# Pressing Needs and Emerging Possibilities: The Dementia Challenge

March 2007

Alzheimer Society ONTARIO

Alzheimer Knowledge Exchange

# Pressing Needs and Emerging Possibilities: The Dementia Challenge

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**March 2007**

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# Executive Summary

This review by the Alzheimer Society of Ontario (AS0) and Alzheimer Knowledge Exchange (AKE) of the Integrated Health Service Plans (IHSPs) of the 14 newly created Local Health Integration Networks (LHINs) focuses on the stated *priorities* and *action steps* of each LHIN as seen through the lens of Alzheimer's disease and related dementias (dementia). Its purpose is to reinforce those priorities and actions that will benefit our clients, identify the common approaches across LHINs, indicate where there are missing links or opportunities to learn from others, and offer recommendations, commitments and resources.

Alzheimer's disease and related dementias are progressive neurodegenerative diseases for which there are currently no cures. The life course of the disease from diagnosis to end-of-life may span around ten years, and care takes place in settings that range from home, with the help of informal caregivers and community supports, to long-term care homes. Age is the primary risk factor and, in Ontario, over 207,000 seniors are expected to suffer from dementia by 2016, a 33% increase over 2006. The cost of care increases with progressive severity of the disease, with long-term care homes responsible for the largest cost component (and the majority of residents of long-term care homes have dementia). Seniors with dementia may incur a greater cost for government services than seniors without the disease.

What we found from the IHSP review:

- Dementia: A few LHINs have made reference to Alzheimer's disease or dementia in their discussions but none have directly included it as one of their priorities or action plans. However, given the link of dementia with aging and that many seniors have multiple diseases, any priorities affecting seniors, chronic disease management and mental health will also benefit people with dementia.
- Seniors: Eight LHINs identify seniors as a priority area and five have developed comprehensive strategies or models of care for seniors, particularly those who are frail, at risk or have complex needs. Models focus on providing an integrated and seamless continuum of care.
- Long-term care services: Two LHINs have made improvements to a range of long-term care services a priority while several others have included action steps in their plans. Priorities and actions include realigning/increasing capacity, improving access to and supports in long-term care homes for people with severe behaviours, and enhancing resources.
- Community care and support: Two LHINs have identified community care and support as a stand-alone priority in helping seniors to live at home while several others incorporate "enabling seniors to live in the community" as a component of their seniors' priority.

- Mental health: A person with a cognitive impairment such as Alzheimer's disease may receive services from mental health professionals, such as psychogeriatric resource consultants or psychiatrists. The majority of LHINs have identified mental health and addictions as a priority. In general, they propose to better align hospital and community-based resources, improve coordination and integration of services across the continuum of care, and establish networks.
- Neurological disorders: One LHIN categorizes Alzheimer's disease with a group of neurological disorders such as stroke, epilepsy and Parkinson's disease, and identifies neurological health services as a priority for action.
- Chronic diseases: The majority of the LHINs are building on the provincial chronic disease prevention and management (CDPM) framework. Since many seniors have multiple chronic disorders, which may include dementia, many of the components of the CDPM strategy are applicable to dementia. At least two LHINs make a direct link between dementia and chronic disease in their IHSPs.

What we missed:

- Overall impact: The extent of the impact of the increasing number of people with Alzheimer's disease or related dementia does not appear to be fully appreciated—neither the impact on the individual and their caregivers nor the challenge to the health system and its resources.
- Caregivers: Informal caregivers are an integral component in the care of people with dementia yet, with a few exceptions, there is little recognition of their burden nor plans to provide the supports they need to continue.
- Co-morbidity: Many seniors suffer from more than one condition, e.g. diabetes, and Alzheimer's disease. In general we missed seeing plans for integrated linkages for the care and treatment of co-morbid conditions.
- Health human resources: Most LHINs plan to develop a health human resources strategy. However, with a few exceptions, the LHINs have not acknowledged the specific skills needed to care for someone with dementia nor have they made provision for specialized training in dementia or dementia care.
- Data collection: There is a paucity of information about the prevalence or cost of Alzheimer's disease and related dementias; including the collection of these data are critical for effective planning, monitoring and evaluating of the care and treatment for people with dementia and their families.

From our analysis of the IHSPs, we recommend that:

- The LHINs and MOHLTC identify up to three LHINs to provide leadership in designing a model service framework for elderly persons with complex needs,

including Alzheimer's disease and related dementias, which can be disseminated to other areas of the province.

- Each LHIN be mandated to adopt the "lead LHIN(s)" system response, adapt it to local conditions and foster implementation by local communities.
- The MOHLTC include "complex elder care" in its Strategic Plan, including Alzheimer's disease and related dementias, and identify specific system goals in LHIN accountability agreements, along with accompanying performance indicators and outcomes.
- That the 'lead' LHINs and the MOHLTC address the issues overlooked in the IHSPs including caregiver support, co-morbidity, health human resources and better data for system planning.

The ASO can provide resources to assist MOHLTC and the LHINs, and will commit to:

- Strengthening its support for LHIN-wide Dementia Networks, which facilitate the engagement of persons with dementia, the people important to them and service providers with the LHINs, in implementing the recommendations in the IHSPs and this report.
- Providing leadership in promoting the inclusion of dementia in all aspects of health service development such as primary care, chronic disease management including prevention, promotion and population planning.

# Introduction

## *Purpose of the Review*

Restructuring the delivery of Ontario's health and social services and creating the 14 Local Health Integration Networks (LHINs) has produced a unique opportunity. First, each region can start afresh in developing flexible and integrated care that responds to local needs, linking local resources with local plans. Secondly, it enables organizations such as the Alzheimer Society of Ontario (ASO) to provide cohesive, consistent and timely input across the province.

The Alzheimer Society and its chapters in Ontario have participated fully with the LHINs in the community engagement phase of developing their Integrated Health Service Plans (IHSPs), offering information and providing feedback to the LHINs with the objective of improving services to its clients. They have also worked with partners such as the Dementia Networks[1] to offer a collaborative approach to providing services and input to the LHINs.

This review looks at the 14 IHSPs (posted in late 2006) from the perspective of those affected by Alzheimer's disease and related dementias (or simply "dementia"). We would like to reinforce those priorities and actions that will benefit our clients, identify the common approaches across LHINs, indicate where there are missing links and gaps or opportunities to learn from others, and offer recommendations, commitments and resources.

The review focuses on the stated *priorities* and *action steps* of the LHINs as seen through the lens of a person with dementia, and is based on a high-level survey of the IHSPs. Most LHINs have articulated sector- or issue-specific strategies. However, a few LHINs (such as LHIN 13) have taken a more systemic approach; as a result, this review may not adequately represent their intentions with respect to people affected by dementia.

This report contains an overview and discussion of the 14 IHSPs as a whole followed by a more detailed review of each LHIN's IHSP. To enhance understanding of the review, the next section gives a brief overview of dementia from a population perspective.

## *About Alzheimer's Disease and Related Dementias*

Alzheimer's disease and related dementias are progressive neurodegenerative diseases for which there are currently no cures. In the early stages, people with dementia experience memory loss and impaired judgment. As the disease progresses and their mental and physical abilities deteriorate, they gradually lose the ability to carry out the normal activities of daily

[1] Dementia Networks are networks of service providers, clinicians, caregivers, agencies and health related organizations that work together locally, regionally and provincially to improve the system of care for individuals with dementia, their families and caregivers. There are 36 Dementia Networks across Ontario.

living, may exhibit challenging behaviours, and will ultimately require constant care. The life course of the disease from diagnosis to end-of-life may span around ten years.

It is a cruel disease. Not only is it devastating for the person affected who suffers a continuing erosion of their mental and physical abilities from which there is no escape, but caring for someone with dementia exacts a high toll on the caregivers.

Care of a person with dementia can take place in a range of settings with a range of supports, according to the need and stage of disease.

An unpaid informal caregiver, with community supports, may work at the home of the person with dementia helping with his or her activities of daily living, such as walking, eating, dressing, personal care, shopping, taking medication, personal finances. The caregiver may forego income (with related loss of tax revenue to government) and lose job security/career momentum—not insignificant given the duration of the disease. Further, with a high level of stress and little respite, he or she may have need of more health and social services for themselves (an additional cost).[2]

In long-term care homes, where the majority of residents have dementia, an increased level of staffing and specialized training is required especially for those with hard-to-manage behaviours.

The achievement of provincial goals, such as equitable, timely and culturally appropriate access to services, will benefit people with dementia. However, issues of particular concern to the Alzheimer community, and where improvements are needed to raise the quality of life for those affected by dementia, include:

- increasing **public awareness** to reduce stigma and enhance respect, dignity and social wellbeing;
- ensuring that professional and unpaid caregivers as well as family members are all **educated and trained** in dementia and dementia care;
- ensuring **coordination of care** with seamless transitions across the continuum of care;
- developing, applying and sharing **evidence-based practices** of care; and
- providing **recognition and support** to informal caregivers.

And, of course, the key to the future from both the personal and system perspective is finding a cure and improving treatment and care. It has been estimated that being able to delay the onset of Alzheimer's disease by five years (e.g., from 70 to 75 years of age) would result in a 50% reduction in prevalence in one generation and that delaying onset by 10 years would

[2] See, for example, the Ontario Dementia Caregivers Needs Project conducted by MAREP (2004). Project reports include: *In Their Own Voices*; and *Caregivers of Persons with Dementia: Roles, Experiences, Supports and Coping – A Literature Review*. University of Waterloo, MAREP.

virtually eliminate the disease.[3] Improved treatment and care options can also delay the need to enter an expensive long-term care home. In other words, heightened research, evidence-based practice and knowledge exchange are vital to managing the impact of the disease.

