SUBMISSION CONCERNING THE PROPOSED HEALTH CARE DIRECTIVES LEGISLATION AND THE

DISCUSSION PAPER FOR THE STANDING COMMITTEE ON LAW AMENDMENTS – SEPTEMBER 2008

PREPARED BY THE:

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PREMIER'S COUNCIL ON THE STATUS OF DISABLED PERSONS

WHO ARE WE?

The Premier's Council on the Status of Disabled Persons is a body for consultation and study that was created to advise the provincial government on matters relating to the status of persons with disabilities. The Council reports directly to the Premier of the Province.

RESPONSIBILITIES

The Act governing the Premier's Council states that the Council shall advise the Minister on matters relating to the status of persons with disabilities; shall bring before the government and the public matters of interest and concern to persons with disabilities; shall promote prevention of disabling conditions; shall promote employment opportunities of persons with disabilities; and shall promote access by persons with disabilities to all services offered to the citizens of New Brunswick.

STRUCTURE

The Council consists of a Chairperson and twelve other members appointed by the Lieutenant-Governor in Council. Provisions in the Act guarantee representation by regions, agencies working on behalf of persons with disabilities and the public at large.

ACTIVITIES

To carry out its functions, the Council will receive briefs and suggestions from individuals and groups concerning the status of persons of any age with disabilities of any type; undertake research on matters relating to persons with disabilities; recommend programs concerning the status of persons with disabilities; make referrals to and consult and collaborate with universities and individuals on matters which affect persons with disabilities; propose legislation, studies and recommendations as the Council considers necessary; appoint special committees when needed; maintain an information library on subjects related to persons with disabilities and on any services/programs likely to be of interest to persons with disabilities; and offer advice and/or intervention in cases where persons with disabilities are having difficulties in gaining access to needed services.

The Premier's Council on the Status of Disabled Persons is pleased that the Government of New Brunswick is seeking input for planned legislation to address the issues around advance health care directives.

The recently released ***Health Care Directives Legislation Discussion Paper for the Standing Committee on Law Amendments*** **(dated September 2008)**, presents a number of appropriate observations and questions for consideration.

While we will be anxious to review the actual wording of such new legislation, we would like to offer some input now to the Standing Committee on Law Amendments before the bill is introduced in the Legislature.

1. PURPOSE OF THE HEALTH CARE DIRECTIVE LEGISLATION: GENERAL

We agree that such legislation is clearly required although it may not be possible to anticipate all of the potential situations that could arise in the future that might require application of advance health care directives.

Medical advances continue to be made and the ability to artificially sustain life through technology means that difficult choices are now necessary as more options become available.

How we define meaningful quality of life can create conflict between health care professionals and family members when the patient is unable to express themselves or have been deemed to be incompetent.

The proposed legislation would enable a competent person, 16 years of age or older, or a younger person deemed to be a "mature minor", the ability to provide binding advance health care directives to indicate what type of care they wish to receive or not receive in situations where they are no longer in a position to communicate their wishes.

This would seem to be a logical protection of a person's legal right to receive or to refuse medical intervention as long as they are competent and can understand the implications of their choices.

2. WHO CAN MAKE A HEALTH CARE DIRECTIVE?

We generally agree with the outline contained in this section of the discussion paper. By expressing their wishes in an advance health care directive, individuals will be able to make their wishes known to their family and to their doctors to reduce conflict and lack of awareness as to what were the wishes of that person.

Too often families do not take the time to frankly discuss their feelings about topics related to organ donation; use of life support technology; use of heroic measures for resuscitation; management of severe pain; and palliative care decisions.

Also it should be clearly stated who they would like to assign the authority or proxy to be able to make other health care decisions that have not been specifically described in the advance health care directive.

The legislation should clearly outline that in the absence of specific instructions in an acceptable advance health care directive, who will have the legal authority to make such decisions for a person who is not able to express their own wishes. For example, will the married spouse automatically have such authority? What are the roles to be assumed for parents, siblings, common law partners, same sex partners, etc and what is the order of priority for decision making?

Do we need to consider conflicting opinions between medical professionals involved in the case and family members who may not agree on what should be done?

What about situations where the financial interests of the person making decisions may be in conflict with decisions about the patient?

Having the legislation passed would be a motivating tool to encourage more people to think about their decisions and to decide who they would trust to make decisions for them should their situation require a substitute decision maker.

The aging population of New Brunswick means we will be expecting increased numbers of persons developing physical disabilities and/or

dementia which could impair their ability to make the necessary decisions for both ongoing health care and/or end of life care.

