HALTON PEEL
DEMENTIA NETWORK
GAP ANALYSIS

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ACKNOWLEDGEMENTS

We would like to express of sincere thanks to the volunteers of the Halton and Peel Dementia Networks, who spent countless hours planning and implementing this Gaps Analysis project.

We also wish to acknowledge the expertise of our consultant, Mindy Ginsler, whose assistance in planning and executing the survey was invaluable, and whose amazing writing skills and in-depth analysis have made this report a pivotal document to guide the Dementia Networks in planning for future dementia services in Halton and Peel Regions.

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EXECUTIVE SUMMARY

In 2002, the ***Halton and Peel Dementia Networks*** were established to improve the system of care for people with dementia and their families. The Networks were to develop a more coordinated and efficient system for service delivery, education, and research related to dementia, and to identify gaps and inadequacies in the system of care for individuals affected by dementia in Halton and Peel.

The findings of a gap analysis of the Networks, conducted in 2005/2006, revealed that there are many positive elements to the existing Halton and Peel Dementia Networks. These Networks are well-positioned to succeed as they move forward into the next phase of maintenance and improvement. Some of the positive elements include:

- an inventory/database of key providers and services
- wide range and availability of programs, group and individual services
- established connections among providers
- teamwork and flexible approach
- provision of ongoing education
- common values
- and a common recognition of what is needed (e.g.,, more money for staff, education and technology); and
- strong support from the Alzheimer Societies, the Ministry of Health and Long-Term Care (MOHLTC), and the Community Care Access Centres (CCACs).

Respondents observed an increased knowledge and sharing regarding diagnosis of dementia among professionals, and improved integration of services in this area. Common meetings and events in the area are leading to increased knowledge of what services are available and which contacts to call.

There are still areas for improvement, and these are noted in the Observations and Summary section of the report. It is important to note that the response rate was lower than anticipated, and reissuing the survey at a later date could provide additional information.

Almost all respondents are affected by the need for funding for skilled staff and services, and generally, feel that there aren’t enough resources to care for hard-to-manage people, or to provide enough supports at home. In addition, respondents expressed several primary concerns.

The first concern was the challenge of providing ***more support and services to the caregiver***, who may be already stressed prior to seeking assistance, and then must face inadequate information, difficult/incorrect diagnoses, demands for physical assistance, transportation issues, etc.

The second concern was the need to ***recruit and retain knowledgeable staff, and provide them with ongoing training*** and education programs to keep them current.

The third concern was the ***stigma and fear associated with dementia and mental health*** generally, and the need for greater education and outreach in this regard in a multi-cultural community.

A fourth concern identified from the survey responses is the need to ***strengthen cultural linkages***, possibly through enhancing and strengthening the information and referral process, and ***through incorporating more multi-cultural information into the existing databases***.

There are 27 recommended actions that the Networks (and individual members) can take to begin to address these concerns, and they are listed in the detailed recommendations at the end of the report.

However, in order to sustain these Networks and allow them to move forward, it is recommended that both the leaders of these Networks and the Networks themselves receive recognition and resources at a higher level. To the extent possible, the Networks should leverage the strategic planning capacity and coordination services of the LHINs and the MOHLTC.

PURPOSE OF STUDY

In 1999, the provincial government invested $68.4 million in *Ontario's Strategy for Alzheimer Disease and Related Dementias*, a ten-point action plan designed to help people with Alzheimer Disease and related dementias, their caregivers and families.

Through one of the action plan's initiatives, *Co-ordinated Specialized Diagnosis and Support*, the Ontario Alzheimer Strategy issued *A Guide to Developing a Dementia Network*, which provided direction to create new Dementia Networks or maintain existing Networks across Ontario.

In 2002, the ***Halton and Peel Dementia Networks*** were established by local providers and community members committed to working together to improve the system of care for people with dementia and their families. Based on the *Guide*, the Networks were also to further develop a more coordinated and efficient system for service delivery, education, and research related to dementia.

One of the main goals of both dementia Networks was to identify gaps and inadequacies in the system of care for individuals affected by dementia in Halton and Peel.

Conducting a gaps analysis would facilitate a systematic approach to describing, reviewing and analyzing the services and supports available to individuals with dementia and their caregivers. Documentation and analysis of the current 'system' of services would permit a comparison of existing supports to what should be available to the community, and identify opportunities to improve the Network and for members to continue working together.

In order to move forward, the Peel Dementia Network conducted a ***gap analysis*** with input from Halton agencies, and an analysis and review is set out below, along with recommendations and next steps. The analysis follows the outline of the survey.

BACKGROUND AND METHODOLOGY

A number of steps were involved prior to issuing the survey.

Developing a Mailing List

A Project Advisory Group and a Sub-Committee were formed with membership from the Halton and Peel Dementia Networks.

The committee used community databases and websites (*www.haltondementia.org*, *www.peeldementia.org*) to identify and compile inventories of organizations that could be targeted for survey dissemination.

It was decided to send the survey to participants in the following sectors: hospital, Community Care Access Corporations (CCAC), long-term care home (LTC), retirement home, Community Support Services (CSS), and government agencies (federal, municipal). The survey was to be sent to as many organizations as possible in order to get a comprehensive picture. The preliminary inventories compiled by the Halton Peel District Health Council were reviewed and a list of organizations was developed.

Building the mailing list was a lengthy process. The original assumption was that there would be a fairly complete database already in existence from which mailing lists could be extracted, but this was not the case. The MOHLTC did not have comprehensive electronic lists that included all the sectors for the region.

A search of the Peel Information Network (PINET) and the Halton Information Providers (HIP) was time-consuming and problematic, and would pose problems for both the lay person and Network members. Subject headings are either quite broad, with no, or inconsistent, cross-references, or very specific, with no broader cross-references. For example, if a user starts by looking up under the heading *elders*, he/she would find the heading *elder abuse*, with no cross reference to *seniors*.

Similarly, if the search started with the heading *seniors*, this is a broad heading with over 177 listings, but contains no sub-category or cross-reference to *abuse*. If the user didn't think to try looking under *elder abuse*, he/she would have to go through all the listings in order to find agencies providing such support. The user would miss a number of agencies that could be of assistance, because the names of the agencies do not always reflect the nature of the service.

In a similar vein, there was no heading for *dementia* or cross-reference, but there was a heading for *senility*, which would lead the user to either, *Alzheimer disease* or *psychogeriatric care*. However, if the user started with the category *Alzheimer disease*, there was no cross reference to *psychogeriatric care*. A search under *Alzheimer disease*, only if opened under that category, would lead to the reference for *geriatric care*, not *psychogeriatric care*. ***If there are insufficient resources to modify the subject headings and make them more consistent, then it***

might be helpful to at least include the cross-references in the main subject listings that the user first encounters, to give the user a better chance of finding the necessary support.

In addition, ***many listings were quite out of date or incomplete*** (e.g., some organizations were no longer in service, some phone numbers were no longer in service, many had different contacts, some did not have e-mail at all, or the e-mail address was incorrect.) Calls to community organizations that provide information in this area led to incorrect referrals, as they were using the same database. Therefore the only recourse was to search the Internet and Bell directories for phone numbers; some organizations were not found, and some had changed their name.

Calls were placed to 48 organizations that were listed on PINET and HIP to get e-mail addresses and confirm contacts. Messages were left, sometimes more than once, and although there were delays in returning the calls, the majority did reply within a week. A few organizations did not have e-mail, but said that they would respond to a fax under certain conditions, e.g., advance notice.

Issuing the Survey and Response Rate

A survey tool was developed based on client and caregiver perspectives as documented in research and literature. The survey focused on the delivery of services and supports and was designed to solicit information from organizations about client involvement, need, diversity, service coordination, information and referral, and the strengths and challenges of organizations and the system. A cover letter accompanied the survey, which was sent out in an easy-to-complete electronic format in late winter 2005.

The survey was sent to 193 organizations, and e-mail reminders were sent out after several weeks. ***Responses were received from 49 organizations (less than one third of the total), and 144 did not respond.***

Of the 144 organizations that didn't respond, 33 were returned with "unable to deliver" messages. It is possible that these organizations were no longer in existence, or had changed contact names/e-mail addresses. This left 111 organizations that didn't respond for other reasons. A number of these organizations (e.g., the federal government) acknowledged receipt and committed to reply within a short timeframe, but failed to reply. Some organizations received the survey (e.g., police, numerous other providers) but didn't acknowledge the receipt.

There may not have been the available resources (e.g., staff turnover) to complete the survey, but regardless, a potential client trying the same approach to make contact would become very aggravated and disillusioned with the system.

More critically, a number of organizations sent back automated replies from their webmaster, indicating that their 'spam stoppers (guard)' were on, and committing to respond on the condition that the e-mail be resent (so that they could confirm validity of the sender). ***E-mails were resent several times to all of these requests and no responses were received.***

Overall, a client seeking assistance (and likely already stressed) would have been very frustrated trying to reach these organizations using e-mail. It is recommended that if possible, this issue be brought to the attention of the Network members and that the impact of security screens be considered in order to address this issue.

The surveys were completed by a mix of front-line staff and/or administrators. In a couple of cases, the surveys were completed by the same individual on behalf of what appeared to be different organizations. Of those who responded, approximately half called to confirm whether it was necessary to complete the document, to note that they were pleased to be included, or to verify how to complete the document (the majority of the calls.)

Some had difficulty completing the survey electronically, and sent responses by mail or fax. ***There did not seem to be a high degree of comfort with technology***, which could be a barrier to the effective use of the Network; there may also be a connection to the rate of response. ***This is an area that requires further exploration.***

Who Responded

There was representation from a variety of not-for-profit organizations, e.g., CCACs, hospitals, Meals on Wheels, Alzheimer Societies, municipal services. Most of the responses were from nursing and retirement homes (see Appendix B). Since most organizations chose not to respond, it is possible that this higher response rate reflects a greater level of involvement with client and family, along with a higher degree of risk and accountability associated with the care of dementia clients, and/or a higher ratio of staff resources. The responses may also be an indication that some for-profit agencies feel isolated. Those organizations who have greater access to in-house services may not feel as great a need to collaborate.

The responses were varied, reflecting the differing nature of the organizations, and to a certain extent, the role and experience of the person who completed the survey. There was also the potential to have slightly skewed results. ***Not everyone completed each question on the survey, and some didn't complete the questions correctly,*** e.g., some did not check *yes* before going on to the appropriate next question, or checked both *yes* and *no,* and answered both questions instead of one. ***In order to address this concern and avoid skewed results, the percentage totals were calculated in each section for the individual questions based on the total of responses for each question, as opposed to being based on the total of overall responses to the survey.***

Responses were input to a summary template for analysis, and the results set out below following the order of questions in the survey.

