

Société Alzheimer Society

ONTARIO

**Dementia-Friendly Communities Ontario:
A Multi-Sector Collaboration to
Improve Quality of Life for People Living With Dementia and Care Partners**

Ontario Trillium Foundation Submission

Stage: Build the Case

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Introduction

This report is the second in a series of reports developed as part of the Ontario Trillium Foundation's Collective Impact Funding Stream requirements. The first report was shared in January 2016, and focused on the Ontario Trillium Foundation's "Groundwork" step.

The "Groundwork" step in the process focused on identifying issues and barriers faced by people living with dementia and their care partners to living well, and supporting the urgency for change from the current realities.

This report focuses on the "Build the Case" step of the Ontario Trillium Foundation's process step, and 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 care partners.

In developing these models and go-forward plans, the Alzheimer Society has been and will continue to invite and welcome 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 care partners.

While the focus of this initiative and report is on people living with dementia and their family and friends, it needs to be acknowledged that there are so many more populations that are touched by dementia, and/or share similar aspirations for improved quality of life. While dementia can be the single diagnosis or condition for many people, it is more likely that dementia is one of many conditions that people live with (e.g. age-related dual sensory loss). It is also a reality that there are other population groups who claim to not live well, and who would benefit from the opportunities for improved quality of life that can come with the models being proposed through a *dementia-friendly communities* movement.

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 care partners 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.

At this point, all the elements seem to be in place to support Ontario's desire to bring *Dementia-Friendly Communities* to this province. Using a collective impact approach, and the *Dementia-Friendly Communities* model, funded by and in partnership with the Ontario Trillium Foundation (OTF), the Alzheimer Society of Ontario proposes to champion a multi-sector collaborative movement focused on improving the quality of life for people living with dementia and their care partners.

The Ontario Trillium Foundation

The Ontario Trillium Foundation 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 Ontario Trillium Foundation 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 Ontario Trillium Foundation's Collective Impact Funding Stream. Collectives would normally move through the stages in order. This report responds to the *Build the Case* Stage.

The stages 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:

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 older adults.

The World Health Organization, as well as the Alzheimer's Disease International organization, both challenge the world to make *dementia-friendly communities* 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.

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 self-managing other chronic conditions¹.

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 disease².

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 all older people have to the highest attainable standard of health³. What is perhaps even more challenging for people living with dementia than the cognitive challenges, is the stigma they face as a result of dementia.

Stigma is something which causes an individual to be classified by others in an undesirable way. Stigma causes individuals and organizations to behave in ways that are unhelpful, emphasizing the symptoms of the disease rather than supporting the abilities that people living with

¹ Dementia evidence brief. 2012.

² Dementia: A public health priority. 2012.

³ Boera, B., Bhushan, A., Abou Taleb, H., Vasquez, J., Thomas, R., Ferguson, L. 2016 (in press); in World report on aging and health. 2015.

dementia have. The resulting social isolation and lack of stimulation causes disability beyond that caused by the condition itself.⁴

Social isolation is commonly defined as a low quality and quantity of contact with others. People living with dementia often report a decreasing circle of family and friends following disclosure of a dementia diagnosis. This is often true for care partners as well. Social isolation is different than loneliness, which is a perception of a lack of interaction or contact with others. Social isolation increases the likelihood of loneliness, and a person living with dementia can perceive and experience being lonely even when in the company of others.

One of the most significant changes in our conversations about dementia is that people living with dementia want to talk. 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 are speaking up. And for perhaps the first time, those around them are starting to listen.

People living 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 living with dementia as well⁵.

People living with dementia define 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 change⁶.

⁴ Batsch, N.L., Mittleman, M.S. 2012.

⁵ Finding out what a dementia-friendly community means to people with dementia and carers: making Hampshire a dementia friendly county. 2012.

⁶ Cantley, C., Woodhouse, J., Smith, M. 2005.; DEEP, 2016.

People living with dementia and care partners describe seven outcomes that are most important to their quality of life:

- they have a personal choice and control or influence over decisions about them;
- they know that services are designed around them and their needs;
- they have support that helps them live their lives;
- they have knowledge and know-how to get what they need;
- they live in an enabling and supportive environment where they feel valued and understood; and
- they know there is research going on which delivers a better life for now and hope for the future⁷.

Family caregiving is not new – most families expect to provide support when a family member needs care. While most embrace the opportunity, the reality is that the responsibilities of a care partner can be challenging, especially given the changing context of caring. People providing care for someone living with dementia provide 75% more care hours than other care partners and experience nearly 20% greater stress⁸.

Recognition of the incidence and impact of dementia is only now becoming better known. 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 care partners to not only address health issues, but also to live well despite any condition that may exist.

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 acute or chronic care; all failing to address the complexity of the disease. Ontario's network of programs and services for older adults is highly complex, with a different set of services organized, delivered and communicated by different ministries and providers.

There is no doubt that the incidence of dementia is increasing rapidly, and that the impact of dementia will continue to rise and spread. In 2016, over 220,000 older adults (65+) are estimated to be living with some form of dementia. The number is expected to increase by 13%

⁷ Kane, M., Cook, L. 2013.

⁸ Seniors in need, caregivers in distress: what are the home care priorities for seniors in Canada? 2012.

to nearly one quarter of a million people by 2020⁹. In 2013, 99,300 Ontarians (40+) living in the community (not including long-term care) were living with a diagnosis of dementia, an increase of more than 40% since 2007¹⁰. National reports in both the United States and the UK indicate that dementia is among the most feared diseases associated with getting older¹¹.

The World Health Organization has declared dementia to be a “public health priority” on a worldwide scale¹². Dementia is the most significant cause of disability among Canadians (65+) and it already costs Canadian society billions of dollars each year¹³. Dementia is a core issue impacting Ontario’s health and social system¹⁴. Finding a cure for dementia is the ultimate goal; however, until that goal is achieved, it is critical to focus on supporting the needs of people living with dementia and their care partners today.

The Alzheimer Society of Ontario is one of many groups 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.

Rarely have the words dementia and rights been 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)¹⁵. 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 a dementia diagnosis alone¹⁶.

At the heart of the disability rights movement is the fact that people living with disabilities want to be seen as people first, to be treated as individuals, to have opportunities to participate in and contribute to society, and not as cases or categories of disablement, powerless to share their lives¹⁷.

⁹ Hopkins, R. 2010.

¹⁰ Bronskill, S.E., Yates, E., Guan, J., Walker, J., Newman, A., Wang, X., Vermeulen, M. 2016.

¹¹ Batsch, N.L., Mittleman, M.S. 2012.

¹² Dementia: A public health priority. 2012.

¹³ Rising tide: the impact of dementia on Canadian Society. Executive Summary. 2010.

¹⁴ Dementia evidence brief. 2012.

¹⁵ Alzheimer Society of Ireland. 2014; Alzheimer Society of Scotland

¹⁶ McGettrick, G., Williamson, T. 2015.

¹⁷ Union of the physically impaired against segregation. 1976.

The disability movement was launched by people living with mobility impairments but has now broadened to include many others with a wide range of physical, sensory, mental health and intellectual impairments.

A sociological overview of the development of the rights movement describes the movement as arising to combat the oppressive marginalization of people living with disabilities¹⁸. 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 living with disabilities into the societal mainstream¹⁹.

The changes being offered through the social model hold that disability is not a tolerable, necessary result of an individual's impairment, but something created in large part by a society's response to the impairment²⁰. Indeed, it is a society's response to an impairment which disables a person, not the impairment itself²¹.

The 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 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 disability, and not on the impairment per se²².

There are several implications for dementia policy and practices/services. In the social model, people living with dementia are center stage, with their voices elevated, and are recognized as equal citizens with rights. They are the agents of change and their agency is valued and recognized²³.

More recently in the dementia context, there is movement to consider a person-centered or individual model. This is evidenced in language around the person, in particular, person-centered language. This approach also presupposes that people must be seen as people not as

¹⁸ Barnes, C. Mercer, G. 2010.

¹⁹ Winter, J.A. 2003.

²⁰ Oliver, M. 2009.

²¹ Winter, J.A. 2003.

²² Winter, J.A. 2003.

²³ McGettrick, G., Williamson, T. 2015

a pathology, and supported as individuals. In this approach, focus is not often on environmental and social issues, but on trying to support the person and his/her support networks.

A social model extends far beyond individual and medical models to shift the focus on seeing people living with dementia as citizens, and looking to environmental and social concerns as the focus for change²⁴. A social model recognizes that social exclusion, stigma, and discrimination are key factors in the quality of life for people living with dementia. A social model of disability shifts focus from “person-centered” to social citizenship²⁵. It moves the focus from what others do to support people with dementia to what rights people living with dementia have as citizens of their communities.

