Dementia-Friendly Communities:
A Multi-Sector Collaboration to
Improve Quality of Life for People Living With Dementia and Caregivers:

*Environmental Scan*

Ontario Trillium Foundation Submission
Stage: Groundwork

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# Dementia-Friendly Communities: A Multi-Sector Collaboration to Improve Quality of Life for People Living With Dementia and Caregivers: Environmental Scan

**Ontario Trillium Foundation Submission**

**Stage: Groundwork (Environmental Scan)**

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**Introduction**

Using a collective impact approach, the Alzheimer Society of Ontario proposes to champion a multi-sector collaborative movement focused on improving quality of life for people living with dementia and their caregivers, using a *Dementia-Friendly Communities* model, funded by and in partnership with the Ontario Trillium Foundation (OTF).

Around the globe, communities have been embracing the concept of creating age-friendly communities. Precipitated by the challenge put forward by the World Health Organization, this movement has been focusing on creating communities that, by broad definition, aim to engage people of all ages in improving the quality of life for older people.

A parallel movement has started, also around the globe, to create dementia-friendly communities. This presents Canadians with an opportunity to engage with stakeholders from many sectors to create a collaborative effort to support people living with dementia and their caregivers to live well.

The World Health Organization, as well as Alzheimer’s Disease International, both challenge the world to make *Dementia-Friendly Communities* a reality within national dementia strategies. Japan, Australia, England, Scotland, Belgium and the United States are already actively doing so.

This Environmental Scan is the first step in the Ontario Trillium Foundation’s Collective Impact Funding Program, designed with the intent to identify issues and barriers faced by people with dementia and their caregivers to living well, and to support the urgency for change from the current realities.

The next step, *Build the Case*, will dive deeper into the models of, and roles for, Dementia-Friendly Communities and Collective Impact in responding to the unique needs of people living with dementia and their caregivers. In developing these models and go-forward plans, the Alzheimer Society will be inviting engagement with many stakeholders from many sectors who do, or could, play a role in a collective strategy. One key stakeholder group is people with lived experience, individuals living with dementia and their caregivers.
**The Ontario Trillium Foundation**

The Ontario Trillium Foundation (OTF) is an agency of the Government of Ontario, and Canada’s largest granting foundation. Over $110 million is awarded annually to some 1,000 nonprofit and charitable organizations across the province.

The OTF has a number of Funding Streams, with the Collective Impact stream being the focus for this initiative.

For all Funding Streams, there are identified action streams, priority outcomes, and grant results. For this submission and initiative, the focus will be on the “Connected People” action stream, with the priority outcome of “reduced isolation”, and grant results being “people who are isolated have connections in their community”.

There are 6 components, or stages, in the OTF Collective Impact Funding Stream. Collectives would normally move through the stages in order. This report responds to the Groundwork Stage, where the nature of the problem and the urgency for change are identified. Further engagement with interested stakeholders will continue and expand through the growth of the initiative.

The components are: groundwork (identify the problem); build the case (having conversations to build a strong case for change); concept design (developing a structure with various stakeholders committed to a plan); proposal development (development of a complete plan); implementation; and evaluation.
Executive Summary

The World Health Organization has declared dementia to be a “public health priority” on a worldwide scale\(^1\). Dementia is the most significant cause of disability among Canadians (65+) and it already costs Canadian society billions of dollars each year\(^2\). Dementia is a core issue impacting Ontario’s health and social system\(^3\). Finding a cure for dementia is the ultimate goal; however while we wait for that goal to be achieved, it is critical to focus on supporting the needs of people living with dementia and their caregivers today.

Dementia is a brain disorder characterized by impaired cognitive functioning that can affect learning and memory, mood and behavior, as well as the ability to conduct daily activities and high level functions such as management of other chronic conditions\(^4\).

Most experts agree that a certain amount of cognitive decline can be expected with normal aging. However, it is important to emphasize that dementia is not a part of normal aging; it is a chronic, progressive and ultimately fatal disease\(^5\). To date there is no known cure or effective means by which to delay onset or progression. The median time of survival for Alzheimer’s disease (which accounts for 60-70% of dementia cases) has been estimated at 7 years\(^6\).

There is no doubt that the incidence of dementia is increasing rapidly, and that the impact of dementia will continue to rise and spread. An estimated 214,000 older adults in Ontario (65+) are currently living with some form of dementia. This number is expected to increase by 17% to nearly one quarter of a million people by 2020\(^7\). National reports in both the United States and UK indicate that Alzheimer’s disease and dementia are among the most feared diseases associated with getting older\(^8\).

While the risk for dementia does increase with age, 2-10% of cases start before the age of 65\(^9\). In 2010, 8,817 Ontarians between the ages of 40 and 65 were diagnosed with some form of dementia, which amounted to 6.5% of the total population (including people living with

\(^1\) Dementia: A public health priority. 2012.
\(^2\) Rising tide: the impact of dementia on Canadian Society. Executive Summary. 2010.
\(^3\) Dementia evidence brief. 2012.
\(^4\) Dementia evidence brief. 2012.
\(^5\) Dementia: A public health priority. 2012.
\(^6\) Dementia: A public health priority. 2012.
\(^7\) Hopkins, R. 2010.
\(^8\) Batsch, N.L., Mittleman, M.S. 2012.
dementia in the community-dwelling and long-term care) diagnosed with dementia that year, 135,756\textsuperscript{10}.

More importantly, the very nature of cognitive decline and its impact on decision making and participation by people with dementia, creates a recipe for stress now and into the future. People with dementia face extraordinary challenges self-managing their general health and chronic conditions due to problems with memory, perceptions of symptoms, decision-making and expressive language\textsuperscript{11}. Potentially treatable chronic conditions become exacerbated in the presence of dementia. The destabilizing effect of dementia on other chronic diseases has been called the “dementia domino effect”.

Family caregiving is not new – most families expect to provide support when a loved one needs care. However, the context for caring has changed. Nuclear families are decreasing; families are smaller and more dispersed; there are more women in the formal workforce; childbearing occurs later in life; and retirement is delayed. The result is a family life course that includes juggling child rearing, working, and caring for a senior family member. With shifting demographics, family members will be called upon more frequently to support a loved one in a time of need. While most embrace the opportunity, the reality is that caregiver responsibilities can be challenging and the increased demand will compound the difficulties. The ballooning dependency ratio will challenge the ability for both the health system and families to respond\textsuperscript{12}.

On average in Canada, family caregivers provide about 7 hours of help to family and friends for every two hours of professional care. Ontario’s health system could not sustain the current levels of care in the community without the continued contribution of family caregivers. If expected to continue to support and care for their loved one, family caregivers will need to be better supported\textsuperscript{13}.

Caregivers are the champions of dementia care, maintaining the connection and dignity for the person with dementia. Caregiving is a physically, emotionally, and financially demanding role that changes throughout the illness, and much support is needed to help the caregiver during this time\textsuperscript{14}.

\textsuperscript{10} Ng, R., Maxwell, C.I., Yates, E.A., Nylen, K., Antflick, J., Jette, N., Bronskill, S.E. 2015.
\textsuperscript{11} Phelan et al. 2012.
\textsuperscript{12} Family caregivers – the essential ingredient to successful health care transformation. 2015.
\textsuperscript{13} Bringing care home: report of the expert group on home and community care. 2013.
\textsuperscript{14} Dementia: A public health priority. 2012.
According to Ontario home care assessments, most people with dementia have at least one individual providing unpaid care. The care needs of people with dementia will increase significantly as the disease progresses. Cognitive decline and intensifying functional impairments result in greater needs for assistance with basic activities of daily living. In the later stages of dementia, estimates of total care hours contributed by family members and friends can range from seven to fifteen hours per day.

People caring for someone with dementia provide 75% more care hours than other caregivers and experience nearly 20% greater stress. In a national survey of Alzheimer’s disease caregivers aged 44 to 64 years old (non-spouse), 35% reported declines in general health – this rate increased to 60% among live-in caregivers.

A Canadian Institute for Health Information study determined that rates of caregiver distress were five times greater among individuals caring for someone with moderate to severe cognitive impairment – likely resulting from Alzheimer’s disease or other forms of dementia – compared to individuals caring for seniors without cognitive impairments.

While the costs associated with dementia are increasing dramatically, perhaps more important is the right for people with dementia to be able to live well. There is the human right that older people have to the highest attainable standard of health. One of the imperatives identified for the creation of the Ontario Action Plan for Seniors was that all people are entitled to be treated with dignity and respect.

Stigma is something which causes an individual to be classified by others in an undesirable, rejected stereotype. Misconceptions of dementia and the people who are affected by stigma are a problem around the world. Stigma prevents people from acknowledging symptoms and obtaining the help they need. It causes individuals and organizations to behave in ways that are unhelpful, emphasizing the symptoms of the disease rather than supporting the abilities that people with dementia have. It is a barrier to improving dementia care and furthering research.

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16 Davis et al. 1997.
17 Seniors in need, caregivers in distress: what are the home care priorities for seniors in Canada? 2012.
18 Black et al. 2010.
19 Supporting informal caregivers – the heart of homecare. 2010.
22 Batsch, N.L., Mittleman, M.S. 2012.
In all stages of the disease, the stigma associated with dementia also leads to a focus on the ways in which the person is impaired, rather than on his or her remaining strengths and ability to enjoy many activities and interactions with other people. This deprives the person with dementia of the companionship of family and friends: the resulting isolation and lack of stimulation causes disability beyond that caused by the illness itself\(^{23}\).

Stigma by association is considered one of the barriers to caregivers’ utilization of community services and obtaining support from family and friends. Moreover, many people find the acceptance of help or care to be inherently stigmatizing. The reactions of the community to people with dementia undoubtedly reinforces negative self-concepts of family caregivers. If caregivers can be helped to modify their own attitudes about the illness and their perceptions of the attitudes of others, then their ability to access social support will be improved\(^{24}\).

Social isolation is commonly defined as a low quality and quantity of contact with others. Social isolation of seniors can cause communities to suffer from higher social costs and the loss of unqualifiable wealth and experience: reduced opportunities for seniors to participate, contribute, volunteer and work; increased risk of abuse; increased risks of negative health behaviours, falls and hospitalization; and increased effects of poor psychological and cognitive health. Specific groups of seniors have been identified as being at greater risk of social isolation, including seniors with Alzheimer’s disease and other dementias, and seniors who are caregivers\(^ {25}\).

Caregivers are also at a greater risk of social isolation. With competing obligations of supporting loved ones, family obligations and employment, caregivers can lose their own sense of personhood and belonging when they adjust their routines for their loved ones. Caregivers are at an increased risk of poor health as they focus on someone else.

One of the most significant changes in our conversations about dementia is that people living with dementia want to talk. For perhaps the first time, people are being diagnosed at early enough stages that they want to be involved in the decisions that will affect their lives. They are shunning the stigma of former times and speaking up.

\(^{23}\) Batsch, N.L., Mittleman, M.S. 2012.  
\(^{24}\) Batsch, N.L., Mittleman, M.S. 2012.  
People with dementia not only want to be more active in their communities, they also want to be more active in designing their communities and their support structures. “Nothing about us without us” is a slogan which carries great resonance for disability rights campaigners – and is one which is increasingly being articulated by people with dementia as well.

One of the most powerful means of reducing the stigma and correcting the common misconceptions surrounding dementia is for those who have the disease to be seen and heard more than they are now. Increasingly, people with dementia are coming forward to show that an active life after diagnosis is possible. Networks are forming around the world, bringing together those living with dementia for mutual support and to strengthen the call for change.

“I am not naïve or in denial about what a dementia diagnosis means for me and my family – incredibly sad, and grossly unfair. But that is then. Knowing what is looming on the horizon makes me all the more determined to have as much now time as possible. I don’t want to just wait and exist – I truly believe that by adapting, making compromises and concessions, with the understanding, help and assistance of family, friends and community, it is indeed possible to live well with dementia now” (Dyan, a person living with dementia).

As more is learned about the experiences of living with dementia, it becomes clear to see why the current infrastructure is not suited to meeting the needs of people living with dementia and their caregivers. Issues arise from multi-sector involvement providing funding and services in silos, and structures that focus on one part of the life span, on single health issues, and on either chronic or acute care; all failing to address the complexity of the disease.

A number of successful programs and services are already in place. However, the challenge remains that Ontario’s network of programs and services for seniors is highly complex, with a different set of services organized, delivered and communicated by different ministries and providers. Ontario requires an overarching plan that provides a framework for addressing the needs of vulnerable seniors, while supporting active, healthy aging for the broader senior population.

Both the Alzheimer Society of Ontario and the Alzheimer Society of Canada are advocating for a provincial and national dementia strategy that will result in better integrated dementia care and support. This focus is about investing now to save later.