### *Prevalence*

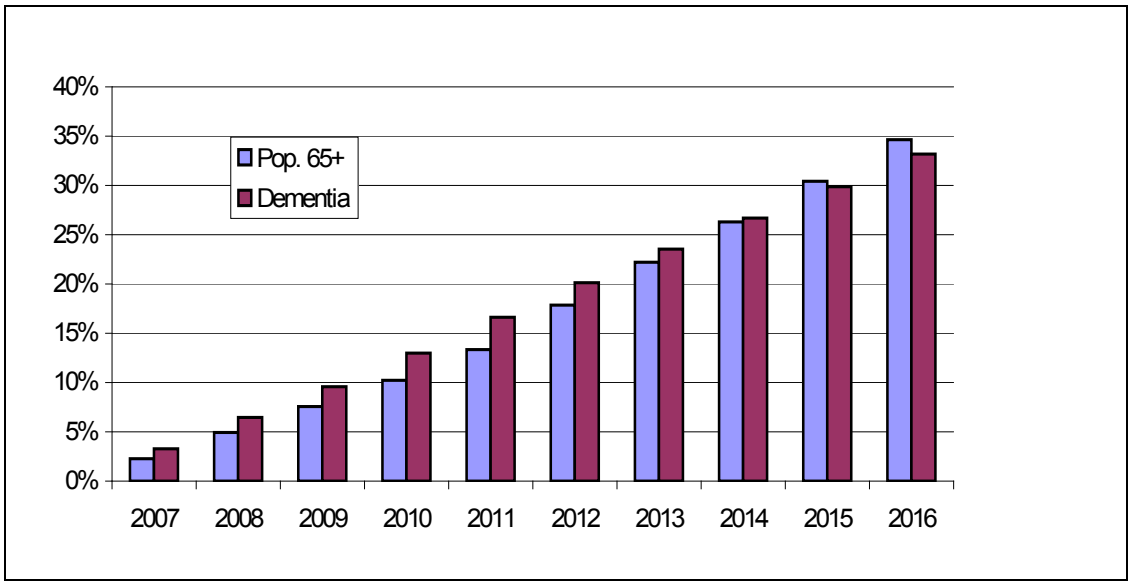
Age is the primary risk factor for Alzheimer's disease and related dementias. As the bulge of baby boomers reach the age of 65, therefore, the number of people with dementia will escalate.

Over 207,000 seniors across Ontario are expected to suffer from dementia by 2016, which represents a 33% increase over 2006. This means an additional 51,000 people with dementia by 2016, each of whom will require additional resources for their care and support. Women make up an overwhelming majority of older seniors who have dementia.

The impact of the aging population on health and social services is well recognized. Less well known is that, in the immediate future, the number of people with dementia in Ontario will increase at a **faster** rate over 2006 levels than the total number of seniors over 65.

**Chart 1**

**Percentage increase in population aged 65+ years and people with dementia over 2006 base levels, Ontario, 2007-2016[4]**



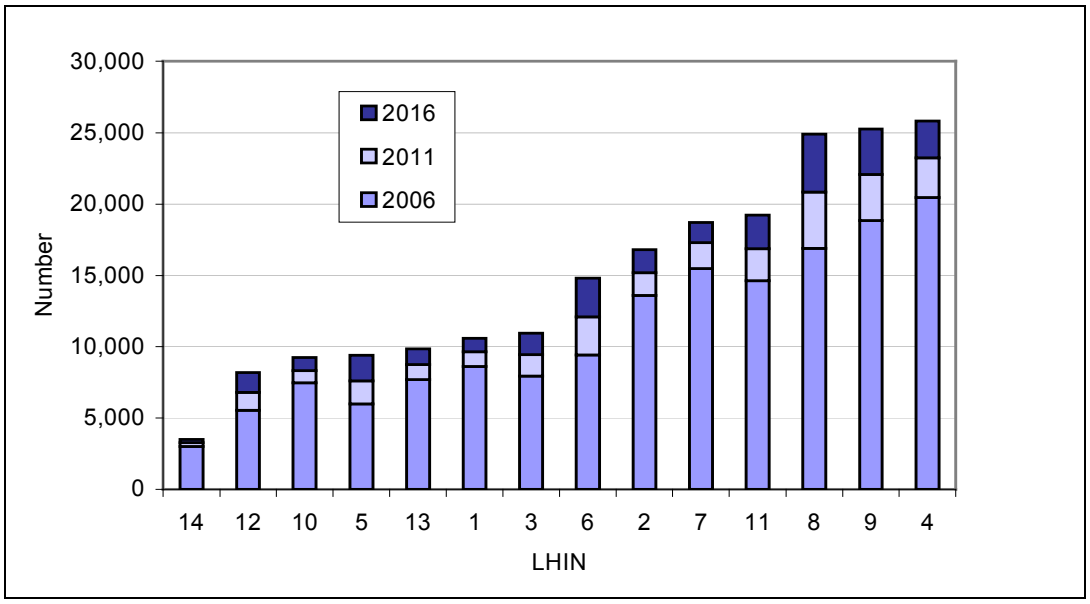

[3] Khachaturian, Z. The five-five, ten-ten plan for AD. (1992). *Neurobiology of Aging, 13*, 197-8.

[4] Source: Unpublished population projections from Ministry of Finance for Ministry of Health and Long-Term Care, revised September 2006; and prevalence rates from Canadian Study of Health and Aging, 1991.

Within the LHINs, Hamilton Niagara Haldimand Brant LHIN (4), Central East LHIN (9) and Central LHIN (8) have the highest number of people with dementia. By 2016, they will each have about 25,000 people with dementia to care for.

**Chart 2**

**Projected number of people dementia, by LHIN – 2006, 2011, and 2016[5]**

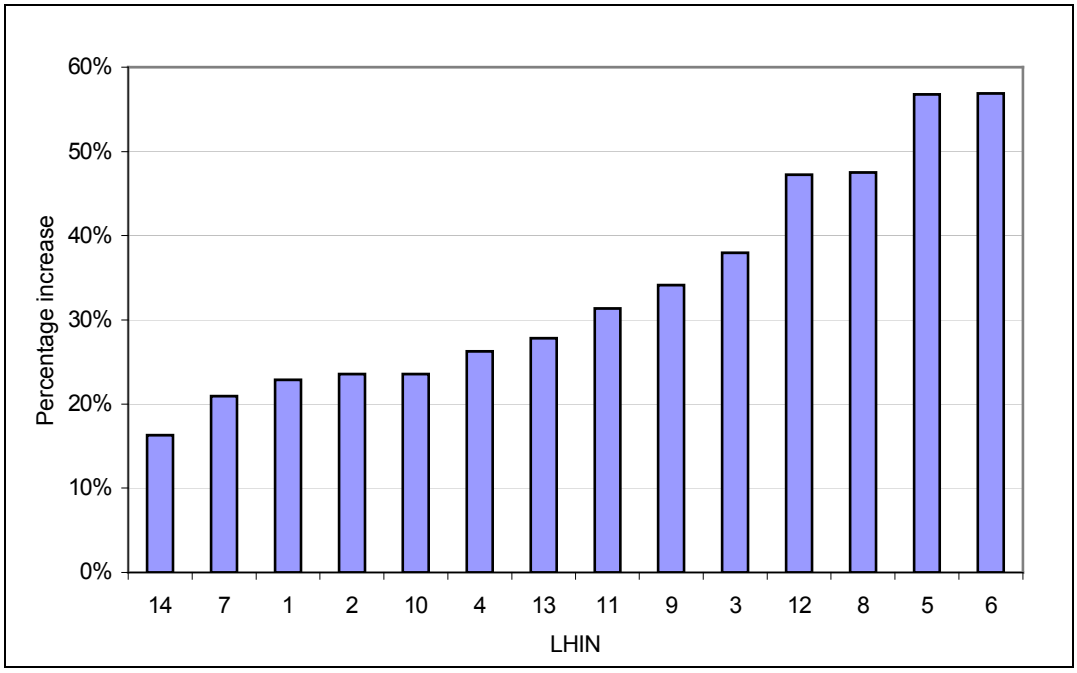



[5] Ibid.

While the number of cases of dementia across the province is projected to increase by 33% in the next ten years, some LHINs will experience increases of over 55%.

**Chart 3**

**Percentage increase in the number of people with dementia, by LHIN, 2006-2016**[6]




### *Cost Estimates*

The costs of caring for someone with dementia are not well documented since care incorporates a full and varying spectrum of paid and unpaid services. But it is clear that dementia is a costly disease both from a societal perspective, which includes unpaid caregiver services, and from a government funder's fiscal perspective. Studies have shown that:

- The cost of care for people with Alzheimer's disease and related dementias increases with the severity of the disease.
- Long-term care homes are responsible for the largest component of that cost.
- The majority of the residents in long-term care homes have dementia.
- Seniors with dementia have a higher use of health services, including hospitals, physician visits, home and long-term care and prescription medication, than seniors without dementia.

[6] Ibid.

# Overview and Discussion

## *What We Found*

### *Seniors' Care*

While none of the LHINs have identified people affected by Alzheimer's disease or a related dementia as a priority and only a few specifically comment on or address their needs, it is encouraging that most have recognized the growing impact of seniors. This is in accord with the provincial strategic directions that include instilling "appropriate supports to enable Ontarians to age in the most appropriate place."[7] With so many seniors either likely to develop dementia or living with a family member who has, any planning for seniors must incorporate their needs at least indirectly. The Hamilton Niagara Haldimand Brant (4), Central West (5), Toronto Central (7), Central (8), Central East (9) and Champlain (11) LHINs, for example, are all developing comprehensive strategies to care for seniors, particularly those who are frail, at risk or have complex needs.

The issue of a seamless continuum of care that incorporates both primary and community-based care was raised frequently, both for the population at large and for specific sub-groups such as seniors or people with mental health problems. It is heartening to note that several LHINs propose to develop, or have already developed, integrated models of seniors care (e.g. GAIN, Seamless Care for Seniors Network, ASSIST, Doorways to Care). These models take the form of a network of seniors' services or create local seniors' health centres as hubs of information and referral services.

While not formalized to the same extent as above, other LHINs outline some of the steps they will take to develop an integrated continuum of care for seniors. These steps include:

- developing best practices in care coordination;
- creating partnerships, sharing resources and knowledge across sectors;
- enhancing specialized geriatric capacity;
- improving linkages and the flow of patients through the system;
- easing transitions between providers and locations;
- improving system navigation; and
- compiling an inventory of services and resources available for seniors.

