

Aging at Home

Enabling Seniors to Live Safely at Home
with Dignity and Independence

November 2, 2007, Provincial Forum for
Information Exchange with Provincial
Associations

Summary of Discussion Questions

1. The Context

On November 2, 2007, the Ministry of Health and the Local Health Integration Networks across Ontario hosted and facilitated a provincial forum for key provincial associations. A complete list of participants is included in Appendix 1. **(NOTE THIS WILL NEED TO BE ADDED)**

The format for the event began with an overview of the Aging at Home strategy followed by a brief question and answer period. Participants were then requested to discuss, in a small group format, the following questions:

1. What services/programs for seniors and their caregivers do you see working well?
 - a. Which of these would you like to see more of?
 - b. Which ones do you think should receive highest priority for expansion?
2. What types of services do seniors and their caregivers need that do not currently exist?
3. What are the barriers to seniors aging at home?
4. What do you consider to be best/leading practices for aging at home in your field (with supporting evidence)?
5. Can you provide information about innovative approaches by your members or in other jurisdictions?

Examples of innovation:

- Modification of an existing program or service for a new type of client (such as preventative participation in day programs for seniors who are essentially well), or to provide service in a new way (offering a meal program at a restaurant instead of in a seniors centre)
- Introduction of a proven program or service from another jurisdiction or discipline
- Formalization of a program or service that has been tried on an informal basis, but has not been funded
- Piloting a completely new service or program.

6. Do you collect data for performance indicators that would be of relevance to this strategy?
7. Do you have advice on how to engage seniors and their caregivers? Existing forums that LHINs could take advantage of?
8. Can you provide research, reports or data (particularly LHIN-specific data) to support planning and implementation of the Aging at Home Strategy?
9. Have you found any evaluation frameworks to be particularly useful that you would recommend to us?

A facilitator and recorder at each table captured the discussion and responses to the assigned questions. As representative from each of the discussion groups provided a summary of their discussion in the final portion of the community engagement session.

Following the event, the responses from each discussion group were consolidated. The purpose of this document is to share with the broad health sector the consolidated responses to help inform the Aging at Home strategy as it evolves within each of the LHINs.

2. Consolidated Responses to the 9 Questions

2.1. Question 1

- What services/programs to seniors and their caregivers do you see working well?**
- a. Which of these would you like to see more of?**
 - b. Which ones do you think should receive highest priority for expansion?**

There are a number of services currently provided to seniors and their caregivers that are working well. Groups discussed both specific services (i.e., names of programs) as well as broader concepts of services such as home care as working well. Beyond the generic description of the types of services and programs that are working well, two further parts of this question explored the need for further enhancements and level of urgency.

Most, if not all, of what is working well requires further enhancements and resources to meet the needs of seniors aging at home. What was considered most urgent included more flexibility in the current delivery of home care in the areas of service maximums/limits and the role of case management. Also considered most urgent were transportation needs of seniors and enhancing supports for instrumental activities for daily living.

Programs and/or services working well

- support and counselling for caregivers to persons with dementia
- early intervention (diagnosis and support) for persons with Alzheimer's disease and related dementias (ADRD)
- respite services: including specialized adult day programs for persons with dementia, paid in-home respite, volunteer visiting, in-home recreational therapy
- Community Senior Centres
- Meals On Wheels
- Home Care
- Supportive Housing

- Regional Geriatric services
- Assistive Devices program – ramps, hearing aids, etc.
- Homecare
- Supportive Housing
- Need information about services available → Integrated information and referral system (for providers as well as consumers)
- Home at Last Program
- GEM Nurses in ER (provide linkages to community)
- Individual funding to seniors / caregivers to select appropriate services (e.g. Veterans Independence Program)
- Integrated transportation system

Services to expand or enhance

- An increase -- by at least 50% -- in the respite programs and support services tailored to the special needs of families providing care to those with Alzheimer's diseases and related dementias
- Services and service coordination targeted for seniors at highest risk
- Early intervention programs – such as the First Link Program now being piloted in 4 sites across Ontario. This program links those at the earliest stage of the disease (diagnosis) to resources, information and education.
- Flexible, accessible and sufficient respite service options for those caring for persons with Alzheimer's disease and related dementias
- Assistive devices for hearing, vision including safety devices like smoke alarms, life line, devices, med-check, etc.
- Enhanced role of community pharmacists to reduce adverse drug reactions
- Need to work more with the private sector such as arrangements for grocery delivery, milk delivery, sponsorships of social functions, etc.
- Need to expand Telecare programs
- Increased support for psychogeriatric care to maximize risk management
- Need contingency planning and increased education of alternatives
- Individual funding to seniors / caregivers to select appropriate services (e.g. Veterans Independence Program)
- Need to strengthen links between hospitals and community through the creation of interdisciplinary professional teams to include physicians, nurses, OT, PT, SW, and PSW).
- Need to add chronic disease prevention and management back into homecare
- Need more and enhanced options for supportive housing
- Need integrated information and referral system (for providers as well as consumers)

