

Advocacy for Vulnerable Adults

A Two-part Article by Patricia Spindel

1: The Ontario Advocacy Act

On December 20, 1990 the New Democratic Party government announced that the long-awaited *Advocacy Act* would be introduced in the Spring Session of the Ontario Legislature. The explanatory notes which accompany it describe an Act which "establishes a framework for the provision of social advocacy services to benefit persons who, because of disability, have difficulty in expressing or acting on their wishes or in ascertaining or exercising their rights" (Bill 74).

What the Advocacy Act Says

This Act has several important features. It establishes an Advocacy Commission which can provide advocacy services directly or through non-profit community programs. Members of the Commission will be chosen through an Appointments Advisory Committee of eight persons, who are appointed by the Minister of Citizenship, from a list of nominees submitted by organizations representing persons with disabilities. These are to be organizations representing those who have physical disabilities, illness or infirmity which is readily apparent (such as paralysis), disability that is not readily apparent (such as AIDS or epilepsy), organizations representing those who are over 65, those representing persons with psychiatric disabilities and neurological disabilities (such as Alzheimer's Disease or autism), and patients' rights organizations.

The Commission will consist of a full time chair, and at least six to twelve other part-time members, appointed by the Lieutenant Governor in Council. The majority of Commissioners are to be people with disabilities, and the principle of equitable representation is to be followed with appointments of persons of both sexes, mem-

bers of minority groups, and residents of all regions of Ontario.

The Commission will have as its functions:

- the promotion of respect for vulnerable persons, especially their rights, freedoms, autonomy and dignity;
- the provision of direct advocacy services and promotion of self-advocacy;
- an emphasis on bringing about structural changes at political, legal, social, economic, and institutional levels;
- ensuring community development strategies in the delivery of advocacy;
- the provision of advocacy as outlined in other Acts, and,
- religious, cultural, and traditional sensitivity in the way advocacy is to be provided.

Advocates have legislated authority to carry out their duties under this Act. They will have rights of entry without a warrant, to facilities or other premises where there are, or may be, vulnerable persons who want or could benefit from the services of an advocate. Advocates will also have the right to meet with a vulnerable person without interference, and without the presence of another person.

Access to records is guaranteed under Section 24(1) of the proposed Act, which allows an advocate, with a client's consent, access to "any record relating to the person that is in the custody or control of a facility."

Any person hindering or obstructing an advocate exercising her or his right of access to records would be guilty of an offence, and liable, upon conviction, of a fine of up to \$5,000 for an individual, and up to \$25,000 for a corporation.

Any advocate who improperly discloses information about a vulnerable person, obtained in the course of her or his duties, would also be liable, upon conviction, to

a fine of up to \$5,000.

Advocates are to have access to clients in agencies, programs and services funded by the Ontario government, and especially to those in group homes, institutions for individuals with developmental disabilities and/or psychiatric disabilities, nursing homes, homes for the aged, correctional facilities, private and public hospitals, and unlicensed facilities (such as boarding homes and rest and retirement homes).

The Advocacy Act is the centerpiece of three pieces of legislation. It received first reading on April 18, 1991, and partial second reading on June 3, 1991. The other two Acts are Bill 109, an *Act Respecting Consent to Treatment*, and Bill 108, an *Act to Provide for the Making of Decisions on Behalf of Adults Concerning the Management of their Property and Concerning their Personal Care*. Bill 108 and 109 received first reading on May 27, 1991.

The Development of Advocacy in Ontario

The Advocacy Act was introduced after years of lobbying by groups representing disadvantaged persons and by the NDP Opposition.

In 1985, Concerned Friends of Ontario Citizens in Care Facilities, worried that the initiatives to establish advocacy in Ontario were bogging down, submitted *A Proposal to Establish Advocacy Ontario* to the Liberal Attorney-General, Ian Scott.

There was considerable resistance to an advocacy system in the Liberal Cabinet, with most of the resistance coming from the Ministers of Community and Social Services and Health, on the advice of their respective bureaucracies. An inter-ministerial committee established by the Lib-

eral government was apparently unable to reach consensus on an Advocacy Act, and it was never introduced by the Liberals — in spite of persistent lobbying by members of the Ontario Advocacy Coalition.