26 Batsch, N.L., Mittleman, M.S. 2012.
Around the globe, communities have been embracing the concept of creating age-friendly communities. Precipitated by the challenge put forward by the World Health Organization, this movement has been focusing on creating communities which, by broad definition, aim to improve the quality of life for seniors.

The World Health Organization, as well as the Alzheimer’s Disease International organization, both challenge the world to make Dementia-Friendly Communities (DFC) a reality within national Dementia Strategies, and as such a parallel movement has started to create dementia-friendly communities. This presents Canadians with an opportunity to now engage in this process.

While people with dementia have some similar needs to other aging adults, they have additional needs that call for unique plans. While there are several models in development worldwide, and several definitions available, they generally align with the following: A Dementia-Friendly Community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value.\(^{28}\)

The DFC model is not about changing the person and getting them to fit in, but is instead about altering the social, attitudinal, architectural, and physical environments in which people with dementia live to be responsive and adapt to situations. DFC’s focus on inclusion and coming together of communities to challenge the current status quo, often characterized by the exclusions and marginalization of people with dementia, and the reinforcement of social isolation and ongoing inequalities.\(^ {29}\)

Key to moving forward, with the support of a Dementia-Friendly Communities model, is the success that comes from an integrated approach through a collective impact model. Stakeholders from across sectors work together on a common vision, with shared and unique outcomes, and shared and unique activities to achieve those outcomes.

Collective Impact\(^ {30}\) is a process to solving complex social and organizational problems. It involves the commitment of a group of actors from different sectors to a common agenda for solving a these problems. To create lasting solutions to social problems on a large scale,

\(^{28}\) Alzheimer Australia. Website.
\(^{29}\) Winter, J.A. 2015.
\(^{30}\) Karnia, J., Kramer, M. 2011.
organizations – including those in government, civil society, and the business sector – need to coordinate their efforts and work together around a clearly defined goal.

Collective impact is not merely a new process that supports the same social sector solutions, but is an entirely different model of social progress. The power of collective impact lies in the heightened vigilance that comes from multiple organizations looking for resources and innovations through the same lens, the rapid learning that comes from continuous feedback loops, and the immediacy of action that comes from a unified and simultaneous response among all participants.

The time for Dementia-Friendly Communities is now. Discussions about dementia are happening more and more each day. Governments, encouraged by both Alzheimer Societies and colleagues around the globe, are actively developing dementia strategies at both provincial and national levels. The federal government has partnered with Alzheimer Society of Canada to implement the Dementia Friends initiative. Other stakeholders in the community have expressed an interest in pursuing activities related to supporting those affected by dementia; and perhaps most significantly, individuals living with dementia have confirmed their desire to be involved in decisions that affect their lives. The time has arrived for a collective group of individuals and organizations to work together to enable and support this developing movement, if not be the drivers of this movement.

The Alzheimer Society is well placed to play a strategic role in moving Ontario towards creation and implementation of a Dementia-Friendly Communities model.

Using a Collective Impact approach, the Alzheimer Society of Ontario proposes to champion a multi-sector collaborative movement focused on improving quality of life for people living with dementia and their care partners, using the Dementia-Friendly Communities model, funded by the Ontario Trillium Foundation (OTF).

This paper and engagement with those reviewing it, is only the first step in developing a Dementia-Friendly Communities (DFC) model, focusing on identifying the challenges faced by people with dementia and their families. Moving through the Ontario Trillium’s Collective Impact model, the next step will be to engage with a broader audience to define and develop a Dementia-Friendly Communities model that fits our own unique and shared realities, and our collective vision for the future.
The Nature of Dementia

Definition

Dementia is a brain disorder characterized by impaired cognitive functioning that can affect learning and memory, mood and behavior, as well as the ability to conduct daily activities and high level functions such as management of other chronic conditions. Degenerative brain illnesses, such as Alzheimer’s disease, vascular dementia, fronto-temporal lobe dementia and Lewy body disease, lead to irreversible forms of dementia that are progressive and shorten life expectancy. To date there is no known cure or effective means by which to delay onset or progression. The median time of survival for Alzheimer’s disease (which accounts for 60-70% of dementia cases) has been estimated at 7 years.

Dementia is one of hundreds of disorders and diseases that are associated with the brain, spinal and/or nerves that connect them.

Prevalence

Most experts agree that a certain amount of cognitive decline can be expected with normal aging. However, it is important to emphasize that dementia is not a part of normal aging; it is a chronic, progressive and ultimately fatal disease.

An estimated 214,000 older adults in Ontario (65+) are currently living with some form of dementia. This number is expected to increase by 17% to nearly one quarter of a million people...
by 2020\textsuperscript{34}. National reports in both the United States and UK indicate that Alzheimer’s disease and dementia are among the most feared diseases associated with getting older\textsuperscript{35}.

While the risk for dementia does increase with age, 2-10\% of cases start before the age of 65\textsuperscript{36}. In 2010, 8,817 Ontarians between the ages of 40 and 65 were diagnosed with some form of dementia, which amounted to 6.5\% of the total population (including people living with dementia in the community-dwelling and long-term care) diagnosed with dementia that year, 135,756\textsuperscript{37}.

In Ontario, nearly three quarters (71\%) of community-dwelling people (66+) with dementia in 2012 were living with two or more co-morbid conditions, and almost one half (45\%) were living with three or more co-existing conditions, such as diabetes, hypertension and cardiovascular disease\textsuperscript{38}.

People with dementia are prone to cycles of emergency department use and hospitalization, stabilization, discharge to home, poor health management, deterioration, and readmission to the hospital\textsuperscript{39}.

Fifty percent of community dwelling older adults with dementia who visited emergency rooms in 2012 were repeat users, with 2 or more visits during the year; nearly 30\% of community dwelling older adults with dementia with acute care hospital admissions in 2012 were repeat users, with two or more admissions during the year. In 2012, community-dwelling persons with dementia over the age of 85 were 1.7 times more likely to experience a falls-related emergency department visit compared to persons over 85 without dementia; and in 2012, community dwelling persons with dementia over the age of 85 were 1.9 times more likely to have an acute hospitalization admission with alternate level of care (ALC) days, compared to persons over 85 without dementia\textsuperscript{40}.

The term “alternate level of care” (ALC) describes the use of hospital beds by patients who no longer require acute care services and are waiting for transfer to more appropriate settings,

\begin{thebibliography}{99}
\bibitem{34} Hopkins, R. 2010.
\bibitem{35} What America thinks: MetLife Foundation Alzheimer’s Survey. 2011.
\bibitem{36} Dementia: a public health priority. 2012.
\bibitem{38} Bronskill, S.E., Gunraj, N., Yates, E. 2015.
\bibitem{39} Report of the Standing Committee on health, chronic diseases related to aging and health promotion and disease prevention. 2012
\bibitem{40} Bronskill, S.E., Gunraj, N., Yates, E. 2015.
\end{thebibliography}
such as residential care or rehabilitation. The Canadian Institute for Health Information has determined that one out of four Canadian seniors hospitalized with ALC days in 2009/10 had a diagnosis of dementia. Moreover, hospital stays involving patients with dementia were twice as long on average as for seniors without the disease 41.

Individuals with dementia are also at a heightened risk for delirium and functional impairments in response to acute illness 42. Recovery from delirium is often slow and sometimes incomplete, resulting in longer hospital stays, increased ALC days, or premature long-term care placement.

Sixty-two percent of residents living in long-term care homes are living with some form of dementia 43. Among residents 65 and above, 70% are living with some form of dementia. In 2013, nearly 80% of residents has some level of cognitive impairment, and almost 30% had severe cognitive impairment 44.

People with dementia face extraordinary challenges self-managing their general health and chronic conditions due to problems with memory, perceptions of symptoms, decision-making and expressive language 45. Potentially treatable chronic conditions become exacerbated in the presence of dementia. The destabilizing effect of dementia on other chronic diseases has been called the “dementia domino effect”.

Being physically active is associated with a 38% reduced risk of developing Alzheimer’s disease in persons who are most physically active. At a population level, potentially 1 in 7 cases of Alzheimer’s disease in Ontario may be preventable (at a per/person cost of $5,700 to $63,000 per year, which could result in a savings to the province of $88-970 million per year) 46.

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42 Phelan. 2012.
43 Building resident-centered long-term care, now and for the future. 2015.
Caregivers

Caregivers are the champions of dementia care, maintaining the connection and dignity for the person with dementia. Caregiving is a physically, emotionally, and financially demanding role that changes throughout the illness, and much support is needed to help the caregiver during this time.\(^{47}\)

Family caregiving is not new – most families expect to provide support when a loved one needs care. However, the context for caring has changed. Nuclear families are decreasing; families are smaller and more dispersed; there are more women in the formal workforce; childbearing occurs later in life; and retirement is delayed. The result is a family life course that includes juggling child rearing, working, and caring for a senior family member. With shifting demographics, family members will be called upon more frequently to support a loved one in a time of need. While most embrace the opportunity, the reality is that caregiver responsibilities can be challenging and the increased demand will compound the difficulties. The ballooning dependency ratio will challenge the ability for both the health system and families to respond.\(^{48}\)

Families are the mainstay of the home care system – with only 2% of home care clients managing without a family caregiver. Family caregivers provide 80% of care at home, supplementing the government-funded service.\(^{49}\)

High-need seniors receive, at most, a few more hours of paid home care per week than those with moderate needs.\(^{50}\) In some cases, seniors with high needs actually receive fewer care hours with the additional care being contributed by family and friends.\(^{51}\)

On average in Canada, family caregivers provide about 7 hours of help to family and friends for every two hours of professional care.\(^{52}\) Ontario’s health system could not sustain the current levels of care in the community without the continued contribution of family caregivers. If expected to continue to support and care for their loved one, family caregivers will need to be better supported.\(^{53}\)

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\(^{47}\) Dementia: a public health priority. 2012.

\(^{48}\) Family caregivers – the essential ingredient to successful health care transformation. 2015.

\(^{49}\) Family caregivers – the essential ingredient to successful health care transformation. 2015.

\(^{50}\) Seniors in need, caregivers in distress: what are the home care priorities for seniors in Canada? 2012.

\(^{51}\) Sinclair et al. 2010.

\(^{52}\) Bleakney, A., Sinha, M. 2014.

\(^{53}\) Bringing care home: report of the expert group on home and community care. 2013.
According to Ontario home care assessments, most people with dementia have at least one individual providing unpaid care\textsuperscript{54}. Primary caregivers are most often spouses or adult children and in-laws. In addition, friends, neighbours or other relatives also contribute time and resources to caregiving.

The care needs of people with dementia will increase significantly as the disease progresses. Cognitive decline and intensifying functional impairments result in greater needs for assistance with basic activities of daily living. In the later stages of dementia, estimates of total care hours contributed by family members and friends can range from seven to fifteen hours per day\textsuperscript{55}.

In 2009, Ontarians caring for family members and friends with dementia contributed an estimated 117 million unpaid caregiving hours. This number is expected to surpass 140 million hours by 2020\textsuperscript{56}. Home Care Ontario estimates the value of the care delivered by family caregivers in Ontario represents $9.7 billion annually if family and friends were reimbursed as employees\textsuperscript{57}. The fact that caregivers are unpaid means that their contributions and concerns have been largely ignored.

People caring for someone with dementia provide 75% more care hours than other caregivers and experience nearly 20% greater stress\textsuperscript{58}. In a national survey of Alzheimer’s disease caregivers aged 44 to 64 years old (non-spouse), 35% reported declines in general health – this rate increased to 60% among live-in caregivers\textsuperscript{59}.

The Canadian Index of Well-being states that Ontarians report a decline in their social networks, suggesting the level of support on which someone can rely has also diminished. The same report indicates there is an increasing rate, primarily with women, of extended unpaid care and assistance to family, friends and neighbours\textsuperscript{60}.

\textsuperscript{54} Gill, S.S., Camecho, X., Poss, J.W. 2011.
\textsuperscript{55} Davis et al. 1997.
\textsuperscript{56} Rising tide: the impact of dementia in Ontario. 2008 to 2038. 2009.
\textsuperscript{57} Family caregivers – the essential ingredient to successful health care transformation. 2015.
\textsuperscript{58} Seniors in need, caregivers in distress: what are the home care priorities for seniors in Canada? 2012.
\textsuperscript{59} Black et al. 2010.
\textsuperscript{60} How are Ontarians really doing? 2014.
Family caregivers experience physical, psychological and emotional strain as well as financial hardship and occupational insecurity. A Canadian Institute for Health Information study determined that rates of caregiver distress were five times greater among individuals caring for someone with moderate to severe cognitive impairment – likely resulting from Alzheimer’s disease or other forms of dementia – compared to individuals caring for seniors without cognitive impairments.

Moreover, one quarter of informal caregivers are living with two or more chronic health problems. Individuals providing informal care for someone with dementia are at high risk for depression and stress that can aggravate their own existing conditions, thereby magnifying the strain that dementia places on scarce health care resources.