[7] As articulated in, for example, a letter from the Minister of Health and Long-Term Care to the LHIN Chairs, June 29, 2006.

### *Long-Term Care Services*

Given the large proportion of people in long-term care homes who have dementia, any improvements in this respect are welcome. At the provincial level, the Casa Verde Inquest recommendations and Bill 140 (*Long-Term Care Homes Act*) propose changes with respect to training on abuse recognition and prevention, caring for persons with dementia, and behaviour management.[8] We are pleased that two LHINs (South East (10) and North West (14)) have made improving long-term care services a priority and others have included action steps to work towards improvements.

In some cases these actions refer broadly to the range of long-term services that includes home support, home care, supportive housing, long-term care homes and complex continuing care. Both the South East LHIN (10) and North West LHIN (14) wish to realign current capacity with needs and/or increase the capacity of one or more of these types of long-term care.

Other actions to improve long-term care homes propose to improve access to, and supports in, long-term care homes for people with severe behaviours, and enhance resources in long-term care homes with, for example, the addition of nurse practitioners or the introduction of special behavioural units.

### *Community Care and Support*

Since many people with dementia, particularly in the early stages, will live at home, the availability and coordination of a wide range of community supports play an important role in maintaining quality of life for both the carers and those cared-for, and in delaying the costs of long-term care placement. One key to the effectiveness of these supports is the flexibility to access them when and where they are needed.

We are encouraged that initial steps are being taken that recognize the importance of community care and support in helping seniors to live at home. Two LHINs—Erie St. Clair (1) and Hamilton Niagara Haldimand Brant (4)—have identified community care and support as a stand-alone priority, while several others incorporate some form of "enabling seniors to live independently in the community" within their seniors' priority. Other LHINs, through their action steps, also recognize the need for augmented community services to enhance community living or promote aging in place as an alternative to long-term care placement. We hope that, by making community care and support a priority, all the LHINs will ensure not only that needed supports and services are available but also that they are well coordinated and integrated.

[8] The Alzheimer Society of Ontario's submission on Bill 140 can be viewed on the ASO website/Public Policy: http://alzheimerontario.org/English/public%20policy/default.asp?s=1

### *Mental Health*

As well as being considered among the population of seniors, people with dementia may also benefit from the plans to deliver services to people with disorders such as mental or neurological health problems, or chronic diseases.

Half of LHINs have identified mental health and addictions as a priority. A person with a cognitive impairment such as Alzheimer's disease may well receive services from professionals such as psychogeriatric resource consultants or physicians in psychiatric hospitals, and will benefit from improvements in mental health services.

In general, these LHINs propose to better align hospital and community-based mental health services, improve coordination and integration of services across the continuum of care, establish and use networks, reduce barriers to access and investigate a shared-care model. These actions are consistent with improved service for people with dementia.

### *Neurological Disorders*

The Central LHIN (8) groups Alzheimer's disease with neurological disorders such as stroke, epilepsy, Parkinson's disease or multiple sclerosis, and sees neurological health services as a priority. The LHIN intends to develop an overarching plan for neurological health and support needs to ensure timely access to appropriate services.

### *Chronic Diseases*

Chronic disease prevention and management (CDPM) is an emerging provincial strategy, and the majority of LHINs have referenced and are building on the provincial CDPM framework.

Many of the chronic diseases, such as arthritis or osteoporosis, develop as a person ages, as do other health concerns such as depression, reduced mobility or difficulty with hearing and vision. Dementia is also most likely to develop as a person ages. As a result, many seniors have multiple chronic disorders, one of which may be Alzheimer's disease. (See also the following discussion on Co-morbidity.)

Many of the components of the CDPM strategy are applicable to caring for people with dementia, e.g., the use of multi-disciplinary teams, provider education, access to specialists, supporting and emphasizing the central role of individuals and their families in care and decision-making, and providing supportive environments. Principles of dementia care and CDPM both place the consumer at the centre of planning.

A few of the LHINs make the link between dementia and CDPM in their IHSPs. For example, the North West LHIN (14), in its chronic disease strategy, discusses specialized programs in long-term care homes for target populations such as those with dementia. The Erie St. Clair LHIN (1) intends to support groups that focus on improving geriatric assessment services as an enabler of the chronic disease management strategy.

### *Networks and Collaboration*

We are encouraged with the proposals to build on and develop LHIN-wide networks for specific communities of interest, such as one for Psychogeriatric/Alzheimer's or a Seamless Care for Seniors Health Interest Network. We can further contribute to these networks and collaborations through the Alzheimer Society chapters, the Dementia Networks, and by implementing the First Link program (the First Link program provides individuals with dementia and their families with the opportunity for comprehensive and coordinated services as early as possible in the disease process.)[9] We can also aid interactive collaboration, sharing of resources and transfer of knowledge through the Alzheimer Knowledge Exchange.

## *What We Missed*

### *Overall Impact*

While the steps that the LHINs are taking to plan for seniors and people with mental health problems or chronic diseases will go a long way towards improving the quality of life of those affected by dementia, it is not clear that the extent of the challenge that dementia presents, both to the individuals and their caregivers and to the health system as a whole, is well understood.

The services and resources that currently exist for those people with dementia today are frequently inadequate, inappropriate or undignified. Yet, not only is the number of people with dementia going to increase rapidly as the baby boomers age but the costs of care will rise even faster, given the additional resources required to care for them. Furthermore, with the increase in the number of people with dementia will be a corresponding increase in the number of informal caregivers, which in turn will lead to a greater loss in productivity and overall health status. In other words, the impact on society as a whole is greater than just the additional number of people with dementia.

Embracing the concept of a multi-sector, integrated and seamless system of care and support, such as that proposed in the *ADRD Planning Framework* developed by the provincial Roundtable on Future Planning for People Affected by Alzheimer Disease and Related Dementias,[10] will lead to improved quality of life for those affected and improved efficiencies in service delivery.

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[9] Components of the First Link project, which has nine demonstration sites and operational funding from MOHLTC, include: linking the patient and family to community services for non-medical management issues; organizing and coordinating dementia education sessions for family physicians, allied health professionals, patients and their families; follow-up and monitoring of patients and family caregivers; and evaluation of patient and caregiver outcomes.

[10] The *ADRD Planning Framework* is available on the Alzheimer Knowledge Exchange (where "ADRD" is Alzheimer Disease and Related Dementias). An accompanying toolkit is being developed.

### *Caregivers*

Informal caregivers are an integral component in the care of people with dementia. While their needs may be addressed somewhat in the plans to improve community supports, with a few exceptions (e.g., Central West (5), Central (8) and Central East (9) LHINs) there is little recognition of their role and sacrifice or of ways to provide them (as opposed to the client) with support. Without their contribution, health costs to government would increase significantly if their loved ones are otherwise prematurely placed in a long-term care home. Overall health costs to government for clients in home care have been estimated to be about one-half to three-quarters of the costs for clients in facility care.[11] Additional solutions, such as respite care, would provide needed support.

### *Co-morbidity*

There is an interaction between aging, dementia and chronic diseases that does not appear to be well articulated. As mentioned earlier, seniors may often suffer from more than one health concern or disease and the treatment and interaction of these co-morbid conditions needs to be understood and managed together. Not only are people with dementia, as seniors, likely to have other health concerns but also one condition may aggravate the other. For example, someone with Alzheimer's disease and diabetes will face greater challenges in managing their diabetes medications or diet requirements than a senior who is not cognitively impaired. Similarly, the presence of dementia makes depression more difficult to diagnose.

What are needed are integrated linkages between seniors, dementia and chronic disease management. At a recent meeting hosted by the Alzheimer Society of Ontario for the First Link demonstration project, a group of experts determined that the chronic disease management approach was applicable to Alzheimer's disease and related dementias. There is an opportunity to use the multiplier effect to enhance health outcomes through an integrated approach to co-morbidity.

### *Health Human Resources*

Caring for and treating someone with dementia who is cognitively impaired, particularly one with challenging behaviours, is different from most other forms of care. To be effective (in human terms) and efficient (in system terms) requires special understanding and training. In long-term care homes, all staff (including supervisors) should receive special training (Bill 140 aims to address some of this requirement). Family physicians are often unaware of best practices in dementia care. In the community, anyone who interacts with the person with dementia, whether a health professional, family, volunteer or someone from the broader

[11] Hollander, M.J. (2001) *Final Report of the Study on the Comparative Cost Analysis of Home Care and Residential Care Services* (NA101-01). National Evaluation of the Cost-Effectiveness of Home Care Project. Available from www.homecarestudy.com.

community, should receive education or training in how to approach the relationship in order to provide quality care.

Most LHINs address the need to develop a health human resources strategy in their IHSPs, often with a focus on increasing supply in order to improve access, i.e. recruiting and retaining professional staff in their area, and we agree that additional professional staff are vital to quality care. Few LHINs, however, have acknowledged or made provision for specialized training in dementia and dementia care. The Hamilton Niagara Haldimand Brant LHIN (4) is an exception and includes dementia education for family physicians, long-term care staff in its Geriatric Access and Integration Network (GAIN).

To address these concerns and contribute solutions, a Task Force of the Alzheimer Strategy Transition Project is developing a health human resources strategy to support the provision of services for people with dementia. The strategy will complement other related HHR strategies. Among the options being considered are a multidisciplinary Dementia Care Institute and a Framework for Dementia Care Education.

### *Data Collection*

The Alzheimer community has not been well served by the paucity of prevalence and cost data that is collected at a system level. Much of the analysis to date is based on a survey that, while well respected, was conducted fifteen years ago under the treatment, health and social regimes that existed at that time. It is impossible to plan adequately and achieve desired outcomes without good input and output measurements. Information about the prevalence and treatment of people with Alzheimer's disease and related dementias should be among the health data that are regularly collected and transmitted to the LHINs.

