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CONGREGATE LIVING AND THE LAW AS IT AFFECTS OLDER ADULTS

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INTRODUCTION

Based on our experiences serving clients for 25 years and our research for this project, it is the opinion of the Advocacy Centre for the Elderly (ACE) that Ontario's current legal structure is inadequate to meet the needs of older adults residing in congregate settings and failing to have their complaints heard and resolved in a timely and satisfactory manner. ACE has used the phrase "congregate setting" to refer to those locations where older adults reside in a group setting – namely, hospitals, retirement homes and long-term care homes – which have a health care component, where resources are shared (e.g., meals, rooms, programming) and where there is an inability to easily move to a different location. Residents of congregate settings are particularly vulnerable as they are dependent on the very institutions that provide their care and shelter, in addition to the fact that they are "out of sight" from public scrutiny.¹

In this paper, the application of a principled framework to the relevant laws, policies and practices impacting older adults living in congregate settings illustrates how this group is unable to effectively access justice. This framework refers to the principles adopted by the Law Commission of Ontario – independence, participation, security, dignity and respect for diversity – which should underscore any approach to the law as it affects older adults.²

In an effort to influence both law reform and best practices, ACE examined legal mechanisms available in different jurisdictions, both within and outside Canada, with respect to the enforcement of rights for older adults in institutions.

ACE also held a series of focus groups and consultations with stakeholders to guide and inform our work. Using the information obtained from our research and the feedback from our meetings, we have developed an "access to justice" model for Ontario that utilizes the principled framework of the Law Commission of Ontario.

Although the phrase "access to justice" is ubiquitous, there is little agreement about what it means. Common features of an accessible justice system include: just results; fair treatment; reasonable cost; reasonable speed; capacity to be understood by its users; responsiveness to needs; certainty; effectiveness; being adequately resourced; and being well-organized.³ ACE interprets "access to justice" in its broadest sense and supports Professor Reem Bahdi's description:

Access to Justice Scholars have moved from a uni-dimensional focus on the procedural and cost barriers that prevent individuals from bringing their claims to court to a more holistic assessment of all aspects of the legal system. Focus has widened from simply an

emphasis on “access” to an examination of “justice” as well. The trend is towards thinking of access to justice as three distinct yet interdependent components: substantive justice which concerns itself with an assessment of the rights claims that are available to those who seek a remedy; procedural aspects which focus on the opportunities and barriers to getting ones claim into court (or other dispute resolution forum); and, the symbolic component of access to justice which steps outside of doctrinal law and asks to what extent a particular legal regime promotes citizens’ belonging and empowerment.⁴

It is important to note at the outset that we are writing this report in advance of two important developments in the long-term care sector which likely would have influenced our findings and recommendations. First, the Ombudsman of Ontario will be releasing a report in the late summer of 2009 scrutinizing the Ministry of Health and Long-Term Care’s oversight of long-term care homes. Second, the *Long-Term Care Homes Act, 2007*⁵ is expected to be proclaimed into force before the end of the year. The stated purpose of the new legislation is to enhance the quality of life for residents of long-term care homes by strengthening enforcement, improving care and increasing accountability. Although one set of draft regulations was recently released to the public for comments, we are still awaiting the second set. As the regulations provide the “nuts and bolts” to support the law, we do not know how the law will be finally implemented. Moreover, we can only speculate as to how the legislation will be interpreted and applied.

After a brief introduction to ACE, we will outline the methodology we employed for this project. We will then examine the regulation of congregate settings in Ontario. The next section discusses, in detail, the legal protections currently available to residents and why they are ineffective. A legal review of congregate settings and legal protections for older adults in four provinces in Canada, as well as Wales, Australia and the United States of America follows. Finally, ACE will propose its model of access to justice for older adults residing in hospitals, retirement homes and long-term care homes.

Advocacy Centre for the Elderly

ACE is a specialty community legal clinic that was established to provide a range of legal services to low income seniors in Ontario. The legal services include individual and group client advice and representation, public legal education, community development, and law reform activities. ACE has been operating

since 1984 and it is the first and oldest legal clinic in Canada with a specific mandate and expertise in legal issues pertaining to older adults.

ACE receives, on average, over 2,500 client intake inquiries a year. These calls are primarily from the Greater Toronto Area but approximately 20% are from outside this region, and may come from any part of the province, as well as from out of province.

The individual client services provided are in areas of law that have a particular impact on older adults. These include but are not limited to the law related to: capacity, substitute decision-making and health care consent; supportive housing and retirement home tenancies; long-term care homes; patients' rights in hospitals; consumer protection law; elder abuse; home care; and income support.

A primary area of practice for ACE has been advocacy and representation of residents in the long-term care system. One of the lawyers at ACE is a full-time Institutional Advocate, who provides advice to seniors considering moving to or living in various forms health care facilities or congregate settings.

Public legal education programs are directed to seniors and their families, as well as health professionals and other service providers working with seniors. These presentations and workshops may be on any topic of law within ACE's practice areas. ACE also produces easy-to-read educational materials, such as booklets and pamphlets on seniors' legal issues.

ACE staff also write papers for continuing legal education programs and engage in other writing on elder law. For example, ACE has produced an extensive publication entitled *Long-Term Care Facilities in Ontario: The Advocate's Manual*. Now in its third edition, this manual is over 600 pages and also includes chapters on retirement homes, home care, and other issues such as substitute decision-making, powers of attorney, and advocacy. It remains the only comprehensive text in this area of the law in Canada. ACE is planning to release the next edition in 2010 or 2011, once the *Long-Term Care Homes Act, 2007* has been enacted.

As part of its law reform mandate, ACE staff frequently participate in government consultations as stakeholder representatives for the seniors' community. We also submit written briefs to policy makers and make oral submissions to legislative committees when new legislation or legislative amendments impacting our clients are proposed. For example, ACE has drafted submissions on various long-term care consultations, including a major brief on the new long-term care home legislation.

Methodology

The methodology was comprised of two main parts: (1) a literature review; and (2) focus groups and meetings with stakeholders who are knowledgeable about the institutional sector.

Literature Review

We conducted a comprehensive literature review of the issues affecting older adults residing in congregate settings by examining the following:

- National and international legislation;
- Policies and practices;
- Case law;
- Academic articles; and
- Web-based materials.

In addition to reviewing the laws and policies of Ontario, ACE examined four Canadian provinces: British Columbia, Alberta, Nova Scotia and Newfoundland. Outside Canada, we examined the laws of Australia, Wales and the United States of America. We chose these jurisdictions for a variety of reasons, including: language (these countries speak and write in English); similar legal systems; varying size (in terms of both geography and population); and noteworthy laws and/or approaches to institutional environments.

The purpose of the comparative literature review was to analyze different legal models to inform an appropriate access to justice model for Ontario. In other words, we did not want to reinvent the wheel, but wished to learn what has worked and what has not worked in other jurisdictions. Due to the time constraints of the project, our analysis was not exhaustive. It is fair to say that there most likely is a gap between what is outlined on paper and what happens in practice in other jurisdictions, as is our experience in Ontario.

Meetings with Stakeholders

We met with a range of stakeholders to obtain their thoughts regarding the rights currently available to residents and how the system should, or should not, be changed to support the enhancement and/or enforcement of the rights of older adults. We also emphasized our desire to learn about practices or initiatives already in place within homes that enhanced resident's access to justice. Of paramount importance to our project, however, was speaking to residents in institutional settings, as this is the group who is the focus of this report.

Due to the tight timelines of the project and our limited resources, it is important to note that we were not able to meet with as many individuals and groups across the province as we would have liked.

As well, we had hoped to hold focus groups with older adults residing in hospitals. Unfortunately, we were unable to do so because the patient population is constantly changing and very few hospitals have a Patients Council or any other organized group with which we could liaise to organize a meeting.

a) *Residents of Retirement Homes and Long-Term Care Homes*

With respect to organizing focus groups in both retirement and long-term care homes, our aim was to choose a variety of types of homes in different geographic locations. In order to be respectful of the autonomous nature of Residents' Councils, our first point of contact was with the individual Residents' Councils to determine if they would be willing to be involved in our project. An explanatory letter about the research project and an invitation to participate in a focus group was sent by mail to the President of the Residents' Council of the selected homes.⁶ An example of this introductory letter is included in Appendix 1. Please note that this letter was slightly modified for each group of stakeholders. If the Residents' Council agreed to meet, we then worked with the Council in contacting the administration of the home to advise them and to make the necessary logistical arrangements.

We encountered several problems in arranging the meetings. In at least one instance of which we are aware, our letter was opened not by the President of the Residents' Council but by an employee of the home. We were also told by quite a few homes that letters addressed simply to the President and without a specific room number (we did not request this information) would take "a long time" to reach the resident. Some homes would disclose the name of the President while others would refuse to do so citing confidentiality concerns. It was not uncommon for several weeks to pass before our letter was received by the Residents' Council. Another resident told us that we needed to get permission from the administrator of the home before we could meet with them.

Several Residents' Councils declined our invitation. One resident at a long-term care home resident advised us that we could not visit due to the H1N1 Influenza outbreak. The home did not have any cases, nor were the ACE staff who wished to visit specifically targeted. Instead, the home had stated that no visitors except immediate family were allowed to visit the home. We are not aware of any such public health requirements. At another long-term care home, where a government imposed ban had recently been lifted with respect to the admission of new residents due to non-compliance, ACE was told that residents wanted to

allow the home some time to make changes and that it would be counter-productive to meet at that point in time. This was unfortunate, as we felt that given their recent experience, they would have been able to provide us with a unique perspective into access to justice for their residents.

Residents of retirement homes tend to be more independent and capable of making decisions. Consequently, they are more likely to be able to go out into the community to seek assistance if so required. We therefore opted to hold fewer meetings in retirement homes than long-term care homes. In selecting retirement homes, we attempted to choose those with an active Residents' Council and geared to lower-income residents. Two focus groups were held at not-for-profit retirement homes in Toronto where approximately 60 residents and seven staff members attended. With respect to long-term care homes, we conducted four focus groups with residents at for-profit, not-for-profit, charitable and municipal homes in Toronto, Kitchener and Port Perry, involving a total of about 80 residents and five staff members.

Each meeting had a different dynamic and level of resident participation, depending on a multitude of factors, including the size of the group, the personalities of attendees and the presence of staff. For instance, at one meeting there were approximately 50 residents and several employees of the home whereas other meetings had as few as four residents and no staff.

While we would have preferred to have meetings without staff members in attendance, this proved to be difficult. In the homes where a large number of residents were in attendance, the meetings were in open areas which were not private and where it was impossible to prevent staff from attending. Even when we asked staff to leave the room, they often returned for a variety of reasons.

With regards to the cultural diversity of the participants, nearly all of the residents were Caucasian. ACE had hoped to hold focus groups with residents at culturally diverse long-term care homes but this turned out not to be feasible due to language and cultural barriers. As well, the amount of time and resources available for this project were insufficient to be able to plan and pay for the translation of documents and interpretation services which would have been necessary to hold these focus groups. This would be an appropriate subject for future study.

In terms of general observations about diversity, we noted that the majority of participants were female: this is consistent with statistics on female residents in these homes. Not all of the residents were older adults as younger residents at long-term care homes attended our meetings as well. Most of those who actively

participated appeared to be mentally capable of making decisions. A significant number of residents used mobility devices such as walkers or wheelchairs.

Finally, ACE had a separate meeting with a representative of the Ontario Association of Residents' Councils. The Ontario Association of Resident's Councils is a voluntary association of long-term care home Residents' Councils which has approximately 270 Resident Councils Members. A Board of Directors comprised of residents from the member Councils governs the Ontario Association of Residents' Councils.

b) *Family Councils*

ACE also felt it was important to consult with the families and, if applicable, the substitute decision-makers, of older adults residing in long-term care homes. More and more residents of long-term care homes are mentally incapable and unable to participate in the resident focus groups. By meeting with the substitute decision-makers and families of these residents, we were able to learn about the issues which affect them.

Family Councils are new in many homes and are not yet supported by the legislation (which will change when the *Long-Term Care Homes Act, 2007* is proclaimed). We met with one Family Council at a home outside Toronto, as well as a representative of the Ontario Family Councils Program. The Ontario Family Councils Program is a support program for Family Councils across Ontario.

We were able to meet with two Family Council Networks (a group of Family Councils based on their geographic location within a Local Health Integration Network (LHIN)) at their annual regional meetings. We attended a regional meeting in the Hamilton Niagara Haldimand Brant LHIN where there were 65 participants representing 36 long-term care homes. We also met with 30 participants in various areas of the North East LHIN via videoconference.

Our goals at each meeting of both residents and families was to learn about any obstacles they might encounter when attempting to enforce legal rights of residents, the remedies they sought and their recommendations of changes which might improve the current system. We anticipated that not everyone would feel comfortable sharing their experiences or ideas in a public forum, and some would require more time to consider the issues raised; we therefore provided participants with a questionnaire. The questionnaire was anonymous and could be completed either during the meeting or sent to ACE afterwards. Please see Appendix 2 for a copy of the questionnaire distributed in long-term care homes and Appendix 3 for the version used in retirement homes. To date, we have only received four completed questionnaires.

c) *Lawyers*

ACE conducted a focus group at the beginning of this project with lawyers whose legal practices relate to elder law. In addition to sending the invitation to a large group of lawyers and posting it to the ACE website, a notice was also posted to the website of the Ontario Bar Association. The purpose of the meeting was to review common scenarios facing institutionalized residents and to brainstorm about the options available to older adults, their advantages and disadvantages, and ways to improve the system. Six lawyers were in attendance.

An article about this project was also published in *Deadbeat*, the newsletter of the Ontario Bar Association's Trust and Estates Section. Lawyers were encouraged to contact ACE with any comments or ideas.

d) *Industry and Seniors Groups*

To determine whether our recommendations to the Law Commission of Ontario would be feasible and practical, it was imperative for ACE to obtain the opinions of industry stakeholders regarding the current remedies and enforcement mechanisms available to older adults, as well as ACE's suggestions for reform.

Accordingly, we held one focus group with industry stakeholders and another with seniors' organizations. Due to scheduling conflicts, we met privately with one industry stakeholder. A separate meeting was held with an administrator at a long-term care home who independently contacted us.

We were unable to meet with some stakeholders due to scheduling conflicts, bureaucratic reasons or lack of interest.

Summary

In total, we conducted 16 focus groups and meetings, involving a total of approximately 255 participants. A complete list of the participants can be found in Appendix 4. The feedback and information received from the different stakeholders was invaluable and will inform our final recommendations to the Law Commission of Ontario. We will incorporate the responses and opinions received throughout this report

CONGREGATE SETTINGS: ONTARIO

A spectrum of accommodation options currently exists for older adults in Ontario, each with its own unique challenges. At one end of the continuum is the idea of “aging in place” in the community, while at the opposite end are long-term care homes designed for people who require 24-hour nursing care and supervision within a secure setting. Retirement homes, which provide some care services to their tenants, sit in the middle of this spectrum. Hospitals can sit almost anywhere on the spectrum, depending on the level of care and the goals of the individual unit on which the older adult resides.

This section of the paper will describe the different institutional settings for older adults in Ontario and how they are regulated.

Hospitals

Pursuant to the federal *Canada Health Act*, all medically necessary services delivered within hospitals must receive full public payment.

The *Public Hospitals Act*⁷ and its regulations provide the framework within which hospitals operate in Ontario. There are 211 hospital sites in Ontario comprised of four different types of hospitals: public hospitals; private hospitals; federal hospitals; and Cancer Care Ontario hospitals. In terms of corporate governance, there are 155 hospital corporations while the remaining 56 facilities are hospitals under an umbrella corporation. Ontario has seven private hospitals currently providing services under the *Private Hospitals Act*, six of which receive funding for their operations from the Ministry of Health and Long-Term Care.⁸

Within these broad groups of hospitals, there is a further categorization into general hospitals, convalescent hospitals, hospitals for chronic patients, active treatment teaching psychiatric hospitals, active treatment hospitals for alcoholism and drug addiction and regional rehabilitation hospitals.⁹

Complex Continuing Care

Complex continuing care refers to the provision of continuing, medically complex and specialized services in either freestanding hospitals or in designated beds within acute care hospitals. Patients typically have long-term illnesses which are unstable, or disabilities typically requiring skilled, technology-based care not available at home or in long-term care homes.¹⁰ However, the legislation sets no specifics as to what type of care these facilities are to offer, and most set their own admission criteria. Therefore, it is difficult to ascertain exactly what services

and to whom these hospitals provide care. In the past, patients would live in these settings indefinitely; however, there is presently a greater emphasis on these settings being temporary and no longer a final destination.

A co-payment fee may be charged to a patient whose doctor has determined that the patient requires complex continuing care and is more or less a permanent resident in a hospital or other institution. The daily fee, as of July 1, 2009, is a maximum of \$53.07 per day.¹¹

In 2005–2006, there were almost 24,000 patients who received complex continuing care: 17% of these patients were aged 65 to 74 while 65% were aged 75 and older.¹²

Rehabilitation

Rehabilitation services can be provided in either a rehabilitation unit or collection of beds designated for rehabilitation purposes within a general hospital.

The Ministry of Health and Long-Term Care list 58 rehabilitation hospitals.¹³ Admission is generally from a general hospital after an acute care admission and many specialize in specific types of rehabilitation. There is no fee for rehabilitation in hospital.

As with complex continuing care, there are no set admission requirements or specifics regarding what kind of care is to be provided and to whom. It can be very difficult to access these coveted spots, and elderly patients, especially those who show signs of dementia, confusion or memory issues may be refused spaces because of difficulties in learning or following instructions.

Palliative Care

Palliative care, or end-of-life care, is a range of services intended to provide comfort and alleviate the pain of a person who is dying. Specialized services are provided in a hospital, either in a palliative care unit or through a team of palliative professionals who will provide care wherever the patient is located in the hospital. These services are provided without charge to the patient.

Retirement Homes

Retirement homes are not part of our health care system; instead, they are tenancies and described as “care homes” under the *Residential Tenancies Act, 2006*:

“Care home” means a residential complex that is occupied or intended to be occupied by persons for the purpose of receiving care services, whether or not receiving the services is a primary purpose of the occupancy.¹⁴

Generally, retirement homes are designed for seniors who require minimal to moderate support with their daily living activities. While retirement homes may make available some care services pursuant to a contract with the tenant, the care services provided are neither funded nor regulated by the Ministry of Health and Long-Term Care, or any other government Ministry.

Many different terms are used to describe what is defined in law as a care home in Ontario. Rest homes, retirement homes, group homes, seniors' homes, and boarding and lodging homes may be “care homes”, provided they offer care services in addition to residential accommodation. It would appear that the care levels provided in retirement homes are also increasing due to demand and lack of available beds in long-term care homes.

Statistics indicate that there are over 700 care homes¹⁵ and 43,380 spaces¹⁶ in retirement homes in Ontario. These statistics, however, may not be accurate because there is no registration system for retirement homes and many homes, while they meet the criteria to be a retirement home, do not self-identify as a retirement home. Some care homes are small, run by an individual or a family. Outwardly, these homes may appear to be a large single family dwelling. Other care homes are very large and have an institutional appearance.

Care homes may offer any of a wide range of services including meals, nursing care, attendant care, assistance with activities of daily living, recreational and social programs, house-cleaning and laundry. Some homes require that these services must be purchased as a requirement of admission, while others will offer them to be purchased separately as needed. Landlords decide which care services will be offered, which will be mandatory, and how much they will cost, although tenants may try to negotiate these matters. The average total monthly cost (including both rent and care) is \$2,750 for a standard retirement space and \$3,440 for a heavy care space (1.5 hours or more of health care).¹⁷

While general provincial and municipal laws apply to retirement homes,¹⁸ the only area of substantial regulation unique to retirement homes is the regulation of landlord-tenant matters under the *Residential Tenancies Act*. There is no provincial licensing or granting of approval to operate, oversight of the services provided, or provincial funding for retirement homes. There is no limit on the maximum amount of care that a home is allowed to provide, although they are prevented from calling themselves nursing homes.

Long-Term Care Homes

In Ontario, there are three kinds of long-term care homes that provide care to eligible persons: nursing homes which are regulated by the *Nursing Homes Act*,¹⁹ municipal homes for the aged which are regulated by the *Homes for the Aged and Rest Homes Act*,²⁰ and charitable homes for the aged which are regulated by the *Charitable Institutions Act*.²¹ A new statute, the *Long-Term Care Homes Act, 2007*, will replace all three pieces of legislation once it is proclaimed into force, hopefully by the end of 2009.

There are currently 622 long-term care homes with 76,109 long-term care beds across the province.²² The size of long-term care homes varies, with the largest home having 472 beds while the smallest home has only 10 beds.²³

Each statute deals with homes with different types of ownership structures. The *Nursing Homes Act* governs privately-owned homes, which may be for-profit or not-for-profit. The majority of nursing homes in Ontario are operated as for-profit enterprises by corporate owners.²⁴ Each municipality must operate at least one home under the *Homes for the Aged and Rest Homes Act*.²⁵ Charities may operate homes under the *Charitable Homes Act*, although some are governed by the *Nursing Homes Act*. It should be noted, however, that some non-profit and nursing homes, while ostensibly not-for-profit, may hire a management company which earns a profit for providing services.

The government pays the cost of providing nursing, personal care and food, as well as programs and support services while the resident pays for "accommodation" only. The average daily cost for a resident living in long-term care is \$142.07 per day; the provincial government pays \$89 per day and residents pay an accommodation fee of \$53.07 (subject to a rate reduction if they are unable to pay this amount).²⁶

Older adults entering long-term care homes tend to be at a more advanced age with increasingly complex health care needs ranging from dementia to major psychiatric conditions combined with physical illnesses. Generally, this

population has a declining level of cognition and capacity, with approximately 55% of residents having a reported diagnosis of dementia.²⁷ The average age of a resident in long-term care today is 83 years.²⁸ That being said, there are many younger residents living in long-term care due to their medical conditions (e.g., acquired brain injury, Huntington's disease) and a lack of alternate accommodation.²⁹ Thus, long-term care homes are now serving a more diverse group of residents than ever before.

An issue which desperately needs a solution is the "difficult" or "high level of care" applicant or resident. These individuals often require high levels of complex care, due to behavioural issues stemming from dementia, psychiatric illness or other neurological issues. Psychiatric facilities will not accept these individuals, as they repeatedly state that they only provide short-term assessment and are not long-term housing facilities. In our experience, the homes that accept high level of care individuals may be the least able to care for them, but who are the only ones willing to admit them in order to fill their bed quotas. Once admitted, the individual may act out, and even harm, another resident. The resulting challenge is how to balance the rights of the each resident. At the El Roubi/Lopez (Casa Verde) inquest in 2006, several recommendations were made about the need for specialized homes and units for this population.³⁰ These individuals need care that does not exist at the present time. Unfortunately, this systemic issue is outside the scope of our paper.

There are five essential features of long-term care homes. First, each home is subject to provincial legislation and inspections respecting its standards of care, physical facility, fees, management and staffing. Second, a person cannot be admitted to a long-term care home without having specific care needs, and without requiring a minimum level of care. Admission can only occur by application to the local Community Care Access Centre, who determines eligibility. Third, a long-term care home assumes responsibility for monitoring on-going care needs and identifying significant changes. Fourth, a long-term care home assumes responsibility for meeting the current and changing care needs of its residents. Fifth, the primary reason for discharging a resident from a long-term care home is that the resident no longer requires the care offered by the home or the resident requires a higher level of care that can only be provided elsewhere, and appropriate arrangements are made for alternate placement.

Long-term care homes are highly regulated by the aforementioned statutes, as well as by policies of the Ministry of Health and Long-Term Care. It is safe to say that the type of regulation can be described as "command and control." Originally referred to as "direct regulation," command and control regulation is typically characterized by "centralized, bureaucratic standard-setting" whereby the government prescribes particular behaviour to further its goals and

establishes a regulatory agency (such as the Compliance Branch of the Ministry of Health and Long-Term Care) to monitor and ensure compliance with its standards.³¹ The major advantage of command and control regulation is dependability: the expected behaviour of long-term care homes, as well as the punishment for any breaches of the standards, is set out with clarity. Other advantages include:

Decreased information collection and evaluation costs, greater consistency and predictability of results, greater accessibility of decisions to public scrutiny and participation, increased likelihood that regulations will withstand judicial review, reduced opportunities for manipulative behaviour by agencies in response to political or bureaucratic pressures, reduced opportunities for obstructive behaviour by regulated parties...³²

However, due to its inflexibility, command and control regulation has several weaknesses.³³ First, it requires regulators to have comprehensive and accurate knowledge of the industry although there is an imbalance between the knowledge levels of the government and the homes. Second, it is expensive for the state to properly enforce the rules. If the authorities cannot adequately monitor compliance, the regulatory regime will fail to control the industry and may even result in defiance or resistance. Third, command and control regulation is not immune to political manipulation. Fourth, the lack of incentives for businesses to go beyond the minimum standards or to continuously improve is a serious drawback. Finally, a multiplicity of laws, procedures and standards may arise in a command and control environment resulting in “a counterproductive regulatory overload” for both regulators and industry.³⁴

ACE’s work is based on the premise, due to the unique position of older adults in institutions, that laws enforced by government and supported by regulatory agencies – as opposed to self-regulation – is the most appropriate mechanism for achieving accountability in hospitals, retirement homes and long-term care homes. It is our position that, given the potential vulnerability of the recipients of this type of care, only government regulation can serve to ensure the continued compliance in these sectors. Our experience is that where such government regulation compliance has not been in place or where compliance has become lax, the rights of residents are not respected.

LEGAL PROTECTIONS: ONTARIO

Access to Justice: Myth or Reality?

There are many protections ostensibly available to older adults in congregate settings in Ontario. At first blush, it appears as if older adults have many rights, and a large array of mechanisms available to them to enforce these rights. Upon further examination, it becomes evident that while these rights look good on paper, they are not truly effective. The next section will analyze the legal protections currently available to older adults residing in congregate settings to systematically show how many of these rights are hollow.

Civil Litigation

One route for residents to pursue if they feel wronged is civil lawsuits. For example, if a staff member at a long-term care home injures a resident, a negligence claim can be initiated. If a resident felt that a retirement home unilaterally changed the care originally agreed to in the terms of their agreement for services, they can sue for breach of contract for care services.

However the civil justice system contains several inherent problems that are particularly detrimental to older adults residing in congregate settings. The following passage, although dealing with American nursing home lawsuits, succinctly summarizes some of the barriers facing older adults residing in congregate settings:

Nursing home claimants have few desirable litigant characteristics because of their pre-existing illnesses, nonexistent imputed earnings, and low overall economic damages. Many nursing home victims have chronic physical or mental diseases that render them incapable of seeking legal representation so many meritorious cases are never filed...The reality is that elderly nursing home residents are too infirm and have such a low life expectancy that they simply cannot wait years for a settlement or jury verdict.³⁵

Turning back to Ontario, one of the most significant impediments to access to justice for older persons is money. The private bar model of law is prohibitively expensive for the majority of Ontarians. A newspaper article, which was quoted by the Honourable Warren Winkler, Chief Justice of Ontario, reported that the cost of taking a routine civil case through to a three-day trial in Ontario is about \$60,000.00.³⁶

Legal Aid Ontario does provide a limited number of services to older adults if they satisfy the financial requirements, but the income level required is so low that only the poorest members of society are eligible. While some older adults do qualify financially, they may own a home. Legal Aid Ontario will usually require individuals to put a lien against their house in order to receive legal assistance. Many older adults are hesitant to enter into such agreements as they are worried that they could potentially lose their home.³⁷ Further, many older persons are precluded from receiving legal assistance for issues affecting security of the person because Legal Aid Ontario does not provide certificates to the private bar for most civil claims, including elder abuse, violation of consent and claims against long-term care homes.

Second, even if a resident is able to afford a lawyer, there is an insufficient number of lawyers with the appropriate knowledge and experience to provide competent representation. At present, only a small proportion of the bar directly advises or represents the older adults themselves. While ACE and community legal aid clinics provide such services, we are inundated with work and have limited resources to assist everyone who contacts us. Few lawyers have experience with the types of legal problems that have a specific impact on the older population, such as issues in retirement homes, long-term care, defence of guardianship applications, health care consent and elder abuse.

Even when lawyers do agree to represent persons with an elder law issue, they often fail to understand their duty to the older person. ACE has received complaints where lawyers have breached the *Rules of Professional Conduct*.³⁸ In some cases, lawyers have failed to consult with the older person who is their client; instead obtaining instructions from the older adult's friend or family member. Besides being contrary to the Rules, they may also be putting themselves in a potential, if not actual, conflict of interest position.³⁹ Other lawyers who are not familiar with particular elder law issues have provided incompetent representation to the older person by not understanding the applicable law.⁴⁰

A third reason why older adults do not have access to the justice system is the lengthy amount of time it takes to resolve a court case. This is especially troublesome for long-term care residents who are often in declining health. According to Justice Winkler, "civil litigation in this province is too expensive and too slow, with the result that many people in Ontario may be denied access to justice."⁴¹ Many older adults choose not to initiate legal proceedings, even if their case appears to be meritorious, because it may take many years and there is the possibility that they may die before a resolution is reached. In fact, this is a strategy used by defendants: stall the process because the plaintiff may die before any resolution, usually resulting in the nullification of the claim.

Fourth, older adults are reluctant to pursue a civil case because there is a lack of an established body of law respecting lawsuits against retirement and long-term care homes. Based on our own research, ACE could find very few reported cases involving actions against long-term care homes or retirement homes by residents.

Fifth, an extra disincentive for older persons in seeking access to justice is the lack of monetary awards in successful cases. ACE generally does not recommend that older adults commence lawsuits where they are primarily seeking financial compensation because very few types of damages options are available and the amounts awarded are small.

Actions for wrongful death are not permitted in Ontario. If an older adult were to die, dependents of the older adult could only bring a derivative action for the loss of care and companionship pursuant to the *Family Law Act*.⁴²

Older persons usually cannot claim damages for loss of income because they are no longer working. As well, the courts have narrowly interpreted damages for loss of companionship. In a British Columbia case where a 77-year old woman died due to the negligence of an aide in a nursing home, the court refused to award any damages to the woman's children because "their mother had long ceased to be a companion for she had been physically, mentally and emotionally incapacitated for a considerable time before her death."⁴³ This judgment is alarming as it infers that a person can harm an older person with impunity and not be held accountable by the civil justice system.

Criminal Penalties

Alleged perpetrators of crimes against older adults can be charged with a myriad of offences under the *Criminal Code of Canada*. There are several provisions applicable in cases of possible abuse of older adults, including: theft; theft by a person holding a power of attorney; criminal breach of trust; extortion; forgery; fraud; failure to provide the necessities of life; criminal negligence causing bodily harm; assault; sexual assault; forcible confinement; criminal harassment; uttering threats; intimidation; and harassing phone calls.

