Planning for the Future

Draft Personal Directives Legislation Discussion Paper

Response submitted on behalf of NSAHO Members

April 14, 2008

NOTE: *NSAHO invited members to participate in a teleconference to provide feedback on the Draft Personal Directives Legislation Discussion paper on Thursday April 10, 2008. The responses below have been compiled on behalf of the members and are based on the discussions held during this teleconference. There were participants from both the acute and continuing care sector.*

The Proposed Personal Directives Act

What is the framework for the proposed Act?

The proposed Act is written for individuals to prepare for the onset of incapacity to make personal care decisions. It will also benefit individuals who have not made personal directives and who are incapable of making medical care decisions or decisions related to placement into a continuing care home.

While the proposed Act has many aspects and details, in general terms it provides for three things.

1. It allows individuals to appoint substitute decision makers to make personal care decisions on their behalf should they become incapable of making such decisions. This must be done in a written document that is signed and witnessed.

2. It allows individuals to set out instructions or general principles about what or how personal care decisions should be made when they are unable to make the decisions themselves. This must be done in a written document that is signed and witnessed.

3. It provides for a hierarchy of statutory substitute decision makers to make decisions regarding medical care and placement in a continuing care home where the individual has not prepared a written personal directive in relation to those decisions. The Public Trustee is listed as the last substitute decision maker in the hierarchy.

Concept of Capacity

Capacity is not a global concept, but rather an individual can be capable of making some personal care decisions and not others. Individuals are not capable or incapable; they are capable or incapable in relation to a specific decision.

To be considered capable under the proposed Act, the individual must be able to understand the information that is relevant to making a particular personal care decision and have the ability to appreciate the reasonably foreseeable consequence of making or not making that particular personal care decision. Throughout the proposed Act, an individual's ability to make personal care decisions is always tied back to the specific decision at issue. To illustrate this point, it is possible that an individual could be incapable of making a complex medical care decision but capable of making decisions relating to social activities.

What types of decisions are covered by the proposed Act?

The proposed Act addresses "personal care" decisions. These include: health care, medical care and treatment, nutrition, hydration, shelter, residence, clothing, hygiene, safety, comfort, recreation, social activities, support services, and other personal matters that could be set out in regulations. Individuals may provide instructions about these types of decisions or they may authorize another person or persons to make these types of decisions on their behalf.

Q: Should the proposed Act address these types of decisions? Should any be added? Should any be excluded?

Members indicated that they like the broadness of what is included in 'personal care' decisions. They also suggested that both funeral and spiritual issues should be included under 'personal care'.

There were some questions around the definition of elements under 'personal care' decisions, such as hygiene. How and where is this to be defined? Is it open to interpretation?

Where an individual does not make a personal directive, the proposed Act provides for a statutory list of substitute decision makers for decisions relating to medical care and to accept placement in a continuing care home.

Q: Should the scope of decision making authority for a statutory substitute decision maker be limited to medical care and these placement decisions?

Members questioned why 'medical care' and 'placement decisions' were narrower in relation to 'personal care'. It appears that the areas in question (i.e., medical care and placement decision) are not as clear in nature, and are therefore limited in scope. It is recommended that clear, concise definitions of both 'medical care' and 'placement decisions' be included to ensure consistency of understanding and application.

However, general consensus was that this should not be limited. If someone has to make decisions for an individual, there should be consistency in the decision making for the individual, thereby enabling a substitute decision maker to provide decisions on behalf of the individual in all areas – personal care, medical care, and placement decisions.

Who may make a personal directive?

A capable individual may make a personal directive under the proposed Act. This includes both individuals who have reached the age of majority (19 years old) and those who have not. The law recognizes that individuals who are under the age of majority may be mature enough to make decisions about, for example their medical care treatment, if they are able to understand the nature and consequences of the decision. These individuals who are under the age of majority are referred to in the law as "mature minors." The proposed Act allows those who would be capable of making a personal care decision themselves to make a personal directive about that personal care decision.

The legislation across the country varies regarding the age for making a personal or health care directive. Some provinces allow only adults to make directives (Alberta, Quebec, British Columbia, Northwest Territories); some allow minors who are 16 years old to make personal directives (Saskatchewan, Yukon, Ontario); and some allow mature minors to make personal directives (Prince Edward Island, Newfoundland and Labrador) and use the age of 16 years to guide them in assuming when an individual is capable of making an advance directive (Manitoba).