People should make their decisions after informed reflection and share their wishes with family members and their doctor before they are actually in a health care crisis and perhaps no longer able to competently give their own input at that time. They should be encouraged to seek advice from health professionals on possible medical scenarios and what options for health care might be considered before they make their informed choices.

The current *Infirm Persons Act* in New Brunswick is a cumbersome tool to determine competency and is both expensive and time consuming.

We agree with the proposed legislation's definition of "competence" to mean that an individual:

- understands the information relevant to making a health care decision;
- understands the reasonably foreseeable consequences both of their decision… or of not making a decision;
- can communicate their decision.

We would suggest that in most situations where a patient is under the care of health professionals that a minimum of two or more of those regulated health professionals would have to agree to make a joint decision about a person's competence. We would suggest that physicians, psychiatrists, psychologists, mental health nurses, mental health social workers, and nurses specifically trained in mental status examination involved in the care of the patient be amongst the pool of professionals eligible to be involved in the assessment of the patient's mental competency.

In situations where there is a disagreement between the health professional's assessment and the opinion of the patient or legal substitute decision maker, then there may need to be a speedy appeal option available through the courts to make a ruling on competency before irreversible actions are taken.

We need to ensure that the legal rights, best interests, and specific wishes of the patient are protected and enforced even when they may differ from the personal or professional views of others involved in that case.

3. ELEMENTS OF A HEALTH CARE DIRECTIVE LIMITATIONS

Obviously we agree that an advance health care directive cannot give instructions that could be enforced if they are contrary to a law of New Brunswick or Canada.

We also agree with the proposed limitations on the power of a proxy to deal with the topics outlined on page 4 of the discussion paper unless expressly authorized to do so in the written health directive. (i.e.: Related to treatment for research purposes; sterilization that is not medically necessary; removal of living tissue for transplantation, education, or research; and other types of health care as described in regulation.)

4. TREATMENT OF HEALTH CARE DIRECTIVES MADE OUTSIDE NEW BRUNSWICK

We would agree that if such health care directives conform to the requirements of the N.B. legislation and that the directive meets the requirements of the jurisdiction in which it was made, it should be honoured in New Brunswick.

5. INSTANCES WHEN A HEALTH CARE DIRECTIVE LOSES EFFECT

We agree with the proposals in the discussion paper.

6. HEALTH CARE PROVIDERS

We agree with the measures outlined in the discussion paper. Persons who draft an advance health care directive should be requested to inform their families, proxy, doctor, and lawyer. They should provide copies to those who should have them to be able to increase the likelihood of their timely use when needed to be put into effect. Health care providers must follow any clear directives and

instructions contained in a valid and legal health care directive or these provided by a legitimate proxy decision maker.

7. PROXIES

We agree with the provisions outlined in this section of the discussion. However we would want to provide some limits to the liability protection of the proxy. We believe that there should still be some potential remaining liability if deliberate malfeasance or gross negligence means that a decision was not taken in the best interests of the patient or was not respecting the known wishes of the patient.

We also support the option of possibly naming more then one proxy but they should only allow one proxy at a time to have such power in the order in which they were listed in the directive.

We would like to see further clarification of the order of priority for a proxy to be assigned to an individual's children or siblings when no proxy was named by the person themselves.

We would like to avoid family arguments when there is more than one child or sibling involved and they may have different views on the health care decisions to be made.

8. GENERAL PROVISIONS

We are concerned about the potential for conflict of interest situations especially when a proxy or substitute decision maker was not chosen and named by the person in an acceptable advance health care directive.

A person may have developed a stroke or advancing dementia that makes them legally incompetent prior the point when they are ready to leave the hospital. A beneficiary of the estate who is also acting as proxy may not wish to see money from the potential estate being spent on home care versus institutional care. The same conflict could come with the decisions around palliative care at home versus care at a hospital or nursing home.

There should be an avenue of speedy appeal through the courts or possibly at a hearing with the Office of the Public Trustee to ensure that the proxy is acting in the best interests of the patient for situations where they were not named by the patient to act on their behalf should decisions be challenged by an interested party.

Also we feel that the proposed penalties for offences proposed under the Act are extremely low and would not likely serve as a meaningful deterrent. Plus the Crown prosecutors could be reluctant to pursue cases when the penalties are so minimal even if successfully prosecuted.

CONCLUSION

We will have to wait to see the actual wording in the new legislation to be able to offer further opinions.

Thank you for allowing us to share our thoughts on the discussion paper.