CULTURALLY RESPONSIVE HEALTHY BRAIN PROGRAM CONCEPTUAL FRAMEWORK

May 2020

This framework is developed as part of the Developmental Evaluation

of the Culturally Responsive Community-Based Healthy Brain program

Special thanks to the partner ethno-cultural groups
providing culturally responsive healthy brain programming
for people living with dementia and their caregivers:

Indo-Canadian Community Centre

Daryeel: A Youth and Senior Serving Organization

Ottawa Valley Filipino Canadian Senior Citizens Association

Kanata Chinese Seniors Support Centre

CONTENTS

ACRONYMS

AFC   Dementia Friendly Community
PLWD   People living with dementia

1- CONTEXT

Meeting the needs of the ageing population and the rapidly increasing incidence of dementia is well recognized as a major pressure on the public purse and individual families. Ethnocultural residents, including immigrants, face unique challenges. Research indicates a lack of knowledge of dementia, and a lack of culturally responsive services lead to a myriad of issues including late diagnosis, minimal support for caregivers and those with dementia. Literature and our research have identified a pressing need for education and outreach services as well as culturally responsive care services.

This initiative is intended to reduce isolation and increase community connections for seniors with dementia and their caregivers from 4 diverse, racialized communities. The project will provide important learning on evidence-based models of care that provide better support to people with dementia and their caregivers, scaling the use of grassroots assets (volunteering, informal groups) to improve quality of life for the participants and maximize effective use of scarce health care resources. This initiative builds on prior work including research on needs/models and consultation with ethnocultural groups re practical solutions they could undertake that would make the most difference, specifically:

- Increase understanding of dementia within diverse cultural communities,
- better equip extended family members and community volunteers to engage isolated community members through regular group activities and home visiting (expanding the reach and quality), and
- pilot cost-effective culturally responsive brain health programs to provide social opportunities for people living with dementia (PLWD) and respite for caregivers.

Goal:

> The goal of the initiative is to design and build an infrastructure of supports for ageing in community and meet the needs of Ottawans for an age- and dementia-friendly community by building social capacity and enabling social support networks of ethnocultural groups.

Long term outcome (Impact):

- Satisfying quality of life for ethnocultural seniors with brain health issues living in community, and enhanced quality of life for their caregivers.

Medium-term outcomes:

- Promote social connections and reduce social isolation among ethnocultural seniors and their caregivers by providing programs and services that are accessible, affordable, and account for brain health, mobility and cultural considerations.
- Enhanced respite programs for caregivers.

Immediate outcomes:

- Increased respite opportunities for caregivers
- Increased culturally responsive brain health programs for older adults

- Increased access to mainstream support services for ethnocultural seniors and their caregivers
- Raise awareness of mainstream health care providers about gaps in service delivery and cultural competence

The following diagram illustrates the conceptual underpinning of the community-based Healthy Brain Program and what it hopes to achieve. The star shows where the Healthy Brain Initiative is situated in the wider social and political landscape.
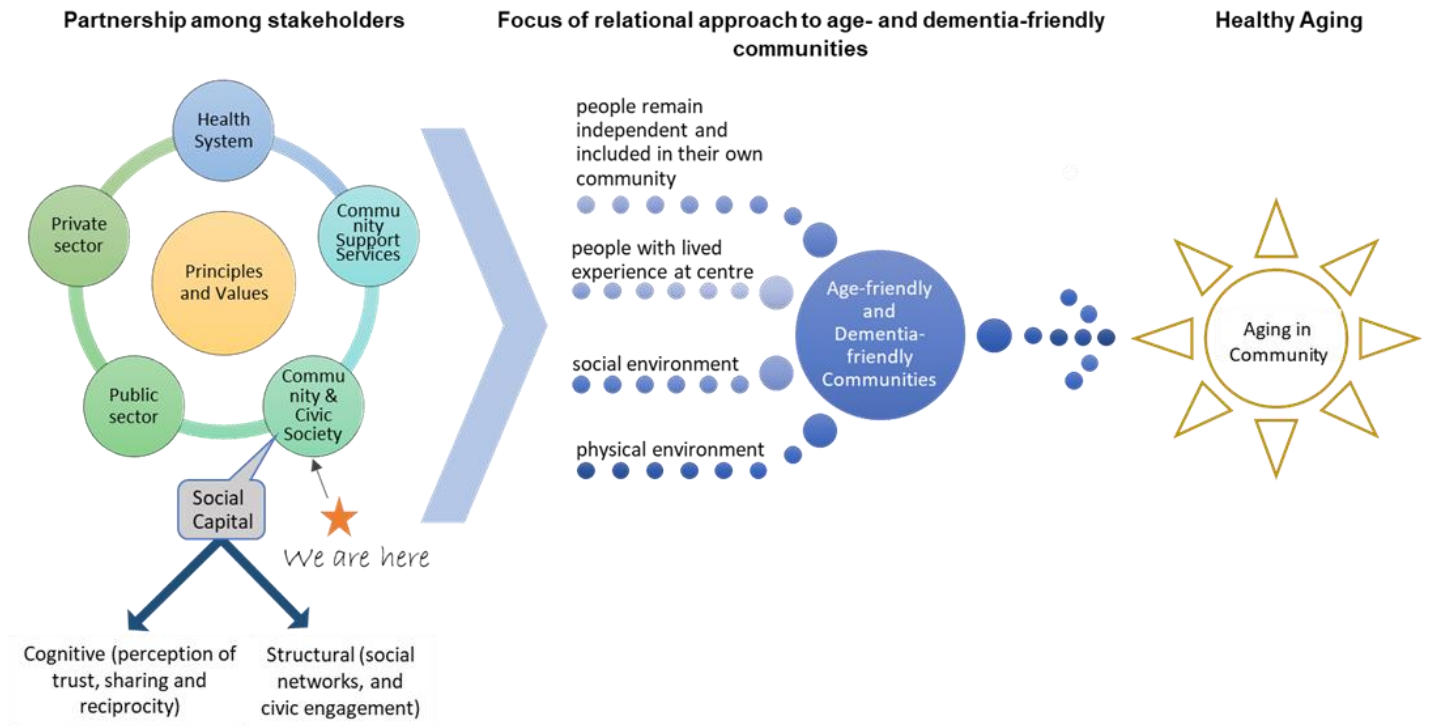
2- COMMON LANGUAGE

The SPCO research team follows the Language Guideline that is developed by the Alzheimer Society of Canada, hoping to promote consistency in the use of respectful language (Alzheimer Society of Canada, 2017). The language guideline is a tool for anyone who lives with, supports, or works with a person living with dementia (Appendix 1). For definitions of commonly used terms relevant to Dementia-Friendly Community (CDF), we refer to the glossary given by the Public Health Agency of Canada, in its dementia Strategy (Public Health Agency of Canada, 2019a) (Appendix 2).

