“Making Every Door The Right Door For Persons With Dementia”

A Response to the Ministry of Health and Long-Term Care’s Discussion Paper

“Every Door is the Right Door: Towards a 10-Year Mental Health and Addictions Strategy”

July 2009

September 1, 2009
The Alzheimer Society of Ontario (ASO) applauds the work of the Minister’s Advisory Group and is encouraged by the recognition of the mental health needs of older persons. In particular we are pleased that the paper “Every Door is the Right Door: Towards a 10-Year Mental Health and Addictions Strategy” discusses the following:

1. A roundtable to be convened to discuss the issues and opportunities for seniors.

2. Mental health across the lifespan and a recognition that with age comes the risk of cognitive and neurological changes.

3. The risk of seniors living with stigma due to the loss of mental functioning, which often prevents them from accessing services and leads to isolation.

4. Seniors services as part of the desired service mix and included as a key setting for early identification and intervention, an area to build stronger links, and services that are in need of increased public awareness.

5. The need for psychogeriatric teams, caregiver supports, and promotion of dementia risk reduction behaviours.

6. Health human resources to ensure that there is an adequate supply of skilled workers that will keep pace with the increasing number and needs of clients.

On June 3, 2009 we were privileged to present to the Select Committee on Mental Health and Addictions and we are attaching a copy of this document. Much of the discussion with the Select Committee is relevant to your work.

Specifically though, we want to address the seven directions outlined in Every Door is the Right Door, describe some positive solutions in play and outline opportunities for advancement.
Direction #1: Act early

This is fundamental to the effective treatment of persons with dementia. We have been working with primary care and specialized geriatric services to increase the capacity of providers to identify persons at risk and to diagnose dementia where present. Our First Link program (McAiney, Harvey, Schulz, 2009) is a specific initiative to work with primary care to enhance diagnostic capacity and to offer self-management education and strategies (additional information is found Appendix A). First Link is recommended in the 3rd Canadian Consensus Conference, March 2006.

A recent study of primary care in Australia found that a significant gap still exists in the development of adequate response to dementia by primary care (Toronto Star, July 24, 2009). While Ontario, may be somewhat better off, much progress remains to be made.

Primary care needs to be strengthened to identify, diagnose and treat dementia.

Direction #2: Meet people on their terms

Dementia intersects with other mental illnesses in one of two ways. A person may develop dementia and some other mental illness, most often depression. In the alternative, a person with a mental illness may develop dementia. In both instances the health system should exhibit the ability to provide integrated supports to the individual, reaching out to other health providers as needed.

All parts of the health system can become competent in responding to the needs and characteristics of persons with co-morbid conditions of dementia and mental illness.
Direction #3: Transform the System

Most persons with dementia, unless they have another mental illness, may not have to call upon the skills and support of mental health providers. A competent primary care service, along with adequate community and long-term care services may be sufficient. Some people, though, develop cognitive impairment in such a way that their behavioural response to their environment might cause harm to self and others. For these people, mental health workers may have much to offer as section 3.4 acknowledges. Significant impediments exist to ‘encumber’ access to these services if people live in long-term care homes or independently in the community. Funding, differences in workplace cultures, legislation, access criteria and simple availability all mitigate against adequate supports for these people. The Ministry and LHINs are embarking on a joint project, along with ASO to design a behavioural support system for Ontario. We urge you to endorse this effort as a key recommendation concerning dementia. Psychogeriatric Resource Consultants (PRC) are located in community mental health centres, geriatric facilities and Alzheimer Society chapter offices across the province. Their primary role is to educate, advise and support staff in long term care homes, community care access centres and other health care settings in the application and interpretation of assessment tools for care planning and treatment for persons with cognitive/mental health needs and associated behavioural issues. They also provide education and support for P.I.E.C.E.S trained staff and are involved in facilitating networking and linkages between local community groups through the Dementia Networks.

Special effort is required to put in place a system of supports for persons with responsive behaviours in whatever setting they live.

Direction #4: Strengthen the Workforce

As section 4.3 suggests, this direction needs to extend beyond mental health and addictions to all points in the health care system where persons with mental health needs, are served. Only this will assure people the “Every Door is the Right Door”. We have addressed primary care and people living in long-term care homes have significant mental health needs with both the prevalence of dementia and depression each, exceed 60%. Further long-term care staff are increasingly caring for more complex residents. Similarly, when 25% of the ALC beds in Canada are occupied by people with dementia, acute care staff need basic mental health competencies as well (CIHI, January 2009).
ASIO is working with collaborators in all sectors to promote and provide training in dementia care for health service providers. Without additional resources for training, this is a slow and uneven process. The growth in the dementia population, the turnover in health workers and the new knowledge emerging all suggest the need for increased support for training in all settings where persons with dementia are served.

**On-going support is needed to train health care workers in the care of persons with dementia in whatever setting they are being served.**

**Direction #5: Stop Stigma**

As with other mental health conditions, there are a number of misconceptions about dementia. Since most persons with dementia are over 75, they often face double stigmas, one associated with mental illness, the other associated with ageism. The second stigma can serve as an additional obstacle in receiving adequate care.