The departments considered setting a fixed age, such as 16 years old, for making personal directives but ultimately decided that a maturity standard was preferable for three reasons. First, it allows flexibility to individually assess each minor. This accounts for the fact that children develop at different rates and their ability to make certain types of decisions evolves over time. Second, the standard of maturity recognizes that a minor's ability to make decisions varies with the seriousness of the decision. For example, a minor may be able to understand the nature and consequences of a simple health decision but not of a complex health decision. As the complexity of the decision increases, so should the assurance that the minor is capable of making the decision. Third, it can account for differences in family relationships in the assessment of the minor's ability to consent to certain types of decisions.

Q: Should any capable person be allowed to make a personal directive?

Members discussed in length who should be allowed to make a personal directive based on information provided in the discussion paper. How do we determine the difference between capability and maturity? Who decides or determines when a person has met the maturity standard? Who is expected to make this determination for each case and how realistic is it to make determinations on a case-by-case basis. Members also wondered whether there would be a process to make challenges.

After much discussion, members indicated the need for a process to be in place that provides a framework on a maturity standard. This process must require individuals to state who and when the document was filled out and provide evidence of the individuals' capacity when making the personal directive.

Finally, it is recommended that 'capability' be defined in the Act. Members do not feel that this definition has been clearly articulated.

Who may be authorized to make substitute decisions under the proposed Act?

This question can be divided into two parts: (1) who may be authorized in a personal directive; and (2) who may be authorized where there is no personal directive relating to the medical care and placement decisions.

Personal Directives

The person authorized to Act under a personal directive (the delegate) must have reached the age of majority (19 years old).

The delegate may not act if s/he provides personal care services to the maker of the personal directive for compensation, unless the person is the maker's spouse, relative or the maker specifically authorizes the personal services for compensation in the personal directive.

An individual may appoint more than one delegate but each delegate must be assigned authority for different types of decisions. The proposed Act does not allow for joint delegates. The proposed Act permits naming an alternate delegate who would act if the first delegate is unable or unwilling to act.

Q: Are these appropriate criteria for a delegate?

"The delegate may not act if s/he provides personal care services to the maker of the personal directive for compensation...". Members feel that it is necessary for 'compensation' to be clearly defined and articulated. Does compensation include monetary reward only? Or, does it include other manners of compensation such as room and board?

In referring to whether or not these are the appropriate criteria for a delegate, members strongly support the idea that the maker is able to assign an alternate delegate/decision maker by including a statement in the personal directive such as the following example: I appoint my sister, Jane Doe as my delegate/decision maker, however if she is not available I appoint my neighbour Jane Smith to this role.

Members agreed that if the main delegate/decision maker is not available or unable to act in this role, the maker should have the first opportunity to appoint an alternate rather than immediately having to move on to the recommended hierarchy in order of priority.

Statutory substitute decision maker

Currently, there is no provision in law that allows for a substitute decision maker for incapable persons who do not have a court appointed guardian or who are not in hospital. The draft Act will provide a hierarchy of persons who are authorized to make decisions regarding medical care outside of a hospital and placement in a continuing care home. This is consistent with the provinces of Alberta, Ontario and Newfoundland and Labrador.

The hierarchy, in order of priority, is:

- spouse
- child
- parent
- sibling
- grandparent
- grandchild
- aunt or uncle
- niece or nephew
- other relative
- Public Trustee

Relatives of the whole blood are given priority to relatives of the same description of the halfblood. Also if there are two or more in a category, the eldest is given priority ranking.

A person who makes a personal directive may state the names of (1) who should or should not be notified when the personal directive comes into effect; and (2) the relatives in the hierarchy who are not to make decisions on her/his behalf.

Q: Should statutory substitute decision makers be authorized to make decisions regarding:

(a) medical care decisions;

Yes

(b) decisions for placement in a continuing care home;

Yes

(c) other types of personal care decisions?

Yes

Are the categories of people named in the hierarchy and their ranking in the hierarchy appropriate?

Members support the hierarchy as listed, however would like consideration to be given to step-children. It was assumed they would be included in the 'other' category, but the challenge is recognizing formally the relationship many individuals have with stepchildren in a world of non-traditional families. It is understood that these individuals could be appointed in the personal directive by the maker, however in instances where the hierarchy must come into play there is a concern that some relatives would not be best suited (e.g., not in contact with the maker on a regular basis), and the stepchild would be 'last in the hierarchical line'.

