Written Submission

Standing Committee on Social Policy

Legislature of Ontario

On

Bill 140 – An Act Respecting Long-Term Care Homes

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Introductory Remarks

In our oral presentation the Alzheimer Society of Ontario's (ASO) to the Committee on Jan. 17, 2007, we focused on those elements of Bill 140 that we believe will have the most significant impact upon persons with Alzheimer disease and related disorders (ADRD) and their families and partners in care.

We identified aspects of the Bill that we view as distinct improvements, as well as areas where we believe there are changes or additions needed.

In this submission we cover a wider set of issues. We repeat the areas covered in our oral presentation in this document so that the reader has all of our views on Bill 140 in one document.

ASO welcomes Bill 140 as comprehensive effort to update three very dated pieces of legislation. We applaud both the updating and the consolidation. We view the Bill in a very positive light inasmuch as it focuses on the LTC home as the "home" of the residents.

We applaud the various funding announcements already made but caution that this field of human services will require tremendous funding increases in the future to cope with the dramatic changes in our population demographics and to make "real" the many laudable aspects of Bill 140.

The ASO has had a Working Group, composed of persons with wide ranging direct experience in long-term care homes, studying the Bill for some months and their proposals are reflected in these remarks.

This presentation addresses the following questions that we expect all Committee member will be considering as they read this presentation.

1) What is the burden of Alzheimer's disease and related dementias (ADRD) in Ontario and in the LTC homes in particular?

2) What credibility does the Alzheimer Society of Ontario have in speaking to this issue and about Bill 140?

3) What aspects already included in Bill 140 are a distinct improvement for persons with ADRD?

4) What should be added to or amended in Bill 140 to better meet the needs of the ADRD affected residents in LTC homes?

1) First, what is the burden of Alzheimer's disease and related dementias (ADRD) in Ontario and in the LTC homes in particular?

In Ontario, 171,000 persons have dementia and this number is growing rapidly as the life span of our population increases.
Over 50% of residents of our long-term care homes have dementia and it is the major cause for admission. The average stay of persons with dementia in long-term care homes is decreasing with some homes having a 50% admission rate in one year. People are moving in to a home when their illness is at the most debilitating stage. The growing numbers of affected persons places pressure on both the space requirements and staff capacity.

In addition, one should not overlook the impact of ADRD on caregivers. Family members and other key persons give a lot and we ask a lot. These lifelong relationships mean that these persons too need special recognition and support as their partner or parent is admitted to a home.

2) Secondly, what credibility does the Alzheimer Society of Ontario and its member chapters have in speaking to this issue and about Bill 140?

No one wants to get Alzheimer's disease, but if they do, our Society's 39 chapters are there for them, their caregivers and for health service providers in every sizeable community in our province. For nearly 25 years, we have remained true to this mission, as well as leading the way in supporting dementia research.
No one wants to live their last years or months in a long-term care home but if they must, our Society will reach out to partners to ensure adequate staff training, informed and supported caregivers, and, to create and disseminate research on better ways to provide care.

The Alzheimer Strategy for Ontario that we, along with the Government of Ontario and our partners launched in 1998 continues its momentum. Among other initiatives, the Strategy emphasizes dementia education, physician education and advanced care planning. While more than 4,000

workers in long-term care have received dementia education over the last seven years, this remains a small segment of the total workforce.

Our chapter staff and volunteers work across the health continuum. We work with our primary care partners to screen and diagnose for the disease and with Community Care Access Centres in their assessments. We assist those who remain in the community to assure that they have adequate services, with acute care diagnostic services, and with mental health referrals. We actively work with long-term care homes as persons reach the later stages of the disease. We know the important contribution each partner makes along the way and the importance that every part of the health system to be competent and caring.

3) Thirdly, what aspects already included in Bill 140 are distinct improvements for persons with ADRD?

a) The rights-based approach taken throughout the legislation will do much, we believe, to assure that all of the activities of long-term care homes have the resident as their primary focus. The Fundamental Principle set out in Part I assures that long-term care homes be operated above all as the "home of its residents".

b) In addition, the Fundamental Principle set out in Part I assures that long-term care homes be operated above all as the "home of its residents".

c) We are very positive about the inclusion of a Resident's Bill of Rights. However, because of the varying cognitive deficits of residents with dementia, we recommend that Section 3, sub-section (3) be amended to include the following:

> "In instances where a substitute decision maker is acting for the resident, the rights of the resident may be acted upon by the substitute decision-maker."