Urgent Priorities

- Instrumental Activities of Daily Living (IADL) such as home repairs and maintenance, snow shoveling, and need more financial subsidies
- Enhance Transportation through partnerships with health care providers, community organizations and through sharing of volunteer drivers and services.
- Expand home care service maximums by increasing flexibility to “bundle services” through the aging process and especially for those seniors who are “at risk” and at the “margins”.
- Enhance case management function by decreasing the caseload to care for frail complex seniors

2.2. Question 2

What types of services do seniors and their caregivers need that do not currently exist?

The following list was captured from a variety of organizations and associations serving different populations of seniors and range from enhancements to current service restrictions and limitations to some new and innovative programs that are provided in other jurisdictions focusing both on the seniors themselves as well as the needs of their caregivers.

- Sufficient respite services for families/caregivers– particularly spouse supporting at home
- Appropriate, flexible options for supportive housing to meet a variety of persons' needs
- Adequate training/education resources for in-home care providers of seniors
- More specific services available for Alzheimer's disease and related dementias
- Enhanced co-ordination of services for at-risk seniors
- Integrated information and referral systems- system navigation – (example – VON caregiver portal)
- Intensive case management for frail, complex seniors
- Management and coordination of volunteers
- Tapping into “non-public” sector
- Secondary health promotion
- Core basket of services to help seniors maintain independence (i.e. reduce / delay functional decline) – Adult Day Programs, transportation, meals, home maintenance
- Integrated geriatric services across continuum
- Need for basic services of snow removal, small home repair, grocery shopping and lawn work and other heavy tasks around the house (prevents falls and other injuries...also has a social interaction benefit) - want consistent providers
(Example of a good program-Veterans Affairs demonstrates that these services help people remain in their own homes)
- Transportation services (needs to be a mix of volunteer transportation and paid) - should be available not only for doctor appts but also for shopping and access to social events - Liability around this is a challenge
 - Home gifting -
 - Car Gifting
 - Coordinating services
 - Toronto Ride
 - Driving MS Daisy (Alberta)_ fleet of PT cruisers..driving seniors and wait for them until they are done and another program in Region of Peel-

Caledon community-drivers are trained to manage people requires specialized care eg., people with dementias, physical limitations, etc.

- Supportive Housing – for people with cognitive impairments / physical
 - For Frail Senior
- Medication administration
- Marginalized seniors who are not identified – need to find innovative ways to identify seniors at risk so that we can catch them before they
- Psychogeriatric outreach and services
- Creating communities of seniors – geographically clustered – non profit organization
- Purchase house together – group of areas
- Language and cultural issues are huge both for providers and seniors as well as cultural issues
- Out reach programs for 24 hour service – we could keep people home if there was a process for 24/7 – call for urgent support - outside of their regular visits – support for the care giver
- Outreach Programs
- Day Programs
- Spiritual care
- Electronic medical records
- Affordable / free homemaking
- Advocates for seniors - seniors are reluctant to complain or draw attention to their needs and very isolated

2.3. Question 3

What are the barriers to seniors aging at home?

- Lack of appropriate and sufficient respite services: the most significant reason for seniors to place a family member with dementia into long-term care is the burden of 24-hour care that is required by someone with dementia (62% of residents in long-term care homes have Alzheimer's or some other type of dementia).
- Lack of supportive counseling or "coaching" throughout the disease progression for caregivers of persons with dementia: caregivers of persons with dementia experience three times the stress and burden than that of other diseases. The impact of caring for someone with dementia places a tremendous toll on senior caregivers who experience emotional stress, physical strain and exhaustion, depression and illness, and financial burdens.
- lack of income or too much income
- isolation (they disappear)
- lack of coordinated, accessible and affordable transportation options
- lack of understanding of what's available to whom and how to access services
- lack of a continuum of services
- fear as they don't want to complain
- lack of advocates to help navigate the system
- discrimination e.g. ageism, sexism
- lack of respect (North American culture does not place a great deal of value on seniors and their respective contributions - note the first nations regard for their elders)
- lack of support for caregivers and family, especially women who typically carry the burden of caring
- people don't ask seniors what they want and don't listen to what seniors have to say
- not enough activities for seniors and/or they are not included assuming seniors would not want to attend
- LHIN boundaries have caused some fragmentation
- Physical barriers in the home (i.e. stairs etc.)
- Lack of sufficient and appropriately trained human resources
- Lack of case management
- Lack of accessible/affordable housing: need to also think of aging at home "safely" as some senior's homes may not be safe, so need a range of options
- Lack of social support (family and friends) and peer relationships
- Fear among seniors in admitting that they need help since they interpret it to mean the readiness or need to go to a long-term care home and loss of control/independence/mortality