There are challenges in using the criminal justice system to seek redress for crimes that take place in congregate settings. Staff at a congregate setting may fail to identify that a crime has occurred and, consequently, fail to report incidents to the police. Some operators may choose to address an issue internally as a matter of staff discipline because they do not want the adverse publicity that may result from criminal proceedings. If staff do report the alleged crime, the police

may not understand the institutional environment or the rules and regulations that apply in these settings. This lack of knowledge may hamper the appropriate investigation of crimes. Police may be uncomfortable in investigating alleged crimes within a facility as they may have limited understanding and appreciation of mental capacity and physical disability and how this may impact on the ability of witnesses to testify and make statements. The police may assume that a resident lacks capacity when in fact that person, although cognitively impaired or diagnosed as having Alzheimer's disease or a related disorder, may still retain the capacity to be an effective witness. Even if they lay charges, the police may face the challenge of a reluctant Crown attorney who feels there is insufficient evidence to proceed to a successful prosecution, despite the results of the police investigation.

For older adults, delays in the administration of justice can mean that the victims are deceased or incapable by the time their case goes to trial. In a Supreme Court of Canada decision, *R. v. Khelawon*, the manager of a retirement home was accused of assaulting five different residents.⁴⁴ By the time of trial, four of the victims had died, and the remaining victim was incapable of testifying because he was no longer competent. This delay ultimately resulted in an acquittal for the accused. Since none of the victims were able to testify on their own behalf, the only form of evidence consisted of videotaped statements made by the victims after the assaults, which were later ruled inadmissible in court. The Supreme Court upheld this decision on appeal from the Crown because of the unreliability of the videotaped statements.

R. v. Campoli was another case where charges of assault against an elderly person were difficult to pursue because the victim was not able to testify on her own behalf.⁴⁵ Here, a personal support worker employed at a retirement residence was accused of assaulting an elderly woman under his care. By the time the case went to trial, the victim had passed away. The Ontario Court of Justice held that a videotaped statement made by the victim some three weeks after the first allegation was hearsay and therefore inadmissible in court. This case has not yet been resolved, so it remains to be seen whether there is sufficient evidence for a conviction to be obtained without the victim's testimony.

Informed Consent

Ontario has comprehensive legislation, namely the *Health Care Consent Act, 1996*⁴⁶ and *Substitute Decisions Act, 1992*,⁴⁷ governing decision-making for all people in the province. The law requires that health practitioners obtain informed consent to treatment from all individuals who are capable. Where the person is incapable, informed consent must be obtained from the person's substitute decision-maker. However, these requirements continue to be ignored and are

often the focus of complaints at ACE by both residents and their substitute decision-makers. We are frequently contacted by substitute decision-makers who have discovered that a mentally incapable person has been given a medication about which the substitute decision-maker knows nothing, and it is often not until they call us do they learn of the health practitioner's legal obligation to obtain informed consent prior to commencing treatment. This scenario is more common in long-term care homes as the substitute decision-maker may not be aware of or present during the resident's appointment with the physician who provides care to the home, whereas in the community, the older adult often would have been accompanied by the substitute decision-maker.

Usually, but not always, the complaints are about the prescribing of antipsychotic medication, which have the potential for serious side-effects or may, in fact, be contraindicated for use in the elderly. Antipsychotic drugs were initially developed in the 1950s to treat conditions such as schizophrenia but have become widely used in long-term care homes to manage behavioural disturbances and agitation associated with dementia. By 2000, in addition to the known side-effects (e.g., sedation, falls and hip fractures, cardiac complications, weight gain, metabolic complications, neuroleptic malignant syndrome and cognitive decline), studies showed that the use of antipsychotic medications for older adults with dementia is associated with a slight increase in the risk of death.⁴⁸ The United States Food and Drug Association and Health Canada subsequently issued regulatory warnings, with the Food and Drug Association also requiring certain medications to be packaged with a "black box" warning describing the risks associated with use of these medications to treat dementia in the elderly.⁴⁹

According to the Canadian Institute for Health Information, in 2006-2007, 37.7% of residents residing in long-term care homes on public drug programs were prescribed antipsychotics versus only 2.6% of older adults living in the community.⁵⁰ During this same time period, 52.2% of residents with claims for anti-dementia drugs also had claims for atypical antipsychotics, compared to 21.3% of older adults living in the community. As a result:

The higher rate of antipsychotic use among seniors using anti-dementia drugs in nursing homes may suggest that there are factors in addition to differences in prevalence of dementia that contribute to variation in the rates of antipsychotic use.⁵¹

Studies indicate that older adults residing in long-term care homes in Canada are more likely to use atypical antipsychotics than those living in the community. The data from the studies of Hagen *et al.* and Conn *et al.*, suggest that "Canadian rates of antipsychotic use in long-term care facilities may be among

the highest in the developed world.”⁵² It was also noted by Hagen *et al.* that there is a tendency to keep residents on antipsychotics once they are taking antipsychotics. This is despite the fact that the risk of side-effects rises dramatically over time and other studies have demonstrated that the majority of long-term care residents receiving antipsychotics for behavioural problems can have these medications safely and effectively withdrawn without an increase in difficult behaviours.⁵³ Bronskill *et al.* found that a quarter of residents were prescribed antipsychotic agents within a year of admission.⁵⁴ Further, 86% of residents were prescribed neuroleptic medications without any specialist contact while 10% of the neuroleptic therapies were dispensed at a dose higher than the recommended threshold.⁵⁵ Rochon *et al.* found that residents with a diagnosis of psychoses or dementia were the most likely to be given antipsychotic therapy if they lived in a facility with a high antipsychotic prescribing rate. In the words of the researchers:

These results suggest that antipsychotic therapy is not being prescribed based on their clinical indication. Rather, the decision to prescribe an antipsychotic therapy appears to be related to the nursing home environment, with some environments being more permissive about antipsychotic use.⁵⁶

Many long-term care homes routinely fail to obtain consent to treatment at all. Other homes attempt to obtain “blanket” consents at the time of admission which purportedly apply to all treatments that might be prescribed during the course of their stay. This is not legal as it in no way meets the requirements of “informed” consent as defined by the *Health Care Consent Act*.⁵⁷ In some homes, treatment will be started, and some time thereafter a staff member will contact the substitute decision-maker to “advise” them that the resident is now taking the medication, leaving no option open for “consent.”

In addition to the requirements of consent, the current legislation governing long-term care homes requires a resident’s plan of care to be reviewed at least quarterly by the multidisciplinary team.⁵⁸ The licensee of the home has an obligation to ensure that the resident and, where applicable, their substitute decision-maker, have an opportunity to participate.⁵⁹ Care conferences are an important right as they are often the only time that the resident and/or their substitute decision-maker are provided with information about the resident’s care and given an opportunity to ask questions. According to the Ontario Health Quality Council, only two-thirds of residents and their family or friends were encouraged to be involved in decisions about the resident’s care. The rest were not encouraged, or only occasionally, to get involved.⁶⁰

Complaints against Regulated Health Professionals

If a capable person or their substitute decision-maker wishes to hold a regulated health care practitioner accountable for their failure to obtain valid consent, a complaint must be made to the regulated profession responsible for overseeing the particular health profession (e.g., College of Physicians and Surgeons of Ontario and College of Nurses).

It is ACE's experience that the complaints process is lengthy and, if legal counsel is retained, expensive. Some of our clients opt not to make a complaint because it will take too long to address a problem that needs to be addressed immediately.

In the past, ACE represented a substitute decision-maker in a case where a physician in a long-term care home prescribed a medication to a resident without obtaining consent. The physician claimed it was standard practice in nursing homes throughout Canada to make treatment decisions and to let the staff at the home "inform" the family of the treatment after the fact. A complaint was made to the College of Physicians and Surgeons of Ontario and the decision of the Complaints Committee was appealed to the Health Professions Appeal and Review Board on two occasions. Eventually, the Committee obtained an expert opinion confirming "it is a long-standing practice for physicians to give orders for patients' medications, and for families, if they have concerns, to discuss these with the attending physician (albeit after the fact of the medication having been prescribed)." Neither the Committee nor the Board disagreed with this opinion, despite what we would argue would be a blatant disregard for the law. Therefore, it can be concluded that even regulatory colleges and administrative tribunals may not promote compliance or enforcement of the existing law.⁶¹ However, it must be emphasized that this case should not stand for the proposition that the requirement for consent should be changed. Instead, it flags the need to look at how the regulatory Colleges ensure compliance with the law, how basic requirements for consent are being operationalized within health facilities and whether the lack of compliance within settings, such as long-term care homes, are reflective of institutionalized discrimination on the basis of age and disability.

It should be noted that the workers who provide the bulk of the hands-on care in long-term care and retirement homes are personal support workers (also known as health care aides). These workers are not regulated and must work under the supervision of a regulated health professional, which is usually a registered nurse. Therefore, when issues arise regarding the quality or competency of these staff members, the only way to bring a College complaint is to bring it against the supervising staff member. While they are ultimately responsible, it is

often felt not to be appropriate to take action against this person. It also means that it is difficult to hold unregulated staff members accountable for their actions, as there is no independent College to complain to, and the institutions themselves are often reluctant or unable to properly discipline these employees.

Finally, the legislation governing long-term care homes requires that consent be obtained.⁶² It would therefore appear that the lack of informed consent could be the basis for complaint to the Ministry of Health and Long-Term Care and be enforceable by their compliance advisors. This would be a quicker and potentially more effective way of dealing with the issue. However, our experience has been that despite this statutory requirement, the standard response is that it should be dealt with by the various professional Colleges.

Consent and Capacity Board Proceedings

Individuals who have been found incapable with respect to treatment, property, personal health information and admission to long-term care may apply to the Consent and Capacity Board to challenge these findings. For persons found to be treatment incapable who are not in-patients at psychiatric facilities, rights information is supposed to be provided to them. Health care practitioners have an obligation to provide information to the incapable person in accordance with the requirements set out by their profession's governing body.⁶³ There are no legislative requirements for any specific paperwork to be completed.

Unfortunately, many health care practitioners fail to satisfy even the minimal requirement of providing rights information to individuals: residents are not informed when they are found incapable nor are they made aware of their statutory rights and the procedures available to exercise these rights.

There are also problems with the policies of the various health Colleges respecting rights information. By requiring health practitioners to follow the policies of their Colleges, they could be subject to discipline proceedings if they fail to provide rights information. However, the policies of the Colleges do not necessarily ensure that the patient would have the information necessary for the purpose of due process. As well, it is questionable as to whether the Colleges enforce this requirement or discipline practitioners who fail to comply.

One illustration of this problem is the rights information policy of the College of Physicians and Surgeons. Physicians are directed by the College of Physicians and Surgeons of Ontario to inform the incapable person that a substitute decision-maker is responsible for making treatment decisions.⁶⁴ Where the patient disagrees with the need for a substitute decision-maker or disagrees with the involvement of the present substitute, the physician "must advise the patient

of his or her options” which “include finding another substitute of the same or more senior rank, and/or applying to the Consent and Capacity Board for a review of the finding of incapacity.”⁶⁵ A physician has a duty to “reasonably” assist the patient if he or she expresses a wish to exercise these options. This policy does not go far enough to ensure that the alleged incapable person can exercise their rights or that the patient is informed of the process to challenge the finding of incapacity. The policy is too narrow, as it suggests that the physician does not have a duty to provide patients with information about their rights before the Board if they disagree with the finding of incapacity (as opposed to having a substitute decision-maker) or if they do not explicitly voice their disagreement.

The *Health Care Consent Act* contains similar requirements for consent to admission to a long-term care home. However, it does not specifically require evaluators, a specified category of health practitioners, to provide rights information to the individuals they find incapable of consenting to admission a care home.⁶⁶ The practice of most evaluators is to give a rights information sheet to incapable individuals, although the information may be unclear and misleading. There is no guarantee that the person will be assisted by the evaluator in obtaining legal assistance or contacting the Consent and Capacity Board to initiate the process to challenge the finding of incapacity.

Statistics obtained from the Consent and Capacity Board indicate that only 61 people in 2007 and 81 people in 2008 had a hearing to dispute the finding of incapacity respecting admission to long-term care.⁶⁷ Considering that there are approximately 76,000 long-term care residents in the province and such a small number of applications, it leads us to speculate that many older adults are not receiving rights information.

Office of the Public Guardian and Trustee

According to its website, the Office of the Public Guardian and Trustee “delivers a unique and diverse range of services that safeguard the legal, personal and financial interests of private individuals and estates.”⁶⁸

Included amongst its responsibilities is a statutory duty to investigate any allegations that a mentally incapable adult is suffering, or at risk of suffering, serious adverse effects.⁶⁹ It has been ACE’s experience, however, that the Public and Guardian and Trustee has interpreted its duties very narrowly, saying it is an “service of last resort,” and does not use its authority to intervene and investigate often enough. Friends, family members and health practitioners concerned about the welfare of an older person often call ACE in frustration after being told by the Public Guardian and Trustee that an investigation will not be completed. These people often feel powerless to help the older person because one of their few legal

options is to make a court application for guardianship. This is a lengthy and expensive process which is inaccessible for the average person.

Landlord and Tenant Board Hearings

Pursuant to the *Residential Tenancies Act*, residents of retirement homes can file an application with the Landlord and Tenant Board to dispute certain actions of the landlord. For instance, if there is no written tenancy agreement, or if the agreement does not set out what has been agreed to for care services and meals, the tenant can file an application with the Board for an abatement of rent.

ACE has been involved in several cases where homes ostensibly appear to satisfy the statutory criteria to be a care home but they do not self-identify as such. Consequently, these homes do not abide by the special provisions in the *Residential Tenancies Act* governing care homes, meaning residents are either not made aware of their rights or are denied their legal entitlements.

One of the protections enshrined in the *Residential Tenancies Act* is the obligation on the landlord of the retirement home to give the new tenant a copy of a “care home information package” (also known as a CHIP) before entering into a tenancy agreement.⁷⁰ If the landlord does not provide the care home information package, the landlord cannot increase the rent or any charges for meals or care services until the required information is given to the tenant.⁷¹

While it is laudable that landlords are required to provide a CHIP, it is logical to assume that if the residents are not given a CHIP, they would not be made aware of their rights under the law, such as the aforementioned abatement of rent application. Further, if the landlord does not comply with this simple legal requirement, one wonders whether they would be in compliance with others.

Residents are often intimidated by the landlord and fear that they will be viewed as a trouble-maker or asked to leave the retirement home if they challenge the landlord. They will therefore not attempt to enforce their rights as they are afraid of the possible implications if they do so. While retirement home residents cannot be evicted without due process, they are often led to believe they can be, and residents are sometimes threatened with immediate eviction or they witness the unlawful eviction of a fellow tenant.

Another requirement under this legislation which is unique to care homes is that residents can be “transferred” from a care home if they no longer need the care required or where their needs are higher than the level the home provides. However, the landlord cannot do this unilaterally: they must obtain an order from the Landlord and Tenant Board. There have only been a small number of these

applications – 12 since June 1998 – to the Board.⁷² Regrettably, it is all too common for landlords to tell residents they have to leave, or to refuse to allow residents to return from hospital, telling them they have been “discharged”, without going to the Board. Residents, as well as hospital staff and other professionals, are often unaware that care homes cannot simply refuse to have residents return, or that they cannot discharge without lawful authority, and therefore simply comply with whatever they are told.

Human Rights Complaints

A person who believes they have been discriminated against on the basis of an enumerated ground(s) in the *Human Rights Code* can file a complaint with the Human Rights Tribunal of Ontario where the discrimination occurs with respect to employment, housing, contracts, services, goods or facilities.

The human rights system was overhauled in June of 2008. Previously, discrimination claims were made to the Ontario Human Rights Commission which investigated complaints before making a decision whether or not to refer the case to the Tribunal. Long delays ensued and it was not uncommon for complaints to take in excess of five years to be determined. Consequently, ACE would not normally recommend that its clients file human rights complaints due to the inordinate delay and the reality that many of our clients would not live to see a resolution. ACE has had little experience with the new system so we are unable to comment on its effectiveness at this point in time.

Community Care Access Centres

A Community Care Access Centre (CCAC) is a non-profit agency, funded by its Local Health Integration Network (LHIN) through the Ministry of Health and Long-Term Care. It is responsible for providing eligible people in a particular geographic area with publicly-funded in-home and community care, as well as to manage the placement process for those requiring long-term care homes. There are 14 CCACs in Ontario and there is no user fee for their services. With regards to long-term care homes, CCACs perform the following functions: completes applications; determines eligibility for admission; authorizes admission; maintains the waiting list for admission to all long-term care homes; and offers placement in the homes.

While outside the purview of our paper, it is important to note that complaints about the placement process are one of the most common calls that we receive at ACE. While the process would appear to be heavily regulated, issues arise daily regarding the actions of both the CCAC and the hospital. The present apparent lack of long-term care home beds, as well as hospital overcrowding,

has led to continued problems in the placement sector which often results in the failure to ensure that the applicant's rights are being respected.

ACTION Line, Compliance and Enforcement in Long-Term Care Homes

The Ministry of Health and Long-Term Care operates a telephone service, known as the ACTION Line, primarily for residents of long-term care homes to report any concerns about their care and the services provided by the long-term care home. Between 2004 and 2008, 19,347 calls were made to the ACTION Line.⁷³ An operator assesses the urgency of the situation and forwards the information to a compliance adviser to complete an investigation. Between 2004 and 2008, 2,895 calls to the ACTION Line were referred to a compliance advisor.⁷⁴ The Ministry also conducts regular annual reviews of all long-term care homes.

ACE is regularly advised by its clients about problems with the Ministry's investigation process, including the following:

- The failure to investigate allegations;
- The inability to conduct a proper investigation and substantiate a claim;
- The inconsistent quality of investigation by individual compliance advisors; and
- The inability of compliance advisors to make a determination about the complaint.

In our practice, ACE has heard about residents who do not have calls returned by the ACTION Line. Furthermore, we are aware of some situations where compliance advisors will not intervene despite the importance of the issue to the resident and the lack of options available to the resident, claiming that the Ministry does not provide assistance for the specific type of issue. For instance, access to residents (visits) is sometimes prohibited by the care providers on the instructions of a third party, despite the existence of the Resident's Bill of Rights which states: "Every resident has the right to communicate in confidence, to receive visitors of his or her choice and to consult in private with any person without interference."⁷⁵ While a third party may have some legal authority to make decisions for the person through a power of attorney or other legal mechanism, these powers are not all-encompassing. The capacity to decide who may visit or what contact an older person may wish to have is one that may remain intact long after other types of capacity have been lost. A senior may continue to enjoy contact with relatives and acquaintances long after the senior has stopped being able to manage property, to make treatment decisions or to retain recent memory. The comfort derived from human contact is a very basic comfort which can have a large impact on an individual's quality of life, and

requires a low level of capacity-making ability. Even where the person lacks this capacity, there may be nobody with the authority to prevent visitors from attending, as this is not an area for which there is always statutory authority to make a decision. However, if the visitor is harming or attempting to harm the resident, a guardian or attorney for personal care may have authority to restrict visitors under their authority to make “safety” decisions in the *Substitute Decisions Act*. Despite the restrictions on substitute decision-makers in making such decisions, and the right of a resident to have visitors, compliance advisors will generally refuse to take action when this issue is brought to their attention.

It should also be understood that most complainants do not receive a copy of the detailed report of the results of the investigation. The information provided to the complainant is usually only whether the complaint was verified, not verified or unable to verify and perhaps a little information about what may have been done to correct the issue. To obtain a copy of the detailed report, one must make a formal freedom of information request.

The Ministry makes it mandatory for long-term care homes to post their inspection reports in a public place in the home.⁷⁶ While potential residents and their families are entitled to receive a copy of the inspection report from the home upon request, they often meet with resistance in exercising this right. The Ministry also posts general information about those reports on its website and encourages those considering admission to a long-term care home to check the reports. Many people are unaware of the existence of the website, nor are they advised that the information is only a small snapshot at the point in time when the inspection was conducted, and is not the detailed inspection report which is, in fact, publicly available. Older adults grew up in a different technological generation and many are not accustomed to using the internet or other electronic resources.

According to information from the Ministry itself, there is “considerable evidence that the current compliance system is not meeting public expectations for ensuring safety and well-being of our seniors.”⁷⁷ A study by the Canadian Press analyzed inspection reports from April 2007 to March 2008 and found that almost three-quarters of homes were not meeting provincial standards.⁷⁸ At one home, it was reported that were 16 residents who had restraints applied incorrectly. Despite this, potential residents and families looking for homes are often pressured to apply for admission to homes with lengthy lists of unmet standards and criteria, citations under the legislation, and verified complaints. Residents of homes with these lengthy lists of violations continue to have to reside there. Even when homes are closed to admissions because of serious deficiencies, residents continue to have to reside in these homes.

Recognizing the need to improve the current system, coupled with the new *Long-Term Care Homes Act, 2007* the Ministry is in the process of transforming its compliance inspection program. The Ministry claims that the new inspection process will be resident-outcome focused rather than process driven. Compliance inspectors will gather information through interviews with residents and family members, as well as visual observations. Information will be collected using clinically validated survey methodology. Inspectors will not be continuing their current practice of inspecting against the more than 400 standards which exist.⁷⁹ Until this process is in place, ACE can not comment on the effectiveness of this system.

Section 25(1) of the *Nursing Homes Act* requires that any person other than a resident who believes that a resident has or may suffer harm as a result of unlawful conduct, improper or incompetent treatment or care or neglect must report it to the Director. While the *Homes for the Aged and Rest Homes Act* and the *Charitable Homes Act* do not include a similar section, reporting is required in those homes as a matter of Ministry of Health and Long-Term Care policy. There is to be no penalty against someone who makes such a report unless it is done maliciously or without reasonable grounds.⁸⁰ This applies to both employees of the home as well as visitors. Unfortunately, this requirement is unknown to most staff and visitors. Despite regulations to the contrary, there are often repercussions against those who have made complaints. Employees have reported being fired, contractors have had their contracts terminated, and family members have been barred from homes for making complaints. In our experience, the Ministry has not taken steps to rectify these situations. Furthermore, in cases where family members are barred by the home under the *Trespass to Property Act*, the Ministry has not acted, although such restrictions do not have a solid legal basis.⁸¹

Complaints Response and Information Service (CRIS Line)

The Ontario government provides funding to the Ontario Retirement Communities Association (ORCA), a voluntary trade organization that sets professional operating standards and accredits retirement residences, to maintain a hotline described as a “Complaints Response and Information Service” (otherwise known as the CRIS Line). Tenants may call to get information about retirement homes services and accommodation options and to obtain help resolving complaints about a retirement home. If complaints against particular homes are not resolved, the date of the complaint, the name of the home, and information as to the nature of the complaint may be posted on the ORCA website. Since its inception on September 1, 2000, the CRIS line has not had any unresolved complaints.⁸²

While the funding for the CRIS Line requires it to attempt to resolve complaints about both ORCA and non-ORCA homes, ORCA does not have the authority to force non-member homes to change in response to complaints. Member homes may be threatened with loss of membership if they fail to comply with ORCA standards. Older adults who know about and have used the CRIS Line have expressed concerns to ACE that it is not independent as it is operated by an industry organization.

Based on our focus groups with residents and conversations with clients, many older adults do not seem to know about the existence of the CRIS Line.

Ombudsman of Ontario

The Ombudsman does not presently have jurisdiction over hospitals and long-term care homes although he does have authority over government services and the actions of government employees. Thus, if residents of long-term care homes or their representatives are dissatisfied with the way in which the Compliance Adviser or the Ministry of Health and Long-Term Care deals with their issue, a complaint can be made to the Ombudsman of Ontario.

At present, the Ombudsman's Special Ombudsman Response Team (SORT) is reviewing the ability of the Ministry of Health and Long-Term Care to monitor long-term care homes and its effectiveness in ensuring the homes meet government standards. This report is due at the end of the summer 2009.

Information and Privacy Commissioner of Ontario

Any person can seek assistance from the Information and Privacy Commissioner if there are issues regarding privacy or access to personal health information. Some examples where recourse may be sought from the Information and Privacy Commissioner include: a breach of a resident's privacy (e.g., a hospital gave personal information to a third party without consent); refusal by a long-term care home to allow the resident or their substitute decision-maker access to the resident's records; and cost issues involving access of resident's records.

One of the overarching purposes of the *Personal Health Information Protection Act* is to provide individuals with a right of access to their personal health information. However, it is our experience at ACE that the public either does not know about the existence of the *Personal Health Information Protection Act* or that it is not well understood (by either health information custodians or the public), leading to a misunderstanding of the law. People are often not advised of their legal rights and, in fact, face numerous barriers when they attempt to do anything connected to their records of personal health information. It is very

common for residents and their substitute decision-makers to be denied access to the resident's health records because of an utter lack of knowledge by the employees of that institution of the rights and requirements under the *Personal Health Information Protection Act*.

As previously discussed, since health practitioners consistently fail to obtain informed consent or even inform older adults about their treatment, it is crucial that they have easy access to their own information.

Another barrier, especially for older adults on a fixed income, is the cost of obtaining copies of health records. Many institutions charge a cost recovery fee for providing access to an individual's personal health record (although the legislation specifically permits a custodian to waive all or part of the fee associated with an access request). The amount being charged varies widely across the province. Clients of ACE, for example, have been asked to pay as much as \$150 for a few pages.

Such discrepancies prompted Ann Cavoukian, the Information and Privacy Commissioner, to ask the government to address the issue of fees through regulation. The Ministry of Health and Long-Term Care published a proposed regulation concerning fees, as well as other matters, in the Ontario Gazette on March 11, 2006. To date, however, there is no regulation in place. The Office of the Information and Privacy Commissioner has mediated several complaints regarding the excessive fees being charged to obtain copies of health records. Generally, the matters were resolved and the parties agreed to pay 20 cents per page for a copy of the record. While residents can ask the Information and Privacy Commissioner to decide whether a fee is reasonable or not, they must be aware of this mechanism and be willing to go through the process.

Residents' Bill of Rights

Upon admission to a long-term care home, a person or their substitute decision-maker must be provided with a copy of the Residents' Bill of Rights. This document is part of the law governing long-term care homes.⁸³ The 19 enumerated rights are as follows:

- Every resident has the right to be treated with courtesy and respect and in a way that fully recognizes the resident's dignity and individuality and to be free from mental and physical abuse;
- Every resident has the right to be properly sheltered, fed, clothed, groomed and cared for in a manner consistent with his or her needs;

- Every resident has the right to be told who is responsible for and who is providing the resident's direct care;
- Every resident has the right to be afforded privacy in treatment and in caring for his or her personal needs;
- Every resident has the right to keep in his or her room and display personal possessions, pictures and furnishings in keeping with safety requirements and other residents' rights;
- Every resident has the right,
 - to be informed of his or her medical condition, treatment and proposed course of treatment,
 - to give or refuse consent to treatment, including medication, in accordance with the law and to be informed of the consequences of giving or refusing consent,
 - to have the opportunity to participate fully in making any decision and obtaining an independent medical opinion concerning any aspect of his or her care, including any decision concerning his or her admission, discharge or transfer to or from a nursing home, and
 - to have his or her records of personal health information within the meaning of the *Personal Health Information Protection Act, 2004* kept confidential in accordance with the law;
- Every resident has the right to receive reactivation and assistance towards independence consistent with his or her requirements;
- Every resident who is being considered for restraints has the right to be fully informed about the procedures and the consequences of receiving or refusing them;
- Every resident has the right to communicate in confidence, to receive visitors of his or her choice and to consult in private with any person without interference;
- Every resident whose death is likely to be imminent has the right to have members of the resident's family present twenty-four hours per day;
- Every resident has the right to designate a person to receive information concerning any transfer or emergency hospitalization of the resident and where a person is so designated to have that person so informed forthwith;
- Every resident has the right to exercise the rights of a citizen and to raise concerns or recommend changes in policies and services on behalf of himself or herself or others to the residents' council, nursing home staff, government officials or

any other person inside or outside the nursing home, without fear of restraint, interference, coercion, discrimination or reprisal;

- Every resident has the right to form friendships, to enjoy relationships and to participate in the residents' council;
- Every resident has the right to meet privately with his or her spouse in a room that assures privacy and, where both spouses are residents in the same nursing home, they have a right to share a room according to their wishes, if an appropriate room is available;
- Every resident has a right to pursue social, cultural, religious and other interests, to develop his or her potential and to be given reasonable provisions by the nursing home to accommodate these pursuits;
- Every resident has the right to be informed in writing of any law, rule or policy affecting the operation of the nursing home and of the procedures for initiating complaints;
- Every resident has the right to manage his or her own financial affairs where the resident is able to do so, and where the resident's financial affairs are managed by the nursing home, to receive a quarterly accounting of any transactions undertaken on his or her behalf and to be assured that the resident's property is managed solely on the resident's behalf;
- Every resident has the right to live in a safe and clean environment; and
- Every resident has the right to be given access to protected areas outside the nursing home in order to enjoy outdoor activity, unless the physical setting makes this impossible.

Although the *Long-Term Care Homes Act, 2007* contains 27 rights in the Bill of Rights, there are very few areas of substantial change. Instead, rights which already existed or were expressed in another form were included or expanded upon in the Bill of Rights.

A licensee is deemed to have entered into a contract with each resident of the home, agreeing to respect and promote the rights of the resident.⁸⁴ Unfortunately, there are no concrete enforcement mechanisms available to the resident in the legislation. The *Long-Term Care Homes Act, 2007* stipulates that "a resident may enforce the Residents' Bill of Rights against the licensee as though the resident and the licensee had entered into a contract under which the licensee had agreed to fully respect and promote all of the rights set out in the Residents' Bill of Rights."⁸⁵ It also states that regulations can be passed

governing how rights set out in the Bill of Rights shall be respected and promoted by the licensee, but is unclear whether there will be any such regulations.⁸⁶

Many administrators and operators are supportive of the Bill of Rights but they express concerns about its interpretation in a collective environment where many residents are living together. How are the rights of an individual to be interpreted in relation to the collective when individual actions may impact on the group and vice versa? Homes have a legal duty to respond to the care needs of all residents but are challenged to do so by funding and staff limitations. When complaints are made to homes about the lack of appropriate care, they are told that is “just the way things are,” or that they do not receive enough funding to provide appropriate care.

Some of the rights involve a degree of subjectivity, such as the right to be treated with dignity and respect. Residents may interpret the rights in a different manner than staff, as they are interpreting these rights through the lens of the long-term care home being their “home.” Meanwhile, staff may have a different view as the long-term care home is their workplace. For instance, one of the rights of residents is to know who is providing them with care but it is not unusual for this request to be refused. Another manifestation of the subjectivity of the interpretation of the Bill of Rights is when residents sometimes encounter difficulties regarding their right to have visitors without interference. As noted earlier in this paper, homes will, on occasion, issue trespass notices against residents’ visitors without lawful authority, usually because the visitor is considered to be too demanding or a “complainer.” ACE lawyers have also frequently had difficulty meeting in private with residents or are questioned about the purpose of their visit by staff members.