SURVEY FINDINGS AND ANALYSIS

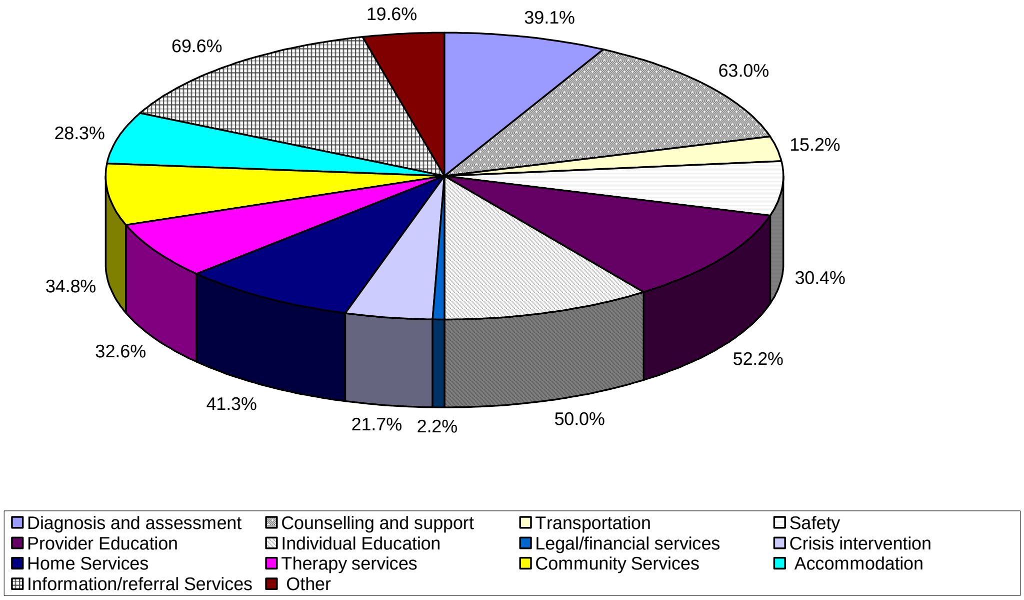
Findings were variable in some areas, and as noted above, this may be reflective of the different type of organizations that completed the survey.

The first section of the survey (questions 1-18) is concerned with *how the organization* provides services and supports to individuals with dementia and/or their caregivers. Questions focused on services and supports, client needs, diversity, service coordination, and information and referral.

Respondents were requested to check off the categories of services provided by their organization. (Note: As this was a multiple-choice question, numbers do not add to 100%.).

Question 1: **Please check the categories that best describe the services your organization provides to individuals with dementia and their caregivers.**

Services Provided to Individuals with Dementia/Caregivers



The majority of respondents are offering five or more services. Nine organizations were providing one service, eight provided between two to four services, 26 provided between five to eight services, and three organizations provided between nine to eleven services.

The majority of the organizations that responded (see below) offer information and referral, followed by counselling and support, education to providers, and education to individuals with dementia and/or their caregivers.

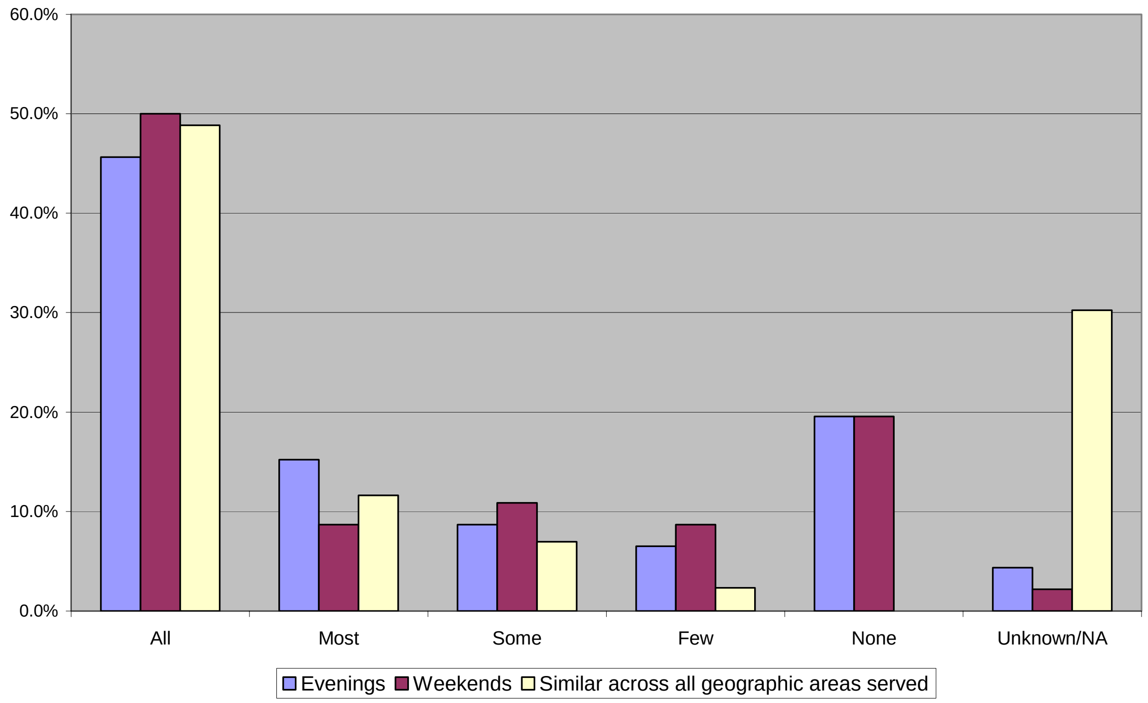
Nineteen organizations offer services in the home and 18 conduct diagnosis and assessment.

Services Provided	**Responses**
Information and referral to other services and supports	32
Counselling and support	29
Education to providers	24
Education to individuals with dementia and/or their caregivers	23
Services provided in the home	19
Diagnosis and assessment	18
Services provided in the community, e.g., adult day programs	16
Therapy Services	15
Safety, e.g., phone safety checks, emergency response systems	14
Accommodation of individuals with dementia, e.g., LTC homes	13
Crisis intervention	10
Transportation	7
Legal and financial services	1
Other	9

Although nine of the organizations noted that they were providing other services, it was unclear from the examples cited how these services differed from the categories already noted.

Question 2: Please check the box that is most reflective of your organization.

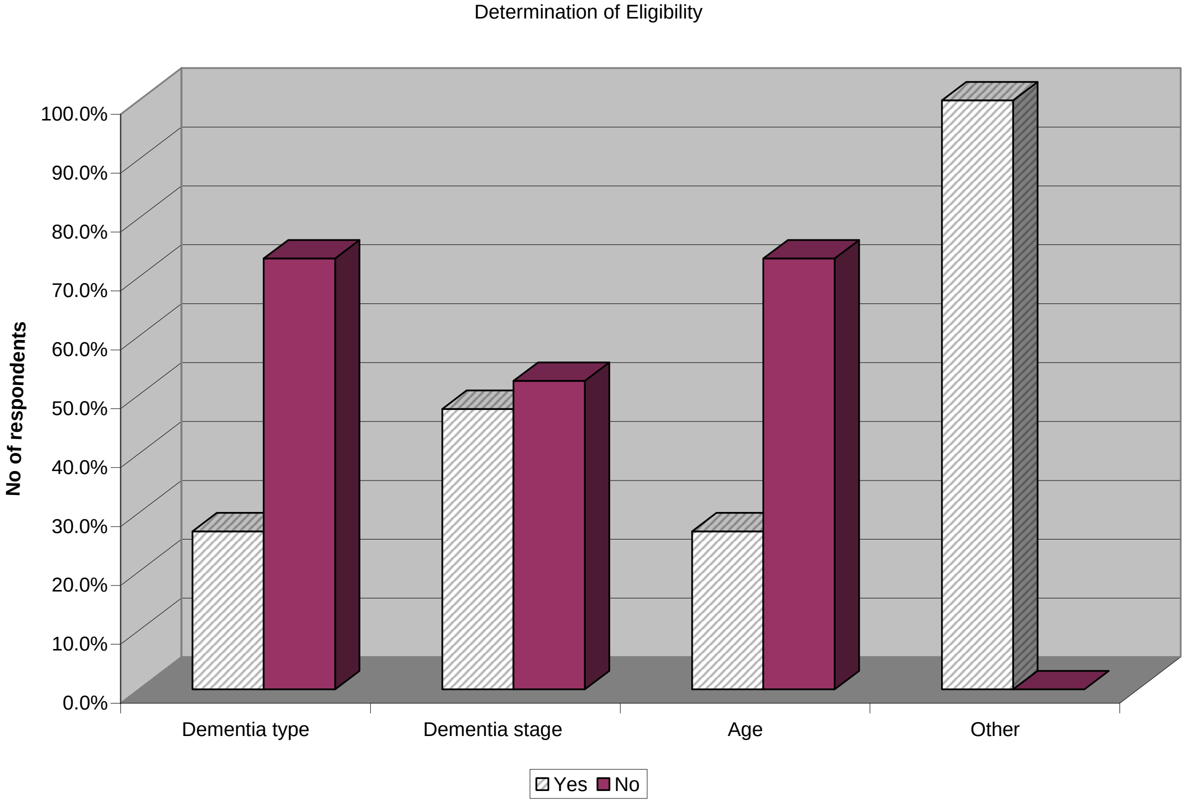
Availability of Services



Almost half of the organizations that responded make their services available on evenings and weekends, and find that service availability is similar across all the geographic areas being served. Some of the organizations may have had difficulty interpreting this question based on the nature of service on offer, e.g., frozen meal delivery on a Friday afternoon that covers needs for an entire weekend. It is also possible that some organizations/specific programs are not resourced or mandated to support evening or weekend service. Given the large response from homes, it is likely that there is still ***a great need for services on evenings and weekends.***

Responses with respect to determining eligibility were very positive, reflecting a comprehensive approach that takes into account the complex nature of dementia. Most of the organizations are considering a combination of factors when determining client eligibility for services. About 26% of the organizations that responded consider dementia type and/or age of the client, about 47% consider the stage of dementia.

Question 3: Do you determine eligibility for your organization's services and supports based on the following?



Fifteen organizations consider other criteria for eligibility and included some of the following examples, which have been grouped together (where possible): and listed below:

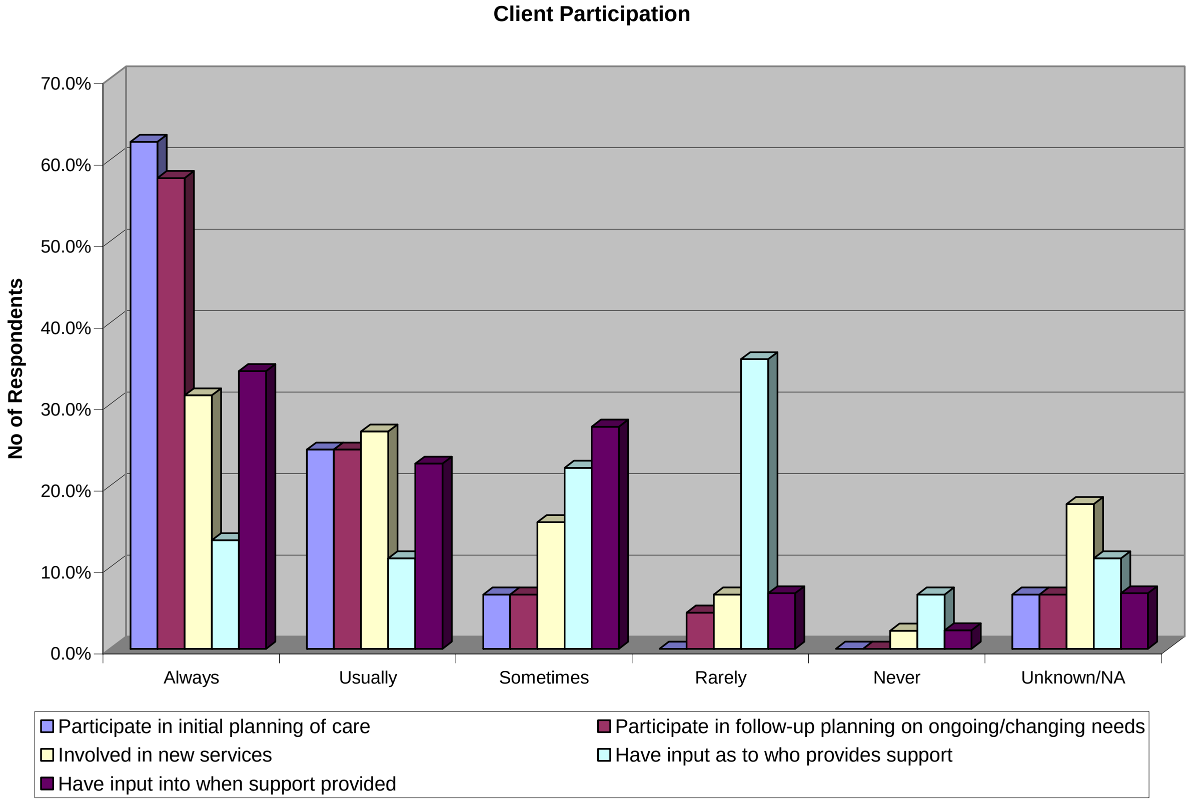
- Must have an Ontario Health Card number
- Anyone eligible
- The CCAC determines eligibility/the person must be eligible for LTC placement

- One person transfer/ability to feed self, prepare meals
- Client need, need for support services to remain in the community (supportive housing may be option for 65+)
- Caregiver burden, primary caregiver/team must be in place at home
- Aggressive behaviour/behavioural issues and issues of safety or exit seeking (not secure environment, so can't have wanderers or aggressive)
- Ethnicity, language; and
- Requirement for acute medical services.