A current manifestation of the social model in practice is the development of *dementia-friendly communities*. Tools have been developed to enable adoption of a rights-based approach and these can be effectively used in developing dementia policy and practice²⁶.

At one level the concept of *dementia-friendly communities* is interestingly simple – namely to work for the common goal of a better life for people living with dementia. But it is much more than this. *Dementia-friendly communities* have the power to change the way society thinks about living with dementia. It marks a fundamental shift from a focus of meeting the physical and health needs of people living with dementia to a holistic approach to supporting the person to achieve the best quality of life reasonably possible²⁷.

The *dementia-friendly communities* 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 living with dementia live to be responsive and adapt to situations. *Dementia-friendly communities* focus on inclusion and coming together of communities to challenge the current status quo, often characterized by the exclusions and marginalization of people living with dementia, and the reinforcement of social isolation and ongoing inequalities²⁸.

²⁴ Barnes, C., Mercer, G. 2010.

²⁵ Bartlett, R., O'Connor, D. 2010.

²⁶ McGettrick, G., Williamson, T. 2015

²⁷ Rees, G. 2015.

²⁸ Winter, J.A. 2003.

Alzheimer's Disease International notes certain key strategic considerations for *dementia-friendly communities*: *dementia-friendly communities'* efforts are a response to pervasive and destructive stigma; *dementia-friendly communities* 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 intertwined²⁹.

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*³⁰.

The work of *dementia-friendly community* initiatives is designed to complement a national strategy (focused on health services). *Dementia-friendly communities* 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 community³¹. *Dementia-friendly communities* are an important vehicle for reducing social isolation and loneliness³².

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 living with dementia and their care partners. Everyone, from governments to the local corner shop, share part of the responsibility for ensuring that people with dementia feel active, engaged, and valued³³.

To achieve success with *dementia-friendly communities* will require a change in attitudes and culture of the kind that people with disabilities and their advocates have fought for over many decades, and are founded in the convention on the rights of people with disabilities.

²⁹ Dementia friendly communities: new domains and global examples. 2015.

³⁰ Alzheimer Australia. Website.

³¹ Dementia-Friendly Communities: learning and guidance for local authorities. Website.

³² Kane, M., Cook, L. 2003.

³³ Green, G., Lakey, L. 2013.

There is growing recognition that, rather than a program or project to support people living with dementia, what is needed is a movement that will take many years and involvement from many stakeholders.

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 Impact³⁴ is a process used in solving complex social and organizational problems. It involves the commitment of a group of individuals and organizations from different sectors to a common agenda for solving these problems. To create lasting solutions to social problems on a large scale, organizations – including those in government, civil society, and the business and non-profit sectors – 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 partners.

The time for *Dementia-Friendly Communities* in Ontario 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 other conditions; 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.

³⁴ Karnia, J., Kramer, M. 2011.

Using a Collective Impact approach and the *dementia-friendly communities* model, funded by and in partnership with the Ontario Trillium Foundation, 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.

This paper and engagement with those reviewing it, is the second step in the Ontario Trillium Foundation's process aiming to develop a *dementia-friendly communities* model, and builds on the earlier "Environmental Scan" report that identified an issue. Moving through the Ontario Trillium's Collective Impact model, this step has been about engaging with a broader audience to build the case for change, using a *dementia-friendly communities* model that fits our own unique and shared realities, and our collective vision for the future.

Results of the Groundwork Environmental Scan:

The nature of dementia:

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 self-managing other chronic conditions³⁵.

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 disease³⁶. 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 years³⁷.

While the risk of dementia does increase with age, up to 10% of cases start before the age of 65³⁸. In 2013, more than 8,900 community-dwelling Ontarians (excluding those living in long-term care homes) between the ages of 40 and 65 were living with a diagnosis of dementia³⁹.

More importantly, the very nature of cognitive decline and its impact on decision making and participation in daily living by people living 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 language⁴⁰. 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".

³⁵ Dementia evidence brief. 2012.

³⁶ Dementia: A public health priority. 2012.

³⁷ Dementia: A public health priority. 2012.

³⁸ Dementia: A public health priority. 2012.

³⁹ Bronskill, S.E., Yates, E., Guan, J., Walker, J., Newman, E., Wang, X., Vermeulen, M. 2016.

⁴⁰ Phelan et al. 2012.

The human right to quality of life and the gap for people with dementia:

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 all older people have to the highest attainable standard of health⁴¹. 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 respect⁴².

“Imagine you woke up tomorrow and were told you had a diagnosis of dementia. How would you like people to view you? Would you like to still be included in your local community or told you could not participate anymore? How would you feel to be ignored, lose friends, and be treated with disrespect? Would this be giving you and your family a fair go? This has been my experience and many others have told me they have had similar experiences.” (Graeme Atkins)⁴³

While the cognitive challenges of dementia are significant, what is perhaps even more challenging for people living with dementia is the stigma they face as a result of dementia.

Stigma is something which causes an individual to be classified by others in an undesirable, rejected stereotype⁴⁴. Misconceptions of dementia and the people who are affected by stigma are a problem around the world. Stigma causes individuals and organizations to behave in ways that are unhelpful, emphasizing the symptoms of the disease rather than supporting the abilities that people living with dementia have. It is a barrier to improving dementia care, to people reaching out for help, and to furthering research⁴⁵.

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. Others interpret and frame their actions, emotions, and expressions, as a result of dementia, rather than as legitimate responses

⁴¹ Boera, B., Bhushan, A., Abou Taleb, H., Vasquez, J., Thomas, R., Ferguson, L. 2016 (in press); in World report on aging and health. 2015.

⁴² Ontario's action plan for seniors: independence, activity and good health. 2013.

⁴³ Atkins, G. 2014

⁴⁴ Goffman, E. 1963.

⁴⁵ Batsch, N.L., Mittleman, M.S. 2012.

to circumstances around them⁴⁶. This deprives the person living with dementia of the companionship of family and friends: the resulting isolation and lack of stimulation causes disability beyond that caused by the illness itself⁴⁷.

Stigma by association is considered one of the barriers to care partners' 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 living with dementia undoubtedly reinforce negative self-concepts of family care partners. If care partners 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 improved⁴⁸.

Social isolation is commonly defined as a low quality and quantity of contact with others. Social isolation of older adults can cause communities to suffer from higher social costs and the loss of unqualifiable wealth and experience; reduced opportunities for older adults 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 older adults have been identified as being at greater risk of social isolation, including adults with Alzheimer's disease and other dementias, and older adults who are care partners⁴⁹.

People with dementia often report a decreasing circle of friends and family following the disclosure of a dementia diagnosis. Social isolation is different than loneliness, which is a perception of a lack of interaction or contact with others. Social isolation increases the likelihood of loneliness, and a person living with dementia can perceive and experience being lonely even when in the company of others.

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

⁴⁶ Mitchell, G., Dupuis, S.L., Kentos, P. 2013.

⁴⁷ Batsch, N.L., Mittleman, M.S. 2012.

⁴⁸ Batsch, N.L., Mittleman, M.S. 2012.

⁴⁹ Report on the social isolation of seniors. 2014.

The desire of people with dementia for change:

One of the most significant changes in our conversations about dementia is that people living with dementia want to talk. 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 are speaking up. And for perhaps the first time, those around them are starting to listen.

People living 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 living with dementia as well.

Until recently, thinking about dementia was dominated by biomedical ideas. However, conversations focused on the interplay between the person living with dementia and their social environment have now advanced substantially. Alongside the psychological approach, the social model of disability is increasingly being applied to understanding dementia care⁵⁰. Researchers and practitioners are finding ways to listen to, and to communicate with, people living 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 living with dementia are enabled to communicate and are listened to, 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 met⁵¹.

Perhaps the most powerful means of reducing the stigma and correcting the common misconceptions surrounding dementia is for those who have dementia to be seen and heard more than they are now. Increasingly, people living with dementia are coming forward to show that an active and fulfilling 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 change⁵².

⁵⁰ Mental Health Foundation, 2015; and Swaffer, 2016.

⁵¹ Cantley, C., Steven, K., Smith, M. 2003.

⁵² Batsch, N.L., Mittleman, M.S. 2012.

Several awareness campaigns have and are now focused on helping people see past the disease to the person, including: Let's face it⁵³; See me not my disease⁵⁴; DeMENTia⁵⁵; I have dementia, I also have a life⁵⁶; and #StillHere⁵⁷.

Older adults in general have contributed to growth and prosperity and continue to help communities and drive the economy. Older adults have said that they want to be recognized for those contributions, and treated as important members of their 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 to choose to live at home for as long as they can, and have attractive alternatives if they cannot⁵⁸.

People living with dementia define 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 change⁵⁹.