Although meant to protect and create a culture within a long-term care home, many of the rights are challenging to enforce in practice.

Residents’ and Family Councils

The majority of long-term care homes have a Residents’ Council. The current legislation says the home must assist residents to create a council if a request is made.⁸⁷ If there is no residents’ council, the home must hold a meeting at least annually to advise the residents of their right to form a council.⁸⁸ Under the new legislation, each home will be required to establish a Residents’ Council.⁸⁹

Residents’ Councils in long-term care homes have legislated powers, including:

- Advising residents respecting their rights and obligations;

- Reviewing certain documentation of the home, such as financial information;
- Attempting to mediate and resolve disputes between residents and a licensee; and
- Reporting any concerns or recommendations to the Minister.⁹⁰

An increasing number of homes have active Family Councils. Although Family Councils are not mentioned in the current legislation, this will change once the *Long-Term Care Homes Act, 2007* is enacted and they will have powers similar to Residents' Councils.⁹¹

The administration and staff at many homes view both these Councils as having a significant function in bringing issues to their attention. While they serve an important role, their actual authority is limited. For instance, Residents' Councils have the legislative authority to report concerns or bring recommendations to the Minister⁹² but this does not appear to happen in practice.

The power and success of a Council is dependent upon several factors, including the level of engagement of its members and the willingness of the home to listen. Residents Councils are also dependent upon the staff that assist them.

Based on information received from industry stakeholders at our focus group, some, but not many, retirement homes have Residents' Councils and none, or very few, have Family Councils.

Patient Representatives or Advocates

Some hospitals, long-term care homes and retirement homes will hire patient advocates to assist patients and residents. One must be wary of this type of advocate because their objectivity may be compromised as they are paid by the institution itself. Furthermore, many of these advocates would appear to have no power and are there merely to placate those who complain when problems arise. Although these advocates can be a source of support and assistance, where there are real difficulties involving serious conflicts with the institution, it is unlikely that they will be able to advocate as strongly as most people would like, or as strongly as an advocate who is not connected with the institution due to a potential conflict of interest. In fact, we have had cases where the patient advocate has threatened the patient on behalf of the hospital!

An increasingly large number of older persons or their substitute decision-makers contact ACE with respect to first available bed policies. Essentially, these policies attempt to force hospital patients or their substitute decision-makers to accept placement at a long-term care home they would not have chosen had it

not been forced upon them, contrary to the *Health Care Consent Act* and the long-term care legislation.⁹³ Although employees of Community Care Access Centres are legally responsible for the placement process, in most instances, the hospital also has a social worker or discharge planner who is the older adult's primary contact regarding placement. One must appreciate that these people are hospital employees who are expected to enforce hospital policy, whether or not it is lawful. Although it is possible that patient advocates assist patients to contest these unlawful first available bed policies, this is generally not ACE's experience.

Legal Clinics and Advocacy Organizations

Legal Aid Ontario funds 79 legal clinics located in communities across the province whose mandate is to provide poverty law services to low income residents of Ontario. Although only one legal clinic, ACE, specifically focuses on the representation of older adults, a number of other general legal clinics provide assistance to residents of congregate settings living within their catchment area. However, these general clinics have a high demand for service in their core practice areas (e.g., landlord and tenant and social assistance law) so the amount of time they can spend on issues affecting older adults is restricted.

Although ACE has some cross-provincial jurisdiction, its funding is limited. ACE is only funded for eight staff and has insufficient resources to provide comprehensive representation to people outside the Greater Toronto Area. Demand for individual services greatly outstrips resources. ACE's ability to offer education sessions to groups beyond Toronto is dependent on the group covering out-of-pocket expenses to permit ACE staff to travel to a particular location. ACE also receives many calls for assistance on legal issues that are not limited to congregate settings and cannot devote all our resources to only these matters.

In addition to ACE, a small number of advocacy organizations for residents exist across the province. Perhaps the most well-known organization is Concerned Friends of Ontario Residents in Long-Term Care Facilities. Founded in 1980, Concerned Friends is dedicated to the reform of the long-term care system and improvement of quality of life for residents. The organization is supported by membership and donations without government funding and its activities are undertaken entirely by volunteers.⁹⁴

Over the years, Concerned Friends has been influential in having resident-centred amendments added to the long-term care legislation. They advocated for the creation of ACE, Residents Councils and Family Councils, as well as the mandatory posting of compliance review reports in each home. Concerned

Friends also reviews all compliance review reports and prepares report cards analyzing the overall performance of long-term care homes.⁹⁵

Concerned Friends is hampered by its small size and lack of permanent funding in respect to the scope of assistance and advocacy it can perform. Its focus is also limited to long-term care issues, not issues impacting residents in retirement homes or hospitals.

Common Concerns from Focus Group Participants

ACE heard several common concerns during our meetings, not only from residents of retirement homes and long-term care homes, but from their representatives and stakeholders in the industry. Many of these concerns were overlapping and interrelated. The identification of some of these issues provides a better understanding of the problems facing older adults and highlights the necessity of effective access to justice mechanisms.

It should be emphasized that the majority of residents who attended our meetings expressed general satisfaction with the retirement or long-term care home where they resided. This is consistent with a recent study by the Ontario Health Quality Council where one out of nine residents felt they were not free to speak to staff when they were unhappy with care.⁹⁶ Having said that, the people who attended our focus groups tended to be the more competent and vocal residents, as opposed to the incapable and non-verbal residents who are at an increased risk of having their rights ignored. Further, as many residents were unaware of their rights, they were not aware that their rights were being infringed: in fact, they believed that they lost many of their rights upon admission to long-term care.

Resident and Family Concerns

The following section will outline, in no particular order, some examples of resident and family concerns.

a) *Power Imbalance*

The power imbalance between older adults and the staff or health care providers in congregate settings is one of the most significant factors contributing to an environment where older people are reluctant to complain and seek justice. Residents are “captives” of the home in which they live: that is, they cannot do without the help that is provided, have little or no say about who provides that care, and cannot leave and go elsewhere if they are unhappy with the care they

receive. We heard from residents at our focus groups that they do not complain due to fear of retribution by staff members and concerns about eviction. Also, residents expressed a reluctance to “make a fuss” or “cause trouble.” Some residents feared they would be “evicted” from the retirement home or long-term care home if they did not comply with the “rules.” In our experience, older generations tend to be more deferential to authority figures while newer generations are less inclined to be so and they feel entitled to assert their rights. For instance, residents advised that their children often want to complain to outside parties or write demand letters, while their mothers or fathers do not want to “rock the boat.”

b) *Family/Friend Involvement*

Long-term care home residents advised us that they need to enlist the involvement of family or friends in their life to observe and liaise with staff, as well as to ensure compliance with the law. One resident told us that her questions and concerns go unanswered but the home will respond to her daughter’s e-mails. Family members explained that, in their opinion, the care of their loved ones is adequately provided only if they visit the home every day or on a regular basis.

c) *Staff Attitudes*

Residents and family members complained about paternalistic and infantilising attitudes of staff. A long-term care home resident who appeared to be quite competent advised us of a situation where she chose to do something that a staff member apparently felt was unsafe. Instead of speaking to her about it, one of her children was contacted about her “behaviour.” Another resident was told by staff that she was not allowed to push her husband in his wheelchair because she might harm herself. Instead of allowing these apparently competent residents to choose to do something which might have some risk attached, they were not given a choice and treated like children.

d) *Privacy and Dignity*

Many long-term care home residents felt that there was a lack of privacy and dignity conferred by service providers. For safety reasons, doors in residents’ rooms in long-term care homes have no locking mechanisms. Residents told us that staff members frequently failed to knock before entering their room or bathroom, even when the door was closed. While this may appear to be a minor infringement of one’s right to privacy, it does not foster positive relationships nor does it contribute to the facility feeling like a “home” environment. Statistics from

the Ontario Health Quality Council show that over 20% of residents do not believe a facility feels like home to them.⁹⁷

e) *Rights Education*

Both residents and families said they required education about their rights in congregate living. Examples abound of situations where residents had no information, or misinformation, about their rights. For instance, during one focus group, ACE was told by the administrator of a home that each resident must have a power of attorney in order to be admitted. Despite being advised that this was not legal, the administrator insisted that it must be done. There are no laws requiring powers of attorney for residents of either long-term care or retirement homes but it is not uncommon to encounter these requirements. While these documents may be helpful in many situations, there are many good reasons why a person should not have such legal documents in place. However, when administrators have these beliefs and insist on these documents, it is difficult for potential residents to disagree with them.

It was also noted that many residents and families did not feel properly prepared for the transition to either a retirement or long-term care home. Participants at our meetings indicated that residents were provided with a vast amount of information, including details about rights and complaint mechanisms, on the day of admission. Many residents and family members described this day as a “blur” and stated they did not retain any of the information provided to them on that day.

Residents and families acknowledged that they also needed to learn about their personal role as a resident, or a friend or family member of a resident, living in a congregate setting. One of the realities of congregate living is that it is a group environment where residents have different personalities – not everyone is going to get along with each other. Compromises will sometimes be necessary. For instance, residents sharing rooms in long-term care homes are placed in whatever room is available and have no choice about roommates.

f) *Specialized Staff Training*

Some family members felt that staff require more specialized training. They commented that while it would be beneficial to have increased levels of staffing, “more care doesn’t necessarily mean better care.” It was noted that the number of staff was not as important as having properly trained staff. Where there were poorly trained staff or a lack of proper staff supervision, it would not matter how many staff were available: they still would not provide the special care that the residents required.

g) *Detention*

It was widely reported that homes were restricting residents' from going outside the long-term care home except in accordance with restrictive rules. While ACE has dealt with many of these types of cases, we were surprised at the pervasiveness of these rules. Almost every long-term care home's Residents' Council spoke of the fact that residents were not permitted to leave the home without an escort or family member. A social worker at one home confirmed that residents are presumed not capable to leave on their own unless proven otherwise. Long-term care homes are just that - homes, not prisons. There is nothing in law authorizing a long-term care home to prevent residents from leaving the home.⁹⁸ In fact, long-term care homes do not have any detention authority unless there is an immediate threat to the resident, at which time common law duties of restraint apply.⁹⁹ It is often assumed that if the resident is found incapable with respect to placement, this gives the long-term care home or substitute decision-maker authority to prevent the resident from leaving the facility. This is not true. If a person wants the authority to detain another person, one would have to go to court to obtain authority to do so. Most of these residents expressed a wish to be able to go to local stores or coffee shops without a family member or paying for an escort. Even when ACE advised residents that they were in fact permitted to leave, several residents did not believe us because it was contrary to common practice.

h) *Barriers to Accessibility*

Residents of long-term care homes and family members expressed concerns about the accessibility barriers affecting residents with physical disabilities. One resident felt that different rules and standards existed for residents with physical disabilities who require wheelchairs. Due to insufficient staffing to provide individual assistance, he is unable to get out of bed or use the bathroom as he sees fit. Instead, he must rely on staff and abide by their schedule. Another resident reported that she is not allowed out of her wheelchair during the day due to inadequate staffing levels. In one home, family members noted that the carpeting makes it difficult to push residents in their wheelchairs. At a different home, residents with wheelchairs have difficulties entering the public washrooms located near the common areas because there are no push buttons to open the doors.

i) *Programming and Staffing Levels*

Many residents said there are insufficient activities, programs and staffing levels at long-term care homes. Reported problems caused by a lack of staff include: prolonged waits or no response after ringing the call bell for assistance; use of diapers instead of assisting the resident to the washroom; minimal assistance at meals; and one staff member providing a service, such as transferring, where two persons are required. This leads to poor quality of care and unsafe conditions for residents.

j) *Access to Physicians*

Residents at long-term care homes were dissatisfied with their limited interaction with the physician providing care to them in the home. While residents are theoretically allowed to have their own physician provide care, the requirements placed on the physician by the home make this almost impossible, since most physicians in the community will not agree to these stipulations. The resident, therefore, must accept the services of the physician who is contracted by the home. Physicians typically visit the home once a week, although there may be more than one physician servicing a larger home. A number of residents noted that it often takes several weeks to see the doctor. At one home, residents said the doctor is reluctant to make referrals to specialists although they feel it may be appropriate. Staff are often reluctant to contact the physician in “off hours” despite the expectation that the home is always to have the services of a physician if required.

Similar concerns about access to physicians were also expressed by some retirement home residents.

k) *Informed Consent*

The failure of health practitioners to obtain informed consent for medical treatment was rampant in both retirement and long-term care homes. Residents and family members reiterated many of the same complaints that ACE has heard from its clients, such as doctors only providing minimal, if any, information about treatments and residents and/or their substitute decision-makers learning about prescribed medications after the fact. One family member commented that “doctors are God but long-term care doctors are higher than God.” At one of our consultations at a long-term care home, a resident who had lived at the home for a number of years asked us if she had the right to attend her own care conference. The home had invited her daughter but did not even inform the resident of the meeting despite the fact that she is competent to make her own treatment decisions.

Industry Concerns

Industry stakeholders spoke about the following constraints they experience with regards to respecting and upholding the rights of residents:

- Homes contend that they have insufficient resources. As a result, they cannot afford to hire as many staff or provide as much training as they would like;
- Industry stakeholders were forthright about the need to not only teach, but to emphasize, the importance of residents' rights to administrators and senior management, as it is sometimes difficult for them to balance their corporate obligations with the rights of residents. A representative of one trade organization pointed out that some staff were trained in an era when paternalistic, not resident-centred, views were the norm. It was acknowledged that without the support and leadership of senior management, the current culture will not change;
- Retirement and long-term care homes consist of a diverse group of residents with unique needs, presenting challenges in ensuring that residents understand their rights;
- Residents and families have unrealistic expectations about congregate living;
- Homes are wary of liability and potential litigation. For instance, a stakeholder presented a fairly frequent scenario where a diabetic resident wants to eat birthday cake but the family forbids it and threatens to notify the government or sue if the resident is allowed to eat the cake;
- Fear of the Performance Improvement and Compliance Branch of the Ministry of Health and Long-Term Care; and
- Disputes with labour unions and grievances contribute to difficulties in resolving issues.

Conclusion

As is evident from the personal experiences of stakeholders, in addition to ACE's work for the past 25 years, inherent in the current legal regime are barriers which prevent older adults residing in congregate settings from accessing justice. In applying the Law Commission of Ontario's principled framework, one can analyze the barriers to determine why they impede the older adult's access to justice.

A major impediment for older adults residing in congregate settings – ageism – is often the underlying cause or contributor to other barriers. ACE adopts the Law Commission of Ontario’s definition of ageism:

Ageism may be defined as any attitude, action or an institutional structure which subordinates a person or a group because of age, or any assignment of roles in society purely on the basis of age. Most often in our society, ageism reflects a prejudice against older persons, a negative bias toward the aging. As such, ageism is broader than stereotyping, although stereotyping may lead to and support ageism.¹⁰⁰

A simple example of ageism is the automatic assumption that older people are incapable of making a decision due to their age. Although there is a presumption in the *Health Care Consent Act* that a person is capable, the onus is often on the older person to prove their capacity.¹⁰¹ Another common example of ageism is the attitude that seniors must be “protected” by restricting their activities because it is in their “best interests.”

In retirement and long-term care home settings, as exemplified by the responses of residents at our focus groups, this ageist approach can include:

- Preventing capable residents from leaving the premises, even for short lengths of time, unless accompanied or if family members give consent;
- Requirements that all residents execute powers of attorney for property and personal care prior to admission, despite the fact that the senior may not want or need to execute such documents; and
- Discussing care issues with the resident’s family instead of the competent resident.

A second barrier for older adults is that while legislation which is more often applicable to older adults generally sets out a positive structure, it is either misapplied, usually in a paternalistic fashion, or simply ignored. Simply stated, the law is good but the practice is bad.

Due to a general misunderstanding of the law within the industry, principles of independence, participation, security and dignity are often not implemented. As already noted in detail, non-compliance with the law is rampant in the area of capacity, substitute decision-making and health care consent, disproportionately impacting older adults living in hospitals and long-term care homes. When health practitioners fail to obtain informed consent, older adults are not afforded dignity

as they are not able to exercise personal autonomy in health care decision-making. Older adults are also precluded from actively participating in their treatment plans although the decisions are about their own bodies. Further, older adults are not afforded security of the person if health practitioners administer treatment without consent. According to the Supreme Court of Canada in *Ciarlariello v. Schacter*:

It should not be forgotten that every patient has a right to bodily integrity. This encompasses the right to determine what medical procedures will be accepted and the extent to which they will be accepted. Everyone has the right to decide what is to be done to one's own body. This includes the right to be free from medical treatment to which the individual does not consent. This concept of individual autonomy is fundamental to the common law...¹⁰²

To combat the phenomenon of “good law, bad practice,” it is important to encourage adherence with the law by increased education and training, as well as minor modifications to relevant legislation. ACE is of the opinion, however, that good laws should not be overhauled merely because there is resistance to comply. We envision law reform in these scenarios as including the entrenchment of special supports and additional protections for older adults (e.g., expansion of the Ombudsman’s jurisdiction and the provision of independent advocacy services for residents).

A third obstacle for older adult residents is the lack of awareness of legal rights on the part of both residents and service providers. While information about rights may be provided upon admission, it is often buried amongst the administrative paperwork. This, plus the fact that the day of admission is a difficult one for the resident and their family and friends, means that the information is often not digested. If older adults, their substitute decision-makers and family members do not have information about residents’ rights, their independence, security and dignity are jeopardized. Living in a group environment is inherently full of compromises; without the necessary knowledge about rights and expectations, the resident will not know what is and what is not acceptable. Lack of knowledge perpetuates the myth that older adults are helpless, as they do not know they can seek resolutions to their problems.

Fourth, the legal options available to older adults to have their rights respected are insufficient. Examples of ineffective legal mechanisms include:

- Complaints to self-regulated health professional Colleges;
- A civil justice regime that discourages older adults or their representatives from initiating lawsuits; and

- A Residents' Bill of Rights for long-term care residents that is lacking in a tangible method of enforcement.

Due to the ineffectiveness of these mechanisms, the security of older adults is at risk because they are not able to receive even basic support from the available legal services.

A fifth barrier facing older residents is the power imbalance that exists between older adults and staff in congregate settings which often discourages residents from lodging a complaint and asserting their rights. This power imbalance is exacerbated because many service providers know there is limited and/or ineffective oversight in the current legal framework.

Another obstacle for older adults in congregate settings is limited resources. There is no dispute that the cost of living in congregate settings is expensive and there is competition for the allocation of scarce health care dollars. However, the government, local health integration networks and service providers must be cognizant of adequately providing for residents.

In our focus groups, residents complained about deficiencies in the level of programming and staffing. Due to the financial diversity of older adults, more affluent individuals are able to purchase extra care services and supports which permit them to enjoy a better quality of life than residents with fewer financial resources. While we recognize that there are certain things that a publicly-funded system can never provide, the system should be sufficient to provide adequate resources for all its residents.

Emerging from our research are several key priorities for law reform with regards to encouraging access to justice for older adults residing in congregate settings: education; independent and systemic advocacy; and increased oversight of congregate living environments. Each topic will be thoroughly examined in this report.

CONGREGATE SETTINGS AND LEGAL PROTECTIONS: A NATIONAL AND INTERNATIONAL REVIEW

This section of the paper provides a national and international overview of the laws and structures governing congregate living for older adults in selected jurisdictions. Within Canada, we examined four provinces: British Columbia, Alberta, Nova Scotia and Newfoundland. Outside Canada, we studied Wales, Australia and the United States of America.

The purpose of this section is to facilitate a basic understanding of the governance systems of other jurisdictions in order to discern innovative approaches to access to justice which could potentially be replicated or adapted in Ontario. Each jurisdiction employs different language to describe its various types of congregate settings and we have chosen to use their own terminology, as no two types of settings are exactly the same between jurisdictions. Please keep in mind that it is beyond the scope of this report to provide an exhaustive review and analysis of the laws and practices of these jurisdictions.

BRITISH COLUMBIA

Regulation of Congregate Settings

Hospitals

Some beds in private hospitals and extended care units in hospitals are also considered to be long-term care facilities in British Columbia. As per the *Hospital Act*, a “private hospital” or “hospital” means a house, in which two or more patients (other than the spouse, parent or child of the owner or operator) are living at the same time, and includes a nursing home or convalescent home, but does not include a regular non-profit hospital.¹⁰³ It is estimated that there are about 10,500 seniors and people with disabilities living in 23 private hospitals and 94 complex care facilities.¹⁰⁴ Provincial consultations were held in 2005/2006 to bring these long-term care units under the long-term care legal regime and to harmonize the regulation of all residential care facilities but this has not yet occurred.¹⁰⁵

Assisted Living

Assisted living facilities in British Columbia have some similarities to retirement homes in Ontario. They are governed by the *Community Care and Assisted Living Act*¹⁰⁶ and the *Adult Care Regulations*¹⁰⁷ with respect to health and safety issues.

Assisted living is defined as “a premises or part of a premises in which housing, hospitality services, and at least one but not more than two prescribed services are provided by or through the operator to three or more adults who are not related by blood or marriage to the operator.”¹⁰⁸ Prescribed services means the following:

- Regular assistance with activities of daily living, including eating, mobility, dressing, grooming, bathing or personal hygiene;
- Central storage of medication, distribution of medication, administering medication or monitoring the taking of medication;
- Maintenance or management of the cash resources or other property of a resident or person in care;
- Monitoring of food intake or of adherence to therapeutic diets;
- Structured behaviour management and intervention; or
- Psychosocial rehabilitative therapy or intensive physical rehabilitative therapy.¹⁰⁹

The types of assisted living residences are varied; they can range from apartment-style buildings to a bedroom in a home with a lockable door and an en-suite or shared bathroom. All residences include common dining and recreational space.¹¹⁰

Residents cannot continue to reside in assisted living facilities if:

- They are no longer able to make decisions related to key areas of function unless a spouse lives with the resident and is willing and able to make decisions on their behalf;
- They are no longer able to express their wishes so as to be understood by staff or by a spouse living with them who can communicate with staff on their behalf;
- They behave in a way that jeopardizes the health and safety of others; or
- Their needs exceed what can be provided in assisted living.¹¹¹

This legislation has been criticized “for trying to regulate based on an inaccurate picture of who is actually in assisted living homes in BC.”¹¹² The legislation was originally designed for a demographic group 15 years younger and more physically active than the actual residents who tend to be older and frailer. As residents are supposed to be able to make decisions (unless the incapable person is living with their spouse who can make decisions on their behalf), the “governing legislation is quite strict on exiting assisted living if more than two

prescribed services are needed by a resident.” This has resulted in “a serious break in the health/housing continuum, as entry to residential care has a very high bar of need.”¹¹³ Consequently, some residents no longer qualify for assisted living yet do not qualify for a community care facility.

Currently, the “renter” of an assisted living unit has few legal tenancy rights as there are no specific consumer protection rights or coverage in British Columbia’s legislative scheme for assisted living arrangements.¹¹⁴ In 2006, the British Columbia legislature passed Bill 27, the *Tenancy Statutes Amendment Act, 2006* to include assisted living facilities, as well as a dispute mechanism for assisted living in the *Residential Tenancy Act*.¹¹⁵ However, it was never proclaimed and various stakeholders believe that this dispute mechanism will likely never come into effect, thereby leaving a gap for residents.¹¹⁶

Community Care Facilities

Community care facilities – also known as residential care homes or facilities, or complex care facilities – are similar to Ontario’s long-term care homes. These facilities provide residential care to three or more persons who are dependent on caregivers for continuing assistance or direction for three or more prescribed services.¹¹⁷

The *Community Care and Assisted Living Act* also governs this type of facility and the standards of care are set out in the *Adult Care Regulations*. Amendments to this regulation, which will be effective October 1, 2009, contain a provision which provides for an internal dispute mechanism.¹¹⁸ The licensee will be required to “establish a fair, prompt and effective process” for residents or their representatives “to express a concern, make a complaint or resolve a dispute” without fear of retaliation. If the internal dispute mechanism fails to resolve an issue, the complaint can then be escalated to the Community Care Licensing Branch of the Ministry of Healthy Living and Sport.

The Community Care Licensing Branch is also responsible for the development and implementation of legislation, policies and guidelines to protect the health and safety of people being cared for in both public and private licensed facilities.¹¹⁹

Legal Protections

Office of the Assisted Living Registrar

If a resident has a problem about an assisted living residence, they can lodge a complaint with the home since all operators are expected to establish an internal complaint resolution process.¹²⁰ If the internal dispute process is inadequate, residents can bring a complaint to the Office of the Assisted Living Registrar. The Registrar has jurisdiction over health and safety standards in assisted living residences.¹²¹ It will use either education or mediation to resolve disputes.¹²² The Registrar has a system of progressive enforcement consisting of education, changes to registration conditions, fines and/or license suspension or cancellation if its requirements are not met.

The Registrar also has authority to:

- Register residences that meet the definition of an assisted living residence in the legislation;
- Enter and inspect any premises related to the operation of an assisted living residence where the Registrar has reason to believe that an unregistered assisted living residence is being operated;
- Inspect and make a copy of or extract from any book or record at the premises, or make a record of anything observed during an inspection;
- Apply conditions to registrations, vary conditions, and suspend or cancel registrations; and
- Fine operators of unregistered assisted living residences.¹²³

The Registrar is required to reconsider any actions it intends to take against an operator.¹²⁴ After reconsideration, operators are advised of the right to appeal final decisions about registration to the Community Care and Assisted Living Appeal Board.¹²⁵

There are several limitations on the Registrar as it cannot investigate complaints related to the following: tenancy issues; operating issues; and case manager assessments respecting eligibility for publicly subsidized assisted living.¹²⁶

The Registrar does not have jurisdiction over community care facilities.

Ombudsman

Further recourse to the British Columbia Ombudsman is available if a resident of an assisted living facility believes the Office of the Assisted Living Registrar did not deal fairly with their complaint.¹²⁷ The Ombudsman also has jurisdiction over public hospitals, regional health boards (including any community care facilities they own) and regional hospital districts.

Medical Officer of Health

Investigations concerning licensed community care facilities are the responsibility of the Medical Health Officer of the local health authority.¹²⁸ Facilities are also inspected regularly to ensure compliance and inspection results are published online.¹²⁹ Either the Medical Officer of Health, or, more commonly, a Licensing Officer who has been delegated the authority, may suspend or cancel a licence, attach terms or conditions to a licence or vary the existing terms and conditions of a licence if the licensee is not complying with the legislation or has contravened a term or condition of the licence.¹³⁰

ALBERTA

Regulation of Congregate Settings

Supportive Living

Alberta's system of supportive living is relatively new. In response to a call for improved accommodations and health care for adults in institutions, the government approved the "Supportive Living and Long-Term Care Standards" and the "Supportive Living Framework" in 2006. The following year, supportive living facilities were being licensed and being monitored by the aforementioned standards.¹³¹

The Government of Alberta describes supportive living as follows:

Supportive living means a philosophy and an approach for providing services within a housing environment. It provides a home-like setting where people can maintain control over their lives while also receiving the support they need. The Government of Alberta has defined four levels of supportive living: residential level, lodge level, assisted living, and enhanced assisted living. These facilities offer increasing levels of hospitality and personal care

support services to match the needs of residents. The buildings are specifically designed with common areas and features to allow individuals to "age in place." Building features include private space and a safe, secure and barrier-free environment. Supportive living promotes residents' independence and aging in place through the provision of services such as 24-hour monitoring, emergency response, security, meals, housekeeping, and life enrichment activities. Publicly funded personal care and health services are provided to supportive living residents based on their assessed, unmet needs.¹³²

Examples of types of supportive living accommodation are lodges, enhanced lodges, designated assisted living, group homes, adult family living and family care homes.¹³³ The four levels of supportive living are described according to their building features, hospitality services, health and wellness services, and resident needs.¹³⁴ Approximately 22,000 people live in about 600 supportive living facilities throughout Alberta.¹³⁵

Residents enter into contracts with the individual supportive living facility. The cost of residing in supportive living is set by the developer or residential operator depending on services, activities and amenities.¹³⁶

All continuing health care services (which includes supportive living facilities) in receipt of public funding must abide by the Continuing Care Health Service Standards.¹³⁷ These standards address personal care and health care services provided to individuals. Alberta Health and Wellness, a government ministry, provides funding to Alberta Health Services (formerly the regional health authorities)¹³⁸ for the provision of health care services. Alberta Health Services must take all necessary steps to ensure that operators comply with these standards if it directly provides or contracts with outside operators to provide services. The Continuing Care Health Service Standards are monitored and enforced by Alberta Health Services.

Supportive living facilities are licensed pursuant to the *Social Care Facilities Licensing Act*¹³⁹ and the corresponding Supportive Living Accommodation Standards. Social care facilities include places of care for persons who are aged or infirm or who require special care. There are eight broad themes and detailed standards within the Supportive Living Accommodation Standards: physical environment; coordination and referral services; hospitality services; residential services; safety services; human resources; personal services and management and administration.¹⁴⁰

The *Social Care Facilities Licensing Act* also sets out inspection powers for social care facilities. The Supportive Living Accommodation Standards are monitored and enforced by Alberta Seniors Community and Support, a government ministry. In addition to suspending or cancelling a license, a director appointed by the Minister may close a facility if it is felt that there is an immediate danger to the safety of residents.¹⁴¹ However, the only regulations related to reviewing social care facilities apply to facilities providing child day care, not those dealing with adult care.¹⁴²

Seniors lodges are not licensed under the *Social Care Facilities Licensing Act*, however, they are subject to the Supportive Living Accommodation Standards. Lodges are operated under the *Alberta Housing Act* and designed to provide room and board for seniors who are functionally independent or functionally independent with the assistance of community based services. Applicants are prioritized on the basis of need, which takes into consideration housing need, level of support required and income. Funding is provided by municipalities and/or the province.¹⁴³

Enhanced lodges are a new type of lodge where additional levels of care are provided. Some enhanced lodges have developed specialized areas within the facility to provide services for persons with Alzheimer's disease and other dementias.¹⁴⁴

Facility Living

Facility living differs from supportive living in that it:

- Cares for residents with medical conditions that may be serious, chronic and/or unpredictable and require access to registered nursing services on a 24-hour basis;
- Provides 24-hour registered nursing care from nursing staff who are able to respond immediately and on a sustained and unscheduled basis;
- Has health professionals that are able to respond to the need for unscheduled assessments and prescribe interventions;
- Has specialized physical design and infrastructure to address highly complex needs; and
- Is governed by the *Nursing Homes Act* or the *Hospitals Act*.¹⁴⁵

Facility living includes nursing homes and auxiliary hospitals (a hospital for the treatment of long-term or chronic illnesses, diseases or infirmities).¹⁴⁶ The provincial government estimates that there are approximately 14,400 people living in approximately 200 long-term care facilities.¹⁴⁷

All long-term care facilities are subject to the provincial Long-Term Care Accommodation Standards. Similar to the Supportive Living Accommodation Standards, there are eight broad themes and detailed standards within the Long-Term Care Accommodation Standards: physical environment; coordination and referral services; hospitality services; residential services; safety services; human resources; personal services and management and administration.¹⁴⁸

All long-term care facilities receiving public funding must also follow the Continuing Care Health Service Standards.

