First Link Demonstration Project: Final Evaluation Report

Submitted to: Alzheimer Society of Ontario

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[1] Available on the Alzheimer Society of Ontario website: www.alzheimerontario.org.

Glossary of Terms

ADRD	Alzheimer Disease and Related Dementias
AS	Alzheimer Society
ASO	Alzheimer Society of Ontario
CCAC	Community Care Access Centre
CHC	Community Health Centre
DNR	Do Not Resuscitate
FHT	Family Health Team
LHIN	Local Health Integration Network
LTC	Long-term Care
MCI	Mild Cognitive Impairment
MMSE	Mini-Mental Status Examination
MOCA	Montreal Cognitive Assessment
POA	Power of Attorney
PSW	Personal Support Worker

EXECUTIVE SUMMARY

Introduction: First Link is an innovative initiative developed and implemented by the Alzheimer Society of Ontario (ASO) with the ultimate objective of significantly impacting the quality of life of individuals living with Alzheimer disease and related dementias (ADRD) and their family members. In 2007, the ASO received operational funding from the Ministry of Health and Long-Term Care for a 24-month First Link demonstration project. Alzheimer Society Chapters in four selected demonstration sites participated in this demonstration project: Kingston/ Belleville/ Prince Edward County, Grey Bruce/ Huron/Perth, Sudbury/ Timmins, and Ottawa (representing a total of 9 Alzheimer Society Chapters). First Link was officially launched in February 2007 and the demonstration project continued to June 30, 2009.

First Link is an innovative collaboration between the Alzheimer Society, primary care providers, and other health professionals that aims to meet the needs of persons with dementia and their caregivers in a more comprehensive fashion, by connecting them to local dementia-specific supports and learning opportunities at the time of diagnosis and throughout the course of the disease. By forging these connections, individuals with dementia and their caregivers have the opportunity to access services earlier in the disease process, which may reduce the number of crises and alleviate caregiver burden.

A key element of First Link is the new referral process to the Alzheimer Society. When a family physician diagnoses a patient with dementia (or another health provider learns that a person has recently been diagnosed), the family physician/health provider can ask the person's permission to share their name and phone number with the local chapter of the Alzheimer Society. If the person agrees, their names is given to the First Link Coordinator and the Coordinator contacts the person by phone to answer any questions they may have and to let them know what information and services the Alzheimer Society has available to them. (This differs from usual practice where the family physician/health provider would suggest that the person contact the Alzheimer Society for information and support.) By putting the onus on the Alzheimer Society to make the first contact with the patient/caregiver, the patient/caregiver has the opportunity to learn more about the disease and can access education and services earlier in the disease process than they might have following the usual process.

The objectives of First Link are to:

(i) Enhance linkages between the Alzheimer Society and: diagnosing primary care physicians and other health care providers (e.g., allied health professionals), diagnostic and treatment services, and community service providers;

(ii) Increase understanding and awareness among family physicians and allied health professionals of: assessment and management of ADRD, the role of the Alzheimer Society and the First Link Program, and other community resources for individuals with dementia and/or their family caregivers.

(iii) Increase understanding and awareness among individuals with dementia and their family members/caregivers of ADRD and community resources, and to increase coping and confidence of caregivers and self-efficacy for self-management.

(iv) Improve coordination of care and linkages to community services for non-medical management issues from time of diagnosis through the duration of the disease.

This report describes the methods and results of an evaluation of the First Link Demonstration Project. This evaluation study was approved by the McMaster University Research Ethics Board.

Evaluation Objectives: The identified objectives of this evaluation were to: i) determine the extent to which the First Link program objectives were achieved and ii) describe the development and implementation of the First Link demonstration project.

Design: A combination of qualitative and quantitative methods was used to assess both process issues and outcomes (mixed methods approach)**.**

Understanding the options for individuals to access the services of the Alzheimer Society is essential to understanding a key component of the evaluation. There are three ways that individuals can access the Alzheimer Society:

i) a First Link referral (where, as described above, a physician or health professional asks the patient/caregiver for permission to share their name and contact information with the Alzheimer Society so the Society can contact them);
ii) a recommendation by a health professional for the patient or caregiver to contact the Alzheimer Society; and
iii) independently, with no referral.

The first type of referral is called a First Link or direct referral; the latter two are considered self-referrals. One of the aims of this evaluation is to compare outcome variables of interest (e.g., timeliness of access to service, caregiver stress and burden) between those referred to the Alzheimer Society via First Link (First Link or direct referrals) and those who were recommended by a health professional or who called the Alzheimer Society independently (self-referrals). It is important to note that everyone has the same access to services and supports regardless of how they were referred to the Alzheimer Society.

Sources of Information:

- ***Referral and Service Tracking*** data collected in e-tapestry (an electronic database) starting in November 2007[2] to June 30, 2009.
- ***Information, Education, and Awareness Raising Activities Tracking*** data collected by First Link Coordinators from February 2007 to June 30, 2009.
- ***Caregivers of Persons with Dementia*** who completed a baseline questionnaire (N = 92) at the time of their first contact with First Link assessing key outcome indicators (knowledge, confidence, ability to manage caregiving, coping, caregiving burden and stress) and follow-up surveys every six months to assess changes in key outcome indicators, up to a maximum of 4 surveys. Although the response rate for the initial caregiver survey was very low (11%);

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[2] Although First Link was launched in February 2007, an information system to track referrals was not in place until November 2007.

the response rate to the follow-up surveys was higher, ranging from 46% to 100% per follow-up survey.

- ***Health Professionals*** (N = 63) who referred their patients and/or their caregivers to First Link were invited to complete a survey to assess key outcome indicators (perceptions of current knowledge of ADRD, practice related to screening, assessment and diagnosis, role of the Alzheimer Society, and availability of other community resources) in comparison to prior to their involvement with First Link. A purposeful sample of health professionals (N = 17) was interviewed to gather more in-depth information about these indicators.
- ***Alzheimer Society representatives*** (N = 10) from each demonstration site were invited and agreed to participate in interviews about their perceptions of linkages and collaborative relationships with First Link and the Alzheimer Society, including information flow, referral trends/patterns, access, communication and information sharing, potential impacts and suggestions for improvement.
- ***Project Leaders and First Link Coordinators*** (N = 10) were interviewed to assess their perceptions of the development and implementation of the First Link demonstration project in terms of: identification of factors that facilitated development and implementation, challenges, lessons learned, and suggestions for improvement, generalizability to other regions, and sustainability.
- ***First Link Clients (Caregivers) and Persons with Dementia*** (N = 21) from each demonstration site were interviewed to determine the ways in which First Link has been helpful and to identify suggestions for improvements.

KEY FINDINGS

Referral and Service Tracking: From November 1, 2007 to June 30, 2009, 3562 individuals were registered as Alzheimer Society clients across all four demonstration sites as recorded in E-Tapestry.

- The Ottawa site had the highest percentage of registered clients (45%). Registration across the remaining sites was generally evenly distributed (17% - 20%).
- The number of monthly referrals ranged from 129 (February 2008) to 237 (January 2008), with the average being 175 (SD=31). Although referrals peaked in January 2008, in the last six months of the demonstration phase they remained relatively consistent (165- 204 referrals per month). Referrals tended to be lowest in winter months (November, December, February, and March).
- The majority (69%) of clients were women and the average age of clients was 65 years, though they ranged in age from 23 to 96 years.
- Although some (6%) clients were the person with dementia themselves, the majority (88%) were either family members or friends of the person with dementia, the majority of these individuals being a child or spouse of the person with dementia. In 6% of cases, no information was provided as to whether the client was a person with dementia or a family member.
- Although a large percentage of clients represented individuals diagnosed with Alzheimer Disease (39%) or with a related dementia (33%), some were without diagnosis (14%) or were still under investigation (4%).

- ***Referral Status:*** A significantly higher number of individuals were referred to the Alzheimer Society via First Link (65%) than those who were self-referred (35%), χ^2 (1) = 303.7, p = .001.
    - Among self-referrals, the Alzheimer Society, public awareness/ community groups, and friends and family were the most frequently identified sources of information about the Alzheimer Society. Those who were directly referred to the Alzheimer Society via First Link were referred most frequently by specialists, family physicians, and the CCAC.
    - For those who were self-referred, the number of monthly referrals ranged from 35 (February 2008) to 91 (January 2008), with the average being 61 (SD = 16). For those who were referred via First Link, the number of monthly referrals ranged from 71 (February 2008) to 154 (April 2008), with the average being 114 (SD = 20). In the last six months of the demonstration phase the number of self-referrals remained relatively consistent (67 - 82 referrals per month), though they dropped to 45 in June 2009. Referrals via First Link also remained relatively consistent in the last six months of the demonstration phase, with referrals ranging from 98-122 per month.
    - There were no differences in demographic information between those self-referred and those referred via First Link. However, a greater percentage of the persons with dementia of clients who were referred via First Link (60%) had a family physician than those who were self-referred (47%).
    - On average, those who were referred to the Alzheimer Society via First Link were referred sooner after the diagnosis of ADRD (7 vs. 18 months, respectively; or average 11 months sooner).
    - Among those with a diagnosis of ADRD, 58% of those who were referred via First Link were referred within the first month of being diagnosed, while only 27% of those who were self-referred were referred within the first month of diagnosis.

Information and Awareness Raising Activities:

- Across all of the demonstration sites for the duration of the demonstration project (February 2007 – June 30, 2009), the First Link Coordinators spent almost 1900 hours raising awareness of First Link within their communities, accessing almost 8,400 individuals in the process.
- Awareness raising activities included visits to family physicians, Family Health Teams, Community Health Centres, Memory Clinics and other specialized diagnostic and treatment services to provide information about the goals and objectives of First Link and services provided, presentations at physician dinners (many conducted in partnership with pharmaceutical company representatives), media presentations (television, radio, newspaper), presentations to local community groups (senior centers, service clubs, academic centers, professional associations, long-term care homes, retirement homes), displays at local malls, community health and service fairs, and conference/ workshop presentations.

- First Link Coordinators provided 2,700 hours of dementia-related education with a total of 6,000 people in attendance. Similarly, 1,300 hours were dedicated to community consultation, serving almost 3,700 individuals.
- In terms of the number of contacts that First Link Coordinators had with Alzheimer Society clients (e.g., to share information, invite them to education series, respond to their queries), in total First Link staff had 11,524 client contacts. For the three sites that provide direct client and caregiver support (e.g., counseling; Ottawa, Kingston/ Belleville/ Prince Edward County, and Sudbury/ Timmins), First Link provided a total of 1,962 hours of support to Alzheimer Society clients, serving 5,800 individuals (this includes one-to-one support and support groups).

Objective I: To Determine the Extent to Which the First Link Program Objectives were Achieved

Nurturing Partnerships:

- The new referral process was perceived by interviewed health professionals as important to ensuring that contact with the Alzheimer Society is made and services and supports are put into place as early as possible. All of the interviewed health professionals reported that the referral process to First Link was extremely easy. The referral process was described as *"easy"* ("*piece of cake*"), "*quick*", "*efficient*", and "*seamless*".
- Generally, interviewed key stakeholders (health professionals, Alzheimer Society representatives, project leaders and First Link Coordinators) believed that significant relationship building has occurred between primary care physicians, community service providers and specialized services aimed at assessment and management of ADRD. Although it was noted that linkages with primary care physicians have been difficult to forge and in some areas continues to be a challenge, significant headway has been made in increasing awareness of the services of the Alzheimer Society. In some settings where it has been difficult to access physicians, the First Link Coordinators have been able to develop linkages and relationships with nurse practitioners, registered nurses and other allied professionals who advocate for or make recommendations for referrals to First Link.
- Alzheimer Society representatives reported that First Link has been instrumental in facilitating referrals from new sources within the community (physicians, geriatric specialists, community support service provider agencies, and geriatric outreach teams and specialized services).
- It was noted that the development of partnerships with Family Health Teams, Community Health Centers, CCACs, and day programs has been instrumental for the delivery of the learning series, particularly in rural and remote areas. These partnerships have been helpful in facilitating referrals to First Link, assisting clients to better navigate the system of care, and ensuring care is better coordinated among partnering organizations.
- In areas (e.g., Sudbury/ Timmins) where there are limited diagnostic services, the First Link program arranges for in-home screening and comprehensive assessments conducted by registered nurses. These nurses work collaboratively with family physicians to assess and develop management plans for ADRD. In these areas, it was noted that First Link

provides a critical service that physicians and health teams may not have the resources or expertise to implement.

- Across all demonstration sites, health professionals were very satisfied with the services provided by First Link as reflected in the mean satisfaction rating of 4.5 (SD = .76; as rated on a 5-point scale: 1 = not at all satisfied; 5 = extremely satisfied). Many of the comments made about First Link reflect the collaborative partnership that First Link has with various health professionals and service providers.

Providing Progressive Education:

- ***Impact on Knowledge:*** Over 65% of health professional survey respondents reported having received material on ADRD and available community supports services/ resources; mean ratings of the usefulness of this material was high.
  - The majority of health professional survey respondents indicated that as a result of First Link their understanding of dementia in general and of identifying seniors with dementia has remained the same. However, the majority of survey respondents reported that as a result of First Link they now have a better understanding of managing seniors with dementia, the role of the Alzheimer Society, and of available community resources.
  - Although 7% of survey respondents commented that they have learned nothing new from First Link because they are experts in the field, most respondents indicated that they learned something new from First Link such as: the services, supports, and resource material provided by First Link/ Alzheimer Society, available community services and resources, information on diagnosis/ assessment (e.g., tools, risk factors, types of dementias) and interventions/ strategies, information on challenging behaviors/ care issues and educational opportunities for care providers.
- ***Impact on Assessment and Diagnosis:*** Ratings on the health professional survey reflected that survey respondents thought that First Link had minimal impact on increasing ADRD diagnosis or on early diagnosis. Interview participants shared similar perceptions.
  - Comments made by survey respondents reflected that their belief that their capacity to diagnose ADRD had not been impacted by First Link because this is their area of expertise and the main purpose of their work. Others commented that there is an increased awareness of ADRD, so that people seek assessment earlier and more people are accessing treatments and support services.
  - Interview participants noted that the impact of First Link on increased detection was greatest in areas where the Alzheimer Society provides an assessment service (Sudbury/ Timmins). These areas have few specialist resources so that the provision of in-home screening and assessment by qualified registered nurses was viewed as critical to increasing timely access to diagnosis and reducing the burden on primary care physicians, many of whom may not have the time or experience to conduct a comprehensive assessment.
- ***Impact on Familiarity with and Use of the Alzheimer Society and Community Services:*** Health Professional survey respondents' mean ratings of their familiarity with the

services of the Alzheimer Society and community support services were high. This is consistent with the perceptions of interview participants who attributed increased awareness of these services and supports to the promotional activities undertaken by the First Link coordinators.

  - The majority of survey respondents reported that they refer most or all of their patients to the Alzheimer Society (68%) and community support services (68%).
  - Although the majority of survey respondents reported that as a result of First Link they are now referring more of their patients to the Alzheimer Society, the majority reported that their referrals to community support services have remained the same.

- ***Impact on Dementia Care:*** Interview participants credited First Link for advocating for early intervention, so that more individuals are now referred for education and support early in the disease process, and more health professionals emphasize the importance of early contact with the Alzheimer Society.
  - Services provided by First Link and the Alzheimer Society (education and support) were described as essential as these cannot be provided to the same extent by physicians or specialized geriatric services (assessment teams, Memory Clinics) because of limited time, resources and expertise.
  - It was noted by interview participants (health professionals, Alzheimer Society representatives, caregivers and persons with dementia) that ongoing education of physicians is needed, as there are still many who fail to recognize the signs and symptoms of dementia, or who attribute symptoms to normal aging. This was evident by the large number of caregivers who report having raised concerns about memory loss/ symptoms numerous times and long before an assessment was conducted and a diagnosis made.

Reaching out to Families:

- ***Impact on knowledge, confidence, self-efficacy:*** Caregiver survey respondents' ratings of their knowledge of ADRD, familiarity with community resources, confidence as a caregiver and self-efficacy in the caregiver role (ability to manage the role) at baseline were moderate, with the highest percentage of survey respondents reporting over the survey times that they were currently more knowledgeable about ADRD, more familiar with community resources, more confident, and better able to manage the caregiver role in comparison to when their care receiver was first diagnosed. This is consistent with the reports of interviewed caregivers.
- ***Impact on coping effectiveness:*** Although there was some variability in caregiver survey respondents' scores on the Coping Effectiveness Scale (higher scores reflect greater coping effectiveness; maximum score = 35), ranging from 14 to 29 across survey times, generally, mean scores reflected moderate coping effectiveness. There were no significant differences in scores across the demonstration sites, across survey times or by referral status (self-referred/ referred via First Link). These findings were not supported by the interview reports: Interviewed caregivers reported that the Alzheimer Society services and supports improved their ability to cope and manage as the disease progressed.

- ***Impact on caregiver stress:*** Although caregiver survey respondents' mean ratings of stress were highest at baseline and decreased across the survey times, this trend was not statistically significant. Interviewed caregivers reported that their stress reduced with the services and supports provided by the Alzheimer Society.
- ***Impact on caregiver burden:*** Although, caregiver survey respondents' scores on the Caregiver Burden Inventory reflected that they were experiencing minimal caregiver burden at the time of the baseline survey, there were significant differences in their scores based on referral status. Those referred via First Link had a significantly lower total score than those self-referred, reflecting lower caregiver burden among those referred via First Link.
- ***Helpfulness of First Link Information:*** The majority of caregiver survey respondents had received information from First Link about ADRD and available community resources and services at the time of the first follow-up. The usefulness of information was moderate with ratings of the usefulness of information about ADRD being highest at the time of the first follow-up survey and ratings of the usefulness of information on available community resources and services being highest at the time of the fourth follow-up survey. Interviewed caregivers described the information that they received from First Link as critical to their understanding of ADRD and how to manage the caregiving role.
    - A small percentage of clients that received information about the education sessions did not attend the sessions (less than 8% across survey times). The usefulness of the education/ information ranged from high at the time of the first and second follow-up survey to moderate at the time of the third follow-up survey.
- ***Satisfaction with First Link:*** Caregiver survey respondents' mean ratings of satisfaction with First Link were highest for the first survey, and then decreased across the survey times. All of the interviewed caregivers and persons with dementia indicated that they were very satisfied with their involvement with First Link and the Alzheimer Society.
- ***Impacts as identified by key stakeholders:*** Interviewed key stakeholders (health professionals, Alzheimer Society representatives, project leaders, First Link Coordinators) identified a number of impacts for clients and caregivers associated with First Link:
    - Increased access to early intervention
    - Increased access to information and education
    - Access to client-focused support to reduce caregiver burden and remain at home as long as possible
    - Reduced use of health system resources related to crisis intervention and support for more appropriate use of existing system resources.
- ***Impact of First Link as identified by caregivers and persons with dementia:***
    - Access to information about ADRD
    - Access to information about community services and resources, including the Alzheimer Society
    - Caregiver support
    - Support for the person with dementia

- Early detection and timely intervention
- Reduced stigma

Objective II: To Describe the Development and Implementation of the First Link Demonstration Project

- ***Factors Facilitating the Development and Implementation of First Link:*** Interviewed project leaders and First Link Coordinators identified a number of factors that facilitated the development and implementation of First Link. In particular, the First Link coordinators identified the importance of health professional champions and the role of First Link in filling an identified dementia care gap. Other facilitating factors included the clear vision for First Link, support from the Alzheimer Society of Ontario, the dedicated project leader position, a consistent information system for data collection (E-Tapestry), the resilience and commitment of the First Link coordinators, the experience of the Ottawa site with First Link, and the application process for selecting demonstration sites which worked to secure Alzheimer Chapter commitment to First Link.
- ***Challenges to the Development and Implementation of First Link:*** Interviewed project leaders and First Link Coordinators identified a number of challenges related to the development and implementation of First Link. Many of these challenges were identified by Project Leaders and Coordinators alike, in particular Coordinators identified challenges related to the limited infrastructure that was in place when First Link was launched, the difficulties associated with data collection via E-Tapestry, different organizational cultures across Alzheimer Society chapters which challenged their ability to provide a consistent service across chapters, leadership issues, establishing relationships with physicians, and developing a mechanism for consistent follow-up of clients. Other challenges, included language and communication difficulties, the Alzheimer Society's shift from charitable organization to intervention service, human resource issues, and initial confusion about the role of First Link within the Alzheimer Society.
- ***Lessons Learned:*** It was noted that to be successful there should be one coordinator per chapter who should: secure their champions; have ongoing engagement with health professionals, and in particular, face-to-face interaction with physicians; adapt processes (e.g., referral processes) to the needs of referral sources; and develop a system for direct follow-up of clients to ensure their access to needed services and supports; and take advantage of resources in the community to support information and learning sessions. Other key lessons learned included the need to have a clear work plan and infrastructures in place prior to the launch of the program, the need for adequate funding, preparedness for increased demands in service, and clear articulation of the appropriate competencies for the First Link Coordinator role.

- ***Suggestions for improvements and Sustainability:***
  - ***Key stakeholders*** (health professionals and Alzheimer Society representatives) identified the need to secure ongoing funding to ensure availability of services that are perceived as critical to the care of persons with dementia and their

    caregivers. Related to programming, it was suggested that there be ongoing education about memory loss and ADRD, ongoing promotion/ marketing of services and supports available through the Alzheimer Society, clarification of the First Link mandate, development of individual peer support programs, programs targeted specifically to different age groups, more education on delirium, and less emphasis on "Alzheimer" in the Society's name (consideration of a name change). Related to health professionals, it was suggested that better strategies are needed to engage physicians in the referral process, as well as more educational opportunities for physicians. It was suggested that health professionals should receive immediate and detailed feedback on client involvement with the Alzheimer Society and receive information on the learning series content so that they can better promote the program.
  - ***Project leaders and First Link Coordinators*** noted that although the two-year demonstration project is over, First Link is still in its development phase (*'a work in progress'*), and that the development of, and improvements to, processes and the services offered are ongoing. Suggestions were made regarding: the provision of support (material and human resources) to the Alzheimer Society chapters; centralized marketing and branding; use of technology to increase access to services and supports, particularly for those in rural and remote areas; continued support for data collection which can be used to secure funding support; creation of more partnerships for implementation of the learning series; strategic planning for the future; and promotion of a core basket of services within each Alzheimer Society chapter, while maintaining the unique culture of each chapter.
  - ***Caregivers and persons with dementia*** noted that they were very satisfied with the services provided by First Link and the Alzheimer Society, with few individuals providing suggestions for improvement. Suggested improvements included increased access to individual counselling; separate support groups for spouses and children of persons with dementia to address their unique needs for support; more frequent support group meetings (more than once a month); provision of transportation to attend Alzheimer Society programs; provision of in-home respite to attend caregiver programs/ groups; increased access to evening respite; and a regular in-home friendly visiting program for persons with dementia to reduce social isolation, help deal with denial and provide support. Interview participants stressed the importance of promoting early identification of ADRD in order to reduce fear and stigma associated with seeking assistance. Several interview participants also identified suggestions for improvements to dementia care namely more specialists (geriatricians) in northern regions of the province and ensuring that physicians are properly educated and trained to assess, diagnose and manage ADRD as they had personal experience with physicians who were not helpful in this respect.
- ***Next Steps: Future Goals and Objectives for First Link***: Project leads and First Link Coordinators were asked to identify their future goals and objectives for First Link. The following objectives were identified:
  - Demonstrate success – identifying key indicators that show success of the program.

  - Secure funding for First Link programs in all Alzheimer Society chapters, particularly, Kingston, which was the only demonstration site that did not receive on-going LHIN funding for continuing the program.
  - Tie First Link into a National Alzheimer's strategy.
  - Develop a unified vision of First Link throughout the province.
  - Develop standardized core services and learning series content.
  - Ongoing quality improvement regarding record keeping (tracking data) to support goals and decision-making.
  - Develop better strategies for engaging caregivers in ongoing data collection; ensuring that strategies exist for recruiting them to complete evaluation surveys.
  - Articulate a clear model of counselling: exploring opportunities for a more consistent, clearer articulation of the counselling services that are offered and measurement of counselling outcomes as the effectiveness of counselling is not clear.
  - Develop strategies for identifying and engaging persons with dementia and their caregivers who are struggling but have not yet been connected with the Alzheimer Society.

Evaluation Challenges and Limitations: A number of challenges and limitations were experienced with this evaluation; these are described in the report. Most important are challenges associated with the use of E-Tapestry as a means of collecting information on the Alzheimer Society clients which represented, in some ways, a new way of doing 'business' in that the First Link Coordinators and Alzheimer Society staff were asking new things of clients and were collecting information that did not directly impact their work with the clients. It is likely that the information collected in E-Tapestry is an underestimation of the number of clients served by the Alzheimer Society Chapters during the demonstration project. Similarly, challenges experienced in engaging health professionals and caregivers/ persons with dementia in the evaluation may have impacted the representativeness of these samples. Despite these limitations, existing evaluation data provides a glimpse into the population serviced, services provided, and the impacts associated with the First Link demonstration project.

Conclusions: Based on the findings of this evaluation, the following conclusions can be made:

- At a minimum 3600 caregivers representing over 3600 persons with dementia have been served by the Alzheimer Society during this demonstration project. Challenges associated with data collection, entry, and maintenance most likely contributed to an underestimation of the number of clients that have been served.

- The evaluation has demonstrated that the objectives of First Link have largely been achieved. The new model of service access as facilitated by First Link represents a major move towards filling dementia care gaps that are well documented within the literature (Pratt et al., 2006). The new referral process helps to ensure caregivers and persons with dementia have the opportunity to be supported as soon as possible after diagnosis and thus, as commonly occurs, reduces first-time contact with the Alzheimer Society at times of crisis.

- Although the number of referrals to the Alzheimer Society via First Link was higher than self-referrals, this trend remained consistent throughout the demonstration project. It is not clear why the number of referrals via First Link did not increase, as expected, as awareness of the program grew. This may be due to marketing of the program or data collection issues, particularly the fact that tracking of referrals did not commence until after the program began accepting referrals.

- Significant headway has been made in the development of linkages and partnerships with primary care physicians, diagnostic and treatment services, and community resources and supports. It needs to be acknowledged that First Link's foray into providing assessment and intervention services with the aim of enhancing system navigation and care coordination and the process in which this occurs represents a significant change in the Alzheimer Society's service provision and generally how they do business. This change has resulted in the need for frontline staff to change how they market and promote ('brand') themselves to effect a change in how they are perceived within the health system.

- Although First Link has had a positive impact on increasing understanding and awareness, among health professionals and particularly physicians regarding the role of First Link, the Alzheimer Society and other community resources, and on how health professionals manage dementia (from the perspective that increased partnerships with and timely referrals to the Alzheimer Society represents a change in how dementia is managed, thereby promoting early intervention), First Link has had less of impact on how health professionals assess dementia. Although specialists and specialized services have the expertise required for optimal screening and assessment of dementia, primary care settings have been described in the research literature as less able to do so (Callahan et al., 2006; Sachs et al., 2004). There are anecdotal reports to support this; many caregivers as well as Alzheimer Society representatives have experienced situations where primary care providers have negated the relevance of memory and behavioral concerns thus delaying the diagnosis of (and intervention for) ADRD. In areas where there are limited specialists and specialized assessment services (e.g., Sudbury/Timmins), the Alzheimer Society plays a significant role in the assessment of ADRD (in-home comprehensive assessments conducted by trained registered nurses); this service is welcomed by health providers who are unable to provide the same level of outreach service due to time constraints, competing priorities for health system resources, and in some cases limited resources and expertise. Clearly, physicians play a key role in facilitating referrals to First Link; a higher percentage of those referred to the Alzheimer Society via First Link had a family physician than those self-referred, and those referred via First Link are referred earlier in the disease process than those who are self-referred. Continued efforts to identify optimal strategies to engage, educate and support family physicians in the care of their patients with dementia should yield positive results in this respect.

- First Link and the Alzheimer Society has had a positive impact on increasing understanding and awareness among caregivers and the persons they care for about ADRD and available community resources as well as on increasing their confidence in their ability to manage the disease. Health professionals and other key stakeholders believe that the education and support provided by the Alzheimer Society better prepares caregivers to understand and manage the psychological and behavioral symptoms that typically result in visits to the Emergency Department and crisis-related long-term care placements, though all of the evidence on health system impacts as a result of First Link and Alzheimer Society is anecdotal.

- One of the key elements of the First Link's success is that it builds upon existing capacity for dementia care within the community. Increased engagement of and collaboration with primary care, diagnostic and treatment services and community resources and services is a significant outcome impacting the Alzheimer Society's success. Suggestions made for improving and sustaining First Link have the potential for further capacity building. In addition to resource supports (funding, information systems, enhanced programming), opportunities for health professional support and continued promotion/ marketing of First Link will strengthen its ability to achieve its objectives.

- Further development, implementation, and expansion of First Link have the potential to significantly impact early detection and quality of dementia care. First Link is a model of optimal service access and delivery for other regions in the province, as well as other disease-specific organizations/agencies aimed at improving chronic disease management. Lessons learned in developing and implementing First Link in this demonstration project can be used to inform the development of First Link in other areas.

1.0 BACKGROUND AND INTRODUCTION

Alzheimer Disease and Related Dementias

The Canadian population is aging. It is estimated that by 2041 the number of people over 65 years of age in Canada will increase to 9.2 million from 3.92 million in 2008 (Health Canada, 2002). As the population ages there will be an increase in age-related disorders such as Alzheimer disease (Hopkins & Hopkins, 2005). Alzheimer disease is a progressive degenerative disease affecting the brain and is the most prevalent type of dementia, accounting for 75% to 85% of dementias (Hopkins & Hopkins, 2005). The cognitive degeneration associated with Alzheimer disease and other related dementias (ADRD) is characterized by significant psychological (mood) comorbidity and behavioral disturbances and results in dependence in activities of daily living and the need for full-time care (Patterson et al., 1999). The progression of ADRD varies from person to person and can span three to 20 years; the average life span after diagnosis is between eight and 12 years (Feldman & Kertesz, 2001).

The Canadian Study of Health and Aging determined that the age-standardized rate of dementia ranges from 2.4% in those from 65 to 74 years of age to 34% in those over 85 years of age (Canadian Study on Health and Aging Working Group, 1994). It was estimated that in 2008, 480,600 Canadians had dementia, representing 1.5% of the Canadian population; it is anticipated that by 2038, the prevalence of dementia will increase to 1,125,200, representing 2.8% of the population (Smetanin et al., 2009). By 2038, there will be an estimated 257,800 new diagnoses of ADRD per year, an increase from 103,700 in 2008 (Smetanin et al., 2009).

Care Gaps

Significant care gaps exist for persons with dementia living in the community and their caregivers. These care gaps are related to limited knowledge and use of available community supports among persons with dementia, their caregivers and health providers, and limited early detection and primary care support.

Limited use of available community supports: Caregivers experience overwhelming challenges as they attempt to care for their loved ones at home; many are ill-prepared for the physical and emotional demands of caring for someone with dementia. Caregiver stress has been identified as a significant predictor of early nursing home placement (Fisher & Lieberman, 1999). Most of the care that is provided to individuals with dementia living at home is provided by family caregivers and this is usually provided with little or minimal formal support or assistance (Peacock & Forbes, 2003).