Given the nature of the overall response it would appear that ***providers are not avoiding/rejecting clients based on diagnosis or stage of dementia, and that behaviour, stage, and need are not the only deciding factors for access to service.***

Responses regarding the extent of client involvement may be influenced by labour or contractual constraints.

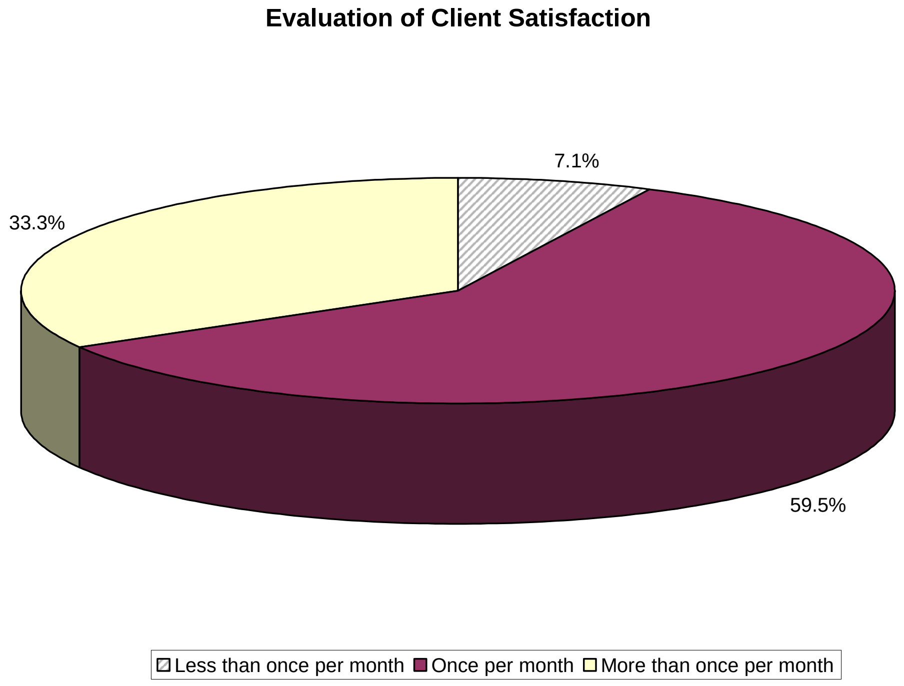
Question 4: For each of the following, please check the box that is most reflective of your organization.



It is encouraging to note that most clients participate in the planning and follow-up stages for their care plans and a smaller percentage have some involvement when new services are developed. ***However, a significantly lower percentage of clients have input into who provides support and when it is to be provided***. These responses may be attributed to the availability of human resources for the requisite hours of service. There may not be enough staff able and willing to work the hours that are needed and/or preferred. Agencies may not be able to bear the costs of meeting these requests. Contractual obligations may also be a factor if agencies must ensure that all providers have a certain percentage of the business. Nevertheless, ***the overall response suggests that service providers are not meeting all the needs of the client.***

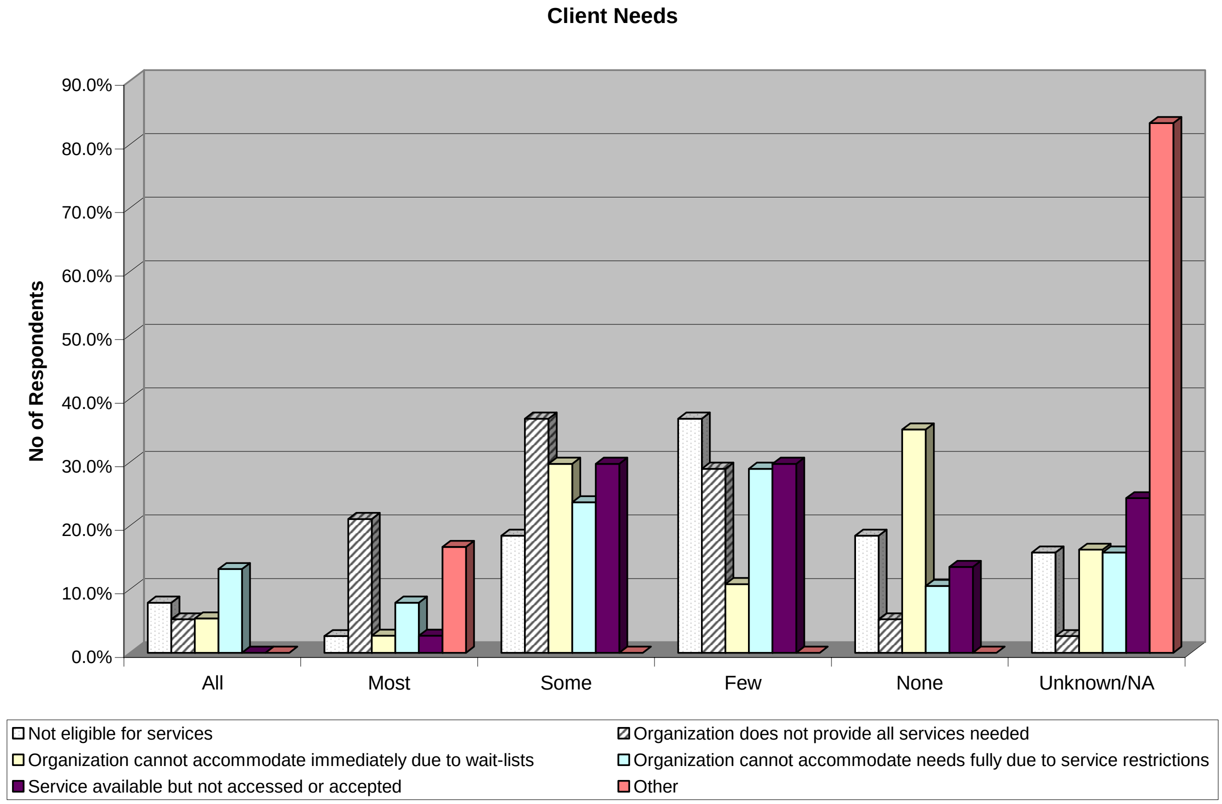
Virtually all the organizations evaluate client satisfaction at minimum once per month to once per year, although one organization conducts surveys every two years, or at discharge from service. The response indicates that all the organizations consider client satisfaction important enough to warrant surveys***. A good percentage of the organizations conduct the surveys frequently enough to permit required changes in a timely fashion, although this does not mean that they act on the changes that are indicated.***

Question 5/6: How often does your organization conduct periodic evaluations of client satisfaction?



The majority of organizations are aware of those clients whose needs cannot be fully met by their organization. Very few of these clients are ineligible for service from the organization, and most of the organizations state that they are able to provide all of the necessary services. Less than half of the organizations said that they couldn't accommodate client needs immediately due to wait-lists, and a small percentage responded that they couldn't accommodate client needs fully due to service restrictions. A relatively small percentage of organizations indicated that the services were available but not accessed or accepted. Some organizations said that they didn't know why client needs couldn't be met.

Question 8: For those whose needs cannot be met, please check the box that is most applicable for each of the following reasons



If most of the clients are eligible for service and the organizations have for the most part the capacity to deliver these services, then the responses may be influenced by other factors. Most of the organizations who responded were long term care/retirement homes, which would be providing many services in-house.

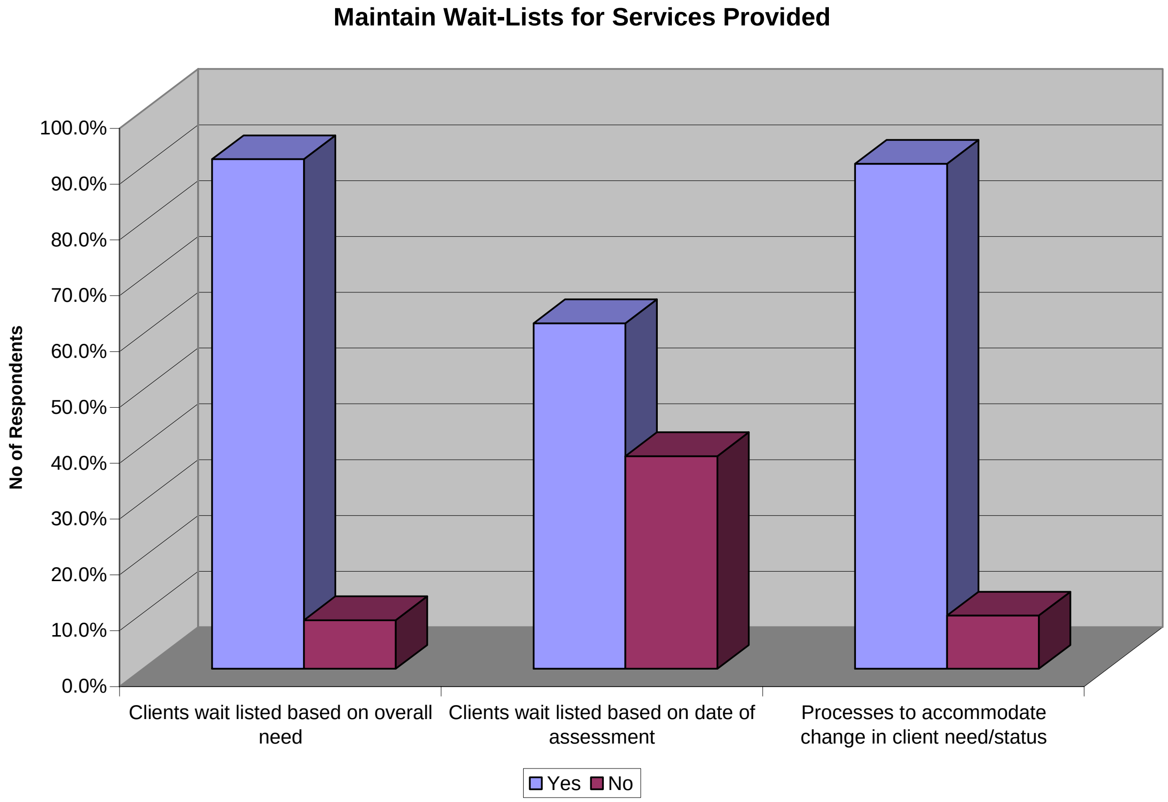
It could be inferred that regardless of the type of organization, the majority of clients are getting most, if not all, of their services from the first organization, or are being referred to the appropriate agency at the first call. It is also possible that these organizations may not be aware of other services being offered.

