



Dementia Care: Diversity, Access, Coordination Final Report

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The Alzheimer Society of Toronto conducted this project for Toronto Central LHIN. The project goals were to develop common definitions, approaches and care paths for agencies serving people with dementia, develop training models for service agencies using culture and language-specific training tools, identify community support services and service gaps in dementia care, map current referral methods and access points for dementia services, and recommend ways to improve access and navigation of dementia services in Toronto.

Dementia Care Project

Executive Summary

Persons living with Alzheimer’s disease and related dementias, and their caregivers, require a wide range of health care and social support services that are sensitive and responsive to changes in cognitive health throughout the lengthy progression of the disease.

A growing body of evidence indicates that when health care and support services are targeted, case managed and integrated, outcomes are better for the individuals receiving care, for their family caregivers, and for the health care system (Williams et al., 2009).

The Toronto Central LHIN asked the Alzheimer Society of Toronto to undertake the *Dementia Care Project*, in order to investigate dementia-specific core services, identify trends, and provide recommendations regarding access to and delivery of these services.

Several encouraging findings and some critical gaps were identified in researching awareness, availability and access to dementia-specific services. Where successes were identified, recommendations encourage the enhancement or expansion of current strategies and offerings. Where gaps were identified, coping strategies and suggestions offered by interview respondents were presented, and recommendations provided.

The *Dementia Care Project* complements two related Toronto Central LHIN projects – the *Community Navigation & Access Project (CNAP)*¹, and the *Seniors Mental Health and Addiction Services – Community Framework Project (C-SMHAS)*.² To avoid duplication, this project built on existing CNAP and C-SMHAS service definitions to develop 17 core dementia services.

Two key components distinguish core dementia services from other core service definitions:

1. Core dementia services are central to the care and well-being of people with dementia and their caregivers.
2. Core dementia services are delivered throughout the continuum of dementia by staff with dementia-specific training, knowledge and skills.

The combination of CNAP and C-SMHAS service definitions, and the 17 core dementia service definitions, were agreed upon by the Toronto Dementia Network Steering Committee, and were used to develop the interview guide for this project. A future goal is to standardize these definitions across organizations in Toronto Central LHIN.

In developing the core dementia service definitions, complementary services were identified and discussed but were excluded from the survey and gap analysis of this project.

¹ www.cnap.ca

² www.csmhas.com

Detailed information regarding the 17 core dementia services was obtained through in-depth telephone interviews with a purposive sample of organizations funded by Toronto Central LHIN, including Toronto Central Community Care Access Centre (TC-CCAC) providers, family health teams, and specialized services such as the Canadian Hearing Society, the Alzheimer Society of Toronto, cultural centres, etc.). The majority of organizations interviewed were non-profit, with some TC-CCAC providers and long term care homes identified as for-profit organizations.

The core dementia services investigated in order of the interview questions are listed below:

1. Adult day programs for persons with dementia
2. Adult day programs with overnight stay for persons with dementia
3. Assistive living for persons with dementia
4. Dementia-specific case-management
5. Dementia-specific counselling
6. Dementia-specific education
7. Support groups for families caring for persons with dementia
8. Support groups for persons with dementia
9. Dementia-specific personal care / personal support
10. Dementia-specific homemaking / home help
11. Dementia-specific respite
12. Dementia-specific friendly visiting
13. Psycho-geriatric mental health services
14. Memory clinic for persons with dementia
15. In-patient behavioural assessment unit for persons with dementia
16. Dementia unit in a long-term-care facility
17. Behavioural unit in a long-term care facility

Key Recommendations

Three strong themes repeatedly emerged with each of the dementia-specific core services:

- ✓ the need for more dementia-specific training and education for people with dementia and all those caring for them (formal and informal caregivers)
- ✓ the need for enhanced transportation options to increase access to dementia-specific programs and services across Toronto
- ✓ the need for more ethno-cultural-language specific offerings to provide better outreach and provision of dementia-specific programs for the diverse multi-cultural population across Toronto.

A series of 12 overarching recommendations highlight a pressing need to address awareness, identification, and access issues related to the needs of persons with dementia and dementia services in Toronto Central LHIN.

1. Expand current transportation services

Lack of transportation (because of cost, location of destination, drivers without dementia training) can inhibit access to dementia services. Funding is recommended to expand transportation catchment areas and to extend hours of service to provide access to programs in late afternoon, early evening and on weekends, or language and culturally-specific programs outside of defined catchments areas.

2. Expand and encourage dementia education opportunities

2.1 For persons with dementia and their family caregivers

Dementia-specific education is beneficial for persons with dementia and their partners in care, helping them to plan for the increased debilitation that will inevitably occur as dementia progresses, and contributing to preventative health interventions and coping strategies.

2.2 For formal care providers

Organizations are encouraged to adopt policies that promote dementia training for all staff working directly with persons with dementia. Where staff members have received prior training, dementia-specific competencies (skills and knowledge) should be assessed during probation, and then refreshed through ongoing professional development that features a dementia-specific curriculum with evidence-based best practices.

3. Increase dementia expertise

To address a gap in the number of health care providers with expertise in dementia care, it is recommended that future funding opportunities specifically target dementia-related training opportunities and programs.

It is also recommended that the Ministry of Health and Long Term Care work alongside the Ministry of Colleges and Training to ensure a mandatory dementia-specific curriculum for certificate and professional programs where staff will likely provide care to persons with dementia (personal support workers, occupational therapists, physicians, etc).

4. Family caregivers considered as a unit and as individuals

It is recommended that recognition be given to the vital role of families who care at home for persons with dementia, and that programs address their needs separately and as a unit of care as appropriate.

5. Build/enhance partnerships between organizations

It is recommended that the CNAP and C-MHAS common referral processes be used to enhance the responsiveness of other service providers. It is also recommended that websites such as the Toronto Dementia Network, C-SMHAS, CNAP and the Community Care Resources (CCR) websites, be linked to facilitate understanding of the wide range of dementia services for referring organizations, for families and for the interested public.

6. Expansion of dementia-specific offerings

It is recommended to expand current dementia care programs and services that support diverse and multicultural populations. Locally-based programs along the continuum of care are also recommended to reduce waitlists and offer partial solutions to transportation issues.

7. Increase flexibility of program offerings

It is recommended that dementia-specific programs be offered outside of traditional business hours, with options to attend programs in early evening, overnight and on weekends.

It is also recommended that necessary funding be targeted toward organizations wishing to expand eligibility criteria for their dementia-specific programs and services, such as extended personal care offerings, more overnight ADPs, more support groups, and dementia-specific recreation in Long Term Care Homes.

Consideration should also be given to dementia-specific programs that target those individuals or communities who are reluctant to access current services because of age (early onset day programs), LGBT populations, housing issues (homeless, under-housed and/or alcohol-related dementia), and culturally specific programs (language, ethnicity).

8. Expansion of supportive housing

To increase access and availability to supportive housing for persons with dementia, it is recommended that expansion funding continue to be made available for current and new supportive housing programs to identify, monitor and support the needs of a growing senior population, especially those experiencing or soon at risk of dementia. In addition, it is recommended that dementia-specific training be provided to all staff in supportive housing buildings so they can better identify clients presenting with dementia-related symptoms, and better manage and accommodate individuals with dementia-related behaviours.

9. Dementia recognized as a chronic condition

It is recommended that dementia be included as a chronic condition in Ontario's *Chronic Disease Management Framework*, along with an educational initiative to increase the knowledge of health care providers about dementia as a chronic condition, and promote best practices in dementia care to address this condition. This recommendation is supported by research in the *Rising Tide* report:

“There are significant data to suggest that recognizing and addressing dementia as a co-morbid chronic disease and as an integral factor in the Chronic Disease Prevention and Management Framework (CDPM) will result in significant cost savings to the health care system. For example, having appropriately educated and trained health and social service human resources who are able to recognize the disease in its early stages will provide opportunities to delay the onset of symptoms, and result in better patient flow across the continuum of care and more effective utilization of costly acute care resources.”

(Rising Tide, 2010)

10. Increase ethno-cultural-language specific offerings

It is recommended that dementia care resources be offered in different languages (more interpreters; multilingual staff; information materials, etc.)

It is also recommended that, recognizing the economic limitations of serving each different community, the health care system capitalize on partnerships with ethno-cultural/linguistic community organizations. These partnerships, which have slowly started to develop on their own, must be viewed as complementary rather than duplicative. Further to this, dementia service organizations must have a role in the service planning and delivery process to ensure that the people they serve will have their particular ethno-cultural/linguistic needs met.

11. Increase satellite programs along the continuum of care

It is recommended that successful dementia service providers offer satellite programs to spread these services more equitably across Toronto. This would improve access and address more ethno-cultural-language specific program needs. This might also reduce waitlists and decrease the use of higher level, more expensive alternatives to health and social care for persons with dementia and their caregivers.

12. Common referral

It is recommended that organizations move toward a common referral process and build on the successes of the current CNAP pilot of a common referral intake form and partnering processes as well as the common intake process currently being used for in-patient behaviour units in the Toronto Central-LHIN area.

It is hoped that this report will serve as a foundational document to promote further discussion and action to optimize access to dementia care for persons with dementia, their families and their caregivers.

Findings of this project will contribute to ongoing Toronto Central LHIN initiatives and future “resource matching” activities that are sensitive to the needs of those with dementia, and representative of the local diversity of a multicultural city as large as Toronto.

Acknowledgements

We would like to thank the Toronto Dementia Network Steering Committee and Toronto Dementia Network Dementia Care Project Work Group for their input towards the development of core dementia-specific service definitions, the various iterations of the survey, and follow-up meetings to discuss findings.

A very special thank you goes out to all of the participating organizations that gave so generously of their time and expertise during the telephone interviews and follow-up meetings to discuss preliminary findings. We applaud each of you for your hard work and concern for people with dementia and their caregivers and for your caring staff who provide such a breadth of health and social care support services to support all those experiencing the effects of the dementia journey across the full continuum of care.

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Dementia Care Project

1. Introduction

The Alzheimer Society of Toronto on behalf of the Toronto Dementia Network, conducted this project for Toronto Central LHIN. Project goals were to develop common definitions, approaches and care paths for agencies serving people with dementia, develop training models for service agencies using culture and language-specific training tools, identify community support services and service gaps in dementia care, map current referral methods and access points for dementia services, and recommend ways to improve access and navigation of dementia services in Toronto.

The Dementia Care Project complements two related LHIN projects: the Community Navigation & Access Project (CNAP)³, and the Seniors Mental Health and Addiction Services Community Framework Project (C-SMHAS).⁴ This report references these initiatives to avoid duplication of effort. In this connection, we utilized CNAP and C-SMHAS definitions to develop 17 Core Dementia-Specific Services for which two key components were required:

1. Core Dementia Services are central to the well-being and care of people with dementia and their caregivers
2. Core Dementia Services are provided, throughout the continuum of dementia, by staff with dementia-specific training, knowledge and skills. (See Appendix A for Core Dementia Services definitions.

In developing the core dementia service definitions, many complementary services were identified and discussed. Although important and beneficial to persons living with dementia and their partners in care, these services were excluded from the survey and the gap analysis: the complementary services were not dementia-specific and applied to a broader population (See Appendix B for a list of Complementary Services).

Definitions from the Toronto Dementia Network website and those from the CNAP and C-SMHAS projects served as a foundation for the final core services definitions and were utilized in the development of the interview guide (See Appendix D) and are expected to be standardized across organizations to better communicate service offerings between and amongst themselves as well as to the broader public.

This report provides working definitions for each core service, and highlights themes relating to current referral patterns, eligibility criteria, target populations, identified enablers and barriers to access for each service, and potential solutions for each of the identified challenges. Key findings regarding diversity issues as they pertain to dementia-specific services are also presented.

³ www.cnap.ca

⁴ www.csmhas.com

Interview findings regarding the 17 core dementia services have also informed the development of an interactive internet based dementia care pathway to be posted on the Toronto Dementia Network website later this year. This care pathway takes into account current referral patterns in Toronto and builds on the work of two key dementia initiatives:

1. The *Rising Tide* report, released by the Alzheimer Society of Canada on January 4, 2010, which presented a Dementia Continuum Map that shows the critical importance of system navigation through the long and difficult course of dementia.⁵
2. The *British Columbia Interior Health Phased Dementia Pathway* project which describes the unique physical, mental, emotional, and social needs of the person with dementia and caregivers across the spectrum of cognitive change from earliest diagnosis to the end of life. The *Pathway* was undertaken to identify and develop evidence-informed dementia practice aimed at addressing the clinical pinch-points or special care needs and issues that arise for persons with dementia, their caregivers and clinicians.⁶

1.1 Background

Toronto, like other jurisdictions, has experienced an increasing need for services for aging seniors due to multiple converging factors. One pressing factor is the concern of our aging population with more seniors living with, and at risk of developing high care needs. This becomes more pressing when one considers that age is the greatest risk factor for developing a dementia.

The term “dementia” refers to disorders of the brain that slowly destroy memory and reasoning, erode independence and eventually, take life. Alzheimer’s disease is the most common form of irreversible dementia, accounting for 64% of all dementias. Other forms of dementia include Vascular dementia, Fronto-temporal dementia (including Picks disease), Lewy body disease and Creutzfeldt-Jakob (mad cow) disease (Rising Tide, 2010).

The impact of dementia has an effect both on a personal level and on a system level. For instance, living with dementia, a long-term (chronic) disease, can burden persons living with the disease and their caregivers, physically, emotionally and financially. According to *Rising Tide*, dementia causes more years with disability than any other chronic disease, severe financial burden for people living with the disease, and dementia can slowly erode the health of caregivers.

From a system level, *Rising Tide* notes that for the past decade, dementia and its impact on national economies has been the subject of increasing focus around the globe as it affects productivity (e.g. people with dementia leaving the work force because of their memory; caregivers juggling, changing or leaving the workforce to care for the person with dementia), and the utilization of health and social care services. Persons with dementia living without support often come into contact with the healthcare system at a point of crisis and may be intensive users of higher level care which may not have occurred if other interventions had been put in place early (Rising Tide, 2010).

⁵ http://www.alzheimer.ca/english/rising_tide/rising_tide.htm

⁶ <http://www.interiorhealth.ca/health-services.aspx?id=328>

The progression of many dementias is generally categorized into stages – early, middle and late stages. For the purposes of this project we inquired about a stage often noticed prior to early stage dementia known as Mild Cognitive Impairment, and also early onset dementia (occurring prior to the age of 65).

An excellent dementia pathway has been developed by Interior Health in British Columbia. This *Dementia Care Phased Pathway* runs from a pre-clinical phase to late stage dementia. This pathway, for the purposes of our project has been adapted (with permission by Interior Health) to align more closely with the findings from our research in Toronto. Please See Appendix C for the adapted Toronto Dementia Care Pathway. This pathway has served as the foundation for an interactive dementia care map scheduled to be posted on the Toronto Dementia Network website later this year.

2. Purpose

This Dementia Care project undertook an examination of core dementia-specific services across the Toronto Central LHIN. Specifically, it aimed to document and analyze trends in eligibility criteria, referral patterns, enablers and barriers to accessing such services as well as suggestions for improvement (See Appendix D for Survey Questions).

2.1 Relevance

The *10by20: Ontario Action Plan for Dementia* report, released on March 24, 2010 by the Alzheimer Society of Ontario and based on the national *Rising Tide* report, showed that

1. Today, 181,000 Ontarians have dementia, a number expected to rise to 255,000 by 2020, ten short years away.
2. Families and friends spend 87.1 million unpaid hours caring for people with dementia. By 2020, they will spend 144 million hours, an increase of 65%.
3. The economic burden (direct, indirect and opportunity costs) of dementia in Ontario is expected to increase by more than \$770 million each year through 2020.
4. All LHINs show an increase in dementia prevalence.
5. Toronto Central LHIN in 2008 had 16,200 people living with dementia. That number will increase 15 per cent to 18,700 by 2016.
6. A survey in November 2009 asked Ontarians with dementia, their caregivers and professional service providers about dementia services in Ontario. Here is what they said:
 - ✓ 93% believe that the range of care and support services needs to be improved
 - ✓ Early diagnosis is the greatest benefit to people with dementia and their caregivers
 - ✓ 75% rank access to specialists and collaboration between healthcare practitioners as having the greatest impact on people with dementia.

The *10by20* report urges a ten step plan to:

1. Launch a public education campaign to overcome stigma, foster supportive communities, facilitate early diagnosis and encourage healthy-brain lifestyles
2. Enable early diagnosis and intervention through accessible primary services integrated with community services via the Alzheimer Society's *First Link* program
3. Increase access to community , respite care and home support services that use best practices in dementia care
4. Introduce flexible workplace policies and income supports for family caregivers
5. Strengthen skills through more dementia-specific training across the health and social service sector
6. Increase accessibility to specialized geriatric services
7. Invest in interdisciplinary research and accelerate findings into practice
8. Partner with the private sector to foster innovation in areas such as housing and assistive technology
9. Establish dementia as a priority in Ontario government policies
10. Lead the charge in making dementia a national priority.

3.0 Data and Methods

3.1 Definition Development

Beginning in March 2009 the Alzheimer Society of Toronto convened a meeting of the Toronto Dementia Network Steering Committee to enlist their support for the Dementia Care Project.

The Toronto Dementia Network website provided a strong foundation to this project as did the complimentary work of two related TC-LHIN projects – the Community Navigation & Access Project (CNAP)⁷, and the Seniors Mental Health and Addiction Services – Community Framework project (C- SMHAS).⁸ The Dementia Care project communicated with members of these two initiatives and where possible utilized and referenced their approach and their information to avoid duplication of effort. In this connection, the Toronto Dementia Network used the CNAP and C-SMHAS definitions of core and complementary services as a foundation for discussion of core services specific to dementia care. Over the course of June – September 2009, these definitions were distilled down to 15 Core Dementia-Specific Services for which two key components were identified:

⁷ www.cnap.ca

⁸ www.csmhas.com

1. Core Dementia Services are central to the well-being and care of people with dementia and their caregivers
2. Core Dementia Services are provided, throughout the continuum of dementia, by staff with dementia-specific training, knowledge and skills (See Appendix A for a listing of Core Dementia Service definitions).

In developing core dementia services definitions many complementary services were also identified and discussed. These services, although important and beneficial to persons living with dementia and their partners in care, were excluded from the TDC project survey interview guide and gap analysis as they were not dementia-specific and applied to a the broader population (See Appendix B for a listing of Complementary Services).

The hope in identifying and standardizing core dementia service terminology is to assist organizations to more accurately and effectively communicate service offerings between and among themselves as well as to the broader public.

3.2 Survey Development and Implementation

In October and November 2009, a telephone survey interview guide was developed and piloted with a small sample of community support agencies in Toronto Central LHIN. At that time it was noted that two additional dementia-specific core services needed to be added to the surveys: Dementia-specific Counselling and Psycho-Geriatric Mental Health Services. The survey, additional core services, and approach were then approved by the TDN Work Group and Steering Committee.

A list of Toronto Central LHIN-funded organizations including CNAP and C-SMHAS organizations, Toronto Central CCAC (TC-CCAC) providers, and data from the Toronto Dementia Network website were cross-referenced and utilized to email invitations to LHIN-funded organizations to participate in the Dementia Care project interviews. A backgrounder to the project was posted on the Toronto Dementia Network website with contact information for the project lead for further information. Follow-up telephone and voicemail invitations were provided to organizations that did not respond by email. Due to time constraints, interviews were restricted to Toronto Central LHIN-funded organizations and TC-CCAC providers, while recognizing that a number of other options exist for persons with dementia.

3.3 In-Depth Telephone Interviews

From December 2009 to February of 2010, information regarding the 17 identified core dementia services was obtained through in-depth telephone interviews with a purposive sample of fifty provider organizations. All telephone interviews were conducted by researchers Frances Morton or Jessica Lansfield, and generally were between one to two hours in length.