This amendment will clarify the role of the substitute decision-maker within Bill 140.

d) Section 27- Minimizing of Restraining

(i) The requirement in Section 27, Minimizing of restraining, that each home be required to have a policy designed to minimize use of restraints is laudable. Restricting such a fundamental right as freedom of movement needs to be approached with the gravity of its consequence.

(ii) Section 30 – Restraint using barriers, locks, etc.
We commend the conditions to be met on restraints using barriers, locks, etc., as clear and helpful and endorse the inclusion of these particular restraints in the client's Plan of Care.

(iii) Section 43 – Admission to a Secure Unit

Especially laudable is section 42, sub-section 11, paragraph d, requiring consent for admission to a specific home. You will hear stories of people in hospital who have been forced to move 60 or more miles from their home to receive long-term care. This must end.

The provisions in Section 43, sub-section 1(5), requiring consent for admission to a secure unit, are very positive.

Some may ask you to modify this provision because of convenience or ease of management. We ask that you not do that. One of the great cruelties of dementia is that its progress is uneven. One part of a person's brain may be compromised, while another part may function adequately. We cannot prejudge the impact of a secure unit on a person.

ŧ) Section 74 (6) – Additional training – direct care staff

We are very supportive of the training requirements in this section for direct care staff to have training in dementia, behaviour management and palliative care.
Much progress has been made in upgrading the training of staff in long-term care homes in dementia care, behaviour management and palliative care but there is so much more to be done. While we will be working with government, professions and educational institutions to improve the pre-service training of long-term care personnel, the Alzheimer Society cannot stress strongly enough the need to train and re-train existing personnel. The proportion of residents with severe dementia will increase and their length of stay is likely to shorten in future. This change will mean an increasing intensity of service and that the usual interval between admission and death will be truncated. This more complex resident population will place more pressure on direct care staff who deserve to have their skill-set continuously renewed.

4) Fourth and especially important for both the Committee and the Alzheimer Society of Ontario, what should be added to or amended in Bill 140 to better meet the needs of the AARD affected residents in LTC homes?

a) Part II – Plan of Care

Sec. 6 (4) – Plan of care to cover all aspects of care

We recommend that the plan of care also be required to cover pharmacy, psychological and psych-social aspects.
Poly-pharmacy, the use of a very wide variety of medications, is a major health issue and needs to be highlighted in plans of care so that periodic, comprehensive drug reviews are scheduled and recorded.

The psych-social aspects of each resident's functioning will be central in any good care program and should, therefore, be in the plan of care document.
Depression is a major diagnosis in long-term care homes with an estimated 33 % of the residents suffering from it. Therefore, each plan of care should have a requirement to address the state of the resident's mental health.

Sec. 6 (7) – Development of initial plan of care

We recommend that a subsection be added here that places an obligation on the operator to augment the assessment team in instances where the existing resources seem insufficient. Examples would include mental health, brain injury and developmental services expertise.
In instances where the apparent needs of the resident exceeds the normal assessment competencies available in the home, the care team should be obliged to call upon external community resources to contribute to the assessment and formulation of the plan of care.

Sec.16 – Standards for program and services

We recommend that a subsection be added here that requires the operator to provide or arrange for the provision of any other programs, services or other requirements deemed necessary in the resident's plan of care.

b) Linkages - Community Care/Mental Health/ Local Health Integration Networks

Bill 140 is focused on institutional care. It will be important to assure that early identification and community care for persons with ADRD is provided, as it is our view that this can delay significantly the need for more advanced and usually, institutionally based care. It is important that the Bill direct Local Health Integration Networks (LHINs) to look first to strengthening community services before calling for more long-term care beds. An institutional waiting list can be as indicative of community service shortages, as of institutional space shortages. This is especially a concern in regard to sections 94 and 95 that deal with Public interest- need.

We recommend that LHINs examine methods to divert residents and prospective residents from LTC wait lists.
We are aware of a reevaluation program in the Hamilton area that resulted in a substantial percentage of individuals being diverted from the LTC waiting lists to other forms of care. This suggests that change is occurring with some individuals that allows for use of less costly and less confining forms of care.