While most persons with dementia are older, a significant number of persons (Rising Tide, 2009) experience the disease earlier in life. Their experience and that of their families is different from the dominant pattern and they often experience added isolation. In addition, some persons with neurological conditions often experience cognitive impairment that is frequently not responded to. ASO is part of a 17 member effort to develop a Neurological Strategy for Ontario. The cognitive and emotional toll of many of these conditions can lead to mental health challenges.

Each of our 39 chapters have publicly funded Public Education Coordinators who undertake conduct a variety of activities to counter stigma, including a special education initiative for grade 4 students.

In many ways, dementia is a women’s issue as it affects more women than men and the role of caregiving is more frequently performed by spouses and daughters. As well, unattached older women continue to experience economic hardship, disproportionately.

**Efforts put forth in the Strategy to address stigma must encompass dementia and ageism and be sensitive to younger persons with dementia and women.**
Direction #6: Create Healthy Communities

As we learn more about dementia and the contributing causes of vascular disease and social isolation, we also learn about strategies to prevent some forms of dementia or to mitigate the impact of the disease and to provide more years of healthy life. Our Awareness months in 2007 and 2008 featured health promotion responses to dementia and the topic of prevention is a favourite request for AS speakers to address. ASO is a member of the Ontario Chronic Disease Prevention Alliance and keenly promotes healthy living to promote healthy brains.

In addition, with the Murray Alzheimer Research and Education Program, we are promoting age-friendly communities to encourage continuing independence and social interaction for all older people, including people with dementia and other disabilities (see Appendix B). We believe you could adopt this principle-based approach in advancing healthy community concepts.

Initiatives to promote healthy communities are integral to promoting good mental health and supporting persons with mental health needs.

Adopt the age-friendly communities approach to advancing healthy community concepts.

Direction #7: Build Community Resilience

Most care for persons with dementia is provided in communities by family and friends. These partners in care are most effective when they are equipped with adequate information and education, supported in their efforts and provided with strategies to alleviate the impact of the disease on the person and the challenges of caregiving on themselves. This issue was not adequately addressed in your paper and we feel strongly that more it warrants more attention. ASO is a partner in the Ontario Caregiver Coalition to promote government wide policies to support caregivers.

The First Link program includes a 4-stage learning series for persons with dementia and their partners in care and is geared to the different stages of the disease. The chronic disease prevention and management model acknowledges self-management and education as an important component of enabling people to live with a chronic condition.
All the initiatives supported by the Alzheimer Society are directed at building the capacity of persons, communities, institutions and the broader society to develop the wherewithal to prevent dementia through research and health promotion, to support persons with the disease and their partners in care and to educate communities and providers to respond with compassion and competence. The demographics of dementia propel us to greater efforts less the disease overwhelm us collectively, as it now overwhelms some of us individually.

**With dementia expected to increase by 32 % in the next 10 years, community resilience is essential for us to be able to respond in accord with our social values.**

**Conclusion**

While the following quotation is in some ways uniquely American, it captures the urgency of our message to you.

The Alzheimer’s crisis, like the disease itself, will unfold gradually, making it too easy to ignore until we have little opportunity to alter its impact. The prospect of an overwhelming hurricane never became real enough to prompt the strengthening of New Orleans’ levies; the result was $82.2 billion in damages ad almost 2,000 lives lost. Concerns about subprime lending never became urgent enough to prompt corrective regulatory actions; we’re still tallying the cost of this crisis as job losses and bank failures mount and stock values plummet. If we fail to address the Alzheimer’s crisis now, we face the prospect of losing lives and dollars on a much larger scale.

- Newt Gingrich
APPENDIX A:


First Link

- helps people with dementia and their families better understand the disease and puts them in direct contact with local resources quickly
- supports those with dementia and their families throughout the course of the disease;
- builds partnerships between the Alzheimer Society, primary care physicians and other healthcare providers;
- increases health professionals’ knowledge of dementia, improving assessment and disease management;
- forges stronger ties and encourages increased care coordination with other community services; and,
- reduces pressure on Ontario’s healthcare system by extending the length of time of informal, family-based caregiving.

Through Aging at Home 25 chapters in 8 LHINs have received funding for First Link.
APPENDIX B:

Age-Friendly Communities

Reference: http://www.marep.uwaterloo.ca/Age-Friendly/Age-FriendlyCommunityInitiative.htm

The toolkit begins with a description of five guiding principles. These principles serve as the foundation for supporting any age-friendly community.

The three building blocks serve as the main structure for an age-friendly community or organization.

A community is made up of many different systems that are interconnected and overlap. The toolkit contains tips and strategies specific to each of these areas in a checklist format.

Principles
- Respect and Support of All Citizens
- Access and Inclusion for All
- Community Engagement in Decision-Making
- Livability
- Accountability

Building Blocks
- An Informed Society
- An Enabling and Supportive Environment
- Personal, Social, and System Connectedness

Community Areas
- Transportation
- Housing
- Health and Social Services
- Recreation, Leisure, and Culture
- Employment and Volunteering
- Education
- Direct Customer Service
- Buildings and Outdoor Spaces
- Emergency Services

The Age-Friendly Community Tool-kit
The toolkit is designed to reflect the how determinants of health reach far beyond the physical well being of an individual to include the community in which the individual lives. It uses reflective questions and practical tips and strategies to help communities identify their strengths and areas of improvement. The tool kit encourages community members to work together especially with older adults to develop a plan to become a more age friendly community.