# Recommendations, Commitments and Resources

## *Recommendations*

From our analysis of the IHSPs, we recommend the following:

1. **That the LHINs and MOHLTC identify up to three LHINs to provide leadership in designing a model service framework for elderly persons with complex needs, including Alzheimer's disease and related dementias, which can be disseminated to other areas of the province.**

Rationale: In health planning, sub-populations are identified by shared characteristics and the system response to these needs is similar in nature. Variation may depend on local differences such as resources or geography. It would be more efficient for the LHINs to allocate leadership roles across the many health issues identified in the IHSPs.

2. **That each LHIN be mandated to adopt the "lead LHIN(s)" system response, adapt it to local conditions and foster implementation by local communities.**

Rationale: Those LHINs that identified elder care as a critical issue will benefit from being able to adopt the leadership model and will be able to modify the model based on their appreciation of local needs and capabilities. As well, they will be able to focus on leveraging local relationships to facilitate implementation.

3. **That the MOHLTC include "complex elder care" in its Strategic Plan, including Alzheimer's disease and related dementias, and identify specific system goals in LHIN accountability agreements, along with accompanying performance indicators and outcomes.**

Rationale: A province-wide action plan is needed to ensure that the growing numbers of persons with Alzheimer's disease and related dementias receive adequate services. The Strategic Planning and Accountability framework exists to provide such assurance to the citizenry.

**4.That the 'lead ' LHINS and the MOHLTC address in their models, the issues which the IHSPs overlooked, including caregiver support, co-morbidity, health human resources in respect to this population and better data for system planning.**

Rationale: This report identifies key items that all or most IHSPs seem to have overlooked. These are key issues, not only for dementia care but also for many other system responses to support older persons.

## *Commitments*

The Alzheimer Society of Ontario commits to:

5. **Strengthening its support for LHIN-wide Dementia Networks, which facilitate the engagement of persons with Alzheimer's disease and related dementias, the people important to them and service providers with the LHINs, in implementing the recommendations in the IHSPs and this report.**

Rationale: Dementia spans the health care continuum and Dementia Networks have emerged as effective mechanisms to promote integration and coordination of care for persons with dementia. They are able to collaborate with other networks at different points on the continuum, e.g., End-of-Life.

6. **Providing leadership in promoting the inclusion of Alzheimer's disease and related dementias in all aspects of health service development such as primary care, chronic disease management including prevention and promotion and population planning.**

Rationale: For various reasons, data gaps being one of them, health care system planning often tends to overlook age-related conditions, such as dementia. The Alzheimer Society of Ontario has an important role to identify opportunities where system improvements can incorporate Alzheimer's disease and related dementias.

## *Resources*

We can offer a range of resources to help develop solutions to the issues and recommendations discussed in this report. In most cases these tools are the result of multi-sector collaboration.

These resources include:

- Alzheimer Knowledge Exchange (AKE) – www.akeontario.org. The AKE is an online tool that facilitates the access and exchange of knowledge for anyone who wishes to enhance the capacity to care for people with dementia or with complex physical and cognitive/mental health needs. It features links to community groups (such as the Dementia Networks), resources, innovations and practical tools as well as an interactive collaborative space. The AKE has close links with the Seniors Health Research Transfer Network (SHRTN).
- *ADRD Planning Framework* (available on the AKE) – an integrated framework that incorporates a vision, set of six guiding principles, three planning pillars, and five enabling mechanisms to address the future impact of Alzheimer's disease and related dementias on government programs, communities, families and individuals. An accompanying toolkit to operationalise the framework is being developed.

- Dementia Networks – networks of service providers, clinicians, caregivers, agencies, and health related organizations that work locally, regionally and provincially to improve the system of care for individuals with dementia, their families and caregivers. Members include local champions, leaders, key service organizations and stakeholders. There are 36 Dementia Networks across Ontario.
- Business cases outlining solutions and outcomes specific to each LHIN for improving services for people with Alzheimer's disease and related dementias, developed by the Alzheimer Strategy Transition Project and Dementia Networks (forthcoming).
- Health Human Resources Strategy for Alzheimer's disease and related dementias (forthcoming).
- Dementia prevalence data by LHIN (available March 2007).
- *Delivering Rural Health and Social Services: An Environmental Scan* (2006).
- *A Survey of Planning Models for Seniors* (2005) – a survey for the Alzheimer Society of Ontario on seniors' planning models or frameworks proposed by the former District Health Councils.

# IHSP Review

This section identifies the *priorities/strategic directions* and *action steps* that each LHIN proposes to take with respect to key issues affecting people with Alzheimer's disease or related dementias and their families.

## *Alzheimer's Disease and Related Dementias*

While some LHINs refer to dementia in their discussions, Alzheimer's disease and related dementias does not play much, if any, direct role in the priorities and proposed activities of any of their IHSPs. There are few disease-specific recommendations in any IHSP with the exception of cancer and chronic diseases such as diabetes.

Where LHINs did refer to Alzheimer's disease or dementia, their comments included:

- reference to the expected increase in dementia cases by 2016 (LHINs 2 and 9);
- recognition that with an increase in seniors will come greater demand for mental health services, which include Alzheimer's disease (LHIN 6);
- reference to the high percentage of residents of long-term care homes with mental illness or some form of cognitive impairment such as Alzheimer's disease (LHIN 7); and
- access to psychogeriatric services (LHIN 10).

Beyond specific comments, there are many recommendations in the IHSPs that could benefit those affected by dementia. Many of these are found under Seniors or Long-Term Care, and some under headings such as Mental Health or Chronic Diseases. In other cases, general priorities such as improving navigation, access to primary care or cultural competence/responsiveness may also benefit those with dementia and their caregivers.

## *Seniors' Care*

Eight LHINs have specifically identified seniors as one of their priority areas with actions that range from developing a formal integrated model of seniors' care to improving access to specialized geriatric services.

The Hamilton Niagara Haldimand Brant LHIN (4), for example, has incorporated a focus on seniors and people with Alzheimer's disease in at least four of its six priorities: specialized services for frail seniors; assisting people to live independently in the community; supporting persons with mental health and addiction issues; and improving the quality of care at the end of life.

The Central East LHIN (9) has already established a Seamless Care for Seniors Network that provides advice on a wide range of issues from housing or placements for people with

cognitive impairments or at-risk behaviours to improved coordination of care and supports for caregivers.

Other priorities include building linkages across the continuum for seniors and adults with complex needs (South West LHIN (2), services to seniors (Central West (5) and Toronto Central (7)), enhancing seniors' health, wellness and quality of life (Mississauga Halton (6)), seniors and specialized geriatric services (Central LHIN (8)) and the elderly with complex and chronic conditions (Champlain LHIN (11)).

### *Integration Models*

At least five LHINs are considering integrated models for seniors' care. These fall into two types and are described more fully below:

- an interconnected network of services (e.g., GAIN – Geriatric Access and Integration Network; and Seamless Care for Seniors Network); and
- a series of interconnected local hubs, or seniors' centres, each of which provides information and referral services (e.g., ASSIST – All-Inclusive Seamless Services for Independence for Seniors for Today and Tomorrow; CACHET – Coordinated Accessible Community Health Care for Elders in Toronto; and Doorways to Care).

*GAIN – Geriatric Access and Integration Network (LHIN 4)*

- The goal of the Hamilton Niagara Haldimand Brant LHIN (4) is to develop an interconnected network of specialized geriatric health care services that will promote:
  - strategies for optimizing care and support for the frail elderly;
  - equitable access to specialized geriatric services in hospitals and in the community;
  - better connections among services to make it easier for people to get the right service at the right time consistent with their preferences, and for providers to organize and deliver best practice care; and
  - advice on the allocation of resources consistent with need and desired outcomes.
- The collaborative network will include those who use and will use specialized geriatric services as well as providers, educators, funders, policy makers and researchers.
- Initial GAIN strategies include:
  - The Dementia Education Program for Family Physicians.
  - Partnerships among key leaders in the provision of specialized geriatric services to improve coordination and availability of gerontology educational

materials especially in the long-term care sector, and through staff training in best practice approaches to the management of challenging behaviour associated with dementia.

- Implementation of the Geriatric Emergency Management program.

*Seamless Care for Seniors Network (LHIN 9)*

- The South East LHIN (9) has established the Seamless Care for Seniors Network, comprising seniors, caregivers and health and social service providers, and chaired by a physician specializing in geriatrics. The network will:
  - provide advice to the LHIN on priorities, goals and strategies to improve the system of care for seniors and their caregivers; and
  - act as a forum for communication, collaboration, knowledge exchange and innovation among stakeholders.
- Action steps include:
  - improving access to supportive housing and LTC placements for people with cognitive impairments;
  - supporting an interdisciplinary approach to care;
  - improving support to seniors and their caregivers during times of transition;
  - improving availability of services and linkages between sectors;
  - improving access to information about seniors' services;
  - providing needed supports to caregivers; and
  - improving coordination of care between providers.

*ASSIST – All-Inclusive Seamless Services for Independence of Seniors for Today and Tomorrow (LHIN 6)*

- Seniors Health and Wellness Centres are a key feature of ASSIST in the Mississauga Halton LHIN (6). They are geographically dispersed and interconnected hubs that provide common information, intake, assessment, referral and service delivery. They may be attached to one or more Family Health Teams and will be integrally linked to secondary and tertiary services.
- The model was developed by the Regional Geriatric Advisory Task Force as input to the LHIN and is based on best practices in service delivery to the frail elderly and seniors.