Information regarding core dementia services was obtained through interviews with a purposive sample of organizations, Toronto Central Community Care Access Centre providers, family health teams, and more specialized services in Toronto (Canadian Hearing Society, Alzheimer Society of Toronto, cultural centres, etc). The majority of organizations interviewed were non-profit, although some providers and long term care homes were designated as for-profit. Similar to many of the inclusion criteria used in the C-SMHAS project, organizations interviewed for this Dementia Care project:

- Served seniors who are age 65 and over (although not always exclusively).
- Were flexible in their ability to address the issues of individuals with earlier onset dementia.
- Provided one or more services as defined in the Core Dementia Services Definitions
- Served clients in the Toronto Central LHIN area although some were not geographically located within the Toronto Central LHIN boundaries.

4.0 Findings

Many themes emerged from interviews with core service providers. These included issues related to language and culture, referral processes, cost, transportation and marginalized groups. Each of these is explained below.

Language and culture

As dementia progresses, persons with dementia lose second and third languages and revert back to their native tongue. Many dementia-specific services are English-focused; hence language can become a major issue when serving people for whom English is a second language, or not a language they speak at all.

Persons with dementia need support and assistance, in a language they understand, by dementia trained staff who speak their language and are sensitive to their cultural traditions. Recognizing and addressing the needs of new and emerging communities in their mother tongue can be difficult. In addition, assessing dementia and the need for dementia-specific services can be problematic when clients and or caregivers cannot read or write English or their native language, or when they do not speak or understand English. For some cultures, the perception or definition of dementia does not exist.

A number of languages were specified by interview respondents as being difficult to serve unless clients were living in or near an ethno-cultural service provider. In particular Aboriginal, African, Arab, Chinese, Francophone, Japanese, Korean, Portuguese, South Asian, Spanish, and Vietnamese were cited as needing culturally-sensitive and language-specific dementia services. A number of organizations also identified that each of these cultures is particularly attached to the notion that parents need to be/should be cared for by the family, at home. Dealing with that issue can be delicate for any family, and without program offerings and sensitivity to language and culturally-specific needs, stress can be heightened in these communities. When a person with dementia experiences issues that might indicate a need for higher level care in a long term care home, many of these families have additional worries about cultural and language issues, given that community service and residential options for these specific communities are limited.

Most ethno-cultural-language based organizations do their best to be flexible in accommodating clients in need of services that live outside of their catchment area, and sometimes outside of the Toronto Central LHIN. They feel frustrated at times as such clients often have few options to turn to when other ethno-cultural-language appropriate organizations do not exist outside of their catchment area or when they do, the wait lists are too long for that service to be of use to a

client with a progressing dementia. They also feel a constant internal pressure that if they help people outside of their catchment area they would then be denying time and access to someone in their own catchment area, yet are torn about leaving someone to fall through the cracks.

Another interesting finding was the lack of francophone services across Toronto Central LHIN. Francophone services tend to be centralized through one provider, Les Centres d'Accueil Héritage. This organization provides services not only to those with French as their mother tongue, but also to others that have French as their working language (African and European immigrants who know some French and their own mother tongue but not English). Thus the French centre must deal with multiple populations and many different cultural considerations beyond language.

Organizations providing non-ethno-cultural-linguistic services often describe coping techniques that range from specifically hiring staff from similar backgrounds as the target communities they serve with the ability to speak English and another language. When necessary or possible they also use volunteers with specific languages – although this can be problematic if the volunteers do not understand dementia as some of the information is not easily translated. One organization found that many of their volunteers with English as a second language chose to go to organizations with English speaking clients over their own ethnicity to try to work on improving their own English. This limited the pool of volunteers to draw upon. Organizations also utilize more “one-off” techniques such as pulling staff from other areas to help with translation / interpretation. The latter was disruptive to staff, and thus not a permanent solution.

Referral Processes

Commonly-cited referral processes for organizations providing non-medical dementia-specific services (e.g. did not require a physician referral but could be referred by a physician) included:

- Self-referral, word-of-mouth, advertising, newspapers, family members, brochures, program managers, CCAC, CNAP organizations, healthcare professionals, COTA Health, Community Health Centres, hospitals, doctors, geriatric medicine clinics, websites, intake coordinators, and internal referrals within community support agencies themselves.

Commonly-cited referral processes for organizations not providing dementia-specific services (e.g. may offer one or more dementia-specific services however need to refer to another service) included:

- Conversations with the individual and/or family members to tease out any programs they may already be connected with and to make additional connections if necessary, (e.g., transportation options, organizations that provide subsidies, etc).
- Referrals to organizations based on client’s geographical area and/or based on cultural/linguistic considerations.
- Directing clients to the Toronto Central CCAC, the CCAC Community Care Resources website, or the Toronto Dementia Network website.

A number of organizations stated that persons with dementia and their caregivers would benefit from standardized information-sharing across organizations in the community. Too many assessments are occurring and clients just want the care, not the processes. It is hard for persons

with dementia to be assessed for each need or each time they are transferred to another program or organization. It is thought that a shared system would save time and be more effective.

Cost

Organizations repeatedly cite cost as both an enabler (e.g. subsidized programs) and a barrier (e.g. some dementia-specific programs can cost more because of the higher care required).

Some areas in Toronto have high populations of people on fixed incomes and even when subsidies for programs and service are available, transportation costs, additional fees for top-up homemaking and personal care services, and the cost of adult day programs are often cited as burdensome.

Transportation

Organizations say that transportation is one of the greatest enablers and barriers to accessing programs and services. Catchment areas for certain programs are commonly identified as barriers for people outside of that area who want to attend a program, yet are not eligible for transportation options provided to those within the vicinity (e.g. van pick-ups for adult day programs).

Early in the dementia continuum persons with dementia become dependent on others for transportation (either provision of rides and/or escorting on rides). Transportation is key to:

- Maintaining previous activities – social, recreational, spiritual – for as long as possible
- Attending dementia-specific programs and services or health care visits (e.g. physician, dentist, memory clinic)

Complications may arise when:

- The person with dementia was the only driver of the caregiving dyad or
- The person with dementia is low income

One organization noted that many people with HIV-related dementia are younger than those with Alzheimer's disease, and are often dependent on Ontario Disability Support Program for financial support. In these cases HIV dementia-related programs may use volunteer drivers or organize a circle of care to share the driving.

Bus or subway is a limited option for persons with dementia, even with an escort, due to:

- Heightened anxiety caused by crowding and/or frequent changes (e.g., bus to subway to bus)
- Physical limitations (e.g. walking to bus stop, climbing onto bus)
- *Wheeltran*, a public transit program in Toronto, is designed for those with physical but not cognitive limitations

- *Toronto Ride*⁹ is designed primarily for medical appointments and operates during normal business hours

Taxis are a limited option for persons with dementia, due to:

- Cost of fares, ability to reserve a cab, and getting to location if there is no escort.

Stigma and Marginalization

Persons with dementia are vulnerable to marginalization due to lack of or misinformed understanding of dementia. This can be exacerbated when they are low-income seniors, are homeless, and/or do not speak English.

Many organizations have an open door policy to Lesbian, Gay, Bisexual and Transgendered (LGBT) populations, but few have knowingly worked with this population. It is important to be aware of the specific challenges LGBT persons with dementia and their caregivers might experience in accessing care, and how their needs may differ from other seniors. For example, many LGBT seniors have a history of hiding their sexual orientation for fear of judgement or persecution. This may be a particular fear of transgendered men and women who may experience additional stress or anxiety accepting personal care and other services due to previous or speculated ridicule or prejudice.

Expanding current services for marginalized groups, and implementing mandatory sensitivity training, would increase awareness of and access to dementia-specific services for marginalized populations.

Themes and Recommendations

The following sections move into themes and recommendations for each of the 17 dementia core services. It is important to remember the common themes noted above, and apply them across all services when considering the recommendations for any of the following services.

4.1 Adult Day Programs for Persons with Dementia

Adult day programs (ADPs) for persons with dementia were described in the survey as *supervised and supported social and recreational activities provided at a location outside the person with dementia's home. Programs generally include meals, transportation to/from the program, some personal care, and appropriate activities. Hours of operation may vary.*

Of the 50 organizations interviewed, 21 offered ADPs for persons with dementia and/or mixed populations (persons with dementia and frail seniors).

⁹ Toronto Ride is a partnership of fourteen not-for-profit neighbourhood-based community support service agencies that provide assisted transportation to the frail elderly and adults with disabilities in Toronto to their healthcare and other appointments. For more information please visit <http://www.torontoride.ca/>.

Organizations providing ADPs to persons with dementia indicated they work primarily with individuals with Mild Cognitive Impairment (MCI), and early-stage dementia. Few support middle, and fewer still work with individuals in the late stages of dementia. Of these programs, 16 were self identified as dementia-specific and the remainder were mixed/integrated programs. Services offered by ADPs were reported as follows: 88% provide recreational programming, 71% provide assistance with daily living, 94% offer light physical activity, 94% provide meals, 82% offer transportation options, and 47% offer minor health care assistance (toileting, medication reminders).

4.1.1 Key Themes

Ten key themes emerged from interviews regarding ADPs for persons with dementia.

i. Multiple Configurations

ADPs serving the needs of persons with dementia come in many forms ranging from lighter care environments as found in Elderly Person Centers, to more extensive programming and assistance such as those located in Healthcare Centres. While most have some degree of flexibility with age criteria (could accommodate persons with early onset dementia occurring before age 65), the majority of programs target seniors aged 65 years and older.

ii. Awareness

Marketing and promoting ADP services for people with dementia can be difficult for a host of reasons, including stigma. A trusting relationship is essential for a person with dementia to feel comfortable attending an ADP, and it is often easier to refer existing clients to the ADP than new referrals. One organization stated that the *process of decision making is difficult*, and another that *information is a multi-layered process that involves orienting clients and caregivers, and maintaining ongoing communication to provide them with an understanding of how to access certain types of programs, including ADPs*. A third offered that *clients and caregivers are not sure which agency provides what and in what area as each have [their own] client populations and specialties*. Anxiety or resistance can occur when these challenges are coupled with the memory issues of persons with dementia and/or the stress of the caregivers during this process.

Information accessible via the web helps to increase awareness of programs when people are internet savvy, however self-advocacy is not always reliable. One organization stated that helpful websites like the community care resources (CCR) website *assumes others are willing to self-advocate, but caregivers are overwhelmed and advocacy can be daunting – many are not sure what questions they should ask*. Trying to find an appropriate ADP can be frustrating to caregivers and referring organizations when website databases are not current (accurate costs, wait times, options), if the websites are not user friendly (small print, jargon), or if the website has a search feature that cannot be specific enough to locate desired the services (e.g. Adult Day Centre not picked up with Adult Day Program, etc.).

Many continue to rely on the referral processes listed at the beginning of the *Findings* section, however, many of these processes do not factor in those who most often fall through the gaps (e.g. those without insight to the need for support services; the homeless). These clients often come to the attention of dementia-specific services at a point of crisis. Coping solutions include marketing non-dementia-specific services first to build trust and then expand offerings (e.g., start with Meals on Wheels and some homemaking, then suggest ADP).

iii. Mixed Populations

Many ADPs support mixed populations of persons with dementia alongside of those without for two primary reasons:

- a. the programs are not targeting those with cognitive impairment however longstanding clients may have developed cognitive impairment and are maintained until it was no longer feasible, or
- b. ADPs specifically offer integrated programs (e.g., programming as a larger group in the mornings and separate programming in the afternoons) with the belief that segregation of individuals with dementia is not appealing to day program clients.

iv. Targeted Programs

ADPs that provide programs solely for persons with dementia feel it is important to do so because seniors without dementia or those with mild impairment tend to be reluctant to participate with persons 20 years older than themselves, and/or farther progressed in their dementia which can cause them anxiety regarding what the future with dementia holds for them. Some even further separate their programs to allow for gender-specific programming and between those with higher cognitive functioning and lower cognitive functioning. Escalating dementia-related behaviours are the primary reason clients are restricted from attending the program. Safety concerns, lack of staffing, and lack of staff training to manage and accommodate for these behaviours are key reasons for restricting client participation.

v. Ethno-Cultural-Language

Ethno-cultural-language specific organizations like cultural centres and elderly persons centres cited that language and cultural considerations take precedence over specialized dementia programs for their clients. They will do their utmost to support them in their current programs rather than refer to a dementia-specific program without cultural or language components.

Culturally and language specific ADPs generally do not restrict people to a specific culture, however clients would generally self-select in or out given that most programming is offered in a language and manner central to the ADP (e.g., programming in one's mother tongue to address needs of new immigrants who may not speak English and those with English as a second language and their mother tongue). The rationale is that those who learned to speak English later in life frequently revert back to their first language as the disease progresses, increasing the need for language and culturally specific programming. This reinforces reluctance by some organizations and caregivers to transition such clients to dementia-specific ADPs and/or other dementia-specific services in general. This is also a key contributor to isolation and to the lack of awareness of services for non-English speaking and non-Caucasian persons with dementia.

Where cultural and language specific ADPs are offered, they are generally very flexible regarding their catchment area for clients in need of these ethnic specific services, as such programs are not plentiful, nor spread out across the Toronto. While this flexibility opens opportunities for some clients, *transportation* to and from the programs remains an issue for many outside of the catchment areas (e.g. arranging for transportation and/or an escort to accompany or drop off and pick up the person; paying for transportation; hours of operation).

Many cultural and language specific ADPs provide ethno-sensitive meals (e.g. kosher meals in Jewish centric ADPs, Asian meals in Chinese and Japanese ADPs) however most ADPs in general have difficulty accommodating “special diets.” For example, one ADP is currently looking for a South Asian caterer to address the dietary preferences of that population.

vi. Flexible and/or Extended Hours for Caregiver Schedules

There is a need for more flexible hours or extended hours to allow caregivers greater opportunity to access ADPs, however due to funding constraints this is not always an option. Programs that begin mid morning and end mid-afternoon are less desirable for caregivers with work commitments who need to drop off individuals before and pick them up after work. These programs however are well suited for those for whom a whole-day option is too exhausting.

vii. Eligibility Restrictions

Progressed cognitive decline, toileting assistance, incontinence problems, dietary restrictions, medication administration, feeding requirements, and mobility issues (e.g. 2 person transfers) are the key eligibility restrictions for many ADPs, due primarily to current staff ratios, staff qualifications, staff mix and dementia-specific knowledge.

viii. Transportation

Transportation is one of the greatest enablers and barriers to accessing ADPs. Many have clients who had attempted to use Toronto’s *Wheeltrans* program as an option, however the dementia became a barrier to accessing or continued use of this service. The regular transit system is not an option for clients with a progressing dementia and taxi services are often cost prohibitive.

Coping strategies include of subsidies for those utilizing and in need of transportation services through their organizations; flexibility by extending transportation to those on the cusp of their catchment areas; purchasing or sharing a van or mini-bus to transport clients to and from ADPs. One organization was in the process training staff for F licences to drive ADP buses. Limitations to these strategies continue to occur if and when there is not a second staff to monitor clients when the driver picks up other clients en route to and from the ADP; if clients were too frail or mobility issues were prohibitive to climbing into the bus, let alone if the person was in need of a wheelchair equipped mode of transportation.

ix. Younger Persons with Dementia

HIV dementia programs generally serve their own populations while other younger persons with dementia (e.g. early onset dementia, frontal lobe dementia) tend to be referred to seniors ADPs that target older seniors (e.g. those in their 70’s and 80’s).

x. Common Referral Process

Informal and formal partnerships with other organizations have enabled greater flexibility in referrals among and between community support organizations (e.g. CNAP common referral process) and rehabilitation organizations with hospitals and LTCHs in the TC-LHIN (e.g. in-patient behaviour unit common referral process)

4.1.2 Recommendations:

i. Increase Ethno-Cultural-Language Opportunities

The need for more language and ethno-cultural options for persons with dementia has been identified for each of the core services, and in all each of the 50 interviews.

As dementia progresses, persons with dementia more than ever need support and assistance in a language they understand, by dementia trained staff who speak their language and are sensitive to their cultural traditions.

To address these needs, many organizations describe coping techniques ranging from hiring staff who speak specific languages, to pulling staff or volunteers from other departments to help with translation/interpretation. The latter option can be disruptive to the other departments and is thus not a permanent solution.

Interview participants recommend that persons with dementia have access to ethno-cultural/linguistic programs locally, or be provided with extended, affordable transportation options when outside of catchment areas. Outreach for these programs needs to be offered in a manner and setting (e.g. signage, gender-based programming) that persons with dementia and their partners in care will understand.

ii. Flexible and/or Extended Hours for Caregiver Schedules or Client Behaviours

Extended hours would give caregivers more opportunity to assist persons with dementia to access ADPs, and might also address times of day when clients are more likely to be disruptive at home (e.g. ‘*sundowning*’ late afternoons¹⁰) and/or permit flexibility with drop-off and pick-up times. For example, Providence Health Care Centre offers 3 full shifts of staff over a 24 hour period. This provides more than just extended hours where a client can stay until 11pm if necessary, but one can also combine day or evenings with an overnight stay.

iii. Enhanced Transportation Services

Organizations have experimented with various strategies to address transportation issues for their clients, however funding restrictions often limit their creativity and flexibility (e.g. purchasing an additional vehicle, hiring and/or training extra staff for transportation purposes). Subsidies are available at some community support agencies for low-income seniors however the cost of ADP programs added to the cost of transportation can be prohibitive for some.

Enhanced and expanded transportation options such as the *Toronto Ride* program and individual ADP transportation offerings are recommended as a priority issue. Additional program funding could enhance the cognitive well-being, independence, and socialization for people with dementia while also reducing the risk for caregiver burnout.

¹⁰ Some people with dementia get agitated or restless late in the day (e.g., near sundown) and this is commonly referred to as *sundowning*.

iv. Enhancing Staff Training Skills and Abilities

Eligibility restrictions and exit criteria often revolve around toileting, incontinence, wheelchair transfers, and difficult-to-manage responsive behaviours.

Coping strategies include getting persons with dementia involved in an ADP as early as possible to promote consistency and familiarity of clients with specific routines and staff, plus staff training and education. To address incontinence, toileting and transfers, some organizations hire staff with personal support worker skills to assist with these activities, or they provide equipment to accommodate lifting and transfers. Some organizations offer partial and full showers to clients and some even do laundry to clean soiled clothes.

Organizations recommend that regardless of being able to offer bathing or showers, ADPs always keep a clean outfit on hand for clients with incontinence issues to promote dignity for the person with dementia and to relieve caregiver stress.

It is also recommended that showering options be added to ADP program offerings as this can be particularly helpful and appreciated by caregivers having difficulty managing and accommodating personal care for the individual at home.

v. Build on Existing Services

ADPs serve and/or could serve a wider array of needs beyond programming. Understanding that routine and consistency are important to persons with dementia, providing regular grooming opportunities (e.g. shower facilities, visiting hairdresser, visiting dentist/denturist, visiting manicurist) within a trusted environment and with consistent staff reduce client anxiety and decrease the burden of family caregivers.

ADPs are also described as an ideal environment in which to offer counselling for persons with dementia and support groups for caregivers of persons with dementia, especially when the ADP has social workers on staff. The rationale is that ADP staff are most familiar with the client, and that supervision can occur if a family support group is offered during one of the days a client is already visiting the ADP.

4.2 Adult Overnight Programs for Persons with Dementia

Adult Day Programs with overnight stay for persons with dementia were described in the survey as including *supervised [non-residential] overnight accommodation at a location outside the person with dementia's home. Programs generally include meals, transportation to/from the program, some personal care, and appropriate activities.*

Of the 50 organizations interviewed, two offer ADPs with overnight stay for persons with dementia (Etobicoke Services for Seniors (ESS), and Providence Health Care Centre (Providence). A third organization (St. Clair West Services for Seniors) also identified itself as a provider of overnight weekend services internally to its own clients through a shared arrangement with a partner organization from a bordering LHIN . Although this respite program has not been publicized like at Providence or ESS, St. Clair West have requested additional funding to open it up to more clients, arguing that quality of life for caregivers of their current clients has been markedly improved. These three organizations work primarily with individuals in middle-stage dementia.