Collectively, Canadian caregivers aged 45 and older spent an average $1,049,600 per month on care-related out-of-pocket expenditures in 2006. Not surprisingly, costs rise with the level and intensity of required care. Caregivers of community-dwelling adults with high needs spent on average $7599 per year.

Low income households are most affected by these additional costs. They pay a disproportionately higher percentage of their incomes on caregiver costs. While assistance for home accessibility is important, the design of the measure is problematic. Because the financial support will be delivered as a non-refundable tax credit, it is of no value to low and modest-income households that pay little or no income tax, even though they may have to incur these costs. While the financial assistance (caregiver tax credit) is important, it is limited in scope. Non-refundable caregiving credits are not helpful to many of these same low and middle income Canadians that derive little or no benefits. These credits are not delivered to households as cash payments, but rather represent amounts that are deducted from tax owing.

In addition to immediate costs, the financial security of caregivers is affected in other ways. Employed caregivers have multiple competing demands. Being responsible for care can result in disruptions to normal work routines. Caregivers’ employment status can be jeopardized by the pressures of their caregiving responsibilities. They may have to refuse a job offer, promotion or transfer; change or resign from a position; reduce the number of hours worked; or take leave.

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61 Miller et al. 2012.
62 Supporting informal caregivers – the heart of homecare. 2010.
63 Seniors in need, caregivers in distress: what are the home care priorities for seniors in Canada? 2012.
64 Fast et al. 2013.
65 Torjman. 2015.
from work. Employed caregivers often lose income, benefits and pensions in trying to balance work and family responsibilities\textsuperscript{66}.

In a national survey of Alzheimer’s disease caregivers aged 44-64 years old (non-spouse), 71% reported disruptions to employment and 14% were forced to leave work or retire early\textsuperscript{67}. Statistics Canada reported that the majority of all caregivers (60%) also participated in the paid workforce\textsuperscript{68}. These consequences have an impact not only on the caregivers but on Canadian employers and society more broadly. The reduced work effort by all caregivers was estimated at 2.2 million hours per week in 2012. In that year, the Canadian economy was deemed to have lost the equivalent of 157,000 full-time employees because of caregiving pressures – a significant loss in productive capacity\textsuperscript{69}.

There is no doubt that the incidence of dementia is increasing rapidly, and that the impact of dementia will continue to spread. Research has demonstrated that promoting brain health through lifestyle choices such as keeping active, being social, protecting your head, eating well, is the most effective way of reducing the chances of developing various forms of dementia, or slowing down the progression of these diseases in people who already have them. These upstream strategies give hope for creating better quality of life.

\textsuperscript{66} Torjman. 2015.
\textsuperscript{67} Black et al. 2010.
\textsuperscript{68} Sinha, M. 2012.
\textsuperscript{69} Torjman, 2015.
Key Focus Areas

Stigma and Social Isolation

Dementia is not the first illness where the conversation and debate around stigma will be necessary. While some drugs provide a form of symptom management, and while a search for a cure remains the ultimate goal, in many places people with dementia are still isolated from their communities. Stigma is something which causes an individual to be classified by others in an undesirable, rejected stereotype. Misconceptions of dementia and the people who are affected by stigma are a problem around the world. Stigma prevents people from acknowledging symptoms and obtaining the help they need. It causes individuals and organizations to behave in ways that are unhelpful, emphasizing the symptoms of the disease rather than supporting the abilities that people with dementia have. It is a barrier to improving dementia care and furthering research.

There is a growing body of work that suggests that stigma promotes social exclusion and reluctance to seek help. The stigma associated with dementia leads to stereotyping of all people with dementia. This lack of understanding contributes to depersonalization of the person with dementia and a lack of sympathy and understanding of the individual needs of those with the illness. Particularly in the early stage of dementia, this stereotyping inevitably leads to devaluing the potential contribution of the person with dementia.

In all stages of the disease, the stigma associated with dementia also leads to a focus on the ways in which the person is impaired, rather than on his or her remaining strengths and ability to enjoy many activities and interactions with other people. This deprives the person with dementia of the companionship of family and friends: the resulting isolation and lack of stimulation causes disability beyond that caused by the illness itself.

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70 Batsch, N.L., Mittleman, M.S. 2012.
71 Batsch, N.L., Mittleman, M.S. 2012.
74 Batsch, N.L., Mittleman, M.S. 2012.
75 Batsch, N.L., Mittleman, M.S. 2012.
Stigma affects not only people with the stigmatizing mark, in this case dementia, but also often extends to those around them, including family members and other caregivers. Due to this “stigma by association”, families are often afraid to bring memory loss issues to the attention of the person who has them76.

Stigma by association is considered one of the barriers to caregivers’ utilization of community services and obtaining support from family and friends. Moreover, many people find the acceptance of help or care to be inherently stigmatizing. The reactions of the community to people with dementia undoubtedly reinforces negative self-concepts of family caregivers. If caregivers can be helped to modify their own attitudes about the illness and their perceptions of the attitudes of others, then their ability to access social support will be improved77.

Some of the symptoms of the middle stages of dementia, such as agitation and incontinence, inappropriate clothes or dishevelment can be embarrassing to family members, who isolate themselves and the relative with dementia to avoid having to expose themselves to the reactions they anticipate from those outside the family. The symptoms of the person with dementia are often regarded as evidence of neglect78. Stigma by association is particularly important in Alzheimer’s disease because the caregiver plays such a vital role in the well-being of the person with dementia.

One Australian survey found that 42% of people with dementia (responding to the survey) found that others avoided spending time with them because of their diagnosis; and 41% of people with dementia wished they had more social contact with others in the community79.

Social isolation is commonly defined as a low quality and quantity of contact with others80. Social isolation is different than loneliness, which is a perception of a lack of interaction or contact with others81. Social isolation increases the likelihood of loneliness, but a person can perceive being lonely even when in the company of others.

All seniors, whether impacted by dementia or not, face the challenges brought on by living longer, being at higher risk of experiencing chronic health conditions, being active as informal

76 Batsch, N.L., Mittleman, M.S. 2012.
77 Batsch, N.L., Mittleman, M.S. 2012.
79 Living with dementia in the community: challenges and opportunities. 2014.
81 Social isolation among seniors: an emerging issue. 2014.
caregivers, having families that are smaller and more dispersed, and facing the number one issue of keeping connected and socially active. While the ability to live alone represents an indicator of independence, seniors living alone are at greater risk of experiencing a sense of social isolation, which in turn increases the risk of depression\textsuperscript{82}.

Social isolation of seniors can cause communities to suffer from higher social costs and the loss of unqualifiable wealth and experience: reduced opportunities for seniors to participate, contribute, volunteer and work\textsuperscript{83}; increased risk of abuse\textsuperscript{84}; increased risks of negative health behaviours, falls and hospitalization; and increased effects of poor psychological and cognitive health. Specific groups of seniors have been identified as being at greater risk of social isolation, including seniors with Alzheimer’s disease and other dementias, and seniors who are caregivers \textsuperscript{85}.

Caregivers are also at a greater risk of social isolation. With competing obligations of supporting loved ones, family obligations and employment, caregivers can lose their own sense of personhood and belonging when they adjust their routines for their loved ones. Caregivers are at an increased risk of poor health as they focus on someone else.

Stigma has long been considered within contexts of other diseases and conditions. There is much to learn from how stigma has been overcome or is continuing to be confronted in cancer, HIV/AIDS and mental health. Thousands of research articles over a 30 year period have been published; first by identifying the stigma, next by conducting awareness campaigns, and lastly by changing laws to reflect the individual rights of people coping with these conditions\textsuperscript{86}. Experiences combating other widespread forms of discrimination, such as sexism and racism, shows that attitudes and norms can be changed.

It is very important that there is better public awareness and understanding to reduce stigma associated with dementia. This can happen only with well-developed and executed political and public campaigns to support a societal shift towards acceptance and inclusion of people affected by dementia\textsuperscript{87}. More public education is needed to help people understand the symptoms of dementia at different stages of the illness, and their progression over time, and

\textsuperscript{82} Canada’s aging population: the municipal role in Canada’s demographic shift. 2013.
\textsuperscript{83} Working together for seniors: a toolkit to promote seniors’ social integration in community services. 2007.
\textsuperscript{84} Truchon, M. 2011.
\textsuperscript{85} Report on the social isolation of seniors. 2014.
\textsuperscript{86} Batsch, N. L., Mittleman, M.S. 2012.
\textsuperscript{87} Batsch, N. L., Mittleman, M.S. 2012.
that the person can do many things he or she used to do, even if the activities need to be adapted for the person to participate and enjoy.

While there is now growing public awareness of dementia, most people are still unaware of the fact that dementia is caused by a medical disorder and that the symptoms of dementia are the result of physical damage to the brain. This leads to inaccurate assumptions about its effect on the person and his or her family and negative stereotypes about how a person with dementia will behave. While public awareness of the existence of dementia has increased, that has not, as yet, led to a greater acceptance of individuals who are coping with dementia\textsuperscript{88}. Some of the worldwide efforts to reduce stigma include: people with dementia speaking out; dementia friendly communities; outreach programs; promoting earlier diagnosis; art and physical activity.

While health and social services play a role in improving the lives of people with dementia, the Alzheimer Society (UK) maintains that momentum needs to be kept up to build communities that support people with dementia – communities where stigma is reduced and isolation can be tackled\textsuperscript{89}.

Stigma continues to present a major barrier to finding solutions for the problems related to Alzheimer’s disease and other dementias, including low rates of diagnosis and service utilization. Therefore it is essential to take action to dispel lingering myths about dementia to reduce stigma\textsuperscript{90}.

**Listening to People Living with Dementia and their Caregivers**

One of the most significant changes in our conversations about dementia is that people living with dementia want to talk. For perhaps the first time, people are being diagnosed at early enough stages that they want to be involved in the decisions that will affect their lives. They are shunning the stigma of former times and speaking up.

\textsuperscript{88} Batsch, N. L., Mittleman, M.S. 2012.
\textsuperscript{89} Kane, M., Cook, L. 2013.
\textsuperscript{90} Batsch, N. L., Mittleman, M.S. 2012.
People with dementia not only want to be more active in their communities, they also want to be more active in designing their communities and their support structures. “Nothing about us without us” is a slogan which carries great resonance for disability rights campaigners – and is one which is increasingly being articulated by people with dementia as well.

Until recently, thinking about dementia was dominated by biomedical ideas. However, conversations focused on the interplay between the person with dementia and their social and psychological environment have now advanced substantially. Alongside the psychological approach, the social model of disability is increasingly being applied to understanding dementia care. Researchers and practitioners are finding ways to listen to, and to communicate with, people with dementia in order that their voices are heard in shaping their lives and the services they receive. Work of this kind has demonstrated that when people with dementia are enabled to communicate, they have important things to say about how dementia affects them, about what they consider important about their present and future lives, including how their health and social care needs should be met91.

Perhaps the most powerful means of reducing the stigma and correcting the common misconceptions surrounding dementia is for those who have the disease to be seen and heard more than they are now. Increasingly, people with dementia are coming forward to show that an active life after diagnosis is possible. Networks are forming around the world, bringing together those living with dementia for mutual support and to strengthen the call for change92.

Several awareness campaigns have and are now focused on helping people see past the disease to the person, including: Let’s face it93; See me not my disease94; DeMentia95; I have dementia, I also have a life96; and #StillHere97.

Seniors in general have contributed to growth and prosperity and continue to help communities and drive economy. Seniors have said that they want to be recognized for those contributions, and treated as important members of our society. They want it understood that they are a diverse group, with different social-economic backgrounds, different skills and abilities, different levels of health and education, and different interests. They want to be able

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91 Cantley, C., Steven, K., Smith, M. 2003.
92 Batsch, N.L., Mittleman, M.S. 2012.
93 Alzheimer Society Canada. Website.
94 Alzheimer Society Canada. Website.
95 Alzheimer Society UK. 2015.
96 Alzheimer Society UK. Website.
97 Alzheimer Society Canada. Website.
to choose to live at home for as long as they can, and have attractive alternatives if they cannot.98

People with dementia are telling us what involvement means: involvement founded on values of personhood, relationship and citizenship, and on the principles of ethical practices; at a variety of organizational levels with purposes and aims ranging from influencing the operations of individual services to influencing social attitudes nationally and internationally; that provides personal benefits including increased self-esteem and confidence that comes from involvement and contributions; with varied approaches that include individual consultation, group consultation, participation and collective action; with recognition that some activities are more empowering than others; and that recognizes the complexities of change.99

People with dementia and caregivers describe seven outcomes that are most important to their quality of life: I have a personal choice and control or influence over decisions about me; I know that services are designed around me and my needs; I have support that helps me live my life; I have knowledge and know-how to get what I need; I live in an enabling and supportive environment where I feel valued and understood; and I know there is research going on which delivers a better life for now and hope for the future.100

“I am not naïve or in denial about what a dementia diagnosis means for me and my family – incredibly sad, and grossly unfair. But that is then. Knowing what is looming on the horizon makes me all the more determined to have as much now time as possible. I don’t want to just wait and exist – I truly believe that by adapting, making compromises and concessions, with the understanding, help and assistance of family, friends and community, it is indeed possible to live well with dementia now.” (Dyan, a person living with dementia).