People living with dementia and care partners describe seven outcomes that are most important to their quality of life:

- they have a personal choice and control or influence over decisions about them;
- they know that services are designed around them and their needs;
- they have support that helps them live their lives;
- they have knowledge and know-how to get what they need;
- they live in an enabling and supportive environment where they feel valued and understood; and
- they know there is research going on which delivers a better life for now and hope for the future⁶⁰.

⁵³ Alzheimer Society Canada. Website.

⁵⁴ Alzheimer Society Canada. Website.

⁵⁵ Alzheimer Society UK. 2015.

⁵⁶ Alzheimer Society UK. Website.

⁵⁷ Alzheimer Society Canada. Website.

⁵⁸ Ontario's action plan for seniors: independence, activity and good health. 2013.

⁵⁹ Cantley, C., Woodhouse, J., Smith, M. 2005.; DEEP, 2016.

⁶⁰ Kane, M., Cook, L. 2013.

“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 living with dementia will need more support to stay active and engaged, but it is still possible⁶¹.

⁶¹ Batsch, N.L., Mittleman, M.S. 2012.

The impact on care partners and family members:

Family caregiving is not new – most families expect to provide support when a family member 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 an older family member. With shifting demographics, family members will be called upon more frequently to support another member in a time of need. While most embrace the opportunity, the reality is that the responsibilities of a care partner 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 respond⁶².

On an average in Canada, family care partners 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 care partners. If expected to continue to support and care for their family members, care partners will need to be better supported⁶³.

Care partners are the champions of dementia care, maintaining the connection and dignity for the person living with dementia. Being a care partner is a physically, emotionally, and financially demanding role that changes throughout the dementia journey, and much support is needed to help the care partner during this time⁶⁴.

According to Ontario home care assessments, most people living with dementia have at least one individual providing unpaid care⁶⁵. The care needs of people living 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 7 to 15 hours per day⁶⁶.

⁶² Family caregivers – the essential ingredient to successful health care transformation. 2015.

⁶³ Bringing care home: report of the expert group on home and community care. 2013.

⁶⁴ Dementia: A public health priority. 2012.

⁶⁵ Gill, S.S., Camacho, X., Poss, J.W. 2011.

⁶⁶ Davis et al. 1997.

People caring for someone with dementia provide 75% more care hours than other care partners and experience nearly 20% greater stress⁶⁷. In a national survey of Alzheimer's disease care partners aged 44 to 64 years old (non-spouse), 35% reported declines in general health – this rate increased to 60% among live-in care partners⁶⁸.

A Canadian Institute for Health Information study determined that rates of distress for caregiving 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 older adults without cognitive impairments⁶⁹.

⁶⁷ Seniors in need, caregivers in distress: what are the home care priorities for seniors in Canada? 2012.

⁶⁸ Black et al. 2010.

⁶⁹ Supporting informal caregivers – the heart of homecare. 2010.

Acknowledging that current structures are not working:

Recognition of the incidence and impact of dementia is only now becoming better known. 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 care partners to not only address health issues, but also to live well despite any condition that may exist.

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 acute or chronic care; all failing to address the complexity of the disease. Ontario's network of programs and services for older adults is highly complex, with a different set of services organized, delivered and communicated by different ministries and providers.

A common theme with various care models is that there is not yet a clear understanding of the nature of dementia. There is no one government department with a responsibility to focus on dementia - each jurisdiction has found its own way to deal with the management of dementia⁷⁰. Dementia care is not central to planning, policy, investment and action, at many levels.

Many "responses" work only when there is a collaborative approach to identify commonalities and design models where stakeholders work together. Current structures and models are not designed to promote cross-sector and multi-level collaborations. One report found that provincial integration efforts for those with needs cutting across health care sectors were stymied when providers were operating under different rules and regulations that prevented the smooth delivery of needed care⁷¹. Many of these health providers are limited to providing actions that can meet the requirements of their funders, so that activities that are not care-based do not receive as high priority.

Many local programs are restricted in how provision is provided for people living with dementia. As an example, in some communities, people with the potential for escalated behaviour are not permitted to be transported in a community vehicle, nor are they permitted

⁷⁰ Rising tide: the impact of dementia in Ontario. 2008 to 2038. 2009.

⁷¹ Hollander, M., Prince, M. 2001.

to have a care partner travel with them to manage any potential behaviour challenges, even if the vehicle is empty of other passengers.

When we think of a “disease”, we often think of having a need for medical treatment to try and fix the person. While we wait for a cure for dementia, there is nothing to fix.

With the current definition of dementia as a disease, there are missed opportunities that can come from defining it as a disability, such as requirements for improvements to accessibility and accommodation practices for people living with dementia that would provide them with increased opportunities to live well in their communities.

While dementia is a chronic disease, it is not always recognized among other chronic conditions, often seen as something that happens with aging, and exists as a co-morbidity with other conditions.

Existing government policies and services most often focus on the health and care needs of a person living 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 people living with dementia and their families as well⁷².

Until now, the design used for chronic disease prevention programs have mostly come down to a series of recurrent interventions aimed at changing individual living habits, with the results that can only be qualified as inconclusive. Dementia, while there is some recent evidence that it can be delayed, cannot be prevented by changing living habits⁷³.

The downloading of services from the provincial to the municipal level of government often leaves municipalities stretched to find resources from their communities, creating a major obstacle to the full implementation of age-friendly (and potential dementia-friendly) initiatives. Programs that do exist tend to start at the ground level in communities, but lack the

⁷² Living with dementia in the community – challenges and opportunities. 2014.

⁷³ Sasseville, N., Simard, P., Mucha, J. 2012.

infrastructure, or knowledge sharing, that can aid in their growth and replication in other communities⁷⁴.

Age-friendly work requires a dementia lens that considers the unique needs of people living with dementia, including their cognitive ability to navigate their social and physical environment, and the unique needs for supporting people living with dementia to engage. Most of the accessibility work to date in the community is focused on changes to the physical environment, with a gap for the cognitive needs of people living with dementia.

One report examines the emerging municipal response to this coming wave of an aging population, noting such things as an awareness of a growing labour force gap, challenges of accommodating an aging population while securing future economic growth. Changes in demographics touch diverse areas such as transportation, land use planning, local economic development, recreation and affordable housing. Older adults who wish to age in place in rural communities face greater barriers to remain in their homes, stay alive, and remain engaged with their communities⁷⁵.

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.

The goal of integrated models of care is to improve the coordination of care for individuals who are reliant on a complex array of specialized medical, community and social systems. However, 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 families⁷⁶. Many respondents to one study said that families have to deal with too many different agencies, and that the current structure is cumbersome, has too much overlap, is not efficient and is not delivering the services that families want. Clients, particularly those who are not urgently ill, are

⁷⁴ Cerda, M., Bernier, N. 2013.

⁷⁵ Canada's aging population: the municipal role in Canada's demographic shift. 2013.

⁷⁶ Bringing care home: report of the expert group on home and community care. 2015.

finding themselves increasingly on wait lists or being deemed ineligible for publicly-funded services they once had⁷⁷.

And while policy makers and providers have long supported the principle of family-centered care, one of the most significant concerns voiced by patients and care partners who are frequent users of health services, is that care is uncoordinated and it can be difficult to tell who, if anyone, is in charge⁷⁸.

A shift towards home and community-based care models forecasts that the demand for long-term care beds based on the projected prevalence and severity of dementia notes the availability of long-term care beds is constrained, and leaves a projected shortfall of beds; and predicts increases in people living with dementia living in their homes with some kind of community care support that will significantly increase community care and the burden on care partners⁷⁹.

Our health system could not sustain the current levels of care in the community without the continued contribution of family care partners⁸⁰. Families are the mainstay of the home care system, with an estimate of only 2% of clients managing without a family care partner⁸¹. Without the contributions of family care partners, there would be an increased risk of institutionalization. Premature placement in institutional care is both costly and socially unacceptable to Ontarians⁸².

Care partners of people living with dementia provide an estimated 75% more care than care partners of individuals with other health conditions⁸³; they experience physical, psychological and emotional strain, financial hardship and occupational insecurity⁸⁴. Care partners themselves are often living with two or more of their own chronic health conditions⁸⁵.

⁷⁷ Bringing care home: report of the expert group on home and community care. 2015.

⁷⁸ Who is the puzzle maker? Patient/caregiver perspective in navigating health services in Ontario. 2008.

⁷⁹ Rising tide: the impact of dementia in Ontario. 2008 to 2038. 2009.

⁸⁰ Bringing care home: report of the expert group on home and community care. 2015.

⁸¹ Canadian Institute for Health Information. 2010.

⁸² Family caregivers – the essential ingredient to successful health care transformation. 2015.