2.1. PRINCIPLES AND VALUES

It is important to talk about values and principles[1] because there are multiple perspectives and assumptions about issues that concern us; there is no one truth; data shift and are usually ambiguous (Gamble, 2008). Consequently, our principles and values create a foundation for our directions and decisions. Dementia Strategy for Canada (Public Health Agency of Canada, 2019a) has five principles that set out values to direct and guide actions on dementia in Canada (Appendix 3). These principles are intended to inform all elements of the strategy, including when evaluating options for policies and programs with a direct impact on dementia-related issues. The strategy calls on all governments in Canada and other stakeholders to consider and support these principles through their own work on dementia.

Dementia Strategy for Canada (2019)
Principles and Values

Prioritizing quality of life- prioritize the wellbeing of people living with dementia and caregivers

Respect and value diversity- inclusive approach, attention to those most at risk or with distinct needs to support greater health equity

Respect human rights- domestic and international commitment to human rights

Evidence-informed- decision making, gathering and sharing the best available knowledge and data

Results-focused- tracking progress, evaluating, and adjusting

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[1] Patton defines a 'principle' as a fundamental proposition that serves as the foundation for a system of belief or behavior or for a chain of reasoning (M. Q. Patton, 2016).

3. PERSON-CENTRED CARE VS RELATIONAL CARE

There is a growing national and international consensus that care should focus on what PLWD need and a shift towards person-centred care approach that challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organizational needs (Fazio, Pace, Flinner, & Kallmyer, 2018). Person-centred care approach emphasizes older adults unique qualities, life history, personal preferences and characteristics (F. Morton-Chang, Williams, Berta, & Laporte, 2019). This approach to care encompasses relationship and input of family and friends, physical and emotional health status, abilities, personal values and interests (Bulsara, C; Etherton-Beer, C; Saunders, 2016). It is not prescriptive and only offers sets of principles. In a study by Alzheimer's Association, National Organization in Chicago (Fazio et al., 2018) a set of practice recommendations for person-centred dementia care are given as follow:

- know the person living with dementia,
- recognize and accept the person's reality,
- identify and support ongoing opportunities for meaningful engagement,
- build and nurture authentic, caring relationships,
- create and maintain a supportive community for individuals, families, and staff, and
- evaluate care practices regularly and make appropriate changes.

Person-centred care should be embedded in relationship/relatedness (Jarrad, 2019), that means all the components of care system need to be studied as a whole in order to understand what care to provide, how to provide it, how it is likely to be received, and therefore how we impact people's wellbeing.

The person-centred approach should not be taken for granted or misconstrued. A person who is cared for should not be considered as a container full of stories, experiences, and habits; someone who should be studied, learned and acted upon. A relational approach to care goes beyond person-as-container model and considers the informal/formal caregiver and care recipient in a relationship and in the constant making. An implication of this approach is caution towards dictated cultural-competency activities that reduce care to stereotypes instead of genuine engagement in a culturally safe environment.

Relational care is built on the notion that all humans, irrespective of their commonalities and differences, are inherently constituted through relatedness (Macdonald, Mears, & Naderbagi, 2019). Humans are not static containers of fixed identities; we have the ability to adjust and be responsive to our environment (Macdonold, 2019). This is applicable in care settings such as residential care homes and long-term care, where positive relationships between older adults, relatives and staff and interdependence matter. This approach recognizes the importance of the interpersonal and intrapersonal relationships that exist between the person and others around them and requires caregivers and staff to listen to older people, gain insights into individual needs and facilitate greater 'voice, choice, and control'(Bulsara, C; Etherton-Beer, C; Saunders, 2016).

Biomedical condition of dementia is not deniable and the medical approach to seek a cure is useful. However, caring for PLWD goes beyond medicine. Living with dementia and caring for PLWD is a shared social experience. Socially-engaged care is the centre of relational care (Jarrad, 2019). It is the responsibility of every

member of the community (e.g. carer, family member, neighbour, service provider) to seek practical and effective engagement measures to keep the PLWD connected. Isolation happens when others withdraw from a relationship (refuse/unable to be in a relationship). This requires compassion, respecting the person's sense of self, and creating a humane environment. This approach involves being less dependent on verbal communication, understand nuances of touch and other forms of non-verbal communication, have the right attitude and behaviour and be emotionally available and engaged (Carr & Biggs, 2019; Goldberg, Price, Becker, & Bindoff, 2019), and instead of a mechanical and routinized task- and medically-oriented care balance multiple frames of reference in order to enable care that (Carr & Biggs, 2019; Goldberg et al., 2019):

- considers dignity,
- respects and appropriates autonomy,
- is compassionate and culturally safe,
- enhances quality of life and social engagement, and
- decreases vulnerability to stigma and discrimination.

Injecting money into care homes that are only medically oriented is a sign of a community that does not care. We need to rethink and reframe dementia within social life (Macdonald et al., 2019), which means shifting our focus from the tunnel vision of brain pathology to a focus on the wellbeing of the person who requires accommodation and reconciliation (Jarrad, 2019). That requires each one of us to learn how to connect and adjust ourselves to the changing ability of the PLWD as the trajectory of their mental and movement ability changes (Macdonold, 2019). Measuring medical outcomes is universal however aspects of well-being for each individual reaches subjective domains of identity, connectedness, trust, autonomy, values and meaning (Jarrad, 2019).

