

STANDING UP FOR QUALITY CARE

Alzheimer Society of Ontario on the Local Health System Integration Act (Bill 36)



January 30, 2006

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Alzheimer Society of Ontario

Submission to

STANDING COMMITTEE ON SOCIAL POLICY

Monday, January 30, 2006

On

Bill 36, An Act to provide for the integration of the local system for the delivery of health services

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Our Organization and its Mission

The vision of the Alzheimer Society is a world without Alzheimer Disease and related disorders (ADRD or AD). 100 years ago this month, Dr. Alois Alzheimer first described the disease we now associate with his name. Each year, we move closer to a cure for a disease that robs us of our memories and loved ones. Along this path, our volunteers and staff have responded with compassion to the pressing needs of persons with the disease and their caregivers. It is our hope that our next centenary celebrates a world long rid of dementia.

But there is a shorter-term reality that we must face with eyes wide open:

"By 2031, Canada's biggest demographic group – the so-called "baby-boomers – will move into the age of highest risk for developing AD. It is estimated that by that time, the number of Canadians who will have AD or a related dementia will have more than doubled from the 2001 figure of 364,000 to 750,000! . . . , these costs will rise exponentially if prevalence projections remain unchanged. Some analysts believe that over the next 25 years, AD – together with other forms of cognitive impairment – will prove to have the highest economic, social and health cost burden of all diseases in Canada."

National Council on Aging, 2004

Our 39 Alzheimer Society chapters in Ontario and provincial association have raised significant funds over our 25-year history. In the past three years, we have contributed more than \$37.5 million towards research and service to Ontarians. These funds have benefited research at the national and provincial levels in both the biomedical and psychosocial spheres. Dollars raised also underwrite support for people with dementia, families and caregivers, information and referral to community services, public education and Safely Home™ — the Alzheimer Wandering Registry. We also acknowledge the ever-increasing support from the Province for our diverse range of in-demand services.

People with dementia require services across the health care continuum, from disease onset to end of life. We have an interest and a presence at every point on the continuum of care, partnering with family physicians to achieve better diagnosis and advocating for better pain management at the end of a person's life. We take a broad perspective on the health system and health care.

As a result, we are keenly interested in the evolution of Bill 36 and hope to offer you a distinctive point of view on the current draft. In the following pages, we will identify five major issues for your consideration and will also propose changes to wording that address our concerns.

1. The Primacy of Quality of Care

Issue A:

The legislation should commit Local Health Integration Networks (LHINs) to high-quality care.

Discussion:

A major concern of Ontarians is quality of care. The concepts of person-centred care provided in the right place and the right time, define key components of quality. Since LHINs will have responsibility for overseeing direct service agencies that have a duty to provide high-quality care, the LHINs themselves should share this duty.

Proposed Changes:

- amend the Preamble by placing the phrase “delivery of high-quality health services to all Ontarians” in a separate clause to afford more emphasis. The new clause would read: “The people of Ontario and their government (i) support the delivery of **high-quality** services to all Ontarians...”;
- amend Section 1, Purpose of the Act to read: “The purpose of this Act is to provide for an integrated health system to improve the health of Ontarians through better access to **high-quality** health services...”;
- amend Section 5 (a), Objects to read: “to promote the integration of the local health system to provide appropriate, **high-quality** ...”; and,
- amend Section 5 (e), to read: “to evaluate, monitor and report on and be accountable to the Minister for the performance of the local health system and its health services, including **high quality, access** ...”

Issue B:

The Bills of Rights in both the Long-Term Care Act (1994) and the various Acts governing Long-Term Care Homes needs to be re-affirmed.

Discussion:

Since powers in these Acts may be delegated to LHINs, LHINs should also be bound by the Bills of Rights in these Acts, so that clients can expect consistency. The legislation before you has been criticized for not being client-centred enough. Re-affirming the rights of clients addresses this shortcoming.

Proposed Change:

- amend the Preamble to read: "The people of Ontario and their government", (j) **re-affirm the rights of residents and clients provided to them by the Long-Term Care Acts ...**

2. Caregiver Recognition

Issue:

The role of informal caregiving merits recognition in Bill 36.

Discussion:

While we benefit from a comprehensive and reasonably well-run health care system, it must be acknowledged that Ontarians — through kinship, friendship and community affiliations — provide most of the care to persons who need it. This is especially so in the care of the dying, the elderly and persons who are severely disabled by chronic diseases.

Most caregivers are women. Many face economic hardship that in turn creates new and unexpected social costs. Our system often fails to support caregivers. Caregiver respite is the first service typically jettisoned in cutbacks. For example, this was true when Community Care Access Centre budgets were scaled back a few years ago. It is also true now, given the pressures to meet acute client needs.

Proposed Change:

- amend the Preamble to read: "The people of Ontario and their government" (k) **value the important role of informal caregivers in providing support in the health system.**

3. Engaging Clients and Caregivers

Issue:

Bill 36 should specify that LHINs consult with clients and caregivers.