⁸³ Seniors in need, caregivers in distress: what are the home care priorities for services in Canada? 2012.

⁸⁴ Miller et al. 2012.

⁸⁵ Seniors in need, caregivers in distress: what are the home care priorities for services in Canada? 2012.

While providing care for family members is not a new concept, the context of caring is different. Social and economic conditions have changed significantly, and with our aging population, shrinking workforce, unstable economy, smaller and more dispersed families, the impact will be further exacerbated over time.

More than 1 in 4 Canadian adults provide care that complements our health care and social service system, however only limited and inconsistent supports are available to these care partners. While care partners are “invaluable” they are also “invisible”. There is little formal recognition of the care partner needs in these key areas: the serious lack of community supports and services to relieve the caregiving burden, limited financial assistance to reduce caregiving costs, and workplace accommodation to ease caregiver time and financial pressures. The fact that care partners are unpaid means that both their contributions and concerns have been largely ignored⁸⁶.

Collectively, Canadian care partners 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. Care partners of community-dwelling adults with high needs spent an average \$7599 per year⁸⁷.

Low income households are most affected by these additional costs. They pay a disproportionately higher percentage of their incomes on care partner 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 owing⁸⁸.

In addition to immediate costs, the financial security of care partners is affected in other ways. Employed care partners have multiple competing demands. Being responsible for care can result in disruptions to normal work routines. Care partners’ employment status can be

⁸⁶ Torjman, S. 2015.

⁸⁷ Fast et al. 2013.

⁸⁸ Torjman, S. 2015.

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 from work. Employed care partners often lose income, benefits and pensions in trying to balance work and family responsibilities⁸⁹.

The non-profit sector most frequently operates using an approach that one group calls “isolated impact”. It is an approach oriented towards 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 world⁹⁰.

No single organization is responsible for any major social problem, nor can any single organization cure it. The problem with relying on the isolated impact of individual organizations is further compounded by the isolation of the non-profit 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 sector⁹¹.

The Alzheimer Society of Ontario, the Alzheimer Society of Canada and other organizations, 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.

⁸⁹ Torjman, S. 2015.

⁹⁰ Kania, J., Kramer, M. 2011.

⁹¹ Kania, J., Kramer, M. 2011.

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

Stigma is a key issue for people living with dementia. From experience with other populations who have and still do experience social isolation from stigma, what is needed is on the scale of a movement, not a program, that will reduce the stigma and increase the experience of belonging that people living with dementia are looking for, and have a right to have. And, with a focus on inclusion of people in the design of their future, within and external to the health care system, more understanding of how to successfully engage with people living with dementia will be required.

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 implementation.⁹²

⁹² Feldman, H. and Estabrooks, C. 2015.

An urgency to finding a new path:

There is no doubt that the incidence of dementia is increasing rapidly, and that the impact of dementia will continue to rise and spread. For the first time in Canada, there are more older adults (aged 65 and older) than children (14 and younger). The aging (boomer) population will significantly impact this incidence. In 2016, over 220,000 older adults (65+) are estimated to be living with some form of dementia. The number is expected to increase by 13% to nearly one quarter of a million people by 2020⁹³. In 2013, 99,300 Ontarians (40+) living in the community (not including long-term care) were living with a diagnosis of dementia, an increase of more than 40% since 2007⁹⁴. National reports in both the United States and the UK indicate that dementia is among the most feared diseases associated with getting older⁹⁵.

The World Health Organization has declared dementia to be a “public health priority” on a worldwide scale⁹⁶. Dementia is the most significant cause of disability among Canadians (65+) and it already costs Canadian society billions of dollars each year⁹⁷. Dementia is a core issue impacting Ontario’s health and social system⁹⁸. 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 care partners today.

Ontario’s Action Plan for Seniors predicts the effect of aging for Ontarians 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 older adults⁹⁹.

⁹³ Hopkins, R. 2010.

⁹⁴ Bronskill, S.E., Yates, E., Guan, J., Walker, J., Newman, A., Wang, X., Vermeulen, M. 2016.

⁹⁵ Batsch, N.L., Mittleman, M.S. 2012.

⁹⁶ Dementia: A public health priority. 2012.

⁹⁷ Rising tide: the impact of dementia on Canadian Society. Executive Summary. 2010.

⁹⁸ Dementia evidence brief. 2012.

⁹⁹ Ontario’s action plan for seniors: independence, activity and good health. 2013.

Digging Deeper and Looking Forward:

Exploring how we define dementia, and the social model of disability:

“I am so frustrated, because no one realizes how seriously disabled I am. If I had a loss of a limb or some other visual ailment, it would make people realize¹⁰⁰.”

The Alzheimer Society of Ontario is one of many groups 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.

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 disability¹⁰¹. 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 situations¹⁰². The Ontario Human Rights Commission provides the most relevant information related to defining disability as it relates to dementia¹⁰³.

Rarely have the words dementia and rights been 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)¹⁰⁴. Organizations are also using the relevant legislation to challenge decisions

¹⁰⁰ Michael Ellenbogen, in Batsch, N.L., Mittleman, M.S. 2012 (p. 15).

¹⁰¹ Mental Health Foundation. 2015.; and Swaffer. K. 2016.

¹⁰² World Health Organization. Website.

¹⁰³ Ontario Human Rights Commission. Website.

¹⁰⁴ Alzheimer Society of Ireland. 2014; Alzheimer Society of Scotland

that are being made by service providers and agencies if they are denying people access to services on the basis of a dementia diagnosis alone¹⁰⁵.

The focus of the current medical model is on impairment, the physical or biological condition of people with disabilities¹⁰⁶. 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 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 impairment¹⁰⁷.

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 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 disabilities¹⁰⁸.

¹⁰⁵ McGettrick, G., Williamson, T. 2015.

¹⁰⁶ Oliver, M. 2009; Swaffer, K. 2016.

¹⁰⁷ Winter, J.A. 2003.

¹⁰⁸ Winter, J.A. 2003.

If dementia was defined as a disability, learning from others:

At the heart of the disability rights movement is the fact that people living with disabilities want to be seen as people first, to be treated as individuals, to have opportunities to participate in and contribute to society, and not as cases or categories of disablement, powerless to share their lives¹⁰⁹.

The disability movement was launched by people living 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, the disability movement has insisted on the right of disabled people to be heard¹¹⁰.

Many years ago people living 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 supports¹¹¹.

A sociological overview of the development of the rights movement describes the movement as arising to combat the oppressive marginalization of persons living with disabilities¹¹². 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 living with disabilities into the societal mainstream¹¹³.

The changes being offered through the social model hold that disability is not a tolerable, necessary result of an individual's impairment, but something created in large part by a society's response to the impairment¹¹⁴. Indeed, it is a society's response to an impairment which disables a person, not the impairment itself¹¹⁵.

¹⁰⁹ Union of the physically impaired against segregation. 1976.

¹¹⁰ Mittler, P, in Batsch, N.L., Mittleman, M.S. 2012.

¹¹¹ Mittler, P. in Batsch, N.L., Mittleman, M.S. 2012.

¹¹² Barnes, C. Mercer, G. 2010.

¹¹³ Winter, J.A. 2003.

¹¹⁴ Oliver, M. 2009.

¹¹⁵ Winter, J.A. 2003.

The 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 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 disability, and not on the impairment per se¹¹⁶.

There are several implications for dementia policy and practices/services. In the social model, people living with dementia are center stage, with their voices elevated, and are recognized as equal citizens with rights. They are the agents of change and their agency is valued and recognized¹¹⁷.

In the dementia context, society has been entrenched in the biomedical and individual model where there is a need to “fix” people living with dementia. Medications, pathology, diagnostic tests, and medical care are indicative of a medical model, where people’s expressions, communication, and behavior are interpreted through a lens of pathology¹¹⁸.

More recently in the dementia context, there is movement to consider a person-centered or individual model. This is evidenced in language around the person, in particular, person-centered language. This approach also presupposes that people must be seen as people not as a pathology, and supported as individuals. In this approach, focus is not often on environmental and social issues, but on trying to support the person and his/her support networks.

A social model extends far beyond individual and medical models to shift the focus on seeing people living with dementia as citizens, and looking to environmental and social concerns as the focus for change¹¹⁹. A social model recognizes that social exclusion, stigma, and discrimination are key factors in the quality of life for people living with dementia. A social model of disability shifts focus from “person-centered” to social citizenship¹²⁰. It moves the focus from what others do to support people with dementia to what rights people living with dementia have as citizens of their communities. This doesn’t negate the need for support services, but rather shifts the focus to understanding how social exclusion marginalizes people living with dementia.

¹¹⁶ Winter, J.A. 2003.