The cost to a resident for facility living is \$54.25 for a private room, \$47.00 for a semi-private room and \$44.50 for a standard ward room.¹⁴⁹ The provincial government pays the health-associated costs.

Legal Protections

Protection for Persons in Care Act

The *Protection for Persons in Care Act*¹⁵⁰ applies to all adults in publicly funded care facilities, including hospitals, seniors' lodges and nursing homes. Private supportive living operators (e.g., where the residents do not receive public funds) are not covered by the *Protection for Persons in Care Act*. However, all supportive living operators are required to develop and maintain policies and procedures requiring all employees to receive education on identification, prevention and reporting of abuse or suspected abuse of residents.

Pursuant to this legislation, every individual or service provider who has reasonable and probable grounds to believe that there is or has been abuse against a client shall report such abuse.¹⁵¹ A telephone hotline is available to report abuse cases.¹⁵²

Complaints are investigated by individuals who are not government employees but are hired under contract and are external to the agencies involved in the allegations. The investigators come from various backgrounds, such as criminology, nursing and social work, and have expertise in areas such as long-term care, mental health, law enforcement and experience working with seniors or persons with developmental disabilities.¹⁵³

After completing an investigation, the investigator will make recommendations to Alberta Seniors and Community Supports, which may include reviewing the facility's funding, recommending that an employee be disciplined or dismissing

the report if there is no reason to believe abuse has occurred.¹⁵⁴ Alberta Seniors and Community Supports will then make a decision based on these recommendations.

The definition of abuse in the *Protection for Persons in Care Act* requires intent.¹⁵⁵ Consequently, many reported complaints do not meet this high legislative threshold.¹⁵⁶ The Legislative Review Committee studied the legislation in 2003 and recommended removing the requirement of intent. While the issue of intent is important, they noted that it “should not be the critical component in the definition of abuse” but should “instead focus on the harm or potential harm to the client, rather than the apparent state of mind of the alleged abuser.”¹⁵⁷ No such changes have been initiated.

Health Facilities Review Committee

The *Health Facilities Review Committee Act* establishes a committee responsible for regularly reviewing and inspecting long-term care facilities and investigating complaints or concerns about care, treatment and standards of accommodation in facility living.¹⁵⁸ However, “the Committee does not have the mandate to determine whether a facility is in compliance with or in contravention of standards set out in the *Nursing Homes Act* and Regulations, or to enforce the standards or to impose sanctions.”¹⁵⁹

The Committee is comprised of two members of the Legislative Assembly and ten private citizens. The positions are part-time and members are not employees of the provincial government.¹⁶⁰

The Committee performs surprise inspections but, in practice, they only inspect each facility approximately every three years.¹⁶¹ If a complaint involves personal health information, the Committee’s rules require permission from the complainant or their legal guardian to investigate complaints.¹⁶² Consequently, many complaints about facilities are never investigated, although they may be considered during the next routine review.¹⁶³ The Committee also restricts its investigations to those made by or on behalf of a specific patient, not complaints involving more than one person.

After its investigation, the Committee sends a report to the relevant parties, as well as the Minister of Health and Wellness. The homes are asked to respond in writing within 90 days, indicating the actions undertaken to address the recommendations. The Committee will follow-up if the response is not satisfactory.¹⁶⁴

Spencer summarized the impact of the Committee's rules on its work:

As a result of these rules, between 2003 and 2006, almost seventy percent of the private complaints made were not investigated because the forms were not returned. In 2003/4, the investigation process took over a year in each of the 6 private complaints heard. In 2004/5, only one private complaint was conducted and concluded in the year, and in 2005/6 only three complaints for long term care (out of eighteen complaints) were conducted and concluded.¹⁶⁵

Ombudsman

The Ombudsman in Alberta has jurisdiction to investigate complaints about the patient concern resolution processes of hospitals, as well as long-term care facilities.¹⁶⁶

NOVA SCOTIA

Regulation of Congregate Settings

Assisted Living Facilities

Assisted living facilities, or "enriched living," are privately owned facilities where residents are independent older adults who do not require substantial care but may be in need of some services (e.g., meals, housekeeping). Residents must be cognitively capable and have the ability to make informed, voluntary decisions regarding care requirements and living arrangements (or, if living with a spouse, the spouse must be able to do so). Some enriched housing units fall under the auspices of the Housing Services Branch of the Department of Community Services.¹⁶⁷ No legal right exists to inspect these facilities.

Residents of assisted living facilities enter into a rental contract or lease agreement with an operator. However, the *Residential Tenancies Act* is silent on the issue of jurisdiction with regard to assisted living facilities.¹⁶⁸

Residential Care Facilities, Community Based Options and Nursing Homes

Three types of long-term care facilities exist in Nova Scotia: community based options; residential care facilities; and nursing homes/homes for the aged. Both community based options and residential care facilities can fall under the jurisdiction of either the Department of Community Services or the Department of

Health, while the Department of Health has exclusive jurisdiction over nursing homes. The *Homes for Special Care Act*¹⁶⁹ and its regulations govern long-term care facilities that are licensed (i.e., residential care facilities and nursing homes).

Community based options are small homes owned and operated by private individuals or organizations for a maximum of three residents who need some supervision and limited help with personal care. Although community based options are unlicensed, they are inspected and approved by the Department of Health.¹⁷⁰

Residential care facilities are similar to community based options but they provide services to more than three residents. They are also licensed and inspected annually by the Department of Health.¹⁷¹ Operators have a duty to permit an inspector at all reasonable times to enter and inspect the residential care facility, its records and equipment, and if required, to have any resident examined by a medical practitioner or registered nurse for the purposes of the *Homes for Special Care Act*.¹⁷²

Nursing homes, sometimes known as homes for the aged, provide accommodation and skilled nursing care to older adults. Residents are referred to this level of care if they: require assistance from a registered nurse; cannot ambulate on their own; have no physical/cognitive ability to evacuate independently; or they need more than 1.5 hours of one-on-one care per day.¹⁷³ These facilities are inspected twice a year by inspectors at the Department of Health.¹⁷⁴ As with residential care facilities, operators of nursing homes have a duty to permit an inspector at all reasonable times to enter and inspect the nursing home, its records and equipment, and if required, to have any resident examined by a medical practitioner or registered nurse for the purposes of the *Homes for Special Care Act*.¹⁷⁵

There are approximately 5,835 licensed beds in 70 nursing homes across Nova Scotia. Statistics show that 22 nursing homes are municipally owned, 21 are private-non profit, 20 are private for-profit and 7 are based in hospitals.¹⁷⁶

The government pays the health care costs for resident care while residents are responsible for accommodation charges and personal expenses. The daily accommodation charges are \$47.50 for community based options, \$52.00 for residential care facilities and \$86.50 for nursing homes.¹⁷⁷

A June 2008 report on the status of persons with disabilities in residential care homes found that the residential sector operates in silos. No standards other than licensing requirements are in place for residential care facilities. Inconsistencies exist across the province with respect to infrastructure

maintenance, the availability of social, vocational and recreational opportunities, as well as bedroom and common area furnishings and aesthetics. The report recommended converting all unlicensed community based options to licensed homes.¹⁷⁸

Legal Protections

Residents' Rights in Long-Term Care Homes

The *Homes for Special Care Act Regulations* sets out a number of requirements for licensed long-term care homes that help to respect the social rights, freedoms and interests of residents.¹⁷⁹ Generally speaking, the legislation is silent about the mechanisms available to enforce these rights.

Protection for Persons in Care Act

The *Protection for Persons in Care Act*¹⁸⁰ applies to residents as defined by the *Homes for Special Care Act* and patients under the *Hospitals Act*.¹⁸¹ Section 4 of the *Protection for Persons in Care Act* places a duty on the facility operator to protect the patients or residents of the facility from abuse and to maintain a reasonable level of safety for the patients or residents. People operating within the care facilities have an obligation to report any abuse. For all other persons, reporting is voluntary.

The Minister is required to make an inquiry into any abuse report received and, depending on the circumstances, may investigate the allegations. The report is then given to the facility with a time limit in which it must comply. Any employees or residents who lodge an abuse report are protected from retaliation under the legislation.

Ombudsman

The Nova Scotia Ombudsman has the authority to investigate complaints about hospitals, residential care facilities for seniors and nursing homes.¹⁸² The Ombudsman has no jurisdiction over assisted living facilities.

The Ombudsman may launch an "own motion investigation" to examine government service delivery if it receives a number of complaints about a particular department or agency. Interestingly, the Ombudsman can also initiate its own motion investigation even if no complaint has been received.¹⁸³

The website for the Ombudsman indicates that it utilizes “a regular visitation process” in residential care facilities and nursing homes.¹⁸⁴ Representatives of the Ombudsman dedicated to seniors issues “visit the facilities, explain the role and function of the office and discuss any concerns the seniors may have.”¹⁸⁵ As necessary, representatives “will assist seniors in navigating through government processes, advising them of avenues of appeal and participate on committees relating to seniors issues.”¹⁸⁶ The Ombudsman hopes this “proactive approach will provide an avenue to ensure seniors’ voices are heard and their issues addressed.”¹⁸⁷

NEWFOUNDLAND AND LABRADOR

Regulation of Congregate Settings

Personal Care Homes

Personal care homes, also known as community care residences, are governed by the *Health and Community Services Act*¹⁸⁸ and the *Personal Care Home Regulations*.¹⁸⁹ These homes provide accommodation for five or more older adults who need minimal assistance with care or activities of daily living. Admissions to personal care homes are controlled through a single entry system by each regional board of health.

Although personal care homes are privately owned, they are licensed and highly regulated by the government. Regional boards of health issue the licenses and monitor compliance with the Long-Term Care Operational Standards.¹⁹⁰ The Standards describes itself as the government’s expectations, rather than requirements, for long term care facilities.¹⁹¹

The Department of Health and Community Services provides monies to the regional health boards to distribute to personal care home residents if they are eligible for financial assistance. The maximum subsidy is \$1,500.00 per month.¹⁹² As of late November 2004, 59% of personal care home residents were subsidized.¹⁹³

The provincial Auditor General identified a number of concerns respecting basic safeguards and standards in personal care homes in a 2005 audit, stating the following: the monitoring of care standards required improvement; fire safety standards were not met; there was a failure to ascertain that policies were followed; and that it questioned whether residents were receiving a consistent and adequate level of care.¹⁹⁴

Residents of personal care homes are precluded from protection under the *Residential Tenancies Act*.¹⁹⁵

Nursing Homes

Nursing homes provide residential care and accommodation to residents who have high care needs and require on-site professional nursing services.¹⁹⁶ Up until the recent repeal of the *Hospital Act*, nursing homes were identified as “scheduled hospitals.” Nursing homes are now primarily administered by regional health boards pursuant to the *Regional Health Authorities Act*.¹⁹⁷

The cost of living in a nursing home depends on the resident’s ability to pay. The maximum monthly amount is \$2,800. If a resident is unable to pay, the government will cover the difference between the resident’s income and the cost of the nursing home, leaving \$115-\$125 per month for spending money.¹⁹⁸

Nursing homes are not licensed but they must be accredited through Accreditation Canada, a not-for-profit, independent organization that provides health care organizations with a “voluntary, external peer review to assess the quality of their services based on standards of excellence.”¹⁹⁹ This process involves self-assessments by facility management in combination with surveyors (doctors, nurses and other health care practitioners working on behalf of Accreditation Canada) who provide feedback.²⁰⁰ The report identifies areas of excellence, as well as opportunities for improvement.²⁰¹

Nursing homes are also expected to abide by the Long-Term Care Operational Standards.

The same complaints procedure for personal care homes applies to nursing homes.

Legal Protections

Residents’ Bill of Rights

Section 5 of the Long-Term Care Operational Standards is entitled “Empowering the Resident” and deals with residents’ rights and responsibilities. There are also 38 personal, legal and human rights and freedoms contained in the Performance Measures found within the Operational Standards. According to the Operational Standards, when taken together, these rights form a Residents Bill of Rights.²⁰²

In the opinion of Professor Charmaine Spencer, “there is no uniform adherence to the standards set out in the Operational Manual.”²⁰³ She reviewed a sample of nine nursing home handbooks and discovered: one handbook referred to its listed rights as “commitments” to residents; three specifically mentioned rights; two included plain language but very truncated versions of residents’ bill of rights; and some failed to even mention a resident’s bill of rights.

Internal Complaints System

An internal complaints system is delineated within the Long-Term Care Operational Standards. Confirmation of receipt of the complaint must be provided within two business days while a post-investigation reply must be supplied within one month. The Canadian Centre for Elder Law has commented that “the complaints system is quite complex” whereby people with concerns have to report them to “a confusing myriad of authorities.”²⁰⁴

Ombudsman

Known as a Citizens’ Representative, this body has the power pursuant to the *Citizens’ Representative Act* to enter and investigate any government department or agency with the exception of the legislature or the courts.²⁰⁵ The jurisdiction of the Citizens’ Representative to investigate complaints about publicly funded long-term care homes flows from its authority over the Department of Health and Community Services and the four regional health authorities who are charged with funding, administering and maintaining these homes. Similar to Nova Scotia, the Citizens’ Representative can also instigate investigations at his or her own initiative.²⁰⁶

WALES

Regulation of Congregate Settings

In Wales, two separate bodies regulate health and social care. The Care and Social Services Inspectorate Wales is responsible for regulating and inspecting establishments and agencies providing social care services in Wales. The Healthcare Inspectorate Wales promotes improvement in the quality and safety of patient care within the National Health Service (NHS) Wales and is the regulator of independent health care in Wales.

Sheltered Housing

Typical sheltered housing schemes are comprised of 30 or 40 apartments and/or bungalows with an emergency alarm system and some communal facilities. On-site support is often provided by a “scheme manager.” Sheltered housing does not normally provide care but residents may obtain care and support from social services.²⁰⁷

Although no one definition exists for extra care sheltered housing, a type of sheltered housing, it can be described as “housing with the full legal rights associated with being a tenant or home owner in combination with 24 hour on-site care which can be delivered flexibly according to a person’s changing needs.”²⁰⁸ Extra care housing is also known as close care, very sheltered housing, assisted living, retirement housing or easy living.

The payment for or ownership of sheltered housing includes rent, outright sale, part ownership or mixed tenure combining homes for sale and rent.²⁰⁹ Four main organizations provide sheltered housing: local councils; housing associations (non-profit organizations, the majority of which receive public money, that provide and manage homes for people who cannot afford to buy a home on the open market); the voluntary sector; and private sheltered housing developments.²¹⁰

Laws against harassment and illegal evictions, such as the *Protection from Eviction Act 1977*²¹¹ and the *Housing Act 1988*,²¹² are applicable to tenants in all forms of sheltered housing. However, there is no formal complaints procedure for tenants renting privately and a tenant may have to go to court to enforce their rights.²¹³ Residents of sheltered housing provided by local councils and most housing associations may make a complaint to the Public Service Ombudsman.

Care Homes

Care homes provide accommodation, together with nursing or personal care, for persons who are or have been ill, disabled, infirm, dependent on drugs or alcohol or mentally disordered.²¹⁴ The *Care Standards Act, Care Homes (Wales) Regulations 2002*²¹⁵ and *Registration of Social Care and Independent Health Care (Wales) Regulations 2002*²¹⁶ form the foundation of the regulatory framework for care homes.

Government-run care homes have been steadily decreasing in numbers and now over 91% of private companies or the voluntary sector runs care homes in the United Kingdom and Wales.²¹⁷

The NHS provides for the full cost of care in a care home for residents whose primary need for being in care is health based.²¹⁸ Otherwise, services in care homes are available to residents through a complicated scheme of means-testing

– one of the most criticized aspects of health care in Wales and England.²¹⁹ In November 2008, the Welsh assembly government launched a consultation to debate the future of adult care funding.²²⁰ Advocacy groups have asked the government to consider the Scottish model where people aged 65 and over living in either their own homes or care homes are entitled to receive free personal care, subject to an assessment of their needs, not their means.²²¹

The *Care Standards Act* empowers the Welsh assembly to set detailed minimum standards for care homes. Wales responded by creating the National Minimum Standards for Care Homes for Older People which contains 40 standards.²²² The standards are fairly detailed and cover such matters, including: staffing levels; quality of care; and protection of legal and civic rights. These standards are used by the Care and Social Services Inspectorate Wales when determining whether care homes are “providing adequate care, meeting the needs of the persons who live there and otherwise being carried on in accordance with regulatory requirements.”²²³ However, the standards are not legally enforceable but are merely guidelines for providers, inspectors, commissioners and users to judge the quality of a service, but can be used as evidence in prosecutions for failure to comply with regulations.²²⁴

Legal Protections

Residential Property Tribunal

The Residential Property Tribunal is an independent statutory body established under the *Rent Act 1965*. The Tribunal's main responsibilities are to form Rent Assessment Committees and Rent Tribunals to consider appeals about rent levels and to fix an appropriate rent where there are disputes between landlords and tenants in the private sector.²²⁵ The Tribunal also sets up Leasehold Valuation Tribunals to settle certain disputes between leaseholders and freeholders.²²⁶

Internal Complaints Procedure for Care Homes

The *Care Homes (Wales) Regulations 2002* requires care homes to prepare and follow a complaints procedure, ensure that any complaint made is fully investigated, and within 28 days from receipt of a complaint, inform the complainant of the action (if any) that is to be taken.²²⁷ The Welsh National Minimum Standards sets out a home's responsibility to provide a “simple, robust and accessible complaints procedure” under which complaints are dealt with “promptly and effectively.”²²⁸ The service provider is expected to supply information on the internal complaints procedure to the resident, in addition to

information on how to raise a complaint directly with the Care and Social Services Inspectorate for Wales and local health and social service authorities.²²⁹

Care and Social Services Inspectorate for Wales

The Care and Social Services Inspectorate for Wales (CSSIW) is an operationally independent division of the Welsh Assembly Government. It ensures that social care meets the regulatory requirements and the National Minimum Standards. The CSSIW regulates more than 6,000 settings and agencies, including care homes for adults.²³⁰

The CSSIW may deal with complaints that have been previously unresolved by a care home or, in certain instances, where the first stage was bypassed (e.g., the complainant is not prepared to follow the internal complaints process first or the issue appears to be serious enough to warrant police involvement).²³¹ Residents funded by the local government authority or the NHS also have recourse to their complaint procedures. In such cases, the CSSIW will inform the relevant agency and agree on who is best placed to deal with the complaint. Joint investigations can also take place.²³²

The outcome of each investigation is sent to the complainant, normally within 42 days, including reasons for any decisions made and the proposed action. Complainants are then given the opportunity to discuss the findings with the Regional Director if they are dissatisfied with the outcome. If the complainant is dissatisfied with the way in which the CSSIW conducted the investigation, they may use the Assembly Complaints procedure and utilize the Public Services Ombudsman for Wales.²³³

The CSSIW has recourse to a range of regulatory requirements or recommendations as a result of a complaint investigation. Serious complaints may result in prosecution and/or cancellation of a care home's registration.²³⁴

Healthcare Inspectorate Wales

The Healthcare Inspectorate Wales “undertake[s] reviews and investigations into the provision of NHS funded care either by or for Welsh NHS organisations in order to provide independent assurance about and to support the continuous improvement in the quality and safety of Welsh NHS funded care.”²³⁵ It reviews and investigates independent health care settings (e.g., acute hospitals, mental health establishments, hospices, private medical practices and specialized clinics) as well as NHS bodies and services (e.g., NHS trusts, local health boards and National Public Health Service).²³⁶ The Healthcare Inspectorate Wales inspects services against the requirements of the *Care Standards Act*, the

Private and Voluntary Healthcare Regulations and the National Minimum Standards.

Older People's Commissioner for Wales

Wales is the only country in the world to have established a statutory, independent Older People's Commissioner. The *Commissioner for Older People (Wales) Act 2006*²³⁷ was passed in 2006 and the first appointed Commissioner started in April 2008.

The Commissioner is not considered to be a servant or agent of the Crown but a "watchdog charged with promotion, consultation, review, advocacy, education and investigative functions."²³⁸ The Commissioner can review, and make recommendations about the adequacy and effectiveness of the law for the protection of vulnerable older people and ask the Assembly Government to consider making changes if she thinks they are needed.

The Commissioner can also examine the way public bodies discharge their functions and their effect on older people, as well as review a failure to discharge a function. Following each of these reviews, the Commissioner can publish a report containing her recommendations for change and take follow-up action to establish whether the recommendations made in that report have been acted upon.²³⁹

The Commissioner can issue guidance on best practices to providers of regulated care services and review their arrangements for whistle blowing, complaints and advocacy to ensure that these are effective in safeguarding and promoting the interests of older people.²⁴⁰

With regards to its investigative functions, the Commissioner is similar to an Ombudsman but her involvement in investigating individual cases is restricted. The Commissioner may only examine the case of an older person where she: (1) considers the representation made about an older person raises a question of principle which has a more general application or relevance to the interests of older people in Wales than in the particular case concerned; (2) she has taken into account whether the issues involved have been or are being formally considered in any way by other persons; and (3) if they have not or are not whether, in the Commissioner's opinion, they are more suitable for consideration by other persons.²⁴¹

In cases where other public bodies, such as the Public Services Ombudsman, provide a more suitable forum for addressing individual complaints, but the

Commissioner proceeds with an investigation, she must inform the Ombudsman, and where appropriate, they should conduct a joint investigation.²⁴²

The Commissioner may also offer assistance, including of a financial nature, to individuals who are: making a complaint to the provider of a regulated service (e.g., private care homes); pursuing a complaint before the CSSIW; or taking a case to a court or tribunal in certain circumstances. She is also able to give help of a “more general kind” (e.g., providing information and referrals).²⁴³

Public Services Ombudsman for Wales

The Public Services Ombudsman for Wales can provide assistance if any older person has been treated unfairly or has received poor service from a public body, including local health boards and National Health Service trusts managing a hospital or other facilities.²⁴⁴

AUSTRALIA

Regulation of Congregate Settings

Retirement Villages

Independent living units, known as retirement villages, offer supportive communities with a range of services for older people. Retirement villages are complexes containing residential premises that are predominantly or exclusively occupied by retired persons (e.g., people over the age of 55 years who have retired from full-time employment). Residents enter into village contracts with the operator of the complex. Retirement villages operate on the basis of residents caring for themselves and being self-funded.²⁴⁵

State and territory governments regulate retirement villages. They can have different legal structures for ownership/use, such as loan/license, lease, strata, purple title and company title. Each has its own advantages and disadvantages, as well as its own applicable legislation.²⁴⁶

In New South Wales, for example, the *Retirement Villages Act 1999* and the *Retirement Villages Regulation 2000* set out the rights and obligations of residents and operators. Together, for example, they explain the type of information that must be given to prospective residents; provide for the establishment of Residents Committees; and explains how and when a contract can be ended. Recent amendments to the *Retirement Villages Act* received assent in December 2008 but they are not yet in effect.²⁴⁷ One of the new

provisions will be the creation of a 90-day settling-in period, during which time, residents may choose to terminate their resident contract.

Aged Care Facilities

The planning, funding and regulation of residential aged care facilities is the responsibility of the Commonwealth government. There are two levels of residential care. Low level care homes (previously known as hostels) generally provide accommodation, personal care and occasional nursing care. High level care homes (previously known as nursing homes) care for people with a greater degree of frailty who often need continuous nursing care.²⁴⁸

Residential care policy in Australia is administered through the *Aged Care Act 1997*.²⁴⁹ The *Aged Care Act* sets out matters relating to the planning of services, the approval of service providers and care recipients, payment of subsidies and responsibilities of service providers. According to Sue Field, the inaugural Public Trustee New South Wales Fellow in Elder Law at the University of Western Sydney: "The *Act* is a voluminous tome comprising parts, divisions, chapters, sections, schedules and, in place of regulations, there are 22 sets of *Principles*, which also incorporate the standards to be met by approved providers of aged care."²⁵⁰ The *Principles* "not only address each aspect of the provision of care that is to be received by the resident but also set out the requirements to be met by the approved provider in areas such as approval, charges to the resident, accreditation, certification, sanctions and advocacy (for the resident)."²⁵¹

One of the *Principles* is the *User Rights Principles 1997*²⁵² which outlines the responsibilities of an approved provider to users and proposed users of the provider's services (e.g., security of tenure, complaint resolution).

Contained within the *User Rights Principles* is the *Charter of Residents' Rights and Responsibilities*. It covers issues of dignity and respect, individual choice, personal privacy, freedom of speech, culture and religion, safety and security, quality care and independence.²⁵³ The *Charter* also outlines the responsibilities of residents to: care for their own health and well-being as much as possible; provide adequate information about their medical history and current health; respect the rights and needs of other residents; and respect the rights of staff to work in a harassment-free environment.

The *Aged Care Act* establishes a national quality assurance framework for residential aged care. It is comprised of three parts: accreditation; monitoring of approved providers for compliance with the accreditation standards and other specific responsibilities to protect resident safety; and a complaints investigation scheme and support for users' rights.²⁵⁴

To be eligible for continued government funding, aged care providers are assessed against a list of standards established by the Aged Care Standards and Accreditation Agency, an independent body appointed by the Department of Health and Ageing. The Agency also monitors facilities through surprise visits, responds to complaints and imposes sanctions if the standards are not met. The accreditation process is voluntary, the incentive being that aged care homes have to be accredited to receive federal funding.

Prior to the 1997 accreditation scheme, Australia had a system of legally enforceable outcome standards.²⁵⁵ Commentators contend that services for the aged have been privatized under the new regime at the expense of the interests of the residents. For instance, accreditation now places greater demands on staffing, resulting in low staff levels, which directly affects quality of care. They also point out that the *Aged Care Act* system was devised in response to the effective lobbying by the service provider industry who found the older system to be adversarial and intrusive.²⁵⁶

Legal Protections

Consumer, Trader and Tenancy Tribunal

Each state has an administrative tribunal which adjudicates cases involving retirement villages. We will examine New South Wales's tribunal as a standard example. The Consumer, Trader and Tenancy Tribunal is an independent decision-making body which hears and decides applications for orders from both residents and village operators. The Tribunal has a Retirement Villages Division that specializes in retirement village matters. There is an application fee of \$32 although pensioners receiving other Government benefits, or Seniors Card holders, only pay \$5.²⁵⁷

Tribunal orders to settle a dispute can include:

- Compliance with the retirement village laws, the terms of a village contract, or a village rule;
- Varying or setting aside a term of a village contract if it conflicts with the retirement village laws;
- The re-instatement of a reduced or withdrawn service or facility;
- The payment of compensation;
- The termination of a residence contract;
- The payment of an amount of money;
- That steps be taken to remedy a breach of any village contract

- or rule;
- The performance of any village contract or rule; and
- The restraint of any action in breach of any village contract or rule.²⁵⁸

Health Care Complaints Commission

New South Wales has an independent Health Care Complaints Commission which “acts to protect public health and safety by resolving, investigating and prosecuting complaints about health care.”²⁵⁹ Complaints can be made about any health service provider in New South Wales, including registered practitioners and health service organizations (e.g., hospitals). Any person can make a complaint to the Commission, including the patient, parent or other concerned person. After making a complaint, the Commission has 60 days to assess the complaint. If the Commission finds that a health organization provided inadequate care, the Commission can make comments and/or recommendations. All recommendations are monitored.

Aged Care Complaints Investigation Scheme

Australia has both an internal and external system for the resolution of complaints about aged care services. All government subsidized aged care services are required to have an internal complaints system.²⁶⁰ However, if people are not comfortable with making an internal complaint, or the complaint cannot be resolved within the facility, they can contact the federal Aged Care Complaints Investigation Scheme.

Anybody can make a complaint about any aspect of a person’s care (e.g., food, nursing care, security, financial matters, hygiene, activities, choices, comfort and security) that may be a possible breach of the provider’s responsibilities.²⁶¹

The Complaints Investigation Scheme has the power to require the service provider, where appropriate, to take action within a prescribed time frame or refer issues to other appropriate resources (e.g., police, nursing and medical registration boards).

Critics claim that while the complaints scheme sounds effective on paper, it is flawed in practice. For example, the investigation process rarely substantiates the submitted complaints unless the investigator can point to a “smoking gun.”²⁶² Further, while the Complaints Investigation Scheme verifies the degree to which the facility’s systems and processes are in compliance with the Aged Care Standards, it does not investigate the actual complaints.²⁶³ The Aged Care Commissioner has stated that half of the Complaints Investigation Scheme

decisions that come to her office are flawed for failing to give reasons for rejecting complaints, poor investigative procedures and denials of natural justice.²⁶⁴

Aged Care Commissioner

The Aged Care Commissioner, a body independent from both the Department of Health and Ageing and the Aged Care Standards and Accreditation Agency, was recently established to examine complaints made about the Aged Care Complaints Investigation Scheme. The Commissioner may also examine complaints about the conduct of the Aged Care Standards and Accreditation Agency and persons carrying out audits, or making support contacts, under the *Accreditation Grant Principles 1999*. Finally, the Commissioner has the power to examine particular matters on its own initiative.²⁶⁵

Detractors of the Commissioner point to the limited powers of the Commissioner. Although the Commissioner is able to review Complaint Investigation Scheme decisions, the recommendations are not binding and can be rejected by the Department of Health and Ageing.²⁶⁶

Aged Care Advocacy Agencies

The *Aged Care Act* directs the Department of Health and Ageing to fund independent advocacy services in each state or territory through the National Aged Care Advocacy Program (NACAP). The services provided are free and confidential. The independent advocacy services are community-based organisations, which give advice about the exercise of the rights of older adults. Advocacy services also work with stakeholders in the industry to encourage the development of policies and practices which protect consumers.²⁶⁷

A NACAP Service Charter outlines the standard of advocacy service that clients can expect.²⁶⁸ Advocacy services can: provide clients with information and advice about their rights and responsibilities; support clients to be involved in decisions affecting their life; assist clients to resolve problems or complaints in relation to aged care services; and promote the rights of older people to aged care providers. The Service Charter is based on principles of autonomy and independence. It defines an “advocate” as “someone who works solely on behalf and at the direction of the client.”

According to the *Charter of Residents' Rights and Responsibilities*, service providers cannot deny a resident's right to an advocate and the provider cannot assume they can handle residents' problems on their own.