*CACHET – Coordinated Accessible Community Health Care for Elders in Toronto (LHIN 7)*

- One of the future activities of the Toronto Central LHIN (7) is to identify a model for seniors, their families, caregivers and seniors' healthcare providers to provide inputs into the LHIN.
- Several models were presented to the LHIN, one of which was CACHET developed by the Toronto District Health Council in 2004. (Models from other jurisdictions were SIPA – System of Integrated Care for Older Persons, Quebec; PRISMA – Program of Research to Integrate Services for the Maintenance of Autonomy (a pilot), Quebec; CHOICE – Comprehensive Home Option of Integrated Care for the Elderly, Edmonton; and PACE – Program of All-Inclusive Care for the Elderly (U.S.).)
- Under the CACHET model, specific agencies or groups of agencies are designated as CACHET agencies. Seniors would register and get all their health services through their CACHET agency.
- The CACHET agencies would either provide the care or arrange for care to be provided with others using the senior's individual care plan. More specifically, their services would include:
    - providing seniors with information and referral services;
    - conducting intakes where seniors would register with the agency;
    - assessing the needs of seniors using a single standardized graduated tool;
    - providing case management and coordinating care for seniors; and
    - monitoring outcomes and changing services depending on the needs of the senior.

*Doorways to Care (LHIN 8)*

- The Central LHIN (8) will pilot Doorways to Care, a new model intended to improve links between providers and strengthen their ability to disseminate information, make referrals and coordinate services.
- The model establishes a Seniors' Central Agency within each of the LHIN's geographic areas. Each agency will provide information and referral services, undertake assessment, system navigation and advocacy roles for vulnerable seniors, and undertake proactive outreach to identify seniors who have fallen through the cracks.

### *Other Actions affecting Integrated Seniors' Services*

*For Seniors*

Other LHINs, without creating a formal model of care for seniors, nevertheless have recognized the importance of an integrated continuum of care for seniors.

Action steps include:

- Develop an integrated continuum of care for seniors and adults with complex needs: define a strategy, research best practices and make recommendations in care coordination, develop implementation plans by geographic area, and identify potential "Early Win' opportunities. (LHIN 2)
- To improve services for seniors, lead the creation of new partnerships and best models of care through sharing of resources and knowledge across different segments of the continuum of care. Develop a comprehensive inventory of services and supports available to seniors in the LHIN. (LHIN 5)
- Build an integrated health system which delivers high quality senior-centred services to seniors and their caregivers. For example, enhance Specialized Geriatric Services capacity, and optimize resources. (LHIN 8)
- Work with health service agencies to identify and adopt best practice models for eliminating barriers and improving the flow of patients along the continuum of care (LHIN 10).
- With respect to the elderly with complex and chronic conditions, ensure there are linkages between the networks and coalitions of community support services in Champlain (LHIN 11).
- Establish a regional action group to address the needs of the frail elderly, including sub-groups such as the cognitively impaired, and complete an inventory of resources available and additional services required (LHIN 12).
- Improve navigation:
    - Provide supports for marginalized and at-risk seniors who need to navigate through the health system. Develop and implement a system that improves access to services by seniors, especially as they transfer between organizations and providers. Address access barriers such as physical, mental health, ethno-racial, linguistic and economic. (LHIN 7)
    - Develop an inventory of health-related information and education activities, resources and services for seniors (social, health and other relevant services) (LHIN 7).
    - Strengthen and organize system navigation resources for seniors (LHIN 8).

*Generally across the system*

As well as specific priorities relating to an integrated system of seniors' care, some LHINs have identified system-wide integration as one of their priorities. These integration activities should also benefit seniors and those with dementia.

- Facilitate current and planned initiatives that help address improving the linkages between primary care providers and CCACs, hospitals and community-based health service providers (LHIN 5).
- Strengthen coordination and integration across providers to improve client/patient access and improvement across the continuum (LHIN 6).
- Provide the right care, in the right place, at the right time. Action steps include: create a patient-friendly integrated health system; improve the continuum of care; reduce barriers to accessing health care; and understand the health care needs of francophones, the frail elderly and women. (LHIN 12)
- Work with health service providers to identify and adopt best practice models for improving the flow of patients along the continuum of care. Focus includes improving information-sharing among providers, facilitating movement of patients between providers in different locations and between providers in different sectors. (LHIN 14)
- Establish a working group to develop a strategic framework for health system navigation, which is a priority. Help organizations identify and/or advance cross-sector positions that would improve navigation. (LHIN 1).

## *Long-Term Care Services*

Improving long-term care services is a priority for two LHINs (10 and 14) and four others have developed action steps in this area.

Proposed activities include:

- Develop a strategy and plan of action to ensure access to long-term care services (LHIN 2).
- Review recommendations from a steering committee on long-term care, develop next steps and implement (LHIN 3).
- Develop a plan to enhance the role of long-term care homes by implementing strategies for filling gaps (including linkages with other sectors and the Palliative Care Network), and for enhancing resources in long-term care homes (such as the addition of nurse practitioners, introduction of special behavioural units) (LHIN 6).
- Improve the availability of long-term care services as a priority. The LHIN will develop a plan to realign current capacity to better meet needs and/or increase the capacity of one or more of the long-term care modalities (home support, home care, supportive housing, long-term care homes, complex continuing care). The objectives are to reduce:
    - the number of people requiring institutional long-term care;

    - the length of time people wait in acute care hospitals for access to long-term care beds; and
    - the length of time people wait in the community for access to long-term care (LHIN 10).
- Improve access to, and supports in, long-term care homes for people with severe behaviours. Steps include: identifying stakeholders and establishing a regional action group; reviewing existing proposals for the provision of long-term care home support for people with severe behaviours and identifying next steps; and implementing those next steps. (LHIN 12)
- Long-term care services, which include not only residential long-term care services but also complex continuing services and the availability of non-residential long-term services, are a priority. (LHIN 14)
    - Activities include developing and implementing a plan to realign current long-term care capacity to best meet the needs of the population.
    - Modalities of long-term care include: home support, home care, supportive housing, long-term care homes, complex continuing care, and respite care.
- Explore specialized programs in long-term care homes for target populations, which includes those with dementia (this action is located under the Chronic Disease priority) (LHIN 14).

## *Community Care and Support*

Community care and support for people at home is woven through the IHSPs in different ways. Two LHINs have made it a priority (LHINs 1 and 4) while four more have included it within other priorities, generally seniors.

Erie St. Clair LHIN (1) has indicated that identifying integration opportunities and strategies are a priority in supporting people at home. Activities proposed by the Hamilton Niagara Haldimand Brant LHIN (4) to assist persons to live independently in the community include developing care plans (with the case of a person with dementia taken to the emergency department because of caregiver burnout as one of the prototypes), and developing a profile of community support services and a guide for transition/discharge planning; solutions will be developed by a subgroup that includes representatives from seniors' services and dementia services.

Central East LHIN (9), on the other hand, has incorporated within its Seniors' strategy actions such as: better support for seniors and their caregivers at times of transition; improved linkages between community support services and hospitals; and providing needed supports to caregivers to enable them to remain healthy and continue to provide support to their loved ones. Similarly, the Services for Seniors strategy of the Central West LHIN (5) indicates that

family caregivers of seniors would have their needs assessed and addressed in the provision of care to the primary client.

Action steps include:

- Develop a strategic framework to improve support for people at home (a priority) through a Long-Term Care and Common Care Working Group; implement, monitor and evaluate (LHIN 1).
- Assess supportive housing needs and develop a plan to enhance supportive housing services (LHIN 3).
- Assist persons to live independently in the community (a priority, LHIN 4):
    - Develop care plans for three target groups, one of which is a person with dementia who has been admitted to the Emergency Department due to caregiver burnout. Care plans include the appropriate mix, sequence and continuity of services to support recovery and reduce the risk of hospital readmission.
    - Develop a profile for community support services and a guide for transition/discharge planning that includes the role of community support services.
- Work with MOHLTC to ensure that funding of the new CCAC adequately reflects the local needs to ensure adequate geriatric assessment and accessibility to community-based services (LHIN 5).
- Assess the availability of current services and gaps, and align capacity to the needs of seniors, founded on an "Aging at Home" philosophy and investigating the use and capacity of community-based services as the preferred alternative to hospital and long-term care home placement (LHIN 5).
- Enable seniors to live independently in the community as long as possible (a priority, LHIN 7).
    - Identify specific projects such as aging in place, holistic care, transportation and escort services.
    - Concentrate on the transition of seniors from one sector to another sector of the health care system.
- Planning broadly-defined long-term care services should take into account the importance of keeping people in their homes and in their home communities for as long as possible, while considering issues of quality of life, quality of care and efficiency of care (LHIN 14). See also LHIN 14 under Long-term care.
- Respite care is not specifically identified as a priority in any IHSP. Action steps include increasing the availability of respite care programs (LHIN 3).

## *Palliative/End-of-Life Care*

Palliative or end-of-life care is important particularly for those living in the community. Two LHINs (4 and 5) have identified it as a priority and three more include it in their action steps. In many cases these build on the provincial end-of-life strategy and focus on developing and training a multi-disciplinary local network of professionals and volunteers.

Action steps include:

- Collaborate with existing networks to identify needs, gaps and priorities in palliative care (LHIN 3).
- Improving the quality of care at the end of life is a priority (LHIN 4). Actions include:
    - Implement specialized education and training programs for volunteer caregivers and health care professionals to support end-of-life care. Two education and skills enhancement programs that will be available to all care providers (including volunteers) across all disciplines and care settings are: the Southwest Learning initiative; and the Pallium Learning Essential Application in Palliation (LEAP).
    - Implement best practice assessment, treatment and symptom management for people with palliative care needs through the Provincial Palliative Care Integration Project. Phase 1 will focus on cancer patients. Phase 2 will be available for all palliative patients.
- Develop and implement a local palliative care services integration plan (a priority, LHIN 5).
- Build on the End-of-Life Strategy to develop a comprehensive approach to palliative care, in particular by integrating and enhancing interdisciplinary palliative care resource team (LHIN 6).
- Identify and implement best practices for residential hospice programs, and pilot a residential hospice program in Collingwood, to be expanded later across the region (LHIN 12).
- Enhance the scope of, and access to, expert teams for palliative care. Activities include securing resources, establishing partnerships (e.g. with Family Health Teams), and providing the teams with necessary training and ongoing education. (LHIN 12).

## *Mental Health*

Mental health and addiction services are identified as a priority by half the LHINs (LHINs 4, 5, 6, 7, 8, 9, 11).