These care approaches lead to a proliferation of patient-centred care. Internationally and in Canada, there is an understanding that a shift is required from a conventional model of provider-centred care to patient-centred care (F. Morton-Chang et al., 2019). The following table lists some of the characteristics of the two approaches.

Provider-centred care	Patient-centred care
- Providers determine what patients need and receive - Siloed healthcare system - Provider prescribes the same treatment for most patients with similar diagnosis or conditions	- The focus shifts to what is best from the perspective of the care recipient - Expand unit of care to both the PLWD and their informal caregiver - Caregivers become partners in care planning and delivery - Recognize that there is no single solution - Creation of supportive neighbourhoods and communities - Community-based innovations become part of the solution - Create working partnerships with other agencies

The above two approaches influence a paradigm shift in dementia health care, from a focus on medicalizations of dementia and physical health to a holistic approach in supporting the PLWD and their caregivers to achieve a quality life and support health equity (Alzheimer's Disease International, 2016). Considering the complex care needs of PLWD, a continuum of care is necessary. It is the responsibility of government to provide health services and equitable access to community health and care services; the Dementia-Friendly Communities approach and grassroots programs complement the government efforts to meet the needs of the PLWD for social engagement and participation in society. An increasing move towards the design of a healthcare system around patients' need, building partnership and coalitions among service providers, community-based services, and grassroots groups are inevitable.

4. SOCIAL CAPITAL

A relational approach to ageing, dementia and care leads us to the concept of social capital. When you are held in connection with others then you have access to social capital (Goeman, King, & Koch, 2016). "The quality of our lives depends on the quality of the relationships within which we are entangled at any point in our lives, and we do not exist outside of these" (Carr & Biggs, 2019).

An asset becomes capital when it is invested[2] (Emery, Fey, & Cornelia, 2006). Social Capital[3] is the glue that holds communities together and makes things happen. It is the combination of civic engagement, neighbourliness, social network, social support, and perceptions of the local area. Social capital has two dimensions (Reyes, Giovannoni, & Thomson, 2019):

- *The Structural dimension* is the visible form of social capital such as networks, relationships, associations, institutions, and organizations that link individuals and communities and even between communities themselves.
- *The Cognitive dimension* is the quality of those social structures in terms of people's perceptions of trust, sharing, and reciprocity. These are subjective interpretations of shared understandings and feelings of trust.

Social capital is not in a vacuum and is situated in socio-economic and political contexts. Turning our assets into social capital requires a mix of investments in individuals, families, and institutions that aim to build trust in existing and new social networks (Jacobs, 2011). You might have a strong or weak tie to a group, however, that bond links us to resources and information. Social capital exists where there are norms of reciprocity, collective action, and a level of mutual trust. Successful civic cooperation (and participatory actions) makes democracy works (Putnam, 1993).

Social capital is an important social determinant of well-being among older populations across countries and cultures (Zhang & Lu, 2018). Theoretically and empirically, a vast literature has linked social networks and social capital to health, life satisfaction, depression, physical disease, and even mortality among older adults (Reyes et al., 2019; Zhang & Lu, 2018). A systematic review on the association between lifestyles and cognition concluded that a socially integrated lifestyle in later life seems to protect against Alzheimer's disease and the extend of social networks provides some type of reserve which reduces the deleterious effect of Alzheimer pathology on cognitive abilities (Reyes et al., 2019). The quantity and quality of an individual's social contact have an impact on health. A study in Japan indicates a relationship between social capital and cognitive function in older adults by gender. The study shows, in their sample, in men cognitive function is associated

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[2] For example, a community with a high population of older adults has assets in historical knowledge, a diverse population, and a potential source of knowledge of the past and wisdom for the future. If a multigenerational mentorship program is developed with the elders and youth, then the asset is invested, becoming capital. Capital is any type of resource capable of producing additional resources (Emery et al., 2006).

[3] Putnam defines Social Capital as "Features of social organization, such as trust, norms, and networks, that can improve the efficiency of society by facilitating coordinated actions." (Putnam, 1993)

with cognitive SC and in women, it is associated with structural SC. This suggests dementia prevention initiatives might need to approach differently with respect to gender (Ito et al., 2019).

Social capital interventions showed a favourable effect on overall, mental and physical health, mortality, and use of health-related resources. However, there is scarce evidence on potential less desirable social capital effects that need to be taken into account before any Social Capital interventions (Baerenholdt & Asrsaether, 2002; Reyes et al., 2019). Social participation in a group might create a demand for conformity and constraints on individual freedom. The ties that bring a group together might create us/them attitude and ban those who do not comply or are considered as outsiders. From the resources available to them, there might be an excess claim on certain members of the group. Reciprocity norms, elicit and implicit, might require returning actions or services provided by another person, however, the recipient of the service might not be able to comply with those norms and that could cause a feeling of inadequacy or dependency (Reyes et al., 2019).

5. DEMENTIA-FRIENDLY COMMUNITIES

Key principles of DFCs are given in Appendix 4. DFCs are dementia-inclusive communities; they create the opportunity for the PLWD to live at home safely, remain active, and meaningfully engaged in their communities.

Age-friendly communities and Dementia-Friendly Communities (DFC) have common goals and principles that challenge ageist stereotyping and promotes ageing in the community (Turner & Morken, 2016). As discussed above relational care is a commitment to continued social connectedness and postponing the processes of disconnection (such as financial hardship, social stigma, sexism, ageism, physical conditions, dementia) for as long as the body allows. The European Union identifies empowering people with dementia and their caregivers to remain independent (personal, family, and social life) for as long as possible as an outcome of the DFCs (European Union Joint Action on Dementia, 2017).

Alzheimer's Disease International identifies two key issues underlying dementia-friendly communities: reducing stigma and empowering PLWD by recognizing their rights and capabilities (Alzheimer's Disease International, 2016). Dementia-friendly communities are social constructs and the key principles are guidelines which need to be contextualized and adapted to local conditions. Similar to age-friendly communities, creating a DFC requires political will along with long-term national commitment and funding from the government for both top-down and bottom-up projects. These two models of intervention have different scopes and level of impact and should work hand in hand. Some of the best examples of the dementia-friendly communities are small locally-driven projects that have focused on creating social opportunities for people with dementia (Alzheimer's Disease International, 2016).