Community Visitors Scheme

The Australian Government also funds a Community Visitors Scheme that is managed by approximately 160 approved community based organisations in each state or territory.²⁶⁹ It is available to all recipients of aged care services, not just residential aged care and provides funding for the training of volunteers who act as community visitors. The recipients are usually identified by their aged care home as at risk of isolation or loneliness, due to disability or social or cultural reasons.²⁷⁰ The scheme is deemed to have “wide acceptance in the community and the aged care sector.” In 2007-08, funding for the Community Visitors Scheme was approximately \$8.85 million, with 7,500 funded visitors.²⁷¹

Community visitors add to the quality of life of the aged care home resident by providing friendship and companionship and minimizing the isolation that residents feel from the general community.²⁷² They visit the resident matched to them at least once every two weeks and undertake to do something together, which can be as minimal as watching television together. Community visitors can be from any background and are trained and matched by a local community service organization.²⁷³

UNITED STATES OF AMERICA

Regulation of Congregate Settings

Assisted Living Facilities

“The definition of ‘assisted living’ is far from clear” but it tends to be a loosely defined term which combines some aspects of both housing and care.²⁷⁴ Typically, assisted living facilities house residents cannot live independently but do not require nursing facility care. Assisted living is known by many different names, including senior housing complexes, residential care, board and care or personal care homes. It is estimated that there are between 20,000 and 36,000 assisted living facilities in the United States with approximately one million residents.²⁷⁵

The federal government does not set any quality standards for assisted living facilities. Instead, each state enacts their own laws and licensing requirements resulting in disparity between facilities in different states.²⁷⁶ For instance, in one state, an assisted living facility may offer “around-the-clock nurse staffing with the capacity to handle a resident with significant health care needs” while an assisted living facility in another state may be a “glorified board and care home, with few services beyond meals and housekeeping.”²⁷⁷ Facility operators also have

considerable discretion respecting discharges. The majority of state laws permit involuntary discharge when a facility cannot meet a resident's needs and it is the facility who decides whether particular needs can be met. In the words of one well-known elder law lawyer, "depending on the observer's perspective, the malleability of assisted living is either its greatest virtue or its most glaring weakness."²⁷⁸

The advantages of assisted living include: increased attention to residents' individual needs; fewer restrictions for operators (which, in theory, means that there is freedom to provide better care); and residents can stay longer and age in place since the facility can accommodate a wide variety of medical conditions. The disadvantages include: relatively flimsy quality of care standards due to a regulatory assumption that service provision will be determined by contract; the care or quality of life of residents may be reduced because the facility has to accommodate a wide range of medical conditions; and prices tend to be high and subject to unpredictable increases.²⁷⁹

Nursing Homes

Nursing homes, or nursing facilities, provide room, board, nursing services and assistance with activities of daily living.²⁸⁰

In response to increasing scandals about poor quality of care and a high incidence of elder abuse, Congress passed the *Nursing Home Reform Law* as a part of the *Omnibus Budget Reconciliation Act of 1987*. The objective of the legislation is to ensure that nursing home residents receive quality care that will result in their achieving or maintaining the "highest practicable physical, mental and psychosocial well-being."²⁸¹ It applies to every nursing home that is certified to accept payment from the Medicare or Medicaid programs, or both, even if the resident is not eligible for either program and is paying privately.²⁸² Further, the legislation includes a Bill of Rights which sets out the minimum requirements for the care of residents. The law also requires each state to maintain an inspection agency (which is often part of the state's Health Department) to certify nursing homes, issue state licenses and monitor compliance. Inspectors issue deficiencies when federal law violations are found and this can result in a range of sanctions. It has been said that "the long-term care industry is one of the most heavily regulated industries in the United States."²⁸³

Legal Protections

Enforcement of Federal Law

Compliance with federal nursing home law is generally monitored by state survey agencies. These agencies are also responsible for enforcing state law, including the issuance of state licenses, inspections and complaint investigations.

Federally-certified nursing homes must be inspected at least once every five years. The survey team is comprised of a multi-disciplinary team of professionals, including at least one registered nurse. The Centers for Medicare and Medicaid Services conduct follow-up validation surveys in at least five per cent of a state's nursing homes to ensure the state survey agency did an adequate job. If a regular survey indicates a "substandard quality of care" (meaning that there are concerns about individual or widespread harm to residents), state survey agencies must also complete an extended survey within 14 days. Each resident's attending physician must also be notified if an extended survey is completed.²⁸⁴

Whenever a state or federal surveyor observes a federal law violation, the deficiency is noted and the facility must submit a detailed plan of correction. All statements of deficiencies and plans of correction must be made available to the public by the state survey agency. It has been opined that a "plan of correction" is often a misnomer for what is actually a facility's unsubstantiated promise to do better in the future."²⁸⁵

Allegations of an immediate and serious threat to resident safety must be investigated by a state agency within two working days, while allegations of actual harm must be investigated within 10 days.²⁸⁶

The following remedies are available to enforce federal nursing home law: termination of the facility's participation in Medicare and/or Medicaid; denial of payment by Medicare and/or Medicaid for new admissions; temporary management; civil money penalties; transfer of residents; closure of facility and transfer of residents; and state monitoring.²⁸⁷

Five-Star Quality Rating System

The federal Centers for Medicare and Medicaid Services launched a rating system in late 2008 in which each nursing home in the country receives a rating from one to five stars.²⁸⁸ One star means "much below average" while five stars signifies "much above average."²⁸⁹ The system is intended to be a tool for consumers and caregivers to compare nursing homes more easily.

The ratings are based on three sources of data: inspection reports; staffing levels; and quality measures. The Centers for Medicare and Medicaid Services concedes that each source has limitations. For instance, there are variations

between states in the way inspection results are carried out. Also, both the staffing data and quality measures are self-reported by the nursing home rather than being reported by an independent agency.

The recommendation of the National Senior Citizens Law Center is for consumers to “use the new rating system with caution, and only as an aid while also pursuing other information and strategies.”²⁹⁰ The quality of a nursing home can shift from one month to the next so the rating system only represents a snapshot at one particular time.

Based on the rating system, almost half of nursing homes are “critically deficient” in the areas which are being measured.²⁹¹

Regulations respecting Antipsychotic Treatment

In response to the prevalence and misuse of antipsychotic therapies in nursing homes, regulations to the *Omnibus Budget Reconciliation Act of 1987* were passed to improve the quality of care in nursing homes. Based on a comprehensive assessment of a resident, nursing homes must ensure the following:

1. Residents who have not used antipsychotic drugs are not given these drugs unless antipsychotic drug therapy is necessary to treat a specific condition as diagnosed and documented in the clinical record; and
2. Residents who use antipsychotic drugs receive gradual dose reductions, and behavioural interventions, unless clinically contraindicated, in an effort to discontinue these drugs.²⁹²

Antipsychotic drug use declined by 30% to 36% after the implementation of these regulations but newer studies indicate prescription rates are on the rise.²⁹³

Long-Term Care Ombudsman Program

Each state must establish a Long-Term Care Ombudsman Program if it wishes to receive federal funds under the *Older Americans Act*.²⁹⁴ Every state has done so. The purpose of the Ombudsman Program is to respond to the needs of residents facing difficulties in long-term care homes, including nursing homes and assisted living facilities. Due to limited resources in many states, assisted living facilities are left relatively under-serviced by the Ombudsman Program.²⁹⁵ While the classic ombudsman model endorses neutrality, the Ombudsman Program was “designed for active democracy and representation of residents’ interests over those of other parties.”²⁹⁶ The Ombudsman Program has several

responsibilities, such as: identifying, investigating and resolving resident complaints; protecting the legal rights of residents; advocating for systemic change; and providing information to residents and their families.²⁹⁷ Additionally, the state may designate local ombudsmen who are considered to be representatives of the Office. The Ombudsman Program relies heavily on volunteer ombudsmen. In 2006, nine out of every ten staff were volunteers.²⁹⁸ State ombudsman programs also accept monetary donations from the public.

In 2006, the Ombudsman Program investigated over 285,000 resident complaints. The largest numbers of complaints received were about: unheeded requests for assistance; problems with discharge planning or eviction notification and procedures; lack of respect for residents by staff; inadequate care plans that did not reflect residents' conditions or did not involve families; and improper handling of residents that resulted in unexplained bruises or cuts.²⁹⁹

The National Long Term Care Ombudsman Resource Center provides support, technical assistance and training to the 53 State Long Term Care Ombudsman Programs³⁰⁰ and their state-wide networks of almost 600 regional (local) programs. The Center is funded by the Administration on Aging but operated by the National Citizens' Coalition for Nursing Home Reform in cooperation with the National Association of State Units on Aging.³⁰¹

The quality of the ombudsman programs varies greatly from state to state and even county to county. We will briefly examine the programs in Wisconsin and the District of Columbia as they are considered to be among the most successful in the country.³⁰²

The Long-Term Care Ombudsman in Wisconsin provides advocacy services and outreach to persons age 60 and older who are receiving long-term care services in nursing homes, assisted living facilities, the homes of older adults and alternate settings. There are 14 Ombudsmen who serve Wisconsin's 72 counties.³⁰³ Besides providing traditional services (e.g., investigating complaints, mediating issues and providing information to residents), the Ombudsman also: assist individuals with choosing a nursing home or residential facility; working with enforcement agencies; assists residents with obtaining financial assistance; and provides individual support during a care planning conference, a facility closure or other event adversely affecting one or more long-term care residence.³⁰⁴ The Ombudsman also relies heavily on Volunteer Ombudsman who makes unannounced weekly visits to an assigned nursing home. At the end of each visit, the Volunteer Ombudsman talks to the staff about their observations. The Volunteer Ombudsman program was recently expanded whereby volunteers now make visits to residential facilities as well.

The Inspector General of the United States Department of Health and Human Services ranked the Office of the District of Columbia's Long-Term Care Ombudsman as one of the two best ombudsman programs in the nation.³⁰⁵ This office contracts its ombudsman services from a community-based senior service agency, the Emmaus Services for the Aging. Emmaus has two full-time local Ombudsmen who advocate and investigate complaints on behalf of residents in nursing homes. Both local Ombudsmen are responsible for having a cadre of trained volunteer advocates to maintain a continuous community presence in the nursing facilities in their service areas.³⁰⁶ The District of Columbia Ombudsman Program uses an aggressive style of advocacy on a more frequent basis than is characteristic of other programs.

According to Sara Hunt, a consultant to the National Long-Term Care Ombudsman Resource Center, the successful ombudsman programs have all or some of the following characteristics:

- Using the ombudsman program complaint data as the basis for identifying and pursuing systemic advocacy;
- Tenaciousness, even if it takes several years to achieve change on behalf of residents;
- Whenever possible, working with other agencies and organizations, including other advocacy organizations, to gather support and to assist with developing strategies;
- Participation in several state level work groups, task forces, and committees to achieve change and to represent the needs of residents;
- Working with the media and issuing press releases to further their advocacy. The media often use the reports issued by the Ombudsman to identify issues for further in-depth reporting;
- Interaction with elected officials at the local, state and federal level;
- A history of continuity (low turnover and longevity) in the person who is the State Ombudsman and in the advocacy direction and management philosophy of the Ombudsman Program; and
- Retain legal counsel available as needed. Wisconsin and the District of Columbia have full-time legal counsel positions working with the program. The Washington State program has legal counsel that provides necessary support via a contractual arrangement. The other programs access counsel as needed. The Oregon and Georgia State Ombudsmen are attorneys.³⁰⁷

Eric Carlson, a leading American elder law lawyer, made the following observations about the strengths and limitations of the program:

The local Long-Term Care Ombudsman Program can be a valuable ally in a dispute with a nursing facility. Because Ombudsman Programs are designed to advocate on behalf of residents, Ombudsman Program representatives generally are more receptive than government surveyors to complaints against facilities. In addition, Ombudsman Programs often have an on-going relationship with facilities that give the Ombudsman Program leverage in coercing a facility into appropriate action.

On the other hand, Long-Term Care Ombudsman Programs have significant limitations. Unlike government survey agencies, Ombudsman Programs have no authority to assess penalties. Ombudsman Programs often are underfunded, and frequently rely on volunteer assistance. In addition, because Ombudsman Programs frequently operate within state government, they are vulnerable to political pressure.

In general, Long-Term Care Ombudsman Programs do a tremendous service for residents, but do not have nearly the resources to carry out all of their statutory duties. Too frequently, the nursing facility industry and (to a lesser extent) the federal government exaggerate the power of the Long-Term Care Ombudsman Program, in order to justify some relaxation in the substance or enforcement of nursing facility law. The Long-Term Care Ombudsman Program is a complement to – but not a replacement for – government survey agencies and private advocacy.³⁰⁸

Mediation

Mediation is a relatively new and growing dispute resolution technique which tends to be used most frequently in the context of guardianship applications. In the mid-1990s, the American Bar Association undertook a three year project respecting elder law mediation in nursing homes. The final report concluded that mediation has the “potential to give voice to residents, to improve their lives in nursing homes.”³⁰⁹

Legal Assistance

The *Older Americans Act* mandates states to provide “assurances that area agencies on aging will give priority to legal assistance related to income, health care, long-term care, nutrition, housing, utilities, protective services, defense of

guardianship, abuse, neglect, and age discrimination.”³¹⁰ Services are also to be targeted at older individuals with economic or social needs. The legislation requires each state to appoint a Legal Assistance Developer who is responsible for developing and coordinating the state’s legal services and elder rights programs. This means that the specific legal services offered in each state can vary widely.

Litigation

Nursing home litigation is considered to be one of the fastest-growing areas of health care litigation in the United States. It has been said that “private litigation can be a counterweight to the power held by long-term care facilities, particularly given the frequently limited efficacy of government enforcement.”³¹¹

Consumer protection statutes exist in every state and are used to create a private right of action.³¹² These statutes are particularly effective in supporting claims based on unethical financial practices or deceptive advertising and agreements.³¹³ However, courts in some states have held that these laws are only applicable to cases involving fraud or deception, and are unavailable for cases of negligence and malpractice.³¹⁴ Also, because nursing-home agreements are often regulated by state law, consumer protection laws from the same state may have specific exemptions for those agreements.³¹⁵

Probably the most common fact pattern in nursing home litigation are injuries arising from simple falls, either from a bed or wheelchair, or transfers from one to the other. Depending on the specific circumstances of the case, fall cases may be treated either as ordinary negligence or medical malpractice. The distinction will hinge largely on what the facility has outlined as its duties, and whether that includes medical assistance, as well as, on whether the fall occurred during medical treatment or some more mundane aspect of caring for the resident.³¹⁶ One factor that has seemed particularly relevant to the decisions in these cases has been the previous history of falls suffered by the resident, and the awareness of the facility of the risk posed by falling.³¹⁷

The award of damages varies considerably from state to state and from case to case. A national survey of nursing home litigators found that the average recovery for a claim is high – \$406,000 – twice the normal amount in medical malpractice cases. There are several cases where the court has awarded compensatory damages as high as half a million dollars.³¹⁸ At the same time though, other plaintiffs who have suffered similar injuries have been awarded substantially lower judgments, based on the fact that cognitive and emotional impairments may have impeded the ability of the plaintiff to understand or appreciate the injuries that were inflicted.³¹⁹ In one case causing death, the jury

awarded two million dollars, a verdict that was upheld on appeal, to compensate a son for the loss of his mother's companionship and as compensation for the pain she must have felt before death.³²⁰ In Texas, a plaintiff was awarded three million dollars for physical pain and another seven million for physical impairment, even though the plaintiff's daily routine remained largely unchanged.³²¹ Punitive damages have been even higher. In Arkansas, in the case of *Advocat, Inc. v. Sauer*, the jury awarded \$78.4 million (although it was reduced to \$26.4 million on appeal) on the basis of negligence where a nursing home resident suffered dehydration and malnutrition.³²²

Several states have enacted elder abuse statutes to encourage litigation pertaining to older adults. In California, if a defendant abuses an older adult and is guilty of recklessness, oppression, fraud or malice, the plaintiff may be entitled to enhanced remedies, including damages for pain and suffering, even after death, as well as attorney's fees. Further, elder abuse causes of action against nursing facilities are not subject to the three year limitation period that applies to other health care malpractice actions.

Bill of Rights and Private Rights of Action

As previously noted, the federal *Nursing Home Reform Law* establishes a comprehensive Bill of Rights for nursing home residents. In addition to the rights afforded by the federal government, individual states may enact their own Bill of Rights to enhance the protections afforded to residents.

Some states also provide for private rights of action for residents. For example, New York permits residents of residential care facilities to seek compensatory damages in an amount sufficient to compensate a resident who has been deprived of a right or benefit with minimum damages fixed at 25% of the daily per-resident rate of payment.³²³ Residents are also entitled to seek legal fees and punitive damages where the deprivation is wilful or in reckless disregard of the lawful rights of the resident. In Florida, residents of both residential care facilities and nursing homes have private rights of action. Each statute permits the awarding of damages for actual and punitive damages, plus legal fees, if the resident's rights have been violated by the facility.³²⁴ If the actions of the facility have allegedly caused the death of the resident, plaintiffs must choose between wrongful death damages or damages based on the pain and injury suffered by the resident before their death. A resident's right of action does not prohibit a separate cause of action for negligence. In New Jersey, violation of nursing home statutes can result in special verdicts, such as treble damages (where twice or three times the amount of damages that would normally be recoverable is awarded to the plaintiff).³²⁵

CONCLUSION

There are numerous similarities, nationally and internationally, respecting both the regulation of congregate settings for older adults and residents' rights. In fact, Ontario may have a better developed system in some areas than many other jurisdictions. However, our system is not perfect and we should not be complacent.

Hospitals in Ontario have limited oversight as compared to the other jurisdictions we examined. Although complaints can be made about an individual health practitioner to their respective College, complaints cannot be made to a third party about the hospital as a whole or the care provided by the treatment team. Outside Ontario, recourse against hospitals can be sought from the Ombudsman (i.e., British Columbia, Alberta and Nova Scotia), Citizens' Representative (Newfoundland), Health Care Inspectorate Wales or Health Care Complaints Commission (Australia). The only other jurisdiction without an independent oversight body for hospitals is the United States. Given the amount of public funding for hospitals, we find this both remarkable and troubling. Furthermore, the ability of the average citizen to complain about issues in hospitals is precluded by the dearth of independent avenues to which to complain. Even the Ministry of Health and Long-Term Care will not deal with individual complaints about care in hospitals, despite being the funder. The only option is litigation, which may be either inappropriate, or out of financial reach for most complainants.

Turning to retirement homes, we studied four jurisdictions which employ a system similar to Ontario where there is no government funding or regulation unique to retirement homes (i.e., Nova Scotia, Wales, Australia and the United States). Three provinces (i.e., British Columbia, Alberta and Newfoundland) provide monies to residents of retirement homes and/or regulate these facilities although the types of regulation do not focus on the rights of residents in those settings or seem to provide effective remedies that the residents themselves can pursue to address residents' issues. Tenancy rights are not included in the legislation nor are there specific consumer rights protections.

Although mechanisms to provide oversight of this type of congregate living may exist in other jurisdictions, it is important to look at their limitations to determine whether it addresses residents concerns. For example, the British Columbia Registrar of Assisted Living cannot investigate complaints related to many issues of particular concern to assisted living residents including tenancy issues and assessments for eligibility for publicly subsidized assisted living. While

Newfoundland has a licensed and highly regulated system, the Auditor General has identified several areas requiring improvement.

Facilities comparable to long-term care homes in jurisdictions outside Ontario also receive partial government funding and are highly regulated. Although Ontario appears to be one of the few places to have a telephone hotline to report concerns (Alberta has a hotline but only for reporting abuse), or a clearly articulated Residents' Bill of Rights, it is lacking in oversight independent of the Ministry of Health and Long-Term Care. In contrast, if a person is dissatisfied with the way in which a complaint was handled by the Aged Care Complaints Investigation Scheme in Australia, a complaint can be made to the Aged Care Commissioner. In the Canadian provinces we studied, the Ombudsman has jurisdiction over the majority of long-term care homes.

Ontario does have independent advocacy resources, such as ACE and Concerned Friends and other non-governmental organizations, but there is no independent government agency which helps individuals navigate this complex system or examines systemic issues. The existing organizations, which can be highly effective, are limited in their scope and ability to handle complaints due to limited staffing and volunteer levels and geographic restrictions. Meanwhile, there is an Older People's Commissioner for Wales who examines systemic (but not individual) concerns. The Australian Aged Care Commissioner has the authority to examine certain matters on its own initiative, as does two provincial Ombudsmen in Canada (i.e., Nova Scotia and Newfoundland). The Ombudsman in British Columbia and Alberta can launch systemic investigations respecting areas within its jurisdiction for which it has received complaints. Although the United States has a Long-Term Care Ombudsman Program, state ombudsmen tend to not to be an office of last resort but more comparable to an advocacy program.

One area which is lacking in Ontario is the ability of residents or their families to be awarded compensation if the resident is harmed. It would appear that when it comes to litigation for negligence and malpractice in long-term care homes, the United States is the jurisdiction which makes it most worthwhile to pursue these cases. While we do not necessarily recommend the same huge punitive damage awards in Canada, we must acknowledge the utility of a civil litigation system which recognizes the inherent value of its citizens.

ACCESS TO JUSTICE: A MODEL FOR ONTARIO

Building on our experience and research, supported by the input of stakeholders, ACE submits that the failure to respect and protect the rights of older people residing in congregate settings occurs due to three primary factors: the power imbalance between older adults and service providers; the limited awareness of legal rights by both older adults and service providers; and ageism. To overcome these barriers, ACE recommends a multi-pronged access to justice model which is consistent with both our expansive interpretation of access to justice and a principled framework, as follows:

1. The independence, participation and security of older adults residing in congregate settings must be encouraged by providing them with the necessary information to understand their rights. As well, enhanced education must be delivered to staff and service providers across the province to ensure they: understand the rights of residents; respect those rights in their daily practice and facility policies; and disseminate the correct information to residents, family members and new staff.
2. An independent Health Care Commission responsible for the provision of education, individual advocacy and systemic advocacy in hospitals, long-term care homes and certain retirement homes³²⁶ should be created. By having an independent third party assist residents with their questions and concerns, the Health Care Commission would promote the dignity and security of older adults. Individual advocacy would also foster the increased participation of older adults in their own decision-making about their care and accommodation. The education and advocacy functions of the Health Care Commission would also support respect for diversity by breaking down stereotypes and challenging discriminatory practices.
3. The jurisdiction of the provincial Ombudsman should be expanded to include hospitals, long-term care homes and certain retirement homes. ACE anticipates that the increased level of education and the assistance of advocates from the Health Care Commission would reduce the number of complaints to the Ombudsman. Nevertheless, oversight by the Ombudsman would provide an extra level of review for a population that is often otherwise marginalized.

4. The regulation of the retirement home industry is necessary to ensure that quality care is provided to residents, as well as creating effective mechanisms to enforce residents' rights. Retirement homes that offer the same level of care services as long-term care homes should be regulated under the same legislation as long-term care homes, while all other retirement homes should be licensed in accordance with the levels of care services they make available. Included in this scheme would be a government-run complaints system to enforce the regulation of retirement homes.
5. The government needs to hear the voices of residents and their representatives to make certain that regulations and policies are meeting their needs. To accomplish this, the government should be required to form provincial advisory groups comprised of residents and their representatives and to meet with them on a regular basis.
6. Older adults must be afforded security of the person and be made aware of their legal rights in the event of findings of incapacity. The law governing capacity should be amended to require health practitioners to provide more detailed information on regulations to persons found incapable respecting treatment and admission to long-term care.
7. The transparency of the compliance and enforcement regime needs to be improved by strengthening the education, skill-sets and qualifications of compliance advisors. Detailed inspection reports should be made easily accessible to the public, by posting them on the internet and providing a central office from which hard copies can be obtained. Complainants should be provided with copies of the findings and reports of their own complaints.
8. To encourage meritorious litigation, the laws pertaining to damages in the civil system should be changed to permit actions without proving damages in the traditional context and allowing the court to award general damages.

Education

First and foremost, we consistently heard from all stakeholders that they lacked awareness of residents' legal rights. Not only are these rights not known by the residents, their friends and family, but staff and management of the various congregate settings do not have a basic understanding of residents' rights. As a result, many policies and practices in congregate settings may either be created without reference to the law or based on a misinterpretation of the law.

Without this awareness of residents' rights by both seniors and service providers, residents are restricted in exercising their independence. The structure of congregate living settings often reinforces ageist stereotypes about older adults (e.g., all older adults in long-term care homes are sickly and incapable of making treatment decisions).

The lack of information about residents' rights, coupled with policies that fail to reflect these rights, limits the opportunities of older adults to participate in a meaningful way at both an individual and group level. In turn, this affects the security of residents, as the environment in which they live may be overly restrictive. Although the principle of security includes an element of protection, that protection and care must be balanced, as overprotection may be abusive.

As previously discussed in this paper, Ontario has good law but bad practice. One way to combat this phenomenon is to equip residents with accurate and accessible information on a regular basis. Armed with this information, residents are in a better position to exercise their rights and force "good practice."

We received several suggestions from stakeholders about ways in which to facilitate education and empower residents:

- Ensure hospital staff, especially discharge planners and social workers, are providing accurate information to older adults;
- Community Care Access Centres should be providing information about the rights and responsibilities of residents, substitute decision-makers and family members prior to admission to long-term care;
- Electronic resources, such as Youtube, should be utilized to provide information;
- Family Councils should take some responsibility for organizing information sessions about the rights and responsibilities of residents and family members;
- Standardized educational tools should be developed to save resources and to relay a consistent message;

- ACE should create more educational tools for residents and staff;
- Lobby law schools to offer elder law courses and expand their clinical programs to include elder law;
- Lawyers knowledgeable in the relevant areas of law should be retained to prepare and/or review educational tools;
- Information about the rights of older persons residing in hospitals should be posted in visible areas;
- Health professionals and health organizations should provide training in the area of residents' rights; and
- The educational requirements contained in the *Long-Term Care Homes Act, 2007* should be capitalized on. The Ministry of Health and Long-Term Care should develop specific educational programmes outlining the expectations in the area of training regarding residents' rights.

ACE's Recommendations

The importance of education cannot be overstated: information is power. The source of many of the problems encountered in congregate settings is poor education and the lack of accurate information.

The most important principle that needs to be conveyed to all stakeholders is the fact that seniors are people. Older adults are presumed to be capable of making decisions, and they have the right to make foolish decisions, just as people living outside a congregate setting do. ACE is of the opinion that many staff members and some families do not understand that older adults are allowed to take risks or make foolish decisions. Educational resources need to emphasize that residents' rights are a two-way street: not only do they recognize the independence and autonomy of residents, but they protect staff from liability. For example, the fact that a capable resident is at risk of falling does not entitle staff to restrict the person from walking altogether. By resorting to unlawful actions to "protect" the resident, the staff violates the law.

ACE recommends the development of a standard curriculum, along with comprehensive training respecting residents' rights, for residents, families and staff of long-term care homes. Residents' rights information should be broadly interpreted to include information on related legal issues such as privacy rights, access to information, substitute decision-making and consent; it should not simply focus on long-term care home legal issues. The training should include segments on care issues that impact resident rights, such as dementia, mental capacity and care planning, as an understanding of this clinical information impacts the application of residents' rights. Long-term care home licensees

should be obligated to provide and make available both training to staff and information to residents and their families about residents' rights pursuant to the *Long-Term Care Homes Act, 2007*.

We believe the Ministry of Health and Long-Term Care should develop and design standardized training tools to ensure consistency, although this should be done in collaboration with ACE, industry stakeholders, Residents' Councils and Family Councils. This also has the benefit of not permitting any one player to selectively choose the information being relayed.

Education needs to be ongoing and held at times when individuals can properly process the information. Thus, there should be regular meetings provided by Residents' Councils, Family Councils and/or advocates for residents and families. These meetings would be voluntary so individuals could attend as frequently, or infrequently, as they please.

Similar education programs should be developed for retirement home tenants and staff, focusing on retirement home tenancy rights and obligations. ACE recommends that retirement homes offering the same levels of care as long-term care homes be subject to the provisions of the *Long-Term Care Homes Act, 2007* (see pages 102 to 106 for a detailed explanation about ACE's proposal for the regulation of retirement homes) and, as such, the same educational programs as described above should be required. As ACE is also recommending provincial licensing of retirement homes that offer lesser levels of care services, similar education programs respecting tenants' rights for residents, families and staff of retirement homes should be developed by the Ministry responsible for licensing of those retirement homes. This should be done in collaboration with ACE, the industry and representatives of retirement home tenants. Licensed landlords of such retirement homes should be obligated to provide and make available this training to staff and information to tenants pursuant to the legislation governing retirement homes.

Professionals, such as physicians and lawyers, also need to be better educated about the rights of residents as they are gate-keepers of information. Thus, ACE recommends that medical schools revisit their curriculum to include more information about the laws pertaining to consent to treatment. Law schools should be encouraged to offer courses on elder law and consider developing clinical programs. An example of such a program is the Center for Excellence in Elder Law at Stetson Law School in Florida, which offers opportunities for specialized courses and research projects for students who wish to focus their studies on elder law.³²⁷ The Law Society of Upper Canada and the legal profession should also provide more opportunities for continuing legal education respecting elder law.

Given the prevalence of paternalism and negative stereotyping, ACE is supportive of a general media campaign to combat myths and raise awareness about issues affecting older adults. As the majority of people do not think about the rights of residents living in congregate settings until it is time for themselves or a friend or family member to move into such an environment, ACE does not believe a media strategy directed at the rights of residents would be practical at this point in time. Nevertheless, issues which pertain to both areas should be incorporated into a public education campaign (e.g., the right to give informed consent to treatment, the presumption of capacity and the right for people to make their own choices).

The Health Care Commission

Very often, people living in institutional settings are unable to speak for themselves. This may not be because they are mentally incapable of doing so, but rather, due to the circumstances in which they find themselves. For example, because of a medical condition, residents may rely heavily on their caregivers to assist in their activities of daily living. The resident may be afraid that if they speak up, they will lose their services or experience retaliation by the caregiver. In other instances, due to the isolation experienced in long-term care homes, residents may be unaware of their rights. Residents living in locked units are particularly vulnerable to potential injustices. The majority of residents in locked units rarely leave the unit: they eat their meals, complete their programming and see their doctors within the unit. Most residents in locked units do not have access to telephones and typically can only use the telephone at the nursing station with their permission. Thus, it is often very difficult, if not impossible, for these residents to seek outside assistance. Residents in both locked and unlocked units may accept questionable situations because they are unaware of alternatives or they feel powerless. In these instances, an advocate may be able to act on the person's behalf to seek change and protect the person's rights.