Services that are available but not accessed or accepted could be the result of families or clients that only want specific issues addressed, geographic constraints, stigmas associated with dementia/mental health issues, and/or language barriers.

Although some organizations didn't know why client needs couldn't be met, it is not possible to comment on this result because they did not provide additional comment.

On a positive note, almost half of those who responded maintain wait-lists mostly based on client need (as opposed to date of assessment.) In addition, the majority of organizations have processes in place to accommodate a change in client need or status.

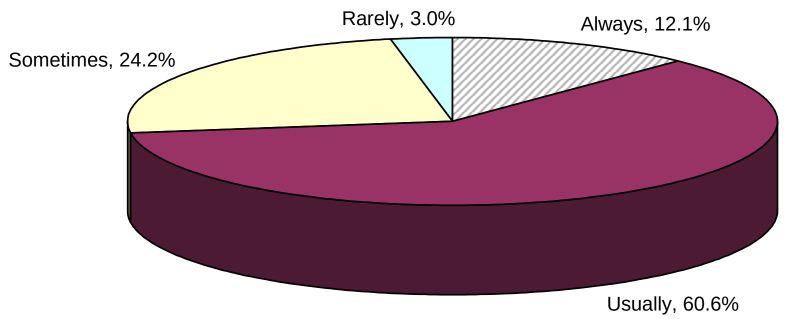
Question 9/10: Does your organization maintain wait-lists for services provided?



Questions 11-13 assess the extent to which the organizations respect the values, beliefs and different languages of an increasingly diverse population. ***Based on the responses, it would appear that most organizations are endeavoring to respect and meet diverse needs, but that they are more successful with oral communication than with written materials.***

Question 11/12: If your organization has front-line staff to deliver services to individuals with dementia (or their caregivers) in the language of their choice, how often is your organization able to accommodate these requests?

Front-line staff provides care in patients' language of choice

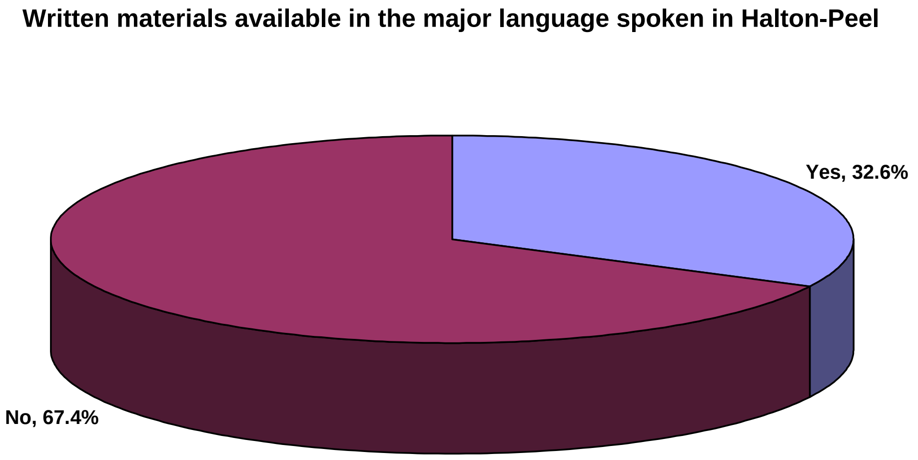


Front-line staff are usually able to deliver the service in the language of choice, although one organization said that it is rarely able to accommodate such requests and relies on a volunteer who speaks Italian. ***However, 67% did not have written materials available in the major languages spoken in Halton and Peel.*** Two of the organizations had material available in 22 and 30 different languages. Others had material available in Ukrainian, Polish, Arabic, Punjabi, Urdu, Vietnamese, Tamil, beginning Chinese and limited information available in Punjabi. Written materials were available in a few more languages in Peel than in Halton. There may be less demand for written materials in Halton at this point. Also, it should be taken into consideration that documentation in French may be mandatory for designated French service agencies.

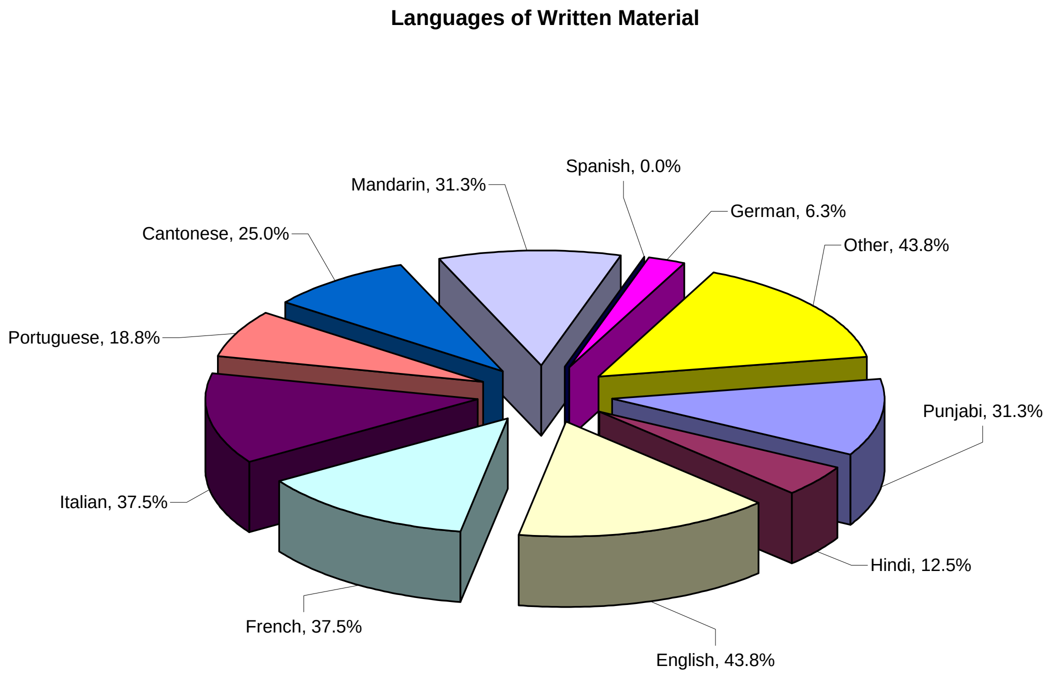
It was noted that materials are being produced gradually as needed, and that family members often provides the most commonly used/needed words and their translations.

The Halton CCAC observed that they service a very dominant English language population, so that when a need arises they link with the Multicultural Organization and pay for a translator to assist with the client assessment and care planning for services.

Question 13: **Are written materials available in the major language spoken in Halton-Peel?**



Question 14: **If written materials available in the major language spoken in Halton-Peel, indicate which language.**



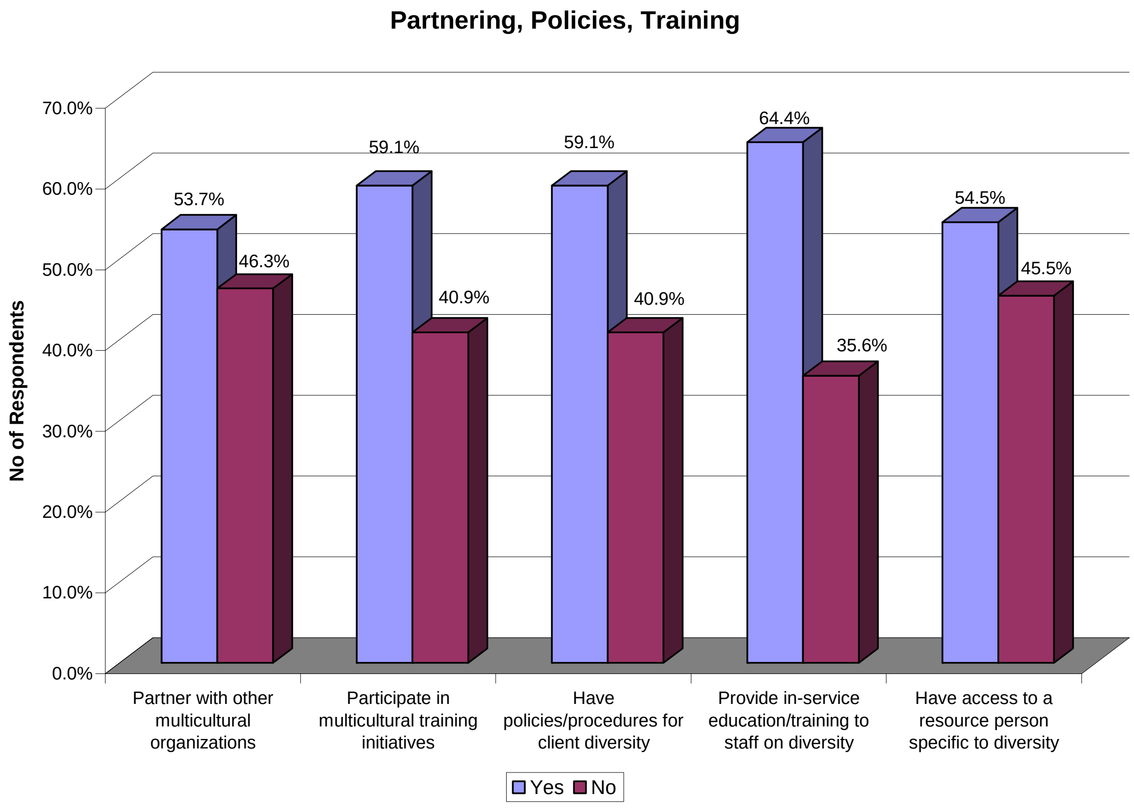
(Note: As this was a multiple-choice question, numbers do not add to 100%.)

It is noteworthy that so few written materials are available in the major languages spoken in the regions, especially considering that majority of organizations provide information and referral services. In addition, it is not certain that the existing materials are helpful and relevant. Researchers in gerontology have observed that language and communication barriers can result in misdiagnoses. (For example, the cultural context is not always present in written materials, and a straight translation of English documents is not always meaningful or useful.)

Rather than issuing new documents or translating existing ones, it might be helpful to conduct a survey of written materials for the client to assess clarity and terminology and determine what information would be helpful. Such a review could help to identify where an emphasis should be placed on interpretation, as opposed to translation. There might also be an opportunity through written materials to address/mitigate the cultural concerns and stigmas associated with dementia and mental illness that respondents noted in the survey.

There was a stronger response to survey questions regarding partnering, policies, and training.