Key action steps include:

- Alignment of hospital and community-based services:
  - Focus on improving the alignment and configuration of hospital and community-based services. Identify strategies for resolving issues related to Alternate Level of Care. (LHIN 1).
  - Reducing dependence on hospital-based services is a priority. Activities include facilitating planning for mental health system divestment, identifying strategies related to Alternate Level of Care, and developing strategies to support the appropriate use of Emergency Departments. (LHIN 1)
- Improved coordination and integration of services across the continuum of care:
  - Improve coordination and integration of services for people with concurrent disorders (LHINs 4, 7).
  - Develop a local integrated mental health and addiction service plan … built on a single coordinated system of access and case management and encompassing the principle of "no wrong door" (LHIN 5).
  - Develop an integrated approach to service delivery across the continuum and life cycle (LHIN 6).
  - Improve access to coordinated and integrated mental health and addiction services. Determine how best to support existing access and integration networks. (LHIN 7)
  - Create a continuum of care for people with addiction and mental health needs, to be extended later to other clinical services (LHIN 12).
- Establish and use networks:
  - Establish a Mental Health and Addictions Network focused on system planning and coordination. Other activities include developing a comprehensive information system, clearly defined systems for access, referral and coordination, an inclusive and responsive system, and service models that provide clients with an integrated continuum of mental health and addictions services and supports. (LHIN 8)
  - Created a Mental Health and Addictions Network of service providers in 2005. Action steps include developing a health human resources strategy for mental health and addictions, promoting knowledge exchange, developing an interdisciplinary team approach to care across agencies and sectors, and maintaining a publicly accessible inventory of agencies, programs and services. (LHIN 9)
  - Recognize the Champlain Mental Health Network and the Champlain Addiction Coordinating Body as a component of the LHIN's planning model (LHIN 11).

- Develop plans to reduce barriers to accessing existing mental health services and increasing the supply of services; investigate a shared-care model. Pay particular attention to the needs of those in more remote areas. (LHIN 10)
- Work to ensure timely access to appropriate mental health and addiction services, including investigating a shared-care model (LHIN 14).

## *Neurological Health Services*

LHIN 8 identifies neurological health services as a priority. "Neurological health services" includes disorders such as headaches, Alzheimer's disease, stroke, epilepsy, brain injury, Parkinson's disease, multiple sclerosis, Huntingdon disease, muscular dystrophy, and Tourette syndrome.

- Overarching goal is to collaboratively plan for a range of services for persons with neurological health service and support needs so there is timely access to appropriate services.
- Activities include: developing a service inventory and piloting delivery mechanisms for coordinated inventory management; strengthening and organizing system navigation resources; designing and testing multiple service delivery methods, using information technology to enable more efficient resource use, and identifying links for collaborative, multi-sector planning for neurological services.

## *Chronic Disease Management*

Most of the LHINs have referenced the provincial Chronic Disease Prevention and Management (CDPM) Framework in their IHSPs and identified developing a local chronic disease strategy as a priority (LHINs 1, 2, 3, 5, 6, 8, 9, 11, 12, 13, 14). In some cases, the strategy will initially focus on a specific disease such as diabetes and will subsequently be expanded to other diseases.

A number of components of the provincial CDPM framework can be relevant to the care of people affected by dementia. For example, Dementia Networks represent a partnership between individuals, health care organizations and the community; the support and education services of the Alzheimer Society chapters contribute to personal skills, self-management and supportive environments. A group of experts at a recent meeting hosted by ASO has determined that the CDPM framework was applicable to Alzheimer's disease and related dementias (report forthcoming).

Action steps include:

- Develop and disseminate integrated, comprehensive care pathways for specific chronic disease issues (LHIN 6).
- Promote the use of the provincial CDPM Framework with a focus on the use of best practice guidelines (under E-Health priority, LHIN 7).

- Create a navigation system; develop and pilot an Information Technology Family eHealth Team partnership that replicates the CDPM Program Best practice Innovations; collaboratively support health promotion and disease prevention initiatives; and develop a self-management network for people with chronic diseases (LHIN 8).
- Created a Chronic Disease Prevention and Management Network (LHIN 9).
- Organize a network to ensure coordination of work related to the prevention and management of chronic diseases; develop an integrated strategy and model; identify priority areas for the development and gaps in data and evidence; develop collaborative links with other external networks and associations dealing with chronic diseases. (LHIN 11)
- Establish a North East LHIN Chronic Disease Prevention and Management Advisory Panel to clarify roles, provide support to existing disease/service networks, and develop cost/benefit analysis models that include chronic disease considerations (LHIN 13).

## *Other Priorities*

Health and community services for people with dementia fall within the broader spectrum of services that will be designed and funded by the LHINs. Among these system-wide initiatives are several that will benefit people with dementia, including actions to enhance primary care, transportation, rural services, linguistic and cultural responsiveness, and health human resources.

### *Primary Care*

- Improve access to primary care (e.g. LHINs 1, 2, 3, 10, 11, 12 and 14). Actions or comments that are particularly relevant to people with dementia include:
  - Identify, and initiate a plan to meet the specific access needs of seniors, people with mental health issues and chronic diseases (LHIN 3).
  - Access to psychogeriatric services is problematic (LHIN 10).
- Improve linkages across the system (LHINs 2, 5, 11).
- Strengthen inter-disciplinary practice (LHINs 6, 10 and 12).
- Develop strategies to support appropriate use of Emergency Departments (LHIN 1).

### *Transportation*

Lack of transportation has been recognized as a barrier to accessing health and social services by at least half of the LHINs.

- Non-urgent transport in both rural and urban settings is a significant barrier to equitable access to services, and a challenge that may affect successful implementation of the IHSP (LHIN 6).
- Review the transportation implications in developing an integrated continuum of care (LHINs 1 and 2).
- Enhance transportation services (e.g., for seniors and those with neurological health disorders) to health, social and recreational services, to and from elective care, and from emergency care (LHINs 1, 3, 8, 10, 11).

### *Rural Services*

- Identify gaps and improve access to services in rural communities that lack access. (LHINs 1, 2, 11)

### *Linguistic and Cultural Responsiveness*

- Cultural awareness is a challenge that may affect successful implementation of the IHSP (LHIN 6)
- Develop competence in service delivery to seniors and to individuals from ethno-cultural, religious and linguistic communities (LHIN 5, 8 and 9).
- Improve French-language services (LHINs 9, 12, 13 and 14).
- Work with aboriginal communities to better understand and address the issues of health care services (LHINs 12, 23 and 14).

### *Health Human Resources*

Health human resources (HHR) has been identified as either a priority or an enabling strategy in almost all LHINs, and most are intending to create some form of LHIN-wide HHR strategy.

More specifically, Erie St. Clair LHIN's (1) immediate plans include establishing a mechanism to develop and deliver an integrated continuing education program in the area, facilitating the development and expansion of mentorship programs for health care professionals, and examining how the recruitment, training and retention of volunteers could be better integrated and coordinated. The South West LHIN (2) also wishes to foster academic involvement and build linkages between academic leaders and providers.

The Hamilton Niagara Haldimand Brant LHIN (4) outlines some sector-specific HHR initiatives.

- To provide specialized services for seniors, it will develop a network (GAIN – Geriatric Access and Integration Network – discussed previously under Seniors) whose initial strategies include:
    - the Dementia Education Program for Family Physicians and

    - partnerships to improve the coordination and availability of gerontological educational materials, especially in the long-term care sector, and staff training in best practice approaches to managing challenging behaviour associated with dementia.
- To help support persons with mental health and addiction issues, it will develop a LHIN-wide plan for cross-training of staff and cross-sector secondments.
- To help improve the quality of care at the end of life, it will implement specialized education and training programs for volunteer caregivers and health care professionals.

## *Ongoing Engagement*

- Build on existing groups and networks; initial suggestions include Psychogeriatric/Alzheimers and Emergency Medicine. Other engagement activities include: continue community engagement with unique population groups; develop a Health Providers Advisory Committee; develop and enhance networks along common functions; and develop sector reviews. (LHIN 1)
- Develop a Community Advisory Council to bring together public representatives from each planning area and from identified specific population groups – champions of change (LHIN 3).
- Communities of Interest roundtables will bring together individuals and provider agencies with diverse perspectives, multi-disciplinary expertise and cross-sectoral practice areas for the purposes of project-oriented strategic planning (LHIN 3).
- Create strategic partnerships and alliances to increase the community capacity for service delivery. Create a health system planning forum with community partners. (LHIN 3)
- Working in partnership with health service providers, lead the creation of new partnerships and best practice models of care through sharing of resources and knowledge across different segments of continuum of care (LHIN 5).
- Three LHIN-wide Health Interest Networks: Seamless Care for Seniors as well as Mental Health and Addictions, and Chronic Disease Prevention and Management (LHIN 9).
- Community engagement is a cornerstone to moving forward (LHIN 11):
    - Establish five local geographic areas as communities of care and organize, with their representatives, three engagement events each year.
    - Recognize the Health Networks as communities of practice and components of the LHIN's planning model. For example, recognize the Regional Geriatric

Advisory Committee (RGAC) and that the Champlain Dementia Network is an important link to the RGAC on issues of dementia.

- Work with Health Networks to develop objectives aimed at improving access, and promoting the link with primary care by encouraging the provision of specific services.
- Develop and put in place a Service Provider Network Communication Forum.

- Organize three regional summits to develop frameworks and workplans to address issues of access with respect to: seniors' health; mental health and addictions; and Alternate Level of Care (LHIN 13).