- Financing of the services needed, for example, Veteran's Independence Program – once services were provided, most veterans elected to stay at home
- Funding for instrumental activities of daily living (e.g. laundry, grocery shopping)
- Lack of funding for specialized services along a continuum of living arrangements e.g. Dixon Hall
- Lack of flexibility re: bundle of care that seniors require
- Barriers with funding/policy such as service providers not having the flexibility (global funding to allow maximum flexibility)
- Primary care is limited or lacking (some LTC Homes have difficulty recruiting physicians)
- Need Aging at Home coaches – to break the silos around the continuum of care
- Lack of public information about the system – more public education is required so people know where they can go. Doctors very often do not know where the services are
- You need to be able to easily connect with services or people who connect you with services
- Diversity Issues – availability of services to respond to diverse populations – ethnic groups, GLBT community – inherent biases of service providers – need education
- Mental Health – big barrier attached to the stigma and as a result people do not want to access services or self identify as needing mental health services
- 30 day limit on End of Life care is a barrier
- Key access points (e.g. Family doctor, grocery stores)
- Outreach and prevention - calls from Public Health Nurse/Family Health Team
- Teams (like PACT) to support seniors
- Recruiting, training and retaining volunteers

2.4. Question 4

What do you consider to be best/leading practices for aging at home in your field (with supporting evidence)?

- Focus resources on meeting needs of seniors at highest risk – i.e. frail elderly, seniors with dementia or caring for those with dementia, isolated seniors (living alone, rural communities), etc.
- Early intervention to support the individual with Alzheimer's disease or other dementia and their caregiver. The First Link Program that is currently being piloted for application across the province was developed and evaluated by the Alzheimer Society of Ottawa and Renfrew. This program provides persons at the earliest point in the continuum of the disease (diagnosis) with links to appropriate resources, community services, information and education, and continues to provide a changing array of supports as the dementia progresses.
- Counseling and support for caregivers. By supporting caregivers of persons with dementia in their role, research has shown improved health of the caregivers and a delay in placement of the person with dementia into long-term care by 1.5 years (Dr. Mary Mittelman, et al).
- Palliative care province wide standards and developed with national standards NOTED: That provincial associations should set standards of care for seniors (accreditation standards). Those organizations not maintaining those standards would not be able to maintain membership.
- COMMUNICATION: provincial associations/organizations need to work together are share with each other what it is that we are developing
- Seniors care is about living..."this is not rocket science"
- Caution government/LHINs/seniors' organization about competition...this should be about working together...worry about the RFP process...there fore the best practice model should promote collaboration and discourage competition
- Nurse lead clinics with wellness focus (chronic disease management) (i.e. Kingston COPD, Diabetes, foot care)(RNAO BP Guideline)
- Need to address cultural diversity (RNAO BP BP Guideline)
- CCAC 2-day workshop – work with providers to make sure needs are met re: cultural confidence – sensitivity
- Need to address spirituality (LTC – how many chaplains are needed / pop.)

What do you consider to be best/leading practices for aging at home in your field (with supporting evidence)?

- Enhanced specialized therapy services in the community (i.e. CCAC) for people with chronic diseases (i.e. stroke etc.) – (Evidence SEO stroke Pilot)
- Need for people with severe stroke to access outpatient therapy (i.e. outpatient services – provide transportation etc. + evidence SWO stroke pilot)
- Continuity of care – consistency of care providers

- Case-management / system navigation (which senior needs a CM?)
- Need for assessment on what seniors need to remain in home of choice
- FITCC – Falls Intervention
- Community outreach programs
- Community-based exercise programs (FAME) Fitness and Mobility Exercise Program
- Social support programs (living with stroke, MOST)
- Continuum of care (health promotion → community engagement / end of life)
- Stroke COPD, diabetes
- Seniors Health Research Transfer Network
- Go where seniors are (VON, Alzheimer's Society)
- Regional multi-faith communities (13 in province)
- Senior Centres
- Senior Buildings
- Fairs (Sarnia)
- Cultural centres – can reach seniors
- Engage formal caregivers at college level
- Symptom Relief Kit for EOL

2.5. Question 5

Can you provide information about innovative approaches by your members or in other jurisdictions?