Question 15: **Partner with other multicultural and cultural-specific organizations and programs to reach diverse populations?**

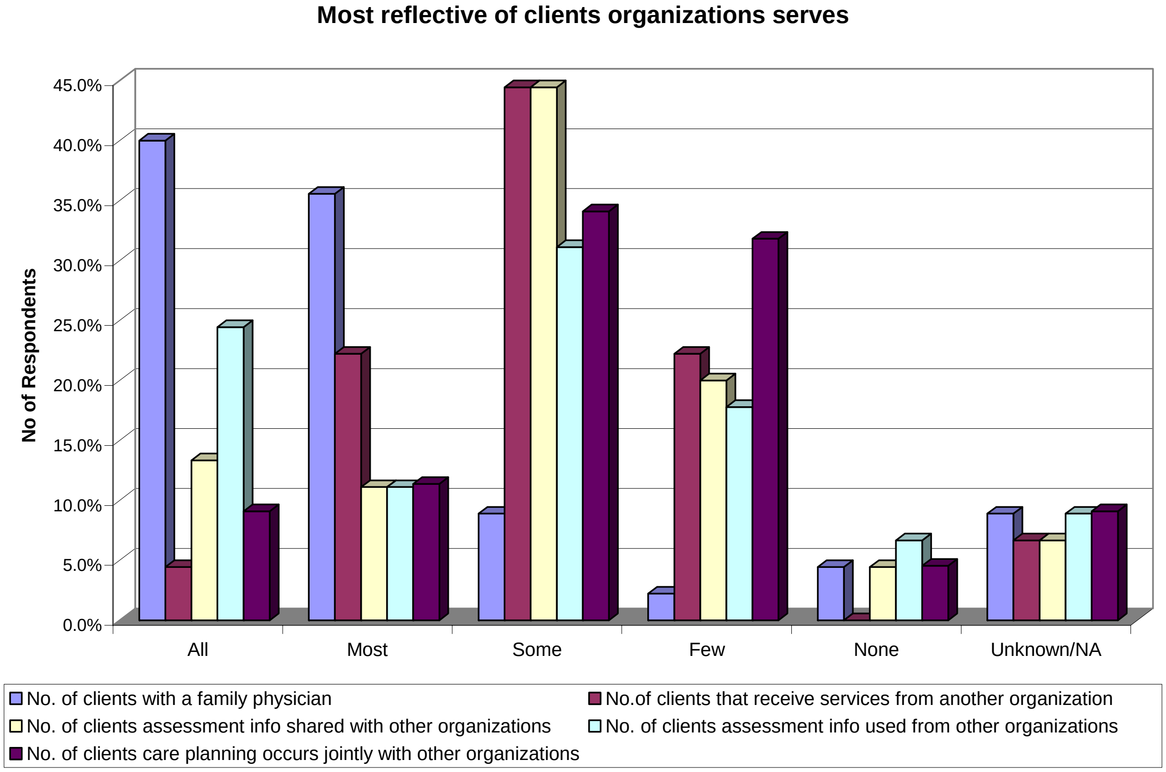


About 64% of the organizations provide in-service education/training to staff on diversity.

A little over half of the organizations partner with other multicultural and cultural-specific organizations and programs to reach diverse populations, participate in multicultural committees/training initiatives, have policies and procedures regarding client diversity, and have access to a resource person specific to diversity. Organizations (especially homes and hospitals) may look internally to address cultural issues, as opposed to seeking external partnerships.

However***, given that 50% of the respondents said that one of their main roles was to provide information and referral to other services and supports, linkages in this area could be strengthened.*** This recommendation is also supported by the results from the following question related to information and referral.

Question 12b: For each of the following, please check the box most reflective of the clients (individuals with dementia and/or their caregivers) your organization serves.



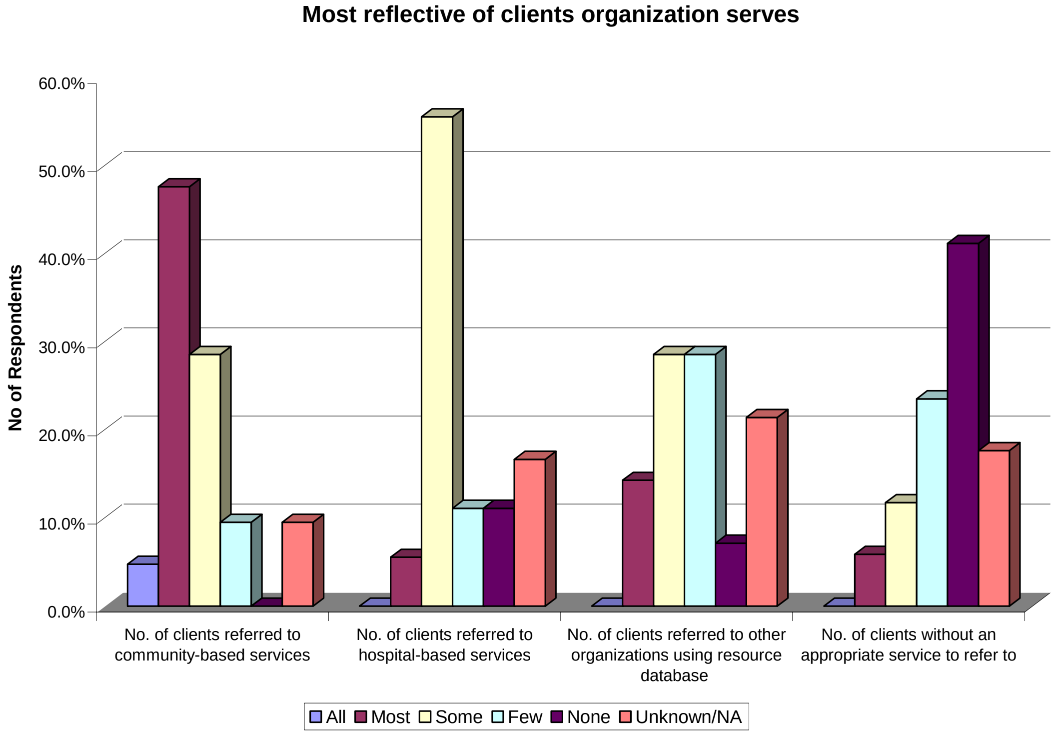
The majority of clients are being referred to either community or hospital-based services, although some are referred to other organizations using resource databases (in Peel-PINET; in Halton-HIP). According to the respondents, almost all the clients were referred to an appropriate service. The implication from this response is that certain client needs must be addressed outside of the organization. There is a discrepancy between this response and the response to survey question # 8, which implies that most clients' needs are met within the organization. It is possible that the needs being addressed outside the organization are for more specialized services (e.g., dental, foot care, therapy.)

In order to coordinate services and refer, the organizations are assisted by the fact that about 75% of their clients have family physicians, and 44% are receiving services from another organization. This is a positive response, because the lack of a family physician can be a barrier when attempting to utilize health services. Again, it is not clear what services are being received from other organizations.

About 44% of the organizations share their client assessment information with other organizations, and most of the respondents are getting some (31%) or the majority (34%) of their information from other organizations. Care-planning appears to be a relatively discreet process, with only: 9% -11% doing all or most of their care-planning jointly, 31%-34% do few/some joint care planning, and 4% don't do any joint care-planning.

Organizations were asked more specific questions in order to better understand the nature of their information and referral services. ***There were very few clients without an appropriate service referral.*** Most clients are being referred to community-based services, and some are being referred to hospital-based services. These referrals could be a reflection of the nature of the organization (i.e., homes, hospitals, community agencies.)

Question 14b: For each of the following, please check the box most reflective of the clients (individuals with dementia and/or their caregivers) your organization serves.



Use of the resource databases (Peel-PINET, Halton-HIP) to make referrals was quite low, especially considering the number of organizations providing information and referral services.

It is not known how these organizations make their referrals and on what basis. Referrals could be based on a preferred set of agencies/providers already known to the organization. If this is the case, such an approach may be doing a disservice to the clients, because the organizations may not be aware of other available agencies and/or services. However, ***organizations may be constrained by the dated content of existing databases or the available technology*. The area of referrals could be further explored.**

At this point, over half the respondents (62%) do not intend to expand their services and supports.* Of the 38% who are planning to expand, by far the emphasis was on *enhancement of care through nursing, family and client education, with specific focus on staff training and support to the caregiver.

Organizations felt that front-line ***staff and supervisors need training and continuous education* to:**

- understand dementia
- recognize its signs and symptoms
- deal with clients and family
- advocate for the family; and
- provide resources if needed in the community.

Educational and training programs under consideration include U First training, P.I.E.C.E.S., partnership with Halton Geriatric Mental Health Outreach Program, and development of a new program with a Crisis Outreach and Support Team (COAST), training from the Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo

Other areas for expansion were ***services aimed at the Client and Care provider***, to assist with clients whose behaviours are deemed extremely difficult to manage. Planned increases in services for the client include enhanced communication memoir programs, linkages with adult day programs, as well as Nora's House-Respite Care.

In addition to increased and more in-depth education (e.g., feeding and eating difficulties, stages of dementia), ***it was felt that caregivers and family needed more support*** in dealing with dementia, end of life and bereavement, and their associated stresses. Organizations are planning more in-services for caregivers, relaxation therapies (e.g., yoga), education sessions, caregivers support groups, and vent-out sessions.

ORGANIZATIONAL STRENGTHS

Respondents were asked to identify their *key strengths* when providing support to individuals. Many respondents identified the same or related strengths, which are loosely categorized below into six themes—staff and training, diversity, caregivers and caregiver support, operations and services, linkages, and special programs.

Staff and Training

Organizations take great pride in their staff and teams, who they consider to be qualified, patient, compassionate, dedicated, caring, knowledgeable and experienced.

Use of a multidisciplinary collaborative team approach (e.g., CCAC, Staff, Social Workers, Therapists, Speech and Language Pathologists, Dietitians, Doctors) supported by professional leaders was also considered a strength. One organization noted that their small team approach ensured that clients were seen by a minimum number of nurses. Several others commented on the consistency of their teams and care providers in the provision of care.

Specific staff roles and skills were highlighted, including in-house champions, and trained staff (e.g., geriatric nurse clinician) who work with clients with Alzheimer's and difficult to manage behaviours. Some organizations felt that their trained seniors' coordinators (who place appropriate staff with clients, follow-up with clients, visit homes on continuous basis) were an asset in providing care.

The ***availability of ongoing education and specialized training packages*** was also considered a strength.

Diversity/Culture

Some organizations prided themselves on their ***capacity to provide culturally sensitive education and support to diverse groups*** in the preferred language of the client/caregiver. Other organizations noted their links with various cultural groups and the capacity to provide a traditional cultural environment, customs, and meals.

Community/Linkages

A number of organizations commented on the great community liaison being provided by the Alzheimer Society. Organizations felt that their knowledge of community resources and linkages with services (e.g., seniors' day programs, mental health) was important.

The capacity of these organizations to refer and access community agency/provider resources and supports, and to coordinate services, was considered a key strength.

General Operations/Services

A variety of responses touched on the nature and ***comprehensiveness of their services,*** e.g., referrals, confirmation of medical status, full services with activities specific to residents needs, respite, and placement.

Organizations felt that their strength lay in their ***approach to services***, such as establishing set routines for residents with early onset dementia, taking a proactive approach when changes occur and communicating with the appropriate party (e.g., CCAC, family members) for follow-up, recognizing patient and family needs (physical and psychosocial/counselling and support to both client and caregiver), promoting choice and interaction with others, and generally having a family-centred and flexible practice.

Some respondents felt that the ***availability of their services*** was key, e.g., no wait-lists, staff available 24 hours per day/7 days per week, and ongoing assessment of client needs (every 180 days).