¹¹⁷ McGettrick, G., Williamson, T. 2015

¹¹⁸ Mitchell, G.J., Dupuis, S.L., Koutos, P.C. 2013.

¹¹⁹ Barnes, C., Mercer, G. 2010.

¹²⁰ Bartlett, R., O’Connor, D. 2010.

It is understood that the need for people living with dementia have the same rights to resources, accessibility, social networks and interactions, freedom from discrimination, the right to having meaning and purpose, to participation in society and decisions that affect their lives¹²¹.

The social model of disability argues that people living with dementia have a range of impairments, and as a result, face a variety of disabling barriers, including attitudinal, social, psychological, architectural, physical and institutional. Such barriers have led to their marginalization, exclusion and oppression¹²².

In a broader context, rather than focusing on solely providing support services, societies and communities would be more open and inclusive of people living with dementia. A social model of disability does not mean that support services, services that assist people living with dementia and their care partners, and health care services, are not needed. Rather, it sees these as a means to an end- how people living with dementia can be integrated into their communities¹²³.

A current manifestation of the social model in practice is the development of *dementia-friendly communities*. Tools have been developed to enable adoption of a rights-based approach and these can be effectively used in developing dementia policy and practice¹²⁴.

However, moving towards a social model requires massive change at the micro and macro levels. There are many stakeholders involved and their roles in this model change significantly and a shift in the power dynamics is necessary. Societal change is also needed in the form of a shift from the current medicalized perspective on dementia to one that is based on the principles of solidarity and inclusion¹²⁵.

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

¹²¹ Bartlett, R., O'Connor, D.; Mental Health Foundation. 2015.

¹²² Swaffer, K. 2016.

¹²³ Swaffer, K. 2016.

¹²⁴ McGettrick, G., Williamson, T. 2015

¹²⁵ McGettrick, G., Williamson, T. 2015

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 living with both dementia and disability¹²⁶.

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 by all people living with dementia. However, what the social model does do is open up the choices and options, and offers alternatives to the current responses and approaches¹²⁷.

Another perspective comes from the "healthy communities movement" that had its origins in Canada during the 1980's. The movement became worldwide when the World Health Organization (WHO) initiated their own healthy cities project. The fundamental core value of the healthy community approach is capacity building and empowerment of individuals, organizations and communities¹²⁸.

Based on the World Health Organization's success factors for any healthy community initiative, the healthy communities approach addresses multiple determinants of health (social, economic, environment, physical) and is based on five essential strategies, or building blocks, to build on a community's existing capacity to improve health and well-being: community/citizen engagement; multi-sectoral collaboration; political commitment; healthy public policy, and; asset-based community development.

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.

¹²⁶ Rees, G. 2010.

¹²⁷ Winter, J.A. 2003.

¹²⁸ The healthy communities approach: a framework for action on the determinants of health. Website.

Recognition of the need for a movement:

As we continue to explore what a response would look like to this growing need and urgency for change, and as we more clearly identify and recognize the need to focus on the human right that people living with dementia have to a high quality of life, we acknowledge that what is required is on the scale of a movement, something bigger than any one or a few programs and initiatives.

Key issues for people living with dementia have been identified that align with the goals of a movement – the need to increase the rights of a certain population, the need to elevate the voices of that population, and the need to empower that population to be agents of change.

Movements of the past have demonstrated their successes in accomplishing, or at least moving towards their goals, through common key elements: a focus on increasing awareness of the condition; enabling the people affected to have a voice; creating environments that are supportive; developing legislation that provides directive; including all stakeholders, top down and bottom up; and providing tools and resources that support a collective approach.

A change management framework provides a simplified and logical approach to not only change the perceptions of individuals, but the community as a whole. An 8-step change model draws on a theory of change that suggests providing guidance and direction to peoples' rational side, whilst also appealing to factors which motivate their emotions: create a climate for change (create a sense of urgency, form a powerful coalition, create a vision for change); engage and enable the whole community (communicate the vision, remove obstacles and empower action, create short-term wins), and implement and sustain change (build on the change, anchor the changes in community culture)¹²⁹.

¹²⁹ Bartholomew, J., Moore, B. 2014.

The need for a collective response (collective impact model¹³⁰) and community engagement:

Collective Impact is the commitment of a group of individuals and organizations 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, the business and non-profit sectors – 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.

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 measurable 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.

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

¹³⁰ Tamarack Foundation. Website.

staff, and a structured process that leads to a common agenda, shared measurement, continuous communication, and mutually reinforcing activities among all participants.

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.

Dementia-Friendly Communities as a framework to guide the movement:

“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”¹³¹.

The concept of *dementia-friendly communities* has captured the imagination of consumers, policy makers and researcher around the world. At one level the concept is interestingly simple – namely to work for the common goal of a better life for people living with dementia. But it is much more than this. *Dementia-friendly communities* have the power to change the way society thinks about living with dementia. It marks a fundamental shift from a focus of meeting the physical and health needs of the people living with dementia to a holistic approach to supporting the person to achieve the best quality of life reasonably possible¹³².

Dementia-friendly communities are a manifestation of the social model of disability in practice. The *dementia-friendly communities* 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 living with dementia live to be responsive and adapt to situations. *Dementia-friendly communities* focus on inclusion and coming together of communities to challenge the current status quo, often characterized by the exclusions and

¹³¹ Finding out what a dementia-friendly community means to people with dementia and carers: making Hampshire a dementia-friendly county. 2012.

¹³² Rees, G. 2015.

marginalization of people living with dementia, and the reinforcement of social isolation and ongoing inequalities¹³³.

Alzheimer's Disease International notes certain key strategic considerations for *dementia-friendly communities*: *dementia-friendly communities'* efforts are a response to pervasive and destructive stigma; *dementia-friendly communities* 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 intertwined¹³⁴.

The rationale for creating *dementia-friendly communities* comes from the voices and experiences of people living with and affected by the condition. It is about ensuring that people living 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 life, affecting not only the individual but also their care partners, family members and friends¹³⁵.

The definition of a dementia-friendly community varies across initiatives, but common to all is an emphasis on the social dimensions of dementia over the medical. Alzheimer's Disease International states that dementia-friendly communities not only seek to preserve the safety and well-being of those living with dementia, but also empower all members of the community to celebrate the capabilities of people living with dementia, and view them as valuable and vital members of the towns, cities, villages and countries in which they reside¹³⁶.

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*¹³⁷.

¹³³ Winter, J.A. 2003.

¹³⁴ Dementia friendly communities: new domains and global examples. 2015.

¹³⁵ Green, G., Lakey, L. 2013.

¹³⁶ Dementia friendly communities: new domains and global examples. 2015.

¹³⁷ Alzheimer Australia. Website.

The work of *dementia-friendly community* initiatives is designed to complement a national strategy (focused on health services). *Dementia-friendly communities* 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 community¹³⁸. *Dementia-friendly communities* are an important vehicle for reducing social isolation and loneliness¹³⁹.

It is important to say what dementia-friendly is not: it is not the same as charity – it is not a gift but a right to participate in society; it is not simply about numbers of dementia friends; it is not about achieving light training of dementia-friendliness if that doesn't lead to *dementia-friendly communities*; and it is not about relieving governments of their responsibilities¹⁴⁰.

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 living with dementia and their care partners. Everyone, from governments to the local corner shop, share part of the responsibility for ensuring that people living with dementia feel active, engaged, and valued¹⁴¹.

To achieve success with *dementia-friendly communities* will require a change in attitudes and culture of the kind that people with disabilities and their advocates have fought for over many decades and are founded in the convention of the rights of people with disabilities¹⁴².

These unique needs (of people living with dementia) 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 people living with dementia¹⁴³.

Just as the majority of *dementia-friendly community* building programs should be driven by those living with dementia, many of the initiatives should also have some fluidity and overlap. Efforts should be streamlined and not duplicate, but should feed into one another, all working

¹³⁸ Dementia-friendly communities: learning and guidance for local authorities. Website.

¹³⁹ Kane, M., Cook, L. 2003.

¹⁴⁰ Rees, G. 2015.

¹⁴¹ Green, G., Lakey, L. 2013.

¹⁴² Rees, G. 2015.

¹⁴³ Dementia friendly communities: new domains and global examples. Website.

towards the common goal of a better life for people living with dementia, with the elimination of stigma¹⁴⁴.

¹⁴⁴ Dementia friendly communities: new domains and global examples. Website.

Dementia-friendly building on age-friendly:

One of many definitions for an age-friendly community 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. Age-friendly communities contribute to good health and allow people to continue to participate fully in society throughout their lifetime¹⁴⁵.

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 country¹⁴⁶.

