Ontario's proposed consent laws: 2. Advocacy

Sujit Choudhry; Peter A. Singer, MD, MPH, FRCPC, FACP

In the Mar. 15, 1992, issue of CMAJ we reviewed the provisions of Ontario's proposed consent laws relating to consent and capacity, substitute decisions, advance directives and emergency treatment. In this article we describe and evaluate the provisions relating to advocacy. Of the many provisions in the proposed legislation none will be as controversial for health care professionals as the extension of advocacy services to all incapable people.

Historical aspects

The past decade has witnessed the entry of the patients' rights movement into the political mainstream in the United States. As medicine has moved from a paternalistic to a participatory model of practice, courts and state legislatures have granted increasing recognition to the right of patients to determine their own health care decisions. At present there is an ethical, legal and medical consensus that patient autonomy constitutes a fundamental principle.1

Alongside this development has been the introduction of procedural mechanisms aimed at protecting patients' autonomy and rights. One such mechanism is advocacy.2 An advocate is defined as "one who pleads for another."3 In many US states advocacy programs have been established to protect patients' rights in psychiatric institutions.4

In 1982 the Ontario government launched the Psychiatric Patient Advocacy Office (PPO) in response to inquests into the deaths of three psychiatric patients and to the adoption of the Canadian Charter of Rights and Freedoms.5 The PPO operates in 10 of the 14 psychiatric hospitals in the province; its mandate is twofold: first, to represent its clients on an individual basis and, second, to lobby for systemic reforms both in individual hospitals and province-wide that will aid psychiatric patients as a group. As well, some of its goals are to (a) inform patients, family, hospital staff and the community about patient rights, (b) help resolve complaints made by psychiatric patients through negotiations according to their instructions, (c) investigate alleged incidents, and (d) refer patients, when necessary, to external advocates (i.e., lawyers).

In response to growing concern for the rights of the mentally disadvantaged in other institutional settings and in the community the Ontario government created, in 1985, the Advisory Committee on Substitute Decision Making for Mentally Incapable Persons, chaired by Mr. Stephen Fram from the Ministry of the Attorney General.6 Part of the committee's mandate included a consideration of advocacy services, a topic that engendered so much debate in 1986 the government created the Review of Advocacy for Vulnerable Adults, chaired by Father Sean O'Sullivan, to consider the issue separately.7 Incapable patients were included in the definition of vulnerable adults.

Both the Fram and O'Sullivan committees en-
endorsed a set of principles that advocacy programs in Ontario should follow. Of particular relevance to health care is the idea that advocates exist “to assist their clients to receive the health care and social services to which they are entitled and which they wish to receive.” The O’Sullivan committee also outlined four basic principles of advocacy: it must be client-directed, independent, accessible and neither adversarial nor passive. Advocates would represent their clients by assessing a situation, advising the client on the best course of action and pursuing his or her wishes within lawful, ethical and reasonable means. Advocates should pursue these aims with “vehemence, vigour, and commitment.”

Legislative provisions

The Consent to Treatment Act in conjunction with the Advocacy Act proposes to extend advocacy services to a wide range of health care situations. If adopted, the legislation would be among the most sweeping of its kind in the world.

Under the Consent to Treatment Act, when a health care practitioner finds a patient incapable of consenting to treatment he or she must notify the patient (in writing) and an advocate that this is the case. The advocate must then promptly meet with the patient and explain both the effect of being designated incapable — that the patient has lost the right to make a particular health care decision and someone else will be making the decision on the patient’s behalf — and the patient’s right to appeal the decision to the Consent and Capacity Review Board. Health care practitioners may not give treatment until (a) the advocate informs them that the patient has received the explanation and accepts the finding of incapacity, (b) the advocate informs them that the patient has refused to meet with the advocate or (c) the board gives a decision on the matter and either the appeal period elapses without appeal or the appeal is disposed of. These provisions only apply in the case of a conscious patient. If the patient is unconscious the health care practitioner must still notify an advocate, although the advocate is not obliged to meet with the patient. Advocates are also involved at various stages in the proceedings of the board.