As the number of people receiving early diagnoses increases, the number of years someone will be able to live well, speak on their own behalf, make decisions about the future and actively participate in society will increase. As the disease symptoms progress, the person with dementia will need more support to stay active and engaged, but it is still possible.101

100 Kane, M., Cook, L. 2013.
101 Batsch, N.L., Mittelman, M.S. 2012.
An Urgency for Change

The World Health Organization has declared dementia to be a “public health priority” on a world-wide scale. With the number of people living with dementia world-wide is increasing rapidly (one new case every four seconds), the huge economic impact of the disease and no cure likely in the immediate future, societies need to invest in effective care and supportive initiatives. Otherwise, care for people with dementia will put an unprecedented burden on health and social systems102.

Dementia is the most significant cause of disability among Canadians (65+) and it already costs Canadian society billions of dollars each year103. Dementia is a core issue impacting Ontario’s health and social system. Canada needs a national dementia strategy104.

For the first time in Canada, there are more seniors (aged 65 and older) than children (14 and younger). In 2011, the first baby boomers turned 65. Between 2% and 10% of all cases of dementia start before the age of 65. The risk for dementia doubles every five years after age 65.

Without improved dementia care, the number of alternative level of care (ALC) hospitalizations involving seniors with dementia is expected to grow in proportion to the increase in dementia prevalence. “Acute care hospital bed gridlock” will continue until dementia is recognized as a central part of the ALC crisis and effective strategies focusing on dementia are put into place105.

A group of American researchers found that dementia involved the greatest health care costs, more than heart disease and cancer, in the last five years of life106.

The World Health Organization says that societies are currently facing a growing phenomenon – that of a burgeoning aging population of individuals living with frailty and/or multiple co-morbidities, all of which may be confounded by the challenges of dementia107.

102 Dementia: a public health priority. 2012.
103 Rising tide: the impact of dementia in Ontario. 2008 to 2038. 2009
104 Lowi-Young, M. 2015.
105 Dementia evidence brief. 2012.
106 Costs for dementia care far exceeding other diseases, study finds. 2015.
Anticipating and responding to the changing health care needs and lifestyle choices of an aging population is already forcing us to acknowledge that aging is an expensive process. The top 10% of Ontario’s seniors, characterized as having the most complex issues, accounts for 60% of the total annual health care spending for this population. The older the population, the more likely older people will develop chronic conditions. Seniors account for nearly half of Ontario’s health care spending. By 2030, without changes to the way health care services are delivered, there is a projected 50% increase from today\(^{108}\).

One of the imperatives identified for the creation of the Ontario action plan for seniors was that all people are entitled to be treated with dignity and respect\(^{109}\).

Thirty-two percent of people with dementia who responded to a UK survey said that they felt they were not living well with dementia or did not know if they were living well. Fifty-three percent of people said they felt anxious or depressed recently. Half of people with dementia said they were not getting enough support from government. Seventy-five percent of people who responded to the survey said that they had another health condition in addition to their dementia\(^{110}\).

People with dementia are often isolated, or hidden, because of the impact of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to hopelessness and frustration. Urgent action is required to improve the understanding of dementia, and in turn, reduce the stigma\(^{111}\).

The Canadian Index of Well-being reports that the percentage of Ontarians reporting they have six or more close friends has dropped, suggesting that the level of support on which we can relay has also diminished\(^{112}\). This report also stated that there has been an increase of 10% of Ontarians, primarily women, reported they have extended unpaid care and assistance to family, friends and neighbours.

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\(^{107}\) Walker, D. 2011.
\(^{110}\) Dementia 2015: aiming higher to transform lives. 2015.
\(^{111}\) Batsch, N.L., Mittleman, M.S. 2012.
\(^{112}\) How are Ontarians really doing? Canadian Index of well-being. Measuring what matters. 2014.
The fact that caregivers are unpaid means that both their contributions and concerns have largely been ignored. However, growing pressures on these and future caregivers, including the aging population, the need to care for both children and elderly parents, the rapidly rising incidence of chronic disease, and people living longer, are forcing Canadians to take notice\textsuperscript{113}.

The World Health Organizations believes that comprehensive public-health action on ageing is urgently needed. Although there are major knowledge gaps, there is sufficient evidence to act now, and there are things that every country can do. The first step will be to focus on optimizing functional ability. Four priority areas for action can be identified: aligning health systems with the needs of the older population they now service; developing systems for providing long-term care; creating age-friendly environments; improving measurement, monitoring and understanding. For those with declining capacity, the objectives extend to revising declines, preventing further declines and enhancing functional ability despite these decrements. For those with or at high risk of, a significant loss of capacity, the objectives shift to a greater focus on enabling them to live with dignity and providing them with the health services to manage advanced chronic conditions\textsuperscript{114}.

Ontario’s Action Plan for Seniors predicts the effect of aging on our society will be profound. The collaboration of numerous agencies, stakeholders, regions and municipalities will be required in creating supportive communities. Senior friendly communities are about building an environment of supports and good health for all of Ontario’s seniors\textsuperscript{115}.

\textsuperscript{113} Trojman, S. 2015.
\textsuperscript{114} World report on aging and health. 2015.
\textsuperscript{115} Ontario’s action plan for seniors: independence, activity and good health. 2013.
Exploring the Strategies and Conversations of Today

Government Systems

The World Health Organization notes that, for people with significant losses of intrinsic capacity (the composite of all the physical and mental capacities that an individual can draw on at any point of time), a dignified and meaningful life is often possible only with the care, support and assistance of others. The form that this long-term care takes varies markedly among, and even within, countries. Responsibility often falls on families, and can present them with significant psychological, social and economic costs. But governments, particularly in high incomes countries, are playing an increasing role. This has led to lively debates in many countries about how care can be delivered in a sustainable manner and the appropriate balance between families and government provision of care and support\(^\text{116}\).

A number of successful programs and services are already in place to respond to the impact of the huge demographic shift in Ontario. However, the challenge remains that Ontario’s network of programs and services for seniors is highly complex, with a different set of services organized, delivered and communicated by different ministries and providers. Clearly what is needed in Ontario is an overarching plan that provides a framework for addressing the needs of vulnerable seniors, while supporting active, healthy aging for the broader senior population\(^\text{117}\).

Ontario’s health system aims to put clients at the center with the right care, at the right time, in the right place. For many Ontarians, the right place is in their homes. An increasing number of people and families are being served in their homes, and there is increasingly more complex care being provided over a longer period of time. With no coordinated system strategy for home and community care, these pressures are creating challenges that need urgent attention. There is far too much variability in access to services and too little accountability for outcomes. Clients, families, providers and funders, are all frustrated with a system that fails to meet the basic needs of client and families\(^\text{118}\).

Frailty is associated with the presence of multiple chronic health conditions, vulnerability to loss of function, and greater health care needs. The proportion of seniors in Ontario’s hospitals is

\(^{116}\) World report on aging and health. 2015.
\(^{117}\) Ontario’s action plan for seniors: independency, activity and good health. 2013.
\(^{118}\) Bringing care home: report of the expert group on home and community care. 2015.
ample justification for a fundamental shift in focus, one that recognizes that the care of older adults is a core business of these institutions. Historically the priorities surrounding hospital design have focused on rapid diagnosis, management of serious illness, and operative procedures. This paradigm has not proven well suited to the complex needs of older persons, who consequently experience adverse events that result in a difficult-to-reverse decline in physical and cognitive function. This, in turn, increases the likelihood of institutionalization and places even greater resource demands on an already burdened health system.\(^\text{119}\)

The Alzheimer Society notes that there is a major disconnect between projected growth and impact of dementia in Ontario, and health care policy and practice at the Ontario provincial and Local Health Integration Network levels. Despite the undeniable fact that dementia is the main diagnosis driving up alternate level of care (ALC) rates, dementia care is not central to either provincial or LHIN level planning. Unless improved dementia care becomes a central part of provincial and LHIN level planning, investment and action, the ALC crisis will not be resolved, but rather will worsen as will acute care hospital bed gridlock.\(^\text{120}\)

At a broader level, no provincial government has a department that deals strictly with dementia. Each jurisdiction has found its own way to deal with the management of dementia, whether through mental health agencies, a senior’s department, and/or long term care of chronic disease management.\(^\text{121}\)

Existing government policies and services often focus on the health and care needs of a person with dementia. While care services are an essential component to supporting a person with dementia and the family caregivers, the disease has profound impacts on the social life of a person with dementia and their families as well.\(^\text{122}\)

According to a Nanos survey, 83% of Canadians believe that Canada needs a national dementia plan, a comprehensive workable dementia strategy that dramatically improves the lives of people living with dementia. Canada trails the United States, France, Australia, the UK and other countries that already have dementia strategies.\(^\text{123}\)

\(^{120}\) Dementia evidence brief. 2012.
\(^{121}\) Rising tide: the impact of dementia in Ontario. 2008 to 2038. 2009.
\(^{122}\) Living with dementia in the community – challenges and opportunities. 2014.
\(^{123}\) Alzheimer Society Canada. Website.
Both the Alzheimer Society of Ontario and the Alzheimer Society of Canada are advocating for a provincial and national dementia strategy that will result in better integrated dementia care and support. This plan is about investing now to save later.

The Ontario Ministry of Health and Long-Term Care has begun the process of gathering information that will guide the development of a comprehensive Ontario Dementia Strategy. This process includes engaging with a variety of stakeholders across the province, as well as completing a capacity planning process to determine the current state of dementia care in Ontario and capacity for the future.

Many levels of government have now identified the need for change, with a need for increased cross-sectoral integration; engagement with seniors in design of health care models, the development of models that are person-centered, or even more recently social citizenship, and life-span care that includes wellness, chronic and acute health components.

The Canadian Academy of Health Science held a forum on dementia in Canada (September 2015). The forum’s overarching message was that while there have been many successful pilot projects across the country, there is no mechanism to ensure that these best practices and evidence are scaled up so that all communities in Canada can benefit. Canada needs a national action plan to address dementia. Drugs are not the answer. Prevention is promising but challenging, with no clear way to scale up current findings for the population. Then, there is quality of life and mobilizing and sustaining safe environments which are also critical for people living with dementia in their homes and community settings. Promising solutions range from age-friendly community design to technology. Dementia-friendly communities and optimizing built environments are being explored internationally. There is no magic bullet, but a need for a multi-faceted approach that requires leadership and adequate resourcing for implementation124.

Aging Population Strategies

Provinces, states and countries everywhere are coming to terms with the challenges, and opportunities, posed by an aging population. The World Report on Aging and Health responds

to these challenges by recommending profound changes in the way health policies for aging populations are formulated and services are provided. Guided by evidence, the report aims to move the debate about the most appropriate public health response to population aging into new, and much broader territory. The report notes that the greater costs to society are not the expenditures made to foster functional ability, but the benefits that might be missed if societies fail to make the appropriate adaptations and investments. The recommended societal approach to population ageing, which includes the goal of building an age-friendly world, requires a transformation of health systems away from disease-based curative models and towards the provision of integrated care that is centered on the needs of older people. \(^{125}\)

The World Health Organization (WHO) released an Active Aging and Policy Framework in 2002. This framework defined active aging as the process of optimizing opportunities for health, participation and security to enhance quality of life as people age. The framework emphasizes the need for action across multiple sectors. Achieving the goals as outlined in the policy framework is not simply a case of doing more of what is already being done or doing better. Systematic change is needed. In high income countries, health systems are often better designed to cure acute conditions than to manage and minimize the consequences of the chronic states prevalent in older age. Moreover, these systems are often developed in professional silos and so address each of these issues separately. This can lead to polypharmacy, unnecessary interventions and care that is less than adequate. \(^{126}\)

Those older people who are able to access health care will typically encounter a system that is not designed to address their needs. Instead, health services are often structured to diagnose and cure time-limited health issues using a bio-medically based approach that emphasizes finding the problem and fixing it, which worked well when acute conditions or communicable diseases were the priority. Historically, paying attention to long-term health and functioning has been less of a priority. In contrast, the health and social needs of aging populations are typically complex and long term, spanning a range of areas of functioning, and waxing and waning over time. Chronic disease processes overlap and intersect with the underlying ageing process and ultimately impact on the intrinsic capacity of the older person. These complex dynamics require approaches that are different from those developed to address more acute problems. \(^{127}\)

Health care that considers and manages complex needs of older age in an integrated way has been shown to be more effective than services that simply react to specific diseases.