Another key strength that was cited was the ***provision of care in a secure and safe environment.***

ORGANIZATIONAL CHALLENGES

Based on the responses, it appears that limited resources and limited, skilled staff are challenges affecting most respondents. When asked to identify the organizational challenges being faced, respondents identified numerous issues. Several of these issues (e.g., staff skills, diversity, linkages) were also identified as organizational strengths in the previous question. ***Respondents were very concerned with behavioural issues, caregiver support, and transportation. Notably, when asked earlier about transportation, respondents didn't know how well these needs were being addressed, or thought that they weren't being well-addressed.***

In addition, none of the organizations identified provision of therapy as a challenge, even though in the previous question, a low percentage thought it was well addressed. There may be a need to explore these two areas, especially since there were similar responses to the question as it related to system challenges. Other challenges have been grouped below under broad categories.

Staff and Training

Organizations commented on the ***need to find appropriate staff, including more geriatric psychiatrists to provide timely psychiatric support***. A number of organizations felt that there was a ***need to provide frontline staff and service providers with more education and training regarding dementia care issues.*** A social worker who completed the survey felt that there was ***inadequate time for counselling. Another respondent stated that health human resources systematic issues were a challenge. This comment could be a reference to staff turnover or funding, but needs clarification.***

The ***impact of the work on staff was also considered a challenge***. Examples include the difficulty in maintaining compassion, burnout from working at several places to make up full time hours, and risks associated with providing service alone to aggressive clients in their homes

Client/Resident Needs and Behaviours

Organizations spoke of ***the need for a safe and secure environment, and of the difficulties of balancing safety concerns with independence***. A number of organizations identified **behaviour management and communication** with the client as a particular challenge. Another key challenge was ***the variability of patients and their diverse needs*** (e.g., clients with dual diagnoses, changing physical ability, different levels of dementia, acutely physically ill dementia, young adult population), which made it hard to make individualized plans and to coordinate and deliver services. Some other miscellaneous examples of challenges included other residents' bias against those with dementia, the identification of individuals early on in their dementia journey, the lack of a family physician, allowing new residents time to fit in, and client rights (to refuse service.)

Information Management

When clients are being referred for services or transferred, assessment information and/or related data is not complete. Organizations noted that they were ***missing information on referrals,*** e.g., specific behaviours, and that there was ***generally a lack of information and/or training on how to perform this function. This might be further explored to get a better understanding of their experience in this area.***

Funding/Operations/Services

Many commented on the ***financial strain resulting from a growing population and increasing needs for increased care-giving***. They spoke of the need for ***funding for dementia programming***, information and referral, for staff for day programs, etc. A number commented on the wait-lists for long-term care facilities and respite care, on the restrictions on the amount of services authorized by the CCAC, and on ***their limited ability to follow a client over an extended period of time*** (the intent of case management service) ***due to the MOHLTC funding models.***

Discharge planning to appropriate care levels was also considered a challenge, given the lack and range of appropriate long term care services.

Caregivers Support

There were many comments in this area, which was clearly felt to be a both a concern and a priority that needs to be better addressed. Most organizations identified some aspect of caregiver support as a challenge. Some focused on the ***stigma associated with mental health***, the reluctance of caregivers to seek information or support until a time of crisis, or the caregiver's lack of support or acceptance of the disease diagnosis.

On the one hand they noted that there is a lack of knowledge by family and caregivers about dementia and the available community/medical supports, but on the other hand there is a very small budget for caregiver education and information. Organizations felt that families and caregivers are demanding more attention, and that although some of their care expectations are unrealistic, more staff are needed to provide family support and to meet caregiver needs.

The ***stress experienced by caregivers*** was frequently noted as a challenge, along with the means to address and/or mitigate this stress. It would appear that a number of organizations are trying to alleviate this stress through support teams for caregivers, and staying with individuals to allow caregivers time to attend support groups. It was suggested that ***caregivers need more than a friendly visit once a week***, given that the 24/7 nature of caring for someone with dementia is extremely enervating.

Transportation/Access

There were ***a number of challenges associated with transportation, including client access to services, and provider access to clients.*** It was noted that it is difficult to access rural clients who require service, and that some clients are isolated and have limited access to appropriate transportation services. One respondent pointed out that many services only exist in south Halton and are hard to access in the north, and similar issues were noted in Peel. Although there were comments that there are issues with transportation to and from appointments, the nature of these issues was not clear. There may be a link with the other challenges noted, such as the mobility challenges (must be able to enter and exit the vehicle without assistance), access to Transhelp, and transportation for early stage support groups. ***This is an area that could be further explored***.

Cultural/Diversity

All of the challenges identified here were of a similar nature, e.g., ***language restrictions, translating resources into major language groups, and easy/immediate access to interpreters.***

Community/Linkages

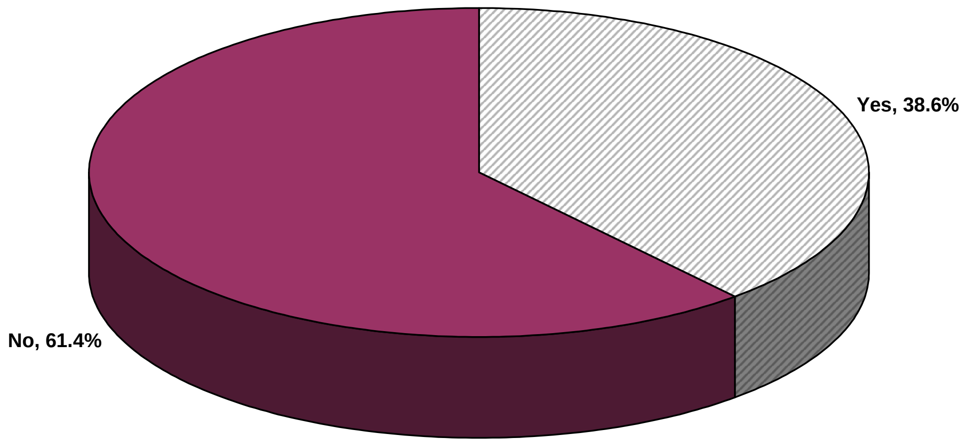
Organizations commented on ***limited referrals and treatment options from CCAC referral sources, limited community resources and staff, and a lack of support at the smaller sites***. There was no explanation of what was meant by "smaller sites."

It is recommended that clarification be sought on this point and in particular on the following two challenges that were identified: 'Other provider's viewpoint on communication needs' was considered a challenge. More critically, it was noted that ***some organizations are "left out of discussions" and that "the current system does not provide collaboration; we are not one of the 'big' companies invited to the 'table(s)' to discuss the issues common to us all in caring for this population demographic."***

Questions 19-21 relate to how well <u>*the system*</u> provides specific services, and supports, to meet the needs of individuals with dementia and/or their caregivers. ***Overall respondents felt that diagnosis, counselling, safety, services in the community, and accommodation, were fairly well addressed***.

Question 15b: **Is your organization planning to expand the services and support you provide to individuals with dementia and/or their caregivers.**

Expanding Services and Supports



As noted earlier, concerns were expressed regarding transportation services. ***Fifty per cent of the respondents didn't know how well legal and financial issues were being addressed. This response (and to a certain extent the responses that follow) is unexpected. If the majority of organizations are providing information and referral services, one would expect greater knowledge in this area, especially since some of the information would have to be collected during intake. There may be gaps in staff training, knowledge and approach, or information and referral services may not be comprehensive or as well-handled as the respondents believe.*** Responses could also be affected by the nature and levels of staff who responded, but since most of the surveys were completed by senior staff, directors of care, administrators, social workers, etc. one could expect a well-informed response.

Although 43% of the organizations thought that crisis intervention services were handled well-fairly well, 33% felt they were handled not very well or at all, and 20% didn't know. Given the divergent nature of the response and the importance of the service, it would be advisable to seek clarification as to what this question meant to respondents.)

Thirty-seven per cent of the organizations felt that services in the home were not handled very well, 33% thought they were, and 16% didn't know. Surprisingly, although only 48% of the organizations felt that therapy services were well handled, 24% felt not very well or not at all, and 25% didn't know this area of service wasn't raised as a challenge. Again, it would be worthwhile to explore these two questions further to better understand their experiences in these areas, and their responses.

SYSTEM STRENGTHS

Respondents felt that the ***system was improved and particularly strong in providing community support services***, including counselling, education, training, day programs, and caregiver support. ***They felt that referrals were well-handled, that it was easier to access information, and made numerous references to the good work done by the Alzheimer Society and CCACs. In addition, they felt that the Networks and communications were strengthened, there was better integration and knowledge of dementia/awareness of services, and that service providers were more willing to cooperate***. Additional comments are grouped into three categories: Staff and Training, Community/Linkages, Programs and Services.

Staff and Training

Again, respondents commented on the ***committed, knowledgeable and compassionate managers, staff, and volunteers to be found in the system***.

Continuing education for staff and caregivers was considered a strength, and particular training programs were identified, e.g., Halton Geriatric/Mental Health Outreach Program training initiatives and assessments, Alzheimer's education programs and initiatives, P.I.E.C.E.S. education for families/caregivers, and MOHLTC support for education.

Community/Linkages/Integration

From the number and nature of examples provided, it was clear that ***most organizations felt that the dementia Network itself was a strength, and that there were excellent system links to the community***. There were numerous service providers who were willing to collaborate and promptly respond to requests.

It was observed that there was an increased knowledge and sharing regarding diagnosis of dementia among professionals, and improved integration of services in this area. Respondents felt that common meetings and events in the area led to increased knowledge of what services are available and which contacts to call. Organizations stated that generally, agencies work well together to coordinate service for clients, and that communication between support services had increased over the past year.

In particular, organizations cited support from the MOHLTC and the excellent responses from CCACs.as strengths.

Programs/Services

The ***wide range and availability of programs, group and individual services, and community supports for clients and caregivers was clearly considered a system strength.***

Respondents listed numerous examples of regionally-based programs and services, e.g., adult/seniors day programs, home visits, physiotherapy, counselling/social workers, diagnostic services, respite services, caregiver support groups, wellness house, safety home programs, new LTC spaces, and mental health and psychogeriatric outreach teams. ***In addition, some organizations felt that the wait-lists for these services were not that long*** (although it is unclear what was meant by “long”).

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Again, a number of organizations felt that the services and supports provided by the CCACs (e.g., wait-lists, admissions and referrals, assessments, services, follow-up) and by the Alzheimer Society (e.g., day programs, educational programs, registry, support groups, other resources for clients and caregivers) were a strong system strength. The role of the CCAC case managers and CCAC therapists was listed by several organizations.

Although some organizations had identified information management as an organizational challenge, others noted in this part of the survey that it was a system strength. Some stated that there was easier access to information and that there was a greater ability to obtain more information regarding a client's circumstances. This is an area that could be explored to better understand the divergent responses.

A similar contradiction can be observed to the previous low response regarding the availability of written materials. In this section, the availability of educational materials, pamphlets, publicity, public awareness campaigns, and dementia care presentations was considered a system strength. It may be that these resources are available, but primarily offered only in English or French.

Two respondents included research (e.g., drug therapy) and the continuation of quality of life as system strengths, and these responses could also be clarified.

SYSTEM CHALLENGES

When asked to describe system challenges, respondents provided considerable specific detail (e.g., availability of expert staff) rather than high-level strategic responses. Some responses were in direct contrast to previous responses.