4.2.1 Key Themes

Providence offers private bedrooms for sleeping and ESS offers a blend of private and semi-private bedrooms. St. Clair West has three private bedrooms in a limited program on alternating weekends offered only to its own clients.

Recognizing the scarcity of overnight and weekend options for caregivers of persons with dementia, Providence and ESS are flexible with their catchment areas and will accept people from Toronto Central LHIN and bordering LHINs as necessary and appropriate.

The limited number of overnight programs is an issue for *transportation* due to the distance required to travel if the client does not live in the vicinity of either program, or if transportation is needed at non-traditional pick-up and drop-off times.

Although Providence and ESS have staff who speak languages other than English, they noted that language can still be a barrier to accessing overnight ADP services.

i. Alternatives

The limited number of overnight programs has led caregivers to investigate other options when needing overnight or weekend breaks, including but not limited to short-term stays in LTCHs, or at retirement homes with dementia facilities. Others have investigated live-in privately paid caregivers to cope with the need for respite. It was also noted that supportive housing programs can provide some overnight monitoring which helps to reduce need for evening ADPs.

4.2.2 Recommendations

i. Expand Overnight and Weekend Programs

Expanding the capacity of current overnight and weekend programs would enable more people to access the existing respected and well attended programs.

Expanding current daytime ADPs to include affordable (e.g. subsidized) extended daytime, night-time, overnight and weekend programs with dementia trained staff in both programming (e.g. Montessori for dementia; Gentle Persuasive Approach) and personal care would address many of the access issues related to client needs (*sundowning*, evening restlessness, wandering). Including transportation for extended services would lessen issues regarding travel to and from. Expanding the hours of ADPs would also better accommodate caregiver needs (family caregivers, private caregivers, and/or personal support workers) requiring some flexibility regarding pick up and/or drop off times for a client (e.g. Providence offers flexible shifts across the 24 hour clock). Extending funding for special equipment and training would also benefit those persons with dementia experiencing increased frailty, mobility issues and incontinence problems.

4.3 Supportive Housing for Persons with Dementia and Mixed Populations

Supportive Housing [also referred to as Assistive Living] was described in the survey as including *designated housing which provides [LHIN-funded personal care] services and support in congregate or individual accommodation, and can meet a wide range of health and social needs of persons with dementia*. For the purposes of the survey the focus was on LHIN-funded non-profit supportive housing (SH) programs, therefore no retirement homes providing assisted living for persons with dementia were interviewed at this time.

Of the 50 organizations interviewed, 12 offer supportive housing for persons with dementia and/or mixed populations (i.e., persons with dementia and frail seniors) and 2 are identified as dementia-specific (Ewart Angus and Cedarhurst). Interestingly, one organization with Supportive Housing (SH) for 10 seniors has now become dementia-specific by default as each of these clients has aged in place and now has some form of cognitive impairment.

The SH programs interviewed assist clients with the following: care coordination (92%), basic activities of daily living such as grooming (92%), instrumental activities of daily living (92%), social activities, 24 hour support services (either on-site or within a specific timeframe) (83%), and security checks (83%). Other services include language specific support (staff speaking languages other than English); social workers affiliated with SH; in-home recreation activities; light homemaking; emergency response systems and/or an offer for SH to be first to receive a call in response to an emergency; health and wellness exercise programs; assistance with arranging meals on wheels or preparing light meals; and regular client assessments.

4.3.1 Key Themes

Ten key themes emerge from the interview with Supportive Housing providers.

i. Dementia-specific and Mixed Populations

Many of the mixed population SH programs indicate that of the clients with dementia they serve, most have mild cognitive impairment or early stage dementia and are still relatively independent. They estimate that dementia accounts for 15% or less of clients served, yet they also monitor and/or assist a number of people without a formal diagnosis, but highly suspected of having some cognitive issues. Less often they assist those with middle or late stage dementia, at which point clients must transition to institutions with the ability to manage heavier care needs and ongoing monitoring and supervision.

Some mixed population SH programs work with individuals who had suffered from a stroke and a resulting dementia, or were younger with mental health issues and a possible dementia. Two programs (LOFT and Neighbourhood Link) assist people struggling with homelessness and alcohol abuse, as these conditions can contribute to cognitive impairment such as Korsakoff's dementia. Conversely, these conditions can also account for some of these individuals having a degenerative form of dementia, such as Alzheimer's, that initially goes undetected.

Catchment areas range from specific buildings (Toronto Housing with SH) to citywide or the Greater Toronto Area, depending on the need (language and/or culturally specific environments such as Momiji). Most mixed SH programs have restrictions regarding ability to self-manage care, a need for basic activity of daily living assistance until reaching the point of needing two-person transfers or 24 hour supervision.

Dementia-specific SH programs (Ewart Angus and Cedarhurst) primarily address the issues of individuals with middle-stage dementia, and sometimes late-stage dementia to palliative care. These programs have dementia-specific education and training and more intensive dementia assistance, appropriate until clients develop heavier medical care needs, and/or when ambulation or behaviour issues become too difficult to manage and accommodate.

Dementia-specific SH programs for persons with HIV are separate and distinct and not generally integrated within the seniors focused programs or the mixed populations. Most organizations make referrals for HIV dementia to Fife House or MacEwan House.

ii. Availability

Toronto Housing is the main organization where SH programs are offered in Toronto Central LHIN, and to qualify to live in one of the buildings that provides SH, one must apply through Housing Connections, or live in a Toronto Housing building and apply to transfer to a building offering an SH program - however there is no guarantee that a person would be accepted into the SH program as community support agencies each have their own eligibility criteria.

Regarding access to Toronto Connections buildings with SH – those with the greatest need may not always get into those buildings. In some cases, acceptance to SH is contingent on age and need for financial assistance. Healthy independent young seniors accepted into buildings with SH, can be a potential waste of an important opportunity and resources. It was suggested that persons with dementia would benefit greatly if they were triaged and accepted into those buildings earlier. In doing so they would potentially function longer in the community. One organization advised that:

“we need to expedite the process of admission... with wait lists for supportive housing not seeming to change, consider the paperwork and processes involved in applying for Toronto Housing and then waiting to get in and hope to transfer to a building with SH. There are costs involved for the paperwork and finding the appropriate documentation, and capacity issues to be able to appreciate and understand consequences of decisions or indecision.” Those costs included loss of valuable time, functional capacity, and emotional toll waiting for a decision.

Some agencies provide SH through partnership with other organizations (a church, charity or cultural organization) and when finances are not an issue, persons with dementia may consider private retirement homes that have assistive living options similar to SH in other buildings.

A benefit and consequence of the integrated care offered in SH buildings is that turnover tends to be slow, thereby limiting availability. One organization has 450 people waiting for 134 rooms and on average a ten-person turnover per year, with the average age of those moving to a LTCH being 94 (higher than the average provincial age). Hence, regardless of the positive aspects associated with SH, clients with mild cognitive impairment or dementia may not have ready access to such programs.

iii. Eligibility and Wait Lists

The organizations interviewed cited issues with access due to the majority of SH being connected to Toronto Housing. This causes confusion as to the role of community support agencies providing services within the buildings (delinked) and the role of the housing providers.

Eligibility criteria varies for SH with mixed populations with some programs accepting adults 55 years of age and older, others 60 and over. Criteria become more restrictive when SH is offered in Toronto Housing buildings as clients need to be living in one of these buildings already or must be expedited to the front of long waiting lists (e.g., the person is experiencing abuse, is homeless or has a major health issue that can move the process along faster). Wait times can range from 6 to 12 years, creating a situation where people will not be able to access such integrated services in time to benefit those with progressive dementia either presently in need of assistance, or those at risk of placement in a LTCH.

If living within a building where SH services are provided, accepting new clients with a recognized dementia becomes restrictive when people live alone without family support, have ongoing co-morbid medical conditions, or dual diagnosis with underlying mental health issues, or communication barriers (aphasia from stroke or dementia; English as a second language), or require palliative care. Some restrictions require individuals to feed themselves and manage their own care. Most programs could not handle individuals that require two person transfers. Other restrictions include that the person must have a certain *MAPLe* score, be in crisis, or need light-to-moderate support with basic and some informal activities of daily living (assistance with bathing, dressing, medication monitoring, light housekeeping, etc.).

Even when people meet SH program eligibility criteria, organizations providing the services are often at capacity, and some have to establish their own wait lists, which they and the potential clients find very frustrating. One organization said it is hard to turn people away and that clients are asking “*when is it going to be my turn so I don't have to go to nursing home?*” Insufficient funding was cited as the reason for not providing service to all in need of service.

iv. Client Challenges

Outside of eligibility criteria, a number of client challenges were cited in offering SH to persons with dementia. These include marginalized populations who struggle with homelessness, substance abuse, behavioural issues, complex medical conditions, complex medication requirements or mental health issues, each of which can interfere with the provision of care.

When mental health or substance abuse are indicated as a reason for referral, LOFT and Neighbourhood Link are two SH programs that address these issues – however wait lists are a reality here as well.

4.3.2 Recommendations

i. Expansion of SH Programs: Availability and Accessibility

Organizations see many benefits of SH for persons with dementia including:

- maintenance of independence for longer periods than without integrated support

- increased life expectancy (citing increases in ages of people dying or being transferred to LTCHs from SH)
- acting as a hub for many services and more integrated care coordination
- a resource seen to decrease need for admission to LTCH and/or hospital
- less restrictive environment than institutional care

Regardless of these perceived benefits, it can be difficult to measure and demonstrate the positive results of SH (e.g., applications and evaluations for Aging at Home funding), thus making it difficult to prove the case for program expansion.

The following recommendations would increase access and availability to SH for persons with dementia:

- The success of SH programs be evaluated over a longer period of time and over a number of qualitative and quantitative indicators that factor in the difficulty of capturing the number and essence of such events as near misses (visits to ER prevented, medication errors prevented, safety issues addressed, etc.).
- Provide expansion funding for SH programs demonstrating good outcomes so they can serve the needs of a growing senior population, especially those experiencing dementia.
- Conduct a review of Toronto Housing admission criteria to expedite those in need of SH programs into appropriate buildings. This may help address issues in a more preventive manner as well as expedite those with more pressing needs for SH care.
- Provide expansion funding for more ethno-cultural/specific SH programs.
- Provide dementia-specific training to all staff working in SH buildings so they can better identify clients presenting with dementia-related symptoms, and better manage and accommodate individuals with dementia related behaviours.
- Expand SH funding to provide on-site Registered Practical Nurses (RPNs) to assist with medications.

4.4 Dementia-specific Case Management

Dementia-specific case management was described as *a specialized, comprehensive, and complex service that involves building a trusting relationship with the client/family/network, to provide ongoing support around dementia related issues; help the client function in the least restrictive, most natural environment and; achieve an improved quality of life (i.e. on-going process of client assessment, service planning, system navigation, care coordination and monitoring).*

Of the 50 organizations interviewed, 33 offered what they consider dementia-specific case management according to the definition provided, yet interpretations vary (CCAC case managers coordinate services but are not service providers; social workers may be housed in service provider organizations such as a community support agency or regional geriatric program and play a more intensive case management role). The remaining organizations mentioned that they often provide case management not designated as dementia-specific; however they serve a number of individuals with dementia and cognitive related issues.

4.4.1 Key Themes

Five key themes emerge from interviews regarding Dementia-specific Case Management.

i. Case Management Across the Continuum

Almost all organizations indicated that case management is important for persons with dementia and their partners in care across the entire continuum of dementia care, from mild cognitive impairment to late and palliative stage dementia. However, they only provide services to their own target populations. Services provided by these organizations under the umbrella of dementia-specific case management include: relationship building, care planning and goal setting (97%), standardized assessments (94%), liaison, advocacy or consultation with other resources based on the client's health and social needs (94%), in-direct service provision (91%), monitoring and follow-up (91%), information and referral (91%), direct service provision/intervention (85%). Other services include caregiver support, drop-in visitations, wandering programs, support groups, choosing a LTC home. A few organizations mentioned that a social worker often fills the role of case manager.

ii. Length and Type of Support

Case management varies by organization ranging from long-term monitoring and follow-up to more short-term crisis intervention. At times case management and counselling are combined, but most often they are considered distinct.

Organizations providing crisis intervention noted that clients with dementia may well benefit from additional visits (some are limited to three) from geriatric crisis teams in helping to settle them and their formal and/or informal caregivers into new routines, regimens or environments. For short-term case managers, repeatedly opening, closing and re-opening files as a client frequently exits and revisits the system or is in constant need of case management can be taxing on the client and frustrating for staff.

Some organizations have limited ability to do outreach visits to a person's home in the community or LTCH, and primarily offer case management to those who are able to come to their office. If and when clients move out of the catchment area, no home visits are permitted and

if follow-up is provided it needs to be as a telephone intervention followed by a referral to CCAC in the new location. This is especially difficult when clients do not speak English.

Regardless of birthplace, many persons with dementia feel it is not “appropriate” to accept help from anyone other than family. This feeling can be further strengthened by cultural norms and expectations from ethnic and cultural backgrounds, especially Chinese and South Asian clients. Case management offered by persons of the same background helps to explain options and work through issues of guilt and entitlement.

For many organizations, case management is not formally funded as a “client-assisted service” however it is often included in the service delivery model. For example, case management might be provided through organizational supports provided by a CCAC case manager, a SH supervisor, to more targeted case management provided by social workers, social support workers, or members of geriatric mental health teams. Case management may not start out as dementia-specific but becomes dementia-specific with time. Geriatric psychiatrists or psycho-geriatricians may also be brought into the case management process to help manage difficult dementia cases.

One organization mentioned that new teams provide intensive case management that follows the person from hospital through the transition back home, with frequent follow up sessions. They also link individuals to broader support throughout the continuum of care.

Another organization mentioned that case management is linked with supportive housing and that referrals are made to specialists and translators when necessary. Programs that provide case management link individuals with several organizations/services including: community service agencies, the CCAC, the Alzheimer Society, memory clinics, escorts for banking and medical appointments, translators, personal support workers, day programs, long term care homes, regional geriatric assessment programs, geriatric psychiatry services, COPA, PACE, and CAMH.

iii. Capacity

Regardless of care setting, capacity is a big issue in offering case management and other services to persons with dementia, especially when the person does not know or remember they have dementia:

“one needs to have the client’s consent and there are clients that say they are just fine and do not need help when really they do. One also needs ‘buy-in’ from informed providers and to better understand the need to build relationships. Serious arm-twisting tends not to have very positive results. People need to accept the support for the right types of reasons. “

Another organization stated:

“Many clients may also have a dementia that has not been formally diagnosed and/or may not have family and when they refuse service it can be difficult as there are few options to turn to. We can’t assist them if they won’t let us - yet we don’t drop the ball on these folks. Instead we offer monitoring and follow-up, and more likely it will be at a crisis point when these folks will accept help.”

One LTCH commented:

“A challenge is when there is no Power of Attorney for personal care or finances; cannot decline people [to your organization] on a financial basis; when a person comes with no POA or Substitute Decision Maker it is up to the home to sort it all out.”

Strategies include monitoring what is outlined above, or investigating the possibility of a capacity assessor completing a capacity assessment. This poses many concerns for organizations, especially the costs and effort involved in getting and following through such an assessment. The inability of clients or family members to pay for this assessment means that individuals may not get the assessment done. One LTCH cited that it will often fall to the home to start the process and that *“it’s \$500 and we have to eat that cost and we do not have the budget for that.”*

iv. Stigma and Denial

Issues of stigma and denial were common in our interviews. Stigma was experienced not only by persons with the dementia but also by their family members, leading to frustration and/or reluctance to be involved in care planning. In some cultures there is no word for dementia and accepting that a person in the family has a mental health condition sometimes seems impossible.

A suggested strategy is to include diversity training for staff to help strategize and address issues related to stigma and denial related to memory loss and dementia. Many organizations tap into expertise from current staff or those from partner agencies to target families and persons with dementia in the discussion and dissemination of practical suggestions and approaches to help get all involved “on-board.”

One LTCH cited a safety issue related to denial when persons with dementia utilize short-term respite beds and are unfamiliar with the smoking regulations:

“If you have family members who do not see the dementia or don’t want to see it, then you can’t put things in place to help the person cope with the new routines, such as smoking when the client is unable to differ between smoking inside and outside.”

v. System Navigation

Some organizations state that it can be tricky connecting people to services when case managers do not work at organizations that actually offer the services they are recommending. It poses a challenge in terms of follow-through and follow-up with arranging and monitoring of services: *“it’s an extra step to have to connect someone as opposed to offering it through one organization.”* One organization does not offer Meals on Wheels and therefore cannot place ongoing orders or monitor them. Another organization stated that just providing information and referral can be a barrier to accessing services as people with dementia *“will just not go [to ADPs, memory clinics] – although they may go if the worker will go and sit with them. Introducing something new and unfamiliar is difficult for them.”*

Case management in a language the person with dementia and their family understand is crucial. Case managers for organizations with language-specific services stated that much time is spent accompanying clients to appointments for translation purposes and to ensure the person has a way to get there and back.

Case management in general, but especially for persons with language or culture-specific needs is crucial to a person with dementia's level of acceptance and awareness of what services and options are available to them.

4.4.2 Recommendations

i. Expand Case Management Capacity (Evening, Weekend and Translation)

Case management is offered primarily Monday to Friday during regular business hours. Expanding the capacity to include more evening and weekend programs would enable more people to access existing and new services.

ii. System Navigation

The *Rising Tide* study recommends assigning a system navigator (case manager) to each newly diagnosed dementia client in order to provide care coordination and to support informal caregivers. The positive effects of a system navigator include:

- Delaying admission into LTCHs
- Lessening the pressure placed on those high intensity resources thus producing significant savings in health costs.
- Increasing the ability by persons with dementia and their informal caregivers to access and rely on community-based care
- Reducing the economic burden on informal caregivers (e.g. savings in informal caregiver opportunity costs, as well as the indirect costs associated with informal care provision throughout the simulated timeframe). (Rising Tide, 2010, pp. 34 – 35)

iii. Dementia-specific Training

Dementia-specific training and sensitivity are necessary for case managers to recognize symptoms and traits of dementia, and to build trusting relationships with persons with dementia. Patience and rapport-building are particularly key to acquiring consent to initiate services and programs, especially with those persons who lack awareness of their condition and state they are fine when they would in fact benefit from help. Without the ability to monitor and/or provide service, persons with dementia may not benefit from many early interventions that can help to maintain independence and better quality of life for longer, and avoid premature or unnecessary use of more costly acute care services.

iv. Increase Options for Consistency

There is a need for intensive long-term case management and flexible points of access with consistent trained intake workers able to build relationships with clients and take detailed notes, so that when and if a client calls back in the future, the intake worker is readily able to pick up the file. The ability to offer a breadth of services can build relationships (Meals on Wheels, community dining) and help progress towards more goal-oriented dementia-specific programming.

While consistency is a key factor in dementia care, organizations also state that there is a need for a team/partnering approach and coordinated intake to address staff vacations and turnover so that no one is left feeling abandoned, or more prone to refusing service.

v. **Increase Language Offerings**

Please refer to the *Findings* section 4.0 for further detail.

4.5 Dementia-specific Counselling

Dementia-specific Counselling was described in the survey in the following way: *Dementia-specific Counselling relates to getting a diagnosis, understanding dementia, immediate and future care of the person with dementia, and/or family coping strategies.* After reviewing the responses to the survey we acknowledge that there was some overlap with case management, education and support groups.