\(^{125}\) World report on aging and health. 2015.  
\(^{126}\) World report on aging and health. 2015.  
\(^{127}\) World report on aging and health. 2015.
individuals. Approaches based on functioning can also be useful in framing a public health response to population aging.\(^{128}\)\(^{129}\)\(^{130}\)

Some of the most important barriers to developing good public-health policy on aging are pervasive misconceptions, attitudes and assumptions about older people. These ageist attitudes limit the way problems are conceptualized, the questions that are asked, and the capacity to seize innovation opportunities. As a starting point for policy making, they often lead to greater emphasis on cost containment.\(^{131}\)

Several governments have developed national policies or dementia strategies to aid the progress in research, provide support for people with dementia and care partners, and address the health and financial impact of dementia within their countries. The national policies also include directives toward stigma reduction, pointing to stigma as one cause of the gap between prevalence estimates and numbers of people with a dementia diagnosis.

The WHO outlines the crucial role of further aspects of an older person’s environments and how other sectors can contribute to harnessing the opportunities and addressing the challenges of population aging. The process of Healthy Aging argues that all sectors share a common goal: to build and maintain functional ability.\(^{132}\)

Physical and social environments are powerful influences on healthy aging. They shape trajectories of capacity and can extend what a person is able to do (their functional ability). Age friendly environments allow older people to be and to do what they have reason to value by enabling them to maximize both their capacity and their ability. Creating environments that are truly age friendly requires actions in many sectors – health, long term care, transport, service providers, civil society, older people and their organizations, families and friends. It also requires action at multiple levels of the government. Aiming towards the shared goal of optimizing functional ability allows these different stakeholders to work within their core areas but in a focused way that complements what is being done by others.\(^{133}\)

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\(^{128}\) Ham, C. 2010.

\(^{129}\) Low, L.F., Yap, M., Brodaty, H. 2011.

\(^{130}\) Eklund, K., Wilhelmson, K. 2009.

\(^{131}\) World report on aging and health. 2015.

\(^{132}\) World report on aging and health. 2015.

\(^{133}\) World report on aging and health. 2015.
Numerous entry points can be identified for actions to promote healthy aging, but all have one goal - to foster functional ability. This can be achieved in two ways: supporting the building and maintenance of intrinsic capacity, and by enabling those with a challenge in their functional capacity to do things that are important to them. The focus of public-health strategies targeting people with high and stable levels of intrinsic capacity should be on building and maintaining this for as long as possible. Health systems will need to detect and control disease and risk factors early. Environmental strategies will be crucial in encouraging health behaviours, but by building persons skills and knowledge, and through the implementation of broader environmental strategies. Environments will also have a role in enabling functional ability during this period, with particular emphasis on removing barriers to the expression of capacity.\textsuperscript{134}

What can, and will, set Ontario apart is the quality of life seniors and their families lead. The provincial government has a mission to make Ontario the best place to grow and grow old, knowing that a longer life is really only a good life if it is lived the way people want. Ontario’s Action Plan for Seniors is about creating the kind of province where seniors are able to do just that – make choices to live the way they want. It is also about harnessing the wisdom and experience of seniors for the benefit of all, and laying the groups work for a healthy, vibrant and active senior population.\textsuperscript{135}

Dementia and Long-term Care

The World Health Organization (WHO) notes that changes need to encompass two broad areas. First, long-term care must be recognized as a public good both societally and politically. The enormous social and economic costs of neglecting this challenge also need to be acknowledged. Second, long-term care must be redefined. Instead of thinking about long-term care as a minimal and basic safety net that provides rudimentary support to older people who can no longer look after themselves, perceptions must shift towards a more positive and proactive agenda. Within this new framework, long-term care must be oriented towards both optimizing intrinsic capacity and compensating for local capacity at a level that maintains an older person’s functional ability and ensures dignity and well-being.\textsuperscript{136}

\textsuperscript{134} World report on aging and health. 2015.
\textsuperscript{135} Ontario’s action plan for seniors: independence, activity and good health. 2013.
\textsuperscript{136} World report on aging and health. 2015.
Although there are numerous definitions of long-term care, the WHO uses the term to refer to the activities undertaken by others to ensure that people with or at risk of a significant ongoing loss of intrinsic capacity can maintain a level of functional ability consistent with their basic rights, fundamental freedoms and human dignity. In other words, long-term care is simply a means to ensure that older people with a significant loss of capacity can still experience healthy aging. As with all stages in the life course, this can be achieved through two mechanisms: optimizing the recipients’ trajectory of intrinsic capacity; and compensating for a loss of capacity by providing the environmental support and care necessary to maintain functional ability at a levels that ensures well-being\textsuperscript{137}.

Although the focus of aging in place has frequently been on ensuring appropriate and affordable housing and age-friendly built environments, as well as providing instrumental support, health services also have an important role to play by providing care that reaches people where they live. Thus, models of care will need to be reoriented towards prioritizing primary care and community based care. This encompasses a shift from inpatient care to ambulatory and outpatient care, to more home based interventions, community engagement and a fully integrated referral system\textsuperscript{138}.

Making functional ability the ultimate goal of long-term care, rather than focusing simply on meeting older peoples’ basic needs for survival, requires caregivers to focus on certain domains. These include older peoples’ abilities to move around, to build and maintain relationships, to learn, grow and to contribute to their communities. For older people with significant losses of capacity to achieve these things, caregivers will need appropriate training, knowledge and support. Achieving these goals is likely to involve a variety of caregivers working in a wide range of settings\textsuperscript{139}.

Many of the largest projects in Canada, as well as the United States, have been in the area of long-term care because providers can see the ways in which non-medical services can improve care for clients and reduce costs. Also it has been easier for non-physician leaders to emerge as project planners and managers\textsuperscript{140}.

One option for delivering services for people with a significant loss of capacity is through hospital-at-home services. These services involve a team of health-care and long-term care professionals who provide treatment at home for people who would otherwise be admitted to

\begin{footnotes}
\item[137] World report on aging and health. 2015.
\item[138] WHO global strategy on people-centered and integrated health services. 2015.
\item[139] World report on aging and health. 2015.
\item[140] MacAdam. 2008.
\end{footnotes}
an acute care hospital. Evidence has shown that these services have high client and caregiver satisfaction, reduce deaths, and reduce readmission rates\footnote{Sheppard, S., Wee, B., Straus. S.E. 2011.} \footnote{Caplan, G.A., Sulaiman, N.S., Mangin, D.A., Aimonino Ricauda, N., Wilson, A.D., Barclay, L. 2012.}.

**Dementia and the Chronic Care Model.**

Dementia appears to be highly suitable to the core principles of chronic disease management. With early diagnoses, individuals with dementia and their families are in a good position to take on the task of self-management. In the addition to self-management, roles are identified for family physicians, specialized experts, community resources providers, and family/informal care partners – each plays an independent role, but all are working together\footnote{Rising tide: the impact of dementia in Ontario: 2008 to 2038. 2009.}.

The Wagner model seems relevant to the discussion on integrated care for seniors, because it views chronic disease management as part of the larger health and social care delivery system. The model is composed of six interrelated pillars: community resources and policies, health care organization, self-management support, delivery system design, decision support and clinical information systems\footnote{Bodenheimer, Wagner and Grumbach. 2002.}.

**Case Management and Integrated Care**

A literature review shared in the “Framework of Integrated Care for the Elderly” found promising indications that some models of integrated health and social care for seniors can result in improved outcomes, client satisfaction and/or cost savings or cost-effectiveness. Among the key elements of these frameworks and in the literature in general are four types of interventions that must be structured in ways that are supportive of each other. These key elements are: umbrella organizational structures to guide integration of strategic, managerial
and service delivery levels; encourage and support effective joint/collaborative working; ensuring efficient operations; and maintain overall accountability for service, quality and cost outcomes, (2) multi-disciplinary case management for effective evaluation and planning of client needs, providing a single entry point into the health care system, and packaging and coordinating services; (3) organized provider networks joined together by standardized procedures, service agreements, joint training, shared information systems and even common ownership of resources to enhance access to services, provide seamless care and maintain quality, and (4) financial incentives to promote prevention, rehabilitation, and the downward substitution of services as well as to enable service integration and efficiency. No single element of integrated models of care has been shown to be effective in and of itself

The goal of integrated models of care is to improve coordination of care for individuals who are reliant on a complex array of specialized medical, community and social services. One of the most significant concerns voiced by patients and caregivers who are frequent users of health service, is that care is uncoordinated and it can be difficult to tell who, if anyone, is in charge. In short, the system is difficult to navigate.

Ensuring collaboration between informal and processional care partners is another aspect of integration. Evidence indicates that the effective transfer of information among different caregivers improves the integration and coordination of care.

In Canada, acute and primary care services are governed by the five principles of the Canada Health Act. But long-term care services, community health services and drug coverage are subject to provincial eligibility, service coverage and payment rules that vary from province to province. The review found that principal integration efforts for those with needs cutting across health care sectors were stymied when providers were operating under different rules and regulations that prevented smooth delivery of needed care.

To date, evidence from most integration efforts indicate that cost savings are hopes, not reality. The investments that have to be made in staff and support costs, services and start-up costs may outweigh the savings achieved from reduced hospital and/or long-term care admissions, Evidence from the UK and US indicates that, unless these investment costs are funded, integration may not occur.

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145 MacAdam. 2008.
146 Who is the puzzle maker? patient/caregiver perspective in navigating health services in Ontario. 2008.
149 MacAdam. 2008.
Case management is a key tool for ensuring that older person’s care is person-centered and integrated across the health and social sectors. Research has shown that care management has a beneficial impact on an older person’s psychological health and well-being, and on the satisfaction and well-being of caregivers. It also has the potential to delay needing home placement, and to reduce admission rates and shorten lengths of stay in long-term care homes. Cost savings have been found in the medium term.

Throughout the continuum, case management planning must enable older people to make their own choices, thereby supporting their autonomy. This holds true for all older people, even for those with significant declines in capacity.

Although case management strategies and the principles that underpin them will help ensure that long term care becomes more person-centered and integrated, health care and social care and support also need to be aligned at the administrative level. This calls for a more unified approach. One option might be for a single government agency to have the lead responsibility for the entire system, not just part of it. However, these government structures are not the only way to facilitate integration.

One paper provides some key findings about the effectiveness and cost-effectiveness of health promotion interventions, strategies and actions. The cited reviews of evidence showed that using a combination of health promotion strategies and actions are effective and cost-effective at preventing and addressing a wide variety of chronic diseases. Several key lessons were identified, including: investment in building healthy public policy, creating supportive environments, interventions employing multiple strategies and actions at multiple levels and sectors are most effective.

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150 Boland, F., Hollander, M.J. 2011.
159 World report on aging and health. 2015.
The Human Rights Approach

There are many justifications for devoting public resources to improving the health of older populations. One is the human right that older people have to the highest attainable standard of health.

A human-rights based approach to health status states that the right to health “embraces a wide range of socioeconomic factors that promote conditions in which people can lead a healthy life, and extends to the underlying determinants of health, such as a healthy environment.

Central to a human-rights based approach is the idea that seniors participate actively and make informed decisions about their health and well-being; this is also a core element of the person-centered public-health approach. Policies and programs should empower seniors to contribute to, and remain active members of, their communities for as long as possible, according to their capacity.

Research from the UK highlights how different the economic picture concerning older populations might appear if the diverse contributions of older adults were taken into account, and notes that when both the costs and contributions of seniors were taken into account, seniors were estimated to make a net contribution to society. So, rather than portraying expenditures on older people as a cost, these are considered as investments that enable the well-being and various contributions of older people. These investments include expenditures on health systems, long-term care, and on enabling environments more broadly.

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163 The right to the highest attainable standard of health. 2000.
164 Kornfeld-Matte, R. 2014.
165 World report on aging and health. 2015.
Healthy Communities

Based on the World Health Organization (WHO)’s success factors for any healthy community initiative, the Healthy Communities (HC) approach addresses multiple determinants of health and is based on five essential strategies, or building blocks, to build on a community’s existing capacity to improve community health and well-being: community and citizen engagement; multi-sectoral collaboration; political commitment; health public policy; and asset-based community development166.

Communities using a healthy communities approach have found that it facilitates innovative and creative solutions to community issues and supports collaborative initiatives that address wide ranging community health challenges. At the heart of the HC process is community and citizen engagement. Wide community involvement is particularly important for creating a shared vision for a common future and provides opportunities for individual and community empowerment and leadership. Engagement strategies are inclusive and take a “whole of community” approach. Community members bring their voice to defining the issues, generating solutions, taking action and evaluating overall successes and learnings. Strong partnerships are also needed within and across a wide range of sectors. While cross-sectoral partnerships are key, equally important are inter-sectoral, inter-departmental and inter-ministerial partnerships. Working together, taking a bottom-up and top-down approach, communities and governments can create conditions for the health and well-being of the whole community167.