The linkage between the mental health and dementia care systems needs to be vastly improved. We are very pleased that the 14 Local Health Integration Network organizations are focusing upon community care as well as institutional and that intra as well as inter system linkages are high on their agenda. This emphasis will have many benefits and, in particular, has the potential to better link the mental health and dementia care service networks.

c) Sec. 24 (1) – Whistle-blowing protection

The whistleblower section is very important and the clauses are clearly set out. Nevertheless, it will be important to assure in the implementation that the whistleblower is protected from retribution.

d) Regulations
It will be especially important to consult in depth on the regulations that will be developed. Consultation could assure a sensible balance of protection for the resident as well as for staff and for other residents by assuring that staff has an ability to cope with clients who are very difficult to care for.

e) Sections 27 to 34 and 74 - Restraints and Training

(i) Training – 73 (6) and Sec. 74

Sec. 73 (6) – Additional training – direct care staff

We commend the Bill's provisions on training but have concerns about the way Section 74 is drafted so that all persons working in the home are subject to similar training requirements. We are concerned that the training requirements may discourage volunteers by requiring a training content that is excessively complex or onerous.

Our Society advocates that section 74 be amended to identify classes of persons who require training and that the types of training are suited to each group's particular involvement with the resident population, an approach that is consistent with best practices in volunteer management.

This change may also alleviate concerns of some providers about the perceived excessive training burden.
We are especially concerned that the training requirements do not discourage volunteers by requiring a training content that is excessively complex and onerous. Therefore, we propose the development of a thoroughly pre-tested training program for this group.

(ii) Training about Restraint

We believe that training of all staff in LTC settings in the application of restraints is crucial and should be a specific requirement of the Bill.
In addition, the frequency and documentation of checks on the restrained client should be in regulation. This will help to avoid the incidence of self-injury that is believed by some to be common at present
Physicians, nurses and other professionals, as well as managers and front line staff, require this training

f)Residents – Information, Agreements, etc.
Sec. 76 – (1) and (2)

We are very positive about the provision of information to residents and substitute decision makers as set out herein.

g) Sec. 77 – Posting of information

Public Information

In several sections, the Bill calls for information to be made public. While this is admirable, it is often difficult for the public to locate and compile the information. We suggest that a section be added in this information section that would require operators to assemble this information in one place that is readily accessible to the public and as specified in the regulations. In today's world, the regulation could call for it to be in the home's business office in a dossier, as well as published on a website.

Section 77 should also include an additional sub-section (3) which would require "every licensee of a long-term care home to make available to the public a "Home Profile"[1] which would contain:

1. The number of beds and classes of beds, including the size of a secure unit.
2. Annual statistics on the number of admissions and transfers
3. The amount of funding received over the past three years
4. The level of care results over the same time period

5. The number of complaints acted upon by the ministry in the past year
6. The number of applications that were refused and the reasons for those decisions
7. A section that provides for the resident and family councils to describe their level of activity
8. The results of satisfaction surveys over the last three years
9. The number of residents restrained in the past year
10. The ministry inspection reports and subsequent plans filed. These documents should be current as of a date specified in the regulations and should be made public as specified in the regulations

The sub section of the Bill regarding regulations would require changes for this provision.

h) Part III - Admission of Residents and Classification within the Population

(i) We are in general support of the thorough provisions of Part III Sections 37 through 53 dealing with Admission of Residents.

(ii) Sec. 42 (11) (a) Conditions of authorization of admission

This subsection requires that the assessment or reassessment occur within three months of the actual admission. Elapsed time between the assessment and the actual admission has been a problem. Waits of up to a year have occurred. We support this section of the Bill.

(iii) Section 51 - Hearing – Ineligibility for Admission

We are in support of the provisions concerning hearings as set out in this section. We think that this right to appeal should be extended to people who are refused admission to the home of their choice as per section 42(9).

(iv) Behavioural Assessment Units

Section 178, sub-section 2(h) that calls for the classification of beds will enable small behavioural assessment units to be established in at least one long-term care home in each LHIN region, modeled on those already in operation in St. Catharines, Hamilton, and Kitchener. Such specialized assessment units would do much to reduce the likelihood of severe aggressive behaviour.

A high level of training and skill in the mental health field will be required for these particular assessments as the presenting problems will often be twofold; dementia and mental disorder.

This type of assessment unit would provide an excellent training location for staff that require special assessment and care skills in working with the most potentially challenging residents.

