t know this until you have been on life support.”

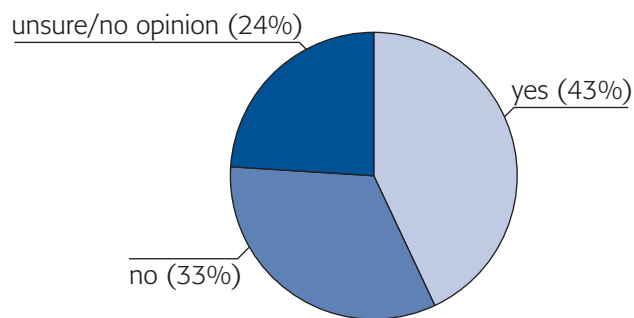
“Personal directives need to be standardized due to confusion. Should have a list of what to include – it then would be at the discretion of each person to tick off what they want and include wishes re: impending death, financial matters, place of residence.”

Question 2

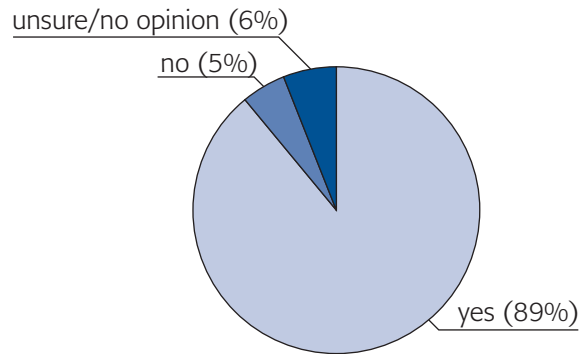
When you make a personal directive, how should others, such as family members or service providers, know you have one?

(Respondents were asked to comment on all options.)

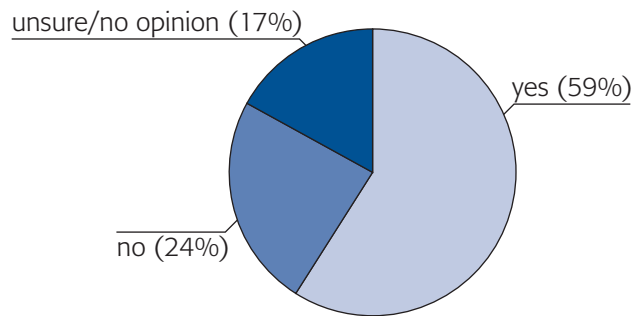
	Yes		No		Unsure/ No Opinion	
	#	%	#	%	#	%
The personal directive must be filed in a central registry	654	43	501	33	361	24
I could decide whether I wanted to file the personal directive in a central registry	833	55	430	28	252	17
I should be required to give a copy of the personal directive to the person named as my agent	1,380	89	76	5	95	6
I should be required to give a copy of the personal directive to a service provider or doctor	908	59	366	24	261	17



I could decide whether I wanted to file the personal directive in a central registry



I should be required to give a copy of the personal directive to the person named as agent



I should be required to give a copy of the personal directive to a service provider or doctor

Comments

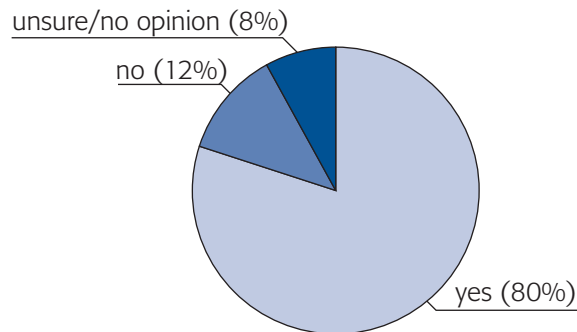
“Family most often has the best interests of individuals at heart. They should be given the most “power” in these cases.”