The concept of third party advocacy to assist individuals who may be vulnerable is not novel. In fact, the Ministry of Health and Long-Term Care itself recommended some form of third party advocacy for seniors in long-term care homes.³²⁸ The Law Commission of Ontario's preliminary consultation revealed that a number of organizations recommended that the Law Commission "examine the desirability and feasibility of some type of individual advocacy for older adults."³²⁹ For example, the Prevention of Senior Abuse Network – Simcoe County said: "Legislating the availability of Senior Advocates would alleviate some of the anxiety and help them navigate through often complex and

intimidating systems.”³³⁰ The Ontario Network for the Prevention of Elder Abuse stated:

In order to secure and assert the rights of older adults, the system should establish a regulatory regime outside the civil service that will have its own director and devoted entirely to problems of elderly people...This regulator will ensure that the checks and balances are adequate and they are effectively enforced in a manner that is timely and that the assets of older adults are protected.³³¹

Other countries have also commented on the need for advocacy for older adults, including the Office of Fair Trading in Wales:

The experience of groups who are involved with advocacy is that older people find complaints procedures more accessible when an advocate is working on their behalf. Advocacy allows them to make their voice heard more easily and they can enjoy support through difficult situations they may not otherwise have had the confidence or ability to address. Advocacy can also prevent complaints from escalating by providing a source of mediation between the care home and resident, ultimately resolving issues more quickly to everyone's benefit. By actively demonstrating that they promote and encourage the use of advocates by residents, care homes could develop an advantage over other homes less keen to do so.³³²

This section of the paper will define advocacy and explain the different types of advocacy before briefly discussing Ontario's defunct Advocacy Commission. Finally, ACE will put forward its proposal to establish an independent Health Care Commission with health care advocates who will perform both individual and systemic advocacy.

What is Advocacy?

Advocacy is defined in the *Oxford English Dictionary* as “the function of an advocate; the work of advocating; pleading for or supporting.”³³³ Advocacy has also been defined as “an activity which involves taking up the case of an individual or group of individuals as speaking on their behalf to ensure that their rights are respected and their needs are met.”³³⁴

Individual or instructed advocacy simply means acting on behalf of an individual. The advocate is instructed directly by the individual or the appropriate substitute if the person is incapable. Systemic advocacy is advocacy on behalf of a group

of people with the same or similar interests and can include such activities as seeking changes to policies or legislation. Acting on behalf of an individual or group, in the best interests of those involved, when it is without instructions from anyone, is non-instructed advocacy.

The Advocacy Commission

In 1987, a government document known as the O'Sullivan Report concluded that advocacy was needed in Ontario. Two of its major findings were as follows:

The concept of "vulnerability" can create a need for advocacy as the vulnerable are often dependent on others which will leave them susceptible to abuse, neglect or abandonment. Institutionalization creates vulnerability by eroding a patient's last resident's rights to self determination and independence.³³⁵

The New Democratic Party government subsequently passed the *Advocacy Act* in 1992. In addition to increasing the number of mandatory rights advice situations to 29 (there are currently only eight situations), this legislation established a formal system of advocacy by creating an Advocacy Commission where employees would act as advocates for vulnerable people, either individually or collectively. The *Advocacy Act* was intended to cover an estimated 600,000 adult residents of Ontario who experienced either moderate or severe mental or physical disabilities and found it difficult, or were unable to, express or act on their wishes or to ascertain or exercise their rights.³³⁶

The Advocacy Commission was an independent body which administered the legislation. A majority of the members of the Commission were persons who either were, or had been, vulnerable. Selection of the members involved a complex community consultation process for nine of the members while the remaining four members were appointed directly by the Minister.³³⁷ The advocates were Schedule III employees, meaning they had no direct links to the permanent civil service.³³⁸

Regrettably, the Advocacy Commission ultimately failed and the legislation was repealed by the succeeding Conservative government led by Mike Harris. It is important to review why the Advocacy Commission did not succeed so that ACE's proposal does not duplicate their mistakes. Ernie Lightman and Uri Aviram studied the Advocacy Commission and arrived at the following conclusions about its failure:

We argue that the demise of the *Advocacy Act* in Ontario resulted in part from the government's attempts to do too much. The coalition

that initially promoted the law tried to achieve too much in the legislation, beyond the capacity of the social, organizational, professional and political environment to absorb it. We also suggest in this paper that the government acted too late. Even if certain aspects of the legislation might have had a chance of long-term survival in some form, the government was too late in starting the implementation process of the law. The administrative, bureaucratic, and political processes associated with the passage of the bill were cumbersome and even sloppy, to the point that the legislation was present through the government's entire five-year term. Although the act received final reading in the legislature and royal assent in December 1992, it was not ultimately proclaimed until April 1995, only months before the next election, which the incumbents were certain to lose. As a result, the act never really had a chance to garner public support and show what it could do. The combined effect of "too much" and "too late" were more than a government that held limited popular support could accommodate within a deteriorating economic environment.³³⁹

The legislation was also criticized for its potentially intrusive nature. Advocates were permitted to enter private residences, on occasion, without a search warrant. The concept of uninstructed advocacy was controversial as it was unclear "who had the right to make what interpretations about the wishes of consumers who could not express themselves clearly."³⁴⁰

After the repeal of the *Advocacy Act*, the Conservative government commented that it was minimizing the role of government in people's lives and putting decision-making "back where it belongs, in the hands of individuals and their families."³⁴¹ Evidently, the Harris government was excluding those residents who were unable to self-advocate or did not have any friends or families to advocate on their behalf from having a role to play.

Stakeholder Feedback

Throughout our focus groups with residents and families of long-term care homes, ACE consistently heard that some form of third-party advocacy where advocates went directly to the homes to meet with residents would be beneficial. Many residents stated they were afraid to voice their concerns for fear of retribution or being labelled a troublemaker. A number of residents complained that their concerns were ignored until a family member became involved. Several family members explained that they were only able to notice and prevent problems if they were at the home on a daily or regular basis.

One Family Council proposed that each home be required to appoint a Rights Officer who would be responsible for: (1) ensuring that the home has policies and procedures which complied with the legislation regarding the Residents' Bill of Rights; (2) ensuring that the Bill of Rights was promoted, distributed and carried out; (3) educating staff about the Bill of Rights; and (4) answering questions about the Bill of Rights from residents, staff, families and persons of importance to the resident. The Family Council also supported the appointment of a Seniors' Ombudsman.

As many long-term care home residents moved directly to a long-term care home from hospital, or previously stayed in a rehabilitation unit or other hospital-based unit, several stakeholders commented about problems experienced by older adults in hospitals. For example, patients are often not provided with accurate information about their health care options (e.g., first available bed policies). Further, it is very difficult for patients to navigate hospital rules and policies regarding admission to specialized units, such as complex continuing care and rehabilitation. Although social workers or hospital patient representatives are supposed to assist patients, they are often overworked or constrained by hospital administrations which attempt to limit the numbers of patients utilizing expensive health care beds to meet budget limitations. Social workers and hospital patient representatives are also paid employees of the hospitals and as such, often feel obligated to follow and enforce hospital policy or risk jeopardizing their employment, even if they believe that the policies conflict with patients' rights.

While the seniors groups with whom we consulted were supportive of independent advocates, industry stakeholders had some reservations about this approach. First, they disliked the terms "advocate" or "advocacy" because they felt it had an adversarial or confrontational connotation. Second, they felt that if advocates only visited homes periodically, they would not have a comprehensive understanding of the situation in the home but merely a snapshot. Third, they were of the opinion that advocacy services would duplicate the new compliance regime under the *Long-Term Care Homes Act*, where inspectors will be expected to speak directly with residents and families. Fourth, they felt that the staff at long-term care homes needed their own advocate.

ACE's Recommendation: The Health Care Commission

ACE believes that the provincial government should establish an independent Health Care Commission to support patients in hospitals, residents of long-term care homes and residents of licensed retirement homes regulated under the long-term care home legislation.³⁴² ACE also feels that the Health Care Commission's mandate should include access to home care services in the community but it is beyond the scope of this paper to discuss this issue. The

Health Care Commission would be responsible for rights education, independent advocacy and systemic advocacy in health care settings.

In researching the various jurisdictions, we did not find one which had an overarching Health Care Commission with the responsibilities which we are proposing. Some models did provide support but we suggest that they do not go far enough.

British Columbia has the Office of the Assisted Living Registrar. This body takes complaints from residents of assisted living facilities but it has no role in complaints about community care facilities. The Registrar is not an advocate for residents but an educator, mediator and licensor of assisted living facilities. The fact that one of its mandates is to “mediate” issues is contrary to our proposal for the Health Care Commission.

Alberta has the *Protection for Persons in Care Act* but it is also limited. It does not investigate any complaints from private operators nor does it provide advocacy services. Investigation reports are submitted to Alberta Seniors and Community Supports who makes a determination about what action, if any, will be taken. Sanctions can only be levied in those cases involving “intent” to abuse persons in care, thereby omitting situations where abuse, although not intentional, should not have occurred. Alberta also has a Health Facilities Review Committee which has an extremely narrow mandate. Complaints are often not thoroughly reviewed due to issues of consent. Moreover, any type of systemic investigation by the Health Facilities Review Committee appears to be prohibited.

Wales is the only jurisdiction which has an Older Person’s Commissioner. This office is independent of the Crown and has a broad mandate to ensure the protection of vulnerable older adults. While the Commissioner has investigative authority and can review public bodies of all types of determine whether they meet the needs of older persons, her involvement in individual claims is limited to cases of general relevance, even if there is no other body which can deal with the problem.

Finally, New South Wales in Australia has several bodies which deal with health care complaints. First, the Health Care Complaints Commission, an independent body, can accept and investigate complaints about any health service provider in the state. Second, the Aged Care Complaints Investigation Scheme has authority to investigate complaints and direct the service provider to take action. Unfortunately, as with the complaints investigation scheme in Ontario, the substantiation of complaints is difficult without indisputable evidence. A third investigative body, called the Aged Care Commissioner, was established in

response to complaints about the Aged Care Complaints Investigation Scheme. The Commissioner may review the conduct of the Aged Care Complaints Investigation Scheme and examine issues of her own initiative. However, the limited scope and non-binding authority of this body is less than ideal.

Each state in Australia has an Aged Advocacy Agency which provides free and confidential advocacy services to older adults. Further, a community visitor's scheme provides funding for visits to residents living in care, which provides support and a watchful eye for those who may not have any other support.

In the United States, each state has a Long-Term Care Ombudsman. We suggest that this system is more similar to an advocacy model than the classical Ombudsman which we have in Canada. The efficacy of each Ombudsman program differs from state to state and most programs heavily rely on volunteers.

Looking at these models from other jurisdictions, while each has its interesting aspects, none completely meets the requirements as identified in this project.

ACE does not support the creation of a specialized Seniors' Advocate. While some jurisdictions, such as Wales and Australia, have limited their services to older adults, we do not believe this is the correct approach. We discourage a framework based on the perception that older adults lack capacity and need protection. Simply stated, older adults are people. ACE believes that all people navigating the health care system could benefit from the services of an advocate, regardless of age. We want to move away from ageist stereotyping towards a rights-based approach. Moreover, as there is no generally accepted definition of an older person, younger individuals residing in long-term care homes or in hospital would be precluded from obtaining assistance from a Seniors' Advocate. For example, while many of the issues experienced in long-term care will be almost exclusively faced by elderly persons, this is not universal. The minimum age for residents in long-term care homes can be as young as 18 years of age, and it would not make sense to restrict their access to advocates on this artificial basis.³⁴³ Given the lack of supportive housing, many retirement homes have also become home to younger disabled persons who should also be able to access this service.

ACE envisions a structure for the Health Care Commission similar to the Office of the Provincial Advocate for Children and Youth. According to the *Provincial Advocate for Children and Youth Act*, the Provincial Advocate is an independent officer of the Legislature whose purpose is to: provide an independent voice for children and youth; encourage communication between children and families and service providers; and educate children, youth and their caregivers regarding the rights of children.³⁴⁴ Advocates receive and respond to concerns from children,

youth and families who are seeking or receiving services under the *Education Act* and the *Child and Family Services Act*.³⁴⁵ The Provincial Advocate is also able to: identify systemic problems involving children; conduct reviews and provide education and advice on the issue of advocacy and the rights of children.³⁴⁶ The Provincial Advocate is obligated to present a written report about the office's activities and finances, as well as whatever he or she considers appropriate, to the Speaker of the Legislative Assembly on an annual basis.³⁴⁷

The Health Care Commission should also be an independent office of the Legislature to reduce any conflicts of interest. The organization would be lead by a Provincial Health Care Advocate who has significant experience in the areas of health and social justice and who does not have any financial affiliations with the hospital, long-term care and retirement home industries. The Provincial Health Care Advocate would be responsible for the oversight of health care advocates working in hospitals, long-term care homes and retirement homes providing a particular level of care. Based on the information provided by the individual advocates, the Provincial Health Care Advocate would perform systemic advocacy. Finally, the Provincial Health Care Advocate would publish annual reports for the Speaker of the Legislative Assembly, in addition to any other reports for the public that he or she felt was necessary.

Due to the fact that hospital patients and long-term care residents often have limited mobility or are unable to leave the facility, ACE believes it is imperative that advocacy services be provided directly to individuals where they are situated. ACE appreciates that it would not be economically feasible to have full-time Health Care Advocates in each hospital, licensed retirement home providing a particular level of care or long-term care home located across the province. We suggest that an advocate be assigned a geographic area where they are responsible for a certain number of smaller hospitals and homes. The advocate would then visit the hospital or home on a regular basis (e.g., biweekly, monthly or as needed due to the circumstances of residents). A full-time advocate should be assigned to larger hospitals due to the size and constant turnover of patients.

In terms of the qualifications of Health Care Advocates, they should possess a university degree, in addition to other skills, such as experience in social justice, advocacy, conflict resolution and the advancement of human rights. It is not intended that advocates be lawyers, although lawyers are not precluded from being advocates. It will be integral, however, for the Health Care Commission to retain legal counsel to provide necessary legal advice to the organization. Further, the advocates must be employees, not volunteers. While many jurisdictions use volunteers for this purpose, we do not believe this is appropriate for a number of reasons. First, the dedication and retention of volunteers is difficult to maintain. Many volunteers start with great enthusiasm but it later

fades. Second, volunteers cannot always be relied upon to perform tasks on an ongoing basis as other obligations in their lives may take priority. Finally, individuals providing advocacy services should receive appropriate remuneration commensurate with the importance of their work. ACE wants advocates to be well-educated in their area of expertise, who are dependable and can bring a wealth of knowledge and experience to their position. We believe this can only occur with paid advocates.

A key component of the work of the advocates would be education. For instance, advocates could provide information sessions for residents, families, staff and management, in addition to working with Residents' and Family Councils to design and disseminate information.

It is important to draw attention to what ACE perceives as the main principles underlying individual advocacy:

- The advocate should respect the individual as an autonomous being;
- The relationship between an advocate and a client is voluntary and consensual;
- The substitution of the advocate's own view with the "best interests" of the client is unacceptable;
- The advocate should empower the person being assisted and support self-advocacy;
- The advocate should follow the instructions of the person being assisted. It is not the role of the advocate to impose the advocate's own values or goals upon the client;
- The advocate should try to resolve issues in the least adversarial and intrusive manner possible by attempting to be non-adversarial in dealing with other parties and using the least intrusive methods possible to resolve issues; and
- The advocate must maintain confidentiality.

The advocate should assume that the person is competent to give instructions unless the advocate has reason to believe otherwise. However, in some cases, a person may be incapable of giving instructions. Where a person is not capable of giving instructions on the issue at hand, the advocate may take instructions from the substitute-decision maker. The advocate must always remember that they are still acting on behalf of the client, not the substitute decision-maker. Where the advocate suspects that the instructions given by the substitute decision-maker are not what the client would have wanted, the advocate must weigh the matter carefully. Where they believe the substitute decision-maker is

not acting appropriately, the advocate should stop following the substitute decision-maker's instructions.

The issue of non-instructed advocacy tends to be contentious because the advocate might substitute their subjective beliefs for those of the resident or intervene in a situation without a full understanding of the individual's unique circumstances and care needs. Alternatively, unbeknownst to the health advocate, there may be a reasonable explanation as to why a resident is being treated in a particular way.

Having said that, non-verbal and incapable residents are the people who are at the greatest risk of having their rights trampled. The work of the local Health Care Advocates with this population would be systemic in nature to avoid the pitfalls associated with traditional non-instructed advocacy. If advocates became aware of systemic problems, they would collect statistics and provide information to the Provincial Health Care Advocate who would then publish reports to expose these issues. If the advocate determines that an incapable resident requires immediate assistance, they could make referrals to the appropriate services, such as:

- Invoking section 25(1) of the *Nursing Homes Act* which requires non-residents who have reasonable grounds to suspect that a resident has suffered or may suffer harm as a result of unlawful conduct, improper or incompetent treatment or care or neglect, to immediately report the suspicion and the information upon which it is based to the Director at the Ministry of Health and Long-Term Care;
- Calling the ACTION Line and/or a compliance advisor;
- Contacting the Office of the Public Guardian and Trustee as sections 27 and 62 of the *Substitute Decisions Act* mandates the Public Guardian and Trustee to investigate allegations that persons incapable of managing their property or personal care are experiencing or may experience serious adverse effects; and
- Notifying the police.

Opponents of the Health Care Commission in long-term care homes might argue that it is replicating the work of the Ontario Health Quality Council (which will soon be reporting on the quality of care in individual homes). However, the work of Health Care Commission can be differentiated because it is providing direct advocacy to individual complainants while the Ontario Health Quality Council is studying the quality of the entire long-term care home sector.

Others may contend that a Health Care Commission would duplicate the Office of the Long-Term Care Homes Resident and Family Adviser. Section 37 of the *Long-Term Care Homes Act, 2007* says the Ministry “may” establish such an Office to: assist and provide information to residents, families and others; advise the Minister; and other duties as assigned or stipulated in the regulations. To date, very little is known about this Office. The government, to our knowledge, has not released any information with respect to its plans for the Office. In fact, the government is not even required to establish such an entity, as the wording of the statute is permissive, not mandatory. Even if the Ministry did establish this Office, ACE stresses that its purpose is not to provide advocacy. Further, it is not independent as it exists at the pleasure of the Minister, who could cease its operations if he or she felt threatened by the Office.

It might be argued by critics of the Health Care Commission that such an entity is an attempt to revive the Advocacy Commission. ACE contends that the Health Care Commission has a narrower mandate, focusing on providing advocacy services to those individuals who are interacting with the health care system. The Advocacy Commission, in contrast, was not limited to health care but had the authority to help any “individual vulnerable persons express and act on their wishes, ascertain and exercise their rights, speak on their own behalf, engage in mutual aid and form organizations to advance their interests.”³⁴⁸

Industry stakeholders claim that a Health Care Commission would be unnecessary due to the transformed compliance regime under the *Long-Term Care Homes Act, 2007*. ACE disagrees because the new system is not about individual or systemic advocacy but ensuring compliance with the legislation. During our focus groups, residents and families continued to complain about a lack of knowledge about their rights and their inability to have their rights enforced. While we agree that the new legislation contains more rights, it still lacks a mechanism for residents and their families to have these rights enforced. This is where the Health Care Commission would play a vital role in assisting people in ensuring these rights are protected.

Although some stakeholders disliked the moniker “advocate,” we feel it is appropriate because it accurately reflects the nature of the work. Suggested titles, such as “communicator” or “representative,” do not adequately express the significance of the health care advocate’s role.

ACE’s recommendation to create a Health Care Commission is consistent with a principled framework for the law as it affects older adults. Advocacy is crucial to the dignity of residents living in congregate settings as it affirms their importance as human beings while recognizing that they may need some assistance in realizing their rights. It promotes participation by allowing older adults to be

consulted by Health Care Advocates on issues affecting them on an individual level. One of the goals of the Health Care Commission is to give seniors the necessary tools to assert their rights and enhance their capacity for independence. Respect for diversity is also fostered by advocacy as individual advocacy can be tailored to meet the unique needs of the resident in resolving their concerns without taking a “one size fits all approach.”

Ombudsman

Various jurisdictions around the world authorize an Ombudsman, or comparable body, to be an office of last resort respecting complaints in hospitals and long-term care homes. The Ombudsmen of several Canadian provinces have such authority while the Welsh have an Older People’s Commissioner for Wales and the Americans have a Long-Term Care Ombudsman Program.

The Role of an Ombudsman

According to the Forum of Canadian Ombudsman:

An ombudsman is an independent, objective investigator of people's complaints against government agencies and other organizations, both public and private sectors. After a fair, thorough review, the ombudsman decides if the complaint is justified and makes recommendations to the organization in order to resolve the problem.³⁴⁹

The Forum of Canadian Ombudsman identifies the two most common types of ombudsman in Canada as legislative or classical ombudsman (established by statute and who can report findings and recommendations to ministers or the legislature) and executive ombudsman (able to report only to the head of the organization whom they investigate, such as government departments or businesses).³⁵⁰ The ensuing discussion will be limited to legislative ombudsmen.

Ombudsmen are generally an office of last resort after all other options have been exhausted. According to one author, ombudsmen generally have the following powers and protections:

- Unimpeded access to information;
- Protection of the confidentiality of the proceedings in order to facilitate co-operation throughout the investigation;
- Protection against the use of their evidence in subsequent proceedings;

- Immunity from prosecution for anything done in good faith while exercising their duties; and
- The right to require information or documents, as well as examine any relevant person on oath.³⁵¹

Proponents of ombudsmen argue they are successful because:

- Their independence is unquestioned;
- While following the rules of natural justice, the procedures of the ombudsmen are informal, inquisitorial and non-adversarial;
- Legal representation is not necessary; and
- The service provided is free and (unlike the court system) there is no risk to the complainant of having to pay the other party's costs if the complaint is not upheld.³⁵²

In Ontario, and the majority of other jurisdictions studied in this report, the Ombudsman does not have the power to enforce compliance with any recommendations, so persuasion must be utilized. In the words of Andre Marin, Ontario's Ombudsman:

The reality of our work is that, academically, we are paper tigers. On paper, most ombudsmen have no power. I can't punish anyone for wrongdoing or force anyone to accept my recommendations. My Office's only power is that of moral suasion. To exercise that power, two things are essential: I have to be right, and I have to have the public on my side.³⁵³

Common criticisms levied against ombudsmen include the following:

- The operation of an ombudsman's office is expensive;
- Vulnerability to marginalization, under-funding and over-management by the powers from which it is meant to protect the citizen;
- Their power and influence is contingent upon the personality of the ombudsman;
- They selectively choose the systemic issues to pursue; and
- Their existence creates an added level of bureaucracy.

The Jurisdiction of Ombudsmen in Canada

Ontario is the only province in Canada where the provincial Ombudsman does not have jurisdiction over any aspect of the health care sector. With respect to

long-term care homes, the Ombudsman has jurisdiction in five other provinces (Alberta, Nova Scotia, Newfoundland, Yukon and Quebec).³⁵⁴ It should be noted that the Ombudsman of British Columbia has jurisdiction over long-term care residences if they are owned by the local health authority.³⁵⁵

In the provinces examined for the purposes of this report, with the exception of British Columbia, residents living in facilities similar to Ontario's retirement homes do not have access to an ombudsman.

A recent attempt in June 2008 to expand the jurisdiction of the Ontario Ombudsman to include both hospitals and long-term care homes was Bill 89, the *Ombudsman Amendment Act*. To date, it has not passed first reading.³⁵⁶ Bill 102, the *Seniors' Ombudsman Act*, was introduced in September 2008. As the title suggests, it proposes to create a separate Ombudsman to consider seniors' complaints. It passed second reading and was referred to the Standing Committee on General Government.³⁵⁷

ACE's Recommendation: Mandate Modernization

While some consultation participants were opposed to the involvement of the Ombudsman, the majority favoured increasing the jurisdiction of the Ombudsman to include both hospitals and long-term care in Ontario.

ACE supports the Ombudsman having authority over these spheres of health care. The lack of an Ombudsman with authority in this billion dollar sector is, in our opinion, a hole which must be filled. Oversight by the Ombudsman serves to strengthen the independence, security and dignity of individuals if they feel they have been improperly treated by institutions which receive public money. The Ombudsman can help promote independence by ensuring programs and supports are being properly delivered. In terms of security, oversight by the Ombudsman provides an extra layer of protection from possible abuse and exploitation. With regards to dignity, the Ombudsman would serve to remind service providers that they must treat all residents fairly and with respect.

The role of the Ombudsman in Ontario should differ from the Long-Term Care Ombudsman Program in the United States. Generally, the Americans utilize a model where the Ombudsman is not an office of last resort but more proactive and akin to an advocacy program.

The Ombudsman should also have jurisdiction over and be able to review the work of the proposed Health Care Commission. As the role of the advocates at the Health Care Commission is very different than the Ombudsman, there would not be a duplication of work.

In line with our arguments against a Seniors' Advocate, we feel that the creation of a separate Seniors' Ombudsman is paternalistic. Further, it would be an unnecessary expense to establish another Ombudsman's office when the structure already exists and is well-developed.

In order to be truly accessible, ACE also suggests that the Ombudsman modify its procedural rules to permit complaints to be accepted by telephone. Currently, the Ombudsman requires complaints to be provided either in writing (via regular mail or email) or in-person.³⁵⁸ Hospital patients and long-term care residents would often have difficulties writing out a complaint or have limited mobility to attend an in-person meeting.

Regulation of Retirement Homes

The Problems Inherent to Self-Regulation

The quality of care in retirement homes cannot be guaranteed under the current model of self-regulation. A commonly recognized definition of self-regulation is "a process whereby an organized group regulates the behaviour of its members."³⁵⁹ As compared to command and control regulation, self-regulation should offer "greater speed, flexibility, sensitivity to market conditions, efficiency and less government intervention."³⁶⁰ The rationale for this statement is that the regulation will respond to the individual needs and circumstances of the industry because experts within industry would develop the necessary standards. However, critics of self-regulation say it does not work in practice. They claim "self-regulatory standards are usually weak, enforcement is ineffective and punishment is secret and mild."³⁶¹ A strong body of cross-jurisdictional evidence indicates that the bulk of self-regulatory regimes are primarily motivated by the fear of government regulation. Thus, as argued by Gunningham and Sinclair, "it seems unlikely that they would perform well in the absence of continuing government oversight and the threat of direct intervention in the event of self-regulatory failure."³⁶²

In Ontario's retirement homes, there is little or no oversight of care services because there are no regulated standards. There are no mandatory inspections from an appropriate third party, like the Ministry of Health and Long-Term Care, who would be able to require compliance with set standards. While some homes are accredited by Accreditation Canada, this is a voluntary process and the organization has no authority to require compliance with its standards.

Although “nursing” care may be offered by the retirement home, it is up to the individual retirement home operator to decide whether this care will be provided by or under the supervision of a regulated health professional; it is perfectly legal to provide what is often advertised as “nursing” care by unregulated, unsupervised workers.

While ACE is definitely not espousing the opinion that all of the residents at retirement homes are vulnerable, many are. Self-regulation requires that the residents must be comfortable complaining and that they have the wherewithal to do so. Unfortunately, this ability is not universal. Residents may not have access to the appropriate information, such as the special rules for giving notice to end a tenancy in care homes. Even those who do know their rights are afraid to ask that they be enforced because they may experience retaliation.

In our view, the largest problem is that some retirement homes are operating, in effect, as “bootleg” long-term care homes: they are offering the same high levels of care as long-term care homes but without any of the rules or accountability that the Ministry of Health and Long-Term Care enforces in the long-term care system through detailed legislation, regulation, policies and enforcement mechanisms. Some retirement homes have locked units and use restraints on tenants, without providing any of the rights protection or other safeguards provided to residents of long-term care homes. This is a double standard, and it fails to ensure the safety and protection of retirement home tenants. Given that the retirement home sector is providing more and more care to vulnerable adults, these concerns cannot be ignored.

In short, there is a clear need for a comprehensive regulatory scheme for retirement homes so that all seniors can live in environments that promote their independence to the maximum extent possible, while also ensuring their safety and protecting their rights.

Ontario Seniors’ Secretariat Consultation

In 2007, the Ontario Seniors Secretariat released a Consultation Document proposing a “third-party regulatory model” for retirement homes.³⁶³ Under this model, the government would create an agency that would develop standards and monitor its member organizations to ensure compliance with these standards. The government itself would not be responsible for creating any minimum standards, conducting inspections or penalizing non-compliance. This is the type of regulatory body the government has set up for participants in industries like travel agencies, real estate agencies and motor vehicle dealerships.

Over 800 participants attended the consultation sessions organized by the Ontario Seniors' Secretariat regarding the regulation of the retirement home industry while over 250 written responses were submitted.³⁶⁴ The following excerpt summarizes the written comments received by the Secretariat (and which was very similar to the feedback received at the consultation sessions):

Although all categories of respondents agreed that the retirement home sector should be regulated (including the vast majority of operators), there was little agreement on the specific features that could be included in a definition of a retirement home (such as size and care services). There was widespread agreement about which administrative, resident care, food services and environment areas should be covered by standards. While the enforcement activities of a monitoring entity were generally agreed by all respondents, there was disagreement about the enforcement body. While the majority of respondents felt that a third party agency was appropriate, a fairly significant number felt that enforcement was a government responsibility.³⁶⁵

ACE believes that the third-party regulatory model is not an acceptable model to apply to an ongoing relationship of providing accommodation and care to members of a vulnerable consumer group.

ACE's Recommendation: Licensed Regulation of Retirement Homes

ACE proposes a government-operated licensing system with grades (or classes) of licence that a home would have to earn if it wished to provide certain classes of service. Consumers would then be aware of what services they can expect in any particular home, and could be assured that such services meet agreed-upon standards for safety, care and quality of service.

As a general outline, for example, the basic class of licence could be granted to homes demonstrating that they can meet agreed-upon standards concerning meals and nutrition, linen service and programming for tenants. An intermediate class of license could be granted to homes that can demonstrate competence in all of the basic features, and also be able to meet agreed-upon standards concerning services like medication administration, assistance with activities of daily living, provision of some nursing care and assistance in transferring residents from bed to chair. A holder of the highest level of license would have to prove competence in all the items mentioned above, and would be required to demonstrate that it could meet agreed-upon standards of care for frail persons including those with mid to late-stage dementia. The highest level of licence would be subject to the *Long-Term Care Homes Act, 2007* and only the lower

levels of licences would be exempt under section 95 of this statute. Section 95(1) stipulates that only persons with licenses are permitted to operate “residential premises for persons requiring nursing care or in which nursing care is provided to two or more unrelated persons.” Section 95(2)(b) goes on to say that section 95(1) does not apply to “other premises provided for in the regulations.”