Communities are particularly well positioned to promote local public policy for three reasons: they tend to have a good understanding of specific local health needs and aspirations; local decision-makers are often closer, more accessible, and more available than those at other levels of government; and the process of developing public policy is often less complex at the local level168.

Whether or not they have experience, community stakeholder groups or coalitions all possess the qualities and skills needed to take part in the process of drafting and developing public policy, and thus improving public health in their community. The Healthy Cities and Towns strategy, which has been adopted by several thousand communities worldwide, is an appealing

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166 Healthy communities approach: a framework for action on determinants of health. Website.
approach because it aims to strengthen cooperation between partners and the community and foster citizen participation\textsuperscript{169}.

**Age-Friendly Communities**

One of many definitions for an age-friendly community (AFC) is a community where policies, services and physical spaces are designed to enable people of all ages to live in a secure and accessible physical and social environment. AFCs contribute to good health and allow people to continue to participate fully in society throughout their lifetime\textsuperscript{170}.

The *age-friendly communities* initiative was introduced to Canada in 2007 with cooperation between the Public Health Agency of Canada and the World Health Organization. In a relatively short time the concept has gained popularity across the country\textsuperscript{171}.

AFCs are a component of *Ontario’s Action Plan for Seniors*. Individuals and organizations in communities across the province are working to create age-friendly communities. These actions are also tied to *The Accessibility of Ontarians with Disabilities Act 2005 (AODA)*, making Ontario the first jurisdiction in the world to proactively mandate accessible reporting. Stakeholders from many sectors are working together to help create more inclusive and environments\textsuperscript{172}. While origins of the age-friendly concept focused on older adults, the model is expanding to include making improvements for people of all ages.

Much of the work of WHO’s approach to develop age-friendly cities and communities is built around key municipal level services: transportation, housing and urban development, information and communication, and health and community services. The WHO complements this approach by framing age friendly actions towards meeting the goal of enhancing functional ability and by extending these concepts in a way that is relevant for all sectors and that can encourage them to work together\textsuperscript{173}.

\textsuperscript{169} Martineau, V., Sasseville, N., St.Pierre, L. 2012.
\textsuperscript{170} Age friendly communities planning outreach initiative. Website.
\textsuperscript{171} Miller, G., Annesley, A. 2011.
\textsuperscript{172} Finding the right fit: age-friendly community planning. 2013.
\textsuperscript{173} World report on aging and health. 2015.
These actions take many forms, but enhance the functional ability in two fundamental ways: (1) by building and maintaining intrinsic capacity, by reducing risks, encouraging healthy behaviours, or removing barriers to them, or by providing services that foster capacity, and (2) by enabling greater functional ability – in other words, filling the gap between what people can do given their level of capacity and what they could do in an enabling environment\textsuperscript{174}.

Ensuring functional ability in older people is important in addressing population aging. Placing an emphasis on maximizing functional ability supports governments, civil society and other partners in increasing their focus on results and impacts. Concentrating on abilities moves the focus from inputs to outcomes. In doing so, it focuses both on what is important to older people and the agendas of various sectors, which is a win-win approach\textsuperscript{175}.

One common obstacle in implementing age-friendly activities is the lack of collaboration between the municipal and provincial governments, as well as between governments and other local agencies and organizations. This can lead to a duplication of services and a lack of understanding about the most suitable options. The lack of coordination as a result of services in silos leads to duplication, mismanagement or resources and a lack of perspectives on the broader issues involved in creating age-friendly communities.

As well, many of the age-friendly programs rely on volunteers, who themselves are aging. This pressure is further increased in rural communities, despite their culture of caring\textsuperscript{176}.

A trend, known as “new localism”, acknowledges that municipalities are increasingly responsible for service delivery and are getting involved in a broader range of policy issues. Because municipalities are often on the front line of contact with the population, they are increasingly expected to employ an age-friendly lens in policy design, urban planning and service delivery; to play a key role in policy planning; and to develop a capacity for research. However, shifting the responsibility for service delivery from the provincial government to the municipalities without providing adequate resources and support can leave municipal governments ill-equipped to implement age-friendly initiatives\textsuperscript{177}.

\textsuperscript{174} World report on aging and health. 2015.
\textsuperscript{175} World report on aging and health. 2015.
\textsuperscript{176} Finding the right fit: age-friendly community planning. 2013.
\textsuperscript{177} Cerda, M., Bernier, N. 2013.
Although the age-friendly movement and initiatives address many issues and makes recommendations that are beneficial to older people in general, there is a need for further inclusion of people with dementia and their caregivers.

The dementia-friendly communities model is a natural extension of the age-friendly movement and initiatives. However, there are unique needs of people living with dementia that challenge the age-friendly model.

While age-friendly features do make mention of other characteristics, they are currently focused mostly on the physical environment, while dementia-friendly features tend to focus more on the person’s abilities to navigate the social and physical environments; age-friendly features make many references to physical and visible disabilities, and fewer references to cognitive and communication disabilities that are more pronounced in the dementia-friendly features; there are growing references to dementia being identified as a (invisible) disability that perhaps should encourage us to continue those discussions; while the focus of age-friendly features began with seniors, it is now expanding, however the dementia-friendly features acknowledge that adults pre-senior age can be impacted; and both age-friendly and dementia-friendly materials strongly encourage inclusive engagement with the “target audience” in identifying needs, and developing appropriate strategies, in the process of designing and building friendly communities.

**Considering Dementia as a Disability**

“I am so frustrated, because no one realizes how seriously disabled I am. If I had a loss of limb or some other visual ailment, it would make people realize.”

The Alzheimer Society of Ontario is currently having conversations about the realignment of dementia as a disease or syndrome, to a disability. This fits within a larger conversation of refocusing its programs to support *living well* as a person with a disability, rather than living poorly as a diseased person, or as a function of a condition.

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178 Michael Ellenbogen, in Batsch, N.L., Mittleman, M.S. 2012 (p. 15).
While dementia or Alzheimer’s disease (the most common form of dementia) are not identified specifically in current legislation, there is a strong reference to cognitive impairment as fitting the definition of disability. The World Health Organization defines disability with an umbrella term covering impairments, activity limitations, and participation restrictions. An impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. The Ontario Human Rights Commission provides the most relevant information related to defining disability as it relates to dementia (Appendix B).

Rarely are the words dementia and rights put together in contemporary debates or discussions on dementia. However, anecdotal evidence suggests that some national dementia organizations are using disability and human rights laws to address the rights issues that people with dementia are facing (for example, in employment issues and entitlements to health and social services). Organizations are also using the relevant legislation to challenge decisions that are being made by service providers and agencies if they are denying people access to services on the basis of dementia diagnosis alone.

Let’s think about the importance of the words we choose, especially when dealing with persons with dementia. It is believed that the major cause of dementia is Alzheimer’s disease. When we are told that a person has a disease, it causes a series of thoughts and assumptions within us. Having a disease is often associated with having a need for medical treatment. In the case of Alzheimer’s disease, drugs are used to try to slow cognitive decline. In addition, drugs are often used to try to treat challenging behaviours in these persons.

While the underlying cause of most cases of Alzheimer’s disease is unknown, there is a great deal of emphasis on trying to find a cure for Alzheimer’s disease today. This emphasis is then translated into finding funding for pharmaceutical research. Drugs are designed to be used both as treatment, and in the case of biomarkers, to detect the presence of Alzheimer’s disease as early as possible.

What would happen if we thought about Alzheimer’s disease, and dementia in general, the way we think about Down syndrome? What if we called it Alzheimer’s Syndrome, rather than Alzheimer’s disease? Imagine, there would be extensive efforts to include people with Alzheimer’s syndrome into society. There might be Special Olympics for people with Alzheimer’s syndrome, educational programs, and training programs. There might be legislation to enable persons with Alzheimer’s syndrome to maintain employment in environments that support their disabilities. Persons with Alzheimer’s

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179 World Health Organization. Website.
syndrome would be protected by the Americans with Disabilities Act. Stigma currently associated with dementia would be greatly reduced and frowned upon by society.

Now think about a world in which we have Down’s disease, a world in which those persons are treated as people with Alzheimer’s disease are treated in our world today. Persons with Down’s disease would be treated by being given drugs, drugs designed to increase their intelligence, but which were expensive, had little effect, and had numerous side effects. In addition, there would be huge fundraising efforts designed to create a cure for Down’s disease. There would be no Special Olympics for these persons, no special education, no training. Persons with Down’s disease would be stigmatized, isolated, kept apart, and disengaged from society.

The messages that we as a society need to view persons with Alzheimer’s disease or any other form of dementia as persons with disabilities. Just as we build ramps to allow persons with challenges to mobility to have access to their environment, to their communities, so we must build cognitive ramps as a society, to allow persons with dementia to have the same access. We need to demonstrate the values of respect, dignity and equality in all of our interactions with persons with dementia, as well as our interactions with persons with Down’s syndrome, and all other members of society.

It is interesting that the man for whom Alzheimer’s disease is named, had this to say about his cases of persons with dementia: there is, then, no tenable reason to consider these cases as caused by a specific disease process. We must change the way we think and talk about persons with dementia. The words we choose will be the words we describe ourselves when we develop this disability. We must choose our words wisely.181

The focus on the medical model is on impairment, the physical or biological condition of people with disabilities. Moreover, the medical model views impairment as a condition which can be, and more importantly, ought to be, repaired, after which the individual may be rehabilitated and return to “normal life” or as close to it as possible. In other words, the medical model treats a person with an impairment as one would a person with an illness such as measles. Consequently, the medical model calls for a person with an impairment/disability to act as a sick person or patient is expected to act, that is, to assume the sick role. Unfortunately, the sick role cancels the impaired person’s obligation to take charge of his or her own affairs. Indeed, it encourages them to accept the dependency under the sick role as normative for the duration of the impairment182.

Under the medical model, the pain of losing one’s autonomy is analogous to pain following a serious operation, or to the side effect of an otherwise beneficial, short-lived, medical

181 Cameron, C. Website.
treatment: unwanted, unpleasant, but avoidable, and thus, an acceptable consequence of a successful treatment. However, many, if not most, impairments are forever. Blindness, MS, development disorders, for example, are rarely cured; thus, if the medical model prevails, a person with an impairment might, justifiably, be asked to forgo his/her autonomy forever. The demonstration that the medical model which, while suitable for a truly temporary, short-lived misfortune, is unsuitable when applied to those with a long-term impairment, was a key facet of the disability rights movement’s efforts to provide an ideological basis for its efforts to provide a solution to the problems facing those with disabilities.\footnote{Winter, J.A. 2003.}

The disability movement was launched by people with mobility impairments but has now broadened to include many others with a wide range of physical, sensory, mental health and intellectual impairments. Working locally, nationally and internationally, it has successfully campaigned for basic human rights, and participation in society. Furthermore it has consistently opposed all forms of discrimination and segregation. Above all, it has insisted in the right of disabled people to be heard.\footnote{Mittler, P, in Batsch, N.L., Mittleman, M.S. 2012.}

Many years ago people with intellectual disabilities were not considered able to speak for themselves. Parents began to form associations to campaign for recognition for themselves and their children. Most of them were successful in influencing governments to develop services and supports.\footnote{Mittler, P. in Batsch, N.L., Mittleman, M.S. 2012.}

A sociological overview of the development of the rights movement describes the movement as arising to combat the oppressive marginalization of persons with disabilities. It sought both to empower them to take control of their own lives and to influence social policies and practices to further the inclusion of individuals with disabilities into the societal mainstream. It developed in three phases. In the first phase a definition of both what the problem is and of what its sources are, was offered. In the second, a consensus was established and acted upon as to a collective solution to the problem. In the third phase, it responded to the after math of new policies and practices.\footnote{Winter, J.A. 2003.}

The changes being offered through the social model holds that disability is not a tolerable, necessary result of an individuals’ impairment, but something created in large part by a
society’s response to the impairment. Indeed, it is a society’s response to an impairment which disables a person, not the impairment itself\textsuperscript{187}.

The new social model is based on two premises (1) social conditions convert an impairment into a disability, not the impaired person, and (2) the focus of efforts on behalf of those with a so-called disability should be rooted in respect for their personhood, on their ability and right to make their own, autonomous, decisions as to how they are to live with their so-called disability, and not on the impairment per se\textsuperscript{188}.

Whether or not dementia becomes defined as a disability, the fact that people with other disabilities will develop dementia as they age, is very real. This situation is exacerbated for people with Down Syndrome, who because of a genetic basis of their impairment, are at significantly greater risk of developing Alzheimer’s disease as they live into their 50’s and 60’s. And people with early onset dementia may find themselves caught between the disability health system and the age-focused health system. Alzheimer’s Australia, as an example, is calling for a single system that delivers care services regardless of age, combining supports for people with both dementia and disability\textsuperscript{189}.