Question 3

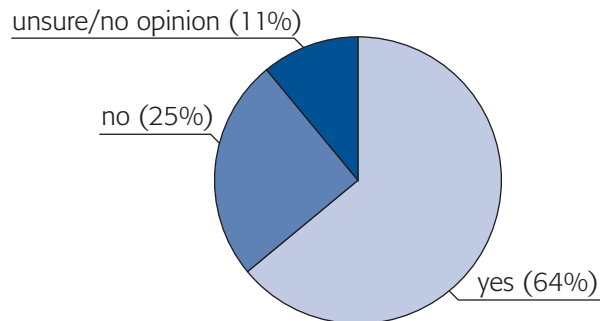
Who do you believe should decide when and if you are no longer capable to make personal decisions?

(Respondents were asked to comment on all options.)

	Yes		No		Unsure/ No Opinion	
	#	%	#	%	#	%
Somebody appointed by me such as my agent	963	64	383	25	166	11
My physician	1,231	80	178	12	121	8
Any physician or psychologist	603	41	620	42	263	18
My immediate family or friend	841	55	490	32	203	15



My physician should decide when and if I am no longer capable



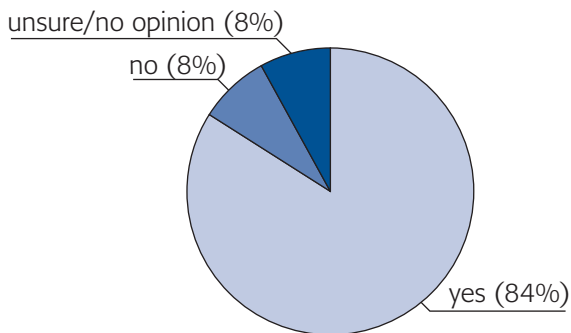
Somebody appointed by me such as an agent.

Question 4

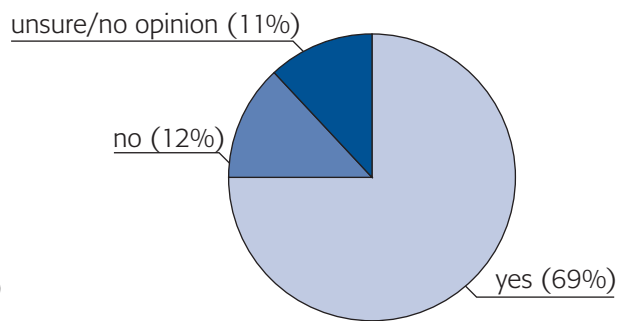
How should agents work?

(Respondents were asked to comment on all options.)

	Yes		No		Unsure/ No Opinion	
	#	%	#	%	#	%
My personal directive must include the signed consent of the agent I have named, to agree to do what is requested in the personal directive if it is ever activated	1,291	84	126	8	127	8
I would like my agent to make decisions based on wishes I have recently told them about, even if they differ from my earlier written instructions	606	39	509	33	428	28
If I do not name an agent in my personal directive or my named agent is unable or unwilling to act, my immediate family should be able to make a decision for me	1,205	77	189	12	166	11
There should be a process to review the decisions made by my agent on my behalf	1,060	69	227	15	248	16



Must include the signed consent of the agent



There should be a process to review my agent's decisions

Comments

“The bottom line is you should be able to trust your agent, and hope he or she is making all the right decisions for you. It is a huge responsibility! If this person is not doing their job properly they should become a non-agent.”

“Family members should be involved with agents and community members if a review is necessary.”

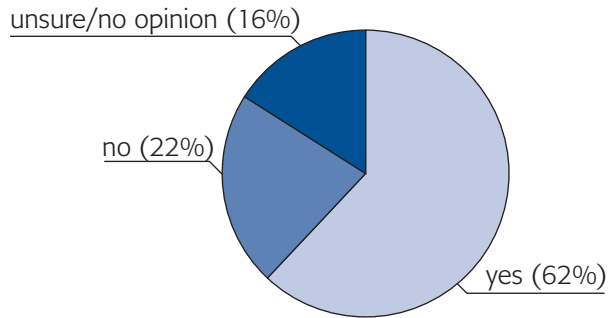
“I feel it’s extremely important for the physician and agent to communicate. It’s a huge responsibility for both parties and each must know what the maker requested.”