There were a number of references to stigma, acceptance of the disease, and multicultural issues. Transportation and information management were again noted as challenges, along with coordination of services and difficulties of access for the lay person. Other challenges cited frequently were funding, client/caregiver support, training, the adequacy and availability of homecare, personal care, respite services, hours of service, and the lack of physicians. Additional specific system challenges are categorized below:

Staff/Training

Respondents listed the ***high turnover*** of staff, and the ***lack of knowledgeable staff*** trained to diagnose, treat, and ***generally work with dementia patients as an ongoing challenge***. The challenges of keeping staff abreast of current information regarding dementia and educating peripheral caregivers, e.g., dietary staff about dementia were noted. Again, the need for more ***funding*** for staff and the need for ***volunteers*** was also listed.

Clients/Caregivers

It was clear from the responses that the needs of the caregivers were of particular concern. Some of the system challenges included the need for more ***evening and weekend relief, and respite services*** for caregivers in the home. The ***safety of caregivers*** in the home was also a concern.

Some respondents commented on challenges associated with early diagnosis, assessment, and treatment of dementia clients. For example, in the early stages, there can be difficulties getting a medical status and meeting personal care needs of a client who has confusion and still has lucid moments. The confirmation of incompetence when program resources no longer meet the client need and the client is still deemed to be able to make his/her own decision regarding placement is also problematic.

Generally, it was felt that there weren't enough resources to care for hard-to-manage people, or to provide enough supports at home (e.g., the system is providing basic personal care needs at home, and there may not be resources or processes in place when family members are away or if a client lives alone.).

Services/Programs

Many specific system challenges with respect to services and programs were listed. Again, ***funding*** and the limited financial resources available for these services were noted, as well as the ***difficulties associated with providing services to individuals that have difficult behaviours*** associated with dementia, mental illnesses, medication changes, etc.

Organizations commented on the need to ***promote more education*** in communities, and for ***more affordable, easily available caregiver relief for the families.*** It was noted that it is ***difficult to access information for lay people, and that there are no dementia outreach programs for families in crisis in the community.*** The ***lack of systemic options available for crisis intervention*** was cited more than once, as well as the ***lack of family physicians and geriatric psychiatrists*** willing or able to provide complete care to this demographic. The ***lack of geriatric mental health crisis teams and the wait-lists for geriatric assessment clinics*** were cited as challenges.

Some of the challenges associated with services in long term care homes included ***accommodation options, and the lack of short-stay beds for dementia patients*** (where staff are trained to care for patients and their families.) It was suggested that there be more life enrichment activities geared for these residents, as well as more social work support for clients and caregivers on site.

The need ***for more respite beds and expansion of in-home respite care services on weekends and evenings*** was observed by respondents.

A number of organizations commented on the ***inadequacy of in-home service levels, long-term follow-up, and of hours for services contracted through the CCACs.*** It was felt that more personal support was required, as well as evening and weekend programs for clients and caregivers. In addition, services should be provided ***at times that met everyone's needs***. A 'cookie-cutter' approach is often taken, and there can be a lack of individualization. It was also noted that there was ***a decrease in physiotherapy when it should be increased***, and that the legislation is behind the times.

A respondent commented that the challenge was to "provide families with adequate resources both public and private, to ensure that individuals have the option of remaining in their homes (if that is their wish) within a safe and healthy framework that supports the family as a whole."

A few examples of system challenges require some clarification (e.g., placement for young adults, sending dementia resident to the hospital, adult day programs, non-Alzheimer's dementia support groups, and psychogeriatric units are not "secure" units).

Transportation

Transportation was again flagged as a challenge, in particular easily accessible transportation for clients, families, appointments, etc.

Community/Linkages

Although the respondents felt that there had been significant gains in community linkages, they also felt that there was room for improvement to the Network. The ***linkages between hospitals, CCACs, long-term care homes, and community services needed to be strengthened***.

Organizations noted that the ***Network does not yet include all providers***, and that ***overall coordination of services with other providers to maximize services for clients is a challenge***. One respondent commented on the lack of consistent communication between agencies providing service to clients, and another commented that it was a challenge "maintaining openness".

It was observed that ***services are fragmented, that there is limited integrated programming, and that few consistent programs exist in the North,*** e.g., caregiver support. Several organizations noted the ***difficulties of access to family doctors, and that there were no doctors available to clients in rural areas.***

Information Management

Organizations also felt that although progress had been made, there was still room for improvement with respect to client data. It was noted that there was ***inadequate or poor flow of information, and that information given to caregivers should be more informed***. (One respondent noted that updating a client's profile when disease has progressed or other medical issues arise, helps the agency inform staff so that they are fully aware of a client's needs.) Generally, ***more client history is needed when being referred*** to an agency, e.g., level of dementia, triggers.

Diversity/Culture

A number of organizations commented on the ***fear and stigmas*** in society associated with mental health issues, and the difficulties clients and their families had in accepting the disease and resources. Organizations noted that it was ***difficult to access information for lay people***, and also suggested that there be public education regarding the stigma of dementia?

Challenges associated with providing culturally sensitive information and support in the various languages were cited, and it was noted that there are many different cultures and languages in Peel.

Other challenges included the growing population and multiculturalism.

OBSERVATIONS AND SUMMARY

Assessment of Respondents and Services

Most respondents are offering five or more services, and many consider the provision of information and referral services to be a main role. Based on the varied and conflicting responses (e.g., weaker links/knowledge re transportation, financial, legal, therapy services), respondents may not have a comprehensive understanding of the information and referral business, and this could have an impact on delivery of the service. The delivery of information and referral services could also be affected by the lack of linkages in specific areas, and the PINET and HIP databases, (which need to be as current as possible). Delivery could also be affected by either a lack of technology, or comfort with technology on the part of respondents (demonstrated in attempts to complete the survey).

Taking into account the difficulties in reaching many organizations, and the difficulties associated with the databases, the first point of contact for the lay person is critical. Attention should be paid to ensure that whoever is the first point of contact, and/or in the information and referral role, receives appropriate training and education regarding provision of support and moving clients through the system**.**

On a positive note almost half of those who responded maintain wait-lists mostly based on client need, and are not avoiding/rejecting clients based on diagnosis or stage of dementia.

Although the majority of organizations have processes in place to accommodate a change in client need or status, only a small percentage of clients have input into who provides support and when it is to be provided.

Respondents have respect for clients and caregivers and their values, and are attempting to meet diverse cultural needs through oral communication, and in-service education/training for staff. There could be a greater use of written materials, and partnering with multicultural and cultural-specific organizations and programs to reach diverse populations. Participation in multicultural committees/training initiatives could also be increased, and perhaps there could be sharing of resource persons specific to diversity.

Respondents felt that most clients were being referred appropriately, to either community or hospital-based services. It is possible that the needs being addressed outside some of the organizations are for more specialized services (e.g., dental, foot care, therapy.) Use of the resource databases (Peel-PINET, Halton-HIP) to make referrals was quite low.

Limited resources and limited, skilled human resources (including geriatric psychiatrists) are challenges affecting most respondents. Most respondents are not planning to expand services, although some are considering further training and education for nursing, family, and client, and support to the client and caregiver.

Although respondents expressed concerns about specific challenges and services (e.g., behavioural issues, transportation, crisis intervention, home services, therapy) ***the primary concerns were focused on the need for increased support and education for caregivers, and the need to provide frontline staff and service providers with more education and training regarding dementia care issues.***

Assessment of the Dementia Network

There are many positive elements to the existing Networks, which would indicate that they are ***well-positioned to succeed*** as they move forward into the next phase of maintenance and improvement. Some of the positive elements include:

- an inventory/database of key providers and services
- wide range and availability of programs, group and individual services
- established connections among providers
- teamwork and flexible approach
- provision of ongoing education
- common values
- and a common recognition of what is needed (i.e. more money for staff, education and technology); and
- strong support from the Alzheimer Societies, the Ministry of Health and Long-Term Care, and the Community Care Access Corporations.

Respondents found that the system networks and communications were improved and particularly strong in providing community support services. They noted that service providers were more collaborative and that common meetings and events led to increased knowledge of available dementia services and contacts.

Generally agencies worked well together to coordinate service for clients, referrals were well-handled, and it was easier to access information.

Although survey responses indicate that the Network is alive and functioning, there is ***clearly room for improvement***, especially given the low completion rate of the survey, even after e-mail and verbal reminders.

Use of the resource databases (Peel-PINET, Halton-HIP) to make referrals was quite low, and respondents are missing information on referrals.

Some organizations feel they were “left out of discussions” on common issues. Others felt that linkages between hospitals, CCACs, long-term care homes, and community services needed to be strengthened, and noted that the Network does not yet include all providers.

Overall coordination of services with other providers to maximize services continues to be a challenge. Services are fragmented, and there is limited integrated programming. In the North and in rural areas there are few consistent programs and difficulties of access to family doctors.

Only a little over half of the organizations partner with multicultural and cultural-specific organizations to reach diverse populations, or participate in multicultural committees and training initiatives.

Given that one of the main roles was to provide information and referral to other services and supports, cultural linkages could be strengthened through the information and referral process.

Generally, it was felt that community resources and manpower were limited, and that there weren’t enough resources to care for hard-to-manage people, or to provide enough support at home. Staff turnover remains high, and there is a lack of knowledgeable staff and volunteers in the system. There is an ongoing need for staff training and education.

KEY GAPS AND AREAS OF FOCUS

Four primary concerns were identified by the respondents and through analysis of the survey.

1. The challenge of providing ***more support and services to the caregiver***, who may be already stressed prior to seeking assistance, and then must face inadequate information, difficult/incorrect diagnoses, physical assistance, transportation issues, etc.

2. The need to ***recruit and retain knowledgeable staff***, ***and provide them with ongoing training*** and education programs to keep them current.

3. The ***stigma and fear associated with dementia and mental health generally***, and the need for ***greater education and outreach*** in this regard in a multi-cultural community.

4. The need to ***strengthen cultural linkages***, possibly through enhancing and strengthening the information and referral process, and ***through incorporating more multi-cultural information into the existing databases***.

There are a number of steps that the Networks (and individual members) can take to begin to address these concerns, and they are listed below in the Recommendations section.

However, ***in order to sustain these Networks and allow them to move forward, it is recommended that both the leaders of these Networks and the Networks themselves receive recognition and resources at a higher level***. To the extent possible, the ***Networks should leverage the strategic planning capacity and coordination services of the LHINs***, **the CCACs, and the MOHLTC.**

DETAILED RECOMMENDATIONS

1. Cultural Issues

   - Develop and share policies and procedures regarding client diversity
   - Identify resource persons specific to diversity who may be able to share knowledge and provide guidance in terms of approach, common issues
   - Identify opportunities for partnering with multicultural and cultural-specific organizations and programs
   - Identify multicultural committees/training initiatives and increase participation
   - Consider sharing cost of developing and producing written materials on common topics in necessary languages, perhaps in consultation with CCACs and Alzheimer Societies
   - Review existing written materials for the client to assess clarity and terminology to determine what information would be helpful, to identify where emphasis should be placed on interpretation, and to address cultural concerns and stigmas associated with dementia and mental illness
   - Establish links with the Canadian Mental Health Association; and
   - Consider sharing cost of developing and implementing education and training programs for staff on multicultural issues.