Of the 50 organizations interviewed, 23 state that they offer dementia-specific counselling to persons with dementia and 21 of the organizations indicate that they provide information and referral to other supports for family partners in care and for personal support workers (PSWs). The majority of these 23 organizations (95%) also offer supportive or therapeutic counselling for persons with dementia and their family partners in care ranging from pre-diagnosis, diagnosis, behaviour management, and late stages and palliative care.

These organizations indicated they provide counselling anywhere along the continuum from mild cognitive impairment to palliative stage dementia for both the individuals and their caregivers. They cited ideally the counselling process would begin as early as possible to provide knowledge about the disease and how it will progress. In the later stages, one organization mentioned that counsellors would primarily be working with the families and another respondent highlighted that counselling can benefit everyone involved in the dementia experience.

4.5.1 Key Themes

Three key themes emerge from the interview with Dementia-specific Counselling.

i. **Multiple Types of Offerings**

Organizations offered dementia-specific counselling through a variety of ‘counsellors’. Respondents stated that sometimes social workers provide the counselling, other times it is the doctor or family health team, chaplain, program staff, administrators, dietician, occupational therapist (OT), physiotherapists (PT), or consulting pharmacist. If dementia counselling begins without a diagnosis, one organization mentioned that they recommend that the person visit a physician to be assessed. Counselling services are also provided to caregivers or partners in care.

Generally most organizations noted that dementia-specific counselling as described in the survey occurs primarily on an individual basis separate from support groups for persons with dementia or for caregivers, and most often provided ad hoc/as-needed basis.

One organization described counselling in this manner:

For some – counselling is a time limited opportunity and does not follow the client through the whole continuum (resource issues) Comes a point when persons with dementia can no

longer participate in counselling (e.g. early stages often benefit, harder as they lose the ability to engage). This is a point when the family needs more counselling however caregivers have difficulty getting out of the home to receive counselling.

ii. Language and Culturally Sensitive Resources

Organizations indicated that there is a noticeable gap in language and culturally specific counselling opportunities for persons with dementia across the TC-LHIN region. To access these services many have to travel long distances across the city which makes it impossible for some (please refer to section 4.0 for transportation considerations). Some organizations will assist with initial telephone counselling, especially when clients are outside of their catchment areas and home-visits are not possible.

Another interesting finding is the lack of culturally specific counselling (e.g. First Nations, French, Korean, Vietnamese, etc.). The way in which different seniors relate and interact with information can differ between cultures, and in some languages there is no word that easily translates the word dementia and/or its progression. In order to feel comfortable some seniors – and especially persons with dementia – need information presented by someone from the same cultural background and in a format (e.g. visual, pictorial) that is familiar. Using First Nations as an example, certain rituals such as ‘smudging’ and sharing information in a circle can ease discomfort and enhance the counselling experience. In this example few organizations outside of the Native Canadian Centre were identified as equipped to share information in this manner and in multiple First Nations languages.

iii. Partnering and Referrals

When organizations do not provide dementia-specific counselling, referrals are made to geriatric assessment teams, the Alzheimer Society’s First Link program, the Centre for Addictions and Mental Health, hospice services, pharmacists, CCAC, case managers from sister organizations, family doctors, and/or system navigators.

Some organizations have dementia-specific trained personal support workers (PSWs) who informally provide assistance to families during their visits in understanding why a person with dementia might be acting a certain way (e.g. identifying responsive behaviours and helping with suggestions to work through them and/or how to connect with other supports). PSWs then report back to their supervisors (e.g. flagging tools, phone calls) when this type of assistance is offered.

In some cases, persons with dementia and their family caregivers pursue individual counselling provided by a private therapist when it is covered by insurance.

4.5.2 Recommendations

i. Expand Capacity of Culturally and Language Specific Counselling:

Organizations stated a need to expand partnering opportunities and funding to address more clients outside of catchment areas – including options for transportation to receive counselling and/or additional staff to provide dementia-specific outreach in a language people understand and in a culturally sensitive manner.

ii. Dementia-specific Training

As mentioned with Case Management, dementia-specific training and sensitivity training are recommended for earlier recognition of symptoms and traits of dementia, and how to build trusting relationships with persons with dementia to acquire consent. This enhances the ability to monitor and provide services to persons with dementia and maintain their independence, quality of life, and avoid premature/unnecessary use of more costly acute care services.

iii. Increase Awareness and Decrease Stigma

Many clients may not recognize the need for counselling or want it. Recommendations to address this issue include using more empowering language, providing hope for a meaningful life despite dementia, and providing useful coping strategies and interventions to maximize independence and decision making abilities.

4.6 Dementia Education

Dementia-specific Education was described in the survey as *education designed for people with dementia, caregivers and/or the broader community*.

Of the 50 organizations interviewed, 29 offer dementia-specific education to various audiences from persons with dementia and their caregivers to staff, other health professionals and/or the broader public. Dementia education in the beginning stages is seen as most beneficial to prepare individuals with dementia for the future. Dementia education should also occur along the full dementia continuum for all caregivers (informal and formal) as this can contribute to general wellness, faster recognition of signs and symptoms for earlier diagnosis and earlier opportunities to benefit from interventions such as cognitive enhancing medications. Appropriate knowledge and understanding of dementia can also lead to a reduced length of stay in higher-cost settings such as acute care. Early treatment will also sustain people with dementia at more optimal levels of functioning, hence improving their quality of life (Rising Tide, 2010).

4.6.1. Key Themes

Five key themes emerge from the interviews regarding Dementia-specific Education.

i. Staff Training in Dementia Education

Of the 29 organizations that provide dementia-specific education, 18 indicated that they have *mandatory internal* dementia training (e.g., education and skills training provided though in-house expertise). *Voluntary internal* dementia training (e.g., education and skills training provided though in-house expertise) is also supported by 18 organizations. In comparison, 16 organizations indicated they have *mandatory external* dementia training (e.g., education and skills training provided through targeted dementia programs) and 30 organizations support *voluntary external* dementia training (e.g., education and skills training provided through targeted dementia programs). Seven organizations have professional staff whose colleges require professional development (e.g., professional colleges licensing requirements) and often chose dementia-specific education as part of this requirement.

There is a strong tendency by organizations to rely on hiring staff with a PSW certificate or degree from a professional or clinical program, however education provided in such training

programs may not require dementia-specific training as part of the curriculum (e.g. could be an elective).

ii. Awareness of Educational Resources

Many organizations are aware of only limited resources for dementia-specific training for both staff and their clients. When seeking information many turn to the Toronto Dementia Network website for current offerings, or rely on well developed partnerships with “expert” organizations.

iii. Strengthen Current Partnering

Organizations that offer internal and/or external dementia-specific education note many constructive partnering opportunities with dementia-specific trained educators from other more specialized organizations, specifically: Psycho-geriatric Resource Consultants from Regional Geriatric Programs, The Centre for Addictions and Mental Health, the Toronto Rehabilitation Institute, and the Alzheimer Society of Toronto. Many organizations also invite guest lecturers (e.g. hospital affiliated psychiatrists, memory clinic neurologists) who provide rich insight into the behaviours of many of their clients.

iv. Broad Dementia Training

While persons with dementia live in all care settings, analysis demonstrates that each organization approaches dementia-specific education in their own way and that no standard dementia program or training is offered across organizations for formal or informal care providers and persons with dementia. Regardless of type of organization (e.g. Community Support Organizations, CCAC provider organizations, LTCHs, etc.) many organizations that employ personal support workers feel their staff have received some dementia training as a part of their certificate program and note that dementia-specific experience is a general criterion for employment at their organization.

The following chart illustrates the varied approaches to dementia education:

Approaches and Audiences for Dementia-specific Education				
	Formal caregivers (e.g. healthcare para-professionals)	Informal caregivers (e.g. family, friend)	Persons with dementia	Broader community (e.g. interested public)
One-on-one education	44%	87%	74%	17%
Formal small group discussions	57%	86%	43%	29%
Interactive workshops	69%	63%	44%	38%

Forums	70%	50%	40%	70%
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Dementia-specific education primarily targets staff while family and persons with dementia tend to be provided education on an as-need or one-off basis. When the latter education is provided it is primarily one-on-one education for persons with dementia and offered one-on-one or in support group settings with informal caregivers.

Long term care homes noted one of the best ways family and other informal caregivers receive dementia-specific education is through presentations and discussions at monthly Family Council meetings. This responsibility often falls to a part-time or full-time in-house staff educator with training in a host of different issues.

v. Current Dementia Education Strategies

The following citations are from organizations regarding the different dementia-specific education strategies they have employed in the past and/or ongoing:

In-House Educator (4 responses)

- Dementia education is provided by staff educator (e.g. behaviour in-services) – sometimes we send PSWs to the Alzheimer Society for PSW training.
- We provide informational sessions in house.
- Public education coordinators from the Alzheimer Society (PECs) do workshops and specific training for health and other professionals to teach about dementia and sometimes to the public. They also provide dementia education at staff training; support groups; workshops; Alzheimer Society counsellors sometimes do the Family Council meetings or present in community agencies. Personal Support Workers have a forum every April. We also have also done a forum for family caregivers and generally try to do a forum every year as well.
- We have a family caregiver connections program with education presentations, transportation and respite available.

Blend of In-House and External (3 responses)

- In house, we have a part-time educator with dementia expertise and also have speakers come in from outside to discuss current Evidence Based Practices; Our general standardized education requirements are U-first for all PSWs and their managers as well as online seniors training, Mental Health RNs and Crisis Team have taken PIECES training and/or in house training. We are developing a resource tool kit with an advanced practice consultant for seniors and mental health, an internal resource and a dedicated coordinator for Personal Support. We also have two clinical resource staff members who have been trained to teach Gentle Persuasion Approaches.
- Some PSWs have GPA training.
- Our workshops are applicable to the types of people we serve or for our front line staff. Staff can also apply to other workshops (outside of our organization). They have the opportunity/financial support as long as it ties back to their job.

Refer Out to External Organizations (11 responses)

- We would refer to organizations that have this specialty.
- Usually bring in another domain expert.
- The Alzheimer Society of Toronto (AST) provides a workshop annually and we may offer education at congregate dining if we bring in a special speaker.
- At this time do not offer dementia specific education but partner with others to get that training (e.g. AST, RGP); however, as we develop our skills may do so. We do not want to duplicate what already exists – it is better to leverage the content experts.
- We will bring in the Alzheimer Society educators and translate.
- We have brought in RGP psycho-geriatric resource consultants, the Alzheimer Society, U-First! and PIECES training, the Alzheimer’s Knowledge Exchange, and other dementia-specific training programs or experts.
- From time to time (e.g. 1 x per year) we have education sessions and sometimes the Alzheimer Society comes in.
- We would bring in someone if there was an identified need.
- The Alzheimer Society may come out to provide dementia training to family support groups and seniors council. We have also had people from the Psycho-Geriatric Program come in.
- There are health sessions at the adult day program for seniors and the ADP invites professional speakers. Our staff receives training through workshops at the Alzheimer Society (PSW program) and we hire personal support workers that have graduated from a PSW certificate program.
- We do not offer education in Toronto Central LHIN at this time. There are offerings in the Central LHIN; through Ryerson; and we are investigating other education.
- We have been sending staff out for training but also will have seminars on dementia for neighbours in supportive housing or the community to better understand why things might be happening (awareness in general).

Public Series or Forums (4)

- Offered a one-time seminar with break-out sessions on dementia and brought in expert key note speakers, but our spring education series is on-going and often has a dementia component to it.
- We offer big education forums, one-on-one education, in-services for staff, information at point of assessment, and provide proactive education for brain health.
- There is an annual Alzheimer Symposium and certain other series that we are involved with that provide education. There is a living with and living well series offered in the early evening to the community on topics throughout the year and [the geriatrics team] usually presents one or two per year (one for dementia and one not for dementia).
- We have open houses to the public for local community, health fairs with information to the public. At one time we had grand rounds – which are a high level of education provided to physicians and senior health clinicians which were well attended. We will also offer information sessions to the police and other community partners through the west end urban health alliance (health service providers - group housed at St. Joe’s hospital).

Partnering (3 responses)

- We are doing some work with [a sister organization].
- We offer support groups and are also working with Mt. Sinai in offering services to Portuguese and Chinese people with dementia and caregivers. We offer a radio program to the Portuguese and workshops at the elder persons centre.
- Family Caregiver Connection Program (FCC) is a partnership of seven Jewish community agencies (Circle of Care, Baycrest, Bernard Betel Centre, Chai Tikvah Foundation, Jewish Family and Child, Jewish Immigrant Aid Services Toronto (JIAS) and the Reena Foundation) who are committed to a collaborative approach to family caregiver support services including a caregiver support program which provides education and information to caregivers on a one-on-one basis.

Resource Centre and Staff (2 responses)

- We have a resource centre equipped with pre-programmed computers with helpful icons, books, DVDs, a children's play centre, quiet room and private room that family and staff may access. The information includes topics that impact on people with dementia, but not always on dementia per se. The resource centre materials are valuable because they are in lay terms and easier to share with family, volunteers and students.
- The Alzheimer Society has a Resource Library and an electronic repository of multi lingual dementia-specific resources.

One-on-one (6 responses)

- Our focus is primarily on staff. If family wants information, we do it on an as needed basis.
- We provide in-services for staff
- When we provide education for families it is mostly on a one on one basis.
- One-to-one education during clinical discussions with regards to persons with dementia in care.
- We provide dementia education within the first two [home] visits.
- We do more counselling then extensive education.

Care Giver Specific Education (2)

- Provide education at Family Council meetings.
- Our education is provided by invitation and we have been doing caregiver education since 1981.

4.6.2 Recommendations

i. Transportation, Location and Respite

Many PSWs have difficulty with transportation and if the educational program is at the other end of the city it can be hard to get to. They, and many clients and caregivers alike, often rely on public transportation to get around. This can take a long time depending on location of the session/workshop, and may dissuade people from taking courses that involve a great deal of effort (e.g. bus to subway and another connecting bus or streetcar).

For persons with dementia and their caregivers it may not always be possible to navigate the transit system or drive to an event (e.g. no night time driving), and it may be difficult to manage stairs or escalators or when a transit station is not equipped with a [working] elevator.

It can also be difficult to qualify for and access *Wheeltrans* due to strict eligibility criteria (accessible transit service for persons exhibiting physical disabilities in need of a modified or accessible vehicle). They can also run into difficulty accessing the *Toronto Ride* program as priority is given to medical appointments during regular business hours.

It is recommended that dementia-specific education opportunities be offered in accessible public buildings in local communities. Earlier identified transportation strategies should also be applied and where respite care is an issue – provision of such either on-site or offering education at times when alternate caregivers may be arranged.

ii. Language

Education needs to be presented in a way that people understand content wise, format wise, and in handouts/literature. Many dementia-specific education programs for staff and for persons with dementia and their caregivers are geared toward English speakers. This can pose barriers to access when newcomers to Canada may not speak or understand English, or for persons that have reverted back to their native tongue due to the dementia.

As one culturally specific organization stated:

“We can usually find one person who can speak English [however] there are differences between basic information sharing and important clinical information sharing. We have an interpretation service available if we really need it, but we wouldn't have these services available for ongoing education.”

It is recommended that recognized dementia-specific education be adapted into other languages with dementia-trained interpreters to help address important translation distinctions and subtle nuances required for multiple non-English speaking audiences.

iii. Human Resources

As mentioned above the tendency of organizations to rely on the curriculum of health and social care training programs (e.g. PSW certificate programs, nursing programs, etc.) provided to potential new employees, it is important that these programs incorporate current and relevant dementia-specific training as a prerequisite in their curriculum.

iv. Improve Awareness of Educational Resources

There is a lack of awareness of a broad range of dementia-specific training options and how best to choose a program that is available.

It is recommended that resources such as the publically available Dementia Education Needs Assessment Tool (DENA tool) be shared with all TC-LHIN funded organizations and beyond. The purpose of the tool as stated on its website (www.denatool.org) is to assist professionals working in organizations that provide care to older persons with dementia to make decisions about continuing education programs related to dementia. The tool assists organizations to support practice change and performance improvement through education. To this end, the tool

assists users to determine whether they need education, whether they are able to support practice change, and what educational opportunities are available to them. It also accounts for the fact that continuing education can take many forms (e.g. informal such as ‘teaching in the moment’ opportunities and case-based learning; formal education initiatives such as workshops and dementia programs). The DENA tool focuses on formal education opportunities.

v. Ongoing Dementia-specific Education Opportunities

Organizations recognize that “one-off” education is not as good as ongoing training opportunities and seek where possible to implement the following coping strategies to address this:

- Mandatory dementia training at orientation & follow-up
- Accessible & brief **in-services** for ease of training
- Coaching to maximize learning and reduce or eliminate many responsive behaviours
- Compensation for external off-site training including wages and/or transportation
- Interpretation when necessary

vi. Additional Funding for Sessions and Back-fill

The desire to provide dementia-specific training to all staff is great, however many organizations have to decline staff the opportunity for such training due to funding issues. They stated that training needs to be provided multiple times (e.g., staff turnover and the need to educate and re-educate new staff). Funding impacts education based on cost, the ability to ‘back-fill’ staff with replacement shifts, and salary costs associated with sending people to the training. Training may be offered only to staff working directly with persons with dementia (e.g., working on the behaviour unit), denying others who also would benefit from this education.

It is recommended that additional funding target dementia-specific training and education in organizations working with persons with dementia and their families to enhance skills, knowledge and abilities by all partners in care – staff, families and persons with dementia and volunteers as appropriate.

Compensation is also an important incentive therefore it is also recommended that organizations consider many options (food provided at in-house training, staff having sessions paid for and going on their own time, protected time for application of course work on-site) to enhance uptake of dementia-specific professional development.

4.7 Family Support Groups – Caregivers of Persons with Dementia

Family Support Groups for Caregivers of Persons with Dementia was described in the survey as *support groups designed to meet the emotional and educational needs of individuals/friends and/or family members who are providing care and support for persons with dementia.*

Of the 50 organizations interviewed, 14 offer various forms of family support groups for caregivers of persons with dementia. Organizations that do not offer support groups indicated that this is an important need and that they refer families to another organization when possible or appropriate, or perhaps offer individual family counselling. Some respondents could not refer to other organizations or support groups due to language or cultural issues.

The eligibility criterion for most support groups is broad and welcoming to all individuals who provide care for a person with dementia. Others restrict access internally to caregivers of persons with dementia within their organization (e.g., long term care homes).

4.7.1 Key Themes

Four key themes emerge from the interviews regarding Family Support Groups for Caregivers of Persons with Dementia.

i. Types of Support Groups

In a diverse society there are different roles and responsibilities for family members and this can be difficult to address one-on-one. Some organizations provide one or many different settings/groups to discuss caregiver issues and receive peer support including:

- Support groups identified by relationship (e.g. a spouses group - male and female; sons and/or daughters group; full family support group).
- A shared program (a couples group) for a caregiver and a loved one who has dementia (feedback and intervention-to allow the couple to engage in recreation and therapy-to have an outing)
- Chronic illness support groups (e.g. dementia considered as a chronic disease)
- Stroke support groups (e.g. includes vascular dementia related issues)
- Language specific groups
- Off-site groups (e.g. members of a church congregation)

Two organizations have developed and/or are investigating some self-management support for caregivers on-line.

Offerings range from pure information sharing, to therapeutic psycho-educational methods, to more counselling-centred approaches geared towards feelings and therapeutic intervention. Variations in target caregiver populations and approaches are the result of differences in types of emotional needs by different groups.

Many organizations do not have ongoing family support groups and only offer them when they see a demand for such groups.

ii. Family Councils

Family Councils in LTCHs are representational bodies often acting as a bridge between families and administration. Some LTCHs access Family Councils as a means to offer caregiver support. Renaming council to circle has helped to take the stigma out of the purpose of these groups. While some educational functions might be sponsored and hosted by Family Councils, they do not as a rule operate as a channel of providing “support” to many families of residents. For those LTCHs that utilize this venue, family circle meetings were typically facilitated by an in-house social worker, social services worker, manager of programs and services and/or the chaplain. Although dementia topics arise in these meetings, they are not designated as dementia-specific meetings. When necessary a social worker may offer further support to families.

iii. Individual Counselling

Individual counselling to family members is the most common form of support followed by making referrals out to other organizations for their support groups

iv. Caregiver Education & Support Combined

Some organizations offer integrated caregiver series with peer support and an education component incorporated (e.g. monthly meetings, 6 week series held in the day, early evening or combined as a one-day workshop on a weekend).