In January of 1987, Attorney-General Ian Scott appointed the late Rev. Sean O'Sullivan "to consider the need for advocacy for adults in institutional care settings, as well as those adults that may require such services, and are living in the community" (Terms of Reference: Review of Advocacy for Vulnerable Adults, 1987). His task was also to develop options on how advocacy services might be established.

In August of 1987 the late Rev. O'Sullivan made his report, entitled *You've Got A Friend: A Review of Advocacy In Ontario*. It recommended a "shared advocacy" model which would make extensive use of volunteers as well as paid advocates.

The need for an advocacy system became more apparent as press accounts mounted of elderly and disabled people being abused, neglected, criminally assaulted in nursing homes or unlicensed facilities, or left to die on the streets. (Inquests were conducted into the deaths of Catherine Jackson, John Dimun, Drina Joubert, Joe Kendall). It was clear that society must respond to their plight.

The advocates envisaged by the *Advocacy Act* are not legal advocates. They will be what would more commonly be called "social advocates." O'Sullivan quotes Wolf Wolfensberger in describing this kind of advocacy as implying "fervor and depth of feeling in advancing a cause or the interest of another person, it calls for doing more than what is done routinely, and what would be found routinely acceptable; in this sense, the advocate acts at least as vigorously for another person or group as for him/herself" (Wolfensberger, 1977).

On June 5, 1991, two articles appeared in the *Toronto Star* which illustrate the reasons why advocates are needed for older citizens, especially those who are institutionalized in hospitals or nursing homes.

The first article described the annual meeting of the Council of the Ontario Medical Association, at which a statement on the need to discuss euthanasia was adopted in a close vote of 37-30. Euthanasia is a process of actively assisting someone who has requested that her or

his death be hastened. Two doctors spoke out forcefully on this issue. Dr. Elizabeth Latimer from Hamilton, a founder of the OMA's section on palliative care, said that "there would be no requests for euthanasia if doctors did a better job of looking after the terminally ill" (*Toronto Star*, June 5, 1991).

Dr. John Scott, chair of the palliative care section, said that "many of the 17,490 people who died in Ontario last year received inappropriate medical care in their last year of life or failed to have their suffering eased." What an indictment by two palliative care physicians!

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The same day, in a much smaller article, buried away on page A6, it was reported that 21 elderly nursing home residents died after an influenza outbreak at North York Extendicare between January 1 and February 26, 1991. In its report, the North York public health department said that the influenza outbreak should have been detected in November or December of 1990. The report further said that several factors contributed to the virus not being detected, including poor recording of influenza symptoms because of the lack of a formal surveillance system within the home; absence of lab work which might have identified the flu virus; poor education of staff on infection control; a high complement of part-time or agency workers; and widespread use of antibiotics in patients with viral illnesses. Antibiotics have no effect upon viruses.

The usual denials were heard from Extendicare executives, in spite of the

fact that Extendicare had an outbreak of E Coli bacteria in its homes in London, Ontario, a few years earlier, in which a large number of people died. Nor were the reports from health experts favourable to the corporation at that time. Extendicare had also been the subject of complaints four years ago when there was an elevated death rate in its Bayview facility in North York. Almost no autopsies were performed, and the Coroner's office had failed to pick up on the high rate of death.

Perhaps most importantly, neither the two palliative care physicians' shocking revelations, nor the deaths of 21 elderly people at Extendicare merited front page coverage by the *Toronto Star*. What did that day? — the appointment of Cliff Fletcher as head of the Maple Leafs' hockey team, and Sunday shopping.

As long as our society places sports and shopping ahead of the tragic deaths of its citizens, young and old, there will be a strong need for advocacy.

Ontario will be the first province in Canada to have a formal system of advocates for those who are disadvantaged by age and disability, and by society's attitudes toward their conditions. Other provinces will likely follow Ontario's lead.

The biggest question the new Advocacy Commission will have to answer is: who will the advocates be, in a society which has shown so little regard for its most vulnerable citizens? And how much support will we expect them to have from the general public, when sports and shopping are of much greater interest than people's pain?