There is evidence that education, use of community services and support, and counseling for caregivers can: increase the length of time that caregivers can provide care for family members at home and delay institutionalization (Mittleman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittleman, 2003; Gaugler et al., 2005), delay death of the care recipient (Brodaty, Gresham, & Luscombe, 1997), improve interactions between caregivers and care recipients (Corbeil, Quayhagen, & Quayhagen, 1999), significantly reduce depressive symptoms in caregivers (Mittelman et al., 1995; Mittleman, Roth, Coon, & Haley, 2004) and delayed institutionalization of individuals with dementia (Brodaty, Gresham, & Luscombe, 1997).

Relatively few individuals and family members access services, such as those provided by the Alzheimer Society, early in the course of the disease and many wait to seek help until they face a crisis or until the burden of caregiving has become too great (Pratt et al., 2006). In general, family caregivers tend to access services late in the disease process (Gaugler, Kane, Kane, & Newcomer, 2005). At this point, caregivers are overwhelmed, distressed, and limited in their capacity to cope. Lack of awareness of available support services has been identified as a significant factor contributing to the non-use of formal support services (Morgan, Semchuk, Stewart, & D'Arcy, 2002).

Limited early detection and primary care support: The health care system is challenged to meet the needs of individuals with ADRD, particularly in primary care settings, which have been described as under-resourced to provide comprehensive management for dementia (Callahan et al., 2006; Sachs, Shega, & Cox-Hayley, 2004). Although primary care settings are in an ideal position to diagnose dementia, cognitive impairment is often unrecognized. (Valcour, Masaki, Curb, & Blanchette, 2000; Iliffe & Manthorpe, 2002). Many barriers to recognition have been identified including lack of time and ability to screen for dementia (Chodosh et al., 2004), lack of knowledge about dementia (Barrett, Hayley, Harrell, & Powers, 1997), lack of symptom recognition and physician belief that early detection is not necessary (Boise, Camicioli, Morgan, Rose, & Congleton, 1999; Woods et al., 2003), and belief that early detection increases patient and caregiver distress (Iliffe & Manthrope, 2004). Moreover, patients and caregivers may neglect to discuss concerns about memory loss because they perceive it to be part of the aging process (Small et al., 1997). There is support for efforts to improve physician ability to recognize cognitive impairment, and in particular to screen for and diagnose dementia in its early stages (Chodosh et al., 2004; Iliffe & Manthorpe, 2002; Iliffe, Manthorpe, & Eden, 2003; Naidoo & Bullock, 2001).

Beyond identifying cognitive impairment, several studies have shown that family physicians are limited in their knowledge and skills to effectively manage ADRD (Barrett et al., 1997; Rubin, Glasser, & Wercke, 1987). In a study examining physician and caregiver perceptions of dementia care provided in family practice (Glasser & Miller, 1998), family caregivers reported that physicians were limited in their ability to assist them with non-medical and psychosocial issues, particularly in terms of providing advice about symptom management, and support services. Since family physicians can play a key role in linking patients with dementia and their family caregivers to community services, there is support for increasing physician awareness of the availability and profile of local support services and to provide them with educational support (Turner et al., 2004).

First Link Demonstration Project

First Link is an innovative health care initiative that has the potential to significantly impact the quality of life of individuals living with Alzheimer disease and related dementias (ADRD) and their family members. Relatively few individuals with dementia or their family caregivers access support services, such as those provided by the Alzheimer Society, early in the course of the disease and many wait to seek help until they face a crisis or until the burden of caregiving has become too great. First Link is an opportunity to provide individuals with dementia and their caregivers with comprehensive and coordinated services by identifying and reaching out to them as early as possible in the disease process. First Link aims to accomplish this goal by enhancing partnerships and linkages between the diagnosing primary care physician and other primary care providers (e.g., allied health professionals), diagnostic and treatment services, community service providers, and the Alzheimer Society (McAiney et al., 2008).

First Link started in Ottawa as a coordinated support and education initiative led by the Alzheimer Society of Ottawa in collaboration with the Dementia Network of Ottawa, and funded by the Ontario Trillium Foundation from April 2002 to March 2004. (A summary of the results of an evaluation of this pilot project is presented in Appendix A[3]; Alzheimer Society of Ottawa, 2004.) Similar pilot projects were launched in various locales (e.g., Toronto, 2003). In 2007, the Alzheimer Society of Ontario (ASO) received operational funding from the Ministry of Health and Long-Term Care for a 24-month First Link demonstration project. Funding for an evaluation of this demonstration project was provided, in part, by the Ministry of Health and Long-Term Care and an Alzheimer Society of Canada research grant. First Link was officially launched in February 2007 and the demonstration project continued to June 30, 2009.

Alzheimer Society Chapters in four selected demonstration sites have partnered with primary care practitioners to participate in First Link. The demonstration sites, representing urban, rural, and remote settings, are: Kingston/Belleville/Prince Edward County, Grey Bruce/Huron/Perth, Sudbury/Timmins, and Ottawa (representing a total of 9 Alzheimer Society Chapters). The selection criteria used to select the demonstration sites are presented in Appendix B; profiles of the services provided in each of these demonstration sites are located in Appendix C.

The ultimate goal of First Link is the increased understanding and effective reduction of the personal and social consequences of ADRD. First Link aims to accomplish this goal by enhancing and strengthening linkages between diagnosing primary care physicians and other health care providers, diagnostic and treatment services, community service providers, and the Alzheimer Society, by assisting more people with dementia and their caregivers earlier in their disease process, by providing more comprehensive and coordinated care throughout the remainder of their lives, and by providing progressive education to health care providers, individuals with dementia and their family caregivers.

The objectives of First Link are to:

(i) Enhance linkages between the Alzheimer Society and: diagnosing primary care physicians and other health care providers (e.g., allied health professionals), diagnostic and treatment services, and community service providers;

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[3] Note: All appendices are contained in a separate document, available on-line at the Alzheimer Society of Ontario website: www.alzheimerontario.org.

(ii) Increase understanding and awareness among family physicians and allied health professionals of: assessment and management of ADRD, the role of the Alzheimer Society and the First Link Program, and other community resources for individuals with dementia and/or their family caregivers.
(iii) Increase understanding and awareness among individuals with dementia and their family members/caregivers of ADRD and community resources, and to increase coping and confidence of caregivers and self-efficacy for self-management.
(iv) Improve coordination of care and linkages to community services for non-medical management issues from time of diagnosis through the duration of the disease.

A program logic model for the First Link Project is located in Appendix D.

Nurturing Partnerships

First Link aims to improve dementia care through partnerships with primary care providers, in particular, family physicians and allied health professionals within Family Health Teams (FHTs) and Community Health Centres (CHCs), both of which are key components of primary care reform in Ontario and represent a change toward a more interprofessional approach to healthcare.[4] First Link aims to meet the needs of individuals with dementia living in the community and their family caregivers by enhancing and strengthening partnerships between diagnosing primary care providers and allied health professionals, diagnostic and treatment services, and community service providers. In addition to FHTs and CHCs, this would include nurturing partnerships with Community Care Access Centers (CCACs), which play play a vital role in helping to maintain individuals in the community by coordinating in-home services, and are also responsible for placement in long-term care homes, community service provider agencies such as VON, St. Elizabeth's Nursing, Bayshore Home Health, ComCare, and the Red Cross, which provide in-home services (e.g., nursing, physiotherapy, occupational therapy, speech-language, homemaking), Adult Day Programs, which provide the person with dementia opportunities for social interaction and engagement in meaningful activities, and much needed respite to family caregivers, and Specialized Geriatric Services (SGS), including geriatric psychiatry and geriatric medicine services, which provide direct and indirect consultative services to individuals living in the community or in long-term care homes in order to optimize health, independence, and quality of life.

First Link has a communication strategy (presentations, written material, media releases) to increase awareness of the First Link Demonstration Project among family physicians and allied health professionals, partner agencies, and the general public, and a strategy to facilitate and encourage referrals to First Link, namely a referral kit consisting of referral contact information and tear away referral note pads for faxing in referrals to the First Link office.

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[4] FHTs consist of teams of physicians and other health professionals including mental health counsellors, dietitians, Nurse Practitioners, nurses, and pharmacists working together to provide more comprehensive, coordinated care to patients. CHCs are non-profit organizations that provide primary health care and health promotion programs for individuals, families and communities.

Reaching Out to Families: Coordinating Care

When a family physician diagnoses a patient with dementia (or another health provider learns that a person has recently been diagnosed), the family physician/health provider asks the person's permission to share their name and phone number with the local chapter of the Alzheimer Society. (This differs from usual practice where the family physician/health provider would suggest that the person contact the Alzheimer Society for information and support, though patients, caregivers and family members are free to independently contact First Link.). Referrals to the First Link program are received from primary care providers, CCACs, SGS, seniors' mental health programs, and other community support services. Patients (or family members) who agree to have their name shared with the Alzheimer Society are contacted by phone approximately 4 weeks later by the First Link Coordinator. (The 4 week delay is given to allow clients time to adjust to the diagnosis.) The coordinator provides the individual with information about dementia, services available in the community, and relevant education sessions. The coordinator offers to mail the person a package with more detailed information about dementia and available services and to have the Alzheimer Society regularly connect with them regarding information and supports. By putting the onus on the Alzheimer Society to make the first contact with the patient/caregiver, the patient/caregiver has the opportunity to learn more about the disease and access education and services earlier in the disease process than they might have following the usual process (See Appendix E). Although First Link is not a case management approach, it is similar in that it is a method of increasing individuals' and caregivers' awareness of and access to community services and can be particularly useful at the client's point of entry into the health care system.

Providing Progressive Education

Despite the prevalence and impact of Alzheimer disease, Canadians know little of this disease (Martin, 2003). By ensuring that all individuals with ADRD and their family caregivers have access to education about dementia, First Link will assist in increasing knowledge and understanding of the nature and course of ADRD and the personal and social consequences of ADRD, improving understanding of the community resources available to support those with ADRD and their caregivers, enhancing caregiver coping skills, and increasing caregiver confidence in their ability to manage ADRD.

Family physicians are challenged by time constraints to provide information, education, and support to patients, family members, and caregivers (Nazerali, 2006). For some physicians, their ability to provide this support is further compromised by limited knowledge of care of the elderly and their ability to keep up with advanced and new information (Williams & Evans, 2004) and by limited knowledge of ADRD (Barrett et al., 1997; Rubin et al., 1987). Family physicians, as the clinician most likely to communicate the diagnosis of dementia to their patient and family, are in an optimal position to provide information to their patients about the disease, interventions, appropriate community services, to assess caregiver coping and burden, and to discuss legal and financial issues (Cohen, Pringle, & LeDuc, 2001). The provision of dementia education sessions for family physicians and allied health professionals could greatly increase their capacity to recognize early signs of dementia and to initiate early intervention.

This report describes the methods and results of an evaluation of the First Link Demonstration Project.

2.0 EVALUATION METHODS

2.1 Evaluation Principles

The development of the evaluation was guided by the following principles:

- Evaluation is an integral part of program development and delivery, and as such is considered a component of the program model.
- Evaluation strategies will be utilization-focused and guided by the information needs of key stakeholders and decision-makers.
- Evaluation strategies will be designed to support, reinforce, and enhance program development.
- The evaluation will include both process and outcome measures.
- Information collection methods will be selected and designed to support and achieve utilization.

2.2 Consultation with Key Stakeholders

An Advisory Group was developed to focus the evaluation. Members of this Advisory Group acted as advisors to the evaluation, providing advice and feedback on the development and implementation of the evaluation plan and tools, suggestions for participants, and interpretation of results. This Advisory Group consisted of representatives from ASO (David Harvey, Chief Member Services Officer, Cathy Conway, Director of Quality Management and Education; Beth Martin, Planning, Quality and Accountability Consultant; Margaret Eisner, Alzheimer Society of Hamilton & Halton, Brant and Haldimand Norfolk), Deana Stephens, First Link Project Coordinator (from inception to October 2008), and representatives from the First Link demonstration programs (Site Coordinators: Kingston: Sue MacDonald, previously, Barbara Thompson; Ottawa: Kelly Robinson (Project Coordinator, after October 2008); Grey Bruce/Huron/Perth: Trish Harris Tousignant; Sudbury/Timmins: Linda Fontaine, Stephanie Welsh, previously, Sandra Gagnon). Caregivers of persons with dementia provided input into the development of the caregiver surveys.

2.3 Evaluation Objectives

The identified objectives of this evaluation were:

1. To determine the extent to which the First Link program objectives were achieved, specifically:
    - To what extent was First Link able to connect caregivers of individuals with dementia to the services of the Alzheimer Society earlier in the disease process than individuals who self-refer to the Alzheimer Society?

- To what extent were linkages between the Alzheimer Society (AS) and diagnosing primary care physicians; diagnostic and treatment services (specialized geriatric and mental health services); and community service providers enhanced?
- To what extent did First Link increase understanding and awareness among family physicians and allied health professionals of assessment and management of dementia, the role of the Alzheimer Society and the First Link program, and other community resources for individuals with dementia and/or their caregivers?
- To what extent did First Link increase understanding and awareness among individuals with dementia and family members/caregivers of ADRD and community resources? To what extent did First Link impact their coping and confidence as caregivers and self-efficacy for self-management?
- To what extent did First Link improve coordination of care and linkages to community services for non-medical management issues from time of diagnosis through the duration of the disease? As a result of First Link were more families linked to AS? Was there increased participation in AS programs and increased utilization of Dementia Network programs?

2. To describe the development and implementation of the First Link demonstration project in terms of:
    - factors that facilitated or hindered (challenges) development and implementation;
    - potential impacts;
    - lessons learned; and
    - suggestions for improvement, generalizability and sustainability.

There are three ways that individuals can access the Alzheimer Society: i) a First Link referral (where, as described above, a physician or health professional asks the patient/caregiver for permission to share their name and contact information with the Alzheimer Society so the Society can contact them); ii) a recommendation by a health professional for the patient or caregiver to contact the Alzheimer Society; and iii) independently, with no referral.

The first type of referral is called a First Link or direct referral; the latter two are considered self-referrals. One of the aims of this evaluation is to compare outcome variables of interest (e.g., timeliness of access to service, caregiver stress and burden) between those referred to the Alzheimer Society via First Link (First Link or direct referrals) and those who were recommended by a health professional or who called the Alzheimer Society independently (self-referrals). It is important to note that everyone has the same access to services and supports regardless of how they were referred to the Alzheimer Society.

2.3.1 Hypotheses

Based on these objectives, the following hypotheses were made:

- Individuals who are referred to the Alzheimer Society by health professionals will be referred sooner after the diagnosis than individuals who self-refer to the Alzheimer Society.

- Over time, the proportion of referrals to the Alzheimer Society from health professionals (i.e., primary care physicians, specialized geriatric and mental health services, and community service providers) will increase compared with the proportion of self-referrals to the Alzheimer Society.

- Health professionals will report that, compared with prior to the initiation of First Link, they:
  a) have a greater awareness and knowledge of the assessment and management of dementia.
  b) have a greater awareness of the role of the Alzheimer Society and the First Link program.
  c) have a greater awareness of other community resources for individuals with dementia and/or their caregivers; and
  d) use these other community resources for individuals with dementia and/or their caregivers.

- Caregiver stress will change over time and differ between those individuals who are referred to the Alzheimer Society by health professionals and those who self-refer. Specifically:
  a) Individuals who are referred to the Alzheimer Society by health professionals will have lower ratings of caregiver stress at the time of first contact with the Society than individuals who self-refer.
  b) Individuals who are referred to the Alzheimer Society by health professionals will have higher ratings of coping effectiveness at the time of first contact with the Society than individuals who self-refer.
  c) Over time, caregiver stress will be lower among individuals who are referred to the Alzheimer Society by health professionals compared with those who self-refer.
  d) Over time, coping effectiveness will be higher among individuals who are referred to the Alzheimer Society by health professionals compared with those who self-refer.

- First Link Program will have an impact on caregivers' knowledge of ADRD and use of available resources. Specifically:
  a) Caregivers' self-reported ratings of knowledge of ADRD and available resources will increase over time.

    b) The number of resources/services/supports accessed by caregivers will increase over time.

- First Link Program will have an impact on coordination of care and linkages to community services for non-medical management issues. Specifically:
    a) The number of First Link clients/families participating in Alzheimer Society programs will increase over time.
    b) The number of First Link referrals to community resources, supports, and services will increase over time.

2.4 Design and Sources of Information

A comprehensive evaluation framework for the First Link demonstration project was developed based on the program logic model for this initiative. The evaluation framework is presented in Appendix F. A combination of qualitative and quantitative methods was used to assess both process issues and outcomes (mixed methods approach)**.** The following sources of information were used to achieve the objectives of this evaluation.

2.4.1 Referral and Service Tracking

All of the demonstrations sites (First Link Coordinators) prospectively collected information on the number of referrals to the Alzheimer Society, referral source, referrals without diagnosis, and refusals for services. Data was also collected on the how clients accessed the Alzheimer Society: via First Link or self-referrals. Analysis of key outcome variable will explore differences between those individuals who access the Alzheimer Society via First Link and those self-referred.

Data tracking was facilitated with the use of E-Tapestry, a software database originally designed to assist charitable organization to manage fundraising activities, however modified for use by the Alzheimer Chapters to manage referral and service activities (Intake). This electronic information system was developed and implemented after First Link started accepting referrals. This information was collected in order to describe the referral source, population served (age, gender, diagnosis) and the services provided (information, education, support, number of contacts). A list of the data tracked using E-Tapestry is presented in Appendix G.

2.4.2 First Link Information and Awareness Raising Activities Tracking

All of the First Link Coordinators prospectively maintained records of all of the: information, education (activities such as the learning series aimed at providing information on early diagnosis, disease management, and available community resources) and awareness raising activities (those activities aimed at raising awareness of First Link, such as the purpose, objectives, services offered, and referral process); volunteer activities (those activities conducted by Alzheimer Society volunteers such as assembling information packages, mailing out information, preparing mail outs for learning series); and community consultations (activities within the community such as involvement with the Dementia Network). For each of these activities, the number of direct hours (logged in 15 minute increments) involved in the activity and number of clients served were tracked. This information was tracked during the entire duration of the demonstration project by the First Link Coordinators. A list of the information that they tracked is presented in Appendix H.

2.4.3 Caregiver Surveys

Caregiver Baseline Survey: Eligible caregivers referred to the Alzheimer Society (via First Link or self-referral) were invited to complete a baseline questionnaire. The questionnaire assessed: care receiver's (the individual with dementia) health status (number and type of comorbidities and overall health ratings); caregiver knowledge of ADRD; primary sources of information about ADRD; familiarity with community resources and caregiver coping using the Coping Effectiveness Scale [a 7-item scale developed for family caregivers of individuals with dementia (Gottlieb & Rooney, 2004) with an internal reliability of 0.69. A total score is obtained by summing the items (after reverse scoring the items reflecting coping ineffectiveness). Higher scores reflect greater coping effectiveness]. Initially, caregiving burden was assessed using the Caregiver Burden Inventory [a 24-item scale developed for caregivers of individuals with dementia (Novak & Guest, 1989). It consists of 5 subscales (time dependence, developmental burden, physical burden, social burden, emotional burden), all of which have demonstrated sufficient internal consistency (α ranging from 0.69-0.86 across the subscales). Higher scores reflect greater caregiving burden]. However due to complaints of the burdensome nature (length) of the Caregiver Burden Inventory and perceptions that this was contributing to the low response rate for the caregiver survey, it was removed from the survey in March 2008. The final survey used in the evaluation is presented in Appendix I.

Follow-up Caregiver Survey*:* Follow-up surveys assessed changes since time of first contact with the Alzheimer Society regarding: the care receiver's health status (new comorbidities, rating of overall health); caregiver's current knowledge of ADRD, familiarity with community resources, confidence with the caregiver role and ability to manage the caregiving role in comparison to when their care receiver was first diagnosed. The follow-up surveys also assessed: caregiver coping (the Coping Effectiveness Scale), access to written material about ADRD, access to information about resources or services, access to information about education or information sessions about ADRD provided by First Link as well as perceived helpfulness of these materials/resources; attendance at education sessions; and overall ratings of satisfaction with the assistance provided by First Link (See Appendix J). Originally, the follow-up survey contained a measure of caregiver burden (the Caregiver Burden Inventory), however this was removed from the survey in March 2008 in attempts to reduce the length of the survey and increase the response rate.

These surveys were reviewed by the First Link Coordinators to ensure content validity and were pilot tested by caregivers of persons with ADRD; revisions were made to the surveys based on the feedback received. The surveys were also available in French.

Procedure: To be eligible to participate in this component of the study, caregivers must have met the following inclusion criteria: a) must be a primary caregiver of someone with ADRD or someone who has not been diagnosed with ADRD but who may be experiencing memory or other symptoms, and (b) must be registered as an Alzheimer Society client. Caregivers were excluded from the study if they were unable to read or write in English or French. When caregivers first registered with the Alzheimer Society they were asked if they were interested in receiving a package of written information about ADRD and available community resources. For this evaluation study, they were also asked if they would be interested in receiving information about a research study being conducted to evaluate the First Link program (these requests were left to the discretion of the First Link Coordinator, as it was felt that in some cases it was not appropriate to make such a request, such as when a client was distressed). Those who agreed to receive information about the study were sent a package that included a letter explaining the study and inviting them to participate, a survey, and contact information sheet (see Appendix I). Participation in this study required the completion of an initial baseline survey and then follow-up surveys every six months for the duration of the two-year demonstration phase to identify changes in the measures over time. Participants could complete a minimum of two surveys to a maximum of four follow-up surveys, depending on when the caregiver was first registered with the Alzheimer Society and when the first survey was completed. Survey distribution began in September 2007 and was terminated in October 2009.

Sample Size Estimate: The sample size for the caregiver survey was estimated based on the numbers required to detect a difference in the change in Coping Effectiveness Scale (Gottlieb & Rooney, 2004) score between caregivers referred via First Link compared to those who self-referred. Using data published by Gottlieb and Rooney (2004) on a similar population, we used 3.4 points as an estimate of SD. Following the approach of Jaeschke and colleagues (1989) for estimating minimal clinically important difference using Likert scales, we determined that 2.5 points was a minimal clinically important difference on the 7 item Coping Effectiveness Scale. With $\alpha = 0.05$ (two-tailed) and $\beta = .20$ (80% power), and using the sample size formula for difference in means in two independent groups (Taylor, 1983), the calculation is as follows.

$N = 2[(Z_\alpha + Z_\beta)\ \sigma/\Delta)]^2$
$N = 2[(1.96 + 0.84)\ 3.4/2.5]^2$
$N = 2[3.81] = 30$ caregivers per comparison group.

Although the sample size recruited was sufficiently powered to make some comparisons between groups, subgroup analysis (e.g., comparisons between follow-up survey times, or between sites) were not always possible because of the low sample size (in some cases analyses were nonetheless conducted in order to understand existing trends in the data).

2.4.4 Survey of Health Professionals

Health professionals who referred their patients and/or their caregivers to the Alzheimer Society were invited to complete a survey to assess their perceptions of current knowledge of ADRD, practice related to screening, assessment and diagnosis, role of the Alzheimer Society, and availability of other community resources in comparison to prior to their involvement with First Link. (See Appendix K)

Although there is a potential for response-bias associated with self-reported measures, the decision was made to use a single survey design in order to reduce the potential burden to participants of other methodologies (e.g., pre-post survey design). Similarly, while formal knowledge testing may be a preferred method of assessing changes to knowledge about ADRD, this type of testing would have been unacceptable to physicians in this context. Self-reported indicators of improvement or change provide at least subjective indicators of the potential impacts of First Link.

Procedure: At the end of the two-year demonstration project, all primary care providers, physicians, specialists, allied health professionals from specialized geriatric and mental health services, and community service providers who referred clients to First Link, either directly by making the referral directly to First Link or by suggesting to their patients or caregivers that they contact the Alzheimer Society (without making a referral for them to First Link), during the demonstration phase were invited to participate in the evaluation of First Link by completing a survey. These individuals were identified by the E-Tapestry database. When an email address was available, health professionals were invited via email to complete an online survey; they were provided a link to the survey, which was posted on Survey Monkey (www.surveymonkey.com). When an email address was not available, health professionals were sent a letter of information and a survey via postal service. A self addressed stamped envelope was provided for returning the completed survey. Responses were anonymous; the identity of respondents was not tracked nor were they asked to identify themselves. Consistent with recommendations for electronic survey distribution (e.g., Shannon, Johnson, Searcy, & Lott, 2002), participants were provided a two-week period in which to complete the survey and received e-mail reminders to complete the survey a week after the distribution of invitation. Those who received the survey via postal service were sent, a week after the distribution of the survey, a postcard reminder to complete the survey. Ninety-two invitations to complete the survey on-line were distributed; 93 individuals received a paper-based survey delivered via postal service. Due to an initially low response rate the deadline date for survey completion was extended by an additional two weeks.

2.4.5 Interviews with Key Stakeholders

Primary care providers, physicians, specialists, allied health professionals from specialized geriatric and mental health services, and community service providers who referred to the Alzheimer Society were identified by the E-Tapestry database. A purposeful sample of these individuals ensuring representation across disciplines, services, areas/locations) were invited to participate in 30 minute individual telephone interviews. Similarly, a purposeful sample of Alzheimer Society representatives was selected from each demonstration site to participate in individual telephone interviews. All of these individuals were sent a letter of information via email inviting them to participate in an interview. A structured interview guide (presented in Appendix L) was used to conduct the interviews to assess participants' perceptions of linkages and collaborative relationships with First Link and the Alzheimer Society, including information flow, referral trends/patterns, access, communication and information sharing, potential impacts, and suggestions for improvement. It was anticipated that 42 health professionals (7 per site), and 2 Alzheimer Society representatives per site would participate in these key stakeholder interviews.

2.4.6 Interviews with Project Leaders and First Link Coordinators

First Link Coordinators were invited to participate in an individual interview held in person within their First Link site or by telephone as relevant. Project Leaders were invited to participate in a group interview conducted via teleconference. A structured interview guide (presented in Appendix M) was used to conduct these interviews to describe the development and implementation of the First Link demonstration project in terms of: identification of factors that facilitated development and implementation, challenges, lessons learned, suggestions for improvement, generalizability to other regions, and sustainability.

2.4.7 Interviews with First Link Clients (Caregivers) and Persons with Dementia

Ten Alzheimer Society clients per demonstration site were randomly selected to receive an invitation to participate in a group interview with other Alzheimer Society clients (caregiver/ individuals with dementia dyads). Although it was expected that four caregiver/ persons with dementia dyads would attend the interview, ten were invited with the expectation of a 40% response rate. A systematic sampling procedure was used to calculate the sampling interval with which clients were randomly selected. The formula for calculating the sampling interval was: the number of clients registered within the demonstration site divided by the number of clients being invited to participate in this study (10). As an example, 200 registered clients divided by 10 = a sampling interval of 20, so that every 20th name on the registration list is selected. The First Link Coordinators completed this sampling procedure and ensured to the best of their knowledge that the person with dementia was not deceased. Those selected received a letter via postal service inviting them to participate in this study. Those not interested in receiving a follow-up call from an evaluation consultant were asked to call the First Link Coordinator to remove their name from the study list.

Unfortunately, attempts to obtain a random sample were not possible as many of the persons with dementia selected to participated were in the later stages of the disease and unable to attend the interview. In some cases, caregivers reported that although they would be willing to attend the interview, their care receiver was not but citing issues related to denial and stigma. First Link Coordinators assisted the evaluators to obtain as random a sample as possible however attempts to recruit a sample of individuals in which the person with dementia was in an earlier stage of the disease process proved to be challenging as clients were difficult to contact and declined participation for a variety of reasons (competing priorities for time, lack of transportation, illnesses). Moreover, completion of the interviews in a focus group format was challenged by adverse weather conditions; interviews in four locations were cancelled due to snow storms. These interviews were rescheduled as individual telephone interviews, which limited the participation of persons with dementia as these are not optimal methods of communication with this patient population. Not all of the individuals who agreed to a focus group interview could be contacted for a telephone interview.

A structured interview guide (presented in Appendix N) was used to conduct interviews with caregivers and persons with dementia to determine the ways in which First Link has been helpful and to identify suggestions for improvements.

2.5 Data Analysis

Quantitative data (referrals, client characteristics & survey data) were analyzed using SPSS 15.0. (Chicago, IL: SPSS Inc, 2007). Descriptive statistics (frequencies, means, standard deviations) were generated for all numerical data. Chi-square, t-tests, and analysis of variance (as appropriate) were conducted to determine differences in measures between demonstration sites, referral status (self-referrals vs. those referred via First Link). Evaluation of pairwise comparisons among means were conducted with Tukey's Honestly Significant Difference (HSD), a widely used post-hoc procedure for testing differences among means. Interviews and focus groups were digitally recorded and transcribed. An inductive analysis of the data was conducted to identify recurring themes in the data without prior assumptions (Patton, 1990).

2.6 Ethics Approval

This study was approved by the McMaster University Research Ethics Board.

3.0 RESULTS

The following is a summary of the highlights and main themes that have emerged from the evaluation regarding Alzheimer Society referrals, First Link activities, caregiver and health professional surveys and interviews with health professionals, Alzheimer Society representatives, caregiver and patients, First Link Coordinators, and Project Leaders. Detailed summaries of the referral and service data as well as information and awareness raising activities tracking are located in Appendices O and P. Responses to each question in the baseline and follow-up caregiver surveys and the health professional survey are located in Appendices Q and R, respectively. Note: all appendices are presented in a separate document available on the Alzheimer Society of Ontario website (www.alzheimerontario.org).

Generally, there were few significant differences between the demonstrations sites in the variables analyzed for the evaluation; consequently, results are presented as totals across all sites. (Significant differences between sites are reported where relevant and detailed results by site are presented in the appendices.)

3.1 Referrals and Activities

3.1.1 Referrals to the Alzheimer Society

From November 1, 2007 to June 30, 2009, 3562 individuals were registered as Alzheimer Society clients across all four demonstration sites as recorded in E-Tapestry (See Table 1). The Ottawa site had the highest percentage of registered clients (45%). Registration across the remaining sites was generally evenly distributed (17% - 20%). Within each demonstration site there was variation in the number of clients registered with the Alzheimer Society Chapters represented in the site. In the Ottawa and Sudbury/Timmins demonstration sites, over 90% of clients were registered with the Ottawa and Sudbury Chapters of the Alzheimer Society. Similarly in the Kingston and Grey Bruce/ Huron/ Perth sites, the majority of clients are registered with the Kingston and Grey Bruce Chapters of the Alzheimer Society.

Table 1: Number of Clients Registered with the Alzheimer Society Across Each Site (N = 3562)

Demonstration Site: Chapter	**Percentage (#)**
Ottawa:	**45.2% (1611)**
Ottawa:	91.2% (1470)
Renfrew:	8.8% (141)
Kingston:	**17.8% (634)**
Kingston:	51.3% (325)
Belleville:	33.9% (215)
Leeds-Grenville:	14.8% (94)
Grey Bruce/ Huron/ Perth	**16.9% (602)**
Grey Bruce:	57.1% (344)
Huron:	16.6% (100)
Perth:	26.2% (158)
Sudbury/ Timmins	**20.1% (715)**
Sudbury:	90.2% (645)
Timmins:	9.8% (70)
Total Number of Clients	3562

Figure 1 presents the number of monthly referrals to the Alzheimer Society during the demonstration phase by referral status (self-referrals vs. referrals via First Link) as recorded in E-Tapestry. The mean number of clients who were referred on a monthly basis via First Link, was significantly higher than the mean number of clients who were self-referred, $F(1,38) = 85.9$, $p<.001$. For those who were self-referred, the number of monthly referrals ranged from 35 (February 2008) to 91 (January 2008), with the average being 61 (SD = 16). For those who were referred via First Link, the number of monthly referrals ranged from 71 (February 2008) to 154 (April 2008), with the average being 114 (SD = 20). In the last six months of the demonstration phase of the project, self-referrals remained relatively consistent (67 - 82 referrals per month), though they dropped to 45 in June 2009. Referrals via First Link also remained relatively consistent in the last six months of the demonstration phase, with referrals ranging from 98 - 122 per month.