Under the Advocacy Act advocates are granted a wide range of powers. These include the right to enter a facility “where there are or may be vulnerable persons, without a warrant and at any time” and the right of access to medical records in any facility. The content of these records is to be confidential. Advocates will be supervised at the provincial level by the Advocacy Commission, whose members are appointed by the Minister of Citizenship according to the recommendations of the Appointments Advisory Committee. The members of this committee represent organizations of vulnerable people, such as rights groups for elderly people and patients. Although excluded as a class from the Appointments Advisory Committee health care practitioners may serve on the Advocacy Commission. The legislation, however, imposes no obligation to appoint practitioners to it or for the commission to elicit practitioners’ comments and advice on its policies and practices. The PPAO will be integrated into this network of advocates, which will focus on advocacy for individual cases and systemic advocacy. The advocates will also visit institutions, collaborate with community advocacy programs and promote public education about and awareness of the rights of vulnerable people.

The idea of advocacy itself is not at issue. Advocacy services have become increasingly popular in response to the growing complexity of the laws, policies and procedures that govern human services programs, including those operating in medical institutions. Patients who are in a state of physical, emotional and cognitive dysfunction can become dependent on their health care providers. Some have argued that the very act of institutionalization creates vulnerability and hence the need for advocacy. The belief in advocacy stems from a strong belief in the right of self-determination.

What is at issue is the operation of advocacy services in practice. In effect, the government is proposing an extension of advocacy services to virtually all health care situations: in institutions (including public general hospitals) and in the community. The scope of this expansion is immense and fraught with potential difficulties.

A social program of this magnitude should meet three basic requirements. First, there should be an established need for the service. Second, it should be effective. Third, the costs must be reasonable in relation to competing social and health programs. To what extent does the plan meet these three criteria?

Need

Proposing a figure of close to 2 million vulnerable adults in Ontario, the O’Sullivan committee supported the extension of advocacy services to all of them, including all incapable patients. The committee’s definition of vulnerable people included those who were physically disabled, frail and elderly, psychiatrically disabled and developmentally handicapped. (According to Statistics Canada 600 000 Ontarians have moderate to severe mental and physical disabilities.) Yet at the same time the committee acknowledged that it was impossible to provide an accurate figure of the number of vulnerable adults. As well, they considered it “even more
difficult” to ascertain how many of them required advocacy services. Without this information the
commitee established only the potential need for such services.

The need for advocacy is dictated not by the
number who are vulnerable but, rather, by the
number who are abused. A rigorous, quantitative
evaluation of the status of vulnerable adults or — in
the case of health care — incapable patients is
required. Without such data the expansion of
advocacy services to all health care settings may be
unnecessary. Moreover, because the incidence of
abuse may vary between types of health care settings,
such as psychiatric institutions, long-term care facili-
ties, public general hospitals and doctors’ and den-
tists’ offices, such data would also help to target
advocacy services where they are most needed. We
admit that data on abuse are methodologically diffi-
cult to collect, but as studies of sexual abuse of
patients demonstrate the research task is not impos-
sible.

To institute the wide-scale provision of advoca-
cy services would suggest that vulnerable adults are
currently not being protected from abuse. This
implies that neither families nor physicians act
adequately in the best interests of vulnerable or
incapable people. Our experience, albeit anecdotal,
is that in the vast majority of cases families or
physicians (and usually both) do act in the best
interests of the patient. In the rare case in which one
party does not act in good faith the other serves as
an appropriate check and balance. This arrange-
ment needs to be considered when the need for advocacy
services is being gauged.

Effectiveness

Although the government has not yet clarified
the details of the expansion of advocacy services it is
possible that the PPAO will be used as a model — at
the very least it is the closest model we have.
However, it is not clear that the PPAO was entirely
effective in meeting its aims; this points to the need
for further planning and studies before a similar
system is adopted on a wider scale.