As the conversation continues about whether or not it is useful to view dementia as a disability, it should not be assumed that this view would be universally accepted and wholly positive. However, what the social model does do is open up the choices and options, and offers alternatives to the current responses and approaches\textsuperscript{190}.

\textsuperscript{187} Winter, J.A. 2003.
\textsuperscript{188} Winter, J.A. 2003.
\textsuperscript{189} Rees, G. 2010.
\textsuperscript{190} Winter, J.A. 2003.
Looking to the Future

Dementia-Friendly Communities (DFCs)

The idea of making our communities better places to live for people with dementia is something which engages the enthusiasm and interest of all sorts of people. Traders, leisure companies, transport providers, planners, service providers, health and social care organizations, charities, governments and researchers are all potentially affected; all have a role to play in forming a vision about what a dementia friendly community should look like. The most important stakeholders in this process of course are people with dementia, and those who care for and support them. “Nothing about us without us” is a slogan which carries great resonance for disability rights campaigners – and is one which is increasingly being articulated by people with dementia as well. The voices of people with dementia and their carers should be at the start and the heart of the process of creating dementia-friendly communities. Dementia-friendly communities need to be responsive to what people want, but perhaps more importantly, people with dementia should have the right to have a sense of ownership, investment, responsibility and of connectedness to their own communities.191

The DFC model is not about changing the person and getting them to fit in, but is, instead, about altering the social, attitudinal, architectural, and physical environments in which people with dementia live to be responsive and adapt to situations. DFC focus on inclusion and coming together of communities to challenge the current status quo, often characterized by the exclusions and marginalization of people with dementia, and the reinforcement of social isolation and ongoing inequalities192.

Alzheimer’s Disease International notes certain key strategic considerations for dementia friendly communities: DFC efforts are a response to pervasive and destructive stigma; DFCs give voice to people living with dementia in their design and execution, understanding that at times there are challenges to listen to the voices of people living with dementia, especially those who have lost the ability to raise their own concerns; the work in developing age-friendly communities and dementia-friendly communities are not mutually exclusive, and likely seriously intertwined193.

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193 Dementia friendly communities: new domains and global examples. 2015.
The rationale for creating dementia-friendly communities comes from the voices and experience of people living with and affected by the condition. It is about ensuring that people with dementia are empowered to live well, and exert choice and control in their lives. Importantly, it recognizes the impact that dementia has on relationships and peoples’ confidence to engage in daily tasks and activities. These all have a profound impact on a person’s quality of live, affecting not only the individual abut also their cares and loved ones\textsuperscript{194}.

While there are several models in development worldwide, and several definitions available, they generally align with the following: A Dementia-Friendly Community is a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value\textsuperscript{195}.

The work of DFC is designed to complement a national strategy (focused on health services). DFC focus on supporting the well-being of those people with mild to moderate cognitive impairment in the early stages of dementia who are trying to live normal lives in the community\textsuperscript{196}.

Dementia-friendly communities are an important vehicle for reducing social isolation and loneliness\textsuperscript{197}.

Creating dementia-friendly communities must be part of a social movement to help people live well with dementia. Both sustained leadership and grass roots action on dementia are required. There is untapped potential in the community to help people with dementia and their caregivers. Everyone, from governments to the local corner shop, share part of the responsibility for ensuring that people with dementia feel active, engaged, and valued\textsuperscript{198}.

Within this process (working with the Ontario Trillium Foundation and stakeholders from across Ontario), guiding principles and values, structures and tools that support the development of dementia-friendly communities, will be developed. Levels of commitment (personal, organizational and system) will be identified, and various focus areas, perhaps with a tag line: empowering individuals, building communities and strengthening systems.

\textsuperscript{194} Green, G., Lakey, L. 2013.
\textsuperscript{195} Alzheimer Australia website.
\textsuperscript{196} Dementia-Friendly Communities: learning and guidance for local authorities. Website.
\textsuperscript{197} Kane, M., Cook, L. 2003.
\textsuperscript{198} Green, G., Lakey, L. 2013.
There will also be consideration for how Dementia-Friendly Communities aligns with the work in developing a Dementia Strategy.

With movement forward, it is hoped that communities that address the needs of persons living with dementia, will have the potential to improve life for all its residents, and could be expected to:

- see increased engagement among all seniors
- witness increased inclusiveness and reduced stigma
- experience improved quality of life
- develop infrastructures that are shaped by the realities of those living actively in them
- appreciate the contributions that can come from all engaged residents
- understand the potential to reduce injury, and the high direct care costs which include long-term residential costs, physician and hospital costs

With dementia-friendly communities, there is hope to:

- build communities that value, include and respect people with dementia
- support a sense of belonging and independence
- recognize signs of dementia and know how to communicate effectively and respectfully
- understand what to do when we see a community member who may be wandering
- complement age-friendly initiatives by adding nuance and emphasizing the needs of people with dementia

*Having dementia is very tough but having a city who excludes dementia – that is really tough. While the world waits for a cure, we need more communities and cities to embrace and engage those living with dementia instead of isolating and excluding them, more organizations, businesses and individuals become aware of the needs of aging community members, and of those with various physical, development and intellectual disabilities, it follows that the unique needs of those with dementia, along with their care partners, must be carefully considered. These unique needs must also be developed into measureable, strategic, actionable and effective programs, initiatives and culture change movements: with the ultimate goal of removing stigma and fostering meaningful engagement for persons with dementia of all stages and in all stages. Dementia Friendly Communities should not only seek to preserve the safety and well-being of those living with dementia, it should also empower all members of the community to celebrate the*
capabilities of persons with dementia, and view them, as valuable and vital members of the towns, cities ... in which they reside\textsuperscript{199}.

Community Engagement\textsuperscript{200}

Based on research by the Tamarack Foundation, community engagement is understood to be people working collaboratively, through inspired action and learning, to create and realize bold visions for their common future. The focus should be on processes that bring people together - the broad engagement of organizations and people. It is believed that these processes can enable collective change and create movement in communities.

Good community engagement will build agreement around issues and create momentum for communities to address issues. Community engagement includes following a process that ensures communities determine local priorities, and all stakeholder groups are represented. Valuable community engagement processes and outcomes can be ongoing or episodic.

The Tamarack Foundation also found sources that listed different benefits of community engagement. From their perspective, the overall benefits of community engagement can include creating higher quality solutions, increasing conflict management and resolutions, strengthening a sense of community and creating communities that take a greater responsibility for what is happening in their area.

Community engagement benefits organizations in that it transforms policy–making at the local level, improves the targeting and effectiveness of services, helps to measure how agencies and partnerships are performing, and helps to build community ownership. The Foundation also suggests that community engagement benefits communities by involving those who might not normally be included, building community spirit, cooperative working and empowering individuals.

Innovative approaches are being tested throughout the world around the co-design and co-production of services. Co-production entails the delivery of services in conjunction with or in replacement of formal service providers. New forms of assistance and support are emerging with citizens playing an active role in their design and delivery.

\textsuperscript{199} Dementia friendly communities: new domains and global examples. 2014.
\textsuperscript{200} Tamarack Institute for Community Engagement. Website.
**Collective Impact**

The non-profit sector most frequently operates using an approach that one group calls “isolated impact”. It is an approach oriented toward finding and funding a solution embodied within a single organization, combined with the hope that the most effective organizations will grow or replicate their impact more widely. As a result of this process, non-profits try to invent independent solutions to major social problems, often working at odds with each other and exponentially increasing the perceived resources required to make meaningful progress. Despite the dominance of this approach, there is scant evidence that isolated initiatives are the best way to solve many social problems in today’s complex and interdependent world.

No single organization is responsible for any major social problem, nor can any single organizations cure it. The problem with relying on the isolated impact of individual organizations is further compounded by the isolation of the nonprofit sector. Social problems arise from the interplay of governmental and commercial activities, not only from the behavior of social sector organizations. As a result, complex problems can be solved only by cross sector coalitions that engage those outside the non-profit sector.

Collective Impact is the commitment of a group of actors from different sectors to a common agenda for solving a complex social problem. In order to create lasting solutions to social problems on a large scale, organizations – including those in government, civil society, and the business sector – need to coordinate their efforts and work together around a clearly defined goal.

Collective impact is not merely a new process that supports the same social sector solutions but an entirely different model of social progress. The power of collective impact lies in the heightened vigilance that comes from multiple organizations looking for resources and innovations through the same lens, the rapid learning that comes from continuous feedback loops, and the immediacy of action that comes from a unified and simultaneous response among all participants.

There are 3 pre-conditions to collective impact that are critical to long term success. These are: having an influential champion around the issue; having a sense of urgency; and having adequate resources of all types to make progress on the issue.

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Stakeholders using the collective impact model must: aim to affect “needle moving change”; believe that long-term investment by several stakeholders is necessary to achieve success; believe that cross-sector engagement is essential for community-wide change; be committed to using measureable data to set the agenda and to improve over time; and be committed to having community members as partners and producers of impact.

Collective Impact brings funders, businesses, nonprofits, governments and impacted people together in a structured and deliberate way to achieve change. It is not an elaborate form of funding or a siloed approach, but a process that is complex, evolving and demands a high degree of commitment and flexibility to realize long-term results.

- Common Agenda – the participating organizations are working towards a common set of outcomes
- Shared Measurement – the organizations share a simple, meaningful measure(s)
- Mutually reinforcing activities – partners work as a team
- Continuous communication – there is routine, planned communications among partners, and
- Backbone support – a dedicated support/coordination team

Large-scale social change requires broad cross-sector coordination, yet the social sector remains focused on the isolated intervention of individual organizations.

Unlike most collaborations, collective impact initiatives involve a centralized infrastructure, a dedicated staff, and a structured process that leads to a common agenda, shared measurement, continuous communication, and mutually reinforcing activities among all participants.
Next Steps: Ontario Trillium Foundation

As part of the Ontario Trillium Foundation process, stakeholders, working together, need to identify/develop a model that will guide the collective forward to a common vision. Once the current state is agreed on, the work can begin to design the vision and model for the new state.

Common ground can already be acknowledged in a need for change, and a need to address the needs of those living with dementia and their care partners.

The next step will be to develop a Dementia Friendly Communities model, and with that model, a clear understanding of how stakeholders can join the movement, and how the model fits with other systems. Stakeholders will be invited to participate in conversations and planning sessions to design a collective model.
### Age-Friendly and Dementia Friendly Communities

*Since age is the greatest risk factor for dementia, communities working towards age-friendly resources may want to consider adding dementia friendly elements to their efforts. The list below, shows dementia friendly elements that communities may want to consider adding to their age-friendly efforts.*

<table>
<thead>
<tr>
<th>Age Friendly</th>
<th>Dementia Friendly</th>
<th>Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>✓</td>
<td>✓</td>
<td>The city is clean and pleasant, with enforced regulations.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>The environment is familiar (the functions of buildings are obvious) and distinctive (urban and building form is varied).</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>The physical environment is easy to navigate and includes a variety of landmarks to aid wayfinding.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>A spectrum of quality housing options, including support for aging in place, is available for older people as their needs change over time.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>A range of quality housing options, including memory care services and supports, exists for people with dementia at various stages of the disease.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>A wide-variety of affordable, convenient and accessible activities is offered to older adults and their companions.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>People with dementia and their caregivers have access to organized activities designed specifically for their needs.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Public transport is reliable, frequent, safe and affordable; serves all city areas; and has priority seating for older adults.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Transport does not require passengers to handle money, and supportive assistance is available along the way to help passengers with dementia travel successfully.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Drivers (public transport, taxis, other services) are courteous and sensitive to older riders.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Drivers are trained to recognize passengers with dementia and how to help them.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Roads are well-maintained, well-lit, and well-signed, and priority parking and drop-off spots are readily available.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Transportation services for people with dementia are well-advertised and promoted as supportive.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Older people are valued and respected by the community.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Community is dementia-aware and puts forth a spirit of support; people with dementia, including those from seldom-heard communities, are free from stigma.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Older people receive services and products adapted to their needs and preferences.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Businesses become educated about dementia, train employees how to support customers with dementia, and offer specialized services to people with dementia and their families.</td>
</tr>
<tr>
<td>✓</td>
<td>✓</td>
<td>Reliable and regular distribution of information to seniors keeps them connected to news, events and activities.</td>
</tr>
</tbody>
</table>

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202 Dementia Friendly America. Website.
Dementia Friendly Communities

Specific outreach to people with dementia and their caregivers keeps them engaged and helps prevent social isolation.

An adequate range of health and community support services is offered.

Home services staff is respectful, helpful and trained to serve older people.

Clinical providers are equipped to screen and diagnose dementia.