# Table 1: Priorities by LHIN

This table identifies the key priorities (but not action steps) of each LHIN as expressed in their IHSPs, presented under topics of interest to people with Alzheimer's disease and related dementias and their families (indicated with a '√'). Enabling strategies, which may be considered a priority in some LHINs and categorized separately in other LHINs, are also identified (indicated with an 'x'). One caveat: the LHINs that have taken a more systemic approach without identifying specific sectors may be less well represented in the table even though their actions may, in fact, have a positive impact on people with dementia.

| **Priority**<br>*√ = priority*<br>*x = enabling strategy* | **LHIN** | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **1** | **2** | **3** | **4** | **5** | **6** | **7** | **8** | **9** | **10** | **11** | **12** | **13** | **14** |
| **Seniors**:<br>• Building linkages across the continuum: all seniors and adults with complex needs<br>• Specialized services for frail seniors<br>• Services to seniors<br>• Enhancing seniors' health, wellness and quality of life<br>• Seniors<br>• Seniors and specialized geriatric services<br>• Seamless care for seniors<br>• Elderly with complex and chronic conditions | | √ | | √ | √ | √ | √ | √ | √ | | √ | | | |
| **Long-term care service**s | | | | | | | | | | √ | | | | √ |
| **Community care and support**:<br>• Supporting people at home<br>• Assist people to live independently | √ | | | √ | | | | | | | | | | |
| **Palliative/end-of-life care** | | | | √ | √ | | | | | | | | | |
| **Mental health**:<br>• Mental health and addiction services<br>• Reduce dependence on hospital-based services<br>• Access to care – mental health services | √ | | | | √ | √ | √ | √ | √ | √ | √ | | | √ |
| **Neurological health services** | | | | | | | | √ | | | | | | |
| **Chronic disease prevention and management** | √ | √ | | | √ | √ | | √ | √ | | √ | √ | √ | √ |
| **Primary care:**<br>• Strengthening and improving primary care<br>• Primary care linkages<br>• Emergency services | | | | | √ | √ | | √ | | | √ | | √ | √ |

| Priority<br>√ = priority<br>x = enabling strategy | LHIN | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 |
| • Wait times | | | | | | | | √ | √ | | √ | | √ | |
| • Family physicians | | | | | | | | x | | √ | | | | |
| • Strengthening and improving access to care | | √ | √ | | x | | | | | √ | √ | √ | | √ |
| • Access to specialty care | | | | | | | | | | | | | | √ |
| • Services closer to home | | | | | | | | | | | √ | | | |
| **Integrated continuum of care**: | | | | | | | | | | | | | | |
| • Integration of services along the continuum | | | | | x | | | | | | | | | √ |
| • Accessing the right services, in the right place, at the right time | √ | √ | | | | | | | | | | √ | | |
| • Moving people through the system/transitions | | | | | | x | | | x | √ | | | | |
| • System navigation | √ | | | | | | | | | | | | | |
| **Cultural and linguistic responsiveness:** | | | | | | | | | | | | | | |
| • Cultural competence | | | | | √ | | | x | | | √ | | | |
| • French-language services | | | | | | | | | | √ | | √ | √ | √ |
| • Aboriginal communities | | | | | | | | | | √ | | √ | √ | √ |
| **Enablers/implementation strategies**: | | | | | | | | | | | | | | |
| • Back office integration and efficiencies | √ | | | | | | √ | | x | | | √ | | |
| • Clinical programs, new approaches | | | | | | | | | | | | √ | | |
| • Decision support | | x | | | | | | x | | | | | | |
| • Education//research/knowledge sharing | | | | | | x | √ | | | | | | | |
| • E-health | | √ | | | | | √ | | x | √ | √ | √ | | √ |
| • Energy and environment management | | | | | | | √ | | | | | | | |
| • Health human resources | √ | √ | | | | x | √ | x | x | √ | √ | √ | √ | √ |
| • Health promotion | √ | x | | √ | | x | | | | | | | | |
| • Increased capacity | | | | | x | | | | | | | | | |
| • Information and communication technology | | | | | | x | | x | | | | | √ | |
| • Mobilizing partnerships | | x | | | | | | | | | | | | |
| • Population health | | | √ | | | | | | | | | √ | | |
| • Standardization and best practice | | x | | | | | | | | | | | | |
| • Transportation | | x | | | | x | | | | √ | √ | | | |
| **Other priorities:** | | | | | | | | | | | | | | |
| • Cancer care | | | | | | | | √ | | | | | | |
| • Maternal, child and youth services | | | | √ | √ | | | | | | | | | |
| • Provincial ministry priorities | | | | | | | √ | | | | | | | |
| • Rehabilitation | | | | | | | √ | | | √ | | | | |
| • Safe environments of quality care | | | | | | | | | x | | | | | |
| • Sustainability | | | √ | | | | | | | | | | | |
| • System effectiveness/performance | | | √ | | | √ | | | | | | | | |

# Appendix 1:

## *People with Alzheimer's Disease or Related Dementias and Seniors – Summary of IHSP Comments (ADRD) and Priorities and Actions (Seniors), by LHIN*

| | Alzheimer's Disease or Related Dementias | Seniors | |
|---|---|---|---|
| | | **Identified Priority** | **Proposed Actions** |
| LHIN 1 | | • Supporting people at home. | • Establish a LTC and Common Care Working Group to develop a strategic framework to improve support for people at home; implement, monitor and evaluate.<br>• To move the project forward, determine if a psychogeriatric urgent response initiative can have wider application. |
| LHIN 2 | • Identified as an issue. | • Building linkages across the continuum – all seniors and adults with complex needs.<br>• Accessing the right services, in the right place, at the right time, by the right provider. | • Develop an integrated continuum of care for seniors and adults with complex needs through a cross-sector Priority Action Team. Include a review of transportation implications.<br>• Develop a strategy to ensure access to long-term care services. |
| LHIN 3 | | | • Long-term care: review recommendations from steering committee, develop next steps and implement.<br>• Respite care: increase availability of programs.<br>• Needs of older adults: increase availability of programs.<br>• Palliative care: collaborate with existing networks to identify needs, gaps and priorities.<br>• Primary care: identify specific access needs of seniors, people with mental health issues and chronic diseases. |
| LHIN 4 | | • Assist persons to live independently in the community.<br>• Improve the quality of care at the end of life.<br>• Specialized services for frail seniors. | • Develop care plans for three target groups (one for a person with dementia and caregiver).<br>• Develop profile of community support services and guide for transition/discharge planning that includes the role of community support services. |

| | Alzheimer's Disease or Related Dementias | Seniors | |
|---|---|---|---|
| | | Identified Priority | Proposed Actions |
| | | | • Develop an interconnected network of specialized geriatric health care services: Geriatric Access and Integration Network (GAIN).<br>• Initial GAIN strategies include dementia education for family physicians, partnerships to improve coordination and availability of gerontology education materials, staff training in managing behaviours associated with dementia, and implementation of geriatric emergency management program.<br>• Implement specialized education and training programs for volunteer caregivers and health care professionals to support end-of-life care. Programs available: Southwest Learning Initiative; and Pallium Learning Essential Application.<br>• Implement best practices for people with palliative care needs; initial focus is cancer patients. |
| LHIN 5 | | • Palliative end-of-life services<br>• Services to seniors; discussion includes that family caregivers will have their needs assessed and addressed in the provision of services to the primary client. | • Funding of CCAC should adequately reflect local needs to ensure adequate geriatric assessment and accessibility to community-based services for seniors.<br>• Develop comprehensive inventory of services and supports available for seniors.<br>• Align capacity to the needs of seniors (founded on Aging in Home philosophy); investigation to include the use and capacity of community-based services.<br>• Create new partnerships and best practice models of care through sharing of resources and knowledge across sectors.<br>• Develop and implement local palliative care services integration plan. |
| LHIN 6 | • Recognizes that with increase in seniors will come greater demand for mental health services "such as Alzheimer Disease and dementia." | • Enhancing seniors' health, wellness and quality of life. | • Implement an integrated service delivery model for seniors – ASSIST (All-inclusive Seamless Services for Independence of Seniors for Today and Tomorrow).<br>• Enhance the role of long-term care homes, including strategies for filling gaps and enhancing resources (e.g. introducing special behavioural units).<br>• Build on the End-of-Life Strategy to develop a comprehensive approach to palliative care, in particular by integrating and |

| | Alzheimer's Disease or Related Dementias | Seniors | |
|---|---|---|---|
| | | Identified Priority | Proposed Actions |
| | | | enhancing interdisciplinary palliative care resource team. |
| LHIN 7 | • Discussion under both Seniors and Mental Health priorities cites 80-90% of nursing home residents as living with mental illness or some form of cognitive impairment including Alzheimer's disease. | • Seniors. | • Provide supports for marginalized and at risk seniors who need to navigate their way through the health system.<br>• Enable seniors to live independently in the community for as long as possible.<br>• Foundational activities include: developing an inventory of health, social and other resources and supports to seniors; identifying a model for seniors their families, caregivers and providers to provide input to the LHIN; and building capacity by expanding existing networks. (One potential model – Toronto's CACHET (Coordinated Accessible Community Health Care for Elders in Toronto).) |
| LHIN 8 | • Neurological health services (which includes AD) is a priority.<br>• Goal: Collaboratively plan for a range of services for persons with neurological health service and supports needs such that there is timely access to appropriate services.<br>• Develop service inventory, strengthen and organize system navigation, test multiple service delivery models, incorporate collaborative multi-sector planning | • Seniors and specialized geriatric services. | • Goal: to build an integrated health system which delivers high quality senior-centred services to seniors and their caregivers.<br>• Enhance Specialized Geriatric Services capacity.<br>• Strengthen and organize system navigation resources for seniors.<br>• Develop competence in service delivery to seniors and to individuals from ethno-cultural, religious and linguistic communities.<br>• Optimize resources.<br>• Enhance transportation for seniors to available health services.<br>• Improve links between providers and strengthen their ability to disseminate information, make referrals and coordinate services by piloting a new model of care – Doorways to Care. (The Doorways to Care model establishes a Seniors Central Agency within each of the LHIN's geographic areas.) |
| LHIN 9 | • Recognizes dementia as a factor. | • Seamless care for seniors. | • Establish a Seamless Care for Seniors Network.<br>• Action steps include: improved access to supportive housing |