Figure 1: Monthly Referrals to the Alzheimer Society by Referral Status

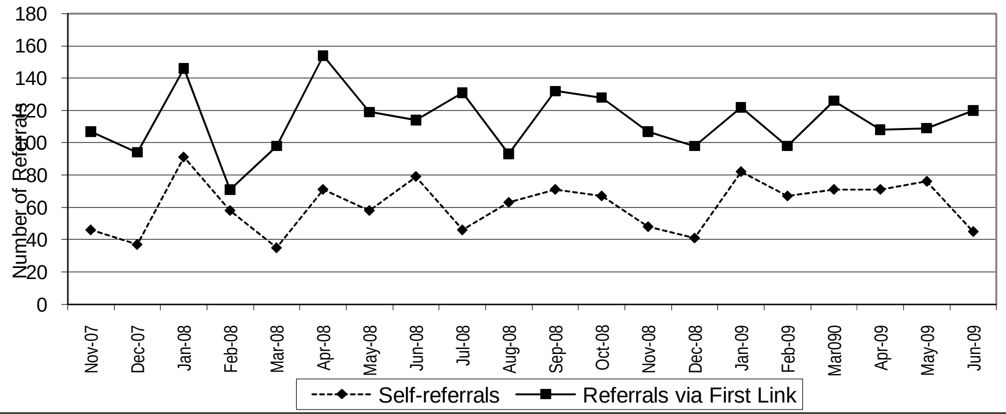


Table 2 presents the number of individuals who self-referred to the Alzheimer Society and those referred via First Link, as well as the distribution of referral status across the demonstration sites, as recorded in E-Tapestry. Overall, a significantly higher number of individuals were referred to the Alzheimer Society via First Link (65%) than those who were self-referred (35%), χ^2 (1) = 303.7, p = .001. However, a greater percentage of clients from the Grey Bruce/ Huron/ Perth site were self-referred in omparison to the other sites, $\chi^2(3) = 503.9$, p<.001. It has been suggested that because of the large geographical area, the coordinator was challenged to promote First Link within the health system, thus resulting in fewer direct referrals from health professionals.

Table 2: Distribution of Referral Status across Demonstration Sites

	Percentage (#)	
Demonstration Site	**Self-Referred**	**Referred Via First Link**
Across all sites	35.4% (1261)	64.6% (2301)
Ottawa (N = 1611)	26.0% (419)	74.0% (1192)
Kingston (N = 634)	34.4% (218)	65.5% (416)
Grey Bruce/ Huron/ Perth (N = 602)	74.6% (449)	25.4% (153)
Sudbury/ Timmins (N = 715)	24.5% (175)	75.5% (540)

Table 3 presents demographic information across all clients and across those self-referred to the Alzheimer Society and those referred via First Link, as recorded in E-Tapestry. There were no statistically significant differences in demographic information according to referral status. The majority (69%) of clients were women. The average age of clients was 65 years, though they ranged in age from 23 to 96 years. Although some clients (6%) were the person with dementia themselves, the majority (88%) were either family members or friends of the person with dementia, the majority of these individuals being a child or spouse of the person with dementia. For the majority of clients, English was their first language. A small percentage (1%) of clients represented more than one person with dementia.

Table 3: Clients: Demographic Information (Across All Clients, Self-Referrals and Referrals via First Link)

Demographic Information	**All Clients (N = 3562) % (#)**	**Self-Referrals (N = 1261) % (#)**	**Referrals via First Link (N = 2301) % (#)**
Gender:			
Female	68.6% (2443)	73.2% (923)	66.1% (1520)
Male	25.4% (906)	23.7% (299)	26.4% (607)
Age (years):			
Mean (SD)	65.2 (14.1)	63.9 (14.2)	65.8 (14.0)
Range	23-96	27-96	23-92
Number	1214	384	830
Relationship with Person with Dementia:			
Self	5.8% (207)	5.9% (75)	5.7% (132)
Child	45.7% (1628)	46.9% (592)	45.0% (1036)
Spouse	31.0% (1104)	32.0% (404)	30.4% (700)
Relative	6.8% (241)	5.9% (74)	7.3% (167)
Sibling	2.4% (85)	2.9% (31)	2.1% (48)
Friend	2.6% (93)	2.5% (32)	2.7% 961)
First Language of Client:			
French:	5.1% (180)	4.3% (54)	5.5% (126)
Registered with a Second Person with Dementia:	1.2% (42)	1.2% (15)	1.2% *27)

Note: Percentages may not sum to 100% due to missing information.

Table 4 presents demographic information on persons with dementia, across all clients and across those self-referred to the Alzheimer Society and those referred via First Link, as recorded in E-Tapestry. The majority of persons with dementia were female (52%). They ranged in age from 45 – 101 years, with an average age of 81 years. Although a large percentage of clients represented individuals diagnosed with Alzheimer Disease (39%) or with a related dementia (33%), some were without diagnosis (14%) or were still under investigation (4%; See Table 4). A small percentage of persons with dementia (7%) were identified as having other health conditions, on average at least one other health condition per person, but overall ranging from 1 to 6 other diagnoses per person. (These other diagnoses were varied and are presented in Appendix O.) The majority of persons with dementia (55%) were identified as having a family physician. This was the only characteristic of the persons with dementia for which there was a statistically significant difference according to referral status: a greater percentage of those referred via First Link had a family physician (60%) than those who were self-referred (47%), χ^2 (1) = 53.6, p = .001. Living arrangement information was provided for 387 persons with dementia, the majority of whom (N =380) were identified as living alone. English was not a second language for 8% of persons with dementia. French was the first language of 75% of those for whom English was not their first language (See Appendix O).

Table 4: Clients: Demographic Information on Their Persons with Dementia (Across All Clients, Self-Referrals and Referrals via First Link)

Demographic Information	**All Clients (N = 3562) % (#)**	**Self-Referrals (N = 1261) % (#)**	**Referrals via First Link (N = 2301) % (#)**
Gender:			
Female	52.4% (1866)	52.1% (657)	52.5% (1209)
Male	35.9 (1280)	36.3% (458)	35.7% (822)
Age (years):			
Mean (SD)	80.5 (8.1)	80.4 (7.8)	80.6 (8.2)
Range	45-101	49-100	45.101
Number	1759	625	1134
Diagnosis			
Alzheimer Disease	39.1% (1392)	45.2% (570)	35.7% (822)
Dementia	18.9% (674)	15.8% (199)	20.6% (475)
Mixed Dementia*	7.4% (265)	4.9% (62)	8.8% (203)
Fronto-Temporal Dementia	.9% (31)	1.0% (13)	.8% (18)
Lewy Body	1.0 (36)	1.2% (15)	.9% (21)
MCI	.6% (21)	.3% (4)	.7% (17)
Parkinsons’	.3% (9)	.3% (4)	.2% (5)
Picks	.2% (8)	.2% (3)	.2% (5)

Demographic Information	**All Clients (N = 3562) % (#)**	**Self-Referrals (N = 1261) % (#)**	**Referrals via First Link (N = 2301) % (#)**
Vascular	3.7% (132)	3.5% (44)	3.8% (88)
Under Investigation	3.6% (128)	3.5% (44)	3.8% (88)
Without diagnosis	14.2% (507)	3.5% (44)	3.8% (88)
Other Diagnoses: Total number of individuals with other diagnoses (other than ADRD)	6.8% (245)	5.9% (75)	7.4% (170)
Average number of other diagnoses per person: Mean (SD) Range	1.4 (.85) 1 - 6	.99 (.72) 1 - 6	1.2 (.85) 1 - 6
Has a Family Physician:	55.1% (1963)	46.9% (59)	59.6% (1372)
Living Arrangement: Alone	10.7% (380)	9.8% (124)	11.1% (256)
Institution	.1% (5)	.2% (3)	.1% (20)
With Care partner	.3% (12)	.6% (7)	.2% (5)
First Language not English:	8.2% (291)	7.5% (95)	8.5% (196)

Note: Percentages may not sum to 100% due to missing information.
*Mixed Dementia: More than one type of dementia noted in the diagnosis

Table 5 presents the sources of information about First Link for those who self-referred, and the referral sources for those who were referred via First Link, as reported in E-Tapestry. A significantly higher number of clients were referred to the Alzheimer Society via First Link (65%) than those who were self-referred (35%), $\chi^2(1) = 303.7$, p=001. Generally the proportion of the clients who were self-referred was consistent across the demonstration sites (ranging from 14% - 22%), with the exception of Grey Bruce/ Huron/ Perth, in which a significantly higher percentage of clients (75%) were self-referred, $\chi^2(3) = 503.9$, p=001 (See Appendix O).

The Alzheimer Society, public awareness/ community groups, and friends and family were the most frequently identified sources of information about the Alzheimer Society as reported by those were self-referred to First Link. Although there were no significant differences across the demonstration sites in the percentage of self-referred clients who heard about the Alzheimer Society from their family physician, more clients in Grey Bruce/ Huron/ Perth (60%) heard about the services and supports available at the Alzheimer Society from Alzheimer Society staff than those in the other sites. The highest percentages of self-referred clients who learned about the services and supports of the Alzheimer Society from friends/ family, public awareness/

community groups, media, and specialists, were from the Ottawa site (41%, 54% , 43%, and 61%, respectively; See Appendix O).

Specialists, family physicians, and the CCAC were the most frequently identified referral sources for individuals referred via First Link. Very few referrals (less than 1%) came from Nurse Practitioners, Day Away Programs, and Senior Centres. More clients in Ottawa (76%) were referred by Specialists than those in other sites (0.8% - 22%); more clients in Kingston (37%) were referred via First Link by community services (37%) than those in other sites (11% - 31%), and more clients in Sudbury/ Timmins were referred by the CCAC (40%) and family physicians (49%), than other in other sites (10% -29%, 13-28%, respectively; See Appendix O).

Across all clients (N=3562), very few (less than 5%) of the referral sources were identified as being members of a Community Health Centre (.7%; N = 25) or Family Health Team (4.7%; N = 169), though it is not clear whether this information was consistently supplied or recorded. This finding is consistent for those self-referred and those referred to the Alzheimer Society via First Link (See Table 5).

Table 5: Source of Information about First Link (Across all Sites; N= 3562)

Demographic Information	**Percentage (Number)**
Self-Referrals (N = 1261) ***Source of Information about First Link:*** Alzheimer Society	35.4% (446)
Public Awareness/ Community Groups	20.5% (258)
Friends/ Family	15.6% (197)
Media	14.4% (181)
Family Physician	7.8% (98)
Specialist	5.3% (67)
Education Session	4.9% (62)
Source of information identified as member of a CHC or FHT (N = 16) Community Health Centre Member Family Health Team Member	.23% (2) 1.1% (14)
Referrals via First Link (N=2301) ***Referral Sources:***	
Specialist	34.0% (783)
Family Physicians CCAC	16.2% (373) 13.0% (299)
Community Services	4.6% (105)
Day Away Programs	.5% (12)
Senior Centres	.4% (10)
Nurse Practitioner	.09% (2)

Demographic Information	**Percentage (Number)**
Referral Source identified as member of a CHC or FHT (N = 177)	
Community Health Centre Member	1.0% (22)
Family Health Team Member	6.7% (155)

Note: Percentages may not sum to 100% due to missing information.

As presented in Appendix O, there were no differences in demographic information (gender, relationship to the person with dementia, first language of the client, first language of the person with dementia) and other characteristics (e.g., diagnosis, living arrangements, and registration with a second person with dementia) between those self-referred and those referred via First Link. However, a greater percentage of the persons with dementia of clients who were referred via First Link (60%) had a family physician than those who were self-referred (47%), χ^2 (1) = 53.6, p<.001.

Time from Diagnosis to Referral: On average, those who were referred to the Alzheimer Society via First Link were referred sooner after the diagnosis of ADRD (Mean = 7.3 months) than those who were self-referred (Mean = 17.8 months), *F*(1, 1965) = 101.5, p=.001 (See Table 6), as reported in E-Tapestry.

Table 6: Average Time from Diagnosis to Referral to First Link

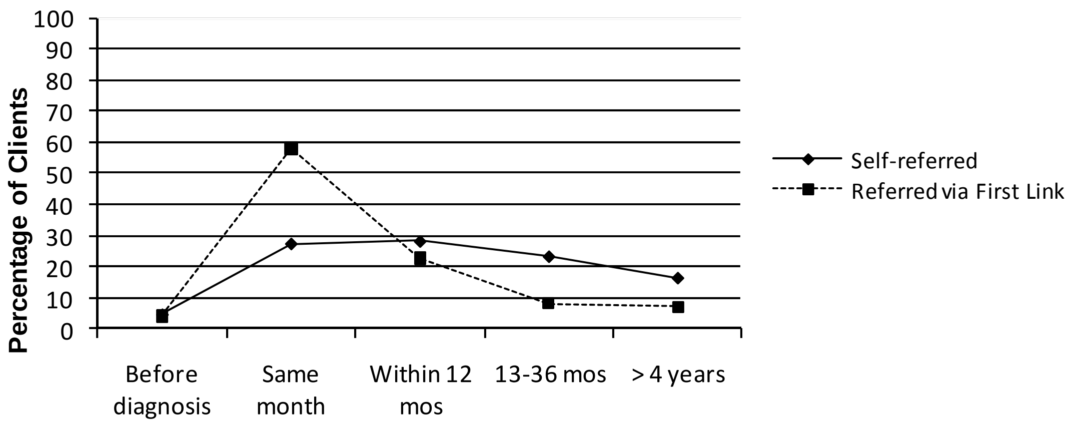
Time from diagnosis to referral	**Self-Referred (N = 627)**	**Referred via First Link (N = 1340)**	***F***	**Total (N = 1967)**
Mean (SD) months	17.76 (26.50)	7.27 (18.74)	*101.5**	10.6 (22.06)
Range (months)	-14* to 148	-14 to 146		-14 to 148

* p<.001

**Negative value refers to the number of months between time of referral and time of diagnosis (i.e., the referral was made prior to diagnosis.

Figure 2 presents the time from diagnosis to referral based on referral status, as reported in E-Tapestry. Although there was no difference in the percentage of clients that were self-referred or referred via First Link to prior to the diagnosis of ADRD (5% and 4%, respectively), a greater percentage of those who were referred via First Link (58%) were referred within the month of diagnosis than those who were self-referred (27.4%), $\chi^2(1) = 201.2$, p<.001). In comparison to those who were self-referred, fewer clients who were referred via First Link were referred later, in the first few years following the diagnosis.

Figure 2: Time from Diagnosis to Referral by Referral Status



Education to First Link Clients: Learning Series Attendance

Overall, 16% (N = 575) of registered Alzheimer Society clients were identified as having attended the learning series (See Table 7), as reported in E-Tapestry. It is likely that this number is an underestimation, as many clients have may attended the Learning Series sometime after they were referred to the Alzheimer Society and this information may not have been up-dated in E-Tapestry. Attendance across sites was evenly distributed. Within each site the overall percentage of registered clients that attended the learning series ranged from 3% - 6% (based on the number of clients per site; See Appendix O). A higher percentage of those who attended the learning series were referred via First Link (60%) than those who were self-referred (41%), $\chi^2(1) = 7.9$, $p<.005$.

Table 7: Learning Series Attendance

Learning Series Attendance	**Attendance Percentage (#)**
Across all First Link Clients (N = 3562)	16.1% (575)
Demonstration Site (N = 575)	
Ottawa	14.0% (226)
Kingston	21.9% (139)
Grey Bruce/ Huron/ Perth	16.3% (98)
Sudbury/ Timmins	15.7% (112)
Referral Status (N=575)	
Self-referred	40.5% (233)
Referred via First Link	59.5% (342)

*Percentage within Referral status.

3.1.2 Information and Awareness Raising Activities

Table 8 presents the awareness raising, education, community consultation, volunteer services, and client contacts made by First Link Coordinators during the duration of the demonstration project. This information was tracked by the First Link Coordinators. Detailed results by demonstration site are located in Appendix P.

Across all of the demonstration sites for the duration of the demonstration project (February 2007 – June 30, 2009), the First Link Coordinators spent almost 1900 hours raising awareness of First Link within their communities, accessing almost 8,400 individuals in the process. Awareness raising activities included visits to family physicians, Family Health Teams, Community Health Centres, Memory Clinics and other specialized diagnostic and treatment services to provide information about the goals and objectives of First Link and services provided, presentations at physician dinners (many conducted in partnership with pharmaceutical company representatives), media presentations (television, radio, newspaper), presentations to local community groups (senior centers, service clubs, academic centers, professional associations, long-term care homes, retirement homes), displays at local malls, and community health and service fairs, conference/ workshop presentations.

In total, 3702 information packages, which included information about First Link, the Alzheimer Society, educational material related to ADRD, and information about available community resources, services, and supports, were mailed to clients. (The number of clients who declined receipt of further information about the study is not known.) In some cases (N = 163) information packages were mailed out without direct (telephone) contact with a First Link Coordinator or Alzheimer Society representative. The First Link Coordinators provided or coordinated 2,700 hours of education with a total of 6,000 people in attendance. Similarly, 1,300 hours were dedicated to community consultation, serving almost 3,700 individuals. In total Alzheimer Society volunteers spent 786 hours supporting First Link activities (e.g., preparing information packages for mail outs, preparation of resource materials, telephone calls), serving 825 clients.

In terms of the number of contacts that First Link had with Alzheimer Society clients (e.g., to share information, invite them to education series, respond to their queries), in total First Link staff had 11,524 client contacts. The majority of these contacts (64%; N = 7,337) were made in Ottawa, with an equal distribution of contacts across the three remaining sites (ranging from 1,068 to 1396 contacts; see Appendix P). For the three sites that provide client and caregiver support[5] (Ottawa, Kingston/ Belleville/ Prince Edward County, and Sudbury/ Timmins), 1,962 hours of support were provided, serving 5,800 individuals (this includes one-to-one support and support groups).

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[5] Note: While First Link provides direct caregiver and client support in some of the sites, those sites that did not have the capacity to do so referred caregivers and clients to other local community resources/ services. The Grey Bruce and Huron chapters were able to provide caregiver and client support in the last three months of the demonstration project.

Table 8: Summary of Public Awareness Raising and Education Activities Across All Demonstration Sites (February 2007 – June 21, 2009)

Activities	**TOTAL**
Awareness Raising Awareness raising activities (# direct hours}	1,887
Awareness raising activities (# served)	8,353
Education Number of Information packages mailed out	3,539
Number of Information packages mailed without contact	163
Learning Series Attendance	2,633
Education (direct hours)	2,730
Education (number served)	6,001
Community Consultation Community Consultation (# direct hours}	1,320
Community Consultation (# served}	3,681
Volunteer Services Volunteers {# direct hours}	786
Volunteers {# served}	825
Client Contacts Number of client contacts	11,524
Client/ Caregiver Support {# direct hours]	1,962
Client/Caregiver Support {# served)	5,799

3.2 Evaluation Response Rates

Table 9 summarizes the response rates for the various evaluation components.

3.2.1 Survey of First Link Caregivers

Of all of the clients registered with the Alzheimer Society during the demonstration project (N = 3562), 836 (23.5%) agreed to receive further information about the study and were sent a survey package and invitation to participate in this component of the evaluation. Across of the sites, the percentage of clients who were sent an invitation ranged from 11% (Ottawa site) to 40% (Grey Bruce/ Huron/ Perth site). In total, 92 of the 836 baseline caregiver surveys distributed were

Table 9: Response Rates Across All of the Evaluation Components

Evaluation Component	Ottawa			Grey Bruce/ Huron/ Perth			Kingston			Sudbury/ Timmins			Total		
	# Dist	# Comp	RR**	# Dist	# Comp	RR**	# Dist	# Comp	RR**	# Dist	# Comp	RR**	# Dist	# Comp	RR**
Caregiver Surveys: Baseline	170 / 1661 (11%)*	24	14.1%	241 /602 (40%)*	25 /634 (26%)	10.4%	162 /634 (26%)*	24	14.8%	263 /715 (37%)*	19	7.2%	836 /3562 (24%)*	92	11.0%
Follow-up #1	24	17	70.8%	25	20	80.0%	24	20	83.3%	19	10	52.6%	92	67	72.8%
Follow-up #2	17	8	47.1%	20	17	85.0%	20	14	70.0%	10	3	30.0%	67	42	62.7%
Follow-up #3	8	3	37.5%	16	6	37.5%	14	8	57.1%	3	2	66.7%	41	19	46.3%
Follow-up #4	n/a	--	--	n/a	--	--	2	2	100%	n/a	--	--	2	2	100%
Health Professional Survey	72	23	31.9%	16	8	50.0%	55	15	27.3%	41	8	19.5%	185	63***	34.1%
Interviews: Health Professional	8	4	50%	6	5	83.3%	9	3	33.3%	12	5	41.7%	35	17	48.6%
AS Representatives	2	2	100%	2	2	100%	3	2	66%	4	4	100%	11	10	90.9%
Caregiver/ PWD Dyads	3 (2 caregivers, 1 PWD)			10 (7 caregivers, 2 PWD, 1 caregiver/PWD**)			4 (3 caregivers, 1 PWD)			4 (4 caregivers)			21 (16 caregivers, 4 PWD, 1 caregiver/PWD‡)		
First Link Coordinators	1			1			2			2			6‡‡		
Project Leaders	n/a			n/a			n/a			n/a			4		

Dist = Distributed (referring to the number of invitations distributed to participate in the evaluation); Comp = Completed; RR = Response Rate; AS = Alzheimer Society; PWD = Persons with dementia

* # of invitations distributed to participate in the evaluation / Total # of clients registered with the AS for that site (% of clients who received an invitation in that site).

**RR = Response Rate: Calculated based on the number of surveys that were completed.

* **Six (9.5%) survey respondents did not identify with which demonstration site they were associated.

‡One caregiver was also a person with dementia.

‡‡Includes current and previously employed First Link Coordinators (in place during the demonstration project).

completed (representing an 11% response rate). Of those that received follow-up surveys, 73% (67) of caregivers completed the first follow-up survey, 63% (42) the second, and 46% (19) the third follow-up survey. Surveys were completed by both of the two caregivers that received a fourth follow-up survey. Although the response rate was low, response rates generated in published studies using mail out surveys with caregivers of persons with dementia (Daire, 2002; Gaugler et al., 2003; McConaghy & Caltabiano, 2005) and with that generated from a major survey of dementia caregivers in Ontario (Smale & Dupuis, 2004) have also been relatively low (less than 30%). It is likely that the timing of the invitation to participate in this study, which occurred at the time of first contact with the Alzheimer Society, was one of high family stress and most likely contributed to the low response rate.

In terms of study completion, 51% (47) of caregivers completed all of the surveys that were distributed to them, 42% (39) of caregivers were considered drop-outs, as they did not return a completed survey (at any point in time during the evaluation, at which point their participation in the study was terminated), 6.5% (6) of caregivers withdrew from the study, either by calling the principal investigator (Dr. McAiney) asking to be withdrawn from the study or because their care-receiver had died, and for one caregiver their final survey was returned as 'undeliverable'.

Table 10 presents demographic information across all of the caregiver survey respondents and for those self-referred to the Alzheimer Society and those referred via First Link; 42% of survey respondents were self-referred, 44% were referred via First Link. The only statistically significant difference according to referral status was demonstration site: more survey respondents from Grey Bruce/ Huron/ Perth were self-referred (44%) than referred via First Link (10%), and more survey respondents from Sudbury/Timmins and Ottawa were referred via First Link (28% and 35%, respectively) than self-referred (13% and 18%, respectively), $\chi^2(3) = 12.67$, $p<.005$.

Survey respondents ranged in age from 37 to 89 years, with a mean age of 63 years (SD = 12). The majority of survey respondents were female (76%) and a large percentage were spouses (44%) or children (39%) of the care receiver. Significantly more of their care receivers had a formal diagnosis of ADRD (41%) than those who have not been diagnosed with ADRD, but have experienced memory loss or other similar symptoms (7%), $\chi^2(1) = 21.4$, $p<.001$. On average, at baseline, care receivers had 3 comorbid conditions (range = 0 – 9 conditions); 11% (N=10) did not identify any comorbid conditions. Half of the care receivers had cerebrovascular disease (e.g., high blood pressure) or experienced a cerebrovascular event (e.g., stroke). Forty-two percent had bone/ joint conditions such as arthritis or osteoporosis and 32% had depression. Fewer than 29% had the other comorbid conditions that are listed in Table 10. An almost equal proportion of survey respondents were self-referred to the Alzheimer Society (44%) as were referred via First Link (42%). All but one survey respondent completed the surveys in English. Survey respondents were equally distributed across the demonstrations (ranging from 21% - 27% per site).

Table 10: Caregiver Survey Respondents: Demographic Information (Across all Respondents and by Referral Status)

Demographic Information	**Total Across All Sites (N = 92)**	**Self-Referred (N = 39)**	**Referred via First Link (N = 40)**
Gender: Male	22.8% (21)	20.5% (8)	25.0% (10)
Female	76.1% (70)	79.5% (31)	75.0% (30)
Age (years): Mean age (SD)	63.2 (12.2)	63.8 (10.9)	63.7 (13.7)
Range	37 – 89	45-83	37-89
Number	92	36	40
Relationship to Person with Dementia Spouse	43.5% (40)	38.5% (15)	60.0% (24)
Child	39.1% (36)	56.4% (22)	32.5% (13)
Sibling	2.2% (2)	0	5.0% (2)
Relative	1.1% (1)	2.6% (1)	0
Friend	1.1% (1)	2.6% (1)	0
Diagnosis Status:* Formal diagnosis of ADRD	41.3% (38)	53.8% (15)	32.5% (13)
Memory loss or similar symptoms	7.6% (7)	5.1% (2)	7.5% (3)
Baseline Comorbid Conditions of the Persons with Dementia: Arthritis/osteoarthritis	42.4% (39)	48.7% (19)	40.0% (16)
Osteoporosis	25.0% (23)	28.2% (11)	25.0% (10)
Cancer	8.7% (8)	19.0% (4)	5.0% (2)
Cardiovascular disease (heart attack, angina)	29.3% (27)	23.1% (9)	27.5% (11)
Diabetes	22.8% (21)	15.4% (6)	27.5% (11)
Cerebrovascular disease/ event (hypertension, stroke)	50.0% (46)	51.3% (20)	42.5% (17)
Depression	31.5% (29)	25.6% (10)	30.0% (12)
Psychiatric disorders (psychosis or personality disorder)	6.5% (6)	5.1% (2)	10.0% (4)
Respiratory disease (COPD, emphysema, asthma)	9.8% (9)	7.8% (3)	10.0% (4)
Problems with drugs or alcohol	2.2% (2)	2.7% (1)	2.5% (1)
Other**	22.8% (21)	25.6% (10)	22.5% (9)

Demographic Information	**Total Across All Sites (N = 92)**	**Self-Referred (N = 39)**	**Referred via First Link (N = 40)**
Baseline mean number of conditions per person (SD)	2.6 (1.9)	2.51 (1.10)	2.64 (1.8)
Range	0*** - 9	0 – 8	0 – 9
Number	92	39	39
Language of Completed survey:			
English	98.9% (91)	100% (39)	% ()
French	1.1% (1)	0	% ()
Site			
Sudbury/ Timmins	20.7% (19)	12.8% (5)	27.5% (11)
Grey Bruce/ Huron/ Perth	27.2% (25)	43.6% (17)	10.0% (4)
Ottawa	26.1% (24)	17.9% (7)	35.0% (14)
Kingston	26.1% (24)	25.6% (10)	27.5% (11)

Note: Percentages do not sum to 100% due to missing values.

*The response rate for diagnosis status is low because the question related to this was added to the survey at a later date (October 2008).

**Other conditions are presented in Appendix Q.

***10 individuals (n = 10.9%) identified no health condition, 7 of whom were self-referred and one who was referred via First Link.

Ratings of Care Receivers' Health Status Over Time: Table 11 presents survey respondents' ratings of the health status of their care receiver over time across all surveys, and for those self-referred to the Alzheimer Society and those referred via First Link; results are relatively consistent according to referral status. At baseline, the mean rating of health status (3.0, SD = 1.0), as rated on a 5-point scale (1 = poor; 5 = excellent), reflected perceptions of their care receivers' health status as "good". At the time of the first follow-up survey, the highest percentage of survey respondents (34%) reported that their care receivers' health had worsened over the previous 6 months. By the time of the second follow-up survey, the highest percentage of survey respondents (36%) reported that their care receivers' health had stayed the same over the previous 6 months, but by the third and fourth follow-up survey, the highest percentage of survey respondents reported that their care receivers health had worsened over the previous 6 months (17% and 100%, respectively).

Table 11: Survey Respondents Ratings* of Their Care Receivers' Health Status Across Survey Times

Referral Status	Second Survey (Follow-Up 1) N = 92			Third Survey (Follow-Up 2) N = 67			Fourth Survey (Follow-Up 3) N = 41			Fifth Survey (Follow-Up 4) N = 2		
	Worse	**Same**	**Better**	**Worse**	**Same**	**Better**	**Worse**	**Same**	**Better**	**Worse**	**Same**	**Better**
All (N = 92)	33.7% (31)	30.4% (28)	7.6% (7)	17.9% (12)	35.8% (24)	7.5% (5)	17.1% (7)	9.8% (9)	7.3% (3)	100% (2)	0	0
Self-Referred (N = 39)	35.9% (14)	30.8% (12)	5.1% (2)	10.3% (4)	35.9% (14)	7.8% (3)	7.8% (3)	15.4% (6)	2.6% (1)	30.8% (2)	0	0
Via First Link (N = 40)	32.5% (13)	30.0% (12)	12.5% (5)	10.0% (4)	22.5% (9)	5.0% (2)	7.5% (3)	7.5% (3)	5.0% (2)	0	0	0

*First Survey: rated on a 5-point scale: 1 = poor; 3 = good; 5 = excellent. Remaining surveys: 5-point rating scale: 1 = much worse now, 2, 3 = about the same, 4, 5 = much better now; Worse = sum of ratings 1 and 2, better = sum of ratings 4 and 5.

3.2.2 Survey of Health Professionals

A total of 63 health professional surveys were completed (34% response rate overall; 27% for paper-based surveys, 41% for the on-line survey). Table 12 presents demographic information for the health professional survey respondents. Across all of the demonstration sites, survey respondents represented a range of disciplines (physicians, specialists, allied health professionals); allied health professionals and physicians (family physicians and specialists) represented a large proportion of respondents (46% and 30%, respectively). A large percentage of survey respondents worked in specialized clinics/ care teams (40%) and primary care settings (33%, N =21), of which 52% (N = 11) were Family Health Teams, 5% (N = 1) were Community Health Centres, and 43% were other primary health settings. There was significant variability in the distribution of survey respondents across the four demonstration sites, $\chi^2(3) = 8.4$, p<.05. The highest percentage of survey respondents were from Ottawa (37%) and the lowest from Grey Bruce/ Huron/ Perth (13%). There was great variability in the percentage of individuals in the participants' practices over the age of 65 years (range = 5 – 100%), with the average being 66%, and in the estimated percentage of individuals in their practice diagnosed with ADRD (range = 0-100%), with the average being 42%. This varied significantly by practice setting. Health Professionals working in specialized clinics and the CCAC had a significantly higher percentage of individuals in their practice that are over 65 years of age (M = 95.10, SD = 11.1; M = 83.00, SD = 10.4, respectively) than those working in primary care settings (FHTs, CHCs, other primary care settings; M = 33.89, SD = 26.0), *F*(1.38) = 46.01, p <.001. Similarly, health professionals working in specialized clinics had a significantly higher percentage of individuals in their practice that have ADRD (M = 67.17, SD = 28.4) than those working in primary care settings (FHTs, CHCs, other primary care settings) and the CCAC (M = 15.72, SD = 26.3; M = 37.00, SD = 32.9, respectively), *F*(1.38) = 15.24, p <.001.