Education and support for caregivers allows them to continue their critical role in supporting people with dementia.

At-home services from dementia-educated staffed help people with dementia maximize independent living and adjust to changing needs.

Age- and Dementia-Friendly Communities: An Overlay

Dementia friendly communities are gaining traction as Alzheimer’s disease and other dementias pervade our aging population. They are a natural extension of age friendly communities, and a necessary one, as one in three people aged 85 or older, and one in nine aged 65 and older, in the U.S. lives with dementia. The following tables reflect the World Health Organization’s eight domains of age-friendliness alongside key characteristics of dementia friendly communities in each domain. A dementia friendly community should possess all qualities of an age friendly one as well as the unique features that address the needs of people living with dementia.

<table>
<thead>
<tr>
<th>Outdoor Spaces and Buildings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age-Friendly</strong></td>
</tr>
<tr>
<td>The city is clean and pleasant.</td>
</tr>
<tr>
<td>There is somewhere to sit and rest, both in buildings and outdoors.</td>
</tr>
<tr>
<td>Good, accessible public toilets are available.</td>
</tr>
<tr>
<td>Pavements are wide, well-maintained, and non-slip, and pedestrian paths are clear, smooth, and separate from cycling paths.</td>
</tr>
<tr>
<td>Safe green spaces, including smaller, more contained areas, are readily available.</td>
</tr>
<tr>
<td>Public safety in all open spaces and buildings is a priority and promoted.</td>
</tr>
<tr>
<td>Roads are safe for pedestrians to cross.</td>
</tr>
</tbody>
</table>
### Housing

<table>
<thead>
<tr>
<th>Age-Friendly</th>
<th>Dementia Friendly</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Sufficient, affordable housing and essential services are available to all older people.</td>
<td>• A range of quality housing options exists for people with dementia at various stages of the disease</td>
</tr>
<tr>
<td>• Housing is close to services and the rest of the community</td>
<td>• Community-based supports and services help people with dementia maximize independent living</td>
</tr>
<tr>
<td>• Home modification options are affordable and available from knowledgeable providers</td>
<td>• Older adult residential settings offer quality memory care services and supports</td>
</tr>
<tr>
<td>• Affordable services enable older people to age in place at home.</td>
<td>• Direct-care staff at care facilities receives best practices dementia training.</td>
</tr>
<tr>
<td>• Housing design facilitates continued integration of older people into the community</td>
<td></td>
</tr>
</tbody>
</table>

### Social Participation

<table>
<thead>
<tr>
<th>Age-Friendly</th>
<th>Dementia Friendly</th>
</tr>
</thead>
<tbody>
<tr>
<td>• A wide-variety affordable activities is offered to older adults and their companions</td>
<td>• There are organized activities that are specific and appropriate for the needs of people with dementia</td>
</tr>
<tr>
<td>• Events are held at times and places that are convenient and accessible to older people</td>
<td>• A befriending service helps people with dementia to participate in community life and provides emotional support.</td>
</tr>
<tr>
<td>• Activities are well-communicated to older people, and there is consistent outreach to include people at risk of social isolation</td>
<td></td>
</tr>
</tbody>
</table>
### Transportation

<table>
<thead>
<tr>
<th>Age-Friendly</th>
<th>Dementia Friendly</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Public transportation is reliable, frequent, safe and affordable; serves all city areas and services; has priority seating for older adults</td>
<td>• Transportation escorts are available to help passengers with dementia use public transport</td>
</tr>
<tr>
<td>• Specialized transportation is available for disabled people</td>
<td>• Transit drivers are trained to be sensitive to riders with dementia and how to help them</td>
</tr>
<tr>
<td>• Drivers are courteous and sensitive to older riders</td>
<td>• Transport does not require passengers to handle money; companions travel for free</td>
</tr>
<tr>
<td>• Transport spots are accessible, comfortable and located near where older adults live</td>
<td>• Transportation services for people with dementia are well-advertised and promoted as supportive.</td>
</tr>
<tr>
<td>• A voluntary transport service is available</td>
<td>• Transportation services can be adapted to the needs of people with dementia, including schedule reminders and help at destinations.</td>
</tr>
<tr>
<td>• Taxis are accessible, affordable and have helpful drivers</td>
<td>• Supportive assistance along the way helps passengers with dementia travel successfully</td>
</tr>
<tr>
<td>• Priority parking and drop-off spots are readily available for people with special needs</td>
<td>• Caregivers have help and support addressing driving cessation for someone with dementia</td>
</tr>
<tr>
<td>• Roads are well-maintained and well-lit.</td>
<td></td>
</tr>
</tbody>
</table>

### Respect and Social Inclusion

<table>
<thead>
<tr>
<th>Age-Friendly</th>
<th>Dementia Friendly</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Older people are valued and respected by the community</td>
<td>• Community is dementia-aware and puts forth a spirit of support.</td>
</tr>
<tr>
<td>• Older people are included as full partners in community decision-making affecting them.</td>
<td>• People with dementia themselves acknowledge the positive contribution they can make in their communities, and maintain and develop new relationships and social networks</td>
</tr>
<tr>
<td>• Intergenerational activities are part of the community fabric and include older adults</td>
<td>• Staff at businesses learn to recognize signs of dementia and how to support customers with dementia</td>
</tr>
<tr>
<td>• Public and commercial services and products include those adapted to older people’s needs and preferences.</td>
<td></td>
</tr>
</tbody>
</table>
### Civic Participation and Employment

<table>
<thead>
<tr>
<th><strong>Age-Friendly</strong></th>
<th><strong>Dementia Friendly</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Older people have a range of flexible and appropriately paid opportunities.</td>
<td>Employers’ policies accommodate caregivers’ responsibilities.</td>
</tr>
<tr>
<td>Workplaces are adapted to meet the needs of disabled people.</td>
<td>The voices of people with dementia and their caregivers are sought in community decisions.</td>
</tr>
<tr>
<td>A range of volunteer options is available.</td>
<td>People with dementia continue to do the activities they did prior to having dementia and to live with independence and purpose.</td>
</tr>
<tr>
<td>People with dementia have meaningful volunteer opportunities tailored to their interest and ability.</td>
<td></td>
</tr>
</tbody>
</table>

### Communication and Information

<table>
<thead>
<tr>
<th><strong>Age-Friendly</strong></th>
<th><strong>Dementia Friendly</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>There is reliable and regular distribution of information to seniors, and in accessible formats that they prefer, including to seniors who have hearing or vision loss</td>
<td>There is work to break down the stigma of dementia, especially in seldom heard communities (such as some ethnic minorities).</td>
</tr>
<tr>
<td>Seniors are kept connected to news, events and activities.</td>
<td>Specific outreach to people with dementia and their caregivers keeps them connected and informed of social activities and services.</td>
</tr>
</tbody>
</table>

### Community and Health Services

<table>
<thead>
<tr>
<th><strong>Age-Friendly</strong></th>
<th><strong>Dementia Friendly</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>An adequate range of health and community support services is offered</td>
<td>Early access to diagnosis and post-diagnostic support exists for patients and caregivers</td>
</tr>
<tr>
<td>Home care services include health, personal care and housekeeping</td>
<td>Education, counseling and support for caregivers and their families allows them to continue their critical role in supporting people with dementia</td>
</tr>
<tr>
<td>All staff is respectful, helpful and trained to serve older people.</td>
<td>Wellness programs help people with dementia and reduce severity of disease</td>
</tr>
<tr>
<td>Economic barriers for lower-income people are minimal</td>
<td>Advance care, financial and legal services with specialized knowledge of circumstances of people with dementia available</td>
</tr>
<tr>
<td>Volunteers of all ages are encouraged to support and assist older people in a wide range of settings</td>
<td>At-home services help people with dementia adjust to changing needs</td>
</tr>
<tr>
<td>Community emergency planning takes into account the vulnerabilities and capacities of older people</td>
<td>Dementia-focused programs such as Dementia Friends and community trainings can leverage the broader community in providing a support network</td>
</tr>
<tr>
<td></td>
<td>Community emergency planning specifies procedures for people with dementia</td>
</tr>
</tbody>
</table>
Appendix B: Ontario Human Rights Commission and Human Rights Code:

The *Ontario Human Rights Commission* provides the most (relevant) information related to defining disability as it relates to dementia:

**2.1 The definition in the Human Rights Code**

Section 10 (1) of the *Code* defines “disability” as follows:

“because of disability” means for the reason that the person has or has had, or is believed to have or have had,

a. any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,

b. a condition of mental impairment or a developmental disability,

c. a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,

d. a mental disorder, or

e. an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997*.

“Disability” should be interpreted in broad terms. It includes both present and past conditions, as well as a subjective component based on perception of disability. Although sections 10(a) to (e) set out various types of conditions, it is clear that they are merely illustrative and not exhaustive. Protection for persons with disabilities under this subsection explicitly includes mental illness, developmental disabilities and learning disabilities. Even minor illnesses or infirmities can be “disabilities,” if a person can show that she was treated unfairly because of the perception of a disability. Conversely, persons with an ailment who cannot show they were treated unequally because of a perceived or actual disability will be unable to meet even the *prima facie* test for discrimination. It will always be critical to assess the context of the differential treatment to determine whether discrimination has taken place, and whether the ground of disability is engaged.

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203 [Ontario Human Rights Commission. Website](http://www.ohrc.on.ca)
2.2 A broader approach to understanding disability: a social perspective

The Supreme Court of Canada has shed new light on the approach to be taken in understanding disability. In Mercier, a case arising in Quebec, the Supreme Court made it clear that disability must be interpreted to include its subjective component, since discrimination may be based as much on perceptions, myths and stereotypes as on the existence of actual functional limitations.

In Mercier, the complainants were denied employment or dismissed when it was discovered that they had medical conditions. However, their conditions did not result in any functional limitations. The employers argued that since the conditions did not give rise to any functional limitations, they could not be “disabilities” under Quebec’s human rights law. The Supreme Court of Canada disagreed.

The Court chose not to create an exhaustive definition of disability. Instead, it opted for an equality-based framework that takes into account evolving biomedical, social and technological developments. This includes a socio-political dimension that emphasizes human dignity, respect and the right to equality. Thus, a disability may be the result of a physical limitation, an ailment, a perceived limitation or a combination of all these factors. The focus is on the effects of the distinction, preference or exclusion experienced by the person and not on proof of physical limitations or the presence of an ailment.

Another Supreme Court of Canada decision has since confirmed that “social handicapping,” i.e., society’s response to a real or perceived disability, should be the focus of the discrimination analysis.

This approach is consistent with the Code, which includes past, present and perceived conditions. It affords a broad and liberal interpretation and promotes the objectives of the Code.

2.3 Non-evident disabilities

The nature or degree of certain disabilities might render them “non-evident” to others. Chronic fatigue syndrome and back pain, for example, are not apparent conditions. Other disabilities might remain hidden because they are episodic. Epilepsy is one example. Similarly, environmental sensitivities can flare up from one day to the next, resulting in significant impairment to a person’s health and capacity to function, while at other times, this disability may be entirely non-evident. Other examples might include:

- persons whose disabilities do not actually result in any functional limitations but who experience discrimination because others believe their disability makes them less able
• persons who have recovered from conditions but are treated unfairly because of their past condition
• persons whose disabilities are episodic or temporary in nature.

Other disabilities may become apparent based on the nature of the interaction, such as when there is a need for oral communication with a person who is deaf, or there is a need for written communication with a person who has a learning disability. A disability might become apparent over time through extended interaction. It might only become known when a disability accommodation is requested, or the disability might remain “non-evident” because the individual chooses not to divulge it for personal reasons.

Regardless of whether a disability is evident or non-evident, a great deal of discrimination faced by persons with disabilities is underpinned by social constructs of “normality” which in turn tend to reinforce obstacles to integration rather than encourage ways to ensure full participation. Because these disabilities are not “seen,” many of them are not well understood in society. This can lead to stereotypes, stigma and prejudice.

2.4 Mental disability

Although mental disability is a form of non-evident disability, it raises particular issues that merit independent consideration. Over the years, many employers have expressed the need for specific guidance on the issue of mental disability. Section 10 of the Code expressly includes mental disabilities. Persons with mental disabilities face a high degree of stigmatization and significant barriers to employment opportunities. Stigmatization can foster a climate that exacerbates stress, and may trigger or worsen the person’s condition. It may also mean that someone who has a problem and needs help may not seek it, for fear of being labelled.

The Supreme Court of Canada has recognized the distinct disadvantage and negative stereotyping faced by persons with mental disabilities, and has held that discrimination against individuals with mental disabilities is unlawful. In Gibbs v Battlefords, the Court struck down an insurance plan for employees with disabilities that limited benefits for mental disabilities to a lower level than for physical disabilities. It is therefore the OHRC’s position that such distinctions are prima facie discriminatory.
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