There is a crucial need to integrate Community Support Services, and community-based initiatives into the range of diverse healthcare services caring for the same patient, i.e. integrating community-based endeavours and primary care clinics, in particular family physicians, nurses and social workers. Social Prescribing is a step towards that goal. Public Health Agency of Canada describes integrated community-based care as follows: "…case managers would not only provide guidance for health support but also for related social support, such as financial and housing." (Public Health Agency of Canada, 2019b)

The shift from a narrow interpretation of person-centred care towards relational care, holistic approach to care for PLWD, and fundamentals of dementia-friendly communities lead to three key strategic topics: a) supporting caregivers including networks of peer supports, b) enabling ground-up innovation and change, and c) strengthening political will and commitment for ageing in community.

5.1. SUPPORT INFORMAL CAREGIVERS

It is the contribution of unpaid or informal caregivers that allow many older persons, including PLWD, to continue to live at home. Without their contribution, the formal care system would not be sustainable (F. Morton-Chang et al., 2019). There should be a caution against off-loading responsibility of care to informal caregivers (Sutherland & Wiersma, 2016). The burden of care can become overwhelming and caregivers are vulnerable to emotional, health and economic distress (Goldberg et al., 2019). Informal caregivers provide

labour and also have valuable knowledge and insight into the social environment of the recipient of care; these characteristics give them a central role as partners of community service providers and health care providers in providing care and service to PLWD (Goldberg et al., 2019).

One of the system challenges in Toronto is the reduction in the number of informal caregivers. In Ontario, informal caregivers provide fewer hours of care compared to the provincial average (Sutherland & Wiersma, 2016). Changes in family structure, demographics, and women's participation in the labour force will lead to a shrinking pool of informed caregivers (Woodgreen Community Services, 2017). The burden of caregiving should not be on the community, however, in Canada caregiver strategy and support at provincial/territorial levels are uneven. Nova Scotia provides tangible supports and labour code amendments, which extend compassionate care leave to 28 weeks and Manitoba has a Caregiver Recognition Act which is symbolic (F. Morton-Chang et al., 2019).

In the UK, the government takes responsibility and recognizes caregivers as essential partners in care. It has established a range of supports, such as access to support services, respite care, support to manage their own health. In Europe and Japan, caregiving is redefined as a shared social responsibility and opening the support network to DFCs by training and equipping tens of thousands of volunteers to provide essential everyday support to PLWD, including telephone calls, companionship, peer support and help to attend medical appointments and social activities.

5.2. ENABLE GROUND-UP INNOVATION AND CHANGE

Ground-up and grassroots initiatives which facilitate engagement of PLWD in community activities are identified as core components of DFCs. These initiatives enhance the social environment of dementia-inclusive communities. Grassroots initiatives do not release the senior levels of government from their responsibility. They give the government an opportunity to establish a clear goal towards enabling ground-up innovations, reduce bureaucratic hurdles, and infuse needed resources (F. Morton-Chang et al., 2019).

Grassroots and ethnocultural groups are parts of the solution to achieve ageing in community and dementia-inclusive communities. Ethnic minority groups are under-represented in dementia services and as a good practice, there should be a systemic outreach to minority groups. Outreach efforts will only work if services can develop trust and credibility in their local communities (Daker-White, Beattie, Gillard, & Means, 2002). Alzheimer Europe has recognized that gaining access to minority ethnic groups is not an easy task. Awareness-raising among members of the community, people who may develop dementia or already have dementia, informal carers and key stakeholders requires proactive actions. The usual channels such as flyers may have limited success. The report suggests approaches used in the UK and the Netherlands are promising practices and are more effective to reach "easy to avoid" and also "hard to reach" people within ethnic minority groups. Those include: reaching out to people in community centres, places of worship, sheltered housings, and ethnic community radio stations (Alzheimer Europe, 2018).

The European Union has identified enabling PLWD to enjoy a better quality of life is a measure for sustainable development. The processes and structures that are at the core of an effective DFCs may vary, however, there

are two pivotal elements: people living with dementia and their carers. In addition to that, a change agent such as a charity which is able to offer leadership can also play a useful role in supporting and sharing learning between local initiatives (Alzheimer Europe, 2018). The European Union, in developing effective DFCs, calls for ensuring that the voices of people with dementia and their carers are heard and further recognizes that the input from people with dementia and some grassroots organizations require support and funding if it is to be effective and sustainable (European Union Joint Action on Dementia, 2017). In Scotland, some trusts and funds support the bottom-up vision of the development of DFCs and particularly support local groups, communities and partnerships where there is a commitment to an approach that is led by people affected by dementia and their families and supporters (European Union Joint Action on Dementia, 2017).

The goal is building social capacity and enabling social support networks of ethnocultural groups in order to empower PLWD and their caregivers to continue their contribution to the social and political fabric of society. This entails, those in power to commit to enabling bottom-up innovations and change by establishing clear goals, reducing bureaucratic hurdles, and securing needed resources (F. Morton-Chang et al., 2019).

The intention is not to institutionalize grassroots initiatives or make them appendixes of Community Support Services. However, a partnership among mainstream services and grassroots initiatives are encouraged as a necessary strategy for the Community Support Services. Grassroots groups, with their extensive network, can significantly facilitate the outreach and promotion of Community Support Services and work of funded organizations. Community engagement at all stages of an initiative augments ownership and sustainably. This collaboration requires genuine engagement policies.