There was also discussion around ensuring that all potential candidates from the list were given the option to participate in this role prior to involving the public trustee. This should only be a last resort!

Should relatives of the whole blood, and the eldest in a category be given priority?

Yes, as long as all individuals involved are educated on the ability to choose NOT to act in this role.

Health stakeholders, in particular, should note that the proposed hierarchy structure differs somewhat from the hierarchy structures in section 54(2) of the Hospitals Act and section 38 of the Involuntary Psychiatric Treatment Act. Also, the definition of "spouse" differs in that there is no time requirement for cohabitation.

Should the hierarchy structures be the same? If yes, which hierarchy structure is preferable and why?

The hierarchy structures should be the same in all of these documents to ensure a consistent, comprehensive format. Members like the list included in the draft Act, as they believe it is as inclusive as possible (with the inclusion of stepchildren as noted above), however they did have some concerns over the definition of co-habitation (only 1 month), so indicated the need to set out a timeframe.

Discussions were held among members as to why there are variances between the Acts related to the hierarchy structures. It's very limited in the Hospitals Act. Will you go back and change the others to match the proposed Personal Directives Act?

Who determines whether a person is capable of making a personal care decision?

In a personal directive, the maker may authorize a person by name, title or position to determine the maker's capacity in consultation with a prescribed person. If the maker does not authorize a person to make an assessment of capacity, the assessment will be made in accordance with regulations that will be developed after legislation is passed.

Q: Should a person be able to name the individual who will determine his or her capacity to make personal care decisions in consultation with a prescribed person? Who should such prescribed persons include?

Yes, the individual should be able to name who will determine his or her capacity to make decisions in consultation with a prescribed person, however, it needs to be clearly articulated that a delegate ***can not*** *be this person. There needs to be assurance that the individual making this decision has nothing to gain from the decision made in relation to an individuals' capacity…therefore the delegate is not an appropriate person.*

In determining who the prescribed persons include, members suggest that qualified professionals (e.g., but not limited to: regulated health providers, social workers, lawyers, etc.) are key to this role. It is expected that these professionals' will work within their scope and have the appropriate competencies to determine capacity of an individual.

Within a personal directive, the maker may authorize a peace officer, at the request of the delegate, to use force that is necessary and reasonable in the circumstances to prevent the maker of the personal directive from leaving the Province, if there is a reasonable basis to believe that the maker lacks capacity to make the decision to leave the province, until an assessment of capacity can be completed.

Q: Should this sort of provision be included?

This would be extremely difficult to implement, and in fact raises more questions than answers as it appears to be more reactionary from past experiences rather than a thought out component. Have peace officers been consulted on this issue? Past experience from members suggests that police would not to be involved in these matters if at all possible. Past experience also suggests that this couldn't or wouldn't be evoked prior to the person disappearing, because these intentions (i.e., leave the jurisdiction) would not be revealed to other family members or health care providers.

Discussion also suggested that if this is to remain in the proposed act, it should be clearer in that it relates to not only individuals leaving the jurisdiction, but also from being taken from the jurisdiction. Finally, the use of force with a maker that lacks capacity was seen as very inappropriate and bad legislation. Therefore, there is a general consensus that this is not an appropriate element for the proposed legislation.

On what basis will the substitute decision maker make decisions?

The substitute decision maker (either the delegate or the statutory substitute decision maker) must follow the instructions in the personal directive unless:

- s/he knows that the maker expressed a contrary wish later;
- technological changes or medical advances make the instructions clearly contrary to the maker's intentions; or
- circumstances exist that would clearly have caused the maker to set out different instructions had the circumstances been known based on what the substitute decision maker knows of the maker's values and beliefs.

If the instructions are unclear, then the decisions must be based on what the substitute decision maker believes the maker would have decided based on the maker's values and beliefs.

If the substitute decision maker does not know the maker's wishes, values and beliefs relevant to the decision to be made, the substitute decision maker must make the personal care decision s/he believes is in the maker's best interests.

Q: Are these appropriate principles to guide a substitute decision maker?

It must be clear that any changes made after the initial directive by the maker is validated in a formal manner ensuring that these wishes are adhered to, and known of, by the substitute decision maker. This will enable the decision maker to make decisions in the best interest of the maker.

The wording should be consistent with those included in the Involuntary Psychiatric Act (see below). It is necessary to update the wording in the new Hospitals Act for additional consistency.