4.7.2 Recommendations

i. Timing

Organizations would like to be more available (e.g. over an 18 hour day) to address the needs of caregivers who work during the day and thus may not access current service offerings as easily.

To increase awareness and attendance of these sessions it is recommended that organizations consider partnering to pool resources and provide multiple offerings at different times and/or days with trained facilitators.

ii. Incentives to Attend

To increase uptake of support group activities it is recommended that organizations consider methods to provide incentives for attendance (e.g. food at the sessions, TTC tokens, onsite respite care for persons with dementia, money to pay for respite while attending the program).

iii. Stigma

There can be much shame associated with cognitive impairment or dementia and until caregivers attend at least one session, it can be a “hard sell.”

To address issues of stigma and caregiver reluctance it is recommended to begin by building relationships through other less threatening services (e.g. Meals on Wheels, congregate dining, drop-in supervisory visits) and then approach the subject of family support groups.

iv. Accessibility: Location, Catchment & Transportation

Many family support groups are flexible without specified catchment areas however organizations stated the reality is their groups tend only to serve persons who live close by as people need to provide own transportation.

As mentioned in previous sections, transportation services outside of public transit and taxis tend to be offered for medical appointments during regular business hours thus limiting older caregivers from accessing affordable options to travel to support groups.

It is recommended that support groups be offered in accessible public buildings (e.g. libraries, community health centres, churches) which can help address the needs of frail caregivers and those reliant on public transportation.

v. Language and Culture

Please see section 4.6.2 (ii) regarding the need to have services provided in different languages or with the assistance of translators who understand dementia and can interpret accordingly.

4.8 Support Groups for Persons with Dementia

Support Groups for persons with dementia were described in the survey as *support groups developed to meet the emotional and/or educational needs of persons who have been diagnosed with a form of dementia.*

Of the 50 organizations interviewed, 18 have offered support groups for persons with dementia, primarily for persons with mild cognitive impairment or early stage dementia – however few groups are still being offered.

4.8.1 Key Themes

One major theme emerged from interviews regarding Support Groups for Persons with Dementia.

i. Very Few Support Groups for Persons with Dementia

Few organizations currently offer formal support groups to persons with dementias. When the need arises for information and counselling, they primarily provide it one-on-one. The primary point of referral to the Alzheimer Society of Toronto or The Toronto Dementia Network is used to locate support groups in a closer geographical location or offered at an ethno-cultural-language specific organization.

4.8.2 Recommendations

i. Expand Support Groups for Persons with Dementia Across More ADPs

An expedient way to address the need for support groups for persons with dementia is to begin by offering more of them at existing accessible sites of dementia-specific programs such as ADPs. Here social workers or other staff with facilitation expertise could conduct these groups.

Organizations such as ADPs can also address some of the issues related to the lack of insight or awareness that a person with dementia might have about how one might benefit from these programs and/or more readily address issues of stigma by virtue of trusted familiar faces both offering and attending the program. Offering support groups at ADPs may also address issues related to transportation as many persons with dementia would already be at the location for the program.

4.9 Personal Care for Persons with Dementia

Personal Care or Personal Support for persons with dementia was described in the survey as *personal care/ support assistance provided to persons with dementia with their hygiene, grooming, dressing and other basic activities of daily living [by staff with dementia-specific training and knowledge]*.

Of the 50 organizations interviewed, 30 offer personal care for persons with dementia. These organizations indicated that personal care can be steadily provided from mild cognitive impairment through to late stage dementia. However, it was acknowledged that the personal care needs of a person in the late stages of dementia may be beyond the scope of some community organizations. Of the organizations that provided personal care 29 (97%) offer assistance with instrumental activities of daily living (e.g., meal assistance, cueing and/or medication monitoring, light exercising); 27 (93%) assist with basic activities of daily living (e.g., personal grooming, hygiene, bathing, transferring and positioning), and 9 (31%) escort persons with dementia to medical appointments. Other services provided under the umbrella of personal care include translation, and reminders to dress or remove clothing.

4.9.1 Key Themes

Two key themes emerge from interviews regarding Personal Care for Persons with Dementia.

i. Resource Matching Not Always Happening

TC-CCAC provider organizations and community support agencies often book clients based on availability and language prior to staff having dementia-specific skills and experience. Some organizations provide dementia training for staff rendering personal care however this ranges from mandatory ongoing training to sporadic or none whatsoever. While not all provide dementia training to staff, organizations conveyed the benefit of such training, especially as it relates to defusing during personal care.

ii. Varying Eligibility Criteria

Each organization has its own criteria for when and how they render personal care (e.g. mandatory, fee for service, monitoring to full bath assist, restrictions on transfers)

Supportive housing offers personal care to their clients, however unlike the TC-CCAC, personal hygiene is not the key eligibility criteria to receive care.

Few adult day programs offer personal care, a barrier for those with toileting and/ or incontinence issues.

Persons with dementia in need of personal care assistance (e.g. cueing, monitoring, bathing assist, full bath) are often referred to TC-CCAC funded services or community support agencies – especially those agencies with subsidies when finances are an issue for the person with dementia. When referring to private organizations, geography and language are usually considered. Depending on level of need, some referrals will go to CCAC for placement in a LTC home, or to seek help accessing supportive housing.

The TC-CCAC has recently moved towards a population health model with one program being particularly relevant to persons with dementia – the Seniors Enhanced Care program. The goal of

this program is to support frail seniors with complex needs and their caregivers to remain at home and in the community as long as possible by providing enhanced support and a range of home and community based services. The objectives cited in their Population Based Model Program Descriptions of September 2009 are:

- *To delay long term care institutionalization & support clients and the system by reducing avoidable ER visits and hospitalization*
- *Support seniors in their choices, enhance their independence, prevent deterioration & improve client outcomes and quality of life*
- *Facilitate a positive client and caregiver experience with their care & support caregivers in their role and prevent caregiver burden*
- *Support clients and caregivers with transitions across the care continuum*
- *Provide support to primary care physicians in caring for frail seniors*

Targeting populations such as these with the aforementioned objectives is expected to expedite initial home visits for clients, better assist with transitions from hospital to other care settings, provide regular follow up and facilitate better linkages between and amongst provider organizations. It is not clear at this time if consideration for relaxing personal hygiene eligibility criteria will be given to those with dementia.

A coping strategy often employed by families is to provide top-up services using private pay services to increase the length of the visit or the frequency of the visit. However, the cost of topping up services can often pose a barrier to some. For example, one community organization stated *“the service costs money and in low income areas we do offer subsidized rates, but it still can be expensive – especially when they can barely afford other necessities.”*

When family or a substitute decision maker are not available to encourage the use of a topping up option, convincing persons with dementia they may need this additional assistance and pay for it can become difficult.

4.9.2 Recommendations

i. Expand Personal Care Capacity at ADPs

Organizations would like to hire personal support workers and other clinical staff at ADPs with dementia-specific training to address issues of cueing, assisting with toileting and/ or incontinence issues and possible showering as required. They also would like to purchase equipment to provide bathing and toileting at ADPs, however funding restrictions for additional staff and/or equipment pose a barrier for many.

One organization that provides an ADP highlighted the benefits that familiar environment of an ADP offers for clients with dementia coupled with staff they felt comfortable with could: *“in some situations where shower is given at the ADP, the clients might be more accepting [than by someone in the community]. This can also thereby address the issue of time of shower [when client prefers to have one].”*

It is recommended that the availability of personal care services in ADPs can be very helpful in situations where clients are resistive to personal care at home and could be a program offering on either a regular or as needed basis.

ii. Flexibility with CCAC Criteria for Persons with Dementia

A number of organizations have issues with the TC-CCAC personal care criteria (e.g. bath, grooming, hygiene required to provide services to persons with dementia) when informal services such as medication monitoring, assistance with meal preparation, light housekeeping, or arranging appointments or transportation may be the current concerns and lead into personal care assistance. Getting in early was noted as key to develop relationships that can be built upon when the person starts losing capacity and may develop paranoia or other challenges that create barriers to personal care services.

As persons with dementia progress, they often need more assistance with incontinence issues and bathing assistance. However, the CCAC only provides limited PSW hours to address these issues including a limit of one full bath assist per week. Persons with dementia will often take a longer time to convince and provide personal care services to and therefore need longer visits to complete the task – especially when trying to incorporate assistance with their bath to promote independence for as long as possible. One organization stated:

“[Persons with dementia] need more time and more cueing and staff need more patience and techniques/skills. We need to be flexible with this - assigned times may not work for them and need to be able to meet changes in their needs.”

iii. Training to Assist with Personal Care Challenges

Training to better manage and accommodate responsive behaviours would assist with personal care challenges such as paranoia or aggressiveness (both verbally and physically). One community organization cited that they experience challenges *“if persons with dementia will not let the [staff] person in or is suspicious of why the person is there.”*

One organization stated:

Even with education, physical aggression can still be challenging for staff (e.g. mostly the hitting, pushing, biting, kicking). There are always ethical considerations of when do you stop, how do you gauge the need for personal care with the risk.

Another stated:

There is a limit to what people can tolerate when working alone in the community; sometimes this can restrict the ability to be there with the client. Alternatively LTCH settings might be able to better handle some challenging behaviours and the risk issues for both client and staff.

Organizations also mentioned that while they may provide dementia-specific training to staff working with that population, many times replacement staff (e.g. PSW vacations, the use of casual and part-time replacement staff in LTCH or rehab settings) will pick up other shifts and they may not have dementia-specific training and understanding. It can be difficult for persons with dementia to accept a new person providing personal care and escalate the possibility of triggering a responsive behaviour that is particularly difficult to manage without training.

It is recommended that regardless of service setting, staff need to feel and be equipped to understand possible triggers and to manage and accommodate behaviours as they arise. This can positively impact staff retention which can in turn benefit consistency of care providers to persons with dementia – a key consideration for greater recognition, trust, and ease of service provision to those struggling with memory loss.

Some of the educational programs and resources cited during the interviews as having benefited understanding of behaviours included U-First! Training, Gentle Persuasive Approaches Training, RGP/PRC consults, and in-house coaching by behaviour nurses. Many of these approaches are explained in the earlier mentioned DENA tool.

It is recommended that organizations provide ongoing training to keep staff current on possible strategies and interventions for managing dementia-specific behaviours. Any additional training needs to be both relevant to current roles of staff and engaging.

4.10 Homemaking Programs for Persons with Dementia

Homemaking or Home Help programs were described in the survey as programs that *generally provide assistance to persons with dementia at home with routine household activities including light housekeeping, laundry, and light meal preparation by individuals with dementia-specific training, skills and knowledge.*

Of the 50 organizations interviewed, 20 offer Homemaking or Home Help programs for persons with dementia. Community based fee for service and brokerage organizations indicated they work primarily with persons with mild cognitive impairment and early stage dementia that are still able to monitor and self-direct the workers. Fewer provided service to persons with middle or late stage unless a caregiver is present to assist with monitoring and direction, and because by middle and late stage persons with dementia are often transitioning to LTCHs.

Two LTCHs provide housekeeping staff with dementia training (one sent a housekeeper to U-First! training and another stated that they provide training on “difficult behaviours” to housekeeping staff. Generally, dementia-specific training is something provided more often to frontline care providers. Many LTCHs cited that their general orientation on hiring new staff provides some information about people with dementia.

4.10.1 Key Themes

Two key themes emerged from interviews regarding Homemaking Programs for Persons with Dementia.

i. Homemaking with and without Personal Care

Individuals providing home help or homemaking services are generally working for a private paying client. Reasons clients would utilize the home help or homemaking programs include a wider array of service offerings (e.g. restrictions in duties that can be paid for by TC-CCAC) and those needing only housekeeping and not personal care requirements for the TC-CCAC program.

Home Help programs in the community are run mostly on a brokerage model and for this reason few home helpers have received or been offered Dementia-specific training. Home help programs are often suggested only to those with very mild cognitive impairment when a person still has an ability to monitor and self-direct the helper to avoid potential client vulnerability or possible vulnerability of the helper with false accusations due to memory loss (e.g. accusations of theft because of paranoia).

On the other hand Homemaking in the community is often provided by universal personal support workers so there is a greater likelihood that staff have some dementia skills and training either through their certificate training or from in-house training provided by their organization. Light housekeeping in this case is either provided in conjunction with personal care duties (e.g. a CCAC client that need help with light cleaning in addition to a bath) or separate as private pay services to the organization the staff are sent from. Cost of private services for elderly clients (perceived or real) is a barrier to accessing heavier cleaning services. Those with financial difficulty are directed to organizations with subsidies.

Homemaking offered in SH programs is often handled similarly to homemaking in the community using generic personal support workers and based on assessed need (e.g. light clean-

up after rendering personal care; assistance with washing occasional heavy pots). Supervisors of these programs often refer to private pay services when clients require heavier cleaning services. Cost of private services is noted as a barrier in this instance and again those with financial difficulty will be directed to organizations with subsidies.

Homemaking services in LTCHs are primarily provided by housekeeping staff and as mentioned earlier, few LTCHs provided dementia-specific training for these staff.

ii. Consistency of Service Providers

Some clients will seek private care options because they feel that by paying for the service they may be better able to acquire consistency of staff than with the service funded by the TC-CCAC. One organization stated:

“People who are not happy with the CCAC community based care may go to a private agency ... because they are not happy with the personal support workers (not being consistent) and they want the same person coming in week after week. Accents can be troublesome for those with visual and hearing impairments. If they had a poor experience in the past and can afford assistance they will ask for a person whom they understand and for the consistency. For persons with dementia this is a key concern because of the need to build relationship and rapport with the caregiver.”

4.10.2 Recommendations

i. Special Consideration in CCAC Eligibility Criteria for Persons with Dementia

Instrumental activities of daily living (e.g. meal preparation, shopping, light housekeeping, transportation) are key drivers of placement on a long-term care home wait lists as compared with basic activities of daily living (e.g. hygiene, grooming, dressing) (Williams et al., 2010).

Persons with dementia, especially those in the early stages and/or those with financial need would benefit from an expansion of TC-CCAC eligibility criteria to allow flexibility with more informal care services (e.g. homemaking and monitoring options) for those without clinical needs such as assistance with a bath. As stated by one organization *“It would be great if the CCAC could offer just a homemaking component, especially for persons with dementia (e.g., meal preparation, laundry).”* The monitoring provided during light housekeeping and other homemaking duties can be invaluable in lending itself towards expansion into personal care when the time does arise, and avoids those with lower needs falling through the cracks until a point of crisis.

ii. Expanding Training Options to Homemaking and Home Help

Brokerage models at this time do not appear to offer dementia-specific training, however home help and homemaking workers can be particularly instrumental in triggering other services when the need arises. Organizations know what to look for and what to do when they notice that food has gone bad. They need to ask ‘if it is because they forgot to cook it, forget how to cook it, or have they actually eaten it spoiled?’

Regular and affordable opportunities for dementia-specific training need to be extended to homemaking and brokerage¹¹ workers where possible. Such training along with incentives (e.g. free transportation, free training) would greater coping skills to these staff and provide greater peace of mind for referring agencies to suggest these services to persons with dementia.

¹¹ Home help workers are generally not employed by the referring agency. The referring agency works as a broker to introduce clients to workers that will work privately for a fee to assist clients with light house cleaning such as laundry, vacuuming, dishwashing, dusting, dishes and cleaning of kitchens and bathrooms.

4.11 Respite Programs for Persons with Dementia

Respite Programs for Persons with Dementia was described in the survey as *support services for persons with dementia, to temporarily relieve their caregivers from care responsibilities including but not limited to monitoring and/or engaging persons with dementia in the daily activities, meal and medication monitoring, safety checks and social interaction.*

Of the 50 organizations interviewed, 21 say they offer programs that provide respite for caregivers of persons with dementia. These services varied and include: designated respite programs in the homes of persons with dementia which offer personal care and monitoring (62%), dementia-specific adult day programs (52%) and friendly visiting by volunteers with dementia-specific training (29%).

Note: Dementia-specific Friendly Visiting in late stage dementia was primarily provided by palliative care volunteers or volunteers in LTCHs and not in the community.

Many organizations that provide respite care target individuals with mild cognitive impairment, early onset dementia or early stage dementia. More detailed assessments would determine if respite services are suitable for individuals living the middle or late stages of dementia.

4.11.1 Key Themes

Four key themes emerge from interviews regarding Respite Care for Persons with Dementia.

i. Respite Provided Through the TC-CCAC

There can be wait lists for both TC-CCAC funded respite care services in the home of the person with dementia or in a short-term bed in a LTCH. This problem can be exacerbated for respite in LTCHs when people back out or cancel last minute, robbing another family of the chance for a break.

Others cited inadequate opportunities for caregiver relief due to limitations to the number of hours provided through the TC-CCAC and in cases where this happened cost was again cited as a barrier to hiring in private care services.

ii. Definitions of Respite

Some persons with dementia and their caregivers utilize one of the overnight ADPs as a form of respite, however these ADPs do not classify or advertise themselves as respite care.

iii. Reluctance of Caregivers

Guilt for leaving, inadequate duration and lack of culturally and language specific respite programs are reasons caregivers are reluctant to utilize respite services. One organization stated that the reluctance sometimes arises when caregivers have previously accessed respite and: *“the picture of the person that was painted is not what they were actually like during the process.”* This may occur when caregivers are told the clients enjoyed themselves yet from the caregiver point of view the client actually came back more agitated than before. Another may be when they expect that the worker has adequate dementia training yet does not demonstrate this during the visit and needs coaching from the caregiver throughout a home visit.

Short-term respite programs in LTCH beds can be disruptive to regular routines both for the LTC home and the visiting person with dementia. This can make it difficult to manage and accommodate resulting behaviours at the home and when the person returns home. As stated by one organization: *“Any change can be upsetting, but especially for persons with dementia – they get used to seeing one face and then a new face can upset them.”*

iv. Awareness

Many people with dementia *“are falling through the cracks because they are unaware of the services available”* or *“lack knowledge in regards to the referral process even when there is a community outreach program.”*

Others stated that persons with dementia and their families might not even seek help due to *“cultural barriers [in] having someone in the home other than family (e.g. South Asian and East Asian population do not tend to access services and tend to their own family needs).”*

4.11.2 Recommendations

i. Sensitivity to Marginalized Groups

Persons with dementia can be marginalized not only by virtue of their cognitive impairment, but also by their living circumstances, a lack of support networks, and/or support that is not knowledgeable about dementia and dementia-specific services. Outreach by provider organizations and respite services need to be offered in languages and methods that are responsive to their populations.

It is recommended to expand outreach and promotional activities, target hiring practices, and provide mandatory sensitivity training on family dynamics, marginalized populations, and cultural issues that may pose barriers to accessing dementia-specific respite care services. This should increase awareness of current dementia-specific offerings in the TC-LHIN, and generate increased interest and demand for more of these services.

ii. Respite Care – A First Line and Second Line Program

Informal caregivers of persons with dementia, many of whom are seniors with health issues of their own, often provide significant amounts of unpaid care that leave them at risk for declines in their own health, and possible burnout (Rising Tide, 2010; Hollander et al., 2009). Accessing respite programs sooner (as a first line program) than later (as an add-on service) would benefit both the person with dementia (e.g. early preparation and familiarity for the routine of respite) and their caregivers (e.g. earlier and more frequent breaks from caregiving responsibilities).