Table 12: Health Professional Survey Respondents: Demographic Information

Demographic Information	Total Across All Sites (N = 63) Percentage (#)
Discipline:	
Family Physician/ General Practitioner	20.6% (13)
Specialist: neurologist, geriatrician, geriatric psychiatrist	9.5% (6)
Allied health professional: Registered Nurse, Nurse Practitioner, Mental Health Counselor	46.0% (29)
Other*	9.5% (6)
Workplace Setting:	
Family Health Team (FHTs)	17.5% (11)
Community Health Centre (CHCs)	1.6% (1)
Primary health care in settings other than FHTs and CHCs	14.3% (9)
Community Care Access Centre (CCAC)	11.1% (7)
Specialized Clinics/ Care Teams (e.g., geriatric medicine, geriatric psychiatry)	39.7% (25)
Other**	6.3% (4)
Location:	
Ottawa	36.5% (23)
Grey Bruce/ Huron/Perth	12.7% (8)
Kingston/ Belleville/ Prince Edward County	23.8% (15)
Sudbury/Timmins	17.5% (11)
Percentage of individuals in practice over 65 years of age (N = 42):	
Mean (SD) Range	65.8% (35.1) 5% - 100%
By Practice Setting:	
Primary Care*** (N = 19): Mean (SD) Range	33.9% (26.0) 5% - 90%
Specialized Clinics (N = 17): Mean (SD) Range	95.1% (11.1) 60 - 100%
CCAC (N = 5): Mean (SD) Range	83.0% (10.4) 70-95%
Percentage of individuals in practice diagnosed with ADRD (N = 42):	
Mean (SD) Range	42.3% (37.3) 0 – 100%

Demographic Information	Total Across All Sites (N = 63) Percentage (#)
By Practice Setting:	
Primary Care*** (N = 18): Mean (SD)	15.7% (26.3)
Range	1% - 85%
Specialized Clinics (N = 18): Mean (SD)	67.2% (28.4)
Range	0 - 99%
CCAC (N = 5): Mean (SD)	37.0% (32.9)
Range	5% - 90%

*Other disciplines: Family Physician with Care of the Elderly training, neuropsychologist, health promoter, LTC Director of Nursing, Geriatric Resource Education Coordinator, Supervisor of Home Support Programs.

**Other workplace settings: Acute care (psychiatry unit, emergency department), LTC home.

***Primary Care = FHTs, CHCs, and other primary care settings.

3.2.3 Interviews with Key Stakeholders

Health Professionals: Interviews were conducted with 17 health professionals: two Physicians, three Nurse Practitioners/ Registered Nurses, two Social Workers, one Psychogeriatric Resource Consultant, seven Geriatric Assessment Resource Team/ Case Managers, one Community Program Manager, and one Education Coordinator. These interviews ranged in length from 10 to 36 minutes (average = 19 minutes).

All but one of the health professionals who were interviewed reported that they are actively referring persons with dementia and family caregivers to First Link. One health professional noted that although it is not her role to refer to First Link she participates in the decision-making regarding referrals as a care recommendation. Although none of those interviewed have been involved in implementing any of the First Link/ Alzheimer Society programs or services (e.g., information or education sessions), one interview participant had been invited to speak at various Alzheimer Society information or education sessions about the services offered by her organization. Almost a third of those interviewed (35%, N = 6) learned about First Link through information/ promotional sessions that were conducted within their workplace; although they may have been previously aware of the Alzheimer Society, this session provided them with more detailed information about the programs and services offered and how they might benefit caregivers and persons with dementia. The remaining interview participants reported that they have had a long-standing knowledge of the Alzheimer Society and the programs offered.

Alzheimer Society Representatives: Interviews were conducted with 10 representatives from the Alzheimer Society Chapters; two interviews per demonstration site. Interviews were conducted with four Public Education Coordinators, three Executive Directors, and three Family Support (Counsellors) and Education Workers. These interviews ranged in length from 10 to 36 minutes (average = 27 minutes).

The Alzheimer Society representatives that were interviewed have been involved with First Link in a variety of capacities, ranging from developing and leading information and education sessions, taking urgent First Link calls when the Coordinator was not available, and referring clients (existing Alzheimer Society clients or those who call the Alzheimer Society for assistance). Although one Executive Director acted as a First Link Coordinator during the demonstration project, the remaining Executive Directors interviewed were involved in overseeing and providing leadership to the First Link programs in their chapters.

3.2.4 Interviews with Project Leaders and First Link Coordinators

Six First Link Coordinators participated in individual interviews, including current coordinators and those employed during the demonstration project. Two coordinators were interviewed in-person and four via telephone. These interviews ranged in length from 16 to 40 minutes (average = 28 minutes).

Five Project Leaders participated in either a group interview (N= 3) or individual interview (N = 2) conducted via teleconference. These interviews ranged in length from 32 to 68 minutes. (average = 47 minutes).

3.2.5 Interviews with Alzheimer Society Clients (Caregivers) and Persons with Dementia

A total of 16 caregivers and four persons with dementia, and one caregiver who was also a person with dementia participated in these interviews; four were conducted as caregiver/ persons with dementia dyads and the remaining as individual interviews. Half of the caregivers (N = 8) reported that they were referred to the Alzheimer Society via First Link, the remaining were self-referred having heard about the Alzheimer Society from neighbours, family members, and friends. Those referred to the Alzheimer Society via First Link were referred by their family physicians and through Alzheimer Society information sessions. These interviews ranged in length from 5 to 65 minutes (average = 21 minutes). Participants represented each of the demonstration sites, with the exception of Timmins for which we were unable to identify individuals interested in participating in the evaluation interviews.

Initially, all of the interviews were to be conducted as group interviews held within the Alzheimer Society chapter (or associated location). In one site (Perth County), those who agreed to participate were unable to attend at the allotted group time, so individual interviews were conducted. In four sites (Ottawa, Sudbury, Grey Bruce, Huron), group interviews were cancelled due to poor weather conditions (snow storms) and were rescheduled as individual telephone interviews. In Kingston, the group interview was conducted as planned.

3.3 Objective I: To Determine the Extent to Which the First Link Program Objectives were Achieved

3.3.1 Nurturing Partnerships

Health Professional's Perceptions of First Link: Interview Results

Use of First Link: Interview participants (N = 17) were asked to provide the criteria they used to make referrals to First Link (types of patients referred, when referred, circumstances/ conditions under which they are referred). It was noted that referrals to First Link were made in the following circumstances: (number in brackets represents the number of interview participants who identified this criteria).

- individuals diagnosed with a new diagnosis of ADRD (16)
- individuals diagnosed with Mild Cognitive Impairment (MCI; 2)
- individuals previously diagnosed and having difficulty coping (2) or needing support or information (2)
- individuals not yet formally diagnosed but who are scheduled for assessment and it is believed that they will likely be diagnosed with ADRD (2)
- individuals who receive a prescription for Aricept (1)
- individuals with memory complaints but no diagnosis of ADRD (1)
- individuals previously diagnosed but not currently registered with First Link or participating in Alzheimer Society programs (1)
- at the time of assessment, regardless of diagnosis as most individuals referred for specialized assessment will have memory difficulties, MCI, or ADRD (1).

In terms of referring practices to First Link, those interviewed reported referral rates ranging from 1 – 20 referrals per month. Generally, all of those interviewed reported that they refer all or almost all ("90 %") of those individuals with a new diagnosis of ADRD at the time of diagnosis, regardless of what stage of the disease process they are in. A referral may not be made in situations where there may be complications that need to be assessed prior to making care/ intervention recommendations, or in some cases of MCI, as noted in the following comment:

> *"The mild cognitive impairments may be, there's a little bit more communication with the family at first because it [referral] may not always be appropriate in that situation."* [KSID#13; Health Professional]

Many of those interviewed who are involved with assessment noted that a referral at the time of diagnosis is important as they often do not have further contact with the patient or family.

> *"We really need to refer as soon as we assess them, because once they leave here we may never see them again and we can't guarantee that somebody else will do it or what will happen with them – they may never go back to their doctor."* [KSID#32; Health Professional]

One individual reported that although he/she will not refer individuals to First Link who have memory concerns but who have not been diagnosed with ADRD, he/she will inform them and/or provide literature about the Alzheimer Society.

Generally, most interview participants noted that caregivers and persons with dementia are receptive about the referral to First Link and although they may be overwhelmed by a new diagnosis, or change in condition (deterioration), they are open to learning about how First Link and the Alzheimer Society may be helpful. Many interview participants reported that their patients have never declined a referral to First Link, though some people may indicate that they are currently coping well and do not need support. It was noted that because of the stigma sometimes attached to Alzheimer disease, some people are initially threatened by or reluctant to accept the referral to First Link, as reflected in the following comments:

> *"Its sometimes difficult because as soon as they hear the word 'Alzheimer Society' you know, and we always have to kind of explain that these are the people that are really the experts on memory and on coping with dementia, usually I offer to make the referral because we've found that you give the number and sometimes people were less likely to use it themselves."* [KSID#13; Health Professional]
>
> *"I think the fact that it's through the Alzheimer Society scares people away, its kind of powerful, so if they are someone that has just a diagnosis with a mild cognitive impairment or early stages of dementia, I find they're less receptive to it, because they say well I'm not, I'm not that bad or I'm not like those people. So the Alzheimer Society name and you try to do the education around that. That tends to be the group that is less than thrilled about it and I find most of the time its children that are more interested in it rather than the spouse or the patient themselves."* [KSID#24; Health Professional]

To overcome potential stigma, many interview participants noted that when discussing referrals to First Link and the Alzheimer Society, they emphasize the potential benefits, while downplaying the emphasis on "Alzheimer", as reflected in the following comment:

> *"There is loaded term with Alzheimer's being there, so I absolutely refer people with all kinds of dementia there, and I'm very clear that although it says the Alzheimer Society you know they help everybody. Sometimes if the patient doesn't have sufficient insight to understand and appreciate their diagnosis, I would be focusing the family on this is as a group that helps people with memory problems."* [KSID#28; Health Professional]

Satisfaction with the Referral Process: All of the interviewed health professionals reported that the referral process to First Link is extremely easy. The referral process was described as *"easy"* ("*piece of cake*"), "*quick*", "*efficient*", and "*seamless*". Health professionals appreciated the readily available referral pads and process of faxing referrals; one participant has recommended this process to another organization that is wishing to streamline their own referral process. Similarly, interview participants reported that sharing information and general communication with the Alzheimer Society is extremely easy.

Many interview participants commented on the importance of health professionals making the referral to First Link, rather than expecting persons with dementia and caregivers to do this, to ensure that contact with the Alzheimer Society is made and services and supports are put into place as early as possible, as reflected in the following comments:

> *"I think that the process is awesome because it used to be I would strongly encourage, I would provide pamphlets, I would at every follow up visit, ask 'have you contacted them yet?' Because people are overwhelmed a lot of the time, they hadn't done so. So now being able to actually send the information to the Alzheimer Society and having them contact people has increased the uptake dramatically and the process with the little prescription pads is about as easy as I could possibly imagine it being made….What the barrier was, and I see this with other equivalent organizations, like the Parkinson's Society, very little uptake when I say I think you should contact them, because people don't seem to want to make that phone call."* [KSID#28; Health Professional]

> *"I think the key to First Link is to reach out to the families, so that's where I think the impact has really been quite significant. Getting to that person earlier and just in fact getting to the person in need because they're much less likely, if given a number to contact on their own, so I think in fact that the First Link contact, the Alzheimer Society contacting them has really made a significant impact."* [KSID#17; Health Professional]

> *"I have always found families to be receptive to the idea of accessing support. What's important about First Link, because I've been working in this field for a long time is how hard it is for patients to initiate anything or for families to initiate when they're already overwhelming the caregiver, and one of the things that, I mean we talked about this years before First Link came in to being how valuable it would be for physicians to say there is help out there and I'm going to have them call you. ….I knew how many people had no hope, no support, and no way to access it because they didn't know about it* [Alzheimer Society]. *So I really do feel very compassionate that it's not enough to tell people, that you need to take that first step, make the phone call."* [KSID#11; Health Professional]

> *"I think it's really critical, and I think not every disease needs to have the service that takes the initiative, but we do with this disease. You wouldn't expect somebody to amputate their leg and be running a marathon. You can't expect somebody with dementia to have the initiative to make a phone call. This is a program that has to start with a phone call from the program to the person. So it just, it makes perfect sense with this disease process, then there won't be the care giver distress and what that does to people."* [KSID#10; Health Professional]

Perceptions of Increased Linkages and Partnerships for Dementia Care: Generally, interviewed key stakeholders (health professionals, Alzheimer Society representatives, project leaders and First Link Coordinators) believed that significant relationship building has occurred between primary care physicians, community service providers and specialized services aimed at assessment and management of ADRD. Although it was noted that linkages with primary care physicians have been difficult to forge and in some areas continues to be a challenge, significant headway has been made in increasing awareness of the services of the Alzheimer Society. In some settings where it has been difficult to access physicians, the First Link Coordinators have been able to develop linkages and relationships with nurse practitioners, registered nurses and other allied professionals who advocate or make recommendations for referrals to First Link.

Alzheimer Society representatives reported that First Link has been instrumental in facilitating referrals from new sources within the community (physicians, geriatric specialists, community support service provider agencies, and geriatric outreach teams and specialized services). Representatives from the Ottawa site, which has had a First Link program since 2002 commented that relationship building with health professionals is critical to the success of First Link and that it takes many years to develop strong relationships, as reflected in the following comment:

> *"First Link has definitely had an impact on awareness in the community, the word is getting out more. I think also the link the First Link coordinator has to meet with the professionals, the health professionals, the medical clinics. You have to get those people first, if they believe in the program it's going to work. Without that, it's very difficult to get more awareness, and support, and just connecting with these centres and so on, it makes a difference. It's a long process, its hard work, it doesn't happen overnight. We started in 2002 and we're in 2009 and it took quite a while to get the professionals to believe and understand the program. It took a lot of effort on our part."* [KSID#4; AS Rep]

It was noted that the development of partnerships with Family Health Teams, Community Health Centers, CCAC, and day programs has been instrumental for the delivery of the learning series, particularly in rural and remote areas. These partnerships have been helpful in facilitating referrals to First Link, assisting clients to better navigate the system of care, and ensuring care is better coordinated among partnering organizations, as reflected in the following comments:

> *"New linkages and partnerships especially with the CCAC I find, and maybe not in all of the communities, but I know that it was definitely a good collaboration because maybe when the person came to the Alzheimer Society in early stage may not have been ready for services from the CCACs,…but I think once the referral was made I think the collaboration between both parties was enhanced as well as the patient being able to access and navigate the system a little bit better was definitely enhanced.*" [ID#6; Project Lead]

> "*Its* [First Link] *just given us more of an opportunity to reach out and connect as well with other partners in our community. We're kind of linking that way and communicating more about the clients we share, so they're not falling through the cracks I would think, as much as they probably used to."* [ID#5; Coordinator]

> *"The whole networking thing….I think First Link has done a great job with the program in terms of that, and just connecting other partners in care as well, the CCAC and long-term care homes."* [KSID#17; Health Professional]

Similarly, in some areas the Alzheimer Society has been embedded into diagnostic and treatment services so that they can make recommendations and provide support directly at the time of diagnosis.

> *"Our staff here at this Chapter are very involved with the geriatric resource team. The team that does assessments for people with memory problems. Our staff don't go out to do the assessments, but they are part of the weekly team meeting where every assessment, the two nursing staff from the CCAC, bring back their report and then a team provides comments and makes recommendations right there at that team meeting."* [KSID#3; AS Rep]

Similarly in areas (e.g., Sudbury/ Timmins) where there are limited diagnostic services, the First Link program arranges for in-home screening and comprehensive assessments conducted by registered nurses. These nurses work collaboratively with family physicians to diagnosis and manage ADRD. In these areas, it was noted that First Link provides a critical service that physicians and health teams to may not have the resources or expertise to implement.

> *"Up here, people have to travel hours to see a specialist and many just won't do it. But they come in and go into the home and do the full assessment. Right there. Done. That's just amazing, because if they didn't do it, it wouldn't get done and people would be lost."* [KSID#17; Health Professional]

Health professionals also commented that they and their organizations have important partnerships with First Link and the Alzheimer Society as reflected in the education and awareness raising sessions being conducted with various groups of health professionals, the inclusion of First Link Coordinators in community planning committees, and the inclusion of health professionals as guest speakers in the learning series as well as the inclusion of First Link coordinators as guest speakers at various community-based meetings as reflected in the following comment:

> *"We have a great partnership with First Link and the Alzheimer Society. Our team is in bed with the Alzheimer Society. We sit on the same committees, participate in their support groups, and help with the education. It's been good all around."* [KSID#32; Health Professional]

Health Professional Satisfaction with First Link: Health Professional Survey Results

Across all demonstration sites, health professionals were very satisfied with the services provided by First Link as reflected in the mean satisfaction rating of 4.5 (SD = .76; as rated on a 5-point scale: 1 = not at all satisfied; 5 = extremely satisfied). Many of the comments made about First Link reflect the collaborative partnership that First Link has with various health professionals and service providers, as illustrated in the following comments:

> *"Staff in both the First Link program and with the Alzheimer Society main office have been great to work with! It is wonderful to find such willing and helpful partners!"*
>
> *"They are a very organized, supportive and collaborative site."*

> *"I had an experience lately which showed me the power of linkages in community agencies. About a year ago, I gave an in-service at a retirement home. As a result of this, the Director of Care contacted our local First Link coordinator to arrange for more education for her staff on supporting families. This month, I learned that client's family had been attending family education sessions at that facility even though their loved one did not live in the facility. As it turned out, they needed to move the person to a facility on an urgent basis and because of their experience at the facility, chose this place, and felt more comfortable because of their previous connections."*
>
> *"Have taught the GPA* [Gentle Persuasive Approaches] *with our PEC* [Public Education Consultant]. *Have completed joint visits with mutual clients. PEC is involved with PIECES* [Putting the PIECES Together education program] *group. First link person has attended my geriatric medicine outreach as well. We have a good working relationship. I attend all the educational opportunities provided by the Alzheimer Society. To outline more here would be extensive."*

3.3.2 Providing Progressive Education

Impact of Education to Health Professionals: Results of the Health Professional Survey

Impact on Knowledge: Over 65% of health professional survey respondents reported having received material on ADRD and available community supports services/ resources (See Table 13). Mean ratings of the usefulness of this material was high (> 4.1 on a 5-point rating scale; 5 = extremely useful).

Table 13: Percentage of Health Professionals that Received Material on ADRD and Available Community Services and Ratings* of the Usefulness of this Material

	Received Information Percentage (#)	Rating* of Usefulness Mean (SD)
Material on ADRD	76.2% (48)	4.1 (.71) Range: 3 – 5
Material on available community support services/ resources	65.1% (41)	4.3 (.76) Range: 1 – 5

* 5-point scale: 1 = not at all useful, 5 = extremely useful

The majority of survey respondents indicated that as a result of First Link their understanding of dementia in general and of identifying seniors with dementia has remained the same (54% and 62% respectively; See Table 14). However, the majority of survey respondents reported that as a result of First Link they now have a better understanding of managing seniors with dementia (57%), the role of the Alzheimer Society (60%), and of available community resources (52%).

Table 14: Health Professionals’ Ratings* of the Impact of First Link on Their Understanding of Dementia and the Alzheimer Society

Level of understanding about…	Understand less**	The same	Understand more**
Dementia in general	0	54.0% (34)	34.9% (22)
Identifying seniors with dementia	0	61.9% (39)	27.0% (17)
Managing seniors with dementia	0	46.0% (29)	57.1% (36)
Role of the Alzheimer Society	0	28.6% (18)	60.3% (38)
Available community resources	0	36.5% (23)	52.4% (33)

Note: Percentages may not sum to 100% due to missing values.
*5 point rating scale: 1 = understand less now; 2; 3 = about the same; 4; 5 = understand more now
** Less now = sum of 1 and 2 ratings: more now = sum of 4 and 5 ratings

Survey respondents were asked to identify one or two things that they learned about ADRD as a result of their involvement with First Link or their local Alzheimer Society chapter; these are summarized in Table 15. Although 7% of survey respondents commented that they have learned nothing new from First Link because they are experts in the field, most respondents indicated that they learned something new from First Link such as: the services, supports, and resource material provided by First Link/ Alzheimer Society, available community services and resources, information on diagnosis/ assessment (e.g., tools, risk factors, types of dementias) and interventions/ strategies, information on challenging behaviors/ care issues and educational opportunities for care providers.

Table 15: Health Professionals’ Learnings from First Link and/ or the Alzheimer Society

Information about services, supports, and resource material provided by First Link/ Alzheimer Society (44.1%, N = 26)

“Availability of group appropriate for client/ families at different stages of the Alzheimer Journey”.

“The availability to have educational sessions for family and support for the person.”

“Have been given a resource package (to give to pts/families) when diagnosis with dementia filled with lots of good resources!! Also like the "heads up for healthier living" pamphlet and give it out +++.”

Information about community services and resources (23.7%; N = 14)

“Community resources for family support.”

“Increased info re: availability of "day away programs"
“The available programs and accommodation options for people with dementia.”

Information on diagnosis/ assessment (tools, risk factors, types of dementia) (10.2%; N = 6)
“Information about different assessments that can be completed.”
“I think the most helpful is being able to explain the difference between A.D., Vascular, Mixed etc. This often reassures the families I work with.”
“More prevalent if client suffering from diabetes, cardiac.”

Information on challenging behaviors/ care issues (6.8%; N = 4)
“Practical info regarding management of behavioral issues in dementia.”
“As a specialist in dementia diagnosis I found I was still able to learn from first Link and the Alzheimer society. Specifically I was able to learn about care issues and community resources.”
“Information on challenging behaviors.”

Information on interventions/ strategies (5.1%; N = 3)
“Communication techniques.”
“Information on medications.”
“New treatments.”

Educational opportunities for care providers (3.4%; N = 2)
“New agency provided trained PSWs, educational opportunities.”
“Upcoming community education days.”

Nothing new learned: Already have expertise in ADRD (6.8%; N = 4)
“Not applicable - specialize in psycho-geriatric assessment.”
“Nothing, but only because I diagnose dementia very frequently as a result of my practice, so I'm "supposed" to be an expert.”
“I am already quite aware about the disease and the community resources available.”

Impact on Assessment and Diagnosis: Average ratings of the impact of First Link on increasing the number of individuals diagnosed with ADRD and health professionals’ ability to identify or recognize dementia sooner/ earlier were low, reflecting that survey respondents thought that First Link had minimal impact on increasing ADRD diagnosis or on early diagnosis (See Table 16).

There were significant differences across the demonstrations sites in ratings of the impact of First Link on early identification of ADRD, *F*(3, 51) = 2.9, $p<.05$. Post hoc tests (Tukey HSD) of demonstration site means revealed health professionals from the Sudbury/ Timmins site had higher mean ratings for their ability to identify ADRD earlier as a result of First Link (M = 3.0, SD = 1.3) than health professionals from the Kingston site (M = 1.8; SD = .89). Similarly, health professionals from the Grey Bruce/ Huron/ Perth site had higher mean ratings for their ability to identify ADRD earlier (M = 2.9, SD = .84) than health professionals from the Kingston site. Although these differences are statistically significant, the mean ratings are nonetheless low.

Table 16: Ratings* of the Impact of First Link on Increasing Health Professionals' Identification of ADRD

	Mean (SD)
Ratings* of the impact on increasing the number of individuals diagnosed with ADRD (N = 53)	2.3 (1.3) Range: 1 –5
Ratings* of impact on health professionals' ability to identify ADRD early (N = 56)	2.4 (1.2) Range: 1 – 5

* 5 point scale: 1 = not at all; 5 = a great deal

Comments made by survey respondents reflected their belief that their capacity to diagnose ADRD had not been impacted by First Link because this is their area of expertise and the main purpose of their work, as illustrated by the following comments:

> *"I work in a specialized setting where patients are referred because of memory complaints, so I already diagnosed a lot of dementia."*
>
> *"It hasn't changed how many I diagnose - it has changed how many end up with contact with the Alzheimer Society."*
>
> *"Not relevant - I felt very comfortable with AD diagnosis without First Link impact given my professional training & experience."*
>
> *"I already screen for dementia, do MMSE, MOCA etc., so I diagnose early. This program for me does not add to diagnosis but helps with patients and their families."*

One survey respondent noted that ADRD continues to remain undiagnosed in some cases:

> *"Our clinic still has undiagnosed patients. Inappropriate screening and risk assessment for the moment."*

Other survey respondents commented that there is an increased awareness of ADRD among the general public, so that people seek assessment earlier and more people are accessing treatments and support services, as illustrated in the following comments:

> *"Likely advertising in the community drives people into clinic for assessments - this would be more difficult to determine - I have had people in lately for assessments that are more aware of dementia because of the increased media last month."*

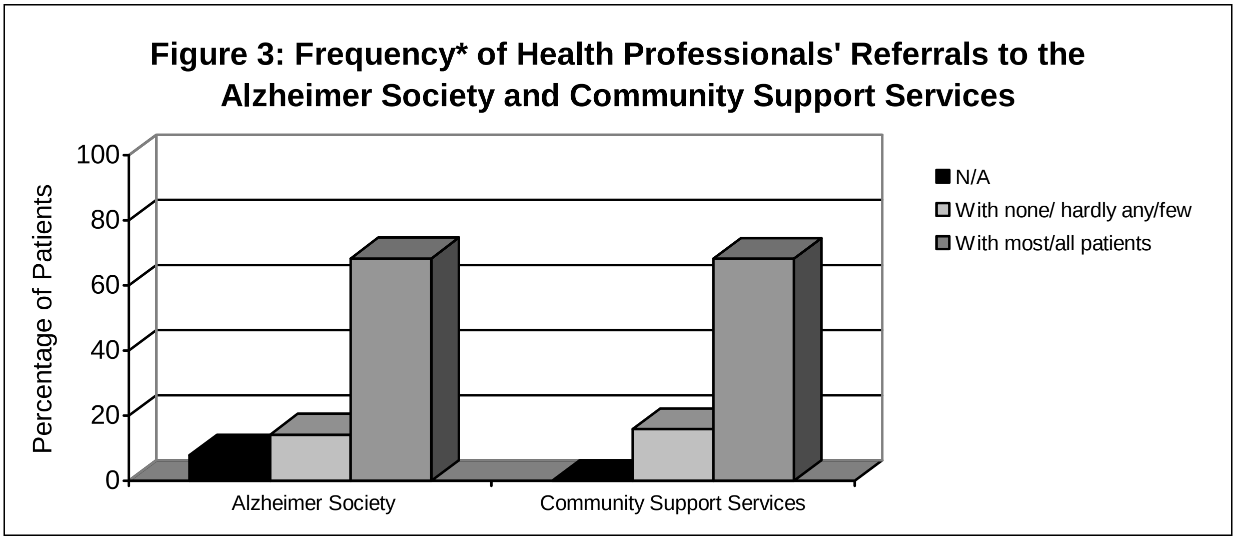
> *"I do not know that it has an impact on increasing the number of patients diagnosed with dementia, but it has increased the number of referrals coming to the Day Program".*
>
> *"Because information about Alzheimer's disease and related dementias are more accessible health professional and family members are more informed about signs and symptoms. More people are referred for treatment or assessment."*

Impact on Familiarity with and Use of the Alzheimer Society and Community Services: Health Professionals were asked to rate how familiar they are with the services and supports provided by the Alzheimer Society (e.g., First Link, support groups, information sessions) and community support services (e.g., respite care, home help, home safety systems) available in their community (5-point scale: 1 = not at all familiar, 5 = extremely familiar). Across all sites, the mean ratings of familiarity with the services of Alzheimer Society and community support services were high (M = 4.0; SD = .93, and M = 4.2; SD = .93, respectively (See Table 17).

Table 17: Health Professionals' Ratings of their Familiarity with the Alzheimer Society and Available Community Services

	Mean (SD)
Familiarity with services and supports provided by Alzheimer Society (N= 57)	4.0 (.93) Range: 1 – 5
Familiarity with available community supports (N = 58)	4.2 (.93) Range: 1 - 5

Figure 3 presents the frequency with which Health Professionals' referred patients to the Alzheimer Society and to community support services. The majority of survey respondents reported that they refer most or all of their patients to the Alzheimer Society (68%) and community support services (68%)



N/A = not my role to refer patients to these types of services.
*With none/ hardly any/ few = sum of "with none or hardly any of my patients" and "with a few of my patients" ratings. With most/ all = sum of "with most of my patients" and "with all of my patients" ratings.

Although the majority of survey respondents (62%) reported that as a result of First Link they are now referring more of their patients to the Alzheimer Society, the majority (56%) reported that their referrals to the community support services have remained the same; 30% reported that they are now referring more patients to community support services as a result of First Link (See Table 18).

Table 18: Ratings* of Changes to Referrals to Alzheimer Society and Community Support Services as a Result of First Link

	Now Referring Less*	**The Same**	**Now Referring More***
Referrals to Alzheimer Society	1.6% (1)	25.4% (16)	61.9% (39)
Referrals to Community Support Services	3.2% (2)	55.5% (35)	30.2% (19)

*5 point rating scale: 1 = less now; 2; 3 = about the same; 4; 5 = more now
** Less now = sum of 1 and 2 ratings: more now = sum of 4 and 5 ratings

Perceptions of Increased Capacity for Assessment and Intervention: Results of the Key Stakeholder Interviews

Although some interview participants thought that First Link has increased physicians' and health professionals' awareness of ADRD as a significant health issue for our aging population, few thought that First Link has had an impact on increased detection of ADRD, some perceiving that the resources for assessment in their area were in place and doing a good job of assessment and diagnosis. The impact of First Link on increased detection was thought to be greatest in areas where the Alzheimer Society provides cognitive testing Sudbury/ Timmins). These areas have few specialist resources so that the provision of in-home screening and assessment by qualified registered nurses was viewed as critical to increasing timely access to diagnosis and reducing the burden on primary care physicians to do this, many of whom may not have the time or experience to do comprehensive assessments.

> *"I know, that some of the physicians weren't doing any of the screening, and I think that some of the chapters by providing that support as benchmarking it definitely assisted and aided in early diagnosis."* [ID#6; Project Lead]

First Link was credited for advocating for early intervention, so that more individuals are now referred for education and support early in the disease process, and more health professionals emphasize the importance of early contact with First Link with their patients. It was noted that the services provided by First Link and the Alzheimer Society, such as education and support for managing psychological and behavioural symptoms, cannot be provided to the same extent by physicians or specialized geriatric services (assessment teams, Memory Clinics) because of limited time, resources and expertise.