2. Client Services

   - Individual organizations to review client satisfaction surveys and identify areas for improvement to the organization/sector
   - Identify referral gaps (see below # 4. Communication, Technology, and Information Management)
   - Ensure that those in the information and referral role receive appropriate training and education regarding provision of support/moving clients through the system
   - Explore capacity and knowledge with respect to therapy, transportation, and legal/financial services
   - Explore possibility of coordinating evening and weekend services in the home, day programs, hospital, short stay, etc., as there is a great need for services on evenings and weekends
   - Identify specific concerns regarding crisis intervention, home care, therapy, respite care, short-stay beds, to determine whether and how to address concerns
   - Consider developing ‘core’ dementia outreach programs and education sessions for clients and caregivers
   - Look for ways to increase family support/end of life and bereavement support for people with dementia
   - Increase service/in-service programs for people who have dementia and for caregivers, and strengthen linkages with Adult Day Programs
   - Provide services to assist care providers with clients whose behaviours are difficult to manage, and more in-depth information on feeding and eating difficulties

- Recruit geriatric psychiatrists, where possible, to provide more timely psychiatric support and assessments, and
- Alert the MOHLTC and/or LHINs regarding the need for geriatric mental health crisis teams and geriatric assessment clinics.

3. Training

- Increase staff training programs on dementia, and on dealing with behavioural issues; and
- Ensure that the educational opportunities are held in locations that will allow for maximum staff access.

4. Communications, Technology, and Information Management

- Alert organizations to the issue of electronic barriers (e.g., spam stoppers, system administrators/auto replies) and consider mechanisms to address the issues.
- Update/maintain the databases to ensure accuracy and comprehensive entries of all providers to extent possible, and consider the use of more detailed, user-friendly categories
- Individual respondents should review and assess existing technological infrastructure and staff skills with a view to improvements as necessary
- Consider the development of a resource manual that could be held and maintained centrally (e.g., in a library, Web-based) and accessible to all, that would include training and education programs, brochures/primers on key topics in various languages; and
- Identify gaps and mechanisms to address the need for comprehensive referral information (e.g., specific behaviours).

NEXT STEPS

A Community Forum will be held in the near future to discuss the findings of the report and to consider next steps. Recommendations from the Forum will be used to develop Action Plans for the coming year.

APPENDIX A: SURVEY

Services and supports for individuals with dementia and their caregivers

Questions 1 – 22 relate to how your organization works to provide services and supports to individuals with dementia and / or their caregivers.

1. Please check the categories that best describe the services your organization provides to individuals with dementia and/or their caregivers. (Check all that apply)

   - ☐ Diagnosis and assessment
   - ☐ Counselling and support
   - ☐ Transportation
   - ☐ Safety (e.g., telephone safety checks, personal emergency response systems)
   - ☐ Education to providers
   - ☐ Education to individuals with dementia and / or their caregivers
   - ☐ Legal and financial services
   - ☐ Crisis intervention
   - ☐ Services provided in the home
   - ☐ Therapy services
   - ☐ Services provided in the community (such as adult day programs)
   - ☐ Accommodation of individuals with dementia (such as long-term care homes)
   - ☐ Information and referral to other services and supports
   - ☐ Other (please specify) ____

Services and supports

This section will ask you to consider some questions related to the availability of services and support your organization provides to individuals with dementia and their caregivers.

2. For each of the following, please check the box that is most reflective of your organization:

	All	Most	Some	Few	None	Don't know / does not apply
a. Services are available on evenings	☐	☐	☐	☐	☐	☐
b. Services are available on weekends	☐	☐	☐	☐	☐	☐
c. Service availability is similar across all geographic areas served	☐	☐	☐	☐	☐	☐

3. Do you determine eligibility for your organization's services and supports based on:

	Yes	No
a. Dementia type (e.g., Alzheimer's disease, vascular dementia)	☐	☐
b. Dementia stage (e.g.,mild, moderate, severe)	☐	☐
c. Age	☐	☐
d. Other (please specify) ________________________________		

Client Involvement

This section will ask you to consider some questions related to involvement of clients (individuals with dementia and / or their caregivers) in service planning and delivery.

4. For each of the following, please check the box that is most reflective of your organization:

	Always	**Usually**	**Sometimes**	**Rarely**	**Never**	**Don't know / does not apply**
a. Clients participate in initial planning regarding their care	☐	☐	☐	☐	☐	☐
b. Clients participate in follow-up planning regarding their ongoing/changing needs	☐	☐	☐	☐	☐	☐
c. Clients are involved when new services are developed (i.e. focus groups, surveys)	☐	☐	☐	☐	☐	☐
d. Clients have input into who provides support (i.e. which staff)	☐	☐	☐	☐	☐	☐
e. Clients have input into when support is provided (i.e. time of day, day per week)	☐	☐	☐	☐	☐	☐

5. Does your organization conduct periodic evaluations of client satisfaction?

☐ Yes ☐ No → *If no, please go to question # 7*

6. If yes, how often: (check most applicable box)

☐ Less than once per month
☐ Once per month to once per year
☐ More than once per year

Client needs

This section will ask you to consider some questions related to your organization's ability to meet the needs of clients (individuals with dementia and / or their caregivers).

7. Are you aware of clients whose needs cannot be fully met by your organization?

☐ Yes ☐ No → *If no, please go to question # 9*

↓

8. For those whose needs cannot be met, please check the box that is most applicable for each of the following possible reasons:

	All	Most	Some	Few	None	Don't know / does not apply
a. Not eligible for services from your organization	☐	☐	☐	☐	☐	☐
b. Your organization does not provide all of the services needed	☐	☐	☐	☐	☐	☐
c. Your organization cannot accommodate their needs immediately due to wait-lists	☐	☐	☐	☐	☐	☐
d. Your organization cannot accommodate their needs fully due to service restrictions	☐	☐	☐	☐	☐	☐
e. Service is available but not accessed or accepted	☐	☐	☐	☐	☐	☐
f. Other (please specify):	☐	☐	☐	☐	☐	☐

9. Does your organization maintain wait-lists for services provided?

☐ Yes ☐ No → *If no, please go to question # 11*

↓

10. If yes:

	Yes	No
a. Are clients wait-listed based on overall need?	☐	☐
b. Are clients wait-listed based on date of assessment?	☐	☐
c. Do you have processes in place to accommodate a change in client need / status?	☐	☐

Diversity

This section will ask you to consider some questions related to how your organization respects the values, beliefs and different languages of an increasingly diverse population.

11. Does <u>your organization</u> have front-line staff to deliver services to individuals with dementia / their caregivers in the language of their choice?

☐ Yes ☐ No → *If no, please go to question # 13*

12. If yes, how often is your organization able to accommodate these requests:

☐ Always
☐ Usually
☐ Sometimes
☐ Rarely

13. Are written materials available in the major languages spoken in Halton-Peel?

☐ Yes ☐ No → *If no, please go to question # 15*

14. If yes, please indicate which language(s)

____

____

____

15. Does <u>your organization</u>:

	Yes	**No**
a. Partner with other multicultural and cultural-specific organizations and programs to reach diverse populations?	☐	☐
b. Participate in multicultural committees / training initiatives?	☐	☐
c. Have policies and procedures regarding client diversity?	☐	☐
d. Provide in-service education/training to staff on diversity?	☐	☐
e. Have access to a resource person specific to diversity?	☐	☐

Service coordination

This section will ask you to consider some questions related to coordinated services and supports to individuals with dementia and / or their caregivers across organizations.

16. For each of the following, please check the box most reflective of the clients (individuals with dementia and / or their caregivers) <u>your organization</u> serves.

	All	**Most**	**Some**	**Few**	**None**	**Don't know / does not apply**
a. Number of clients with a family physician	☐	☐	☐	☐	☐	☐
b. Number of clients that receive services from another organization	☐	☐	☐	☐	☐	☐
c. Number of clients where assessment information from your organization is shared with other organizations	☐	☐	☐	☐	☐	☐
d. Number of clients where assessment information is used from other organizations	☐	☐	☐	☐	☐	☐
e. Number of clients where care planning occurs jointly with other organizations	☐	☐	☐	☐	☐	☐

Information and referral

17. Is one of the main roles of <u>your organization</u> to provide information and referral to other services and supports for individuals with dementia and / or their caregivers?

☐ Yes ☐ No → *If no, please go to question # 19*

↓

18. For each of the following, please check the box most reflective of the clients (individuals with dementia and / or their caregivers) <u>your organization</u> serves.

	All	**Most**	**Some**	**Few**	**None**	**Don't know / does not apply**
a. Number of clients <u>referred to</u> community-based services	☐	☐	☐	☐	☐	☐
b. Number of clients <u>referred to</u> hospital-based services	☐	☐	☐	☐	☐	☐
c. Number of clients referred to other organizations using resource database (in Peel – PINET; in Halton – Halton Community Services Database)	☐	☐	☐	☐	☐	☐
d. Number of clients without an appropriate service to refer to	☐	☐	☐	☐	☐	☐

19. Is <u>your organization</u> planning to expand the services and supports you provide to individuals with dementia and / or their caregivers?

☐ Yes ☐ No → *If no, please go to question # 21*

20. If yes, please describe your organization's plans for expansion.

____

____

____

____

21. Please describe three key **strengths** that <u>your organization</u> has when providing support to individuals with dementia and / or their caregivers?

    1. ____________________________________
    2. ____________________________________
    3. ____________________________________

22. Please describe three key issues / **challenges** that <u>your organization</u> faces when providing support to individuals with dementia and / or their caregivers?

    1. ____________________________________
    2. ____________________________________
    3. ____________________________________

Questions 23 – 25 relate to how the system works to provide services and supports to individuals with dementia and their caregivers.

Systems Issues

This last section will ask you to consider some questions related to all of the services and supports available to individuals with dementia and / or their caregivers (not just your organization).

23. Overall, how well do you think the needs of individuals with dementia and / or their caregivers are being met with respect to (check most applicable box for each service):

	Very well	**Fairly well**	**Not very well**	**Not at all**	**Don't know**
a. Diagnosis and assessment	☐	☐	☐	☐	☐
b. Counselling and support	☐	☐	☐	☐	☐
c. Transportation	☐	☐	☐	☐	☐
d. Safety	☐	☐	☐	☐	☐
e. Education	☐	☐	☐	☐	☐
f. Legal and financial services	☐	☐	☐	☐	☐
g. Crisis intervention	☐	☐	☐	☐	☐
h. Services provided in the home	☐	☐	☐	☐	☐
i. Therapy services	☐	☐	☐	☐	☐
j. Services provided in the community (such as adult day programs)	☐	☐	☐	☐	☐
k. Accommodation options (such as long-term care homes)	☐	☐	☐	☐	☐

24. Please describe three key **strengths** that the system has when providing support to individuals with dementia and / or their caregivers?

1. ______________________________

2. ______________________________

3. ______________________________

25. Please describe three key issues / **challenges** that the system faces when providing support to individuals with dementia and / or their caregivers?

1. ______________________________

2. ______________________________

3. ______________________________

Please provide your contact information in case we need to get in touch with you regarding the survey.

Your Name ______________________________

Position ______________________________

Organization ______________________________

Phone # ________________ Fax # ________________

If you have any questions regarding this survey, please contact XX

Thank you for your time

Please return by XX to XX

APPENDIX B: RESPONSES RECEIVED

Responses were received from a variety of organizations, with no significant difference in responses from the two regions.

PEEL	HALTON	TYPE OF PROVIDER
7	11	Community Service Provider
3	6	Day Programs
	5	Hospitals
6	3	Long-Term Care
3	3	Retirement Homes
1	1	Seniors Apartments

APPENDIX C: CONSULTANT CONTACT INFORMATION

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