Keeping Ottawa Seniors Connected (KOSC), a Collective Impact initiative[4] to reduce social isolation of seniors in Ottawa, in its final report concludes that working with funded service providers can be challenging for ethnocultural groups. They serve as valuable bridges of contact and trust between given communities and mainstream organizations, but there is a significant power imbalance between the seniors' ethnocultural groups and low-income tenant groups and funded organizations. Consequently, the value of the human capital contributions and the work done by those groups become invisible, unless there is a strong commitment on the part of funded organizations, funders and decision-makers to recognize and to support the work of the ethnocultural groups and low-income tenant groups. Service providers should consider community members as equal in planning, governing and implementing community programs. That means the seniors' ethnocultural groups and low-income tenant groups will function as partners if they are treated equally. Seniors and community members who offer their time and resources to participate and contribute should be compensated. Building trust with the community is a long process and needs patience, consistency, and support. Funders, decision-makers, and service providers should take deliberate actions toward funding grassroots innovations, and planning and implementing community-based initiatives to address the social isolation of seniors and unblock barriers to social inclusion of risk groups.

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[4] Partners in the KOSC initiative: Catholic Centre for Immigrants; Nepean, Rideau, and Osgoode Community Resource Centre; Ottawa West Community Support; South-East Ottawa Community Health Centre; Social Planning Council of Ottawa; Western Ottawa Community Resource Centre; Council on Aging of Ottawa

5.3. STRENGTHEN POLITICAL WILL, COMMITMENT, AND SUPPORT FOR AGEING IN COMMUNITY

Ageing in community is complicated and requires vast horizontal and vertical collaboration among stakeholders. One of the principles of the Dementia Strategy for Canada (2019) is 'respect and value diversity' (Appendix 3). It encourages community involvement and community input to support community-based and community-led initiatives, and local capacity building is leveraged to reflect the diversity within Canada. Ontario has identified performance measures such as expanding community programs; enhancing caregiver supports (e.g. respite); enhancing education and training for caregivers; increasing training for primary-care providers; behavioural supports at home and in community.

Not all service providers and health and social care professionals in Ottawa are at the same point regarding developing and providing intercultural care and support. Addressing health inequalities requires a commitment to tackling social inequalities that are multisectoral and require intersectoral actions at multiple levels of the government and all the relevant sectors (economic, labour and employment, education, transportation, housing, environment, etc.) and a commitment to include civil society (Fiorati, Arcencio, Segura del Pozo, Ramasco-Gutierrez, & Serrano-Gallardo, 2018).

Age-friendly and dementia-inclusive communities require political will along with long-term national commitment and funding from the government for local initiatives. Morton-Chang emphasizes "the need for senior levels of government to create the conditions, and provide tangible support for local innovations, which build capacity within and beyond healthcare to maintain PLWD as independently as possible, for as long as possible, closer to home" (F. Morton-Chang et al., 2019). Ontario's Dementia Strategy (2017) identifies the importance of people with dementia to be able to stay in their homes and community longer ("Ontario's Dementia Strategy," 2017) and its Capacity Planning in 2017 was focused on "ensuring community-dwelling persons with dementia safely remain in their homes and communities longer and care partner well-being."

In 2007 the liberal government introduced a four-year, $1.1-billion Aging at Home Strategy which promised to expand community living options for all older persons to enable them to continue leading healthy and independent living in their own home (F. Morton-Chang et al., 2019). In less than a year after the strategy's rollout, the government redirected the money to hospital alternative level of care patients in order to improve hospital 'flow-through'. In 2010 Ontario government developed Older Adults behavioural Support System to provide support for older Ontarians whose cognitive impairment is accompanied by responsive behaviours living at home, in acute care facilities or in long-term care homes (F. Morton-Chang et al., 2019; Frances Morton-Chang, Williams, Berta, & Laporte, 2016).

6. ETHNIC AND CULTURAL MINORITY COMMUNITIES

Using the term ethnocultural groups in this report should be recognized in the context of the following discussion.

Intercultural care and support require cultural awareness and cultural competence. Alzheimer Europe (Alzheimer Europe, 2018) defines 'minority ethnic group', 'cultural competence' and 'interculturalism' as follow:

> **Minority ethnic group**: a group of people who share a common cultural identity which differs in some way to that of the majority ethnic group in a particular country.
>
> **Cultural competence**- as knowledge combined with appropriate attitudes and skills (e.g. openness, respect, awareness of one's own background, readiness to question one's own assumptions, ability to communicate with people from different cultures and readiness to use external help when needed.
>
> **Interculturalism**: the acceptance and promotion of cultural diversity, reflected in the way that people interact, understand and relate to each other, and through policies and practice which help ensure equal opportunities, respect and fair treatment of people from all ethnic groups.

6.1. HETEROGENOUS AND DYNAMIC

The names that are given to ethnocultural groups are usually geography-based and that might create an assumption that each group is uniform and overlook the significant differences among them in terms of languages, religious beliefs, socio-economic status, education etc. Ethnic groups are not homogenous and static. Using the term ethnocultural groups does NOT imply that the group is an absolute representation of the culture, has pre-written and defined rules, or that the group is a permanent and homogenous entity. Ethnocultural groups are social constructs, have fluctuating and porous boundaries and are dynamic. The group define their commonalities, however, has within-group differences. A person might feel connected to a group in relation to a certain aspect of their life but related to another group concerning another aspect of their life. Moreover, people have multiple, intersecting and overlapping identities. The sense of belonging and different aspects of the cultural identity of a person may fluctuate over time and according to different situations (Alzheimer Europe, 2018).

6.2. INDIVIDUAL RIGHTS

The Alzheimer Europe clarifies that awareness and acceptance of cultural differences should not deprive people of ethnic groups the care and support that is truly person-centred (Alzheimer Europe, 2018). Awareness and acceptance of cultural difference provide a basis from which we can explore and understand the needs and wishes of each person, in his/her own right as a unique individual. There is a risk of stereotyping

if services over-emphasize similarities of people belonging to certain ethnocultural groups and jeopardize the right of people from minority ethnic groups to care and support that is truly person-centred. Awareness and acceptance of cultural differences should not over-shadow recognition that members of ethnocultural groups have in common and can provide a basis from which to explore and understand the needs and wishes of each person, in their own right as a unique individual.

PLWD and caregivers should have a choice. There is an assumption that ethnic minority populations prefer to 'care for their own', whilst the literature supports this to some degree, this should not be taken for granted and the patient and caregiver get deprived of available alternatives (Kenning, Daker-White, Blakemore, Panagoiti, & Waheed, 2017). Interventions at different levels should be inclusive and occur at all levels at the same time. Mainstream services working at community level and grassroots initiatives should work together to provide services that matter to vulnerable groups and have impact on their wellbeing.