(v) Sec. 43 – Admission to a secure unit

We recommend that consultation with a mental health professional, usually a psycho-geriatric resource consultant, should be a requirement of the assessment for admission to a secure unit, whether the resident is admitted directly from the community or from within the home itself.

We support the provisions of Sec. 43, sub (2) (a) and (b) that sets out the advice requirements if substitute consent is required concerning admission to a secure unit.

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We believe that standardized criteria are needed for admission to a secure unit. In some facilities, wandering is the criterion and in others the criterion is issues of safety of self. We believe that professionals, such as RNs, should be trained to carry out these assessments. These staff would be quite capable of carrying out consultations with specialists recommended in the first paragraph of this section.

(vi)Sec. 43 - Advice to and Education/Information for Families about Admission to a secure unit

We believe that a resident's family needs to be advised when their family member is to be admitted to a secure unit and that they should be provided with information/education about the reasons for this decision.

(vii) Reassessment while in a secure unit
We believe that reassessments of residents placed in secure units should occur regularly, at quarterly intervals, to determine if the individual needs to remain in the secure unit. Transfer to such a unit should not be considered as a one-way trip for any and all residents.

i) Part IV – Councils

(i) Sections 54 through 56 - Residents' Council

We are very positive about the provisions in the Bill with respect to Residents' Councils.

(ii) Sections 57 through 59 – Family Council

It is often difficult to interest and engage family members in Family Councils. Training of family members and substitute decision makers as to the benefit of their involvement in the activities of their family member's LTC home could prove very beneficial.

Family Councils should provide information to families of prospective applicants in areas such as: income tax, advocacy, fundraising and education.

j) Volunteerism

In addition to Resident and Family Councils, it is important that the Bill recognize the role of the general community in relation to its long-term care facilities.
Interested volunteers, who represent the general public, can add much to the public education, advocacy and impetus for research so much needed in this field.
It is recommended that Section 15 be amended to require each home to establish a volunteer services committee to assure the full utilization of community volunteers.

k) General management
Sec. 82 – Quality management
We believe that what constitutes a quality management system should be explicitly specified in the regulations, as contemplated in Sec. 87 (2) (a) of regulations

l) Part VI - Funding

(i) It is not clear in the Bill how funding for indigent persons will be managed and we suggest that this should be explicitly stated in the Bill. We believe that any resident can be granted a reduced rate if they provide an income tax form indicating a limited financial capacity.

(ii) Newcomers to Canada and those who have moved between provinces who do not have an OHIP registration could present an unusual situation that should be addressed in the legislation or its regulations. The Bill should state that, "no person legitimately resident in Canada will be refused admission to a LTC home for financial reasons".

(iii) Full funding for provision of necessities such as hearing aids, dentures and wheel chairs for residents who do not have sufficient financial capacity should be covered in regulations.

(iv)We believe that funding is too limited to allow for adequate staffing. In addition, limited funding often does not allow for less intrusive restraint devices to be purchased and employed such as light beams to detect patient movements.

m) Part IX – Compliance and Enforcement Sections 139 to 159

(i) Achievement of Excellence - Positive Incentives

The Bill is based on a belief that inadequate care can be remedied by inspection and enforcement, but we contend that excellent care can only be encouraged through positive incentives. Bill 140 needs to give more prominence to its provisions for the Minister to recognize and reward excellence in all aspects of training, programming and management of Long-term care homes. Such initiatives as the Alzheimer Knowledge Exchange, the Registered Nurses Association Best Practice Guidelines and the proposal for 'Teaching long-term care homes', similar to teaching hospitals and health units, are initiatives through which the Minister can encourage the pursuit of excellence.

We recommend that Section 178, sub-section 2, paragraph r be elevated to form its own clause and that section 141, sub-section 2 be moved to this section. This change emphasizes the Minister's obligation and ability to foster positive incentives.

(ii) Sec 146 – We are very supportive of the inspection reports being shared with Resident and Family Councils. In addition, the Action Plan provided by the LTC home, following receipt of an inspection report, should be shared.
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Conclusion

While there is much in the Bill to commend it, the success of the Bill in its implementation will depend heavily upon the content of the regulations. We believe that it is crucial that the regulations for the Bill be publicly consulted before their approval.

The success of the new Bill, however satisfactory it becomes with further changes, will depend upon adequate funding based upon the standards set out in both the Bill and the regulations that will accompany it.