10) Chapter 208 is further amended by adding immediately after Section 54 the following Sections:

54A The substitute decision-maker shall make the decision in relation to specified medical treatment

(a) in accordance with the patient's prior capable informed expressed wishes; or

(b) in the absence of awareness of a prior capable informed expressed wish, in accordance with what the substitute decision-maker believes to be in the patient's best interest.

54B In order to determine the best interest of the patient for the purpose of clause (b) of Section 54A, regard shall be had to

(a) whether the condition of the patient will be or is likely to be improved by the specified medical treatment;

(b) whether the condition of the patient will improve or is likely to improve without the specified medical treatment;

(c) whether the anticipated benefit to the patient from the specified medical treatment outweighs the risk of harm to the patient; and

(d) whether the specified medical treatment is the least restrictive and least intrusive treatment that meets the requirements of clauses (a), (b) and (c).

54C Whoever seeks a person's consent on a patient's behalf is entitled to rely on that person's statement in writing as to the person's relationship with the patient and as to the facts and beliefs mentioned in clauses (a) to (c) of subsection (5) of Section 54, unless it is not reasonable to believe the statement.

54D (1) Where a substitute decision-maker approves or refuses treatment on behalf of a patient pursuant to subsection (2) of Section 54, the Supreme Court of Nova Scotia (Family Division) or the Family Court where there is no Supreme Court (Family Division) may review the provision or refusal of consent when requested to do so by the psychiatrist or the patient to determine whether the substitute decision-maker has rendered a capable informed consent.

(2) Where the court finds that a substitute decision-maker has not rendered a capable informed consent, the next suitable decision-maker in the hierarchy in subsection (2) of Section 54 becomes the substitute decision-maker.

Access to information

Subject to any limits set out in the personal directive, the substitute decision maker will have the right to access all information and records pertaining to the maker that are relevant to the decision to be made.

Q: Are there any restrictions that should be placed on the substitute decision maker's access to information about the maker? Should the maker be able to place restrictions on the information that will be available to the substitute decision maker?

No, there should not be restrictions, however it must be relevant information as indicated in the statement: "...the substitute decision maker will have the right to access all information and records pertaining to the maker that are relevant to the decision to be made."

The maker, however, should be able to put restrictions on historical information in their file if desired. Individuals must be educated on these restrictions, and the potential outcomes and impacts related to their care in the future if decisions are required on their behalf.

What responsibilities does the proposed Act place on health care providers?

Health care providers must make a reasonable attempt to find out if a person has made a personal directive and whether it meets the requirements of the Act. They must also make a reasonable attempt to clarify the maker's wishes if the personal directive is unclear. The health care provider must place a copy of the personal directive in the maker's health record.

Health care providers must follow the instructions of a substitute decision maker acting in accordance with the Act and the instructions, general principles or expression of the maker's wishes set out in a personal directive, unless they are inconsistent with legal requirements, policies relating to personal care services and the availability of personal care services.

If the maker requires emergency medical care, the proposed Act does not require health care providers to obtain consent from a substitute decision maker if the care is necessary to preserve the maker's life or health, if the delay in obtaining the consent may put the maker at significant risk, and there is no personal directive available that makes it clear the maker would not want the proposed treatment.

Q: Are these appropriate responsibilities?

After much discussion, it was determined that the responsibilities of health care providers outlined in the proposed legislation are appropriate. Questions for consideration, however, include what constitutes a 'reasonable' attempt to clarify the maker's wishes? Members determined that there did need to be trust and acceptance that the individual and/or their families would provide correct information, and therefore the onus would be on them to provide the information to health care providers when asked.

The definition of a "health care provider" includes (1) a person licensed or registered to provide health care in the province; and (2) an administrator of a health care facility or continuing care home.

Q: Are these appropriate categories of individuals to exercise responsibilities under the proposed Act?

*It is felt that these are appropriate categories of individuals. Members like a broader definition and the fact that it is either a "person licensed or registered to provide health care in the province; **AND** an administrator of a health care facility or continuing care home."*

Members did indicate a strong concern over statements 19B and C on page 10 of the Act (see below). How far must a health care provider go to clarify? And what process will be expected in the instance where the maker is incapable, yet the provider is expected to clarify the maker's wishes if there is ambiguity in the directive?

19 (1) A health care provider must make a reasonable attempt to:
...
(b) ensure that the personal directive is valid under this Act;
(c) clarify the maker's wishes if there is ambiguity in the personal directive.