6.3. INTERCULTURAL CARE AND SUPPORT

PLWD from minority ethnic groups are potentially vulnerable due to a combination of several factors such as age and ethnicity and in many cases a history of discrimination, a lower level of education and lower socioeconomic status (Chaouni & Donder, 2019). They use fewer services compared to people from the majority ethnic groups which might be due to culturally inappropriate services; perception of dementia; beliefs on care-seeking; stigma; language and cultural sensitivities; incompatible cognitive assessments; methods of help-seeking; beliefs of service providers; lack of awareness of services.

Developing and providing services which are culturally sensitive and responsive to the needs and wishes of people from different ethnic groups is a necessary step toward the wellbeing of people and equitable health care. Aspects of cultural habits can be both overt and covert in nature and people generally not aware of how it impacts them. There are numerous ethnic differences in the experiences of family and informal caregivers of people with dementia. The differences can be linked to cultural, socioeconomic and language factors (Richardson et al., 2019). Cultural influences on caregiving are more complex than researchers have previously assumed. A study about the well-being of ethnically diverse dementia caregivers shows similarities and differences. Cultural factors are especially relevant to ethnically diverse dementia caregivers' comfort in using services (Richardson et al., 2019). In the US, it has been demonstrated that where mainstream services have matched clients with staff according to ethnicity and language, patients' outcomes were improved. A comprehensive study in Europe suggests that the service solution lies in investing in community minority ethnic organizations that are already providing services. However, they argue that such services should not become exclusive. A fundamental finding is that it seems the major issue is the language ability and the ethnic minority group membership *per se* is a secondary factor (Daker-White et al., 2002). A study in 2017 suggests that inadequacies of services are not about simply translating generic versions of patient information, there are inadequate measures for inclusive awareness and education. There is a need for a redesign of the literature and communication materials, making them socially and culturally appropriate, for example, by featuring pictures and case examples from the relevant community. Research suggests conventional

approaches may not have enough penetration into the ethnic groups, therefore dissemination of information is also important (Kenning et al., 2017). Interventions as part of this process require (Daker-White et al., 2002):

- for dementia staff in all services to receive cultural awareness and sensitivity training,
- services should be suited to local conditions and delivered in local communities,
- some interpreters should be specifically trained in the assessment of language and cognition, and
- culturally appropriate diagnosis instruments need to be developed.

Lack of knowledge and understanding of dementia, as well as a lack of culturally responsive care services, lead to late or non-diagnosis, minimal support for family members, and less than optimal support for those affected with dementia. The concept of stigma and how people think about dementia requires a cultural shift which needs long-term commitment from all stakeholders (government, public, private, and non-profit sectors, and community groups).

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APPENDIX 1- LANGUAGE GUIDELINES

The Alzheimer Society has developed language guidelines as a tool for anyone who lives with, supports or works with a person living with dementia[5]. The following table is derived from the guidelines.

Language to be avoided	Why should you avoid it?	Person-centered language
Informal caregiver Professional caregiver	May offend people in the early stages who do not need 'caregivers' but rather people who will support them • Caregivers may not identify themselves in this way (e.g. "I am his wife, not his caregiver") • Lack of consistency in terms • Families who provide care often feel their care is "professional"	• Ask caregivers what terms they prefer on an individual basis. • Examples: Family member, caregiver, care partner, care provider, care team member, practitioners of care • Health-care professionals, name of actual professional • Cite title or name of professional
Support group leader	Sounds "expert" and disempowering of group	Group facilitator (e.g. person's role is not to be an expert but rather to facilitate group discussion) A good facilitator is neither a content expert nor a lecturer. A facilitator guides a process that will help participants to reach their stated goals and objectives within the time allotted.
Adult Day Care Centre/Day Care	More appropriate for children's services than for adults.	Adult Day Centre/Programs Provincially-specific term Support program

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[5] Person Centered Language Guidelines (2017) Alzheimer Society of Canada. Retrieved from:
https://alzheimer.ca/sites/default/files/files/national/culture-change/person-centred-language-guidelines.pdf

APPENDIX 2- GLOSSARY

The following definitions are derived from the dementia strategy for Canada[6], published by the Public Health Agency of Canada in 2019.

Age-friendly communities: In an age-friendly community, the policies, services and structures related to the physical and social environment are designed in ways that allow seniors to be involved and active. In other words, the community is responsive to vulnerable groups' need to live safely and stay involved in their communities. There are eight domains through which communities can become more age-friendly: housing, transportation, outdoor spaces and buildings, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services.

Care provider: A person who provides care and support to a person with dementia, in a paid or unpaid role. Includes, but is not limited to, the following groups:

- **Caregiver**: A caregiver is defined as a person who provides care and support to a person with dementia, and who is not a paid care professional or personal care worker. A caregiver is likely to be a relative, close friend, neighbor or volunteer. Support provided by a caregiver may include assisting with the activities of daily living and helping with advance care planning.
- **Developmental service worker**: Provides support to individuals who have intellectual or developmental disabilities. Support can be provided in homes, at work, in schools and to families.
- **First responder**: A person who goes immediately to the scene of an accident or emergency to provide assistance and is often the first to provide care. First responders include police, paramedics, and/or firefighters.
- **Health professional**: Includes but is not limited to, physicians (including family doctors and specialists such as psychiatrists and geriatricians), nurse practitioners, nurses, social workers, psychologists, chaplains, pharmacists, and physical or occupational therapists.
- **Personal care worker (PCW)**: A paid caregiver who assists people with daily personal care needs that may arise from the effects of aging, injury or illness. PCWs may work in private homes, assisted living homes, and long-term care homes. PCWs in home care or long-term care may be referred to as health care aides, home support workers, personal support workers, or attendants and their work is mostly unregulated in Canada.

Dementia-inclusive communities: Communities that allow people living with dementia and caregivers to optimize their health and wellbeing; live as independently as possible; be understood and supported; safely navigate and access their local communities; and maintain their social networks.