“There should be a simple process to resolve any disputes over the agent’s decisions as a result of a review process.”

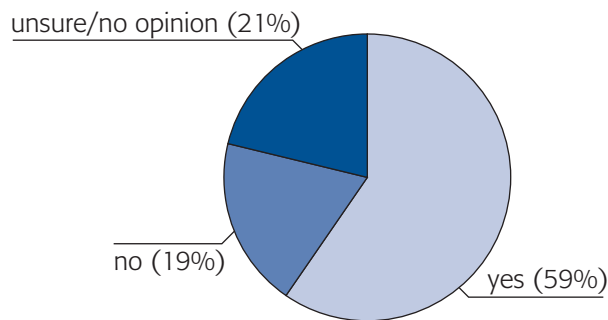
Question 5

If you agree there should be a process to review decisions made by your agent on your behalf, who should do that review?

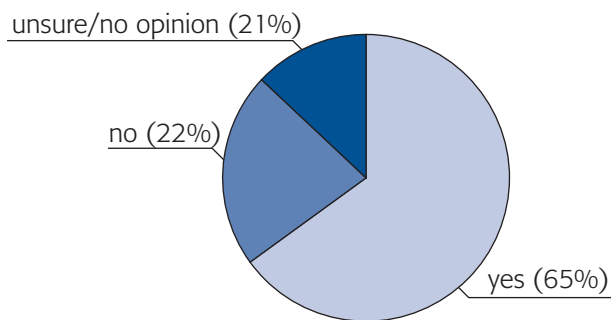
	Yes		No		Unsure/ No Opinion	
	#	%	#	%	#	%
My agent’s decisions should be reviewed by any or all other agents I have named who are able and willing	722	62	252	22	185	16
My agent’s decisions should be reviewed by a monitor I named in my personal directive	682	59	224	19	247	21
My agent’s decisions should be reviewed by an administrative panel of community members	197	17	689	60	259	23
My agent’s decisions should be reviewed by a judge	355	31	501	44	292	25
My agent’s decisions should be reviewed by my immediate family	783	65	271	22	158	13



Decisions should be reviewed by any or all other agents



Decisions should be reviewed by a monitor I named



Decisions should be reviewed by my immediate family

Comments

“After finishing these questions I went over our will and found that we have a will, power of attorney, but no personal directive. We have an appointment with our lawyer.”

Do you have any other issues you wish to raise or comments about the *Personal Directives Act*?

The government received 1,596 completed surveys for the *Personal Directives Act*.

The following is representative of these comments.

Some respondents commented on the importance of having a personal directive in place:

“A personal directive is desirable.”

“I believe family is very important, however, it is vital that an individual get a personal directive early and one’s wishes should be discussed regularly.”

“It is important to have a personal directive for when you become incapacitated, but it is a huge responsibility for the agent.”

“A personal directive saves time and money; helps eliminate all problems that arise if I become unable to decide my own business.”

“Get people to have a personal directive while they are still capable of deciding what is best for them.”

Some respondents suggested personal directives should be required:

“There should be more incentive to encourage more people to make a personal directive. Possibly a requirement.”

“Every adult should be required by law to have this document.”

“The use of a “living will” must be a standard form for anyone with a chronic illness. This form should be given at the time of diagnosis.”

“Could be a condition of employment to have one in place.”

Others disagreed:

“The act needs to state that ANY service provider who requires the writing of a personal directive is subjected to fines.”

Some respondents suggested that the government's and court's involvement in personal directives should be minimized or avoided:

“Personal directives should be simple and avoid too much court or government administration.”

“The more that can be done to keep court/government intervention to a minimum the better – keep the costs down. Personal directives should be personal.”

“Although I am in favour of a checks and balances system to ensure that decisions made by an agent are appropriate and not involving a conflict of interest, I do feel that the government should avoid putting cumbersome, bureaucratic systems in place.”

“Allow people to control their own personal directive, with as little government involvement as possible - perhaps an ombudsman to address abuse is better than continual government interference.”