> *"I think that the key thing that is most helpful to us* [health professional] *is the education that they provide to families. We couldn't ever provide this amount of education. Once we know that someone has dementia, it's so good to be able to refer them to a service that will educate them about what is happening and can link them to appropriate supports, because we just can't do that the same way. They know it all and do it well."* [KSID#32; Health Professional]

> *"I think it's great because the doctors, there's been a lot of education for the doctors, which is very pivotal because a lot of times the clients listen to their doctors before they listen to anybody else. So if you've got them on board it makes a big difference and we find that the doctors have been educated. They are very aware, so a lot of the clients are being linked up early, and getting that education a lot earlier than they did."* [KSID#21; Health Professional]

Although it was noted that great strides had been made in increasing health professional awareness of the need for early intervention, several Alzheimer Society representatives and First Link Coordinators commented on the need for ongoing education of physicians, as there are still many who fail to recognize the signs and symptoms of dementia, or who attribute symptoms to normal aging, as evidenced by the large number of caregivers who report having raised concerns about memory loss and symptoms many times and long before an assessment was conducted and a diagnosis made.

> *'I've had in the last month I've had two women come to me in tears, both on the point of leaving their marriages…their husbands have had symptoms for several years. One of the husbands has tried to commit suicide twice. One of the wives has been taking money out of the bank and hoarding it thinking she's going to have to separate from him because she's taking the behaviour personally and the physicians are saying 'oh well, it's just old age. They're getting a bit strange you know."* [ID#33; Coordinator]

Similarly, there are some health professionals that believe that cognitive decline is inevitable and thus intervention not necessary as noted in the following experience of a First Link Coordinator after conducting a First Link presentation with a group of health professionals:

> *"We did our presentation and at the end I said, I really wish that when you're seeing patients that you believe are showing signs of cognitive impairment or dementia and you've tested them or made referrals, that you consider a cholinesterase inhibitor for them, I said I've included in your package research that substantiates the benefit of using them, and anecdotally we hear from families what a difference it makes. A physician puts up his hand and he said I just want to remind the residents that everything we do is evidenced based, that dementia is a terminal illness and that I think we should be considering whether society should be paying for medication for people that they might be on for ten years, when what they have is terminal… And that's what you are still encountering nowadays."* [ID#33; Coordinator]

It was noted that in some of the demonstration sites (e.g., Ottawa) there is a good process in place for increasing health professionals' opportunities for ongoing education regarding diagnosis and treatment through, for example, lunch and learns, newsletters. Other sites are in the process of developing these systems and partnerships for continuing education.

Increased awareness of First Link, the Alzheimer Society and other community resources: The majority of interview participants across all of the demonstration sites noted that First Link has had the greatest impact in increasing health professionals' awareness of the Alzheimer Society services/ programs and available community resources and supports and in ensuring that persons diagnosed with ADRD have access to these services as early as possible in the disease process, as reflected in the following comments.

> *"Well I think certainly the awareness to the front line physicians has been very significant as well. So just bringing about that awareness you know, of the services offered in the community and just heightening their awareness around dementia, around the differential diagnosis, around the need for doing proper assessments and connecting people with proper supports."* [KSID#17; Health Professional}

> *"I think that the primary care circle of care, so the primary care practitioners, better understood what the Alzheimer's Societies were able to provide and what the role exactly was, and in terms of what they were able to support, not just in the latter stages of the disease, but also in the early stages of the disease. So if anything, in the beginning maybe it was a learning for them to see, oh there is an Alzheimer Society out there. This is actually what they do, and once they provided screening, early screening to a couple of patients and saw their patients and the continuity of care and the continuum, and providing these physicians with follow up in terms of you know, what the chapter was doing for this person, what they've linked them up with and that, they were more apt to continue that process with other patients as they, you know, introduced themselves and introduced the idea of memory loss."* [KSID#6: Project Lead]

> *"I think that also there's been a much greater awareness with the family physicians to the Alzheimer Society. I really think that every time they send a referral in, I'm thinking hey, they're thinking Alzheimer Society. And they never would have done that before. So I think that that's a really good thing."* [ID#30; Coordinator]
>
> *"I would say that the doctors are realizing that there is a place where they can go. It's hard to say, in some ways because we're not in the doctor's office, and we don't do the diagnosing. But what we've seen is that people are coming to us earlier so the assumption would be that the docs are you know saying there's something here, I want you to go to the Alzheimer Society earlier and people with the disease, because we're seeing couples come, the person with and the caregiver, where before we saw the caregiver. So that's definitely the change."* [KSID#7; AS Rep]

3.3.3 Reaching out to Families

Services Recommended to First Link Clients

As part of the E-Tapestry database, Alzheimer Society staff maintained notes of their discussions with clients, including any services that they may have recommended to clients. These recommendations are presented in Figures 4 and 5. As these were derived from case notes and there is some indication that these were not regularly maintained, these data may represent a small proportion of the recommendations made to clients. There may also be differences in recommendations across sites based on what services are available.

Figure 4 presents the percentage of clients who were recommended services offered by the Alzheimer Society, which ranged from 0.8% (Advanced Care Planning) to 13.4% (caregiver support groups) across all sites. There were some differences across each site in the percentages of clients that were recommended these services; a higher percentage of clients from the Grey Bruce/ Huron/ Perth site were recommended individual support (29.9%) and caregiver support groups (31.6%) than clients in other sites. Similarly, a higher percentage of clients from Sudbury/ Timmins were recommended person with dementia support groups (34.5%) and safely home programs (37.9%) than clients in other sites.

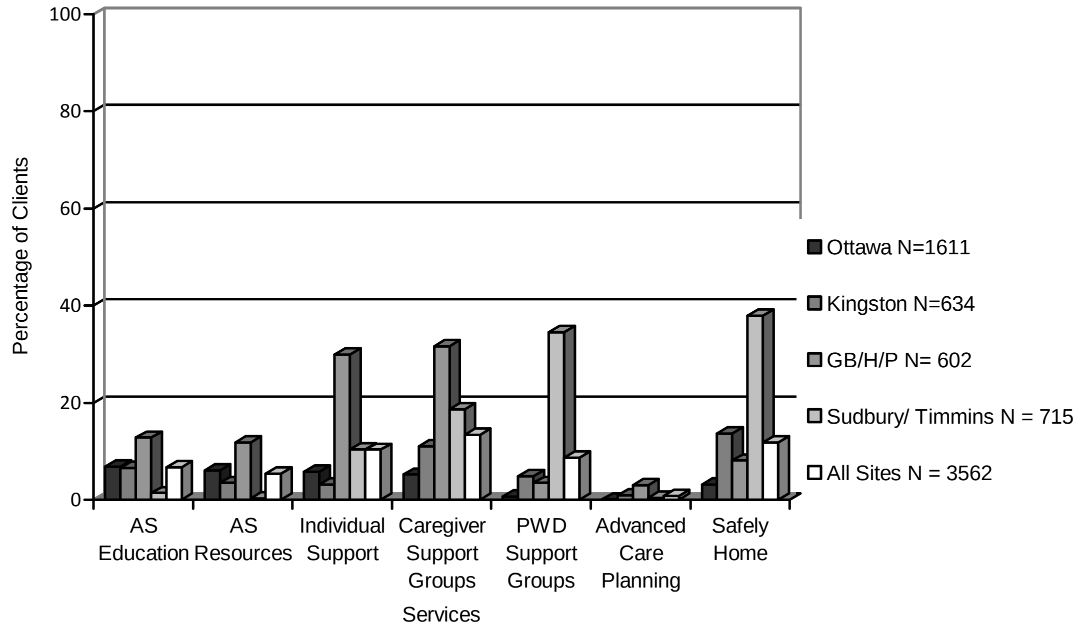
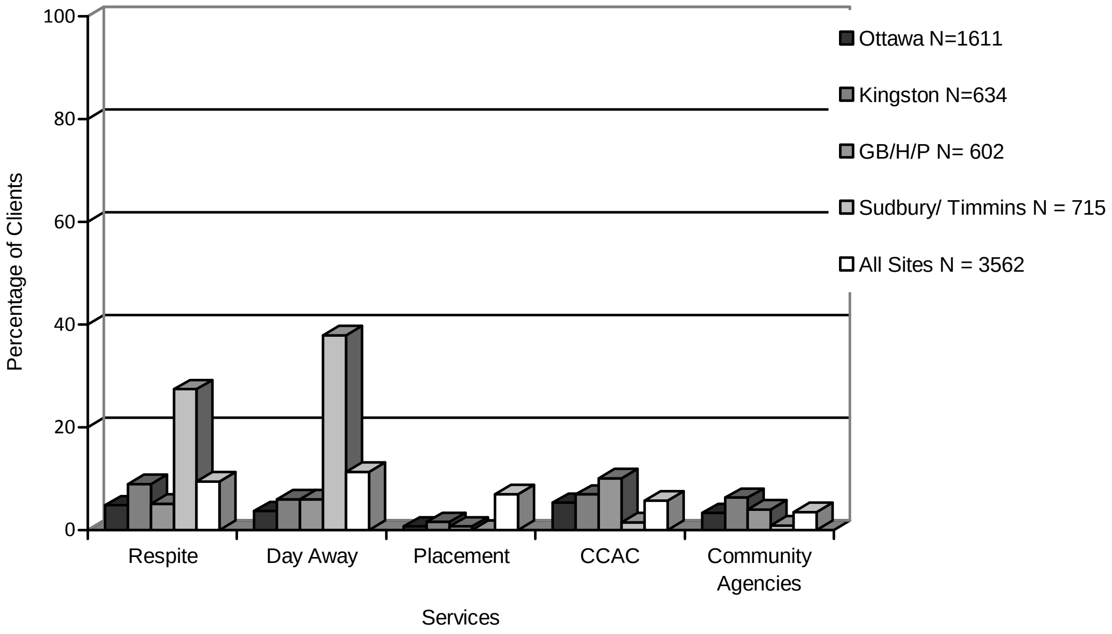


Figure 4: Recommended Services Provided by the Alzheimer Society Across Sites

Figure 5 present the percentage of clients who were recommended community services, which ranged from 3.5% (Community Agencies Programs) to 11.3% (Day Away programs) across all sites. There were some differences across each site in the percentages of clients that were recommended these services; a higher a higher percentage of clients Sudbury/ Timmins were recommended respite (27.4%) and Day Away programs (37.9%) than clients in other sites.

Figure 5: Recommended Services Provided by the Alzheimer Society Across Sites

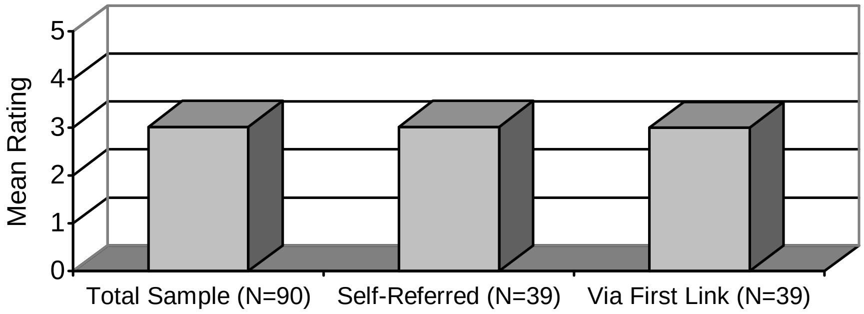


Changes in caregiver competency over time: Results of the Caregiver Survey

Knowledge, confidence, self-efficacy: Using a 5-point rating scale (1 = not all; 5 = extremely), caregiver survey respondents were asked in the first survey (baseline) to rate their knowledge of ADRD, familiarity with community resources, confidence in managing the caregiver role, and self-efficacy (ability to manage) with the caregiver role. In the subsequent follow-up surveys, respondents rated these elements of the caregiver role currently, in comparison to when their care receiver was first diagnosed. Of particular interest are changes in these outcome variables by referral status (self-referred/ referred via First Link); it was expected that changes will be greater in those who are referred to the Alzheimer Society via First Link as they will be referred earlier in the disease in the process.

Figure 6 presents survey respondents' baseline ratings of their knowledge of ADRD for the entire sample of caregiver survey respondents and by referral status. (Note: referral status is known for only 79 of the 92 survey respondents). There were no significant differences in these ratings according to referral status; for both those self-referred to the Alzheimer Society and those referred via First Link mean ratings of knowledge of ADRD were moderate (Mean = 3.01; SD = .97, and Mean = 2.99, SD = 1.0, respectively).

Figure 6: Mean Rating* of Knowledge of ADRD by Referral Status at Baseline



*5-point scale: 1 = not at all, 5 = extremely knowledgeable

Table 19 presents changes in knowledge of ADRD across each survey time for the total sample of survey respondents and by referral status. There were no significant differences in these ratings according to referral status. At each survey time, the highest proportion of survey respondents reported that they were currently more knowledgeable about ADRD in comparison to when their care receiver was first diagnosed.

Table 19: Ratings* of Changes in Knowledge of ADRD Across Surveys and Referral Status

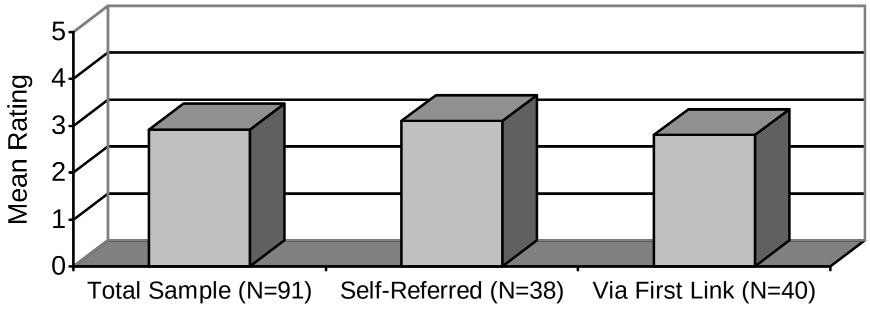
Survey **Referral Status**	**Less knowledgeable Now**	**About the same**	**More knowledgeable now**
Second Survey (Follow-Up 1) Total Sample (N = 92)	0	14.1% (13)	58.7% (54)
Self-Referred (N = 28)	0	10.7% (3)	89.2% (25)
Referred via First Link (N = 30)	0	26.7% (8)	73.3% (22)
Third Survey (Follow-Up 2) Total Sample (N = 67)	0	16.4% (11)	44.8% (30)
Self-Referred (N = 21)	0	23.8% (5)	76.2% (16)
Referred via First Link (N = 15)	0	33.3% (5)	66.7% (10)
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	0	14.6% (6)	29.3% (12)
Self-Referred (N = 10)	0	40.0% (4)	60.0% (6)
Referred via First Link (N = 9)	0	22.2% (2)	55.6% (5)
Fifth Survey (Follow-Up 4)	0	50.0% (1)	50.0% (1)

Survey **Referral Status**	**Less knowledgeable Now**	**About the same**	**More knowledgeable now**
Total Sample (N = 2)			
Self-Referred (N = 2)	0	50.0% (1)	50.0% (1)
Referred via First Link (N = 0)	0	0	0

*First Survey: rated on a 5-point scale: 1 = not at all; 5 = extremely. Remaining surveys: 5-point rating scale: 1 = much less now, 2, 3 = about the same, 4, 5 = much more now; Less = sum of ratings 1 and 2, more = sum of ratings 4 and 5.

Figure 4 presents survey respondents' baseline ratings of their familiarity with community resources for the entire sample of caregiver survey respondents and by referral status. There were no significant differences in these ratings; for both those self-referred to the Alzheimer Society and those referred via First Link mean ratings of familiarity with community resources were moderate (Mean = 3.10; SD = 1.1, and Mean = 2.80, SD = 1.1, respectively).

Figure 4: Mean Rating* of Familiarity with Community Resources by Referral Status at Baseline



*5-point scale: 1 = not at all, 5 = extremely familiar

Table 20 presents changes in familiarity with community resources across each survey time for the total sample of survey respondents and by referral status. There were no significant differences in these ratings according to referral status. At the second survey the majority of survey respondents reported that they were currently more familiar with available community resources in comparison to when their care receiver was first diagnosed, this decreased across the subsequent survey times.

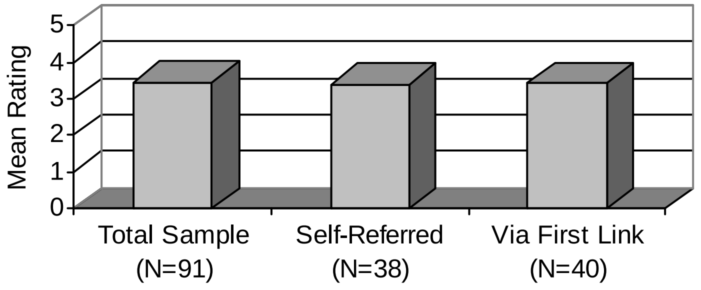
Table 20: Ratings* of Changes in Familiarity with Community Resources Across Surveys and Referral Status

Survey Referral Status	Less familiar Now	About the same	More familiar now
Second Survey (Follow-Up 1) Total Sample (N = 92)	0	13.0% (12)	59.8% (55)
Self-Referred (N = 28)	0	17.9% (5)	82.1% (23)
Referred via First Link (N = 30)	0	13.3% (4)	86.7% (26)
Third Survey (Follow-Up 2) Total Sample (N = 67)	0	16.4% (11)	41.8% (28)
Self-Referred (N = 21)	0	23.8% (5)	66.7% (14)
Referred via First Link (N = 15)	0	33.3% (5)	66.7% (10)
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	0	26.8% (11)	17.0% (7)
Self-Referred (N = 10)	0	80.0% (8)	20.0% (2)
Referred via First Link (N = 9)	0	33.3% (3)	44.4% (4)
Fifth Survey (Follow-Up 4) Total Sample (N = 2)	0	100% (2)	0
Self-Referred (N = 2)	0	100% (2)	0
Referred via First Link (N = 0)	0	0	0

*First Survey: rated on a 5-point scale: 1 = not at all; 5 = extremely. Remaining surveys: 5-point rating scale: 1 = much less now, 2, 3 = about the same, 4, 5 = much more now; Less = sum of ratings 1 and 2, more = sum of ratings 4 and 5.

Figure 7 presents survey respondents' baseline ratings of their confidence in their ability to manage the caregiver role for the entire sample of caregiver survey respondents and by referral status. There were no significant differences in these ratings; for both those self-referred to the Alzheimer Society and those referred via First Link mean ratings of confidence in their ability to manage the caregiver role were moderate (Mean = 3.40; SD = .92, and Mean = 3.41, SD = .81, respectively).

Figure 7: Mean Rating* of Confidence in Ability to Manage the Caregiver Roleby Referral Status



*5-point scale: 1 = not at all, 5 = extremely confident

Table 21 presents changes in confidence in their ability to manage the caregiver role for the total sample of survey respondents and by referral status. There were no significant differences in these ratings according to referral status. Across survey times, the percentages of survey respondents that reported that they were more confident in their ability to manage the caregiver role in comparison to when their care receiver was first diagnosed was low, ranging from 27% to 39%.

Table 21: Ratings* of Changes in Confidence in Ability to Manage the Caregiver Role Across Surveys and Referral Status

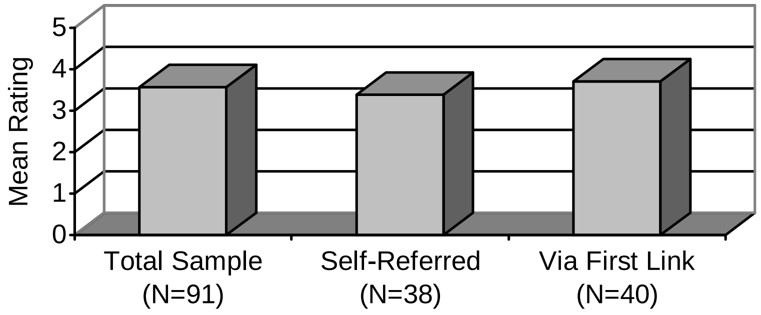
Survey Referral Status	**Less confident Now**	**About the same**	**More confident now**
Second Survey (Follow-Up 1) Total Sample (N = 92)	8.7% (8)	22.8% (21)	39.1% (36)
Self-Referred (N = 28)	7.1% (2)	46.4% (13)	46.4% (13)
Referred via First Link (N = 30)	16.7% (5)	16.6% (5)	53.3% (16)
Third Survey (Follow-Up 2) Total Sample (N = 67)	4.5% (3)	19.4% (13)	37.3% (25)
Self-Referred (N = 21)	9.5% (2)	28.6% (6)	61.9% (13)
Referred via First Link (N = 15)	6.7% (1)	40.0% (6)	53.3% (8)
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	2.4% (1)	19.5% (8)	26.8% (11)
Self-Referred (N = 10)	10.0% (1)	50.0% (5)	30.0% (3)
Referred via First Link (N = 9)	0	33.3% (3)	44.4% (4)

Survey Referral Status	Less confident Now	About the same	More confident now
Fifth Survey (Follow-Up 4) Total Sample (N = 2)	0	100% (2)	0
Self-Referred (N = 2)	0	100% (2)	0
Referred via First Link (N = 0)	0	0	0

Note: The total sample may not equal the sum of the subgroups (self-referred / referred via First Link) because the referral status of some respondents was not known.
*First Survey: rated on a 5-point scale: 1 = not at all; 5 = extremely. Remaining surveys: 5-point rating scale: 1 = much less now, 2, 3 = about the same, 4, 5 = much more now; Less = sum of ratings 1 and 2, more = sum of ratings 4 and 5.

Figure 8 presents survey respondents' baseline ratings of their self-efficacy in the caregiver role (ability to manage the role) for the entire sample of caregiver survey respondents and by referral status. There were no significant differences in these ratings; for both those self-referred to the Alzheimer Society and those referred via First Link mean ratings of confidence in their ability to manage the caregiver role were moderate (Mean = 3.38; SD = .98, and Mean = 3.70, SD = .76, respectively).

Figure 8: Mean Rating* of Self-Efficacy by Referral Status at Baseline



*5-point scale: 1 = not at all, 5 = extremely capable

Table 22 presents changes in self-efficacy in the caregiver role (ability to manage the role) by referral status. There were no significant differences in these ratings according to referral status. The percentage of survey respondents that reported that they were currently more able to manage the caregiver role in comparison to when their care receiver was first diagnosed was low (less than 43%) and decreased over time.

Table 22: Ratings* of Changes in Self-Efficacy Role Across Surveys and Referral Status

Survey Referral Status	Less capable Now	About the same	More capable now
Second Survey (Follow-Up 1) Total Sample (N = 92)	8.7% (8)	18.5% (17)	43.4% (40)
Self-Referred (N = 28)	10.7% (3)	32.1% (9)	53.6% (15)
Referred via First Link (N = 30)	13.3% (4)	16.6% (5)	36.7% (11)
Third Survey (Follow-Up 2) Total Sample (N = 67)	6.0% (4)	14.9% (10)	38.8% (26)
Self-Referred (N = 21)	9.5% (2)	19.0% (4)	66.7% (14)
Referred via First Link (N = 15)	1.3% (2)	33.3% (5)	53.3% (8)
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	0	19.5% (8)	22.5% (9)
Self-Referred (N = 10)	0	50.0% (5)	30.0% (3)
Referred via First Link (N = 9)	0	33.3% (3)	55.6% (5)
Fifth Survey (Follow-Up 4) Total Sample (N = 2)	0	100% (2)	0
Self-Referred (N = 2)	0	100% (2)	0
Referred via First Link (N = 0)	0	0	0

*First Survey: rated on a 5-point scale: 1 = not at all; 5 = extremely. Remaining surveys: 5-point rating scale: 1 = much less now, 2, 3 = about the same, 4, 5 = much more now; Less = sum of ratings 1 and 2, more = sum of ratings 4 and 5.

Coping Effectiveness: At each survey time, survey respondents completed the Coping Effectiveness Scale (Gottlieb & Rooney, 2004), the results of which are presented in Table 23 (Higher scores reflect greater coping effectiveness; maximum score = 35.) Although there was some variability in the scores, ranging from 14 to 29 across survey times, generally, mean scores reflected moderate coping effectiveness. There were no significant differences in scores across survey times or by referral status (self-referred/ referred via First Link).

Table 23: Mean Coping Effectiveness Scale Scores* Across Survey Times

Survey Time	Mean (SD)	Range
First Survey Total Sample (N = 89)	21.3 (2.6)	14 – 28
Self-Referred (N = 38)	21.2 (2.5)	16 – 28
Referred via First Link (N = 39)	21.5 (2.7)	14 – 27

Survey Time	Mean (SD)	Range
Second Survey (Follow-Up 1) Total Sample (N = 66)	21.5 (2.9)	15 - 28
Self-Referred (N = 28)	21.8 (3.1)	16 – 27
Referred via First Link (N = 29)	21.2 (2.9)	15 - 28
Third Survey (Follow-Up 2) Total Sample (N = 41)	21.6 (2.5)	15 - 29
Self-Referred (N = 21)	21.6 (3.0)	15 – 29
Referred via First Link (N = 15)	21.4 (1.7)	19 – 24
Fourth Survey (Follow-Up 3) Total Sample (N = 17)	21.1 (2.6)	17 – 26
Self-Referred (N = 9)	20.6 (3.3)	17 – 26
Referred via First Link (N = 7	22.0 (1.2)	20 – 23
Fifth Survey (Follow-Up 4) Total Sample/ Self-Referred (N = 2)	20.0 (2.8)	18 – 22

*Higher scores reflect coping effectiveness; Maximum score = 35.

Caregiver Burden: As measured by the Caregiver Burden Inventory, First Link clients were experiencing minimal caregiver burden at the time of the baseline survey (Mean total score = 35; maximum score = 100; higher scores reflect greater caregiver burden); See Table 24. Subscale scores were highest, but still moderate for time and developmental burden (maximum subscale scores =20), reflecting that caregivers were experiencing burden associated with restrictions on their time and on feeling ‘out of sync’ in development (i.e., how they live their lives) relative to their peers.

There were significant differences in mean total caregiver burden scores based on referral status. Those referred via First Link had a significantly lower total score (M = 28.6, SD = 21.8) on the Caregiver Burden Inventory than those self-referred (M = 44.8, SD = 24.1), *F*(1.37) = 4.77, p <.05, reflecting lower caregiver burden among those referred via First Link.

Table 24: Results of the Caregiver Burden Inventory* by Referral Status

Subscale	Total Sample Mean (SD) N = 44	Self-Referred Mean (SD) N = 17	Referred via First Link Mean (SD) N= 23
Time Dependence	9.8 (6.1)	11.7 (6.8)	8.0 (5.4)
Developmental Burden	9.9 (6.5)	11.8 (6.9)	8.0 (6.2)
Physical Burden	5.9 (5.0)	7.9 (4.3)	4.2 (4.8)

Subscale	**Total Sample Mean (SD) N = 44**	**Self-Referred Mean (SD) N = 17**	**Referred via First Link Mean (SD) N= 23**
Social Burden	6.2 (5.8)	5.6 (5.9)	4.7 (5.7)
Emotional Burden	3.9 (3.8)	4.5 (4.6)	3.7 (3.3)
Total Score	**35.1 (22.9)**	**44.8 (24.1)**	**28.6 (21.8)**

*Subscale scores range from 0 – 20; Total score ranges from 0 to 100; higher scores reflect higher levels of caregiver burden.

Caregiver Stress: Given concerns of the burdensome nature (length) of the Caregiver Burden Inventory and perceptions that this was contributing to the low Caregiver Survey response rate, this inventory was removed from the survey in March 2008 and replaced with a 6-point scale question (1 = not at all; 6 = the most stress I've ever experienced related to this person) on the amount of caregiving stress experienced. There were no significant differences in ratings of caregiver stress across the demonstration sites or by referral status. The mean ratings of stress were highest at baseline and decreased across the survey times; stress ratings were lowest at the third follow-up survey (See Table 25). Paired t-tests revealed a significant difference in mean stress scores between the first follow-up survey (M = 4.35, SD = 1.2, N = 17) and the third follow-up survey (M = 3.35, SD = 1.2, N= 17), t(16) = 3.52, p = .003.

Table 25: Ratings* of Stress Scores across Survey Times

Survey Time	**Mean (SD)**	**Range**
First Survey (Follow-Up 1)		
Total Sample (N = 43)**	4.65 (2.6)	2 – 6
Self-Referred (N = 21)	4.57 (1.4)	2 – 6
Referred via First Link (N = 16)	4.81 (1.3)	2 – 6
Second Survey (Follow-Up 2)		
Total Sample (N = 65)	4.49 (1.0)	3 – 6
Self-Referred (N = 27)	4.48 (1.3)	2 – 6
Referred via First Link (N = 29)	4.69 (1.2)	2 – 6
Third Survey (Follow-Up 3)		
Total Sample (N = 41)	4.15 (1.2)	2 – 6
Self-Referred (N = 21)	4.19 (1.2)	2 – 6
Referred via First Link (N = 15)	4.07 (1.2)	2 – 6
Fourth Survey (Follow-Up 4)		
Total Sample (N = 17)	3.35 (2.6)	2 – 6
Self-Referred (N = 9)	3.44 (1.2)	2 – 6
Referred via First Link (N = 7)	3.14 (1.3)	2 – 5

Survey Time	Mean (SD)	Range
Fifth Survey (Follow-Up 5) Total Sample/ Self-Referred (N = 2)	5.0 (0)	5

* 6-point rating scale: 1 = no stress at all; 6 = the most stress I've ever experienced related to this person.
** The response rate to this question was low in the first survey because it was added at a later date (October 2008).

Helpfulness of First Link Information: Table 26 presents the percentage of survey respondents that received written information about ADRD in the previous six months from the Alzheimer Society and their ratings of the usefulness of the information. The majority of respondents had received information from First Link about ADRD at the time of the first follow-up, with the number of clients receiving information over time (i.e., in subsequent follow-up surveys) decreasing. The usefulness of this information was moderate (mean ratings were 3.3 or greater on a 1-5 scale); ratings of usefulness were highest at the time of the first follow-up survey. There were no significant differences in ratings of helpfulness of the material across the demonstration sites or by referral status (self-referred/ referred via First Link).

Table 26: Percentage (number) of survey respondents that received written information about ADRD in the previous six months from the Alzheimer Society and ratings* of the usefulness of the information

Survey Time	Percentage (#) Information Received	Rating of Helpfulness Mean (SD)
Second Survey (Follow-Up 1) Total Sample (N = 92)	57.6%(53)	3.65 (.93) N = 52
Self-Referred (N = 28)	82.1% (23)	3.48 (.95) N = 23
Referred via First Link (N = 30)	60.0% (24)	3.78 (.95) N = 23
Third Survey (Follow-Up 2) Total Sample (N = 67)	44.8%(30)	3.30 (.99) N = 11
Self-Referred (N = 21)	71.4% (15)	3.33 (.90) N = 15
Referred via First Link (N = 15)	86.7% (13)	3.23 (1.2) N = 13
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	29.3%(12)	3.42 (.99) N = 12

Survey Time	**Percentage (#) Information Received**	**Rating of Helpfulness Mean (SD)**
Self-Referred (N = 10)	50.0% (5)	3.00 (.71) N = 5
Referred via First Link (N = 9)	66.7% (6)	3.83 (1.2) N = 6
Fifth Survey (Follow-Up 4) Total Sample/ Self-Referred (N =2)	0	n/a

* 1-5 scale; 1 = not at all helpful, 5 = extremely helpful; Ratings of the helpfulness of education sessions attended.

Table 27 presents the percentage of survey respondents that received information about community resources or services from First Link or their local Alzheimer Society Chapter (including those who did not contact any of these resources and those who used the resources) and their ratings of the usefulness of this information. There were no significant differences in ratings of helpfulness of this information across the demonstration sites or by referral status (self-referred/ referred via First Link).The majority of respondents had received information from the Alzheimer Society about available community resources and services at the time of the first follow-up, with the number of clients receiving information over time (i.e., in subsequent follow-up surveys) decreasing.