Discussion:

Ontarians welcome the opportunity to engage with LHINs on key issues, but the current Bill 36 wording is vague on this score. Historically, District Health Councils drew a third of their members from the client, caregiver and consumer community, and the original Community Care Access Centre boards also provided for client membership. While we acknowledge the Government's focus on skill-mix for LHIN boards, Bill 36 needs to be more explicit about meaningful client and caregiver consultation and involvement.

After all, the Act provides a structure for service providers and healthcare professionals. The people they serve as well as the persons providing the most service, deserve no less.

Proposed Changes:

- amend section 5 (c) , Objects to read: "to engage the community of persons, **including clients, informal caregivers** and ... ";
- amend section 16 (1) to read: "A Local Health Integration Network shall engage the community of persons, **including clients, informal caregivers** and ... ";
- amend section 16 (3) to read: "Each health service provider shall engage the community of persons, **including clients, informal caregivers** ..."; and,
- add section 16 (4) to read: "**Each Local Health Integration Network shall establish a client and caregiver advisory committee consisting of the persons that the network appoints from among the communities served.**"

4. Unreasonable Encroachment

Issue:

Bill 36 unnecessarily extends the reach of Government into the affairs of health charities.

Discussion:

Our 25-year history is one of uncovering unmet needs and developing innovative services with funds raised from our communities. In time, some services are funded by Government and extended across Ontario. Our clients are appreciative, and we are as well. After the public sector assumes some of these costs, we continue to explore how, through charitable funds raised, we can deepen our supports to persons with ADRD and their caregivers. An innovation currently underway in some parts of Ontario is the concept of *respite bungalows*, where persons with ADRD can go for a short time while their caregiver is relieved of their commitment.

Other health charities have done the same thing – hospices for the dying, services for the addicted, coffee houses for the mentally ill. These are all now a part of our range of services for Ontarians, all introduced by health charities in our communities.

The public sector needs to manage its resources, and we support LHINs having jurisdiction over funding from Government. It is a principle of our parliamentary democracy that governments should only take on the powers required in order to achieve the goals for which they were elected. Section 28 gives the Minister powers beyond what are required and which strike at the core of our civil society. We resist strongly the provision that the Minister would have jurisdiction over the entirety of an organization with which a LHIN has a funding relationship. This is unnecessary, unreasonable, counter-productive and we believe, undemocratic.

Some of our member chapters receive only a small percentage of their overall budget from Government. For example, the Alzheimer Society of Toronto receives only 8 per cent of its \$1.3 million operating budget from Government. On the other hand, the Alzheimer Society of Elgin-St. Thomas receives 50 per cent of its \$200,000 operating budget from the Province. In neither case, however, should the Minister have authority to interfere with our mission-related services that are not funded by Government. Section 28 gives powers to the Minister to issue directives on all of the Alzheimer Society activities. These powers need to be restricted to services funded by Government as per sections 26.2.b or 27.3. Our accountability for charitable dollars should remain to our donors for purpose, and to the Government, for tax-status.

Proposed Change:

- amend Section 28 (1) to read: "After receiving advice from the Local Health Integration Networks involved, the Minister may, if the Minister considers it in the public interest to do so and subject to subsection (2), order a health service provider **in respect to services for which it receives funding from a Local Health Integration Network...**"

5. Diffusion of Accountability

Issue:

Bill 36 can undermine the accountability relationship for both LHINs and health service providers.

Discussion:

Section 25 enables a LHIN to integrate "persons or entities" with a "person or entity that is not a health service provider." Given that LHIN jurisdiction is restricted to health service providers, the subsequent accountability relationship of a non-health service provider is unclear. To whom is the 'non-health service provider entity' accountable? Is it to the original health service provider? If so, what are the mechanisms for accountability? Are the contractual rights of the service provider compromised by the third-party interests of the LHIN? These questions demand clear answers.

This section has the capacity to undermine the not-for-profit sector by transferring services as defined in section 23 to the for-profit sector, blurring accountability and narrowing the LHIN and the Minister's reach since it does not extend, in an effective manner, to the private sector.

Proposed Change:

- add Section 2 (1)(f) to read: "to contract with a third party for the provision of specific services such that the contracting health service provider retains its full rights and accountability as per its accountability agreement with the LHIN."

Summary

The Alzheimer Society of Ontario appreciates this opportunity to raise these important issues, and we are confident that you will recommend amendments:

- that extend the rights of clients already found in other legislation;
- that recognize informal caregiving;
- that assure clients and informal caregivers of engagement;
- that circumscribe LHIN and Ministerial powers so that charities are not jeopardized; and,
- that clarify accountability relationships.

The thousands of Ontarians with Alzheimer Disease and related disorders and the thousands more who will contract it, benefit greatly from our partnership with Government. We have outlined how Bill 36 threatens this collaboration and our proposed amendments show how Bill 36 can be improved. Ontario and Ontario's health system was built on such partnerships, and this is where our future lies. We ask your support for our amendments.



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