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2: Anne Coy, Patients' Rights Advocate

One spring evening this year, Anne Coy managed to squeeze in an interview between her many advocacy activities on behalf of patients. After being an advocate for much of her life, she has learned to be philosophical about her work: "Nothing is ever as bad as it could be, or as good as you would like it to be," she mused. Nevertheless, some things were bad enough to spur Anne to become an advocate — the way her husband died, for instance. Her experience with the medical profession is what led her to become a patients' rights advocate for eighteen years. Before that she was an advocate for workers' rights for twenty-six years.

Anne Coy has been an advocate for longer than many of us have been alive. She still puts in sixty to seventy hours a week of volunteer time as President of the Patients' Rights Association.

"My mother taught me there was such a thing as justice," she remarked, remembering how she got involved in workers' rights at Eatons in 1948. "People didn't get paid when they were sick, they lost a day's pay for being late, and some of the people who worked for Eatons lived in cellars," she recalls. She joined Lyn Williams, now head of the Steelworkers, riding around with him in his little Volkswagen, trying to sign up members for the union. "I didn't even know what a steward was!," she laughed. All she did was ask a question at a union meeting, and next thing she knew, she was a steward.

Anne also remembers losing the vote to bring in a union at Eatons, and she recalls that Lyn Williams cried. "Management tried to get people not to vote at all. They stood outside the polling booths because they knew that any vote was a vote for the union," she said. When she was called into the boss's office because of her union activities, she informed him that she was just as interested in making progress — as Timothy Eaton was, and that she felt certain that Eatons was not going to look after her future interests. Anne was not fired, but some time later, in 1952, she gave her notice. Her boss asked if she was sure that she was making a wise choice.

Single-minded as always, Anne said she was sure. "I went to the CBC," she remembers, "wouldn't you know it, they were forming a union — the Association of Radio and Television Employees of Canada." She asked another question at a union meeting, and ended up a steward, then a chapter chair. She became a member of the negotiations committee, chaired the grievance committee, and became president of her chapter.

Anne is still not afraid of authority figures. Power doesn't impress her: intelligence and compassion do. She remembers being inspired by David Lewis. "I can't remember a word he said when he came to talk to the Eatons workers," she grinned, "I just remember thinking he didn't have to care about us, but he did." She was also impressed with the late Rev. Sean O'Sullivan, author of the *Commission Report on Advocacy for Vulnerable Adults*. "I could never call him Father," Anne quipped: "I might have called him son." She respected his compassion and sense of fairness. Rev. O'Sullivan felt that because the Patients' Rights Association dealt with short-, not long-term patients, an advocacy system might not be of much help. But he offered to pray for Anne and her work. In speaking with him, Anne realized that prayer was one strategy she had never tried. "I hadn't tried the avenue of prayer," she smiled. It must have worked: the new Advocacy Act does mention Patients' Rights Associations.

There are some who might have trouble believing that Anne is a fierce advocate who never takes no for an answer. She is an elegant woman who looks more like a successful businesswoman than a former union organizer. A retired deputy minister once told her she looked like such an innocent old lady. Her family certainly expected her to be. She confided, "my family has disowned me because there hasn't been an aggressive person in our family for decades. They don't know how I got into the family!"

Personal tragedy prompted her to become a patients' rights advocate. In 1970, her dear husband Harold found that he was unable to play golf because of bursi-

tis. His attending physician prescribed butazolidin, a medication which caused him to black out and develop a rash. It apparently also caused perforation of his stomach. After never having been in hospital in his life, Harold was hospitalized five times, and operated on four times in two and a half years. He was left with a cancerous ulcer which killed him. When Anne and her lawyer contacted the College of Physicians and Surgeons to ask what their complaint procedure was, they did not get an answer. "I think the fact they didn't answer was good," Anne said, "because I became annoyed then." A follow-up letter in February resulted in the reply that the College was investigating. Anne could not understand that, since she and her lawyer had only asked for information about the complaint procedure. During a later interview with the College, the Associate Registrar subjected Anne to what she described as an insulting meeting, where she was quickly characterized as "a bitter woman," and given a lecture about how guilt feelings cause spouses to blame the doctor when a loved one dies. Years later, the College would be in the position of having to ask this same "bitter woman" to sit on a task force examining its complaints procedure. During Anne's interview, the doctor engaged in a conversation with another doctor about their plans for the weekend. Some time later, Anne received a letter from the College, saying that her husband had received adequate care. "He was dead, mind you, but he received adequate care," she said sadly.