An evaluation of the PPAO in 1987 by Professor
Alan Manson showed that the program had had
mixed success in meeting its objectives.11 Although
patients were more knowledgeable about and exer-
cised their rights to a greater extent than before,
there were a number of negative results as well. Most
of these were cited by the health care practitioners
who worked in the facilities involved and included
the following: the increased amount of time spent on
paperwork because of appeals to a review board;
fears leading to legal self-protection, caution and
indifference in dealing with patients; and the erosion
of the practitioners’ role as staff advocates. Indeed,
to some the presumption behind advocacy is one of
mistrust, a notion that is very much at odds with the
mission of caring in health care.

A number of health care providers levelled
criticism at advocates for an approach that promo-
ed the right of the patient to refuse treatment
without a full discussion of the clinical outcomes of
these decisions. Informing patients of their rights
may be construed by them as “advice to exercise
those rights.”11 Although this is a charge that adva-
ciates deny, it raises serious questions as to whether
dthey discuss or are able to discuss the pros and cons
of clinical decisions with their clients.

The debate regarding rights versus clinical out-
comes is part of a larger one regarding responsibil-
ity and accountability. The perception among some
health care practitioners was that PPAO advocates
could not be held accountable for the advice they
offered patients. This created an asymmetry, since
the advocates policed the actions of health care
practitioners, but no mechanism operated to police
the advocates. Formally, advocates were accountable
to the provincial coordinator of the PPAO. In
practice, this line of authority did not seem to
function well.11 The question of policing is of funda-
mental importance to counterbalance the sweeping
powers granted to advocates under the Advocacy
Act.

Even if one accepted the claim that the PPAO
has been successful it should not be concluded that a
similar program could function effectively in other
settings. The PPAO was designed to suit the needs of
psychiatric institutions. Under the proposed legisla-
tion similar programs would be in operation in
various milieux, such as public general hospitals. As
yet, there is no evidence that advocacy programs
would be effective in those settings. Moreover, we
envision potential problems. In a physician’s office
or hospital emergency department, where would the
patient go while the advocate responded to a call
from the physician? The delays could create chaos.

Cost

An advocacy program on the scale suggested in
the legislation would surely cost millions of dollars
annually. Yet the government has proposed the
program at a time when the provincial health care
system is operating under severe financial con-
straints and the provincial deficit has recently in-
creased. The government will have to assess whether
the provision of advocacy services on the proposed
scale merits support at the expense of other services
(or with an increase in taxes or the deficit). What
priority should be placed on advocacy relative to
medical research, inpatient hospital beds, commu-
nity health clinics, public health prevention or other social programs? It is clear that these decisions are not only economic but ethical as well. The ethics of resource allocation must play a vital role in shaping the future of these proposals.

Conclusions

Ontario's proposed consent laws contain a mixture of extremely helpful and potentially troublesome components. On the benefits side of the ledger, the laws provide authority for substitute decision-makers and clarify the guidelines under which such decisions should be made. They legalize advance directives. They provide a nonjudicial mechanism for conflict resolution — the Consent and Capacity Review Board. Finally, regulations will provide procedures for the assessment of capacity and a recommended advance directive document for a Power of Attorney for Personal Care; if the regulations are carefully crafted these items may be very helpful.

On the negative side of the ledger are the advocacy provisions. The problem is not with the concept of advocacy but, rather, with its proposed scope of application. The need for and effectiveness of wide-scale advocacy services in Ontario has not been established. The costs have not been adequately justified relative to those of other programs competing for a strained provincial budget. Given these uncertainties we recommend a trial of mandatory advocacy services in a few designated facilities with formal evaluation of the impact. At the same time advocacy services could be made available on request in all health care facilities; patients and families would be informed at the time of admission about the availability of such services. However, requiring physicians to notify advocates of every proposed treatment for all incapable patients is a sweeping change not supported by the available data. Until further evaluation has been done other jurisdictions should be cautious before adopting the advocacy elements of the proposed Ontario legislation.

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References

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