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[6] A Dementia Strategy for Canada, Together We Aspire (2019) Public Health Agency of Canada. Retrieved from:
https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html

Evidence-based: The thorough, clear and careful use of existing evidence for example, in developing guidelines, implementing interventions and making decisions about the types of care and therapies that an individual receives.

Evidence-informed: Emphasizes flexibility regarding the nature of the evidence and its use. It implies that many different types of evidence are needed and used to support decisions and using the right evidence that matches the context.

Health equity: Achieved when everyone has an equal opportunity to reach their fullest health potential regardless of factors such as social class, gender, or ethnicity.

Person-centred care: An approach to the planning and delivery of health care founded on mutually beneficial partnerships among care providers and the people receiving care. Person-centred care is respectful of, and responsive to, the preferences, needs and values of the care recipient.

Stigma: A negative stereotype often influenced by public attitudes, misconceptions and fear. Stigmatizing language and behaviours related to dementia may include: making assumptions about a person's abilities; ageism or implying that dementia is a normal part of aging; and dementia-related jokes.

Quality of life: The ability of individuals to do the things they value, such as maintain their physical health, mental wellbeing, level of independence, social relationships, and personal beliefs.

APPENDIX 3- VISION AND PRINCIPLES- A DEMENTIA STARTEGY FOR CANADA (2019)[7]

Vision: Setting a clear path forward

The vision we hope to achieve is a Canada in which all people living with dementia and caregivers are valued and supported, quality of life is optimized, and dementia is prevented, well understood and effectively treated.

Achieving the best quality of life for people living with dementia and caregivers is at the centre of the strategy. The vision prioritizes the need to support and value people living with dementia to make it easier to live well for as long as possible, to deepen the understanding of dementia, and to raise awareness of dementia and of stigmatizing behaviours. It also recognizes the importance of improving therapies and investing in efforts towards prevention and a cure, including through research.

Principles

Five principles set out values to direct and guide action on dementia in Canada. These principles are intended to inform all elements of the strategy, including when evaluating options for policies and programs with a direct impact on dementia-related issues. This strategy calls on all governments in Canada and other stakeholders to consider and support these principles through their own work on dementia.

PRIORITIZING QUALITY OF LIFE

Actions taken to implement the strategy prioritize the wellbeing of people living with dementia and caregivers.

- Living well for as long as possible: It is widely recognized and accepted that greater understanding and better access to supports[8] and tools will enable living well with dementia.
- Access to quality care and supports: The availability and quality of care and supports helps people live as well as possible each day and make choices that are important to them.
- Supportive communities: Community leaders and the general public are knowledgeable and committed to initiatives that make their communities more dementia-inclusive, including by raising awareness and making it easier for people living with dementia to participate.

RESPECT AND VALUE DIVERSITY

Actions and initiatives undertaken by all partners maintain an inclusive approach, with special consideration given to those most at risk or with distinct needs in support of greater health equity.

- Inclusive: All forms of diversity are considered in developing and implementing initiatives.

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[7] A Dementia Strategy for Canada, Together We Aspire (2019) Public Health Agency of Canada. Retrieved from: https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy.html

[8] "Supports" in the Dementia Strategy for Canada refers to a variety of ways that support can be provided to people living with dementia and caregivers such as assistance with activities of daily living, financial assistance, information and training, and assistive devices.

- Most at risk: Initiatives are tailored as needed and when appropriate to reach those most at risk in order to support health equity.
- Distinct Indigenous needs: The distinct needs of Indigenous communities and individuals are identified by Indigenous peoples and recognized by others. Indigenous communities and organizations are supported in addressing dementia in culturally appropriate and culturally safe ways, including through a distinctions-based approach that recognizes differences among First Nations, Inuit and Métis cultures.
- Community involvement: Community input is gathered to support community-based and community-led
- initiatives, and local capacity building is leveraged to reflect the diversity within Canada.

RESPECT HUMAN RIGHTS

Actions taken under the strategy respect the human rights of those living with dementia and reflect and reinforce Canada's domestic and international commitments to human rights.

- Human rights lens: A person-centred approach that focuses on respecting and preserving an individual's rights, autonomy and dignity in alignment with Canada's human rights commitments.
- Inclusion: Steps are taken to enable the participation of people living with dementia.
- Respects choice: The rights of individuals living with dementia to make their own decisions are broadly understood and facilitated.
- Hears the voices of those living with dementia: Actively including and consulting those living with dementia on matters that affect their quality of life.
- Caregiver perspectives: Consideration is given to the needs of the family and friends who care for people living with dementia.

EVIDENCE-INFORMED

Partners implementing the strategy engage in evidence-informed decision making, taking a broad approach to gathering and sharing the best available knowledge and data.

- Best evidence: Identification, creation and access to the best available research findings, data and knowledge.
- All forms of knowledge: A broad approach is taken when gathering evidence, including scientific data, traditional knowledge and the experiences of those living with dementia and of those caring for people living with dementia.
- Working together: Collaboration is used to build evidence and knowledge, including sharing research results.
- Informed decision-making: Policies and programs are informed by a thorough and rigorous examination of the evidence.

RESULTS-FOCUSED

Partners maintain a results-focused approach to implementing the strategy and tracking progress, including evaluating and adjusting actions as needed.

- Initiatives that support reporting: Implementation activities are clearly linked to the areas of focus and national objectives, and are designed to support reporting on results.
- Enabling evaluation: Data and evidence are gathered to support evaluation and inform future efforts, both on activities undertaken and their impacts.
- Measurement: Indicators are identified and developed to support tracking of progress.
- Accountability: Annual reports to Parliament demonstrate accountability by sharing the results gathered from monitoring and evaluation.
- Flexibility to evolve: A flexible approach enables priorities to evolve as needed through continued dialogue, ongoing collaboration, and consideration of new evidence and information.

Dementia friendly communities: the principles

Overview

A dementia friendly community can be defined as: a place or culture in which people with dementia and their carers are empowered, supported and included in society, understand their rights and recognise their full potential.