It is recommended that awareness activities not only target users of respite services but also referring healthcare organizations and professionals to better understand and promote the use of these services.

iii. Expand Respite Options at Home

It is recommended that respite providers consider providing some element of activation and or cognitive stimulation training to staff offering respite visits to persons with dementia in all settings and capitalizing on new and emerging programs (*Memory Connections, Montessori for Dementia, Pose It Science, etc.*) that can provide meaningful engagement and opportunities to maintain and sometimes enhance cognitive performance.

iv. Respite Beds in LTCHs

Short-term respite care beds may be located in behaviour units which can scare family members from accessing the service.

It is recommended, where possible and as appropriate, that respite beds be located in dementia units or lower security units if care needs do not warrant locked units.

v. Transportation

Please refer to section 4.0 regarding the need for expanded transportation options for persons with dementia.

4.12 Dementia-specific Friendly Visiting

Dementia-specific Friendly Visiting was described in the survey as *regular home visits from a dementia trained volunteer to a person with dementia, to provide companionship and social support.*

Of the 50 organizations interviewed, 10 offer friendly visiting for persons with dementia. Many of these organizations indicated that their friendly visiting services are not dementia-specific, however they sometimes inadvertently provide services to individuals with dementia. Friendly visiting is done through volunteers. These volunteers primarily work with persons with dementia who have mild cognitive impairment or early stage dementia yet have not received a formal diagnosis. Hence volunteers do not always have experience or training with dementia and when the diagnosis occurs, the friendly visiting is discontinued.

Some noted that because their volunteers work with only mild impairment, their general volunteer training may be adequate for this population. Dementia-specific training for friendly visitors would mean that more individuals could be supported along the lengthy continuum of dementia.

4.12.1 Key Themes

Two key themes emerge from interviews regarding Friendly Visiting for Persons with Dementia.

i. Limited Options for Persons with Dementia

Many of the friendly visiting programs assisting persons with dementia work with them prior to a diagnosis or suspicion of dementia. They continue as usual and provide ongoing monitoring and companionship until the person is not able to self-manage their visits. Issues brought to their attention by the volunteers sent in to do the visits are addressed by the organization.

Alternatively, in the late stages of dementia the provision of friendly visiting is often taken on by palliative care volunteers who provide comfort and companionship to primarily non-ambulatory and non-communicative clients.

Many organizations that do not offer friendly visiting programs indicate that they rarely or never refer individuals with dementia for friendly visiting programs due to limited community offering and strict eligibility criteria (e.g. ability to self-direct visits and manage mobility devices on their own). When a client receives a diagnosis of dementia, because the volunteers are not trained for this condition, organizations are often not prepared to send in a friendly visitor. When asked about this situation, providers of friendly visiting stated that they would likely try to retain existing clients that develop a dementia until such time as those behaviours become difficult for volunteer visitors to handle.

ii. Palliative Care

Hospice organizations take a very proactive approach in recognizing the extended duration of the late stages of dementia. Palliative care volunteer visits can offer many benefits to persons with dementia and their family caregivers in the late stages of dementia in a person's home, an ADP, or visiting facilities like nursing homes and palliative care units in hospitals.

4.12.2 Recommendations

i. Maintain Friendly Visiting for Existing Clients

Friendly visiting was cited as one service that can help unobtrusively monitor persons with dementia living in the community, especially by maintaining those who received visits prior to the diagnosis of dementia and in need of the continuity.

It is therefore recommended that where possible, organizations maintain existing friendly visiting clients who receive a diagnosis dementia of for longer durations over the course of dementia as the companionship can help reduce the social isolation that often comes with this condition.

ii. Culturally Appropriate Volunteers

Please refer to the Findings section 4.0 for the importance and benefits of ethno-cultural-language appropriate services.

iii. Increase Awareness to Palliative Care Services

Many organizations are unaware of the opportunities to connect persons in late and palliative stage dementia and their families with palliative/hospice care services. As noted earlier, there can be great value and comfort provided by these visits (e.g. companionship, comfort care, caregiver relief)

It is recommended that organizations providing palliative care to person with dementia invite Hospice organizations in to explain mutually beneficial program offerings (e.g. volunteers, expressive arts program).

4.13 Memory Clinics for Persons with Dementia

Memory Clinics for Persons with Dementia were described in the survey as *an out-patient clinic that offers diagnosis, care and support to ambulatory or out-patient clients who are experiencing memory disorders or some type of dementia.*

Of the 50 organizations interviewed, 2 offer memory clinics for persons with dementia. These organizations primarily work with persons with mild cognitive impairment, early onset or early stage dementia and less frequently middle stage dementia. Organizations with memory clinics indicated that they have no defined catchment area and often serve much of Southern Ontario.

4.13.1 Key Themes

Four key themes emerge from interviews regarding Memory Clinics for Persons with Dementia.

i. Wait Lists

Persons with dementia often wait for 6 months to a year for a full assessment by a memory clinic. Wait list may possibly be reduced if general practitioners are provided with greater knowledge to enhance their ability to diagnose and suggest relevant treatment options and interventions from their office. This might reduce unnecessary referrals, and more expedient linkages to services directly from the doctors' office.

Providers of memory clinics also indicated that wait lists are also affected by “no-shows” where persons with dementia forget to come to the clinic, cannot access transportation to get there, or the family is not able to get out of previous commitments to take or accompany them. Coping strategies include reminder phone calls to persons with dementia and/or their caregivers a week before and the day of.

ii. “Gaming” the System

When looking around for the first available memory clinic clients, their families and/ or their case managers may put client names on multiple wait lists. This becomes a problem when they do not remove their names from the list when they get seen at one clinic, or when they attend more than one clinic to compare information.

Seeking too many medical opinions can contribute to increased wait times, duplication of effort and inappropriate use of services.

iii. Must be Referred by a Physician

A few organizations indicated that preliminary assessments, memory tests, referrals and follow-up are normally facilitated by in-house social workers or quality management coordinators. Written requests or phone referrals are the most common methods of referral. Referring to a memory clinic is particularly difficult when no family doctor or specialists involved.

iv. Awareness of Options

A person's ability to appreciate the need for a referral to a memory clinic and their ability to remember to go – especially with they lack family supports, pose a barrier in accessing these clinics. Some organizations have also found reluctance by family practitioners to make the referrals. This can sometimes stem from a lack of understanding about how healthcare providers can help. For example some may feel *why bother, will it help?* or lack awareness as to when and where to refer patients. Organizations that are not providers of memory clinics also stated that they and their counterparts may be less familiar with different needs of the population and it is sometimes difficult to know when and how to refer to a memory clinic.

4.13.2 Recommendations

i. Lack of Recognition of Dementia as an Illness

Some psycho-geriatric mental health teams identified a need for more general practitioners to become more educated about dementia (e.g. recognition, diagnosis, treatment options). This would limit the need for referring for diagnostic services that may just as well be diagnosed by a family doctor/health team.

It is recommended that education opportunities be promoted to physicians and family health teams about community organizations in the TC-LHIN so they become more knowledge about dementia and the community supports and programs that can support persons with dementia and their caregivers at home.

ii. Language and Cultural Appropriate Testing

Please refer to the *Findings* section 4.0 for further information on the important of ethno-cultural-language appropriate assessments and testing.

4.14 Psycho-Geriatric Mental Health for Persons with Dementia

Psycho-Geriatric Mental Health Support Services were described in the survey as *community based services for seniors with chronic mental health/substance abuse conditions or seniors that experience mental health issues/substance abuse related to the aging process (specifically dementia for this project)*.

Originally these services were not included in the survey because mental health and addictions services were reviewed during the exhaustive Community Seniors Mental Health and Addictions Services Project.¹² However, in piloting the survey it was noted that these are important core dementia services.

Of the 50 organizations interviewed, 12 offer Psycho-Geriatric Mental Health Support Services for persons with dementia. Although psycho-geriatric mental health services are supported throughout the continuum, most organizations work with persons with dementia living in the community and thus target individuals in the earlier stages of dementia. Moderate and late stage dementia tend to be supported in LTCHs. These homes often access mental health services through a variety of sources including resident physicians, psychiatrists, behaviour response teams, an in-house behaviour nurse or an external in-patient behaviour unit.

4.14.1 Key Themes

Four key themes emerge from interviews regarding Psycho-Geriatric Mental Health Support Services for Persons with Dementia.

i. Partnerships

There are good partnerships and working relationships with other doctors and specialists. Mental health teams provide much education and support in community and in LTCHs.

Regional Geriatric Programs (RGPs) provide very comprehensive write ups for the medical doctor who refers clients to the service. It is recommended that a copy of this write-up be provided to the person with dementia or their caregiver to share the information with other providers of care.

ii. Age Requirements

To qualify for most of these mental health services, individuals need to be 60 years of age and over, have behaviour changes, or must be coping with a mental health issue. Organizations make special allowances when clients had early onset dementia or behaviours arising from stroke or earlier forms of dementia like Frontal temporal and Lewy-body dementia.

iii. Treatment Suggestions versus Implementation

Many psycho-geriatric outreach teams do not provide treatment. They provide assessment consults and recommendations for other service providers and professionals to implement the treatment. For example, they may utilize a pharmacist who will do home visits but not offer treatment. The medical professional needs a referral from another physician for a consult whereas the inter-professional outreach team can receive a referral from anyone.

¹² Full details and information about the C-SMHAS project is available at their website: www.csmhas.com.

iv. Referrals by Non-Providers of Psycho-Geriatric Mental Health

Organizations stated that they provide information about these services to persons with dementia and more often to their family caregivers, based on information found on websites such as the Toronto Dementia Network, C-SMHAS and RGP websites.

Direct referrals are also made to psycho-geriatric outreach teams based out of hospitals (e.g. RGPs from North York General, St. Michael's, Sunnybrook and Toronto East General Hospital) or specialized healthcare centres (e.g. Baycrest, Centre for Addictions and Mental Health, Providence, West Park), and in some instances Community Health Centres.

Other more targeted assistance may be referred to and provided by COPA and/or Alcoholics Anonymous for persons with dementia also suffering from addictions and substance abuse issues.

4.14.2 Recommendations

i. Increase Resources

An increase in funding/resources for psycho-geriatric mental health services is recommended to increase clinician time to see more people in need of help. The current infrastructure makes it difficult for physicians to add more patients to their roster. One organization said: *"We need the extra hands-on-folks like clerks who are good gatekeepers and keep the clinics running smoothly."*

Another organization suggested that mental health services: *"need their resource issues equalized across Toronto (e.g. would like to see consultants doubled)"* and suggested reviewing a study done in the 1990's titled the Clark Report which provides specific recommendations on mental health outreach teams.

ii. Homelessness

The issue of homelessness posed difficulty in getting some people with dementia a psychiatric hospitalization because they do not have a referring family doctor. It also is hard to provide follow-up to these clients. Sherbourne Health was identified as a good program to address these issues, but it can be difficult to get into because it is well utilized.

It is recommended that additional resources to programs that address the issues and needs of the homeless be provided to expand access to dementia-specific services for marginalized populations in need.

4.15 In-Patient Behaviour Units for Persons with Dementia

In-Patient Behaviour Units for Persons with Dementia were described in the survey as *in-patient assessment units in a hospital / health centre / rehabilitation centre which provides an interdisciplinary evaluation of people with dementia who have complex or severe behavioural issues and develop comprehensive treatment plans take into consideration the needs of both the client and caregiver. Treatment plans are used in the development of a discharge plan and include an education component and referral to community resources.*

Of the 50 organizations interviewed, 2 offer In-Patient Behaviour Units for persons with dementia. These organizations indicated they primarily worked with persons with middle to late stage dementia.

4.15.1 Key Themes

Two key themes emerge from interviews regarding In-Patient Behaviour Units for Persons with Dementia.

i. Main Providers in TC-LHIN

The Centre for Addictions and Mental Health (CAMH), Baycrest Healthcare Centre, and the Toronto Rehabilitation Institute (TRI) are the main providers of in-patient behaviour units. Ontario Shores is contacted less frequently because it is not geographically located in the TC-LHIN.

While behaviour units often do outreach or offer client specific education about the dementia and mental health populations, they note the serious impact of staff turnover experienced by healthcare organizations and a great need for more frequent opportunities for dementia-specific education for all remaining and new staff.

ii. Referrals and Wait Lists

Organizations providing in-patient behaviour units mainly receive referrals from hospitals and LTCHs. Due to wait lists, coping strategies include seeking assistance through referrals to the TC-CCAC, family physicians, hospitals with geriatric psychiatry beds such as St. Joseph's, Mount Sinai or psycho-geriatric outreach teams (e.g. St. Michael's, Sunnybrook Hospital and COTA).

LTCHs and some community agencies, that when they have no choices, will send clients to a hospital emergency room. This can be very disruptive to persons with dementia as they are not usually admitted or properly assessed and may return more agitated than before.

Wait lists can occur at the behaviour unit (e.g. people wait in the behaviour unit, taking up a bed that could benefit another client in crisis) and at the LTCH (homes taking time when trying to manage the return of a client that has been away for a substantial period of time).

It is sometimes hard to reintegrate a person that has been aggressive back onto a unit. There is much follow-up involved (e.g. with ministry, family) and other residents often resist having these clients return.

4.15.2 Recommendations

i. Language

Addressing behaviour issues in a language that someone understands is very important to the success of behaviour strategies and interventions. Please see section 4.0 for more information on the need for ethno-cultural-language specific services for persons with dementia and their caregivers.

ii. Enhance Existing Centralized Service Coordination

It is recommended to expand the common central intake which helps to address issues with wait times for TC-LHIN organizations. Currently there is one central intake process for organizations in the TC-LHIN to access in-patient behaviour units yet this does not encompass those organizations servicing persons with dementia outside the TC-LHIN boundaries.

iii. Responsive Referral Process

To expedite assistance with behaviour issues, organizations will often help to link families and other organizations caring for persons with dementia to agencies that provide assistance with mental health.

To help with the process of flow through to In-Patient Behaviour Units it is recommended to relax the referral criteria to allow occupational therapists to refer directly in addition to a physician referral.

4.16 Dementia Units in LTC Homes

Dementia Units in LTC Homes were described in the survey as *those that are specifically devoted to the care of persons with dementia. These programs are generally secure (locked) and possibly further subdivided based on the level of care needed.*

Of the 50 organizations interviewed, 2 offer Dementia-specific Units in LTC Homes. These organizations indicated they primarily work with individuals in middle and late stages of dementia as well as palliative care.

4.16.1 Key Themes

Three key themes emerge from interviews regarding Dementia Units in LTCHs.

i. Flexible Age Range

The organizations providing dementia-specific units, and many of their affiliates identified flexibility with age criteria in these units. Younger ages primarily comprise those with developmental disabilities and early onset dementia (e.g. admitted between the ages of 50 – 65 years) to those with more moderate and late stage dementia (e.g. admitted after age 65).

ii. Issues of Capacity and Consent

Issues related to identifying and accessing a proper substitute decision maker (SDM) or power of attorney (POA) can be very troublesome. LTCHs often hope that such matters get settled when the client is still in the community or in hospital before coming to live in their home. When there is no family member, SDM or POA of personal care and/or finances available, or if these parties are embroiled in legal battles, then LTCHs have to have to get a public trustee involved as a public guardian of the person with dementia. It is both expensive and time consuming to initiate a capacity assessment and provide the necessary follow-up. When this happens in LTCHs the cost of the assessment (~\$500) and other related costs fall on their shoulders and often are not recovered even when the matter is resolved.

iii. Ethno-Cultural-Language Specific Facilities

Ethno-cultural-language specific LTCHs often have very long wait lists such that most people with a progressing dementia waiting for admission will die before they will be able to transition into these homes.

Current coping strategies employed by non-ethno-cultural-language specific LTCHs include drawing on their larger pool staff and volunteers to receive translation assistance. This can be a short term solution as many staff (e.g. housekeeping or dietary staff) or volunteers can assist with interpretation. As mentioned earlier, if these staff and volunteers do not have dementia-specific training, the way they interpret and translate may not be adequate to address the needs at hand. In addition, depending on their shift or visit, they may not be available at times when they are most needed.

4.16.2 Recommendations

i. Expand Capacity of Current Ethno-cultural-language Specific LTCHs

Please refer to the *Findings* section 4.0 for further information on the important of ethno-cultural-language appropriate environments and services.

ii. Bed Placement and Wait Lists

Each of the 6 LTCHs interviewed, whether they have a dementia unit or not, will move people around to make sure that residents are well matched (although this is difficult with ward rooms). It is not good practice to place people in the first available bed on a LTCH waitlist. The TC-CCAC should only offer available beds near family, so they can continue to visit.

An additional issue now facing persons with dementia and their caregivers are stricter criteria for entry into a LTCH which has created greater strain on the community to support clients with increasing acuity and cognitive needs.

When placement is necessary, it is recommended that referrals to “first available beds” be LTCHs near the community in which the person with dementia lives or that of a caregiver willing to visit. It is also recommended that more funding be directed to home and community care services to address the strains of increasing acuity and cognitive needs while waiting to meet increasingly tighter LTCH eligibility criteria.

iii. Provide Funding for Dementia Trained Translation and Interpretation Services

Please refer to the *Findings* section 4.0 for further information on the value of these services.

4.17 Behaviour Units in LTC Homes

Behaviour Units in LTC Homes were described in the survey as *primarily secured units devoted to the care of individuals with severe behavioural issues as a result of dementia and/or other mental illnesses that provide an array of interventions based on needs.*

Of the 50 organizations interviewed 3 offer behaviour units for persons with dementia and indicated they primarily work with middle, and late stage dementia and palliative care.

4.17.1 Key Themes

Two key themes emerge from interviews regarding Behaviour Units in LTCHs.

i. Common Behaviours

The most common reasons for placement into these units include, but are not limited to: oppositional behaviours, sexual behaviours, verbally and physically aggressive behaviours.

ii. Least Change Philosophies

Change of environment can be difficult for persons with dementia – especially if they become palliative (e.g. persons with dementia in the dementia unit might remain in that unit even if the increased palliative care needs warrant a shift to the heavy care floor).

LTCHs try not to move persons with dementia around to different rooms or units and try to manage and accommodate behaviours as they progress unless they present challenging behaviours that put them or others at risk.

4.17.2 Recommendations

i. Least Change Philosophies

It is recommended where possible that organizations keep people on a familiar floor – especially when they require palliative care. In some cases the use of a private room for persons with dementia experiencing behavioural issues may reduce triggers for such behaviours and may be suggested to family or SDM to consider this option if available.

ii. Address Ethno-Cultural-Faith-Gender Identity and Diversity issues

Please refer to the *Findings* section 4.0 for further information on the important of ethno-cultural-language appropriate environments and services.

5.0 Conclusions and Final Recommendations

Persons with dementia and their families need access to qualified health care and social support services that are able to recognize and manage the different manifestations of dementia through the stages of the disease.

Finding from this project conclude that a great number of complementary efforts are underway to address these needs.

Three strong themes repeatedly emerged with each of the dementia-specific core services: the need for more dementia-specific training and education for people with dementia and all those caring for them (formal and informal caregivers); the need for enhanced transportation options to increase access to dementia-specific programs and services across the TC-LHIN; and the need for more ethno-cultural-language specific offerings to provide better outreach and provision of dementia-specific programs for the diverse multi-cultural population across the TC-LHIN.

Rather than recreating programs or duplicate current efforts, this report suggests expanding services identified as meeting dementia-specific service needs and creating bridges to these programs and services to enhance offerings of other organizations. Additional partnerships and shared processes will improve access to dementia-specific services across the TC-LHIN, offered by providers trained in best dementia care and support practices.

A series of 12 overarching recommendations highlight a pressing need to address awareness, identification, and access issues related to the needs of persons with dementia and dementia services in Toronto Central LHIN.

Final Recommendations

1. Expand current transportation services

Lack of transportation (because of cost, location of destination, drivers without dementia training) can inhibit access to dementia services. Funding is recommended to expand transportation catchment areas and to extend hours of service to provide access to programs in late afternoon, early evening and on weekends, or language and culturally-specific programs outside of defined catchments areas.