Age-friendly communities 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. Stakeholders from many sectors are working together to help create more inclusive environments¹⁴⁷. While the origins of the age-friendly concept focused on older adults, the model is expanding to include making improvements for people of all ages, as accessible and inclusive physical and social environments are beneficial for everyone.

Much of the work of World Health Organization's approach to developing 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 World Health Organization 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 together¹⁴⁸.

These actions take many forms, but enhance 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 environment¹⁴⁹.

¹⁴⁵ Age friendly communities planning outreach initiative. Website.

¹⁴⁶ Miller, G., Annesley, A. 2011.

¹⁴⁷ Finding the right fit: age-friendly community planning. 2013.

¹⁴⁸ World report on aging and health. 2015.

¹⁴⁹ World report on aging and health. 2015.

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 approach¹⁵⁰.

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 development to ensure inclusion of the needs of people living with dementia and their care partners.

The *dementia-friendly communities* model is a natural extension of the age-friendly movement and initiatives. Those already engaged in age-friendly work can easily add to their efforts without the need to create all new parallel action groups. 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 focused mostly on the social and physical environment, while dementia-friendly features tend to focus more on the person and their cognitive ability to navigate their social and physical environments;
- The ability to navigate social and physical environments is more challenging for people living with dementia when you consider the reality of managing perceptual disturbances, confusion, agitation, behaviours and memory issues – people living with dementia have a very different experience of the world;
- Age-friendly features make reference to physical and visible disabilities, and fewer references to cognitive and communication disabilities, or the invisible disabilities, that are more pronounced in the dementia-friendly features;
- While the focus of age-friendly features began with older adults, it is now expanding; however the dementia-friendly features acknowledge that middle-aged adults, those more likely to be living in the community, can be impacted;

¹⁵⁰ World report on aging and health. 2015.

- Age-friendly materials strongly encourage engagement of older people, and dementia-friendly materials strongly encourage engagement with people living with dementia and care partners, in identifying needs and developing appropriate strategies in the process of designing and building friendly communities; however, this engagement brings its own unique challenges such as transportation to meetings and events, communication, and being nimble enough for people living with dementia to see the results of their contributions;
- The significant role care partners play in the lives of people living with dementia, and their ability to move throughout the community, has to be acknowledged; and
- The significant focus for *dementia-friendly communities* on changing attitudes, reducing stigma, and increasing belonging, also has to be acknowledged.

Dementia Friendly Communities successes:

Hampshire County Council (UK)¹⁵¹:

- Within the UK’s National Dementia Strategy, there were a range of objectives that included: improving public awareness and reducing social exclusion; increasing access to good quality information, advice, care and support for people following a dementia diagnosis; and improving community support for people living with dementia and their care partners;
- Hampshire experienced an unexpectedly high volume of demand for the dementia awareness sessions following the launch of their Dementia Friends campaign, with participant targets exceeding fourfold in areas where dementia-friendly high street¹⁵² activities were carried out;
- Dementia action groups were recommended for investigation in the project implementation, to note that these have grown organically over the life of the project out of the work of the dementia-friendly high streets. These action groups were composed of volunteers, professionals, care partners and some people living with dementia, and were seen by staff as a key ingredient in maintaining sustainability. Finding a lead person/organization was seen as critical to their ongoing success and survival;
- Two main benefits were identified in the dementia-friendly high streets work. Staff reported feeling more confident in dealing with incidents involving customers living with dementia, in terms of how to talk to the customer and care partner; and there were a number of examples where someone living with dementia had wandered away from the care partner and dementia-aware staff had been able to help;
- While there were some differences in emphasis, it was clear that there was a common understanding of increased awareness and understanding in the communities which would enable people living with dementia and their care partners to feel safe and comfortable in the community; both in the number of people attending dementia awareness sessions voluntarily; and the success of the dementia-friendly high streets work, along with the large number of signatories to the Hampshire Dementia Action Alliance, and the establishment of their own individual action plans;
- Dementia Advisory Groups indicate that the project was able to contribute to the development of an engaged community seen to promote inclusivity; many

¹⁵¹ Hampshire County Council: evaluation of Hampshire dementia friendly communities. Final Report. 2015.

¹⁵² “high streets” and “memory aware schemes” are similar in nature to Alzheimer Society of Ontario’s pilot “blue umbrella” program

interviewees were striking in their passion and commitment to the *dementia-friendly community* concept and their wish to create more inclusive communities. This generated a high level of engagement among these members of the local community; there was widespread consultation and engagement, especially in the first year of the project, with people living with dementia and their care partners to share their views about what would help or hinder the development of *dementia-friendly communities*;

- An important outcome mentioned by interviewees was turning dementia into something that can be talked about – normalizing it; interviewees thought that levels of awareness about dementia had increased significantly, with a shared understanding of what a *dementia-friendly community* means; the project also reached a diverse range of organizations across private, public, and voluntary sectors; and equally from retail to leisure to local groups and clubs, to care providers and general practitioners, to firefighters, police and education;
- Project staff commented on the difficulty of finding people living with dementia who were willing to participate in the project – there were no pre-existing groups of empowered people living with dementia;
- There is no evidence that *dementia-friendly communities* directly affect the need for more intensive support and care of people living with dementia; however, over the long run, by improving the quality of life for care partners and people living with dementia and reducing the stigma of dementia, it may be possible that it enables people with dementia to live longer and better in their communities.

York (UK)¹⁵³:

- The approach of encouraging “many flowers to bloom” has led to a range of small initiatives springing up;
- There needs to be greater focus on integration of health and social care for people living with dementia; organizations need to consider how to use relevant legislation to protect peoples’ rights and to enable people living with dementia to engage in community life;
- It feels good to people living with dementia and their care partners, to be seen as active participants in development and informed contributors to a movement, with rights as well as needs;
- It is still difficult to engage with some individuals and smaller groups of people who are marginalized by their economic, social or environmental situations or their fear

¹⁵³ Dean, J., Silversides, K., Crampton, J., Wrigley, J. 2015.

- of stigma, as well as by the degenerative nature of their dementia; what most people want is the right to live as normal a life as possible for as long as possible;
- Awareness and training are becoming more embedded into the flow of life in York, with many more training opportunities and positive media coverage; it is positive to see more schools and young people engaged in training opportunities and in regular contact with people living with dementia; there have been improvements in awareness of dementia, more people talking about dementia, evidence that people were looking beyond the label to the person; a sense that greater awareness of dementia was resulting in actual willingness to help; awareness of the dementia-friendly program appeared to be high, with many people recognizing the “working to become dementia-friendly” ; work in schools with young people has shown some real innovation and creativity;
 - Respondents said that people in York seemed more dementia-friendly in some shops and other places; there was a sense that employees benefit from the satisfaction of doing their jobs better; the evidence collected from people living with dementia and their care partners suggested that there was more of a “can do” attitude, that staff conveyed the message that “nothing is a problem” and “it’s fine, we can sort it out”;
 - Groundbreaking work pioneered by transport police to raise awareness involves training colleagues to become dementia friends and champions, and building travel confidence in people living with dementia and care partners; an acute ward at hospital developed into a dementia-friendly environment and is spreading throughout the hospital community;
 - The relationship between the concept of a *dementia-friendly community* and a “rights movement” is interesting; for some a *dementia-friendly community* is about making a place easier to live in for a person living with dementia; for others the notion of inclusion is more explicitly about rights; dementia has only recently become something which people are prepared to discuss, and for some it is still a matter which bears a great deal of stigma and shame; but given the progress that has been made through the disability rights movement, and the challenge to age discrimination, there are suggestions that it could be time to consider the particular need of people living with dementia as an equality issue;
 - Learnings: general awareness needs to grow but a rights movement is emerging; dementia has different consequences for women; faith groups have physical resources; the role and contribution of care partners is vital; there is a need to invest long term in community support for people living with dementia; effort is needed to connect *dementia-friendly community* initiatives to mainstream work; people living with dementia need to network; professional networking is crucial for a *dementia-friendly community*; personal and organizational networking helps to build the *dementia-friendly community movement*; social capital and human scale support the

creation of dementia-friendly communities; involve people living with dementia and care partners and supporters in defining and promoting *dementia-friendly communities*.