| | Alzheimer's Disease or Related Dementias | Seniors | |
|---|---|---|---|
| | | Identified Priority | Proposed Actions |
| | | | or LTC placement for those with cognitive impairments and at-risk behaviours; evidence-based patient safety programs; interdisciplinary approach to care; during transitions, better support for seniors and caregivers and improved coordination of care; improved availability of services, linkages between sectors, and access to information; sharing resources and expertise, support for caregivers. |
| LHIN 10 | • Access to psychogeriatric services identified as problematic under Access to Care priority. | • Availability of long-term care services. | • Develop plan to realign current capacity of long-term care to better meet needs and/or increase capacity of one or more long-term modalities (which are home support, home care, supportive housing, LTC homes, complex continuing care). |
| LHIN 11 | | • Elderly with complex and chronic conditions. | • Recognize the Regional Geriatric Advisory Committee (RGAC) as a component of the LHIN's engagement and planning model. Invite it to provide a forum for continuing work related to Alternative Level of Care.<br>• Recognize the Champlain Dementia Network as an important link to the RGAC on issues of dementia and promote close collaboration between the two groups. |
| LHIN 12 | | • A component of the priority "Provide the right care, in the right place, at the right time" includes understanding the health care needs of the frail elderly. | • Establish a regional action group to address the needs of the frail elderly, including sub-groups such as the cognitively impaired, and complete an inventory of resources available and where additional services are required. Take next steps.<br>• Identify and implement best practices for residential hospice programs. Pilot a rural residential hospice program.<br>• Enhance the scope of and access to expert teams for palliative care. The teams will get training and ongoing education. |
| LHIN 13 | | | • Organize three regional summits to develop frameworks and workplans to address the issues of access with respect to seniors' health as well as mental health and addictions and alternative level of care. |
| LHIN 14 | • Exploring specialized programs for people | • Long-term care services is a priority: this includes residential long-term care | • Develop and implement a plan to realign current long-term care capacity to best meet the needs of the population. |

| | Alzheimer's Disease or Related Dementias | Seniors | |
|---|---|---|---|
| | | **Identified Priority** | **Proposed Actions** |
| | with dementia in LTC homes is part of the chronic disease priority. | services, complex continuing care services, and non-residential long-term care services. | Consider all modalities: home support, home care, supportive housing, long-term care homes, complex continuing care, and respite care.<br>• An important consideration is keeping people in their homes and communities for as long as possible. |

# Appendix 2:

## *Mental Health, Chronic Diseases, and Relevant General Initiatives – Summary of IHSP Priorities and Actions, by LHIN*

| LHIN | Other Conditions | | General Initiatives |
|---|---|---|---|
| | **Mental Health** | **Chronic Diseases** | |
| LHIN 1 | • Improve alignment of hospital and community-based services (re mental health divestment).<br>• Identify strategies re Alternate Level of Care. | • Chronic disease strategy (priority) | • Reduce dependence on hospital-based services (priority.<br>• System navigation (priority).<br>• Identify priority access issues including transportation<br>• Strategies to support appropriate use of Emergency Departments |
| LHIN 2 | • Early intervention and wellness for people with mental health and addiction conditions; includes developing local delivery systems that … address specific age-specific population recommendations. | • Preventing and managing chronic illness (priority). | • (see Seniors re integrated continuum of care and transportation implications)<br>• System navigation: Support development of a more connected system across primary health care.<br>• Support rural community providers with links to specialized resources. |
| LHIN 3 | | | • Work with community partners to ensure common understanding of evidence-based approach to service delivery.<br>• Supportive housing: enhance community capacity.<br>• Transportation: collaborate with community partners; develop plan to enhance transportation needs. |
| LHIN 4 | • Support persons with mental health and addiction issues (priority) | | |

| LHIN | Other Conditions | | General Initiatives |
|---|---|---|---|
| | Mental Health | Chronic Diseases | |
| | • Coordinate approaches to assessment and treatment for persons with concurrent disorders. | | |
| LHIN 5 | • Mental health and addictions services (priority)<br>• Develop a local integrated mental health and addictions services plan … built on a single "coordinated system of access and case management" encompassing the principle of "no wrong door". | • Chronic disease prevention and management (priority)<br>• Define a local chronic disease prevention and management model (referencing the provincial framework) for specific client populations with chronic health conditions. | • Primary care linkages (priority)<br>• Where appropriate, facilitate initiatives that improve linkages between primary care providers and CCACs, hospitals and community-based health service providers<br>• Promote initiatives that expand capacity of CHCs to meet needs of population with difficulty accessing primary care.<br>• Responsiveness to cultural diversity (priority).<br>• Establish a strategic diversity plan that incorporates guidelines on best practice cultural competencies. |
| LHIN 6 | • Integrating mental health and addictions services (priority). | • Preventing and managing long-lasting (chronic) conditions (priority).<br>• Develop a comprehensive chronic disease prevention and management approach to service delivery across the continuum.<br>• Develop and disseminate integrated comprehensive care pathways for specific chronic disease issues.<br>• Identify issues raised during community engagement that could be used as the basis for further development, e.g. the success of the Alzheimer Society in bringing groups together. | • Strengthening primary care (priority)<br>• Strengthen inter-disciplinary practice across providers by improving communications and linkages among physicians and primary health service providers and partners. Activities include building on the National Home Care and Primary Health Care Partnership Project.<br>• Strengthen coordination and integration across providers to improve client/patient access across the continuum. |
| LHIN 7 | • Mental health and addictions (priority).<br>• Improve access to coordinated and integrated mental health and addictions services.<br>• Improve coordination and integration of services for people | • Included in E-health priority. | |

| LHIN | Other Conditions | | General Initiatives |
|---|---|---|---|
| | Mental Health | Chronic Diseases | |
| | with concurrent disorders. | | |
| LHIN 8 | • Mental health and addictions (priority).<br>• Proposed actions incorporate steps to improve access, coordination, quality, efficiency and integration. | • Chronic disease prevention and management (priority).<br>• Proposed actions incorporate steps to improve access, coordination, quality, efficiency and integration. | • Neurological health services (priority).<br>• Migration plan for neurological health service actions based on needs that transcend sectors: transportation, ethno-cultural and inclusive services; and trans-sector collaboration. |
| LHIN 9 | • Mental health and addiction services (priority).<br>• In 2005 created a mental health and addictions network of service providers. | • Chronic disease prevention and management (priority).<br>• Created a Chronic Disease Prevention and Management Network with initial focus on cardiovascular disease and stroke, chronic kidney disease and diabetes, respiratory disease, and arthritis and related conditions. | • Developing cultural competence includes creating a publicly available inventory of existing culturally competent health services. |
| LHIN 10 | • Develop plans to reduce barriers to accessing existing mental health services and increasing supply of services.<br>• Investigate a shared-care model. | | • Integration of services along the continuum is a priority.<br>• Integration action steps include adopting best practice models for eliminating barriers and improving flow along the continuum of care.<br>• Further develop integrated multi-disciplinary models of primary health care. |
| LHIN 11 | • Addictions and mental health (priority). | • Chronic disease prevention and management (priority). | • Primary health services for healthy communities (priority).<br>• Establish a Council of Expertise on Primary Health Services and Public Health to develop appropriate linkages fostering access and coordination with primary care.<br>• Identify and focus on specific rural and urban communities that lack adequate services.<br>• Work closely with CHCs and Family Health Teams to improve access to a broader range of primary health services. |

| LHIN | Other Conditions | | General Initiatives |
|---|---|---|---|
| | Mental Health | Chronic Diseases | |
| | | | • Develop a task force to improve coordination of transportation. |
| LHIN 12 | • Create a continuum of care for people with addiction and mental health needs.<br>• Implement a regional acute care bed registry and a regional on-call psychiatry service.<br>• Develop broad partnerships with other organizations serving people with mental illness.<br>• Identify opportunities to implement integrated continuums of care for people with other complex and continuing needs. | • Improve chronic disease management and prevention (component of "Improve the health of residents" priority).<br>• Assess the current state of chronic disease prevention and management programs. Focus first on diabetes. | • Provide the right care, in the right place, at the right time (priority).<br>• Action steps include: create a patient-friendly integrated health system; improve the continuum of care; reduce barriers to accessing health care; and understand health care needs of francophones, frail elderly and women.<br>• Identify and reduce the system barriers to accessing health care.<br>• Support clinical integration through regional clinical programs and clinical support services.<br>• Enhance options along the continuum of care, including developing processes and structures to provide people with care in the setting that best meets their needs. |
| LHIN 13 | | • Chronic disease prevention and management (priority).<br>• Establish an advisory panel to clarify roles, consult with, and provide support and advice to existing disease/service networks, and develop cost-benefit analysis models that include chronic disease considerations. | |
| LHIN 14 | • Access to mental health and addiction services (component of the Access to Care priority).<br>• Action steps: working to ensure timely access to mental health and addiction services, including investigating a shared-care model. | • Chronic disease prevention and management (component of the Access to Care priority).<br>• Action steps: develop and implement health education, disease prevention and diseases management strategies.<br>• Explore specialized programs in long-term care homes for target populations (which | • Integration of services along the continuum of care (priority).<br>• Action steps: work with health service providers to identify and adopt best practice models for improving the flow of patients along the continuum of care.<br>• Develop and implement regional and sub-regional strategies to increase local access to |

| LHIN | Other Conditions | | General Initiatives |
|---|---|---|---|
| | Mental Health | Chronic Diseases | |
| | | includes those with dementia). | primary health care services, and to increase the volume of service delivered.<br>• Focus on integrated multi-disciplinary models of primary health care. These teams to include not only primary health care providers but also dietitians, social workers, health educators etc. |

# Appendix 3:

## *List of LHINs, by number*

| | |
|---|---|
| 1 | Erie St. Clair |
| 2 | South West |
| 3 | Waterloo Wellington |
| 4 | Hamilton Niagara Haldimand Brant |
| 5 | Central West |
| 6 | Mississauga Halton |
| 7 | Toronto Central |
| 8 | Central |
| 9 | Central East |
| 10 | South East |
| 11 | Champlain |
| 12 | North Simcoe Muskoka |
| 13 | North East |
| 14 | North West |

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