Table 27: Percentage (Number) Of Survey Respondents That Received Information about Community Resources or Services in the Previous Six Months from First Link and Ratings* Of the Usefulness of the Information

Survey Time	**Percentage (#) Received Information But Did Not Contact Them****	**Percentage (#) Information Received and Used the Resources/ Services**	**Rating of Helpfulness Mean (SD)**
Second Survey (Follow-Up 1) Total Sample (N = 92)	5.4%(5)	58.7%(54)	4.3 (1.0) N = 53
Self-Referred (N = 28)	3.6% (1)	82.1% (23)	3.6 (.95) N = 23
Referred via First Link (N = 30)	10.0% (3)	80.0% (24)	3.8 (1.1) N = 23
Third Survey (Follow-Up 2) Total Sample (N = 67)	3.0%(2)	38.8%(26)	4.3 (1.0) N = 28

Self-Referred (N = 21)	0	71.4% (15)	3.3 (.95) N = 15
Referred via First Link (N = 15)	13.37% (21)	60.0% (9)	3.1 (1.3) N = 10
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	7.3%(3)	14.6%(6)	3.7 (.57) N = 7
Self-Referred (N = 10)	10.0% (1)	20.0% (2)	3.0 (1.0) N = 3
Referred via First Link (N = 9)	22.2% (2)	44.4% (4)	4.3 (.50) N = 4
Fifth Survey (Follow-Up 4) Total Sample/ Self-Referred (N = 2)	0	0	n/a

* 1-5 scale; 1 = not at all helpful, 5 = extremely helpful.

* *The percentage of individuals that received information about community resources but who did not contact any of these resources.

Table 28 presents the percentage of survey respondents that received information about education or information sessions about ADRD and their ratings of the usefulness of this information. There were no significant differences in ratings of helpfulness of this information across the demonstration sites or by referral status (self-referred/ referred via First Link). The majority of respondents had received information from the Alzheimer Society First Link about information and education sessions at the time of the first follow-up, with the number of clients receiving information over time decreasing. A small percentage of clients received information about the sessions did not attend (less than 8% across survey times). The usefulness of the education/ information ranged from high at the time of the first and second follow-up survey (mean ratings were 4.0 or greater on a 1-5 scale) to moderate (mean = 3.1) at the time of the third follow-up survey.

Table 28: Percentage (number) of survey respondents that received information about education or information sessions about ADRD in the previous six months from First Link and ratings* of the usefulness of the information

Survey Time	**Percentage (#) Received Information But Did Not Attend**	**Percentage (#) Received Information and Attended the Sessions**	**Rating of Helpfulness Mean (SD)**
Second Survey (Follow-Up 1) Total Sample (N = 92)	6.5%(6)	53.3%(49)	4.3 (1.1) N = 46

Survey Time	**Percentage (#) Received Information But Did Not Attend**	**Percentage (#) Received Information and Attended the Sessions**	**Rating of Helpfulness Mean (SD)**
Self-Referred (N = 28)	3.6% (1)	78.6% (22)	4.1 (1.3) N = 22
Referred via First Link (N = 30)	16.7% (5)	73.3% (22)	4.6 (.84) N = 19
Third Survey (Follow-Up 2) Total Sample (N = 67)	4.5%(3)	43.3%(29)	4.0 (1.1) N = 27
Self-Referred (N = 20)	10.0% (2)	80.0% (16)	4.0 (1.2) N = 1.2
Referred via First Link (N = 15)	6.7% (1)	80.0% (12)	4.0 (.94) N = 10
Fourth Survey (Follow-Up 3) Total Sample (N = 41)	7.3%(3)	24.4%(10)	3.1 (1.7) N = 12
Self-Referred (N = 9)	0	55.6% (5)	2.5 (2.0) N = 6
Referred via First Link (N = 8)	37.5% (3)	62.5% (5)	3.7 (1.2) N =6
Fifth Survey (Follow-Up 4) Total Sample/ Self-Referred (N = 2)	0	50.0% (1)	1.0 (.00) N = 1

* 1-5 scale; 1 = not at all helpful, 5 = extremely helpful; Ratings of the helpfulness of education sessions attended.

Satisfaction with First Link: The mean ratings of satisfaction with assistance received from First Link or their local Alzheimer Society were highest for the first survey, and then decreased across the survey times (See Table 29). The only significant difference in satisfaction ratings by referral status occurred in the third follow-up survey: those who were referred via First Link had higher satisfaction ratings (M = 4.6, SD = .53, N = 8) than those who were self-referred (M = 2.6, SD = 1.2), N = 7), *F*(1,13) = 15.87, p = .002. For the entire sample, paired t-tests revealed a significant difference in mean satisfaction scores between the first follow-up survey (M = 4.04, SD = .89, N = 39) and the second follow-up survey (M = 3.72, SD = 1.0, N= 39), t(38) = 2.18, p <.05.

Table 29: Ratings* of Satisfaction with Assistance Received to Date from First Link or the Alzheimer Society

Survey	Mean (SD)	Range
Second Survey (Follow-Up 1) Total Sample (N = 92)	4.2 (.94)	1 – 5
Self-Referred (N = 28)	4.0 (1.1)	1 – 5
Referred via First Link (N = 28)	4.3 (.72)	3 – 5
Third Survey (Follow-Up 2) Total Sample (N = 40)	3.7 (1.2)	1 - 5
Self-Referred (N = 21)	3.6 (1.1)	1 – 5
Referred via First Link (N = 14)	3.8 (.89)	2 – 5
Fourth Survey (Follow-Up 3) Total Sample (N = 16)	3.6 (1.4)	1 – 5
Self-Referred (N = 8)	2.6 (1.2)	1 – 5
Referred via First Link (N = 7)	4.6 (.53)	4 – 5
Fifth Survey (Follow-Up 4)		
Total Sample/ Self-Referred (N = 2)	1.0	1

* 5-point rating scale: 1 = no at all satisfied; 5= extremely satisfied.

Perceptions of the Role of First Link in Supporting Families: Results of the Health Professional Survey

As reported earlier, health professional survey respondents were very satisfied with the services provided by First Link. Many of the additional comments made by survey respondents reflected their perceptions that First Link provided an essential and valued service to caregivers and persons with dementia in terms of the supports provided and timeliness of access to support/ services, as reflected in the following comments:

> *"First Link has been very helpful in assisting patients/families who are reluctant, or have difficulty, in making that first contact to the immense resources and support available through the Alzheimer Society. It is a tremendous resource."*
>
> *"First Link is a wonderful service. I refer the majority of my patients there, especially when they are first diagnosed with a dementia. The fact that First Link will call them I think very much increases the number of patients/caregivers that actually have contact with the society."*

> *“Many people are not comfortable with their family physician or are not feeling 'heard' by their family physician. Building that connection with the Alzheimer Society helps people learn about, plan for and adjust to dementia. They are feeling 'heard' and less frustrated.”*
>
> *“The First Link program has been of immense value to me as a social worker. I have made many referrals with exceptionally good feedback from the clients/ families referred. They have appreciated the emotional support, proactive ideas and linkages with other community resources. First Link has been very responsive, providing feedback on all referrals. I truly feel this is an ESSENTIAL service in our community. Highly recommended. I recommend First Link to all clients/ families dealing with dementia. Having cared for a parent with dementia, it would have been invaluable to have had this resource available at that time. Referred clients comment on timely, respectful response, support, a good conduit to resources through the Alzheimer Society.”*
>
> *“Very happy with First Link. Huge help for the family members. First Link accepts and activates referrals quickly.*
>
> *“I have been very impressed by and grateful for the First Link services. I feel that there is a safety net, a place where families can be helped to be part of the caregiving process in a mutual way, equipped with information which increases their confidence, decreases the sense of helplessness which many feel, and comforted with knowing they are not alone.”*

Perceptions of the Role of First Link in Supporting Families: Results of the Key Stakeholder Interviews

Interviewed key stakeholders (health professionals, Alzheimer Society representatives, project leaders, First Link Coordinators) identified a number of impacts for clients and caregivers associated with First Link; these are summarized in Table 27.

Table 27: Summary of Client and Caregiver-Related Impacts Associated with First Link

Client and Caregiver Related Impacts:

- Increased access to early intervention:
    - Proactive approach
    - Reduces distress created by diagnosis
    - Reduces isolation with peer support
    - Provides follow-up not available elsewhere
    - Provides screening to support early intervention
    - Delays further cognitive decline
- Increased access to information and education
    - Supports understanding of information
    - Increased understanding of available supports/ resources

    - Aids in future planning
    - Instills confidence in decision-making
    - Supports caregiving
    - Reduces stigma associated with ADRD
    - Prevents crisis
    - Supports self-advocacy
    - Facilitates early identification
- Access to Client-focused Support
    - Reduces caregiver burden/ stress
    - Supports persons with dementia to remain at home as long as possible
- Reduced use of health system resources:
    - Reduced need for crisis intervention
    - More appropriate use of system resources

Access to Early Intervention

Overwhelmingly, all of the key stakeholders (health professionals, Alzheimer Society representatives, and project leaders) described the role of First Link and the Alzheimer Society in providing resources and supports to persons with dementia and their caregivers as early as possible in the disease process as critical to ensuring a proactive approach to the disease, reducing distress caused by the diagnosis, developing a support system to reduce isolation, providing follow-up that is not available elsewhere, and providing screening to support early intervention, all of which work to reduce potential crises and facilitate a less distressing disease process for both the person with dementia and their family caregivers. Several interview participants noted that although early intervention is a laudable goal, many individuals are still not diagnosed until later in the disease process. The current process of having health professionals refer their patients to First Link was perceived as a significant step toward early intervention.

Proactive approach: Given the nature of the disease process, it was noted that early intervention is critical to preparing caregivers for what lies ahead so that they can take a proactive approach to future planning such as planning for substitute decision makers, power of attorney, and care planning including long-term care placement. Many key stakeholders described this as *"empowering"* clients to manage the future. Moreover, intervening early in the disease process provides persons with dementia the opportunity to direct their future care. The importance of providing caregivers with information for future planning before it is actually needed was viewed as critical to avoiding crises and to avoid having to make important decisions in crisis situations. It was noted that early intervention is tailored to the needs of persons with dementia and their caregivers so that as the disease progresses they have access to the services and supports needed, as reflected in the following comments:

> *"It's quite easy for people to say, "Oh, I don't need that yet", these are words we hear repeatedly. "I'm not there yet." I think it's a program that needs to know where they're*

> *at, which is really important, so we don't expect them to either not know anything or to have a certain amount of knowledge, so we find out what they already know and what they want to know, and how much support they want and need, and then we can keep in touch with them."* [KSID#2; AS Rep]

> *"I think people feel really empowered and better equipped to deal with it* [ADRD]*."* [KSID#34; Coordinator]

> *"It's a good objective to start people off on the right path at an early stage in the disease process, even if they don't need a lot of resources at that time. But they need to learn what the path will be, what they will face in the future."* [KSID#32; Health Professional]

> *"I think that by getting the information early the person is better equipped, better prepared to be able to face the obstacles in the journey at hand, I think that, I hope that the data is able to support the fact that it may reduce some caregiver burn out by providing them and equipping them with the tools that are required to face these challenges throughout the journey of the disease. I think that they were able to learn about what was being offered and then they were able to access it when it came time or when it was needed, but they knew ahead of time, let's say for day program or support group, whatever they might have required, they may not have been ready for it early when they first learned about it, but being comfortable and being able to receive that knowledge and that information at the time that they did better prepared them for the day that they did require it. For making sure that they get the right services at the right time."*[ID#6; Project Lead]

> *"We're finding that people are getting that education and a lot earlier than they did, so we're having less crises. Because before they weren't prepared, weren't as prepared for what was happening and they were really advanced and the caregivers were already burning out. In a crisis things are hard to repair."* [KSID#21; Health Professional]

Reduces Distress Caused by Diagnosis: The time of diagnosis was described as very distressing and overwhelming; early access to information and support contributes to reducing this distress and accepting the diagnosis (reduced denial), as reflected in the following comments:

> *"When I'm making the diagnosis of dementia, I assume they remember nothing from that interview other than have dementia, and maybe about medications if that's the route that we're going. So I really rely on First Link and the Alzheimer Society to help people get past that initial diagnosis and start figuring out what their needs are."* [KSID#28; Health Professional]

> *"It* [First Link] *kind of eases some of the shock of the diagnosis. Well this is what this is, and this is what's happening to you, it's a process, this is the medication you can use. So I just think that them having all of that information enables them to better cope with the initial shock of the diagnosis."* [KSID#8; AS Rep]

> "*I think that education and understanding what's happening is vital to help caregivers cope with dementia. Usually I think the results are better if it's early rather than later. It's difficult, the whole diagnosis and acceptance and that whole process. So I think often the Alzheimer Society is helping people understand and accept the diagnosis.*"
> [KSID#13; Health Professional]

Reduces Isolation With Peer Support: Early involvement with the learning series and various support groups offered by the Alzheimer Society provides persons with dementia peer support, which works to reduce their isolation over the course of the disease.

> "*Based on my experience and over the years that I've been teaching the learning series, I find that really the goal when we developed the support system among the people that were attending the groups, and learning series, also it's a way to decrease isolation, we know most people become more isolated because of the impact that Alzheimer disease has on family and friends…, they feel comfortable in that set up. They also don't have to pretend that there's nothing wrong, and can express themselves the way they are.*"
> [KSID#4; ASO]

> *"Often people, people really do want to be independent. It's just so hard to reach out and ask someone for help. So in many cases, normalizing it, that you know this is a very difficult thing and most people struggle, this will be for the group of people that are in a similar circumstance to them, you'd be able to help each other. You can often phrase it in such a way that it becomes helpful to people, otherwise most people do try to go it alone and then ask for help only when it become exceptionally difficult, and I really do think early intervention makes a difference, I have seen that."* [KSID#11; Health Professional]

Provides Follow-up Not Provided Elsewhere: It was noted that early involvement with First Link and the Alzheimer Society ensures that persons with dementia and their caregivers are followed because the health care system is unable to do this consistently. Those employed in assessment settings that see patients primarily for diagnosis emphasized the need for follow-up once the diagnosis is made.

> *"Our clinic used to do follow up with patients when they finish our program, but they do that now only when there is behaviour issue. When they leave here, I don't have any place to send them. The only place I have is First Link to send the patient. It's very, very important for me to know they have a place to go, they have people who will take care of them. Because I can't do any follow up. It's not part of my job, so I think it's very important."* [KSID#9; Health Professional]

Provides Screening to Support Early Identification: It was noted that Alzheimer Society Chapters that have been involved with screening (e.g., Sudbury/Timmins) have been instrumental in ensuring early detection and intervention, as reflected in the following comment:

> "*Our Chapter here does early screening and detections and I think that has certainly increased their numbers in terms of getting out to people and being able to take on that*

> *aspect of it too and getting a lot more people screened and connected with the proper services early."* [KSID#17; Health Professional]

Delays Further Cognitive Decline: It was noted that further cognitive decline can be delayed or stalled with the introduction of medication (cholinesterase inhibitors) as well as the support provided to caregivers. This allows persons with dementia to live independently longer and caregivers to provide care at home as long as possible.

Access to Information and Education

Many interview participants highlighted the important role that First Link plays in ensuring that persons with dementia and their caregivers have access to information and education about ADRD and available community resources and supports that are not available elsewhere. Several health care providers noted that while they may diagnose and follow individuals with dementia they are not in a position to provide the detailed level of education that is provided by the Alzheimer Society; many expressed gratitude for having a resource to refer their patients. The education activities provided by the Alzheimer Society were described as important because it helps persons with dementia and their caregivers to understand how learned information is relevant for them, aids in future planning, instills confidence in decision-making, supports caregiving, prevents crisis, and supports self-advocacy.

Supports understanding of information: It was noted that the Alzheimer Society is a respected and trustworthy source of information that assists people to understand how the information is relevant to them, as reflected in the following comment:

> *"I trust you know, that they're giving reliable information, I know people can access information on the internet, and some sources are excellent. But you know sometimes I talk to people that are confused because even if they've sometimes accessed good information, they still have questions and just need sometimes a little bit of guidance about what to do with it."* [KSID#13; Health Professional]

Increased understanding of and access to available supports/ resources: Information provided by First Link regarding available community services, supports, and resources has been informative for clients and has ensured that they have access to the supports needed. It was also noted, particularly by Alzheimer Society representatives, First Link Coordinators, and Project Leaders, that the First Link has increased caregivers' and persons with dementia's awareness of the services offered by the Alzheimer Society, as evidenced by the increased attendance at Learning Series sessions, support groups, and other programs.

> "*Reaching out to the people that have dementia, the caregivers, in terms of attracting them and getting them the information and the supports that they need... I think there is increased awareness of the chapter services."* [ID#22; Project Lead]

> *"I think people are more knowledgeable about who to call for what. I've asked, 'Do you need help with such and such, like housekeeping or personal care?' and they'll say 'Oh,*

> *yes, the Alzheimer Society told us about this and we have someone coming in."* [KSID#23: Health Professional]
>
> "*I think that the impact in terms of case finding is huge. So we have a lot more client contact, we have many more clients certainly in our chapter than we would have seen otherwise, that's a very positive thing... We, because of First Link have, I believe two or three more support groups than we had before."* [ID#30; Coordinator]

Aids future planning: It was noted that the information and education provided by First Link and the Alzheimer Society highlight what services and resources people will need as the disease progresses, many of which will assist persons with dementia to remain in their own homes as long as possible.

> *"Well, definitely the knowledge and, is increased, and knowing about POAs or financial issues or DNRs or what other services are out there to help them as the disease progresses, the goal being to keep them in their homes as much as we can and out of the long term care…. it's good to be able to give them some information a little bit ahead of time, and then, so they're not going into it so blind."* [KSID#29; AS Rep]

Instills confidence in decision-making: Caregivers and persons with dementia, when informed about the disease process and strategies and options for management, are more confident about making decisions about future care. Conversely, the ill-informed often find themselves in crisis situations and being uncertain about important care decisions.

Supports caregiving: Through the information and education sessions, as well as the caregiver support groups, caregivers learn strategies and skills that assist them with caregiving and problem-solving, as reflected in the following comment:

> *"Sharing of information, tips, strategies. A lot of participants, individuals in the early stages will share a lot of skills that they've tried and that work. And for those that are not knowing and are fairly new and are not sure how to support them when they lose the ability of doing certain things, its impressive…The personal experience also has a great impact on others."* [KSID#4; AS Rep]

Reduces stigma associated with ADRD: There continues to be significant stigma associated with ADRD that prevents people from accessing the care that they need. As families learn more about the disease and available resources, and as they meet others who are dealing effectively with and living a quality life with dementia, the stigma of coming forward with memory concerns is reduced.

> *"I think we're starting to see a reduction in the stigma of dementia. Families are hearing more about it and seeking out help and more information. Doctors aren't as afraid to bring it with patients and more people are using the services that are out there. First Link helps to normalize it so people get the help they need."* [KSID#21; Health Professional]

> “*We’re seeing that more people are getting involved earlier in the disease process, they’re learning more about what’s going on and I think that’s all worked to reducing the stigma to come forward.*” [FG#18-20; Project Lead]

> *“This [First Link] is a giant step for clients and taking dementia out of hiding, and letting everyone know what’s out there. It really helps to reduce the fear of dementia.”* [KS ID#21; Health Professional]

Prevents crises: It was noted that with information and education, caregivers have a better understanding of the behavioral and psychological symptoms that occur with the disease and are better prepared to manage this, which in the long-run can prevent the crises that occur when caregivers are ill-prepared for these symptoms, as reflected in the following comment:

> *“Once the family is better educated they can anticipate some of the management problems that will come up, rather than await for crisis to occur, they can sort of head the problem off at the pass and deal with it while its still a small issue. It decreases the emotional trauma for the families, you know, they know what to expect and how to deal with it.”* [KSID#16; Health Professional]

Supports self-advocacy and self-management: It was noted that many individuals who have concerns about memory loss are unable to secure support from their family physician for screening or assessment. Information obtained from the information and education sessions can provide people with the tools and information needed to advocate for assessment. Similarly, the information they receive about the disease and available community resources helps caregivers to manage care independently and to better navigate the system of care.

> *“We have trouble here with family doctors and getting a diagnosis. We can give them that information and then they will talk to their family doctor. We can equip them with the information and maybe the skills or the tools that they need to talk to their doctor in order to get him to do something. … So think it does help them with getting a diagnosis early.”* [KSID#8; AS Rep]

Facilitates early identification: It was noted that the information and education sessions, as well as public promotion of First Link has increased attention to memory problems, so that many people are informing themselves about the need for early screening, identification, and intervention. For many individuals who contact the Alzheimer Society with concerns about memory problems, they learn more about how to get assessed and if diagnosed, how to get support.

> *“We have had people calling indicating that they are having problems with their memory and wondering what they could do about that, and that is new. We just didn’t used to get those kind of phone calls.”* [KSID#3; AS Rep]

> *“First Link is educating and informing people who contact us for information about symptoms of disease. We then inform them of how to obtain diagnosis and perhaps what they may be talking to their primary health practitioner about and so I think more people*

> *are aware of their health and perhaps the changes in their spouse for example. So they're actually initiating an assessment and going through those channels of using the family physician and then in turn the assessment clinics… so I think that individuals are informed so they're asking about how to assess."* [KSID#1; AS Rep]

Access to Client-focused Support

One of the key impacts of First Link has been its focus on identifying and meeting the multiple needs (home support, respite, social and emotional support) of persons with dementia and caregivers. Through the information and education sessions, Alzheimer Society clients learn about what resources, supports and services are available, both at the current time and as the disease progresses. Although, the Alzheimer Society attempts to anticipate clients' future needs they focus on providing supports resources as needed ("*the right services at the right time*"). It was noted that the Alzheimer Society has been responsive to the needs of persons with dementia and their caregivers, as for example, with the development of a support group for those in early stage dementia as result of interest expressed at a learning series and the development of a mental stimulation program as a result of increased interest for this type of program. Generally, most of the Alzheimer Society representatives that were interviewed commented that the demands for programming (support groups, learning series, counseling, screening) have increased significantly since the inception of First Link. Coordinators, at the time of intake and at regular follow-up, assess the needs of client to ensure that their multiple needs are met. This client-focused support reduces caregiver burden/ stress, supports persons with dementia to remain at home as long as possible, and reduces use of health system resources.

- ***Reduces caregiver burden/ stress:*** All of services and supports provided by First Link and the Alzheimer Society were believed to impact caregiver burden/ stress. Information, education, peer support, individual counseling, respite, and the many other services offered were reported to significantly reduce caregiver burden and increase their ability to cope as the disease progresses.

  "Many patients and families will say that they have found it very helpful to go to sessions and find that, you know, that they're really not alone and to see people coping with the same stuff and the emphasis on coping with this at home and realizing that its not the end of their world and there is stuff that is going on to help." [KSID#28; Health Professional]

  "Sometimes when people, when caregivers are stressed and at the end of their rope, they don't realize it and they don't seek help. They just keep trying the best they can. But the nice thing about First Link is that they monitor and follow-up on people even those that resist help, so that they can see when the person is struggling, even if they don't recognize it themselves. And they give them the help they need, even if it's just reassurance and a shoulder to cry on. That goes a long way to reducing caregiver stress." [KSID#23; Health Professional]

- ***Supports persons with dementia to remain at home as long as possible:*** Attention to all of the challenges faced with persons with dementia and caregivers, in terms of ensuring that all the relevant supports are in place (e.g., day programs, respite, home support, safety programs, counseling, social support) work to improve caregivers' abilities to maintain the person with dementia at home as long as possible, which is most often their primary objective.

"I strongly believe that it [First Link] may have also delayed placement in long term care facilities because I think that the caregiver burden was not as prominent because we were able to provide those care givers with support and a way to navigate the system so that they could utilize community based programs and services, so they could keep that individual at home for a longer period of time." [ID#6; Project Lead]

"Sometimes when people, when caregivers are stressed and at the end of their rope, they don't realize it and they don't seek help. They just keep trying the best they can. But the nice thing about First Link is that they monitor and follow-up on people even those that resist help, so that they can see when the person is struggling, even if they don't recognize it themselves. And they give them the help they need, even if it's just reassurance and a shoulder to cry on. That goes a long way to reducing caregiver stress and to helping them keep their loved one at home…. They learn the tips and strategies to deal with the stuff that often makes people go to long-term care. Not that you can prevent that, because at some point they'll need more care than can be provided at home, but they might be able to stay home a little longer, which is what most people time me they want. They really want that." [KSID#23; Health Professional]

"I think that also placement is possibly delayed by educating people about the life style changes and help them live healthier lives. So they may actually live healthier because of changes in their life style, keeping active." [KSID#2; AS Rep]

Reduced use of health system resources

Generally, key informants believed that the services offered by First Link and the Alzheimer Society have significant impact on reducing the use of health system resources or ensuring a more effective/ appropriate use of system resources. Ensuring that caregivers and persons with dementia have access to the services and supports they require can prevent the crises that often result in emergency room visits and long-term care placements. The information and education provided assists caregivers to make better informed decisions about when to access health services and assists them to make the better use of their time with physicians.

- ***Reduced need for crisis intervention:*** Many key stakeholders believe that ensuring that persons with dementia and their caregivers have access to the right services at the right time reduces the need for early long-term care placement and visits to emergency departments and primary care for crisis intervention.

  "So it's a valuable resource in terms of making visits to the doctor an effective visit and hopefully minimizing the number of crisis that may then go back to the primary health practitioner." [KSID#1; AS Rep]

> *"I know of one case in particular that came through ER that was really a problem case in terms of this couple's ability to work with the health care team. They were very confrontational. We linked with them and they came to a learning series and you know, rather than going down to the ER they started calling us. Which was a little problematic for us, but is okay. Better us than the ER. So that was a positive outcome I think of that, that at least they knew who to call when they were in trouble.*" [ID#30; Coordinator]
>
> *" I think there are pin points in this disease, the first one is diagnosis, the second one is when behaviours emerge, and the third one is I think when things become uncontrollable and people have to think long term care or placement, and I think we often miss the first two and we often see people when all hell breaks lose, that's the second point, and if you can provide information and get normalizing things, this is how it progresses, this is how the disease unfolds, this is what other people have had, that are out there, that we can help you connect with during that difficult time, if you get those kinds of interventions in place and they feel part of something and that its normal, they're not, if you can do that. The second part of the disease is not as severe and I think it has savings to the health care system, you know, if you put, and I've seen it, I've had support groups and often with regards to the families and if you can get those resources in or the knowledge in early, then, then people don't fall apart to the same degree, and hopefully they won't need as much."* [KSID#11; Health Professional]
>
> *"In terms of the ER visits a lot of times what we had seen, is people who say "I can't do this anymore" and drop them [person with dementia] off in the ER and walk away with the hospital system having to take that person in to wait for a hospital bed. But by providing the community supports and opportunities you know not to be alone and look after that person in their home dwelling definitely you are preventing them from doing that drop off to Emerge because they did have what they needed in their community, they did have a lot of supports and an opportunity for someone to help through the navigation of all those programs and services."* [ID#6: Project Lead]

- ***More appropriate use of system resources:*** Some key stakeholders noted that they were uncertain whether First Link and the Alzheimer Society impacts delayed long-term care placement or reduces use of hospital resources, suggesting perhaps that the information and education caregivers receive assists them to make better decisions about when a hospital visit is necessary (e.g., in the case of delirium) and assists them to make more informed decisions about long-term care placement. Similarly, it was noted that caregivers who have participated in Alzheimer Society information and education sessions are better informed and thus make better use of their time with their physician.

> *"With the knowledge base that's now out there, as a result they may not go to emergency with somebody who's in the early stages not knowing what to do and utilizing hospital time for something that may be non-medical, behavioural, those*

> *kinds of things… I see that those kinds of hospital visits, the emergency visits aren't occurring as much anymore."* [KSID#14; Health Professional]

> *"I think it just prepares them better for long-term care, I'm not sure about delaying it, it depends on where the person with dementia is at before they contact the facility. Sometimes they do contact us and they're already fairly close to either caregiver burnout or crisis."* [KSID#29; AS Representative]

> *"They've got sort of that basic knowledge and certainly around the issues like delirium, which is has landed them in emergency. That's something they learned a bit about. They learned how to talk to their family doctor about it, and that this is not normal, and not to think that this is just dementia. It's a medical emergency. That's what I see often drives our emergency room visit. So that piece, of giving them that information, or even just raising their level of trust in themselves that I know what normal should look like and this doesn't fit with what they told me."* [KSID#11; Health Professional]

> "*We find that when patients have been involved with First Link, they are better prepared for their appointments. They ask really good questions and in some ways they're asking the right questions because they've got all the other stuff covered. In way, it does make our job a bit easier, as we probably spend less time having to do that education as we explain things to them."* [KSID#25; Health Professional]

> *"They [caregivers, as a result of First Link] are better able can pick up when their loved one is not going to be safe to live alone in home, so they don't wait for the fall or the fracture or you know, the trauma. They start the relocation process early, and the respite stays. It's kind of pay a little now or pay a lot later at the hospital."* [KSID#16]

It was noted by a health professional, that First Link's impact on the health system is dependent upon the amount of services that are available in the community, so that where services are limited to keep people in their homes, long-term care placement is inevitable.

> *"It's difficult to know if First Link has an impact on the health system. I still see crisis long-term care placements, but I think that's mostly because the services available in the community are limited. At some point people are going to need 24 hour care. So regardless of what First Link does, if there are limited supports in the community, that placement can't be prevented."* [KSID#13; Health Professional]

Although long-term care placement is almost always inevitable and may not in some cases be able to be prevented or delayed, First Link assists families with the decision making process and facilitates a less crisis oriented or distressing placement to long-term care.