The cornerstones of a dementia friendly community

In addressing the twin objectives of reducing stigma and increasing understanding of dementia and empowering people with dementia, Alzheimer's Disease International suggests that the four essential elements needed to support a dementia friendly community are people, communities, organisations and partnerships.

People

Involvement of people living with dementia

Dementia friendly communities should be shaped around information about the social and economic impacts of dementia, the needs and opinions of people living with dementia, together with input from carers. Only by ensuring that initiatives are inclusive of people living with dementia at all stages of development, will we succeed in giving them the sense of respect, dignity and purpose they seek.

Some of the ways to achieve this include:

- Community consultations and workshops on strategies for the development of dementia friendly communities
- A charter of rights on the model of the Scottish Charter that identifies the rights of people with dementia and their family carers at every stage of the illness
- A consumer survey to seek feedback on the experiences of people living with dementia in their community and changes they would like to see put in place
- Resources (for example, how to communicate with people with dementia and information on dementia) to support the inclusion of the views and voices of people living with dementia in their community

Communities

The social environment

There is a need to tackle the stigma and social isolation associated with dementia through strategies to engage and include people with dementia in community activities. The availability of accessible community activities that are appropriate to the needs of people living with dementia, along with suitable transport options, are important for a community to become dementia friendly. The engagement of people living with dementia in existing community activities rather than only specialised activities is also important. Providing people with dementia the opportunity to remain in their homes and within their communities should be a guiding principle.

These are the opportunities we all have a right to expect: paid or unpaid activities, social opportunities though sporting activities such as golf and bowls, meeting with friends, participation in community activities such as choirs and walking clubs, access to retail, banking and other services.

Some of the ways to achieve this include:

- A Dementia Friends initiative that builds community understanding of dementia
- Working with schools to raise awareness in younger people about dementia
- Showcasing the stories of people with dementia volunteering within the community
- Programmes to support people with dementia to remain in employment
- Collaborations with local community organisations to provide education on dementia in order to support continued involvement of people with dementia in community activities

The physical environment

A physical environment that supports the needs of people living with dementia is critical. It needs to be accessible and easy to navigate. Pathways, signage and lighting all need special consideration.

Some of the ways to achieve this include:

- An assessment of the local environment to identify key spaces and ways to improve them for people with dementia
- Identification of opportunities for collaboration with age friendly initiatives

Organisations

Dementia friendly organisations

For people living with dementia to remain engaged within their communities, businesses and organisations need to demonstrate

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[9] Alzheimer's Disease International (2016) Dementia Friendly Communities, Key Principles. Retrieved from https://www.alzheimers.org.nz/getattachment/News-and-Events/Global-information/Alzheimer-s-Disease-International-Report/Alzheimers-Disease-International-1.pdf/
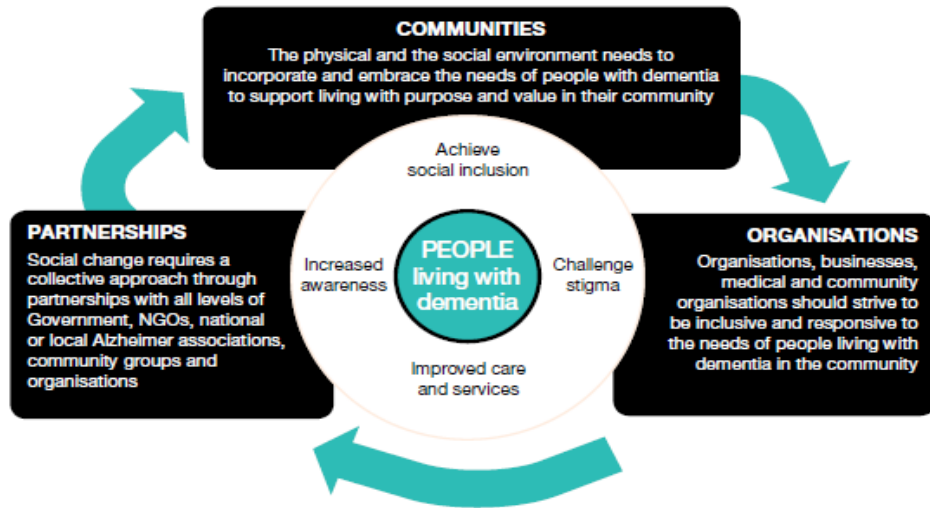
awareness, respect and responsiveness. Encouraging organisations to establish dementia friendly approaches and implement strategies that help people with dementia will contribute to a dementia friendly society.

Some of the ways to achieve this include:

- Guidelines on the key principles of dementia friendly organisations
- Consultation on the possible use of a symbol to denote dementia friendly organisations
- Develop a dementia friendly symbol to support organisations that are working towards becoming dementia friendly
- Work with key government agencies, emergency services, retail and banks to encourage uptake of the programme
- Promote becoming dementia-friendly to mainstream businesses and provide advice and support to encourage uptake
- Develop a dementia friendly organisations resource kit, which includes an action plan to support the establishment of dementia-friendly organisations

Access to appropriate health care

A timely diagnosis of dementia and early treatment is a critical component of a dementia friendly community. Delivering dementia friendly services that respond to the unique needs of people with dementia at the right place at the right time.

Some of the ways to achieve this include:

- Activities that encourage total health and wellbeing

- Timely diagnosis and post diagnostic support
- Promoting the message of timely diagnosis and treatment through appropriate professional bodies and primary health care professionals
- Seeking to make hospitals more dementia friendly

Partnerships

The establishment of dementia friendly communities as a social action initiative needs cross-sectoral support and collective action to effect change. It is no one organisation's sole responsibility to effect change of this scale, therefore the collective commitment to this cause and working in collaboration and partnership is critical. The strengths and focus of organisations within a community need to be identified and built into the plan for establishing a dementia friendly society.

Some of the ways to achieve this include:

- Meetings with ministers, local governments, business organisations, consumer groups, service agencies
- Development of a partnership agreement template to assist communities to strengthen local partnerships
- Identify the critical partnerships at the national level to support this work and establish relationships through possible partnership agreements
- Explore opportunities to further represent the views and priorities of people living with dementia and the importance of creating dementia friendly communities