2. Expand and encourage dementia education opportunities

2.1 For persons with dementia and their family caregivers

Dementia-specific education is beneficial for persons with dementia and their partners in care, helping them to plan for the increased debilitation that will inevitably occur as dementia progresses, and contributing to preventative health interventions and coping strategies.

2.2 For formal care providers

Organizations are encouraged to adopt policies that promote dementia training for all staff working directly with persons with dementia. Where staff members have received prior training, dementia-specific competencies (skills and knowledge) should be assessed during probation, and then refreshed through ongoing professional development that features a dementia-specific curriculum with evidence-based best practices.

3. Increase dementia expertise

To address a gap in the number of health care providers with expertise in dementia care, it is recommended that future funding opportunities specifically target dementia-related training opportunities and programs.

It is also recommended that the Ministry of Health and Long Term Care work alongside the Ministry of Colleges and Training to ensure a mandatory dementia-specific curriculum for certificate and professional programs where staff will likely provide care to persons with dementia (personal support workers, occupational therapists, physicians, etc).

4. Family caregivers considered as a unit and as individuals

It is recommended that recognition be given to the vital role of families who care at home for persons with dementia, and that programs address their needs separately and as a unit of care as appropriate.

5. Build/enhance partnerships between organizations

It is recommended that the CNAP and C-MHAS common referral processes be used to enhance the responsiveness of other service providers. It is also recommended that websites such as the Toronto Dementia Network, C-SMHAS, CNAP and the Community Care Resources (CCR) websites, be linked to facilitate understanding of the wide range of dementia services for referring organizations, for families and for the interested public.

6. Expansion of dementia-specific offerings

It is recommended to expand current dementia care programs and services that support diverse and multicultural populations. Locally-based programs along the continuum of care are also recommended to reduce waitlists and offer partial solutions to transportation issues.

7. Increase flexibility of program offerings

It is recommended that dementia-specific programs be offered outside of traditional business hours, with options to attend programs in early evening, overnight and on weekends.

It is also recommended that necessary funding be targeted toward organizations wishing to expand eligibility criteria for their dementia-specific programs and services, such as extended personal care offerings, more overnight ADPs, more support groups, and dementia-specific recreation in Long Term Care Homes.

Consideration should also be given to dementia-specific programs that target those individuals or communities who are reluctant to access current services because of age (early onset day programs), LGBT populations, housing issues (homeless, under-housed and/or alcohol-related dementia), and culturally specific programs (language, ethnicity).

8. Expansion of supportive housing

To increase access and availability to supportive housing for persons with dementia, it is recommended that expansion funding continue to be made available for current and new supportive housing programs to identify, monitor and support the needs of a growing senior population, especially those experiencing or soon at risk of dementia. In addition, it is recommended that dementia-specific training be provided to all staff in supportive housing

buildings so they can better identify clients presenting with dementia-related symptoms, and better manage and accommodate individuals with dementia-related behaviours.

9. Dementia recognized as a chronic condition

It is recommended that dementia be included as a chronic condition in Ontario's *Chronic Disease Management Framework*, along with an educational initiative to increase the knowledge of health care providers about dementia as a chronic condition, and promote best practices in dementia care to address this condition. This recommendation is supported by research in the *Rising Tide* report:

“There are significant data to suggest that recognizing and addressing dementia as a co-morbid chronic disease and as an integral factor in the Chronic Disease Prevention and Management Framework (CDPM) will result in significant cost savings to the health care system. For example, having appropriately educated and trained health and social service human resources who are able to recognize the disease in its early stages will provide opportunities to delay the onset of symptoms, and result in better patient flow across the continuum of care and more effective utilization of costly acute care resources.”

(Rising Tide, 2010)

10. Increase ethno-cultural-language specific offerings

It is recommended that dementia care resources be offered in different languages (more interpreters; multilingual staff; information materials, etc.)

It is also recommended that, recognizing the economic limitations of serving each different community, the health care system capitalize on partnerships with ethno-cultural/linguistic community organizations. These partnerships, which have slowly started to develop on their own, must be viewed as complementary rather than duplicative. Further to this, dementia service organizations must have a role in the service planning and delivery process to ensure that the people they serve will have their particular ethno-cultural/linguistic needs met.

11. Increase satellite programs along the continuum of care

It is recommended that successful dementia service providers offer satellite programs to spread these services more equitably across Toronto. This would improve access and address more ethno-cultural-language specific program needs. This might also reduce waitlists and decrease the use of higher level, more expensive alternatives to health and social care for persons with dementia and their caregivers.

12. Common referral

It is recommended that organizations move toward a common referral process and build on the successes of the current CNAP pilot of a common referral intake form and partnering processes as well as the common intake process currently being used for in-patient behaviour units in the Toronto Central-LHIN area.

It is hoped that this report will serve as a foundational document to promote further discussion and action to optimize access to dementia care for persons with dementia, their families and their caregivers.

Findings of this project will contribute to ongoing Toronto Central LHIN initiatives and future “resource matching” activities that are sensitive to the needs of those with dementia, and representative of the local diversity of a multicultural city as large as Toronto.

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Appendix A

Core Dementia Service Definitions*

*Core dementia services are central to the well-being and care of people with dementia and their caregivers, and are provided throughout the continuum of the disease by staff with dementia-specific training and knowledge.

Service	Core Definition	May Include
Adult Day Program for people with dementia	Supervised and supported social and recreational activities provided at a location outside the person with dementia's home. Programs generally include meals, transportation to the program, and some personal care. Hours of operation may vary.	May include light physical activity, assistance with the activities of daily living, and minor health care assistance (for example, monitoring of medications, weight and blood pressure monitoring).
Adult Day Program with Overnight Stay for people with dementia	Supervised and supported overnight accommodation at a location outside the person with dementia's home. Service includes personal care, meals and appropriate activities.	
Assistive living for people with dementia	Designated housing which provides services and support in congregate or individual accommodation, and can meet the wide range of needs of people with dementia.	May include individualized assessment, planning and a choice of service options, homemaking, light housekeeping, shopping, laundry, personal support, medication monitoring, social activities, nutrition programs, security checks, and planning and coordinating other services that enable independent living. Support service may be available on a 24 hour basis.
Behavioural Unit in a Long-Term-Care Facility	Units that are specially devoted to the care of individuals with severe behavioural issues, as a result of dementia and or other mental health illnesses. Generally, these units are secure and provide an array of interventions based on needs.	May include assessment, on-going care planning, interventions, and medication and behaviour management.

Service	Core Definition	May Include
Dementia-specific Education	Dementia-specific education for people with dementia, caregivers and the broader community.	May include formal didactics, interactive workshops, or forums.
Dementia-specific Friendly Visiting	Regular home visits from a dementia-trained volunteer to a person with dementia, to provide companionship and social support.	May take a senior out for activities, such as light shopping.
Dementia-specific Respite	Support services for persons with dementia, to temporarily relieve their caregivers.	May include Adult Day Programs, Personal Care, Long-term care, Homemaking, Retirement homes, monitoring medications, safety checks or social interaction.
Dementia Unit in a Long-Term Care Facility	Units that are specifically devoted to the care of persons with dementia. These units are generally secure (locked) and they may be further subdivided based on the level of care needed.	
Home Help or Homemaking for people with dementia	Assisting people with dementia at home with routine household activities including light housekeeping, laundry, and light meal preparation.	May include assistance with banking, shopping and errands, or shopping on the person with dementia's behalf.
In-patient Behavioural Assessment Unit	Units that provide an interdisciplinary evaluation of people with dementia who have complex or severe behavioral issues. The comprehensive treatment plans take into consideration the needs of both the client and caregiver, in order to develop a discharge plan that includes education and referral to community resources.	May include a diagnostic work-up, using various behavioural tools to make a diagnosis, develop a care plan/intervention and provide medication management. May also include education and transitional plans to discharge patient back to the community/home.

Service	Core Definition	May Include
Memory Clinic	Out-patient clinics that offer diagnosis, care and support to ambulatory or out-patient clients who are experiencing memory disorders or some type of dementia.	May include a multidisciplinary approach.
Personal Care or Personal Support for people with dementia	Helping persons with dementia with personal hygiene and other activities of daily living.	May include bathing, hair, skin and mouth care, help with toileting, getting dressed, feeding, transferring and positioning, medication reminders, light exercising, and escorting to medical appointments.
Support Groups for Individuals or Families Caring for people with dementia	Support groups for individuals and/or family members who are providing care and support for someone with dementia.	
Support groups for people with dementia	Support groups for persons who have been diagnosed with a form of dementia.	

Appendix B

Complementary Services Diverging from and Aligned with the Community Navigation Access Project (CNAP)

Services which are not viewed as being core dementia services and which differ from the current CNAP complementary service definitions.		
Service	Core Definition	May Include
Palliative Care	A combination of therapies, such as nursing and social work, delivered by a multidisciplinary team, intended to comfort and support individuals, and their families, who are living with or dying from a progressive, life-threatening illness.	May increase an individual's understanding of their illness or assist with treatment planning; may also include hospice care, plans for palliative care unit admission, DNR orders, living wills; and bereavement support for caregivers. Not all palliative care services will serve people with dementia.
Home Safety Assessment	A formal assessment of the person with dementia's environment (physical, social, cultural, institutional) and their ability to manage safely at home.	

Services which people with dementia and their caregivers may use, but are general to all seniors and not essential to dementia care		
Service	Core Definition	May Include
Case Management (General)	Conducting an assessment, and planning and coordinating services to meet a senior's needs, goals and expected outcomes. Service may be provided at a senior's home or another location.	May include advocacy to assist seniors or caregivers in navigating and accessing needed services, to help them avoid "falling between the cracks" during service delivery

Services which people with dementia and their caregivers may use, but are general to all seniors and not essential to dementia care		
Service	Core Definition	May Include
Crisis Support and Assistance	Support and assistance for a senior in a crisis situation (e.g., an abusive situation), including planning and coordinating other services.	May develop into ongoing Case Management, with a follow-up plan to prevent further crises. May include physical, mental, financial or emotional crisis situations.
Dietetics	The assessment, treatment, education and prevention of nutrition-related disorders. The goal of this service is to maintain or improve a client's nutritional status and contribute to the client's overall health.	
Elder Abuse Services	Programs and services are aimed at preventing, identifying, investigating and/or mitigating the effects of elder abuse. Elder abuse includes any action or neglect that results in harm (e.g., physical, psychological, emotional, and financial) to an elderly person.	
Foot Care	Helping a senior with the care and condition of their feet including monitoring for health conditions.	May include chiropody, podiatry or the services of a foot care nurse. May include trimming toenails, monitoring the condition of their feet and/or bathing and massaging their feet, dealing with calluses, open sores, or corns.

Services which are not viewed as being core dementia services and which differ from the current CNAP complementary service definitions		
Service	Core Definition	May Include
Geriatric Mental Health Community Support Services	Community based services to seniors with chronic mental health/substance abuse conditions or seniors that experience mental health issues/ substance abuse related to the aging process.	Range of team-based treatments and supports include family and caregiver health promotion and education, assisting with accessing services, behaviour management services and follow-up/care coordination with the appropriate service providers until the client's condition is stabilized.
Group Dining	A nutritious meal for seniors, provided at a central location on pre-arranged days.	May include social, recreational, educational or wellness activities. May include transportation to and from the location.
Home Maintenance and Repair	Repairs and maintenance to a senior's home, performed regularly, occasionally, or just once.	May include heavy or seasonal housecleaning, lawn maintenance, snow shovelling, or washing windows.
Meals on Wheels	Nutritious meals delivered to seniors at their home. Meals are delivered by volunteers or staff who provide seniors with regular social contact and check on their safety.	May include hot meals, frozen meals, milk, bread, fruit and vegetable baskets or organic food baskets.

Services which are not viewed as being core dementia services and which differ from the current CNAP complementary service definitions		
Service	Core Definition	May Include
Medication Management	Consultation by a nurse/pharmacist to complete a comprehensive medication assessment with the client/caregiver by reviewing all medications in the home that a client is taking and resolving any discrepancies or medication related issues. The nurse/pharmacist with permission from the client/SDM will speak with their primary physician and community pharmacist to: devise a medication plan; arrange any necessary follow-up services	
Nursing	Health promotion, assessment, care and treatment of health conditions to reach or maintain optimal health.	May include supportive, preventive, therapeutic, palliative and rehabilitative nursing. May include specialty nursing services and wound care.
Rehabilitation	A variety of therapies and /or education, such as occupational therapy and physiotherapy, to reach and maintain optimal physical, emotional and psychiatric health and independence.	May include social work, speech language pathology, the services of a dietician and specialized programs such as acquired brain injury. May include therapy and/or education to minimize future risk.
Security Check	A regular phone call or face-to-face visit in a senior's home to check on their safety and well-being.	May include reminders to take medications, help with shopping, errands, or other activities of daily living, and telephone reassurance.

Services which are not viewed as being core dementia services and which differ from the current CNAP complementary service definitions		
Service	Core Definition	May Include
Sensory Impairment Support	Services include assessment, intervention and/or support of seniors with visual, hearing or other communication impairments. The goal is to develop, maintain or augment sensory capacity to promote maximum independence.	
Shopping Assistance	Escorting seniors to a store and helping with the purchase of groceries or medications. Seniors are responsible for the cost of shopping items.	
Shopping List Pickup	Pickup of grocery items on a senior's behalf, and delivery of the items to their home. Seniors are responsible for the cost of shopping items.	May include grocer who delivers items to senior's home.
Shopping Trips	Transportation for groups of seniors from their homes to designated neighbourhood stores or malls and back home. Seniors are responsible for the cost of shopping items.	Service may be available for individuals to preferred shopping locations.
Social and Recreational Activities	Social and recreational activities for a range of seniors, from those who are very healthy, to those needing many services to remain living independently.	Activities may include exercise programs, wellness programs, games, cultural events, outings and/or crafts.
Social Work	Trained professionals providing support and counselling to help seniors, their families and other individuals to develop the skills and abilities to function as independently as possible.	May address a variety of social, economic and personal needs, including adjusting to chronic illness, elder abuse, providing care to a senior, advocacy, service referral, information and education.

Services which are not viewed as being core dementia services and which differ from the current CNAP complementary service definitions		
Service	Core Definition	May Include
Specialized Geriatric Services	A variety of health care services that diagnose, treat and rehabilitate frail seniors with complex medical, functional and psychosocial issues. Services provided in the senior's home, in inpatient, or clinic /outpatient settings by a team of health professionals including geriatricians, nurses, social workers, and occupational and physical therapists.	May include rehab and wellness programs, comprehensive medical/functional and psychiatric assessments, diabetic foot care, memory clinic programs, and osteoporosis, Alzheimer's, dementia, and Parkinson's programs.
Transportation	Rides for seniors who are unable to use public transportation and are not eligible for "Wheel Trans", York Region Mobility or other municipal transport programs. Rides are provided to medical or therapy appointments, shopping and various social activities and programs. Transportation is provided by staff or volunteers.	May include escort assistance for frail seniors who need more "hands on" help and translation support.

Appendix C

Toronto Dementia Care Pathway*

This Pathway was adapted with thanks and permission from Interior Health British Columbia Dementia Phased Pathway Project available at <http://www.interiorhealth.ca/health-services.aspx?id=328>

This Pathway informs the Toronto Dementia Care Project survey development and resultant internet based interactive care map to be posted for use on the Toronto Dementia Network Website.

Please note that although each person with dementia will generally progress through all stages of the following pathway, the timing, severity and overlap of symptoms vary considerably from person to person and between types of dementia (e.g. faster decline for those with frontal-temporal dementia than with Alzheimer's).

Modifiable Risk Factors	At this early stage preventative interventions for brain health are considered (e.g. increased physical activity, healthy diet and lifestyle programs). Brain health risk factors associated with dementias are also identified to modify risk of development (e.g. Type 2 Diabetes, head Injury, high cholesterol levels, high blood pressure, and obesity). Identifying risks early on can potentially reduce these factors from exacerbating the potential development of dementia.
Mild Cognitive Impairment	<p>This is the earliest clinically recognizable stage of cognitive loss but does not meet the criteria for a diagnosis of dementia. Clients with MCI are at increased risk to progress to an early Alzheimer's type dementia, but not always.</p> <p>Clinical recommendations in this phase of the pathway look at how to recognize cognitive-related changes, how to refer for further investigation, the clinical and ethical challenges of diagnosis and disclosure, and how to effectively support clients who live with MCI and their caregivers.</p>
Early Onset Dementia	This type of dementia occurs earlier than age 65 years (as early as in one's 40's or 50's). Services for persons with dementia often still target those in older age brackets thus sometimes limiting a person with dementia's interest or willingness to utilize them. This in addition to general issues of stigma and lack of awareness of the types of services available can jeopardize opportunities for early intervention with this type of dementia. Regardless, many needs arising from early onset dementia are parallel to other dementias and for the purposes of this care pathway, will not be considered as a separate phase.

<p>Early Stage Dementia</p>	<p>In the early stage symptoms may include inability to concentrate, memory and word finding failures, and mistakes in judgement. When and if left unnoticed this can lead to safety issues for the person with dementia (e.g. missing important medications; forgetting to shop or cook; decline in their ability to drive due to poor concentration and lapses in short-term memory and judgement) and potentially those around them. People in this stage of dementia are often aware they are experiencing these issues, thus it can be both frustrating and worrisome to them and their partners in care.</p> <p>A common reaction/coping strategy employed is denial or covering up when these symptoms arise. In so doing, this creates a barrier to help-seeking behaviour from a physician for assistance with early diagnosis and accessing dementia support services. <i>Education</i> needs are greatest in this stage to understand why changes are occurring and future prognosis. This may help slow the loss of functional abilities, while at the same time create an opportunity to discuss around advance care planning in anticipation of future losses.</p> <p>Clinical recommendations in this stage continue to address clinical and ethical issues arising from early symptom recognition through to diagnosis by supporting help-seeking behaviours along the way. Following diagnosis, practice recommendations focus on optimizing quality of life at home and in community by supporting client and caregiver transitions with their emotional, informational and practical caregiving needs. Early identification of depression and delirium conditions superimposed on dementias are also addressed.</p>
<p>Middle Stage Dementia</p>	<p>The middle stage of dementia is hallmarked with multiple transitions, and often when, the client often first comes to the attention of the health care system (e.g. frequently in crisis). Identification of dementia prior to and during this stage can support care planning that may mitigate or minimize crisis. Memory loss and other earlier symptoms become more severe in this stage. Speech difficulties, disorientation and wandering increase and significant losses in function and independence are evident in this stage. The need to prevent and manage caregiver stress or burnout becomes more pressing.</p> <p>Clinical recommendations include continuing supports to persons with dementia and their caregivers, the ethics of capability and living at risk, supporting disease and environmental transitions, and understanding and accommodating responsive behaviours commonly associated with dementia.</p>
<p>Late Stage Dementia</p>	<p>This stage of dementia reflects severely compromised needs due to dementia. Verbal communication may be non-existent, the person requires full assistance with all activities of daily living (e.g. eating, bathing, grooming, dressing, etc.) and incontinence will increase the burden of care for both formal (paid) and informal (not paid) caregivers. The person with dementia is frequently (but not always) institutionalized.</p> <p>Clinical recommendations focus on supporting the person and their caregiver, direct care strategies that preserve a person's sense of self and self-worth, accommodate responsive behaviours, and provide quality care environments that include ethical, optimized person-centred care approaches.</p>

Palliative Care Stage	<p>This final phase of the pathway reflects severely compromised needs due to dementia. The person with dementia is frequently (but not always) institutionalized and often at this point unable to speak, swallow, or ambulate.</p> <p>Clinical recommendations focus on supporting the person and their caregiver, direct care strategies that preserve personhood, optimize any spiritual care needs, and provide quality care environments that include ethical, optimized person-centred care approaches and end-of-life care supports.</p>
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Appendix D

Text of Toronto Dementia Care Project Survey

Toronto Dementia Care Project

The purpose of this project is to:

- 1) Identify dementia-specific community support services and service gaps in dementia care in the Toronto Central LHIN
- 2) Map current referral methods and client access points for dementia care for persons with suspected memory issues; Mild Cognitive Impairment (MCI); early-stage dementia; mid-stage dementia; and late stage dementia
- 3) Recommend improvements for improved access and navigation of dementia services for persons with dementia and their partners in care.