On the other hand, some suggested an expanded role for government:

“I should be able to appoint the Public Guardian as my agent.”

“I believe that any activity of an agent should be subject to a review by an impartial body such as the Public Trustee and/or Public Guardian that can be taken to court on the affected person's behalf if the agent or family are interfering with the stated wishes of the person.”

“The public guardian or trustees office could be used to mediate between family and/or physicians if they disagree.”

“There should be a process to review the agent's decisions, when the decisions appear to conflict with the personal directive, but the review process should be done by an external body, assigned by Justice or Alberta Health, or a combination of both and perhaps overseen by a judge, for legal purposes.”

Some respondents suggested that there should be no cost or minimal cost involved in preparing a personal directive:

“The process should be easily handled by laymen so time and expenses are kept to a minimum.”

“Some who are aware feel that they cannot afford legal fees to complete the exercise. A standard form would make it easier for proper planning and if supported by a provincial registry, then there would be more likelihood of better control and access of this vital information.”

Some respondents suggested that there should be no need to involve lawyers in developing a personal directive:

“A person should be able to pick up a free copy say from a registry office, and then fill it in to suit his or her personal need, using the accepted form. It should be in a simple format, so that there would not be a need for a lawyer to assist in filling out the form.”

“Personal directives should be simple enough that all people can fill out their own form without seeking legal advice.”

“Continue to allow personal directives without lawyer involvement.”

Some respondents commented on the need for detailed personal directives. For example:

“Directives need to be specific not just giving the agent’s name and stating they will act on their behalf. Actions need to be spelled out or if too general are the directives really being followed. Perhaps a more standard format would help to solve this.”

“In my opinion personal directives often don’t give enough detail to guide decisions. A directive may say they don’t want to be tube fed, but after a stroke when they are enjoying fair quality of life but can’t swallow safely what should we do?”

“Make the directive clear cut with no areas for questions to come up to debate the issues.”

“Do not resuscitate orders should be clearly stated on the personal directive. There are often instructions for not prolonging life artificially, but no instructions for starting CPR if the heart stops, either by massive MI or terminal/critical disease.”

“My sense is that it is not straightforward to respond to personal directives because of the often vague directives provided.”

“Personal directives should also specifically include statements related to: 1. psychiatric treatment, 2. participation in research.”

Some respondents commented on the need for more public education/awareness of personal directives. For example:

“More public information required as general population not aware of personal directives nor are they aware of how to enact a personal directive.”

“More education on personal directives to public. Many seniors not aware of personal directives and do not have one.”

“Further education required. All Albertans should receive the new personal directives and seminars on how to complete it.”

“Education of family physicians to discuss personal directives with their patients especially with elderly.”

“Need education of the public re: these issues. Start in secondary school.”

“This should be a program that is advertised to make the public aware of how important this is. These should be delivered to every house in this province regardless of the age of the people living there and the ad program should also make it clear that EVERYONE needs one of these.”

“The government should publicize widely the need for personal directives.”

“It would be helpful if personal directives could be advertised to the general population as anyone 18 years of age or older may need one at any time in life and guardianship and trusteeship are costly and time consuming processes.”

□ Next Steps

The survey responses will be used to frame questions for the public consultation sessions that will be held in fall 2005. Input from these sessions will be compiled into a report and used to draft options for legislative changes.

These options will be discussed during stakeholder consultation sessions. Stakeholder sessions will include private guardians, trustees, lawyers, judges, clerks of the court, dependent adults, advocacy groups, government ministries, health regions and long-term care facilities.

After input from these sessions is reviewed, legislative revisions will be made and submitted to the Minister of Seniors and Community Supports for consideration by the Government of Alberta.

□ Concluding Comments

The Seniors and Community Supports and Justice ministries would like to sincerely thank all of the participants in the legislative review of the *Dependent Adults Act* and the *Personal Directives Act*.

This legislation has the potential to touch all Albertans, and it is important that it be responsive to those who need it. The input that we have received and will receive during the public consultation sessions will help us to frame legislation that will meet the needs of all Albertans.