With this type of graded licensing system, consumers would know in advance what levels of care or assistance they are entitled to expect, and what standards they can expect their licensee to meet. In tandem with a meaningful system of complaint resolution, which would have to be developed, this type of regulatory model would provide an important level of consumer protection in an industry where consumers can be very vulnerable. Further, retirement home operators would be able to decide what level of licence to seek, according to the needs they perceive in the market. This system would allow the market to respond to the needs of changing demographics, help support seniors who wish to “age in place” and preserve freedom of choice for consumers.

Outcomes such as skin integrity (including avoiding and treating bedsores) and continence care are no less important for a person in a retirement home than they are for someone in long-term care. At these high care levels, it must be recognized that the services being provided are health care services, and they must be regulated as such. Retirement homes providing such care should be subject to the same inspection and compliance regime as the long-term care home system. The same Ministry of Health and Long-Term Care compliance advisors should be responsible for ensuring compliance by operators licensed to provide high levels of care. For the lower tiers of licence, a system of inspections and administrative orders should be implemented. This administrative compliance system could be modeled on other legislated inspection models such as that found in the *Fire Protection and Prevention Act, 1997*.

Further, when the services being provided are health care services, it must be recognized that retirement homes are health facilities. It is at least arguable that certain high-level care services being provided within retirement homes fit within the definition of “home care services” as found in the regulation to the *Health Insurance Act*.³⁶⁶ ACE sees no principled reason why such services should not be funded as insured extended care services under the *Health Insurance Act*. The failure to fund such services leads to the clear creation of two-tiered health care in Ontario. Retirement homes holding the highest level of license should be eligible for the same type of health funding as long-term care homes so that the residents have public health coverage.

By submitting that retirement homes could qualify for licences to provide health

care services for persons with high health care needs, ACE should not be taken to support a two-tiered health care system. In such a system, those who can afford to purchase private care can do so, while those who cannot afford private care rely on the publicly-funded health care system. Our proposal should be understood as proposing that if the same health care services are provided both in the retirement home setting and in long-term care homes, then persons contracting for high-level care services in the retirement home context should be protected by the same standards and expectations of care providers in the long-term care home system. Holders of the highest level licence should be subject to the same regulatory scheme as provided in the *Long-Term Care Homes Act, 2007*. Please note that ACE is not campaigning for the repeal of the *Residential Tenancies Act* and its protections for residents. Instead, we believe licensing requirements should be added to the current legislation or, if new legislation is created, it should incorporate the tenancy protections.

It has been said that it may not be reasonable to expect small and large homes to achieve the same regulatory standards. In this context, one possibility would be to consider the model found in the *Accessibility for Ontarians with Disabilities Act*³⁶⁷ whereby standards may be slightly different, or rolled out along different timelines, for different sizes of organization when it is appropriate to do so. All care home tenants should receive equal benefit and protection of any regulatory structure. The suggestion is made in order to draw attention to other legislated approaches to standard-setting in organizations of vastly different sizes.

It is important to ensure that the implementation of a regulatory system is not simply lip service. For example, in Newfoundland and Labrador, the sector is heavily regulated. However, a 2005 audit by the provincial Auditor General revealed that monitoring was not taking place, being held, standards were not being met and it was questionable whether residents were receiving a consistent and adequate level of care.³⁶⁸ Models in other jurisdictions have shown similar weaknesses. British Columbia's Office of the Assisted Living Registrar licenses, inspects and tries to resolve disputes, yet it is limited in its authority to look at care and other non-tenancy issues.

Advisory Councils

Advisory councils are created for the purpose of offering guidance and support to the government. These groups are usually composed of people who are in some way familiar with the relevant issues.

In Western Australia, the Minister for Health established the Western Australia Aged Care Advisory Council pursuant to the *Health Legislation Administration Act*

1984.³⁶⁹ The Council was set up to provide ongoing advice to government on the health and related aged care needs of older people in Western Australia and to oversee a system-wide, whole-of-sector approach to the planning and provision of State programs and services. The Council provides an important linkage between the state government and aged care providers and consumers. The members of the Council are chosen by the Minister as he or she sees fit. Generally, members are selected to provide a broad representation of key health and aged care interest groups including health consumers, residents of rural and remote areas, geriatric and rehabilitation clinicians, health management, peak industry bodies and relevant government departments.

At present, there are at least a few advisory councils pertaining to seniors' issues across Canada. In Alberta, the Seniors Advisory Council was created by the *Seniors Advisory Council for Alberta Act* to, among other things, advise, report and make recommendations to the government on matters relating to seniors in Alberta.³⁷⁰ The National Seniors Council was established to advise the Government of Canada on all matters related to the quality of life of seniors. According to its website, the National Seniors Council "delivers well-balanced advice, taking into account the views of experts, seniors, organizations and groups that provide seniors programs and services, provincial/territorial advisory bodies on seniors, and other relevant stakeholders and interested parties."³⁷¹

None of these councils require members to be older adults. In contrast, the Governor's Council on Aging in Missouri, which investigates and advises the Governor on quality of life issues for older adults, specifies that half of its 12 members must be over 60 years of age.³⁷²

There appears to be a trend within disability legislation to require the involvement of persons with disabilities. For instance, a majority of the member of the Accessibility Standards Advisory Council, pursuant to the *Accessibility for Ontarians with Disabilities Act*, must be persons with disabilities.³⁷³ This reflects the notion that the best candidates to offer advice on issues that face a unique group of people are members of that group, who can use their personal experience to help resolve those issues.

Generally, stakeholders with whom we consulted felt that advisory councils whose membership includes residents of congregate settings are a good idea. One seniors' group commented that advisory councils need a requirement that their work be made public and "not buried."

Critics of advisory councils claim that members are often hand-picked, not for their skills or expertise, but political opinions or malleability. Advisory councils

are also accused of being mere “window-dressing,” resulting in tokenism and creating a false appearance of inclusive practices.

ACE’s Recommendation: Resident Representation

In order for government to hear the voices of residents directly, as opposed to being filtered by representatives, ACE supports the use of advisory councils whose composition includes residents of congregate settings. Residents should be consulted as they are experts on the issues unique to congregate settings. Participation is one of the principles adopted by the Law Commission of Ontario as the basis for its approach to the law as it affects older adults. An “important aspect of participation is the right of older adults to be meaningfully consulted on issues that affect them, whether at the individual or the group level.”³⁷⁴

Although there are statutory provisions in the current and future legislation permitting Residents’ Councils in long-term care homes to report concerns or recommendations to the Minister of Health and Long-Term Care, the onus should not be on residents to navigate a bureaucratic regime to put forward their ideas to the government. Even if residents were able to get their opinions to the Minister, there is no obligation for the Minister to respond or engage with the Residents Council.

ACE proposes that the relevant legislation be amended to include a requirement for the Ministry of Health and Long-Term Care to strike advisory councils of seniors’ stakeholders whose membership includes a significant percentage of older adults living in congregate settings across the province. Their role would be to provide information and feedback about issues impacting their daily lives, as well as policies and legislation respecting their living environments. The councils would meet at least annually with the Minister. The costs associated with travel (including the services of a caregiver, if necessary) would be paid by the government. One method of choosing members for advisory councils would be to choose members from existing Residents’ Councils, taking into the consideration the need for diversity.

Due to the high number of residents in long-term care who are lacking capacity, family representatives should also be members of the advisory council. There should be an equal number of residents and family members.

While there are some possible disadvantages associated with advisory councils, ACE believes they are far outweighed by the advantages.

Informed Consent

Earlier in this report, we highlighted the serious problems associated with antipsychotics, the misapplication of consent laws and the lack of rights information provided to residents or their substitute decision-makers.

Under the regulations to the *Mental Health Act*, patients in psychiatric facilities must be provided with rights advice if they are found to be incapable with regards to treatment.³⁷⁵ Rights advice is a process whereby an individual is informed of their rights by a rights adviser shortly after their legal status has changed. The rights adviser cannot be a person involved in the direct clinical care of the person to whom the rights advice is given. There are eight mandatory rights advice situations, most of which only affect patients in psychiatric facilities. The rights adviser has the responsibility to explain the significance of the legal situation to the individual. If requested to do so, the rights adviser will the person to: apply for a hearing to challenge the finding before the Consent and Capacity Board, retain a lawyer; and apply for financial assistance from Legal Aid Ontario. Prescribed government forms must be completed to verify that rights advice was given. The lack of, or untimely, rights advice can invalidate a finding of capacity. Rights advice is viewed as a legal protection to ensure fairness and access to justice.

ACE's Recommendations

ACE considered recommending a legislative amendment to require the provision of independent rights advice to each individual when they are found to be incapable regarding treatment or admission to a care home, or alternately, to every resident of a retirement or long-term care home found to be treatment incapable. We abandoned this idea due to its impracticality. There are in excess of 76,000 long-term care home residents in the province, and likely at least that many in retirement homes, with a large number of incapacity decisions being made daily, making the expense exorbitant.

In order to protect the security of individuals by educating them about their legal options after a finding of incapacity, ACE is of the view that section 17 of the *Health Care Consent Act* should be reinforced. Instead of allowing health practitioners to follow the policies of their regulated College, there should be a duty on health practitioners to provide specified rights information which would be set out in regulation. Further, there should be a requirement for health practitioners to complete a regulated form, similar to the Form 33 that is currently

used if a patient in a psychiatric facility is found incapable of a mental disorder, to give notice of the finding to the person.³⁷⁶ The form should include a checklist indicating that the health practitioner has done the following: satisfied the statutory requirements for consent (e.g., discussed the risks and benefits of the proposed treatment); provided information about the appeals process; and, if instructed to do so, assisted the person to submit an application to the Consent and Capacity Board.

As part of the Ministry of Health and Long-Term Care's compliance process, special attention should be made to ensure that informed consent to treatment is obtained in long-term care homes. At present, while the Residents' Bill of Rights includes the requirement that this law be followed, there appears to be little attention paid to it during the inspection process.

There are significant concerns regarding the use of antipsychotic medication in the elderly in general and, more specifically, the long-term care sector. This topic was discussed at length earlier in this paper. According to Hagen *et al.*, if the American regulations requiring safeguards for antipsychotic use were applicable to the Canadian long-term care homes in their study, "84.3% of the prescriptions could be deemed to be inappropriate, due to the lack of timely efforts to reduce the amount of antipsychotic medications received."³⁷⁷ Thus, we recommend that similar regulations be passed and enforced by the Ministry of Health and Long-Term Care to ensure the careful and appropriate use of these medications.

Enforcement and Sanctions in Long-Term Care Homes

Inspections in long-term care homes are carried out by compliance advisors. Although the legislation is silent about the qualifications of these advisors, the Ministry of Health and Long-Term Care has decided to appoint registered nurses to this position, as opposed to trained investigators.³⁷⁸ ACE recommends that the Ministry examine the appropriate skill-sets necessary to be a compliance advisor. Further, the Ministry should employ special investigators who would be trained to investigate serious or potentially serious issues, such as elder abuse or neglect. One can look, for example, to the investigators under the *Protection for Persons in Care Act* in Alberta. Their investigators may come from a variety of backgrounds, such as criminology, nursing and social work, and have expertise in areas such as long-term care, mental health and law enforcement. While we are not proposing that investigators must be independent of the Ministry, we believe that one of the drawbacks of the present system is the fact that compliance advisers both inspect and investigate complaints. This can cause problems as the compliance advisers often have an ongoing relationship with the home, which can be perceived as prejudicial when it comes to the investigation

stage. A separate unit of investigators with diverse backgrounds and no ties to the homes would likely improve both perceptions about the complaints process and the actual results.

ACE also believes that there needs to be increased transparency respecting the public inspection reports available on the Ministry website. The available information is not up-to-date or organized in a manner which is easy to understand. It also provides insufficient details about the actual infractions as it merely states which general criteria or standard was unmet. Posting the actual inspection report (minus any identifying information about residents or staff) would be beneficial for several reasons. First, it would be an impetus for homes to improve as the public would have greater access to detailed information and be less inclined to choose homes with a higher number of complaints and unmet standards. Second, it would benefit some homes by showing that their infractions were administrative in nature and not reflective of poor resident care. The Ministry should look to other countries (e.g., Wales and Australia) which post significantly more comprehensive reports as examples.³⁷⁹

ACE does not recommend a rating system similar to that of the United States for retirement or long-term care homes because it is a blunt instrument which does not capture the subtleties of the reality of a home.

As there is no concrete enforcement mechanisms in the Residents' Bill of Rights, ACE also suggests an intermediate sanction such as fines payable to aggrieved residents and families. For instance, the new *Long-Term Care Homes Act, 2007* allows the Ministry to levy fines against homes where convicted of an offence under the legislation.³⁸⁰ We propose that either a portion or the entire sum should be allotted to the resident or family member who experienced an infringement of their rights, as opposed to going to the Ministry of Health and Long-Term Care.

Specialized Tribunals, Expedited Court Processes and Damages

To combat barriers inherent to the justice system, ACE contemplated the creation of a specialized tribunal or an expedited court process to deal with issues affecting older adults.

We could only find two precedents for tribunals dedicated to the elderly, or at least one aspect of elder law. In India, the *Maintenance and Welfare of Parents and Senior Citizens Act* directs states to create Maintenance Tribunals which have the powers of a civil court to determine claims for maintenance. The legislation places an obligation on children and relatives to provide sufficient

maintenance to enable the older adults to live a “normal life.” Although the legislation was created in 2007 and stipulated that the tribunals were to be set up within six months, it appears that the government has not yet done so.³⁸¹ In China, article 43 of the *Law of the People’s Republic of China on Protection of the Rights and Interests of the Elderly* stipulates that a court will “accept and handle” cases involving the abuse of the rights or interests of older adults without delay.³⁸²

Neither residents nor other stakeholders endorsed a specialized tribunal or expedited court system for older adults. Residents were opposed to litigation as a tool to enforce their rights because they preferred a non-adversarial approach with quick results.

Unfortunately, some cases will be so egregious that court proceedings may be the best option. However, if an older adult or their dependent wanted to pursue a claim of negligence, one of the elements that must be proven is the suffering of damages. As previously discussed, the measure of damages is tied to income and life expectancy.

ACE’s Recommendations

Administrative tribunals, by their very nature, are supposed to have expertise in the areas in which they adjudicate. As elder law is not homogenous, ACE does not believe it is appropriate to create a tribunal with jurisdiction over a broad range of areas of law. We do not recommend an elder law tribunal for this reason, as well as the lack of support from stakeholders.

To encourage older adults to pursue litigation, where appropriate, ACE believes statutory provisions should permit civil actions without proving damages and permitting the court to award general damages.

Mediation

Mediation is “a process in which a trained neutral assists disputants in framing issues in dispute, enhances communication between parties, helps parties develop possible solutions, and aids them in reaching mutually acceptable agreements.”³⁸³ Characteristics of mediation include confidentiality and voluntariness. Cited advantages of mediation have been described as follows:

Mediation can be quick, flexible, inexpensive, convenient, humane, empowering. It allows the parties to talk to each other in a setting that is constructive and secure. Solutions that emerge can be more

creative and more suited to individual needs than might be possible through traditional legal channels. Parties may adhere better to solutions they have designed themselves.³⁸⁴

American scholars, mediators and lawyers have identified serious ethical concerns in the area of elder and guardianship mediation, such as:

- Impartiality of mediations;
- Ensuring capability to mediate;
- Risk management in terms of abuse, neglect and self neglect;
- Conflicts of interest;
- How to decide if mediation is appropriate;
- Funding/fees; and
- The necessity of legal advice or representation.³⁸⁵

It has been said that using mediation to resolve conflicts in the long-term care sector may be one of the most challenging settings because:

It combines all the usual problems of a workplace and an intense living place, overlaid with deep emotional responses to aging, negative stereotypes of nursing homes, and the wrenching surrender of loved ones to the care of an institution...Conflicts occur between and among all of the primary constituents: nursing home staff, residents, and families of residents.³⁸⁶

In response to new legislation in British Columbia requiring mandatory mediation for adult guardianship applications, as well as the lack of substantive literature or educational materials about elder law mediation, the Canadian Centre for Elder Law is undertaking a comprehensive research project. It will be the first research study of its kind in Canada to substantively address legal, ethical, social and legal practice issues raised by both mandatory and voluntary elder and guardianship mediation.³⁸⁷ Consequently, ACE believes it is premature to make a recommendation respecting mediation in advance of this study.

CONCLUSION

Older adults residing in congregate settings in Ontario are unable to effectively access justice in the present system. Unfortunately, there are multiple reasons for this conclusion, many of which are interrelated.

The type of congregate setting where an older adult resides can make an immense difference in one's ability to access justice. There are few oversights in the area of hospitals or retirement homes, thus making accessing justice extremely difficult. While there are numerous legal protections in place for residents of long-term care homes, there are limited mechanisms available to effectively enforce these rights. Legislation containing residents' rights applicable to all three settings, such as the *Health Care Consent Act*, is often ignored, no matter where the person resides due to the recurrent theme of "good law, bad practice."

In some instances, such as the retirement home sector, legislation will be required in order to regulate the industry and to provide residents with the tools to ensure they are receiving appropriate and adequate care. In other sectors, such as long-term care homes, both the current and pending legislation, subject to minor modifications, are satisfactory; however, it is the implementation and enforcement of this legislation which is paramount to ensuring that residents are able to access justice.

The focus groups conducted by ACE, as well our review of other jurisdictions, indicate that education about the applicable law is key to ensuring access to justice for adults residing in congregate settings. The enactment of legislation alone is insufficient: residents must be provided with the tools and assistance necessary to make it work. To this end, education of residents, families and service providers is the first step.

However, even if education is provided, residents in congregate settings require assistance to implement their rights. We believe that the creation of an independent Health Care Commission, whose purpose is the provision of both individual and systemic advocacy, is essential. Advocates would provide residents with the knowledge and support necessary to take their concerns to the appropriate entities. Further, the systemic advocacy function of the Health Care Commission would be a positive force in the health care system to ensure that the rights of all, even those who cannot speak for themselves, are heard.

We have also recommended the expansion of the jurisdiction of the provincial Ombudsman into the health care sector. With many thousands of residents living in congregate care, costing billions of public dollars, such oversight is important to ensure that the needs of the users of the sector are met in an appropriate fashion.

As indicated above, a significant proposal we are putting forward is the regulation of retirement homes. This sector continues to grow and to provide more care to a larger segment of our population who have frailer health. Legislation is required to ensure that quality care is provided to residents and their rights are respected.

The goals of the recommendations contained in this paper are to ensure that residents in congregate care settings are able to access justice in a meaningful way. The present system, while in many senses providing the framework for justice, does not go far enough to ensure that justice is actually done.

ENDNOTES

¹ For ease of reference, we will refer to older adults living in all three congregate settings as “residents” although persons living in hospitals are legally known as “patients” and persons in retirement homes are “tenants” pursuant to the *Residential Tenancies Act*.

² Law Commission of Ontario, *The Law as it Affects Older Adults: Moving the Project Forward – Report of the Preliminary Consultation* (December 2008) at 4-10, online: <<http://www.lco-cdo.org/en/documents/OlderAdultPreStudyConsultationRpt-FINAL.pdf>>.

³ Roderick MacDonald, “Access to Justice in Canada Today: Scope, Scale and Ambitions” in Julia Bass *et al.* eds., *Access to Justice for a New Century: The Way Forward* (Toronto: Press, 2005) 19 at 23-24.

⁴ Reem Bahdi, *Background Paper on Women’s Access to Justice in the MENA Region* (2007) at 3, online: <http://www.idrc.ca/uploads/user-S/12151851101Women's_access_to_justice_in_MENA-Bahdi_En.doc>.

⁵ S.O. 2007, c. 8.

⁶ The *Canada Post Corporation Act*, R.S.C., 1985, c. C-10 makes it an offence to open or abandon mail. Section 48 says: “Every person commits an offence who, except where expressly authorized by or under this Act, the *Customs Act* or the *Proceeds of Crime (Money Laundering) and Terrorist Financing Act*, knowingly opens, keeps, secretes, delays or detains, or permits to be opened, kept, secreted, delayed or detained, any mail bag or mail or any receptacle or device authorized by the Corporation for the posting of mail.” Section 49 says: “Every person commits an offence who unlawfully and knowingly abandons, misdirects, obstructs, delays or detains the progress of any mail or mail conveyance.”

⁷ R.S.O. 1990, c. P. 40.

⁸ Ontario, Ministry of Health and Long-Term Care, *Hospitals*, online: <http://www.health.gov.on.ca/english/public/contact/hosp/hosp_mn.html> (last modified: 15 June 2009).

⁹ *Public Hospitals Act*, R.R.O. 1990, Reg. 964, *Classification of Hospitals*, s. 1(1).

¹⁰ *Public Hospitals Act*, R.R.O. 1990, Reg. 552, s. 10.

¹¹ *Ibid.*, Table 2.

¹² Canadian Institute for Health Information, *The “Younger” Generation in Ontario Complex Continuing Care* (June 2007) at 2 and 20, online: <http://secure.cihi.ca/cihiweb/products/cc_aib_younger_patients_e.pdf>.

¹³ Canadian Institute for Health Information, *Hospital Report: Rehabilitation* (2007) at 2, online: <http://secure.cihi.ca/cihiweb/products/OHA_Rehab_07_EN_final_secure.pdf>.

¹⁴ S.O. 2006, c. 17, s. 2(1).

¹⁵ Ontario Seniors’ Secretariat, *Consultation Backgrounder for Ontario’s Consultation on Regulating the Retirement Home Industry* (Winter 2006-2007) at 4, online: <<http://www.culture.gov.on.ca/seniors/english/programs/rhc/docs/RHC.Backgrounder.pdf>>.

¹⁶ Canadian Housing Mortgage Corporation, *Seniors Housing Report* (2009) at 4.

¹⁷ *Ibid.* at 5.

¹⁸ For example, see the *Building Code Act, 1992*, S.O. 1992, c. 23; *Fire Protection and Prevention Act, 1997*, S.O. 1997, c. 4; *Health Protection and Promotion Act*, R.S.O. 1990, c. H.7; *Regulated Health Professions Act, 1991*, S.O. 1991, c. 18; *Substitute Decisions Act, 1992*, S.O. 1992, c. 30; *Health Care Consent Act, 1996*, S.O. 1996, c. 2,

Sched. A; *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3; *Human Rights Code*, R.S.O. 1990, c. H.19; *Criminal Code of Canada*, R.S.C. 1985, c. C-46.

¹⁹ R.S.O. 1990, c. N.7.

²⁰ R.S.O. 1990, c. H.13.

²¹ R.S.O. 1990, c. C.9.

²² Email from Kim Hewitt, Information Request Coordinator, Health System Information Management and Investment Division, Ministry of Health and Long-Term Care, to Lisa Romano, Research Lawyer, ACE (16 July 2009).

²³ *Ibid.*

²⁴ *Ibid.* Ontario has 354 for-profit nursing homes and 113 not-for-profit nursing homes.

²⁵ *Ibid.* There are 103 municipal homes for the aged in Ontario.

²⁶ Telephone conversation between Richard Lee, Senior Financial Consultant, Financial Management Branch, Ministry of Health and Long-Term Care, and Lisa Romano, Research Lawyer, ACE (22 July 2009).

²⁷ Canadian Institute for Health Information, *Antipsychotic Use in Seniors: An Analysis Focusing on Drug Claims, 2001 to 2007* (2009) at 15, online:

<http://secure.cihi.ca/cihiweb/products/antipsychotics_aib_en.pdf>.

²⁸ Ontario, Ministry of Health and Long-Term Care, prepared by Monique Smith, Parliamentary Assistant, *Commitment to Care: A Plan for Long-Term Care in Ontario* (Spring 2004) at 8, online:

<http://www.health.gov.on.ca/english/public/pub/ministry_reports/ltc_04/mohlrc_report04.pdf>.

²⁹ According to the Ministry of Health and Long-Term Care, based on the fall 2008 Levels of Care Classification review of 43,334 residents, 6.26% of these residents are younger than 65 years of age. There are more than 76,000 long-term care beds in the province, and it is not known how these residents were chosen to be classified, therefore the numbers may not be statistically accurate: *supra* note 22.

³⁰ Recommendations 22 through 25 deals with specialized facilities and units, Office of the Chief Coroner, Recommendations from the Inquest into the Deaths of Ezzeldine El Roubi and Pedro Lopez (Inquest Dates: January 31 – April 18, 2005).

³¹ Neil Gunningham & Duncan Sinclair, "Instruments for Environmental Protection" in *Smart Regulation: Designing Environmental Policy* (Oxford: Clarendon Press, 1998) at 42.

³² *Ibid.*

³³ *Ibid.* at 44.

³⁴ *Ibid.* at 46.

³⁵ Michael Rustad, "Neglecting the Neglected: The Impact of Noneconomic Damage Caps on Meritorious Nursing Home Lawsuits" (Suffolk University Law School: Legal Studies Research Paper Series, 2007) at 46, online:

<http://papers.ssrn.com/sol3/papers.cfm?abstract_id=959714>.

³⁶ The Honourable Warren Winkler, The Warren Winkler Lectures on Civil Justice Reform, University of Ottawa, Faculty of Law, *Civil Justice Reform – The Toronto Experience* (September 12, 2007), online:

<<http://www.ontariocourts.on.ca/coa/en/ps/speeches/civiljusticereform.htm>>.

³⁷ It should be noted that ACE exempts the client's principal family residence in arriving at the total value of assets in determining financial eligibility for services.

³⁸ Law Society of Upper Canada, *Rules of Professional Conduct* (2000).

³⁹ Rule 2.04(1) refers to the definition of a conflict of interest while Rules 2.04(2) and (3) refer to the avoidance of a conflict of interest.

⁴⁰ The commentary for Rule 2.01(1) says: "As a member of the legal profession, a lawyer is held out as knowledgeable, skilled, and capable in the practice of law. Accordingly, the client is entitled to assume that the lawyer has the ability and capacity to deal adequately with legal matters to be undertaken on the client's behalf."

⁴¹ *Supra* note 36.

⁴² R.S.O. 1990, c. F.3, s. 61(2).

⁴³ *McDonnell Estate v. Royal Arch Masonic Homes Society*, [1998] 5 W.W.R. 268.

⁴⁴ *R. v. Khelawon*, [2006] 2 S.C.R. 787.

⁴⁵ *R. v. Campoli*, [2009] O.J. No. 2114 (O.C.J.).

⁴⁶ S.O. 1992, c. 30.

⁴⁷ S.O. 1996, c. 2, Sched. A.

⁴⁸ Brad Hagen *et al.*, "Antipsychotic Drug Use in Canadian Long-Term Care Facilities: Prevalence, and Patterns Following Resident Relocation" (2005) 17:2 *International Psychogeriatrics* 179 at 180.

⁴⁹ *Supra* note 27 at 1.

⁵⁰ *Ibid.* at 16.

⁵¹ *Ibid.* at 15.

⁵² These comments are based on statistics from two different studies indicating that 29.8% and 30.8% of long-term care home residents are prescribed antipsychotic medications: *supra* note 48 at 188.

⁵³ *Ibid.* at 188-189.

⁵⁴ Susan Bronskill *et al.*, "Neuroleptic Drug Therapy in Older Adults Newly Admitted to Nursing Homes: Incidence, Dose, and Specialist Contact" (2004) 52 *Journal of the American Geriatrics Society* 749 at 753.

⁵⁵ *Ibid.*

⁵⁶ Paula Rochon *et al.*, "Variation in Nursing Home Antipsychotic Prescribing Rates" (2007) 167 *Archives of Internal Medicine* 676 at 682.

⁵⁷ *Health Care Consent Act*, s. 11.

⁵⁸ *Nursing Homes Act*, R.R.O. 1990, Reg. 832, s. 127(1).

⁵⁹ *Nursing Homes Act*, Reg. 832, s. 127(2)(b).

⁶⁰ Ontario Health Quality Council, *Q Monitor: 2009 Report on Ontario's Health System* (2009) at 80-81, online: <http://www.ohqc.ca/pdfs/ohqc_2009_report_-_english.pdf>.

⁶¹ *K.P. v. C. P.* (April 15, 2004) File No. 7690, Health Professions Appeal and Review Board.

⁶² *Nursing Homes Act*, s. 2(2)6ii.

⁶³ *Health Care Consent Act*, s. 17.

⁶⁴ College of Physicians and Surgeons of Ontario, *Consent to Medical Treatment*, Policy Statement #4-05 (January/ February 2006), online:

<<http://www.cpso.on.ca/policies/policies/default.aspx?ID=1544>>.

⁶⁵ *Ibid.*

⁶⁶ The definition of evaluators can be found in Reg. 104/96 pursuant to the *Health Care Consent Act*.

⁶⁷ Email from Lorissa Sciarra, Registrar and Senior Manager, Consent and Capacity Board, to Lisa Romano, Research Lawyer, ACE (19 June 2009).

⁶⁸ Office of the Public Guardian and Trustee, *The Role of the Office of the Public Guardian and Trustee*, online:

<<http://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/overview.asp>>.

⁶⁹ *Substitute Decisions Act*, ss. 27 and 62.

⁷⁰ *Residential Tenancies Act*, s. 140(1).

⁷¹ *Residential Tenancies Act*, s. 140(2).

⁷² Telephone conversation between Susan Bengler, Freedom of Information Coordinator, Landlord and Tenant Board and Lisa Romano, Research Lawyer, ACE (30 June 2009).

⁷³ The ACTION Line is staffed by employees of the Ministry of Government Services: Letter from Lynne Gottschling, Access and Privacy Coordinator, Ministry of Government Services, to Lisa Romano, Research Lawyer, ACE (16 July 2009).

⁷⁴ Of the 2,895 calls to the ACTION Line, 1,152 calls resulted in an investigation by a compliance advisor where no complaint was filed, 1,578 calls resulted in an investigation where a complaint was verified and 165 calls had no investigation status identified: Letter from Mary Salvatore, Program Advisor, Access and Privacy Office, Ministry of Health and Long-Term Care, to Lisa Romano, Research Lawyer, ACE (17 July 2009).

⁷⁵ *Nursing Homes Act*, s. 2(2)9.

⁷⁶ *Nursing Homes Act*, Reg. 832, s. 121.

⁷⁷ *Supra* note 28 at 21.

⁷⁸ Chinta Puxley, "Majority of Ontario nursing homes fail some basic standards" *Globe and Mail* (2 July 2008), online:

<<http://www.theglobeandmail.com/servlet/story/RTGAM.20080702.wnursinghomes0702/BNStory/National/home>>.

⁷⁹ Ontario, Ministry of Health and Long-Term Care, Performance Improvement and Compliance Branch, *New Inspection Process – Fact Sheet* (June 2009).

⁸⁰ *Nursing Homes Act*, s. 25(2) - (4).