- Caregiver wellness centre - offers persons with dementia and their families with a multi-service centre that brings together agencies that support caregivers for seniors with chronic illnesses requiring high levels of care
- Respite facility - offers 'vacation' respite services in a residential home setting
- Residential facilities - home-like setting specially designed to provide 24 hour care and daily support programs
- Seniors foster care
- Caregiver (in-family?) funding
- Technology such as video-conferencing to access specialized services such as geriatricians, psychiatrists, SLP,
- Caregiver coaching
- Consumer survivor groups
- Safety technology such as auto-off stovetops
- Tracking of high ER use residence codes to identify areas/buildings for CCAC case manager assignment
- Letter carriers, pharmacies, bank tellers flag unusual behaviour in isolated seniors and report to central monitor
- Electronic safety monitoring
- Mobile palliative care teams
- Rent supplement
- Funding for home renovations/refits
- Seniors 'villages' with mutual services paid by membership fees and bequests
- Seniors spa

2.6. Question 6

Do you collect data for performance indicators that would be of relevance to this strategy?

- ER visits
- ALC days
- General considerations:
 - The community sector does not have the appropriate tools and training to collect comparable, valid data for measuring progress in supporting seniors to age at home
 - Data and indicators for community supports should be consistent with data and indicators in other sectors and from other measures such as
 - health system scorecard
 - LHIN accountability agreements
 - customer satisfaction indicators
 - indicators require at least 3 years of trend monitoring to establish validity and reliability
 - current data, where available, should be used as a beginning
 - Need to ensure common definitions (e.g. inconsistency in use of ALC def'n at different hospitals creates incompatible and unreliable ALC measures)

2.7. Question 7

Do you have advice on how to engage seniors and their caregivers? Existing forums that LHINs could take advantage of?

Seniors and their care givers can be engaged through:

- Alzheimer Society conferences, public forums and support groups can provide access to seniors and their caregivers
- Dementia Networks – 36 networks across Ontario that bring together health and community care providers with specialized knowledge and practice in serving persons affected by dementia.
- Annual Changing Melody Forum for persons with early stage dementia and their care partners (next conference is November 17, 2007, Toronto)
- Community support groups e.g., seniors centres, congregate dining,
- Places of worship and faith gatherings such as churches and mosques.
- Communicate in different languages and be sensitive to the cultural needs of seniors from diverse cultural backgrounds and values.
- Each LHIN to have a repository of information on what senior services are available in their region.
- Utilize existing groups for example,
 - Adult Day programs
 - Seniors Centres
 - Social activities
- Seniors advisory group (for every LHIN)
- Need to include families / caregivers
- invite LHIN reps to speak to provincial associations, forums and conferences
- do not necessarily need to be a health forum but can be local events that have large concentration of seniors (e.g. Healthfairs)
- connection with seniors who are not traditionally involved
- need to set up a repository of ideas for engagement
- Non-profit service association buildings as one location to provide congregate services
- 100+ US cities have providers fairs where seniors come to actually get services (not just information)
- need destigmatizing events

2.8. Question 8

Can you provide research, reports or data (Particularly LHIN-specific data) to support planning and implementation of the Again at Home Strategy?

- The Alzheimer's Society has a number of research reports related to the challenges of seniors living with dementia. In particular, the report on projected prevalence of dementia in Ontario provides data specific to each of the 14 LHINs in Ontario. All of these reports are available at the Alzheimer Society of Ontario website, www.alzheimerontario.org under the Public Policy section.
- LHINS should look to what is happening in Sweden
- The consulting firm Deloitte has huge pool of data world wide on innovative strategies and on use of technology
- Quality of Life indicators
- "the Big 5" predictors of hospitalization – falls – isolation – dementia etc
- just beginning to shift data collection to be LHIN specific
- Ontario Association of CCACs is releasing LHIN level data this month (November 2007)

2.9. Question 9

Have you found any evaluation frameworks to be particularly useful that you would recommend to us?

- The Balance of Care methodology provides a means for identifying at-risk seniors who could safely remain in the community with improved outcomes for seniors, care providers and funders and also identifies priorities for investments which might improve care provision in future. The model is based on work done in the U.K. by Dr. D. Challis and currently under study by researchers in partnerships with Waterloo-Wellington Community Support Service Network and the LHIN, CCAC and local hospital and will compare outcomes for seniors and their caregivers as well as costs of community service versus placement in long-term care.
- The ADRD Planning Framework and Toolkit provide a means for evaluating the planning for dementia-friendly services and environments. See attached brochure for copies of the Framework and Toolkit or visit www.alzheimerontario.org
- Standardized, province-wide performance indicators/evaluation framework to ensure quality equity among the 14 LHINs as each LHIN proceeds with implementation of the Strategy.
- Inter-RAI for community support services – Alzheimer Society commissioned a study – to capture the need of caregivers
- RAI data not being utilized to support policy and program development
- Veterans Independence Program
- Self-Reporting of Patients Experiences in Hospital – develop a hospital report card – must develop a community report card