Bradford (UK)¹⁵⁴:

- The *dementia-friendly community* program is managed by the Alzheimer Society; governance of the *dementia-friendly community* programs is the responsibility of the project advisory group; also established a Dementia Action Alliance, known to be working towards *dementia-friendly communities*, and attracts interest from around the world; successful in engaging with different communities of interest, for example faith groups, LGBT and learning disability;
- The concept of *dementia-friendly communities* was thought to be snowballing as a social movement;
- The program has found it difficult to engage with businesses; by focusing on training, action planning and sharing good practice, local shops and branches of larger organizations have demonstrated that they can remove barriers for people living with dementia;
- Lessons – focus on local communities; inequality of access, including transport, is a barrier to *dementia-friendly communities*; the housing needs of people living with dementia are not well understood; awareness is building but change takes longer; there is an increasing focus on the rights of people living with dementia; it is important to understand diversity and address its impacts; the role and contribution of care partners is vital; more support is needed from general practice; investment in health and social care needs balancing; there is scope for more dementia-friendly resources to be identified; should dementia-friendly activities be integrated or separate?; the idea of a *dementia-friendly communities* movement is growing in importance; professional networking is crucial for a *dementia-friendly community*; the active involvement of people living with dementia, care partners and supporters, is vital to the future of *dementia-friendly communities*;
- Conclusions: the *dementia-friendly community* program in Bradford has been successful overall; there are visible strengths in local focus, addressing diversity and inclusion, supporting and networking between groups, business engagement with key players and in certain locations, and impacting on the strategic partnership agenda;

¹⁵⁴ Dean, J., Silversides, K., Crampton, J., Wrigley, J. 2015.

- Within local communities the influence on local perceptions and understanding of the experience of living with dementia has been strong; a sense of inclusion for people living with dementia is developing, and local political support is very strong in some areas;
- For some people living with dementia and their care partners, involvement in the program itself has been transformational; it has increased insight into their own dementia and given them the confidence to live the life they want;
- Organizations that have embraced the *dementia-friendly community* program have seen benefit, primarily in good customer relationships and fulfilling corporate responsibility obligations.

Dorset (UK)¹⁵⁵:

- The evaluation provides the following recommendations: actively involve people living with dementia and their care partners in the development of *dementia-friendly communities*; define a clear structure from the outset; focus on the whole community; promote the role of an action alliance coordinator when setting up *dementia-friendly communities*; create a steering group with the right mix of people with a “can do” approach; obtain support from key strategic figures within the community; understand the difference between being dementia aware and dementia-friendly; promote transparency between the strategic committee and delivery team; develop and promote a launch event as a means of attracting good publicity and stimulating local interest; promote a *dementia-friendly community* as a community inclusive for all; and share ideas and best practices across *dementia-friendly communities*;
- There was limited contact with people living with dementia in the communities; no members on steering committee were living with dementia, with the feeling that family members spoke for people living with dementia;
- Wide range of evidence that dementia action alliances have been raising awareness; there are examples of simple actions that help individuals living with dementia;
- Felt businesses generally positive, especially those with personal experience of dementia; businesses with social focus and larger organizations with corporate responsibility easier to get on board;
- Evidence suggests that those who used a dementia action alliance approach and set up a steering committee are reporting more progress than the localities that

¹⁵⁵ Innes, A., Cutler, C., Heward, M., Hanbidge, S. 2014.

adopted a memory aware scheme¹⁵⁶; steering groups need “can do” people, a challenge to find people with right attitude and resources/capacity to share.

¹⁵⁶ “high streets” and “memory aware schemes” are similar in nature to Alzheimer Society of Ontario’s pilot “blue umbrella” program

Dementia-Friendly Communities – a high-level glimpse for Ontario:

An early look at the Dementia-Friendly Communities Ontario concept: (note – these statements are all in draft form and will be developed in further detail once the Steering Committee structure is confirmed and members identified, and through the Concept Design and Proposal Development process steps of the Ontario Trillium Foundation’s Collective Impact Funding Stream)

Using a Collective Impact approach and the *dementia-friendly communities* model, funded by and in partnership with the Ontario Trillium Foundation, the Alzheimer Society of Ontario proposes to champion a multi-sector collaborative movement focused on improving quality of life to people living with dementia and their care partners.

Dementia-Friendly Communities Ontario (DFCO) recognizes that people living with dementia are often isolated from their communities. Stigma, and stigma by association, play significant roles in increasing this social isolation and exclusion. The increasing number of people being impacted and the inability of health and social systems to provide supports, compound the opportunities for people living with dementia to live well.

DFCO (draft) defines a *dementia-friendly community* as a place where people living with dementia are supported to live a high quality of life with meaning, purpose and value.

DFCO recognizes that needle-moving change to reduce stigma and increase belonging of people living with dementia in meaningful ways in their communities, will take many years.

DFCO (draft) recognizes the key components of a movement as: provide a voice for people living with dementia; develop and implement the *dementia-friendly communities* model; develop and implement an awareness campaign(s); encourage knowledge exchange (information – research, position papers and strategies; and communication – encourage interaction through website, meetings/introductions and conferences); develop

implementation resources to support action groups (guides, tip sheets, seminars/workshops, focus groups) and respond to targeted interest areas.

DFCO will develop broad end goals that align with empowering individuals, building communities, and strengthening systems.

DFCO will develop broad objectives that align with raising awareness, creating safe spaces, building partnerships and coalitions.

DFCO will support activities and outcomes that are both common and/or unique across the province, but align with the broad goals and shared vision.

DFCO recognizes the need for multi-sector engagement that could include: multi-level governments (municipal, provincial, federal); multi-sector government departments (municipal affairs and housing, tourism and recreation, aboriginal affairs, community safety and correctional services, health and long-term care, women's directorate, senior's secretariat, training colleges and universities, labour, and education); academic ; interest groups (faith, LGBT, formal and informal retired social groups, etc); profit and non-profit groups; businesses; corporate planners; researchers; and most importantly, people living with dementia and care partners.

DFCO recognizes that activities will take place at various levels: Provincially (Steering Committee and province-wide working groups), and through Action Alliances (provincial, local, organization, geographic, sector, long-term and temporary).

DFCO will develop a recognition program that recognizes individual, organization and community commitment levels.

DFCO will develop a process and tools to support the monitoring of progress and evaluation of activities within this collective.

A Movement:

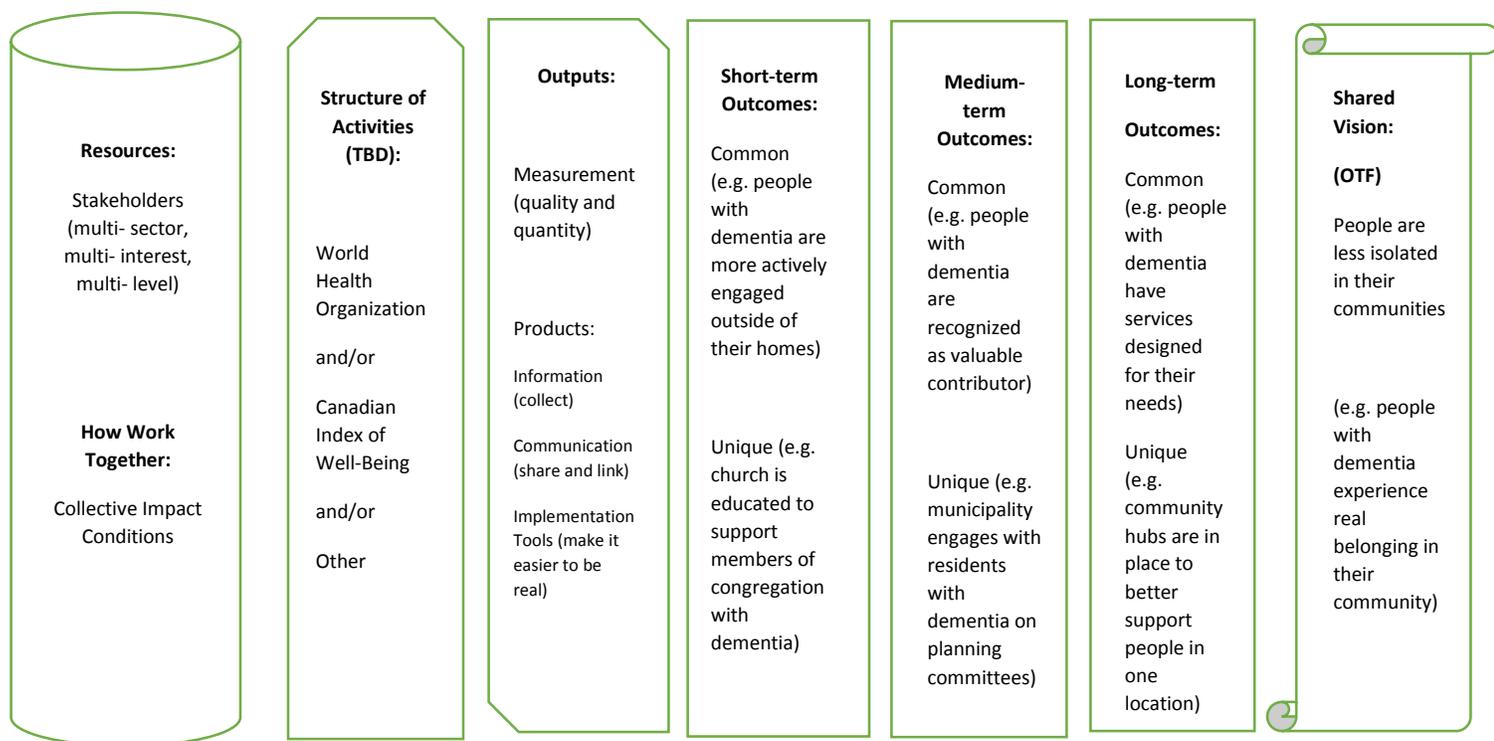
Provide a voice, increase awareness, build supportive environments, develop legislation, provide tools and resources, work top down and bottom up