> *"Placement and long term care, again, I'm not sure that something like First Link necessarily delays that, I just think it makes the journey easier. I think that they get*

> *connected earlier, they get information in a timely way. Hopefully they know who to call, so they make good strong connections. Does it make a difference in long term care? Oh, probably not. It's going to happen anyway you know, so I'm not sure it delays it but I think it makes the coping and it makes the journey easier."* [ID#30; Coordinator]

Perceptions of the Role of First Link in Supporting Families: Results of Interviews with Caregivers and Persons with Dementia

Accessing First Link: All of the interviewed caregivers and persons with dementia commented that accessing First Link and the Alzheimer Society was extremely easy, particularly since the Alzheimer Society follows up regularly to ensure that their needs are being met. Two caregivers commented that their only challenge with accessing the Alzheimer Society was their care receivers' denial that a problem existed requiring support, as reflected in following comment:

> *"I was just so happy when they called and invited us to go to the first information session. The woman on the phone was just so welcoming. I told her just a bit of what I was going through and the things she said made me feel like she'd been living in my home and knew us. The biggest problem I had was that [care receiver] was not at all interested. He didn't want to hear about it or talk about it. He had no interest in going to any of session. I went anyway and am so glad I did."* [CGID#9]

One caregiver commented that her own fear challenged her to seek assistance:

> *"The hardest part was for me making up my mind to do that. I walked past the door four times thinking, I'm not going in there, but then thinking I have to help her, and our doctor was not agreeable, I mean was not helpful at all. ... they [First Link] were quite welcoming and I was, I was still ashamed."* [CGID#2]

Impact of First Link: Caregivers and persons with dementia were asked to identify the ways in which First Link has been helpful to them; these impacts are summarized in Table 28:

Table 28: Summary of the Ways in Which First Link has been Helpful to Caregivers and Persons with Dementia

Caregiver/ Person with Dementia Related Impacts

- Access to information about ADRD
- Access to information about community services and resources
    - Information about Alzheimer Society services and supports
- Caregiver support
    - Morale support
    - Practical strategies
    - Assistance with decision-making

    - Reduced stress
- Support for the person with dementia
    - Reduced stigma
    - Reduced social isolation
- Early detection and timely intervention
- Reduced stigma

- ***Access to Information About ADRD:*** All of the caregivers and persons with dementia reported that they received information about ADRD from the Alzheimer Society, all of which was described as extremely helpful, as reflected in the following comments:

> *"We received tons of information! We got it in both French and English so there was a lot. It gave us insight into something we didn't know anything about. It gave us pointers and ideas and that what we were seeing was not unusual."* [CGID#10]

> *"I get the newsletter that they send every month and I look forward to that. It has a lot of useful tips and ideas in it."* [CGID#15]

Similarly, all reported receiving information about information and education sessions. All but two individuals attended one or more session; one caregiver reported that he was unable to leave his care receiver alone in order to attend sessions and he has declined respite because his care receiver becomes agitated in new situations, a second caregiver reported that she lives at a distance from the centre where the sessions are held and is unable to obtain transportation to travel there. The education sessions (Learning Series) were described as helpful in terms of providing information about the disease, how it will progress, and what to expect, as reflected in the following comments:

> *"At the first session I was blown away. I knew absolutely nothing about Alzheimer disease. I learned so much.... I don't know where I'd be today without them to give me knowledge. I'd be like my brother and sister and just think that mom's old and losing her mind. They saved me in understanding my mother."* [CGID#18]

> *"When you get that kind of a diagnosis, first of all, I know I myself wasn't familiar enough with Alzheimer's, you hear about it over the years but you never really were directly involved with it, so not only did it give us a better understanding of Alzheimer's and the potential causes and treatments.... they talked about you know, how the disease progresses and what's in store down the road and at each stage, what potentially, what assistance is there for you and maybe even just to kind of prepare the caregivers as to what's coming. You know and how to, how to even deal with the, the person who has Alzheimer's, and understanding of you know, there's going to be some behavioural changes and what causes the behavioural changes, and things that you can do to perhaps assist them that you wouldn't think of, when you don't know much about the disease to start off with. For me it was very enlightening."* [CGID#12]

> *"I mean I think that education is power and as much as it's such a negative disease, they offered some hope as far as new medications that were being discovered and what the actual causes of Alzheimer's were so that they design medications that would t least interrupt the forming of the plaques, and so it gave hope in that way. Plus it also encouraged us to keep her as active as we could because if you didn't use it, you'd lose it, so as much as there was a lot of negative stuff that we learned, there was still enough hope to balance it out."* [CGID#13]

> *"I think these people at the Alzheimer Society have a more intimate knowledge of the disease than even many doctors have. It was very useful, a lot of new information, even to me as a retired physician."*

Attendance at the education sessions had motivated some caregivers to get more actively involved with the Alzheimer Society, as reflected in the following comments:

> *"I found it was very good. It was a lot of information to take in, that was actually my first meeting, and I found it was so much to take in and a lot of the stuff though that I had picked up on, I seen it in mom. And I thought you know what, it makes sense. I said to my sister, why don't we just give them [First Link] a call and maybe we can have an appointment, one to one, because with so many people there and it was kind of hard to talk or you know, so that's when we decided to make the appointment."* [CGID#11]

- ***Access to Information about Community Resources and Supports:*** Caregivers noted that an important function of the Alzheimer Society is to prepare people for what services they will require as the disease progresses and to recommend services and supports as they become necessary and to provide support in decision-making regarding long-term care placement. Several caregivers commented that much of what they learned was new information that they believe they would not have learned from other sources.

> *"He [care receiver] really doesn't like others to be in the house. For a long time I felt like I had to do it all on my own, all by myself because it's less upsetting to him. But they [First Link] told me that it was time for me to give some of this up or I just couldn't have gone on.... They referred us for community services... He gets help now with physio and someone comes in twice a week for personal care, they help him shower and shave and that's a big help... They helped me to set it up so that he wouldn't get upset by this... Because I was real worried that he'd yell at them or something worse, but it was good."* [CGID#9]

> *"They [First Link] helped us with the CCAC, to get them to come in to the home and do an assessment, and they recommended that we do that, and the timing was perfect. Without them [First Link] helping us along, it would have been a totally different scenario. There were other services that we haven't had the need for but we definitely used the CCAC and had a home assessment done and they [First Link] helped us along with the capability kind of issues, are they capable of making decisions and it*

> *helped us. It helped us make the decision to actually get her into a retirement home, so it was hugely helpful for our family."* [CGID#13]
>
> *"Well I think it's the unknown, there's just so much you don't know about the disease. And I find by talking to them, they're so informative and they can link you to different programs or different things that are out there, that you wouldn't know otherwise. Sitting down with them I just felt more confident like that there could be more help for her and stuff."* [CGID#11]
>
> *"They've just been so helpful in telling us about all the programs and things that we could access to learn more about Alzheimer's and what we need to be doing. I didn't know a lot about the services out there. It's really opened a lot of doors for us... We wouldn't have known otherwise.*" [CG&PWD#1617]
>
> *"Well of course it opened up a number of important areas. One is housing, and the future and so we've, we've had special sessions on the kinds of housing that are available and the whole process of the CCAC, and so on, that's been one specialized thing, and really, really helpful."* [FGCG&PWDID#678]

In addition to learning about available community resources and supports, several caregivers noted that First Link has assisted them to learn more about the Alzheimer Society and the services and supports it offers, as reflected in the following comment:

> *"Its [First Link] just given me a better understanding of Alzheimer's itself, and I guess it gave me a better appreciation of the Alzheimer Society and really what they do for people that have that diagnosis and I didn't realize to what extent the Alzheimer Society, what services they offered to people that are diagnosed with it. It was a learning for me, because you know, and I imagine its probably no different than the MS Society or the Arthritis Society; unless you're actually thrown into that you probably don't realize what do those societies do for people that have that kind of diagnosis. So I think it was very, enlightening for me and it was very comforting to see that there is actually an organization like that, that exists. We're all getting older I mean who's to say that myself, my husband, someone else in my family might develop that."* [CGID#12]

- ***Caregiver Support:*** The majority of caregivers, and all of the persons with dementia interviewed reported that they regularly attend the support groups offered through the Alzheimer Society. One caregiver reported that she attends support group meetings intermittently primarily because those in attendance are mostly the children of persons of dementia and as a spouse of a person with dementia she feels her experiences are different and thus the group does not entirely meet her needs. Support groups were described by caregivers as critical to their ability to continue with caregiving, as they provide non-judgemental morale support, disease related information, practical solutions/ strategies for challenging behaviours and psychological symptoms, and support with caregiving decision-making, as reflected in the following comments:

> *"I think that people learn more from each other in these groups than they do in the information sessions or from the facilitators of the sessions. First of all you learn that there's others who are having the same problems as you are and also how each of them deals with the problem and you learn from the others how they manage it and also how not to manage it is an another aspect. I think you get a lot of support, mental and physical support from the others who say how they're managing it. And also when it gets to the point when it gets to be beyond them with the caregiving and it's getting to be a 24 hour care process, you learn from the others that you have to back away from the idea of not ever saying I'll never give up in caring for my loved one and be prepared to put them into nursing care."* [CG/PWDID#14]

> *"We were in a pretty good position because she was early on in the disease, but some of the people there, honestly, they were struggling and had just so much pressure on themselves and they never got a break and you know, it just really was good for, not just myself, but you know, to hear other people's stories and know that you weren't alone and be able to you know, just listen to them."* [CGID#13]

> *"The morale support from the group is so good. You hear worse stories than your own and know you're doing okay. It helps you put things into perspective so you don't start feeling too sorry for yourself.... I always feel so welcomed when I go. It's such a relief to be there, I just feel my stress leaving me.""* [CGID#9]

> *"We're noticing that her pills, I don't think she takes them right. It's the little things, and now we've got them all done by the pharmacist and he puts them in blister packages and stuff for her, so that's much easier. So all these little tips, it's nice to be able to talk to them and say hey, you know, this is where we're at, this is what we're doing, what else can we do to help and stuff."* [CGID#11]

> *"They're helpful to the point of they're making me understand more of what I'm not coping with, but when you leave here they make you feel that yes, this is what might happen or this is perhaps what you should do and for myself ."* [CGID#12]

> *"I think one of the most important things is that no matter what you say in these workshops, it's respected. And you don't feel as if there's finger pointing at you at any time, there's only help, and that's what I think is so important."* [CG&PWD#3]

In general, many caregivers commented on ongoing access to support and feeling comforted in knowing that they could call the Alzheimer Society at any time for support:

> *"Well they're always here when you call. If you call or if you come in, they're very, very sociable, very caring, they always seem to have time for you."* [CGID#2]

- ***Support for the Persons with Dementia:*** Support groups for persons with dementia were seen as important opportunities to reduce the stigma associated with ADRD and to reduce social isolation, as reflected in the following comments:

> *"The meetings are good. We get along well together. We can discuss any problems and anyone can talk about what they run into and we talk about ideas or things to help."* [PWDID#17]
>
> *"I think just listening to the people right here. I haven't seen any, any attempts to negativity, I would say it's completely the reverse and that's quite a thing to say because you got a wide range of people, so somebody is doing something to create an environment that's helpful."* [PWDID#7]
>
> *"And even for the person who has Alzheimer's, being with other people who had it, I think was somewhat reassuring because I know that my mother-in-law felt like she had a blinking light over her head. That everybody would know that she was forgetful and they could tell, and I think it really reassured her that you couldn't tell who had it when we were together, you know, so I think that was helpful."* [CGID#13]
>
> *"Her [care receiver] life had shrunk a lot. She wasn't as confident with her friends, she didn't want to go out. So pretty much the Alzheimer Society was our excuse to get her out, get her socializing. They had the support groups and the friends group. They just had everybody get together, so it was really back then her life line."* [CGID#9]

- ***Early Detection and Timely Intervention:*** It was noted that information and education provided by First Link and the Alzheimer Society increases access to early detection and timely intervention.

> *"... I think it helps, it helps you to prepare for what's coming or to understand what potentially is going to be coming. I mean it's no different than cancer, early detection, that whole thing how they stress it, I don't think it's any different for Alzheimer's.* [CGID#12]

- ***Reduced Stigma:*** Both caregivers and persons with dementia noted that the information and supports provided by First Link and the Alzheimer Society work to reduce the fear and stigma associated with ADRD.

> *"I like to go there [Alzheimer Society support group]. I can be myself and there's others there like me, who have this, so it's okay there."* [PWDID#8]
>
> *"Education of the community, I feel they are helpful. When you read the statistics about how many people there are with this disease you wonder where they are all. When I ask people how many people there are in this community have Alzheimer's they look at me with a blank face and no answer to it. People still aren't prepared to name it or to realize what it is. The only person I know in this community who has Alzheimer disease lives up the street from me and we go to the Day Away Program together... even in that family they don't talk about Alzheimer. They probably know she has it but they don't ever talk about it. So with the Alzheimer group with amount of material they put out its really fantastic, all the information of Alzheimer disease*

> *that they explain in pamphlets, it helps people not be afraid of it and to talk about it."* [CG/PWDID#14]

Satisfaction with First Link: All of the interviewed caregivers and persons with dementia indicated that they were very satisfied with their involvement with First Link and the Alzheimer Society. One caregiver, who has not had an opportunity to participate in any of the education sessions or support groups, has been nonetheless satisfied with the regular telephone contact that he receives from the Alzheimer Society. Several caregivers became emotional as they described how special the staff were to them and the significant role they have played in providing support to their family.

> *"I'm going to get emotional here, because honestly, I credit them so much for helping us. I can't say enough about every single person there, from [name] who would come into the home and be so kind and do her assessments without mom even knowing she put her at ease and [name] runs the groups and is just so compassionate. I mean honestly, I don't want to even say names because every single person there, I can't say enough about them."* [CGID#13]

Suggestions for Improvements: Generally, interviewed caregivers and persons with dementia noted that they were very satisfied with the services provided by First Link and the Alzheimer Society, with few individuals providing suggestions for improvement. Suggestions for service improvements are summarized in Table 29 and included increased access to individual counselling, separate support groups for spouses and children of persons with dementia to address their unique needs for support, more frequent support group meetings (more than once a month), provision of transportation to attend Alzheimer Society programs, provision of in-home respite to attend caregiver programs/ groups, increased access to evening respite and a regular in-home friendly visiting program for persons with dementia to reduce social isolation, help deal with denial, and provide support. Interview participants stressed the importance of increasing public awareness of the importance of early identification of ADRD so that affected persons are identified early and increasing awareness of ADRD to reduce fear and stigma associated with seeking assistance. Several interview participants also identified suggestions for improvements to dementia care namely more specialists (geriatricians) in northern regions of the province and ensuring that physicians are properly educated and trained to assess, diagnose and manage ADRD as they had personal experience with physicians who were not helpful in this respect. Suggestions for improvements are reflected in the following comments:

> *"I think it's really important to get early onset information out there so that you know, people who might be in denial or not you know, not want to, you know, address it early, it, it's for me I can't say enough how important it is to acknowledge it, get on medication, so some, somehow getting education out there for people."* [CGID#13]

> *"Advertise. Advertise. Advertise. Hit people over the head with information about Alzheimer's disease or even just memory problems. Then people might not be so afraid of it, because really its fear of the unknown that makes people hide from this. Most are terrified and a lot are in denial and they need to know that it can be stalled and there is help out there and it's nothing to be embarrassed or ashamed about."* [CGID#9]

> *"I think the main thing is to get the community to understand what is Alzheimer's disease, what you can do about it and where they can get help for it. I find the community as a whole is not really very knowledgeable and they're still kind of afraid of it."* [CGID#14]
>
> *"I haven't really gone to a lot of the support group meetings. I get to the occasional meeting, but I don't go regularly. Sometimes because it's not convenient but mostly because my situation is different. The meeting is mostly with people who have elderly parents who have Alzheimer disease and I feel my experience is different from theirs because it's my husband that has Alzheimer's. We have different experiences… It would be nice if there was a support group just for spouses.*" [CGID#20]

Table 29: Caregivers and Persons with Dementia's Suggestions for Improvements to First Link and the Alzheimer Society and for Dementia Care

Improvements to First Link and the Alzheimer Society

- More individual counselling
- Support groups targeted to specific relationships with persons with dementia (spouses vs. children)
- More frequent support group meetings
- Provision of transportation to attend programs
- Provision of in-home respite to attend caregiver programs/groups
- Increased access to evening respite
- Regular home-visiting program for persons with dementia
    - Reduce social isolation
    - Reduce denial
    - Social support
- More promotion of early onset ADRD to increase early identification
- More promotion of ADRD to reduce fear and stigma

Improvements to Dementia Care

- Greater access to specialists (geriatricians) in northern Ontario
- Physicians better educated on the assessment, diagnosis, and management of ADRD

Key Stakeholders: Case Illustrations of the Impacts of First Link

The following cases were described by interviewed health professionals and Alzheimer Society representatives to illustrate the key benefits associated with First Link.

Reaching out to Families

"I have an example that reflected the perseverance of the program and how valuable that was. It was the care provision situation, the daughter who had moved in with the mother, long family history with a lot of complexity and the son living in a different county was criticizing everything

done here. I made the referral to First Link when I first saw this family and then First Link made an immediate connection. They invited her to the sessions but the daughter rejected everything. I know she was fine, she was just going on her own. First Link was just so good about saying: 'This is what she said, but my gut feeling is that she needs this and I'm just going to phone again.' So actually it took three invitations to three different sessions before the daughter was in a place where she was ready to accept that kind of education and support, and when she finally went and connected, I could see the impact it made because the care was driven by a lot of discordance between the two of them, and a lack of understanding of the illness, but it wasn't until she first met in that group with other families and realized she wasn't a wicked daughter because of her failure. It was that group setting, that validation she got from the First Link coordinator and the other families. There are programs that if you make a referral and the patient says: 'Oh no, I don't need it,' then they drop them like a hot potato. You know perfectly well that someone with dementia doesn't have the insight and judgement or the care provider is so overwhelmed they can't even imagine introducing something at this point. And so First Link has that sensitivity to say I know this will be valuable, I'll ask again. First Link has the insight to say: 'Yea, I've hit her on a bad day, but we'll call again.'" [KSID#11; Health Professional]

Educating Caregivers

"There was a woman whose husband had recently died and her son, who lived near her, was really trying to get her to be more independent and do things on her own. She started acting bizarrely and they knew something was wrong. At the time she was assessed she was referred to First Link. They really helped the son and his wife to understand their role. Up to that point they had stepped back so the mom could be more independent. First Link helped them figure out their role and what they should be doing, and what they could realistically expect. It really did help to reduce the burden felt by the mom." [KSID#25; Health Professional]

"There's a patient that I diagnosed with mixed Alzheimer's and vascular dementia, and we had a family meeting with him and with his son…we went through why we thought it would be a good idea for him to look at other places to live where he'd have more support and help. And I did what I often do, which is write a letter to him and a copy to his son just to outline the points of our discussion. Most of the time that goes over fine, but this particular case, the patient got the letter, picked up the phone, called the police, to say he didn't know who this doctor was but she and his son were clearly conspiring to put him away. The police were very good, but obviously this was quite distressing to the son… he has now been going to the education sessions and he has been using the resources to help him manage his father's behaviours and that's been very helpful to him. I know, because the last update I got just yesterday is that he's recognizing that even a retirement home isn't going to work because he thinks his father needs more help, which I think is completely correct. I think a lot of that insight came from learning what he learned at the Alzheimer Society." [KSID#28; Health Professional]

Supporting Caregivers

"We had a couple; he was early stage, very early and she was the caregiver. They came to our First Link learning series, and that was quite beneficial. He became quite independent he joined a walking group in the community so he would come in and just chat with us and really built a great relationship. He knew where he could come and his wife as well, and they came together, but they also came separately. Then he was still driving and felt that he could still drive, so he

one day decided he was going to drive to the city from rural Ontario, was gone missing. So the thing was that the caregiver knew where she could come for help and then we got the police involved and then we did actually get him home safely. They know where they can come and we have the safely home program and he went through it as well." [KSID#7; AS Rep]

"We had one family that was a late stage dementia that we referred to First Link about 2 years ago. The family was not at all receptive. Well, just this week the family presented here in crisis. Even though it was later than they would have liked, First Link was there to hook them up with all that the Alzheimer Society had to help them. They were there to help them with information, services and supports. The family really needed this and they certainly wouldn't have gotten that level of support elsewhere." [KSID#32; Health Professional]

Crisis Support

"I'm thinking I guess of a person whose husband was diagnosed by the family physician with vascular dementia and she kind of puddle along on her own for oh a year or more, and I was aware of her but she had not contacted the Alzheimer Society and finally she called. And I said 'I'd like to bring you in through the First Link program, which is just a way of making sure we stay in touch and you get the information, and so we did. So through First Link and we let the family physician know that she was now linked, we were able to link her to a wonderful women's support group that we run as a life line for her. She has attended every single learning series that came up. She went into a crisis situation, her husband ended up being admitted to hospital, but I think because of First Link she was able to get the support all the way through that and I think if she hadn't had that First Link and that ongoing contact and all those learning series, I think she would have probably floundered much sooner. She never did flounder in the end, she knew exactly what to do. So it strengthened her during those crises. I can think of other situations again where without the family physician referral, they probably never would have contacted the Alzheimer Society you know and then again I can think of situations where there would have been an early admission or there would have been a crisis, but I can't name them specifically, there's so many." [ID#30; Coordinator]

Supporting Persons with Dementia at Home

"There was one family we had referred to the Alzheimer Society support group. They were really struggling. She [person with dementia] *was leaving home, there were a lot of issues happening. The daughter was feeling like she wasn't sure what to do and just wanted to kind of touch base with them* [Alzheimer Society]*, so they followed up that way, it is nice, I know that they do connect with a lot of them and the family will call.…They had moved her into long term residential care and it was not working, she was just wanting to go home, hitchhiking and was doing some very unusual things… because they weren't ready to place her yet. It had not gone well with placement, so they had supports in the home and made everybody aware of what they were and made it as safe as possible and so I think it was positive."* [KSID#10; Health Professional]

3.4 Objective II: To Describe the Development and Implementation of the First Link Demonstration Project

3.4.1 Factors Facilitating the Development and Implementation of First Link

Interviewed project leaders and First Link Coordinators identified a number of factors that facilitated the development and implementation of First Link; these factors are summarized in Table 30. Many of these factors were identified by Project Leaders and Coordinators alike. In particular, the First Link coordinators identified the importance of health professional champions and the role of First Link in filling an identified dementia care gap. Other facilitating factors included the clear vision for First Link, support from the Alzheimer Society of Ontario, the dedicated project leader position, a consistent information system for data collection (E-Tapestry), the resilience and commitment of the First Link coordinators, the experience of the Ottawa site with First Link and the application process for selecting demonstration sites, which worked to secured commitment to First Link.

Table 30: Summary of the Factors Facilitating the Development and Implementation of First Link

Facilitating Factors:

- Clear vision
- Alzheimer Society support
- Health professional champions
- Need for service (First Link as filling an identified care gap)
- Funding
- Aging at Home Strategy
- Dedicated point person
- Consistent information system for data collection (E-Tapestry)
- Resilience and commitment of First Link Coordinators
- History/ experience of the Ottawa site with First Link
- Application process for selecting demonstration sites secured commitment

- ***Clear vision:*** The development and implementation of First Link was facilitated by a clear vision of how the demonstration project could inform the implementation of the program across the province.

> *"We had a vision for the province that recognizing that we could try it at various sites as a pilot project kind of fit in our plan that if we tried different ways and got some new strategies as how to implement it in the best way possible, the best change for people with dementia and their caregivers then maybe we would then learn and then be able to roll it out across the province."* [ID#22; Project Lead]

- ***Alzheimer Society support:*** Alzheimer Society Chapters' commitment to the concept of providing a consistent experience in terms of availability of and access to services and supports for persons with dementia and their caregivers across the province and their diligence and persistence in moving this initiative forward was identified as an important facilitating factor. Similarly, it was noted that having First Link centralized through the Alzheimer Society of Ontario head office helped to facilitate the province-wide implementation of the demonstration project.

- ***Health professional champions:*** Support from individuals, particularly physicians, psychogeriatric resource consultants, and geriatricians, and groups (health teams, specialized clinics), who advocated for referrals to First Link during case conferences and team discussions, provided their peers with information about First Link, provided positive feedback to patients and families and regularly referred patients to the program, were described as instrumental to the implementation of First Link.

  > *"There has been some really good physician leadership. Physicians who have seen the worth of the program and have promoted it locally and nationally."* [FGID18-20: Project Leads]

  Similarly the openness of health professionals to meet with First Link coordinators, and others who facilitated access to health professionals (e.g., pharmaceutical representatives who supported First Link presentations during physician's dinners) were identified as facilitating implementation of the program.

- ***Need for service:*** It was noted that one of the reasons that First Link has been successful is that it was a needed service that filled an existing gap in dementia care.

  > *"The other thing that worked really well was the fact that it was needed. It was a program that was definitely identified as a need. We saw where the gaps were in the referral process from primary care to the chapters and it was not trying to sell something that wasn't doable. It was something that was welcomed by the primary care practitioners in most of the communities."* [KSID#6; Project Lead]

  Similarly, it was noted that the service was highly needed by health professionals as First Link took on the responsibility of linking caregivers and persons with dementia with needed services and supports allowing health professionals to focus on assessment, diagnosis and medical management. Interview participants from demonstration sites involved with assessment noted that this service facilitated good support from physicians as this service is of benefit to them and facilitated increased referrals to First Link.

- ***Funding:*** Ministry of Health and Long-Term Care funding allowed for the development and implementation of First Link.

- ***Aging at Home Strategy:*** The potential for on-going funding through the Aging at Home Strategy, with which First Link shares common objectives, motivated and sustained commitment to this initiative.

> *"People could see that First Link was consistent with the Aging at Home Strategy when it came out in August 2007. The potential for on-going funding sustained and motivated people. Without this people might have become disillusioned."* [FGID18-20; Project Leads]

- ***Dedicated point person:*** A dedicated project manager helped to guide the development and implementation of First Link across the demonstration sites.

- ***Consistent information system:*** E-Tapestry provided an opportunity for all sites to maintain consistent information (data) on First Link clients and activities, and although there were challenges associated with this, the struggles experienced worked to bring the demonstration sites together to work on resolving common issues.

> *"There were challenges with E-Tap, no doubt about it, but it also binded people as they struggled with this."* [FGID18-20; Project Leads]

- ***Resilience and commitment of First Link Coordinators:*** It was noted that despite challenges and road blocks, those implementing First Link remained committed and devoted to the principles of the program and moved it forward and advocated for it.

- ***History/ experience of the Ottawa site with First Link:*** Ottawa's positive experience with First Link, with a well fine-tuned system in place and champions supporting the program, informed the development and implementation of the other demonstration sites and provided encouragement to those in the other demonstration sites as they could see the potential benefits of the program.

- ***Application process for selecting demonstration sites secured commitment:*** The application process used for the selection of the demonstrations sites, which clearly outlined the expectations of each chapter, was viewed as securing their commitment to implement First Link as outlined.

3.4.2 Challenges to the Development and Implementation of First Link

Interviewed project leaders and First Link Coordinators identified a number of challenges related to the development and implementation of First Link; these challenges are summarized in Table 31. Many of these challenges were identified by Project Leaders and Coordinators alike, in particular Coordinators identified challenges related to the limited infrastructure that was in place when First Link was launched, the difficulties associated with data collection via E-Tapestry, different organizational cultures across Alzheimer Society chapters which challenged their ability to provide a consistent service across chapters, leadership issues, establishing relationships with physicians and developing a mechanism for consistent follow-up of clients. Other challenges, included language and communication difficulties, the Alzheimer Society's shift from charitable organization to intervention service, human resource issues, and initial confusion about the role of First Link within the Alzheimer Society.

Table 31: Summary of the Factors Challenging the Development and Implementation of First Link

Challenges
• Limited infrastructure in place at time of launch • Terminology and communication difficulties • E-Tapestry (data collection) • Different organizational cultures across the Alzheimer Society Chapters • Project leadership issues • Shift from charitable organization to intervention service • Establishing relationships with physicians • Human resources issues • Initial confusion about the role of First Link within Alzheimer Society Chapters • Developing a mechanism for consistent follow-up of clients

- ***Limited infrastructure in place at time of launch:*** Lack of infrastructure, including marketing and communications strategies, limited technology (computers) and IT support, and data tracking mechanisms challenged coordinators to implement the program at the time of program launch.

- ***Terminology and communication difficulties:*** In moving the program forward the demonstration sites had to work together to create a common language to consistently describe what they were communicating about. Struggles were often resolved once it was discovered that certain language was being used to describe different things. As an example, there were great difficulties defining some of the fields included in E-Tapestry, such as who is the First Link client (the person with dementia? the caregiver?), as this definition differed across the sites.

- ***E-Tapestry:*** The development and implementation of E-Tapestry was a challenge as related to setting consistent definitions of the data being collected, how to use the software (data entry), and understanding the importance and potential benefit of having a technology-based and uniform information system. Data collection also required a degree of diligence to enter and monitor data collection so that discrepancies/ problems could be identified and resolved early. Challenges were related to the time consuming nature of data collection, limited manpower, limited experience/ expertise with the technology and limited IT support. As mentioned earlier, although E-Tapestry was a challenge, it also helped to unit the group of coordinators.

- ***Different organizational cultures across the Alzheimer Society Chapters:*** Attempts to provide a consistent and uniform service across the demonstration sites, while still allowing for regional uniqueness, was challenged by the different organizational cultures that exist across the chapters, so that the different ways of doing things among the chapters made it sometimes difficult to develop consistent processes among the demonstration sites as well as within the demonstration sites (for those sites consisting of more than one chapter). This sometimes made it challenging to provide equal access to First Link across all of the demonstration sties. Related to this, it was noted that in some instances there were different expectations of the First Link Coordinator across the chapters within a demonstration site.

> *"A staff person was hired, but we didn't do enough I think in terms of insisting the chapter to absorb that role into their chapters. We had some difficulty where there was a First Link coordinator hired for three chapters. Each of those three chapters would have a different culture, and different expectations of what that role was. I made an assumption that the chapters would all be in agreement in terms of partnership with that role."* [KSID#22; Project Lead]

Consistent with this, it was noted that some chapters were more supportive of First Link than others, with some chapters making few referrals to First Link in preference of maintaining their current process of providing service.

- ***Project leadership issues:*** Several coordinators noted that they were initially challenged to implement the program due to lack of clear direction and minimal communication from their immediate leader. It was noted that as the program was initially developed and implemented there were so many issues to deal with that problem-solving became reactive without attention to the how solutions impacted other components of the program.

> *"The process became reactive rather than proactive. We didn't always feel as if we were being led."* [FGID18-20; Project Leads]

- ***Shift from charitable organization to intervention service:*** The Alzheimer Society's shift to providing increasing amounts of intervention services (more support groups, more counselling, assessment services) was described as a huge shift in practice and philosophy as maintaining an intervention service required new processes in place (e.g., data collection).

> *"Collecting client information was interesting because we were asking questions we weren't used to asking"* [FGID18-20; Project Leads]

Similarly, it was noted that it was challenging to move First Link from a service that provided community support to one that supported primary care health professionals toward a disease management model, as this required the Alzheimer Society to reposition itself within the health system, to change it's philosophy and culture of doing business, and to develop new linkages consistent with how people work within the health system.

- ***Establishing relationships with physicians:*** Trusting relationships between First Link and primary care physicians were viewed as critical to the success of the program. Coordinators were challenged in their efforts to establish relationships with these physicians, to access them and effectively promote the program with them. However, it was also noted that this is an ongoing challenge that for the most part has been an important success and strength of the program.

  > *"It takes time to get around. It takes a lot of time to develop the relationship with the secretary who will then open that door, but whenever I sort of wouldn't get past the nurse or the secretary and it was nurses, I didn't have the same positive outcome. But I needed to get to the doc and then I was a winner. So it took a lot of time to work that through and to make those phone calls and be patient and get the appointment set up. So I think time sort of made a difference there."* [KSID#33; Coordinator]

  Similarly, it was noted that providing education to physicians about assessment and diagnosis was challenging and not entirely successful for a number of reasons: In cities/towns affiliated with a medical school or university, continuing medical education was considered their domain; physicians were reluctant to accept medical education from non-physicians; physicians had other priorities for education; or did not feel they needed additional knowledge on assessment and diagnosis.

- ***Human resources issues:*** With the increasing success of First Link there was increasing demand for services. Each Alzheimer Society chapter has faced human resources challenges related to how they can most effectively and efficiently respond to increasing referrals for services. Some of these challenges are related to how each chapter is organized to deliver their services (for example, policies and procedures regarding registration, delivery, and administration of various programs and services).

- ***Initial confusion about the role of First Link within Alzheimer Society Chapters:*** It was noted by several coordinators, that as First Link garnered attention and demands for First Link increased, there was some confusion of the role that it played within the services offered by the Alzheimer Society chapters. In some respects the emphasis of the implementation was on the First Link coordinator role rather than on the roll out of the program and how each chapter would implement the program.

  > *"I went into First Link with the approach that the real innovation was the referral partnership. The direct referrals and need to establish relationships with referral sources. I began to hear back that people were trying to figure out whether or not First Link was focused on the First Link coordinator or the entire work of the chapter. Some staff within the chapter resented the First Link staff, that they were getting special attention."* [ID18-20; Project Leads]

- ***Developing a mechanism for consistent follow-up of clients:*** With the increasing referrals to First Link, it became difficult for the coordinators to follow-up with clients who may not have yet engaged with the Alzheimer Society.