Personal Directives from other jurisdictions

The proposed Act allows for instruments authorizing a person to make personal care decisions on behalf of another and instruments setting out instructions made outside of Nova Scotia to have the same effect as a personal directive made under the proposed Act, so long as they meet the requirements of the other jurisdiction's legislation.

Q: Are there any concerns associated with accepting personal directives from other jurisdictions?

Health care providers will have no way of knowing the limitations/requirements from other jurisdictions. Expecting them to become knowledgeable in these requirements will be a time factor issue in providing care to individuals. It is recommended that directives from other jurisdictions be honoured as long as they meet Nova Scotia requirements.

Protections from Liability

The proposed Act protects substitute decision makers from liability so long as they act in good faith.

The proposed Act protects health care providers from liability so long as they act in good faith according to the substitute decision maker's decision or in accordance with the instructions set out in the personal directive. Health care providers are also protected if they did not know of the existence of the personal directive.

Q: Are these protections appropriate?

These protections are appropriate. Members suggested that it is important to note that although "health care providers are also protected if they did not know of the existence of a personal directive" this does not mean it eliminates their accountability in making an effort to determine whether or not there is a directive in existence.

Offences

The Act makes the following persons guilty of an offence:

- a person who willfully destroys, conceals, alters, or forges a personal directive or a revocation of a personal directive;
- a person who willfully misrepresents himself or herself in relation to a personal directive or willfully misrepresents the wishes of the maker;
- a person who requires another person to make a personal directive as a condition for obtaining any goods or services;
- a person who coerces or exerts undue influence on another person to make a personal directive.

Q: Are these appropriate offences? Should there be others?

These are most definitely appropriate offences; however the proposed Act must also clarify the reporting process and penalties which are not currently outlined in the document.

Court applications

The Act allows a person who has made a personal directive or any other interested person to apply to the court for any one or more orders set out in section 32.

In making a decision the court may not add to or alter the intent of an instruction contained in a personal directive unless the court is satisfied that the maker's instruction or wishes changed subsequent to the making of the instruction.

Q: Is this appropriate authority for the court?

Yes

The court is authorized to appoint another person to be the delegate to act under a personal directive.

One could argue that this is appropriate as it is consistent with the court's authority to substitute one attorney for another under the Powers of Attorney Act when dealing with financial issues. The Act allows individuals to name who should not make decisions for them. Authorizing the court to appoint another person to be the delegate may prevent the need to draw upon the Public Trustee services or it may prevent the need for a guardianship application.

The concern, however, is that the court will override the intentions of an individual by substituting a decision maker which the individual would not have chosen. The Act does give the individual a right to name alternate delegates in the personal directive. One could argue that if the court is to make such a significant decision of replacing a delegate, it may be better that the court be required to appoint a formal guardian under the Incompetent Persons Act.

Q: Is the authority set out in the Act appropriate? Should there be conditions attached to this authority?

The authority as set out in the Act is appropriate, however there should be conditions attached. It is important to reinforce the notion that the Court must not appoint someone who the maker requested to NOT be a decision maker, and the individual that is appointed must have a choice as to whether or not to accept the position. If the individual decides to decline the role of decision maker, the court must return the hierarchical list – only appointing the public trustee as a last resort.

General feedback

Q: Do you have any other comments?

Public education is key to the successes of this proposed legislation. *The public and health care workers need to understand the importance of having a Personal Directive, as well as what it means for them now and in the future. Educating the public on the requirements related to the legislation, and the difference between a Personal Directive and a Power of Attorney, etc., is crucial to ensuring that individuals can prepare for the future in an informed manner. It is necessary to develop a sustainable implementation plan for rolling out the legislation to both the public and health care providers to ensure consistency of application and understanding of the personal implications to makers.*

It is assumed that financial issues will still be addressed through the Power of Attorney. However, it was noted, that these 2 documents (i.e., Personal Directive and Power of Attorney) need to compliment one another in order to eliminate any confusion in the future.

Questions still remain among members as to the process for decision makers in making decisions for the maker who is waiting for placement in long term care. Many clients are in limbo as they wait for long term care beds, and it was not clear as to the process of how decisions regarding individuals in acute care beds would be made in relation to a Personal Directive.

There are a couple of sections in the proposed Act that are not clear to members:

- *Section 2(H) is unclear*
- *Section 10 on assessments raised many questions such as: Who would pay for the assessment? Who would do the assessment?*