Goal: Goals: Empower individuals, build communities, strengthen systems

Objectives: Raise awareness, create safe spaces, build partnerships and coalitions

Dementia Friendly Communities:

Definition; Principles; Building Blocks; Commitment Levels; Recognition; Branding



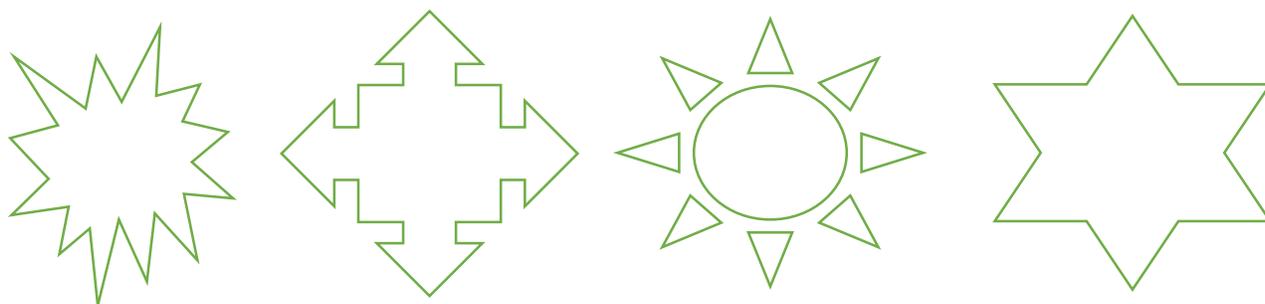
Leadership: Steering Committee and working groups; Backbone Organization (Alzheimer Society)

Fitting the People Together:

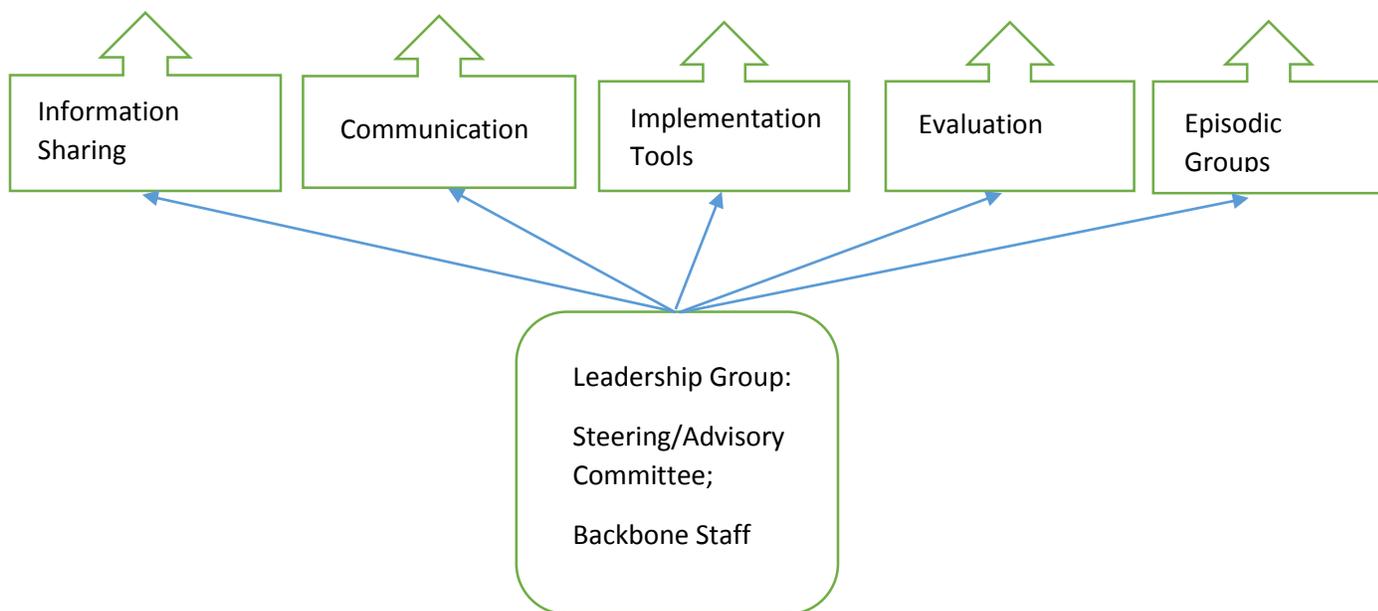


Becoming Dementia Friendly:
Individuals (Dementia Friends),
Organizations, Communities

Action Alliances: Provincial, local, organization; geographic, sector; long-term, temporary.



Working Groups (examples)



Glossary of Terms for the People of DFCO:

DFCO / OTF Leadership Group:

- Steering Committee: a partnership of stakeholders, representing key focus areas/sectors, communities and skill sets, that will provide guidance to the DFCO movement and activities
- Backbone Organization: a staff team that will provide leadership and operational support to the DFCO movement and activities

Partners/Members:

- Individuals and/or organizations who are engaged in the DFCO movement as members of the Steering Committee, and/or through provincial and/or local action groups

Working Groups:

- Working groups are established to address a specific need for focused attention (e.g. develop a communication plan, engage with a unique non-geo community sector to address certain target issues, etc.)

Action (Alliance) Groups:

- Provincially and/or locally, action groups are formed to develop, monitor and evaluate community action plans – they are the enablers of dementia friendly communities

Community:

- A community is a group of people, or population, who have something in common (e.g. geography, language, culture, age ability, sector, interest, need, socio-economic status, etc.)

Dementia Friendly Individuals:

- An individual who becomes more aware of dementia, and commits to personal action

Dementia Friendly Organizations:

- A business/organization who forms an action group, becomes aware and educated, creates a vision, develops guiding principles, assesses their business, identifies short and long term goals, commits to action, and reviews/adjusts over time.

Dementia Friendly Communities:

- A community that forms an action group, engages with persons with dementia, becomes aware and educated, creates a vision, develops guiding principles, assesses their community, identifies short and long term goals, commits to action, and reviews/adjusts over time.

Dementia Friendly Communities Ontario alignments for success:

Ontario Trillium Foundation

Funding Stream	Collective Impact
Action Stream	Connected People
Priority Outcome	Reduced Isolation (people with dementia will experience a high quality of life, with meaning, purpose and value)
Grant Results	People who are isolated will have connections in their community (people with dementia and caregivers will experience belonging in their communities)

Collective Impact

Common agenda	A common vision (TBD) to improve the lives of individuals with dementia and their caregivers
Shared measurements	An evaluation program (TBD) will be developed, that aligns goals, objectives, activities and outcomes towards a common vision
Mutually reinforcing activities	Using the <i>dementia-friendly communities</i> model, and the collective impact model, partners will work together
Continuous communication	Communication will be a key component of this movement
Backbone support	Alzheimer Society of Ontario

Conclusion

Information gathered through various conversations and document scans, have helped to:

- Better identify that there is a significant population impacted by dementia, individuals living with dementia and their family, friends and other care partners;
- Confirm that this is a need for change, and an urgency for that change;
- Better understand the complexity of the issue;
- Confirm there is a need to address the stigma attached to dementia, and to understand how this stigma results in social isolation;
- Better understand how this stigma is not only about being physically limited to social connections, but also about being excluded from meaningful engagement in the community, and about being excluded from connections even when in the same vicinity
- Better understand the potential benefits to re-defining dementia from a disease to a disability;
- Better understand how a social model of disability can help frame the change needed; and
- Better appreciate the social movements of other populations and how a similar model could help people living with dementia.

The next step for this group of individuals and organizations, becoming known as *Dementia-Friendly Communities Ontario*, will be to proceed through the Ontario Trillium Foundation's Collective Impact Stream process.

While there are high-level models and concepts in draft form, DFCO will engage further with the current, and invite and welcome new, stakeholders to develop in more detail the various components of a *dementia-friendly communities* concept.

Appendix A: Groundwork References

Age Friendly Communities Planning Outreach Initiative. Seniors Health Knowledge Network.
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