The rest, as they say, is history. Anne phoned Sidney Katz at the *Toronto Star*, who wrote a full-page article on how the College dealt with complaints, which featured Anne and Harold's picture. From 4:00 p.m. that Saturday until Sunday evening, Anne did not move from her telephone. The article had struck a chord with the public. "You have no idea the stories people told me," she said.

She, Sidney Katz, and many of the callers got together for a meeting at her home. Without knowing it at the time, they were participating in the founding meeting of the Patients' Rights Associa-

tion. That was 1974, and Anne has been helping people in pain ever since. People like the couple whose child was born with a hole in her heart. They were advised that such a hole often closes by itself, but the doctors wanted to operate, even though the family was refusing. The parents were religious, and preferred to leave the matter "in God's hands," but the doctors continued to press them. When the baby was a year old, they allowed the operation. Something went terribly wrong. The baby was left with irreparable brain damage. The nurses began insisting that she required tube feeding; the parents again refused and were, predictably, labelled "uncooperative." The child now lives in a group home where she is fed by mouth according to the parents' wishes.

Does Anne ever become numb at hearing so much agony? "I haven't gotten to the point where I'm shockproof," she responds, as she remembers that doctors were billing OHIP for the time they spent sexually abusing their patients, according to testimony at a recent task force examining sexual abuse of patients by doctors.

It is tragedy like this that fuels Anne's motivation to set things right. How does she manage to put in so many fourteen-hour days? "At my age you don't want old age creeping over you," she jokes. Indeed. The next thing she did was ask me for dating tips for the 1990s. "These days if you have a cup of coffee with someone, they want to go to bed," she laughs.

Anne has some strong ideas about how medical care should be delivered. She politely comments, "the Ministry of Health should not simply be a collection agency for doctors." Anne has this 'strange' notion that doctors should be truly accountable for the care they provide. Some people certainly agreed. Edward Pickering, the first chair of the Health Disciplines Board, referred to people like Anne as the "conscience" of the medical profession, adding, "if we won't make the necessary changes, they will be imposed on us."

His words were prophetic. New health disciplines legislation, task forces into sexual abuse by doctors, reviews of the College's complaints procedures — Anne had a lot to do with them all, as well as with the introduction of the new Act, which she sees as "a good beginning."

What exactly is wrong with our health care system in Anne's view? "Doctors can't decide if they're gods or human beings," she says.

What is her advice to younger women seeking to become advocates? "Do it!" she exclaims. "Become involved, you're doing something for yourself and the system. We can politely suggest reforms, but nothing will happen until there is pressure from an informed and outraged public."

It is obvious that Anne believes more people need to be recruited for the cause. She tells me, "maybe we should consider getting admitted to a nursing home, then we could organize the residents!" (I'm not sure my own commitment stretches quite that far).

Was Anne ever nervous or unsure of herself? "Yes, a little," she says, when she was asked to speak to a group of lawyers and doctors about patients' rights at the Institute of Law and Medicine. As soon as she spoke, the problem was solved: "Good morning, potential patients," she said, with an oblique look at the audience. "I really don't know what could intimidate me now." Certainly not an audience of doctors and lawyers. Apparently practice makes perfect.

Anne's deep sense of responsibility sets her apart from so many others, and prevents her from losing sight of the fact that advocacy is an art and a calling, requiring commitment to those for whom you are advocating, and responsibility to society as a whole. "There is no excuse for not acting — not in this society," she says. "It has to be done. Someone has to do it, and it is up to us."

Who better to have paved the way for the rest of us than Anne Coy — a woman who has been able to link her voice to her heart, and to speak from that place with wisdom, compassion and purpose, for the benefit of us all.

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She was a member of the Consumer Committee of the Attorney General's Review of Advocacy for Vulnerable Adults, a co-founder of the Advocacy Centre for the Elderly, organized the Ontario Coalition for Nursing Home Reform, and is a past president of Concerned Friends of Ontario Citizens in Care Facilities. She also served on the Metro Toronto Homes for the Aged Task Force on Advocacy.

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no issue
that is not a
women's
issue."

—Charlotte Bunch

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