⁸¹ ACE is of the opinion that in these circumstances, the *Trespass to Property Act*, R.S.O. 1990, c. T.21 cannot be used to prohibit visitors. Section 2(1) of the *Trespass to Property Act* says:

Every person who is not acting under a right or authority conferred by law and who, (a) without the express permission of the occupier, the proof of which rests on the defendant, (i) enters on premises when entry is prohibited under this Act, or (ii) engages in an activity on premises when the activity is prohibited under this Act; or (b) does not leave the premises immediately after he or she is directed to do so by the occupier of the premises or a person authorized by the occupier, is guilty of an offence and on conviction is liable to a fine of not more than \$2,000.

Residents of long-term care homes have the right to have a visitor without interference. Section 9 of the Resident's Bill of Rights states: "Every resident has the right to communicate in confidence, to receive visitors of his or her choice and to consult in private with any person without interference." Thus, section 2 of the *Trespass to Property Act* confers a right at law for the resident to have a visitor, meaning the *Trespass to Property Act* cannot be used to bar visitors from entering the premises.

⁸² Email from Tracy Fairfield, Complaints Response and Information Service, Ontario Retirement Communities Association to Judith Wahl, Executive Director, ACE (2 July 2009).

⁸³ *Nursing Homes Act*, s. 2(2).

⁸⁴ *Nursing Homes Act*, s. 2(4).

⁸⁵ *Long-Term Care Homes Act*, s. 3(3).

⁸⁶ *Long-Term Care Homes Act*, s. 3(4).

⁸⁷ *Nursing Homes Act*, s. 29(1).

⁸⁸ *Nursing Homes Act*, s. 29.1.

⁸⁹ *Long-Term Care Homes Act*, s. 56(1).

⁹⁰ *Nursing Homes Act*, s. 30.

⁹¹ The powers of Family Councils are set out in section 60 of the *Long-Term Care Homes Act*.

⁹² *Nursing Homes Act*, s. 30(e).

⁹³ For a thorough explanation of the problem and ACE's interpretation of the legal issues, please refer to Jane Meadus' paper entitled *Discharge to a Long-Term Care Home from Hospital* at www.ancelaw.ca.

⁹⁴ Concerned Friends of Ontario Citizens in Care Facilities, *Home Page*, online: <<http://www.concernedfriends.ca/>>.

⁹⁵ Concerned Friends of Ontario Citizens in Care Facilities, *History*, online: <<http://www.concernedfriends.ca/hist.htm>>.

⁹⁶ *Supra* note 60 at 75.

⁹⁷ *Ibid.* at 83.

⁹⁸ While residents may leave the home as they wish, it is acceptable for the home to require them to sign in and out in order to know their whereabouts in the event of a fire or other emergency.

⁹⁹ Under the *Long-Term Care Homes Act*, incapable residents can apply to the Consent and Capacity Board to challenge the decision of their substitute decision-maker to admit or transfer them to a secure unit: ss. 32 and 45.

¹⁰⁰ Law Commission of Ontario, *The Law As It Affects Older Adults – Consultation Paper: Shaping the Project* (May 2008), online: <http://www.lco-cdo.org/en/documents/OlderAdultsMay08/documents/ConsultationPaper-OlderAdultsFINAL.pdf>> at 16.

¹⁰¹ *Health Care Consent Act*, s. 4.

¹⁰² (1993), 100 D.L.R. (4th) 609 at 618 (S.C.C.).

¹⁰³ *Hospital Act*, R.S.B.C. 1996, c. 200, ss. 1 and 2.

¹⁰⁴ Charmaine Spencer, *An Introduction to Canadian Laws and Regulations to Protect Adults in Institutional Care Settings from Abuse and Neglect: British Columbia* (2008) at 6, online: <<http://elderabuse.aging.utoronto.ca/files/Prevention%20Laws%20-%20British%20Columbia.pdf>>.

¹⁰⁵ *Ibid.*

¹⁰⁶ S.B.C. 2002, c. 75, Part 3.

¹⁰⁷ B.C. Reg. 536/80.

¹⁰⁸ *Community Care and Assisted Living Act*, s. 1.

¹⁰⁹ *Adult Care Regulations*, s. 2.

¹¹⁰ British Columbia, Ministry of Health Services, Office of the Assisted Living Registrar, *Services Offered in Assisted Living Residences*, online:

<<http://www.health.gov.bc.ca/assisted/about/services.html>>.

¹¹¹ British Columbia, Ministry of Health Services, Office of the Assisted Living Registrar, *Exiting from an Assisted Living Residence: If a Resident's Health Changes*, online:

<<http://www.health.gov.bc.ca/assisted/about/exiting.html>>.

¹¹² Canadian Centre for Elder Law, *Discussion Paper on Assisted Living: Past, Present and Future Legal Trends in Canada* (October 2008) at 17, online:

<http://www.bcli.org/sites/default/files/2008-10-31_Assisted_Living.pdf>.

¹¹³ *Ibid.* at 23.

¹¹⁴ *Ibid.* at 18.

¹¹⁵ Charmaine Spencer, "A First Step in Consumer Protection for Seniors" in *Seniors' Housing Update* (Gerontology Research Centre: Simon Fraser University, 2006), online,

<<http://www.sfu.ca/uploads/page/28/SHUPv15n1.pdf>>.

¹¹⁶ *Supra* note 112 at 18.

¹¹⁷ *Community Care and Assisted Living Act*, s. 1. Please refer to the preceding section of this paper regarding assisted living facilities for a list of the prescribed services.

¹¹⁸ *Residential Care Regulation*, O.I.C. 225 (12 March 2009), s. 60, online:

<http://www.hls.gov.bc.ca/ccf/pdf/Deposited_Residential_Care_Regulation_96_2009.pdf>.

¹¹⁹ British Columbia, Ministry of Healthy Living and Sport, *The Community Care Licensing Branch*, online: <<http://www.hls.gov.bc.ca/ccf/index.html>>.

¹²⁰ *Supra* note 104 at 13.

¹²¹ *Community Care and Assisted Living Act*, s. 25.

¹²² *Supra* note 104 at 13.

¹²³ British Columbia, Ministry of Health Services, Office of the Assisted Living Registrar, *Mandate of the Registrar*, online: <<http://www.health.gov.bc.ca/assisted/mandate.html>>.

¹²⁴ *Ibid.*

¹²⁵ The Community Care and Assisted Living Board also hears and decides appeals from licensing and certification decisions about assisted living residences.

¹²⁶ *Supra* note 112 at 20-21.

¹²⁷ British Columbia, Ombudsman, *What We Do*, online:

<<http://www.ombudsman.bc.ca/what-we-do/index.htm>>.

¹²⁸ *Community Care and Assisted Living Act*, s. 15.

¹²⁹ British Columbia, Ministry of Healthy Living and Sport, *Community Care Facility Licensing Program*, online: <<http://www.hls.gov.bc.ca/ccf/facilityinspections.html>>.

¹³⁰ *Community Care and Assisted Living Act*, s. 13.

¹³¹ *Supra* note 112 at 24-25.

¹³² Alberta, Seniors and Community Supports, *Definitions – Affordable Supportive Living Initiative*, online: <<http://www.seniors.gov.ab.ca/continuingcare/ASLI/Definitions.asp>>.

¹³³ Charmaine Spencer, *An Introduction to Canadian Laws and Regulations to Protect Adults in Institutional Care Settings from Abuse and Neglect: Alberta* (2008) at 6, online:

<<http://elderabuse.aging.utoronto.ca/files/Prevention%20Laws%20-%20Alberta.pdf>>.

¹³⁴ Alberta, Seniors and Community Supports, *Supportive Living Framework* (March 2007) at 1, online:

<http://www.seniors.gov.ab.ca/housing/continuingcare/standards_framework.pdf>.

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- ¹³⁶ Alberta, Health and Wellness, *Continuing Care Strategy: Aging in the Right Place* (December 2008) at 19, online: <<http://www.health.alberta.ca/documents/Continuing-Care-Strategy-2008.pdf>>.
- ¹³⁷ Alberta, Health and Wellness, *Continuing Care Health Service Standards* (July 2008), online: <<http://www.continuingcare.alberta.ca/download/Continuing-Care-Standards-2008.pdf>>.
- ¹³⁸ Effective May 15, 2008, the twelve former regional health authorities were replaced by the Alberta Health Services Board: Alberta Health Services, *Our History*, online: <<http://www.albertahealthservices.ca/57.htm>>.
- ¹³⁹ R.S.A. 2000, c. S-10.
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- ¹⁴² *Supra* note 133 at 12.
- ¹⁴³ Alberta, Seniors and Community Supports, *Seniors Lodge Programs*, online: <http://www.seniors.gov.ab.ca/housing/seniors_housing/lodges/>.
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- ¹⁴⁵ *Ibid.* at 4.
- ¹⁴⁶ *Hospitals Act*, R.S.A. 2000, c. H-12, s. 1.
- ¹⁴⁷ *Supra* note 135 at 1.
- ¹⁴⁸ *Ibid.* at 1-2.
- ¹⁴⁹ Alberta, Seniors and Community Supports, *Long-Term Care Accommodation Fees*, online: <<http://www.seniors.gov.ab.ca/housing/LTCare/>>.
- ¹⁵⁰ *Protection for Persons in Care Act*, R.S.A. 2000, c. P-29.
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- ¹⁵² Alberta, Seniors and Community Supports, *General Information and Reporting Line*, online: <http://www.seniors.gov.ab.ca/CSS/persons_in_care/general_info/index.asp#how%20do%20report%20abuse>.
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- ¹⁵⁵ *Protection for Persons in Care Act*, s. 1(a).
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- ¹⁵⁷ Alberta, Legislative Review Committee, *Report on the Review of the Protection for Persons in Care Act* (March 2003), online: <http://www.seniors.gov.ab.ca/css/persons_in_care/Leg_review/CommitteeReport_March2003.pdf> at 10.
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- ¹⁵⁹ *Supra* note 133 at 11.
- ¹⁶⁰ Alberta, Health and Wellness, *Health Facilities Review Committee*, online: <<http://www.health.alberta.ca/about/HFRC.html>>.
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- ¹⁶³ *Supra* note 133 at 11.
- ¹⁶⁴ *Supra* note 160.
- ¹⁶⁵ *Supra* note 133 at 11.
- ¹⁶⁶ Ontario, Ombudsman Ontario, *The Push for Mush* (25 July 2008), online: <<http://www.ombudsman.on.ca/en/hot-topics/push-for-mush.aspx>>.
- ¹⁶⁷ *Supra* note 112 at 63-64.
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- ¹⁶⁹ *Homes for Special Care Act*, R.S.N.S. 1989, c. 203.
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<<http://www.ag.gov.nl.ca/ag/annualReports/2005AnnualReport/CH2.12.pdf>>.

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¹⁹⁵ S.N.L. 2000, c. R-14.1. s. 3(2)(e).

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²²⁷ *Care Homes (Wales) Regulations* at Regulation 23.

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²⁷⁵ *Ibid.* at 8.

²⁷⁶ *Ibid.* at 12.

²⁷⁷ Kerry Hannon, "Eric Carlson: On Elder Care – and Elder Law," *U.S. News and World Report* (11 March 2009), online: <<http://health.usnews.com/articles/health/best-nursing-homes/2009/03/11/eric-carlson-on-elder-care--and-elder-law.html?PageNr=3>>.

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²⁷⁹ Eric Carlson, *Long-Term Care Advocacy*, looseleaf (N.p.: Matthew Bender & Company; LexisNexis, September 2008) at 5-46 and 5-49.

²⁸⁰ *Ibid.* at 1-3.

²⁸¹ 42 U.S.C., s. 483.25.

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²⁸³ Kevin Dreher, "Enforcement of Standards of Care in the Long-Term Care Industry: How Far Have We Come and Where Do We Go From Here?" (2002) 10 *Elder Law Journal* 119 at 124.

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nearly 25%: Pravin Kamble *et al.*, “Antipsychotic Drug Use Among Elderly Nursing Home Residents in the United States” (2008) 6(4) 187 at 188 and 192.

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²⁹⁹ *Ibid.* at 1, 5 and 6.

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³⁰¹ National Long Term Care Ombudsman Resource Center, *About the National Long Term Care Ombudsman Resource Center*, online:

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<<http://longtermcare.state.wi.us/home/biennial%20report%202006%207.pdf>>.

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³⁰⁵ American Association of Retired People, *D.C. Long Term Care Ombudsman* (June 2003), online: <http://www.aarp.org/family/caregiving/articles/lce_longtermcare.html>.

³⁰⁶ Office of the District of Columbia Long-Term Care Ombudsman, *Annual Report 2008* (2008) at 3, online:

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³⁰⁸ *Supra* note 279 at 2-118 - 2-118.1.

³⁰⁹ *Supra* note 296 at 81.

³¹⁰ 42 U.S.C. 3027, s. 307(11).

³¹¹ *Supra* note 279 at 10-7.

³¹² *National Consumer Law Center, Unfair and Deceptive Acts and Practices*, s 1.1 (4th ed. 1997).

³¹³ *Podolsky v. First Healthcare Corp.*, 58 Cal. Rptr. 2d 89 (Cal. Ct. App. 1996).

³¹⁴ *Mulligan v. Beverly Enterprises-Texas Inc.*, 954 S.W.2d 881 (Tex. App. 1997).

³¹⁵ *Brogdon v. National Healthcare Corp.*, 103 F. Supp. 432 (E.D. La. 1996).

³¹⁶ *Supra* note 279 at 10-67.

³¹⁷ *Long v. HCA Health Servs. of Tennessee, Inc.*, 2002 Tennn. App. LEXIS 211 (Tenn. Ct. App. 2002).

³¹⁸ *Healthcare Ctrs. of Texas, Inc. v. Rigby*, 97 S.W.3d 663 9Ky. Ct. App. 2004).

³¹⁹ *Lemoine v. Insurance Co. of North America*, 499 So. 2d 1004 (La. Ct. App. 1986).

³²⁰ *Redfield v. Beverly Health and Rehab. Servs., Inc.*, 42 S.W.3d 703 (Mo. Ct. App. 2001).

³²¹ *Casa v. Paradez*, S.W.3d, 2007 Tex, App. LEXIS 7218.

³²² 353 Ark. 29, 111 S.W.3d 346 (2003).

³²³ *N.Y. Public Health Law*, s. 2801-d.

³²⁴ Fla. Stat. Ann., s. 400.023(1) and s. 400.29.

³²⁵ N.J.S.A., ss. 30:13-8(b).

³²⁶ ACE is referring to those retirement homes providing the same or similar care services as in a long-term care home or those receiving government funding for care services.

³²⁷ Additional information about this program can be found at Stetson Law School's Center for Excellence in Elder Law's website:

<http://gpiis05.law.stetson.edu/tmpl/academics/elder/internal-1_sub.aspx?id=566&ekmense=c580fa7b_84_132_btnlink>.

³²⁸ *Supra* note 28 at 16.

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³³⁰ *Ibid.*

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³³² *Supra* note 217 at 131.

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³³⁵ *Ibid.* at 5.

³³⁶ Ernie Lightman & Uri Aviram, "Too Much, Too Late: The *Advocacy Act* in Ontario" (2000) 22 Law and Policy 25 at 30 [Lightman & Aviram]; *Advocacy Act, 1992*, S.O. 1992, c. 26, s. 2, as repealed by the *Advocacy, Consent and Substitute Decisions Statute Law Amendment Act, 1996*, S.O. 1996, c. 2, s. 1.

³³⁷ Lightman & Aviram, *ibid.* at 31.

³³⁸ *Ibid.* at 38-39.

³³⁹ *Ibid.* at 27.

³⁴⁰ *Ibid.* at 33.

³⁴¹ *Ibid.* at 40.

³⁴² The Health Care Commission's jurisdiction over retirement homes is contingent on the regulation of retirement homes. Please refer to the section about retirement homes on pages 102-106 for more information. It may not be appropriate to have an advocate in all retirement homes as many residents are capable and might be offended by the assumption that they require assistance.

³⁴³ *Nursing Homes Act*, Reg. 832, s. 130(1)(a).

³⁴⁴ *Provincial Advocate for Children and Youth Act, 2007*, S.O. 2007, c. 9, s. 1.

³⁴⁵ *Provincial Advocate for Children and Youth Act*, s. 15.

³⁴⁶ *Provincial Advocate for Children and Youth Act*, s. 16.

³⁴⁷ *Provincial Advocate for Children and Youth Act*, s. 21.

³⁴⁸ *Advocacy Act*, s. 1(b).

³⁴⁹ Forum of Canadian Ombudsman, *What is an 'Ombudsman'?*, online:

<http://www.ombudsmanforum.ca/whatis_e.asp>.

³⁵⁰ *Ibid.*

³⁵¹ Mary Marshall, "Seniors Need Resources to Pursue Complaints" (2005) 26 Health Law in Canada 1 at 4.

³⁵² *Ibid.*

³⁵³ Andre Marin, "Vital Watchdog vs. Paper Tiger: What Kind of Ombudsman do You Want to Be?" (Closing remarks to the Association of Canadian and University Ombudsmans at Halifax, Nova Scotia, 29 May 2008), online:

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³⁵⁴ Ontario, Ombudsman Ontario, *Annual Report 2008-2009* (June 2009) at 15, online:

<<http://www.ombudsman.on.ca/media/89799/ar09-english.pdf>>.

³⁵⁵ *Ombudsman Act*, R.S.B.C. 1996, c. 340, Schedule of Authorities at Number 28.

³⁵⁶ Bill 89, *Ombudsman Amendment Act (Hospitals and Long-Term Care Facilities)*, 2008, 1st Sess., 39th Leg., Ontario, 2008, online:

<http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2030&detailPage=bills_detail_status&Intranet>.

³⁵⁷ Bill 102, *Seniors' Ombudsman Act, 2008*, 1st Sess., 39th Leg., Ontario, 2008, online:

<http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=2060&detailPage=bills_detail_status&Intranet>.

³⁵⁸ Ontario, Ombudsman Ontario, *Making a Complaint*, online:

<<http://www.ombudsman.on.ca/en/make-a-complaint.aspx>>.

³⁵⁹ Gunningham & Sinclair, *supra* note 31 at 50.

³⁶⁰ *Ibid.* at 52.

³⁶¹ *Ibid.* at 53.

³⁶² *Ibid.* at 55.

³⁶³ Ontario, Ontario Seniors' Secretariat, Consultation Backgrounder for Ontario's Consultation on Regulating the Retirement Home Industry, online:

<<http://www.culture.gov.on.ca/seniors/english/programs/rhc/docs/RHC.Backgrounder.pdf>>.

³⁶⁴ Ontario, Ontario Seniors' Secretariat, *Retirement Homes Consultations*, online:

<<http://www.culture.gov.on.ca/seniors/english/programs/rhc/>> (last modified: 30 July 2007).

³⁶⁵ Ontario, Ontario Seniors' Secretariat, *Regulating Care in Ontario's Retirement Home Industry: The Findings from 13 Consultations* (2007), online:

<<http://www.culture.gov.on.ca/seniors/english/programs/rhc/docs/ConsultationSummary.pdf>>; Ontario, Ontario Seniors' Secretariat, *Regulating Care in Ontario's Retirement Home Industry: The Findings from Written Submissions to the Ontario Seniors'*

Secretariat (2007) at 10, online

<<http://www.culture.gov.on.ca/seniors/english/programs/rhc/docs/WrittenSubmissions.pdf>>.

³⁶⁶ R.S.O. 1990, c. H.6.

³⁶⁷ *Accessibility for Ontarians with Disabilities Act, 2005*. S.O. 2005, c. 11.

³⁶⁸ *Supra* note 193.

³⁶⁹ (W.A.), s. 11.

³⁷⁰ R.S.A. 2000, c. S-6, s. 2(2).

³⁷¹ Government of Canada, National Seniors Council, *About Us*, online:

<http://www.seniorscouncil.gc.ca/eng/about_us/index.shtml> (last modified: 3 February 2009).

³⁷² Office of Missouri Governor, *Governor's Advisory Council on Aging*, online: <<http://governor.mo.gov/boards/show/AGING>>.

³⁷³ *Accessibility for Ontarians with Disabilities Act, 2005*. s. 31.

³⁷⁴ *Supra* note 2 at 4.

³⁷⁵ Pursuant to the *Mental Health Act* and R.R.O. 1990, Reg. 741, the following eight situations require mandatory rights advice: (1) a physician's decision that the patient's status in a psychiatric facility must change to involuntary; (2) a physician's decision that the patient's involuntary status must continue; (3) a physician's decision that the patient is incapable to manage property; (4) a physician's decision that the patient's incapacity to manage property must continue; (5) a physician's decision that the patient is incapable to consent to treatment for a mental disorder; (6) a determination that the patient is incapable of consenting to the collection, use or disclosure of personal health information; (7) when a twelve to fifteen year old is admitted to a psychiatric facility as an informal patient, and every three months thereafter; and (8) before issuing or renewing a community treatment order, a physician must be satisfied that the person who will be subject to the order (and their substitute decision-maker, if any) has consulted with a rights adviser and have been advised of their legal rights.

³⁷⁶ *Mental Health Act*, Reg. 741, s. 15(1)(a). A copy of the Form 33, Notice to Patient under Subsection 59(1) of the Act and under Clauses 15(1)(a) and 15.1(a) of Regulation 741, can be found at

[http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/GetAttachDocs/014-1088-41~3/\\$File/1088-41.pdf](http://www.forms.ssb.gov.on.ca/mbs/ssb/forms/ssbforms.nsf/GetAttachDocs/014-1088-41~3/$File/1088-41.pdf).

³⁷⁷ *Supra* note 48 at 189.

³⁷⁸ Both section 23 of the *Nursing Homes Act* and section 141 of the *Long-Term Care Homes Act* merely say that the Minister "may appoint inspectors."

³⁷⁹ To view reports in these two countries, please refer to the respective websites of the Care and Social Services Inspectorate of Wales and the Aged Care Standards and Accreditation Agency at <<http://www.csiw.wales.gov.uk/dataviewer/index.asp> and <http://www.accreditation.org.au/report-advanced/>>.

³⁸⁰ *Long-Term Care Homes Act*, s. 182.

³⁸¹ Neeta Lal, "India's senior citizens finally get a hearing" *Infochange* (July 2007) online: <<http://infochangeindia.org/200707205548/Human-Rights/Analysis/India-s-senior-citizens-finally-get-a-hearing.html>>.

³⁸² China.org.cn, *Law of the People's Republic of China on Protection of the Rights and Interests of the Elderly, 1996*, online:

<<http://www.china.org.cn/english/government/207403.htm>>.

³⁸³ *Supra* note 296 at 36.

³⁸⁴ *Ibid.* at 40.

³⁸⁵ Canadian Centre for Elder Law, *Backgrounder: Elder and Guardianship Mediation* (24 February 2009) at 2, online:

<http://www.bcli.org/sites/default/files/backgrounder_elder_guardianship_mediation_24Feb09.pdf>.

³⁸⁶ *Supra* note 296 at 31.

³⁸⁷ *Supra* note 385 at 1.

APPENDICES

Appendix A: Example of an Introductory Letter sent to Stakeholders

ADVOCACY CENTRE for the ELDERLY

2 Carlton Street, Suite 701
Toronto, Ontario M5B 1J3
Tel: (416) 598-2656
Fax: (416) 598-7924
www.ancelaw.ca

Chair, Board of Directors
Paula Psyllakis, B.A. (Hons.), M.A.

Lawyers
Judith A. Wahl, B.A., LL.B.
Rita A. Chrolavicius, LL.B.
Graham Webb, LL.B., LL.M.
Jane E. Meadus, B.A., LL.B.
Lisa Romano, B.A., LL.B., LL.M.

PERSONAL AND CONFIDENTIAL

Sent via regular mail

President, Residents Council

To Whom It May Concern:

RE: Research Project – *Institutional Living and the Law as it Affects Older Adults*

We cordially invite the residents of Community Nursing Home to participate in a research project conducted by the Advocacy Centre for the Elderly (ACE). We would welcome the opportunity to meet with residents in order to obtain their feedback about living in a long-term care home and the law as it affects older adults.

Overview of the Project

ACE is pleased to be working with the Law Commission of Ontario (LCO) with its project to analyze and understand the impact of law on older persons. Specifically, ACE has been awarded a research grant from the LCO to research the best ways of enforcing the rights of older adults in institutional settings, specifically long-term care homes.

ACE will be holding meetings and focus groups with a variety of stakeholders in order to obtain their opinions regarding the various methods that might help older adults enforce their rights in long-term care homes.

Research Statement

It is argued by some people that the legal system in Ontario is unable to meet the needs of older adults in institutional settings (e.g. hospitals, retirement homes and long-term care homes) in having their complaints heard and resolved in a timely and satisfactory manner.

Residents may be particularly vulnerable as they are often dependent on those very institutions that have violated their rights. Additionally, the fact that residents are “out of sight” compounds the problem and means that public scrutiny is lacking.

In an effort to influence both law reform in Ontario and the best practices of institutions, ACE will also be examining the law in different provinces and countries work to determine how they enforce the rights and remedies for older adults in institutions. These “access to justice models” will be analyzed to determine whether they could work in Ontario.

Scope and Type of Work

We would like to study an assortment of different methods of enforcing older person’s rights available in other jurisdictions, including the following:

- Ombudsman models;
- tribunals/administrative boards;
- government regulatory bodies;
- industry regulation;
- education;
- advisory groups to government comprised of older adults living in long-term care homes;
- legal supports;
- alternative dispute resolutions;
- advocate programs;
- court proceedings; and
- other models.

Residents' Councils

ACE hopes to speak directly to residents so they can:

- advise us about any obstacles, if any, they encounter when they attempt to enforce their legal rights;
- the remedies they are seeking; and
- what changes, if any, should be made to the current system to make it more accessible to residents.

Obviously, this is the most important group for us to meet with as the law directly impacts residents and affects their daily lives.

We would like to schedule a one or two hour long meeting to discuss these issues with residents. Due to the tight timelines in this research project, we would like to hold the meeting as soon as possible. ACE will provide food and refreshments, as well as a small stipend of \$25.00 to cover the costs of organizing this meeting.

More information about the LCO's project on older adults can be found at their website: <http://www.lco-cdo.org/en/olderadults.html>.

If you have any questions, please do not hesitate to contact either Jane Meadus, Institutional Advocate, or Lisa Romano, Staff Lawyer.

We look forward to working with you.

Yours truly,

ADVOCACY CENTRE FOR THE ELDERLY

Jane Meadus
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**Appendix B:
Questionnaire Distributed at Consultations in Long-Term Care Homes**

**“ACCESS TO JUSTICE”
CONSULTATION**

Circulated by the Advocacy Centre for the Elderly (ACE)
June 2009

1. Have you experienced any problems while living in a long-term care home?

For example:

- Your doctor doesn't explain and get proper consent from you or your substitute decision-maker before giving you a medication
- You are not allowed to see or visit your friends or family members
- Staff members at the long-term care home mistreat you
- The attorney named in your power of attorney doesn't let you have any or your money

2. Do you feel there are any barriers or obstacles when you try to solve your problems or enforce your rights?

For example:

- You don't know your legal rights
- You don't know how to find a lawyer and/or it's too expensive to talk to a lawyer
- The home won't take action to resolve your problem
- The Compliance Advisor at the Ministry of Health and Long-Term Care doesn't call you back or take your concerns seriously
- Nobody believes you

3. Do you have any suggestions about how the current system can be changed in order to help older adults solve any problems?

For example:

- The Ombudsman of Ontario should be allowed to hear complaints about long-term care homes
- It should be easier to go to court or to have a lawyer
- An advocate who does not work for the long-term home should be available to help me voice my concerns

Please complete and return the completed questionnaire to an ACE lawyer at the end of the session. You may also mail or email your responses to the addresses below.

Feel free to use extra sheets of paper, if necessary.

If you have any questions, you can call Lisa Romano or Jane Meadus at **(416) 598-2656**.

Our address is:

Attention: LCO Project

**Advocacy Centre for the Elderly
2 Carlton Street, Suite 701
Toronto, ON M5B 1J3**

Our Email Addresses are:

romanol@lao.on.ca or meadusj@lao.on.ca

Thank you for your participation!

**Appendix C:
Questionnaire Distributed at Consultations in Retirement Homes**

**“ACCESS TO JUSTICE”
CONSULTATION**

Circulated by the Advocacy Centre for the Elderly (ACE) -
May 2009

1. Have you experienced any problems while living in a retirement home?

For example:

- Your doctor doesn't explain and get proper consent from you or your substitute decision-maker before giving you a medication
- You are not allowed to see or visit your friends or family members
- You are told that you have to move to a different unit
- Staff members at the retirement home mistreat you
- The attorney named in your power of attorney doesn't let you have any or your money

2. Do you feel there are any barriers or obstacles when you try to solve your problems or enforce your rights?

For example:

- You don't know your legal rights
- You don't know how to find a lawyer and/or it's too expensive to talk to a lawyer
- The home won't take action to resolve your problem
- You call the Complaints Response and Information Service (CRIS) but they don't call you back
- Nobody believes you

3. Do you have any suggestions about how the current system can be changed in order to help older adults solve any problems?

For example:

- There should be more regulation of retirement homes by the government
- It should be easier to go to court or to have a lawyer
- An advocate who does not work for the retirement home should be available to help me voice my concerns

Please complete and return the completed questionnaire to an ACE lawyer at the end of the session. You may also mail or email your responses to the addresses below.

Feel free to use extra sheets of paper, if necessary.

If you have any questions, you can call Lisa Romano or Jane Meadus at **(416) 598-2656**.

Our address is:

Attention: LCO Project

**Advocacy Centre for the Elderly
2 Carlton Street, Suite 701
Toronto, ON M5B 1J3**

Our Email Addresses are:

romanol@lao.on.ca or meadusj@lao.on.ca

Thank you for your participation!

**Appendix D:
List of Participants**

Residents' Councils

- Baycrest Centre
- Community Nursing Home, Port Perry
- Kensington Gardens
- Fellowship Towers Retirement Community
- Meighen Retirement Residence
- Sunnyside Home

Family Councils

- Family Council Network Four
- North East Family Council Network
- Sunnyside Home

Lawyers

- Jan Goddard, Jan Goddard and Associates
- Ryan Kirshenblatt, Eisen Graham
- Alex Procope, Swadron Associates
- Lonny Rosen, Gardiner Roberts LLP
- Dina Stiga
- Anita Szigeti, Hiltz and Szigeti

Industry and Seniors Groups

- Alzheimer Society of Ontario
- Canadian Pensioners Concerned
- Concerned Friends of Ontario Citizens in Care Facilities
- Family Councils Program
- Hillside Estate
- Ontario Association of Community Care Access Centres
- Ontario Association of Non-Profit Homes and Services for Seniors
- Ontario Association of Residents' Councils
- Ontario Long-Term Care Association
- Ontario Retirement Communities Association

- United Senior Citizens of Ontario
- Yee Hong Centre

Individuals

- Gary Bowers