This project compliments two related TC-LHIN projects – the Community Navigation & Access Project (CNAP), and the Seniors Mental Health and Addiction Services – Community Framework project (CSMHAS) – which you may have been a part of. This project will also build (with permission) on foundation materials from the B.C. Interior Health’s Phased Dementia Pathway project and thereby limit the need for lengthy and complex re-conceptualization of person-centered navigational approaches to dementia care.

In this connection, the Toronto Dementia Network (utilizing the CNAP and C-SMHAS definitions) has further noted 15 Core Dementia-Specific Services for which two key components have been identified:

- 1) Core Dementia Services are central to the well-being and care of people with dementia and their caregivers
- 2) Core Dementia Services are provided, throughout the continuum of dementia, by staff with dementia-specific training, knowledge and skills.

We are currently surveying/interviewing providers of core dementia-specific services utilized by persons with dementia and their partners in care. Findings from this process will highlight the flow of persons with dementia and their partners in care through the Toronto Central LHIN region, and inform the development of standardized care paths for core dementia-specific services.

Your time is very valuable and we thank you in advance for your valuable insight and participation in this TC-LHIN Dementia Care Initiative.

If you have any questions about this project, please do not hesitate to contact Frances Morton, the Dementia Care Project Lead at elder.coach@hotmail.com or by phone at (416) 422 -1292.

Sincerely
Frances Morton
Dementia Care Project Lead
P: (416) 422-1292
E: elder.coach@hotmail.com

As you go through the following questions, please keep in mind that they relate to Core Dementia Services and not the whole host of complementary services that are also important to well-being of persons with dementia.

In this connection, answers to Core Dementia Service questions should be answered in the context that they are:

- 1) Central to the well-being and care of people with dementia and their caregivers
- 2) Provided, throughout the continuum of dementia, by staff with Dementia-specific Training and Knowledge.

Please also consider at which stage in the dementia continuum the service may be offered (e.g. Mild Cognitive Impairment; Early, Middle or Late Stages of Dementia)
 Thank you in advance for answering the following questions.

 Please indicate the name of your organization and primary contact information for survey follow-up.
 Contact Person for Dementia-Related Services:

Organization:
 City/Town:
 Contact Person's Email
 Address:
 Phone Number:

1. Adult Day Program for Persons with Dementia

1.0 Does your organization offer an Adult Day Program for Persons with Dementia?
 Adult day programs are supervised and supported social and recreational activities provided at a location outside the person with dementia's home. Programs generally include meals, transportation to/from the program, some personal care, and appropriate activities). Hours of operation may vary).

- Yes
- No

1.1 If applicable, please indicate all types of service offerings that apply to this adult day program for persons with dementia.

- Recreational programming
- Assistance with personal care/activities of daily living
- Light physical activity
- Meal(s)
- Transportation options
- Minor health care assistance (e.g. monitoring of medications, weight and/or blood pressure)
- Other (please specify)

1.2 If applicable, what are the referral method and eligibility criteria for the adult day program?

1.3 If applicable, what is the catchment area for your adult day program?

1.4 Do you offer an Adult Program that host Mixed Populations (e.g. persons with MCI or early stage dementia with other seniors)? If yes how do they transition from one to another (or do they)?

1.5 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

1.6 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

1.7 Which of the following target groups does this service apply to?

Mild Cognitive Impairment
Early Onset Dementia (before the age of 65)
Early Stage Dementia
Middle Stage Dementia
Late Stage Dementia

1.8 NOTES

2. Day Program with Overnight Stay for Persons with Dementia

2.0 Does your organization offer an Adult Day Program with Overnight Stay for Persons with Dementia? An adult day program with overnight stay includes a supervised accommodation at a location outside the person with dementia's home. Programs generally include meals, transportation to/from the program, some personal care, and appropriate activities.

- Yes
- No

2.1 If applicable, please indicate all types of service offerings that apply to this Adult Day Program with Overnight Stay for Persons with Dementia

- Recreational programming
- Assistance with personal care/activities of daily living
- Light physical activity
- Meal(s)
- Transportation options
- Minor health care assistance (e.g. monitoring of medications, weight and/or blood pressure)
- Other (please specify)

2.2 If applicable, what are the referral method and eligibility criteria for this program?

2.3 If applicable, is the catchment area for the Adult Day Program with Overnight Stay?

2.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

2.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

2.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

2.7 NOTES

3. Assistive Living for Persons with Dementia

3.0 Does your organization offer Assistive Living for Persons with Dementia?

Assistive living (i.e. supportive housing) is designated housing which provides [LHIN-funded personal care] services and support in congregate or individual accommodation, and can meet a wide range of health and social needs of persons with dementia.

3.1. If Yes, which of the following best describes the nature of your assistive living program?

3.2 If your program serves a mixed population, what is the estimated percentage of persons with dementia you are supporting at this time?

Solely persons with an identified dementia

Mixed populations of persons with a suspected and/or diagnosed dementia with others not living with a dementia

Both types of programs

3.3 If applicable, please indicate all types of service offerings that apply to the Assistive Living Program for Persons with Dementia

Care Coordination (e.g. service planning and/or health and social system navigation)

Basic Activities of Daily Living (e.g., assistance with personal care, grooming, hygiene)

Instrumental Activities of Daily Living (e.g., meal assist, medication monitoring, light housekeeping, laundry, shopping)

Social activities (e.g. congregate dining, book club, music programs)

Security indicators (e.g. phone or face-to-face)

24 hour availability to support services (e.g. on-site or on-call)

Other (please specify)

3.4 If applicable, what are the referral method and eligibility criteria for this program?

3.5 If applicable, what is the catchment area for the assistive living program?

3.6 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

3.7 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

3.8 Which of the following target groups does this service apply to?

Mild Cognitive Impairment

Early Onset Dementia (before the age of 65)

Early Stage Dementia

Middle Stage Dementia

Late Stage Dementia

3.9 NOTES

4. Dementia-specific Case Management

4.0 Does your organization offer Dementia-specific Case Management?

Dementia-specific case management is a specialized, comprehensive, and complex service that involves building a trusting relationship with the client/family/network, to provide ongoing support around dementia related issues; help the client function in the least restrictive, most natural environment and; achieve an improved quality of life (i.e. on-going process of client assessment, service planning, system navigation, care coordination and monitoring).

- Yes
- No

4.1 If applicable, please indicate all types of service offerings that apply to your dementia-specific case management.

- Standardized assessments (e.g., RAI-HC/CHA, functional assessments, cognitive assessments)
- Relationship building, care planning and goal setting
- Direct service provision/intervention (services aimed to achieve the highest level of functioning possible)
- In-direct service provision (obtaining necessary services through linking and collaboration with other health and community providers)
- Monitoring and follow-up
- Information and referral
- Liaison, advocacy and consultation with other resources based on client's health and social needs
- Other (please specify)

4.2. If applicable, what is the referral method and eligibility criteria for dementia-specific case-management at your organization?

4.3. If applicable, what is the catchment area for your dementia-specific case management?

4.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

4.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

4.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

4.7 Notes:

5. Dementia-specific Counselling

5.0 Does your organization offer Dementia-specific Counselling? Dementia-specific Counselling relates to getting a diagnosis, understanding dementia, immediate and future care of the person with dementia, and/or family coping strategies?

- Yes
- No

5.1. If applicable, please indicate all types of service offerings related to your dementia-specific (supportive or therapeutic) counselling.

- Supportive or therapeutic counselling for persons with dementia and their family partners in care ranging from
 - Pre-diagnosis, diagnosis, behaviour management, on through late stages and palliative care.
 - Information and referral to other supports for persons with dementia and their partners in care
 - Other

5.2. If applicable, what is the referral method and eligibility criteria for your dementia-specific counselling?

5.3 If applicable, what is the catchment area for your dementia-specific counselling?

5.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

5.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

5.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

5.7 Notes

6. Dementia-specific Education

6.0 Does your organization offer Dementia-specific Education? Dementia-specific education designed for people with dementia, caregivers and/or the broader community.

- Yes
- No

6.1. If applicable, please indicate all types of service offerings that apply to your dementia education program(s)?

Formal caregivers (e.g. healthcare (para) professionals)
Informal caregivers (e.g. family, friend)
Persons with dementia
Broader community (e.g. interested public)

Through:

One-on-one education
Formal small group discussions
Interactive workshops
Forums
Other (please specify)

6.2 If applicable, what are the referral method and eligibility criteria for dementia education?

6.3 If applicable, what is the catchment area for dementia education?

6.4 As it pertains to resource matching client needs with staff skills, knowledge and training, please highlight how your organization addresses ongoing education for staff providing care to persons with dementia.

Mandatory internal dementia training (e.g. education and skills training provided through in-house expertise)

Voluntary dementia training (e.g. education and skills training provided through in-house expertise)

Mandatory external dementia training (e.g. education and skills training provided through targeted dementia programs)

Voluntary external dementia training (e.g. education and skills training provided through targeted dementia programs)

Required Professional Development (e.g. professional colleges licensing requirements)

Other (please specify)

6.5 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

6.6 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

6.7 Which of the following target groups does this service apply to?

Mild Cognitive Impairment

Early Onset Dementia (before the age of 65)

Early Stage Dementia

Middle Stage Dementia

Late Stage Dementia

6.8 Notes

7. Support Groups for Family Members or People Caring for Persons with Dementia

7.0 Does your organization offer Support Groups for family members or other individuals caring for persons with dementia? These support groups are designed to meet the emotional and educational needs

of individuals/friends and/or family members who are providing care and support for persons with dementia.

Yes
No

7.1 If applicable, please indicate all types of service offerings that apply to your support groups for family members or other individuals providing care for persons with dementia.

In person/on site
Online
Other

7.2 If applicable, what are the referral method and eligibility criteria for your support group program?

7.3 If applicable, what is the catchment area for your support group program?

7.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

7.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

7.6 Which of the following target groups does this service apply to?

Mild Cognitive Impairment
Early Onset Dementia (before the age of 65)
Early Stage Dementia
Middle Stage Dementia
Late Stage Dementia

7.7 Notes

8. Support Groups for Persons with Dementia

8.0 Does your organization offer Support Groups for persons with dementia? These support groups are developed to meet the emotional and/or educational needs of persons who have been diagnosed with a form of dementia.

Yes
No

8.1 If applicable, please indicate all types of service offerings that apply to your support groups for persons with dementia.

In person/on site
Online
Other

8.2 If applicable, what is the referral method and eligibility criteria for support group for persons with dementia program?

8.3 If applicable, what is the catchment area for this support groups for people with dementia program?

8.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

8.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

8.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

8.7 NOTES

9. Personal Care

9.0 Does your organization offer Personal Care or Personal Support for persons with dementia? Personal care/support is assistance provided to persons with dementia with their hygiene, grooming, dressing and other basic activities of daily living [by staff with dementia-specific training and knowledge].

9.1 If applicable, please indicate all types of service offerings that apply to this personal care program for persons with dementia

- Basic activities of daily living (e.g., personal grooming; hygiene; bathing; transferring and positioning)
- Instrumental activities of daily living (e.g., meal assist; cueing and/or medication monitoring; light exercising)
- Escorting persons with dementia to medical appointments
- Other (please specify)

9.2 If applicable, what are the referral method and eligibility criteria for your personal care program?

9.3 If applicable, what is the catchment area for your personal care program?

9.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

9.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

9.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

9.7 NOTES

10. Homemaking or Home Help programs for persons with dementia

10.0 Does your organization offer Homemaking or Home Help programs for persons with dementia? These programs generally provide assistance to persons with dementia at home with routine household activities including light housekeeping, laundry, and light meal preparation by individuals with dementia-specific training, skills and knowledge.

- Yes
- No

10.1 If applicable, please indicate all types of service offerings that apply to the homemaking/ home help program for persons with dementia.

10.2 If applicable, what are the referral method and eligibility criteria for the home help programming?

10.3 If applicable, what is the catchment area for this home help program?

10.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

- Assistance with laundry
- Assistance with light housekeeping
- Assistance with meal preparation
- Assistance with banking
- Assistance with shopping and errands
- Assistance with shopping and errands on the person with dementia's behalf
- Other (please specify)

10.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

10.6. Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

10.7 NOTES

11. Dementia-specific Respite Care

11.0 Does your organization offer Dementia-specific Respite Care? Dementia-specific respite care refers to support services for persons with dementia, to temporarily relieve their caregivers from care responsibilities including but not limited to monitoring and/or engaging persons with dementia in the daily activities, meal and medication monitoring, safety indicators and social interaction.

11.1 If applicable, please indicate the respite care service offerings that your organization makes available to offer relief to caregivers of persons with dementia.

11.2 If applicable, what are the referral method and eligibility criteria for the dementia-specific respite program?

11.3 If applicable, what is the catchment area for the dementia-specific respite program?

11.4. If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

11.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

- Dementia-specific adult day programs
- Designated respite programs in the homes of persons with dementia which offer personal care and monitoring
- Friendly visiting by volunteers with dementia-specific training
- Short-term respite offered in long-term care home beds which offer dementia-specific programming/care planning
- Short-term respite offered in retirement homes with dementia-specific programming/care planning
- Other (please specify)

11.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

11.7 NOTES

12. Dementia-specific Friendly Visiting

12.0 Does your organization offer a Dementia-specific Friendly Visiting? Dementia-specific Friendly Visiting is regular home visits from a dementia trained volunteer to a person with dementia, to provide companionship and social support.

- Yes
- No

12.1 If applicable, please indicate all types of service offerings that apply to this Dementia-specific Friendly Visiting Program

- Social support/interaction and companionship with persons with dementia in their own home
- Escorting persons with dementia out for activities
- Light shopping with the person with dementia
- Accompaniment to medical appointments
- Other (please specify)

12.2 If applicable, what are the referral method and eligibility criteria for the Dementia-specific Friendly Visiting program?

12.3. If applicable, what is the catchment area for this Dementia-specific Friendly Visiting?

12.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

12.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

12.6 Which of the following target groups does this service apply to?

Mild Cognitive Impairment

- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

12.7 NOTES

13. Memory Clinic

13.0 Does your organization offer a Memory Clinic?

A memory clinic is an out-patient clinic that offers diagnosis, care and support to ambulatory or out-patient clients who are experiencing memory disorders or some type of dementia.

- Yes
- No

13.1 If applicable, please indicate all types of service offerings that apply to your memory clinic?

- Multi-disciplinary approach (e.g., physicians, nursing, social work, dietician, occupational therapy, speech language pathologists, pharmacists)
- Assessment, diagnosis and/or management of dementia related illness
- Pharmacotherapy
- Non-pharmacological assessment
- Counselling
- Education
- Other (please specify)

13.2 If applicable, what are the referral method and eligibility criteria for this memory clinic?

13.3 If applicable, what is the catchment area for this memory clinic?

13.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

13.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

13.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

13.7 NOTES.

14. Geriatric Mental Health Community Dementia-specific Support Services

14.0 Does your organization offer Psycho-Geriatric Mental Health Support Services?

Psycho-Geriatric Mental Health Support Services are community based services for seniors with chronic mental health/substance abuse conditions or seniors that experience mental health issues/substance abuse related to the aging process (specifically dementia for this project).

- Yes
- No

14.1 If applicable, please identify the following psycho-geriatric mental health support services that are available to persons with dementia.

- Multi-disciplinary team-based treatments
- Family and caregiver health promotion and education
- Multi-disciplinary team-based assistance with accessing services
- Multi-disciplinary team-based behaviour management services
- Multi-disciplinary team-based follow-up/care coordination with other service providers until client's condition is stabilized
- Other

14.2 If applicable, what are the referral method and eligibility criteria to access your geriatric mental health support services?

14.3 If applicable, what is the catchment area for your geriatric mental health support services program?

14.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

14.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

14.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

14.7 NOTES

15. In-Patient Behavioural Assessment Unit

15.0 Does your organization offer an In-Patient Behavioral Assessment Unit? An in-patient behavioural assessment unit in a hospital/health centre/rehabilitation centre provides an inter-disciplinary evaluation of people with dementia who have complex or severe behavioural issues and develop comprehensive treatment plans take into consideration the needs of both the client and caregiver. Treatment plans are used in the development of a discharge plan and include an education component and referral to community resources.

- Yes
- No

15.1 If applicable, please indicate all types of service offerings that apply to your in-patient behavioural assessment unit for persons with dementia.

- Diagnostic work-up, using various behavioural tools for diagnostic work-up (e.g. physiological and cognitive assessments)
- Care planning including transitional plans to discharge patient back to the community/long-term care home
- Behaviour interventions/management
- Medication review and management
- Education to key partners in care
- Other (please specify)

15.2 If applicable, what are the referral method and eligibility criteria for the Inpatient Behavioural Assessment Unit?

- Yes
- No

15.3 If applicable, what is the catchment area for this In-patient behavioural assessment unit?

15.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

15.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

15.6 Which of the following target groups does this service apply to?

- Mild Cognitive Impairment
- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

15.7 NOTES

16. Dementia Unit in a Long-Term Care Home

16.0 Does your organization offer a Dementia Unit in a Long-term Care Home? Dementia units are those that are specifically devoted to the care of persons with dementia. These programs are generally secure (locked) and possibly further subdivided based on the level of care needed.

Yes

No

16.1 If applicable, please indicate all types of service offerings that apply to the dementia units.

- Cognitive support for residents with challenging behaviours
- Secure unit for residents with severe cognitive impairment prone to wandering
- Other (please specify)

16.2. If applicable, what are the referral method and eligibility criteria for the dementia units?

16.3 If applicable, what is the catchment area for the dementia units?

16.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

16.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

16.6 Which of the following target groups does this service apply to?

Mild Cognitive Impairment

- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

16.7 NOTES

17. Behavioural Unit in a Long-Term Care Home

17.0 Does your organization offer a Behavioural Unit in a Long-Term Care Home? Behavioural units are primarily secured units devoted to the care of individuals with severe behavioural issues as a result of dementia and/or other mental illnesses that provide an array of interventions based on needs.

Yes

No

17.1 If applicable, please indicate all types of service offerings that apply to the behavioural units in your long-term care home for persons with dementia.

- Functional and/cognitive assessments
- On-going care planning
- Behaviour interventions/management
- Medication management
- Other (please specify)

17.2 If applicable, what are the referral method and eligibility criteria for your behavioural unit?

17.3 If applicable, what is the catchment area for your behavioural unit?

17.4 If you do not provide this service, do you refer persons with dementia to other organizations that do provide this service? If so, when and how do you refer?

17.5 Please describe some of the enablers and barriers to persons with dementia regarding access this type of service?

17.6 Which of the following target groups does this service apply to?

Mild Cognitive Impairment

- Early Onset Dementia (before the age of 65)
- Early Stage Dementia
- Middle Stage Dementia
- Late Stage Dementia

17.7 NOTES

18. Diversity Issues

18.0 Does your organization provide services that address issues of Diversity?

- Yes
- No

18.1 If yes, please indicate the service offerings that your organization uses to address diversity issues for persons with dementia (e.g resource matching for clients and services).

- Resource matching based on ethnicity considerations
- Resource matching based on language considerations
- Resource matching based on faith/spirituality considerations
- Resource matching based on sexual orientation considerations
- Other (please specify)

18.2 Based on the previous question, please elaborate on your programs which address issues of diversity.

19. Wish List

19.0 What would be your [holiday] wish list to help persons with dementia access the services they need in Toronto?