> *"The hardest part I think is developing, for us, was doing that follow up, particularly if you have 250 referrals that come in to your chapter in First Link in the first year, trying to develop a system for follow-up if they don't attend the learning series, or don't join the support groups. How do we keep in touch with those folks?"* [ID#30; Coordinator]

3.4.3 Lessons Learned

Interviewed project leaders and First Link Coordinators were asked to identify lessons learned in the development and implementation of First Link that could serve as advice for other Alzheimer Society chapters planning to implement First Link; these are summarized in Table 32. It was noted that to be successful there should be one coordinator per chapter who should secure their champions, have ongoing engagement with health professionals, and in particular, face-to-face interaction with physicians, adapt processes (e.g., referral processes) to the needs of referral sources, develop a system for direct follow-up of First Link clients to ensure their access to needed services and supports and take advantage of resources in the community to support information and learning sessions. Other key lessons learned included the need for a clear work plan and infrastructures in place prior to the launch of the program, the need for adequate funding, preparedness for increased demands in service, and clear articulation of the appropriate competencies for the First Link Coordinator role.

Table 32: Summary of the Key Lessons Learned in the Development and Implementation of the First Link

Lessons Learned:

- Develop a clear work plan prior to implementation
- Infrastructures should be in place prior to launch
- Have one coordinator in place for each chapter
- Ensure availability of adequate funding
- Secure champions
- Ongoing engagement with health professionals
- Face-to-face engagement of physicians
- Adapt processes to the needs of referral sources
- Preparedness for increased demand in service
- Develop processes to ensure direct follow-up of First Link clients
- Need to understand the value of First Link
- Need to articulate the appropriate competencies for Coordinator role
- Take advantage of resources available in community to support information and learning sessions

- ***Develop a clear work plan prior to implementation:*** It was noted that in some cases challenges experienced in the demonstration project were related to the lack of a clear work plan prior to the implementation of First Link. A work plan should include marketing and communication strategies, objectives and goals, and roles and responsibilities of the First Link Coordinator and Alzheimer Society chapter staff. As an example, brochures describing First Link were not available until 10 months after the launch of the program; for effective implementation these should have been available at the launch.

  > *"Get your ducks in a row before you get going. Decide as a chapter who's going to do what, how you're going to roll it out, how is the process going to be."* [ID#33; Coordinator]

- ***Infrastructures should be in place prior to launch:*** Dedicated staff to oversee implementation (e.g., Project Manager role) was considered essential to oversee implementation across the demonstration sites, as well as clear processes (referral, service coordination) within each chapter.

- ***Have one coordinator in place for each chapter:*** Challenges experienced by First Link coordinators who were assigned to more than one Alzheimer Society chapter as well as the increased referrals and demand for services highlight the need for one First Link coordinator per chapter. It was also noted that dedicated staff to First Link should be full-time to ensure effective implementation of the program.

- ***Ensure availability of adequate funding:*** It was noted in hindsight that not enough funding was secured for infrastructure expenses (e.g., database development, interface across sites, space), as most of the funding of the demonstration project went to direct service expenses.

- ***Secure champions:*** The value of champions external to the Alzheimer Society was viewed as important to promoting the program among health professionals within their own organizations. Relationships with health professionals who are trusted and respected among their colleagues should be nurtured and supported.

- ***Ongoing engagement with health professionals:*** Outreach to health professionals was described as an ongoing process requiring patience and persistence; relationships with health professionals need to be nurtured.

  > *"I think that physicians and primary health care providers, whether they're a nurse practitioner or other key partners in the community want to help their patients, but they need to be reminded as to how we can do that. So I think that my advice would be you have to keep at them, keep building that trust in that relationship and don't give up, because they said no, we don't' have time or we don't' know anything about you so we're not doing it. The idea was I think you have to have persistence in terms*

> *of making sure those relationships are maintained as well as developed. "[*KSID#22; Project Lead]
>
> *"You need to emphasize the benefits. "This is how I can help you." Don't ever think a doctor will remember you. You need to go to see them at least twelve times and to keep going even if you've been there three times before. Be persistent."* [ID#34; Coordinator]

- ***Face-to-face engagement of physicians:*** It was noted by many of the coordinators, that First Link has its greatest success when coordinators are able to promote the program to physicians face-to-face rather than in written material.

> *"Lessons learned, well for primary care providers for sure, face to face is best. Letters, mailings, I think are a waste of time. I don't think they read. I did try a newsletter, that was a pretty sharp looking package but I don't know if it was read or not, but I thought well if they open it just see First Link, it'll be a memory jogger if nothing else. But certainly that face to face contact, being able to present First Link in terms of what it will do for them, and what it'll do for their patients, keeping the message and keeping the whole, the whole thing as simple as possible."* [ID#33; Coordinator]

- ***Adapt processes to the needs of referral sources:*** To engage ongoing support of physicians and other health professionals it was noted that First Link needs to adapt to their needs, particularly around the referral process. It was noted that while most health professionals accepted the referral pads, others wanted the referral process integrated into their electronic medical record system.

- ***Preparedness for increased demand in service.*** A key lesson learned in the demonstration project was the notion of "*if you build it, they will come.*" New First Link programs need to be prepared to meet the increased demands for service by identifying prior to implementation what they will need to provide service and ensure that it is in place.

> *"I'd also recommend that the chapter sort of prepares themselves for new referrals. If you're going to do outreach then you have to be prepared that they're going to come."* [ID#22; Project Lead]

- ***Develop processes to ensure direct follow-up of First Link clients:*** Direct contact with First Link clients on a regular basis was perceived as critical to ensuring that all caregivers and persons with dementia have access to needed supports and services. A system is needed for identifying those who require follow-up and ensuring that follow-up is completed in a regular and timely manner.

- ***Need to understand the value of First Link:*** It was noted that it is important to understand the "value proposition" of First Link – that the value of First Link is based on what the client values and that the process is *"transformative of the client throughout their experience with First Link"*.

- ***Need to articulate the appropriate competencies for the First Link Coordinator role:*** It was noted that the competencies for the coordinator role are multifaceted and it may be unrealistic to expect that any one person will be competent at all areas. Passion for dementia care was identified as an important criterion for First Link Coordinators, as well as ability to promote and "sell" the program.

  > *"The coordinators, they had to be the outreach person, in terms of marketer and doing cold calls with doctors and almost a sales type position. We also expected them to do education and be team builders and to communicate with care givers. It could have been a super human person that could have done everything we were looking for. "* [KSID#22; Project Lead]

- ***Take advantage of resources available in community:*** Creating partnerships with other professionals within the community, such as lawyers, pharmacists, community service provider agencies can enrich information sessions, as these professionals can be invited to be guest speakers to share their tools and experience.

3.4.4 Suggestions for improvements and Sustainability: Results of Interviews with Key Stakeholders

Key stakeholders (health professionals and Alzheimer Society representatives) identified a number of strategies for improving and sustaining the services offered by First Link and the Alzheimer Society (these are summarized in Table 33), namely the need to secure ongoing funding to ensure availability of services that are perceived as critical to the care of persons with dementia and their caregivers. Related to programming, it was suggested that there be ongoing education about memory loss and ADRD, ongoing promotion/ marketing of services and supports available through the Alzheimer Society, clarification of the First Link mandate, development of individual peer support programs, programs targeted specifically to different age groups, more education on delirium, and less emphasis on "Alzheimer" in the Society's name (consideration of a name change). Related to health professionals, it was suggested that better strategies are needed to engage physicians in the referral process, as are more educational opportunities for physicians. It was suggested that health professionals should receive immediate and detailed feedback on client involvement with the Alzheimer Society and receive information on the learning series content so that they can better promote the program.

Table 33: Key Stakeholder Suggestions for Improving and Sustaining the Services and Supports Offered by First Link and the Alzheimer Society

Improvement/ Sustainability Strategies

- Secure Ongoing Funding
- Programming:
    - Provide ongoing public education about memory loss and ADRD
    - Provide ongoing promotion/ marketing of Alzheimer Society services
    - Clarify First Link's mandate
    - Develop individual peer support programs
    - Target information delivery and programs to different age groups
    - Develop more education on delirium
    - Reduce emphasis on "Alzheimer" in the society name (consider name change
- Health Professional Support:
    - Develop strategies to better engage physicians
    - Provide more opportunities for physician education about ADRD
    - Provide immediate and detailed feedback on client involvement with Alzheimer Society
    - Provide health professionals information on learning series content

- ***Secure Ongoing Funding:*** It was noted by both Alzheimer Society representatives and health professionals that there is a need to advocate for First Link to be publically funded as a core component of all Alzheimer Society Chapter programs to ensure equal access to the service across the province and country. It was noted that on-going funding, is needed, particularly in Kingston which did not receive based funding to continue the program. Ongoing funding should be targeted for public education, advocacy, and support functions, particularly for those individuals who do not have family support, as reflected in the following comments:

> *"I think that educational and support piece of the Alzheimer Society has to be funded. You need to have some trustworthy consistent community resource where families can receive the help they need and because of the nature of dementia, it has to be initiated outside the patient's family…I'm the squeaky wheel in my family. I'm a health care provider, I know what's out there, I advocate. People who have advocates might get help, but that's not much of the population and it's the people who live in the north end of the city who are struggling to get by on social assistance. Those people are not getting help. Unless an authority figures say you have the right, there is something for you and I'm going to have them call you. Then they get it, but otherwise I have seen people muddling along in the most ghastly circumstances because they couldn't be bothered, they won't ask for help, they've got it for other people, but not for them. So we have a huge portion*

> *of the population that's not being served unless there's a First Link."* [KSID#10; Health Professional]
>
> *"It's almost a shame that the programs offered are coming from a charitable organization, because in a sense they are health care treatments, sort of like treatments people get for depression or other mental health issues. They should receive ongoing funding just as any other heath care service. The education and support programs are really important for the survival of these families. There's no cure for Alzheimer's disease so what the Alzheimer Society does is really the treatment for this disease."* [KSID#32; Health Professional]

To this end, it was suggested by one interview participant that the program needs to be promoted to policy and decision makers as an efficient use of health system resources, as reflected in the following comment:

> *"First Link certainly needs to let the hospital administrators know and the politicians know that this type of out-patient activity is saving the system money and is helping the aging at home process, the aging at home being the sort of hot ticket item right now."* [KSID#15; Health Professional]

Related to funding, it was reported by several interview participants representing the Alzheimer Society that there is a need for more resources (human, physical) to meet the increased demands for services and supports created by First Link. Specifically, it was noted that there is a need for:

- Full-time First Link Coordinators, as Coordinators in part-time positions are stretched and there are delays contacting clients or returning calls or responding to inquires.
- More counsellors to avoid waiting lists and to prevent crisis situations.

Programming:

- ***Provide Ongoing Public Education about Memory Loss and ADRD:*** It was noted that ongoing education of the general public on the early signs and symptoms of ADRD, potential treatments to delay decline, and how to advocate for screening and assessment is critical to ensuring early diagnosis and intervention.

> *"The important thing is really getting the general public to understand about dementia and the signs and the symptoms so that they can either get help that they need for themselves, or if children or other family members recognize the signs and symptoms in somebody else they can get the helps that's needed."* [KSID#26; Health Professional]

- ***Provide Ongoing Promotion/ Marketing of Alzheimer Society Services:*** To promote early detection, improve access to services and resources, and reduce the stigma associated with Alzheimer disease it was noted that there be ongoing marketing of the variety of services offered by the Alzheimer Society. It was suggested that regular multi-media resources (television, radio, newspaper) be used to educate the general public about ADRD and the Alzheimer Society.

It was noted by an Alzheimer Society representative that although First Link has been marketed to those who are newly diagnosed with ADRD, it is not clear that this is the group that is currently accessing the service. Marketing should be targeted, in addition to the newly diagnosed, to those living with the disease at middle and late stages of the disease, as reflected in the following comment:

> *"I think the marketing of it up to this point has been focused on individuals newly diagnosed with Alzheimer's disease and I don't know that that's necessarily who we're providing the services to. We may have some people who've been living with the disease for years, but aren't willing to face it and have never contacted us. But then they hear about First Link and they think well maybe that's the way to go. It's not really a program only for people newly diagnosed. It's really for people who are living with Alzheimer's disease. And the learning series is for all stages of the disease. For those who are newly diagnosed they're not going to want to hear the sessions about the end stages of the disease, that's part of the learning series."* [KSID#3; AS Rep]

- ***Clarify First Link's Mandate:*** It was noted by one Alzheimer Society representative that there needs to be some clarity as to who the First Link client is – the caregiver or the person with dementia, or both, as there is no consistent definition of what this is. It was also suggested by a health professional that the role of First Link within the Alzheimer Society needs to be clarified as some professionals are confused about whether access to services is different with First Link in place.

- ***Develop Individual Peer Support Programs:*** It was noted by several Alzheimer Society representatives that in addition to the group support programs that are offered, there is a need for one-to-one support provided by other caregivers as there are some issues that people would like to discuss privately rather than in group setting.

- ***Target Information Delivery and Programs to Different Age Groups:*** It was noted by an Alzheimer Society representative that the format in which information is shared with Alzheimer Society clients needs to be consistent with the age group accessing their services: Younger people access information via the internet and other technologies, so the Alzheimer Society should endeavor to develop strategies to engage younger age groups in ways that are relevant to their generation. Similarly, the needs of younger persons with dementia are different from those of older persons with dementia, and thus information and programming should be different for these age groups.

- ***Develop More Education on Delirium:*** There is a need for more education on delirium, signs and symptoms, and how to request assessment, as reflected in this comment:

> *"One thing I was hoping for would be to educate the client, to educate the family about delirium. It's a huge role of First Link, sending out information, but a little more information or resources related to delirium would be useful to educate the families on*

> *what to look for and how to ask for a delirium work up. That's helpful."* [KSID#12; Health Professional]

- ***Reduce emphasis on "Alzheimer" in the Society name (Consider name change):*** It was noted by several health professionals that there continues to be a stigma associated with the term "Alzheimer disease" and that people, particularly those experiencing memory loss in the absence of a formal diagnosis of cognitive impairment, those with MCI, or early onset dementia might be more receptive to accessing the services of the society if the term "Alzheimer" was not in its name. It was suggested that a name change for the society be explored further.

> *"The association with "Alzheimer disease" is really scary for people. People have said to me "I just don't know if I would ever get mom down there." If it was called something else people might be more willing to go. I'm not sure what you would call it, but something less threatening. First Link is a great name. It describes what it does and it's in no way scary or threatening. Actually, it does sound a little hopeful doesn't it? That you'll get linked to help. Because, really these people are looking for help."* [KSID#32; Health Professional]

Health Professional Support:

- ***Develop Strategies to Better Engage Physicians:*** Several interview participants, both Alzheimer Society representatives and health professionals identified the need to develop more strategies and more effective strategies for securing physician support, as it is currently difficult to engage physicians in awareness raising and education activities. Although many physicians have been engaged, many family physicians still have a limited understanding of how First Link can benefit their patients. Given the difficulties that First Link Coordinators face in trying to access physicians, it was suggested that within FHTs or CHCs it might be better to secure the support of nurse practitioners, nurses, and other allied health professionals who can promote and champion First Link with physicians, as reflected in the following comment:

> *"I think it's difficult for the First Link coordinators and workers to promote themselves to the physicians because the physicians are overwhelmed with drug reps, product reps, that continually bother them and they really try and hide from them. And even though First Link isn't trying to promote for profit, there's still someone who's in the works, so I think the best way that First Link can probably access physicians is through the staff, such as myself, who get on board and then communicate via email messages and just whenever we have meetings, and make the physicians aware that this service is there, and by doing the referrals and keeping the physicians on top of knowing that the referrals are occurring. This is probably the best because since I've been doing this a couple of months now, we at least have a couple of the physicians that are fully aware now that First Link is available."* [KSID#15; Health Professional]

It was suggested that more attention needs to be placed on meeting with physicians face-to-face to promote First Link, with an emphasis not only on how First Link can be of benefit to patients, but how it can support/ be of benefit to health professionals with the use of screening tools for monitoring changes in cognitive function, as reflected in the following comment:

> *"The other thing I think that First Link could be improved is if the Alzheimer Society got on board with the benchmarking, with the screening tools, I think that there are some great examples out there that there are chapters that are doing it, although they are very few. I think that the physicians really appreciate that support because cognitive screening tools take time and a lot of them are leery to appoint someone within their offices to administer those. If they had the support from qualified people from the chapters that they could then take that information and can put those pieces of the puzzle together along with the other screening that's required to get to a diagnosis…looking at some of the screening tools for cognition like the MMSE, like the Montreal Cognitive Assessment, doing those screening tools but for benchmarking purposes, not as diagnostic tools. The identifying of more people in the early stages, a hundred percent, is a need in each of the communities and that's why I think if the Alzheimer Society supported it, was providing this benchmarking opportunity that we'd see more and more physicians more apt and willing to administer and follow that person through the screening process as opposed to either washing their hands of it till the person is at the moderate stage, or just making that referral to a specialist when it's not necessarily required."* [KSID#6; Project Lead]

- ***Provide More Opportunities for Physician Education about ADRD***: It was also suggested that to ensure early detection of ADRD, there is a need for greater physician education about ADRD and how to screen and diagnose it, as many individuals continue to be diagnosed well into the disease process despite signs and symptoms being brought to physician's attention earlier in the disease process.

- ***Provide immediate and detailed feedback on client involvement with Alzheimer Society:*** Several health professionals noted that although they receive a letter from First Link indicating that their referral was received and contact has been made with the client, they would like more detailed feedback on how the person with dementia and caregivers have been involved with First Link/ Alzheimer Society, in terms of number of contacts, what services were needed and accessed, and any relevant outcomes that health providers should be aware of. One interview participant noted that in an acute care setting they could benefit from immediate follow-up on the referral so they could provide families with information about when they will be contacted, as reflected in the following comment:

> *"From a hospital perspective, I know when I fax it* [referral], *I know it's in very capable hands. And I do tend to get a letter months and months after the patient has gone saying thank you for the referral and we followed up with this person. My only comment sometimes is I'm more curious like right away, like if they could email or fax back a receipt to give us a time line of when they're going to contact the family. That might be*

> *more helpful so we could let families and patients go with a very concrete idea of when they'll hear from someone."* [KSID#24; Health Professional]

Similarly, a health professional suggested that to support early detection First Link should either inform family physicians that one of their patients has contacted the Alzheimer Society with concerns about memory loss, and/or that they have encouraged a client to see their family physician for screening and assessment.

- ***Provide Health Professionals Information on Learning Series Content:*** It was suggested that health professionals could better promote the learning series if they had greater knowledge of the curriculum (content covered), through perhaps a course outline and calendar of when different sessions were being delivered.

> *"I think it would be good for the primary health care providers, the one making the referral, actually to be better informed of what the teaching sessions are, like they refer them, but I think it's kind of a black box when they send them to the Alzheimer Society but many of us don't know exactly what the sessions are. The family docs will not know what the sessions are so if there's any sort of one pager or calendar, something that they can keep in their office, that can help them just remember you know, this is what families will be taught."* [KSID#16; Health Professional]

3.4.5 Suggestions for Improvement and Sustainability: Results of Interviews with Project Leaders and First Link Coordinators

Interviewed project leaders and First Link Coordinators identified a number of suggestions for improvements, sustainability and further development of First Link; some of these suggestions address the challenges that were identified earlier (See Table 34). Many of those interviewed noted that although the two-year demonstration project is over, First Link is still in its development phase (*'a work in progress'*), development and improvements to processes and services offered are ongoing. Suggestions were made regarding provision of support (material and human resources) to the Alzheimer Society chapters, centralized marketing and branding, use of technology to increase access to services and supports, particularly for those in rural and remote areas, continued support for data collection, which can be used to secure funding support, creation of more partnerships for implementation of the learning series, strategic planning for the future and promotion of a core basket of services within each Alzheimer Society chapter, while maintaining the unique culture of each chapter.

Table 34: Project Leaders and First Link Coordinators' Suggestions the for Improvement and Sustainability of First Link

Improvement and Sustainability Strategies
• Provision of support to chapters • Centralized marketing and branding • Explore use of technology to increase access to services/ support

- Support data collection
- Secure LHIN support
- Create more partnerships for the Learning Series:
- Strategic planning for future
- Maintain culture of each chapter while promoting a core basket of services

- **Provision of support to chapters:** To reduce the strain on chapters and not to impose on chapter resources, the systems, tools and materials (e.g., referral pads) needed to implement First Link should be widely available and shared among programs. Similarly, there should be support for the human resources (e.g., Family Support Worker, educators, navigation role) needed to respond to increased demands in service.

- **Centralized marketing and branding:** Promotional materials and communications should be developed by the Alzheimer Society of Ontario, allowing for opportunities for each chapter to promote their unique support resources, with branding to be facilitated by the Alzheimer Society of Canada.

  > *"The logistics of First Link should be centralized, so that chapters don't have to spend all their time if they design the brochure or a banner. There should be a centralized way that we could make sure that all the material has a brand. That branding is actually a national program, I think Alzheimer's Canada has the brand of First Link trademark. So, what would that mean then? What does it look like? So if you're in Saskatchewan or you're in Ontario, here is the First Link. When you see this you think of First Link."* [ID#22; Project Lead]

- **Explore use of technology to increase access to services/ support:** Given the challenges experienced accessing available services/ supports by First Link clients living in rural and remote areas, it was suggested that use of technologies, such as Telehealth (videoconferencing), be explored as an opportunity to increase access to learning series and support groups without the need to travel long-distances.

- **Support data collection:** Supports (manpower for data entry, IT support) are needed to ensure that data on First Link clients and services can be collected reliably and consistently. Related to this, identification of key outcome indicators to demonstrate success is needed.

- **Secure LHIN support:** Data collected on outcome indicators should be used to secure support from the Local Health Integration Networks for ongoing funding for First Link.

- **Create more partnerships for the Learning Series:** More health professionals should be engaged to assist in developing the content and delivering the learning sessions, not only to the general public but to other health professionals.

- **Strategic planning for future:** Planning should identify priorities for further implementation with clearly articulated goals and objectives.

- **Maintain culture of each chapter while promoting a core basket of services:** It was noted that while it is important to ensure that each chapter represents the unique needs of its constituency, there should be a core basket of services that are common to all chapters, one of which should be First Link.

  > *"We need to set the target that each person who encounters dementia for the first time should have access to caregiver support, education and counselling. We need to advocate for each chapter to have this, or to have it available in the community."* [ID18-20; Project Leads]

3.4.6 Needed Resources and Supports for Persons with Dementia and Caregivers

Interviewed key stakeholders identified a number of resources and supports that are either limited or not available, but that would improve the quality of life and/or care of persons with dementia and their caregivers; these included:

- A National Strategy for both Alzheimer's disease and home care is needed to ensure a consistent standard of dementia across the country.
- Improved access to screening and diagnosis – particularly in areas where there are limited geriatricians and specialized geriatric services.
  - Increased Alzheimer Society involvement in screening/ assessment
- Increased access to home support services available through the CCAC so that caregivers do not have to access private and costly services.
  - Better and more home care services
  - Greater access to housekeeping and maintenance (snow removal, grass cutting) services needed to keep people in their homes safer and longer
  - More services targeted to ensuring that persons with dementia living alone are taking their medication (e.g., daily/ twice daily in-home follow-up)
- More extensive respite:
  - after hours (evenings) and weekends
  - longer periods of time
  - increased access to short-stay respite beds
  - within home respite (day time and overnight)
- Improved access to family physicians, as many seniors are orphaned making it difficult for them to get diagnosed or referred to geriatricians
- Improved local access to geriatricians and specialized geriatric services to reduce stress created by having to travel long distances for care
- Increased access to transportation, particularly in rural and remote areas where access to programs and services becomes difficult when persons with dementia and caregivers are no longer able to drive

    - Transportation systems specifically targeted to persons with dementia
- Increased promotion of day programs as these are not utilized as much as they should be
- More supportive housing as this is currently limited
- Improved coverage from the Ontario Drug Formulary so that all relevant medications are covered and everyone has equal access to medication.
- Improved recreational-physical programs for persons with dementia
- Increased programming for those with early onset dementia (many existing programs are targeted to older adults)
- Increased access to individual counseling
- More social worker support
- Increased opportunities for friendly visiting programs
- Improved access to technological devices (e.g., GPS systems to locate wanderers) to help keep people at home safer and longer
- Financial incentives (tax credits, payments) to keep people at home longer and out of long-term care
- Improved care for persons with dementia living in long-term care
    - More staffing to attend to the needs of those with dementia
    - More dementia related continuing education for long-term care staff
    - Environmental designs to support the needs of persons with dementia

3.4.7 Next Steps: Future Goals and Objectives for First Link

Project leads and First Link Coordinators were asked to identify their future goals and objectives for First Link. The following objectives were identified:

- Demonstrate success – identifying key indicators to show success of the program.
- Secure funding for First Link programs in all Alzheimer Society chapters, particularly, Kingston, which was the only demonstration site that did not receive on-going LHIN funding for continuing the program.
- Tie First Link into a National Alzheimer's strategy.
- Develop a unified vision of First Link throughout the province.
- Develop standardized core services and learning series content.
- Ongoing quality improvement regarding record keeping (tracking data) to support goals and decision-making.
- Develop better strategies for engaging caregivers in ongoing data collection; ensuring that strategies exist for recruiting them to complete evaluation surveys.
- Articulate a clear model of counselling: exploring opportunities for a more consistent, clearer articulation of the counselling services that are offered and measurement of counselling outcomes as the effectiveness of counselling is not clear.
- Develop strategies for identifying and engaging persons with dementia and their caregivers who are struggling but have not yet been connected with First Link.

4.0 CONCLUSIONS

4.1 Evaluation Challenges and Limitations

The following challenges were experienced with this evaluation:

Referral and Service Tracking: The demonstration sites, while very committed to providing information for the evaluation, were challenged to do so by time constraints, competing priorities, and limited manpower. In particular, the use of E-Tapestry as a means of collecting information on First Link clients represented, in some ways, a new way of doing 'business' in that First Link Coordinators and Alzheimer Society Chapters were asking new things of clients and were collecting information that did not directly impact their work with the clients. The provision of clear definitions of the data being collected remained an ongoing challenge and in some cases impacted the reliability of the data that were collected. As an example, year of birth of the First Link client was collected in order to able to describe the age distribution of clients. However, with confusion as to whether the client was the person with dementia or the caregiver, sometimes the caregiver year of birth was provided, and in other cases the person with dementia's year of birth was provided. Recognizing that some of the information required in E-Tapestry would not be available for all clients, the software was set up without 'forced fields' (i.e., those entering the information were not "forced" to enter information before saving a person's file). Although, referral status (self-referral vs. referral via First Link) was known for all clients, the fact that it was not a forced field meant that there was no cue for providing this information so that in many instances it was not recorded. Similarly, client age was to be entered as a numerical variable (e.g., '69'), however, in many instances a range or approximation was provided ('84-85',' 70's', '60ish'), posing a challenge to data analysis. In a fair number of instances there was missing information. This may have occurred when clients were registered with First Link after their attendance at a learning series session without follow-up to obtain additional information for their E-Tapestry profile or when someone other than the First Coordinator (i.e., other Alzheimer Society staff) registered new clients. The number of clients registered in E-Tapestry may be an underestimation of the actual total number of First Link clients. An information system for tracking referrals was not in place until after First Link had begun accepting referrals, which may explain why an increase in referrals overtime was not demonstrated. It has been suggested that other Society staff who accepted calls from new clients in the coordinator's absence may have initiated the clients' involvement with the Alzheimer Society without informing the First Link Coordinator or formally registering them into E-Tapestry. It is likely that the information collected in E-Tapestry is an underestimation of the number of clients served by First Link and the Alzheimer Society.

Caregiver Surveys: As Coordinators were working towards developing effective therapeutic relationships with their clients, concerns were raised that evaluation demands, particularly as related to inviting clients to complete surveys and participate in interviews impacted this relationship building. Processes related to the distribution of caregiver surveys were modified to address these concerns, so that invitations to complete the caregiver surveys were left to the discretion of the First Link Coordinator. It is likely that the timing of the invitation to participate in this study, which occurred at the time of first contact with the Alzheimer Society, was one of high family stress and most likely contributed to the low response rate. To increase the response rate coordinators attempted to recruit participants from information and education sessions. This change in recruitment strategy confounded attempts to recruit participants at the time of their first contact with the Alzheimer Society; there was no way to guarantee that those recruited from learning series were new to the Society. The lack of support for hypotheses related to caregiver effectiveness and stress may be a function of the method by which these were measured, however given the low response rate this is difficult to determine for certain All of these challenges impact the representativeness of the final sample; given the low response rate caution is heeded in drawing conclusions from these data.

Survey of Health Professionals: E-mail addresses were not available for half of the health professionals who were identified to receive an invitation to complete a survey; paper-based surveys were distributed to these individuals via postal service. Consistent with what is known about survey response rates (Dillman, 2000), the use of paper-based surveys contributed to the low response, as the response rate for the paper based surveys was much lower (27%) than that of the on-line survey (41%). Attempts to increase the response rate by extending the deadline date were not particularly successful.

Survey of Key Stakeholders: According ethical research practices, potential participants were to be sent a letter of information about the evaluation interview prior to being contacted to schedule an interview. E-mail is the most time and cost efficient manner to distribute these letters and then to contact health professionals (as they are extremely difficult to reach via telephone), selection of health professionals to participate in the interviews was limited to those whose e-mail addresses were available, potentially impacting the representativeness of the sample. An attempt to increase the response rate by having the First Link Coordinators send health professionals a letter explaining the importance of the evaluation and encouraging their support was somewhat successful as a few additional health professionals expressed an interest in the interviews, though the response rate was low nonetheless (it was hoped that a total of 42 health professionals would be interviewed across all of the site, only 17 agreed to participate in the interviews).

Interviews with Caregivers and Persons with Dementia: Attempts to obtain a random sample of caregiver and persons with dementia dyads to participate in the interviews were unsuccessful. Although a random sample of First Link clients were contacted for participation, extremely few were able to participate primarily because the person with dementia was in the later stages of the disease process and was unable to participate. In some cases, the caregiver was interested in participating, but because of issues related to denial and stigma, their care receiver was not interested. Although First Link Coordinators attempted to obtain as random a sample as possible, this was not always possible so the final sample may not be representative of all caregivers and persons with dementia. Moreover, many of the in-person interviews were cancelled due to inclement weather, rescheduling these to individual telephone interviews (to meet the report timeline) compromised the optimal participation of persons with dementia.

Despite these limitations, existing evaluation data provides a glimpse into the population serviced, services provided and the impacts associated with the First Link demonstration project.

4.2 Support for Hypotheses

As part of the application process for funding from the Alzheimer Society of Canada's Research Program, hypotheses were generated to reflect anticipated differences in outcome measures according to how clients accessed the Alzheimer Society (i.e., whether they were referred via First Link or were self-referred). However it is important to note that these hypotheses focus on *access/ introduction* to the Alzheimer Society, and do not reflect access to Alzheimer Society services. Regardless of how clients are connected with the Society, all have access to the same services. These hypotheses were generated by the evaluation consultants and do not completely reflect the values of the Alzheimer Society of Ontario. The Alzheimer Society of Ontario is more interested in the goal that underlies these hypotheses, that is, whether access to the education and support earlier in the disease process is beneficial for clients.

Individuals who are referred to the Alzheimer Society via First Link will be referred sooner after the diagnosis than individuals who self-refer to the Alzheimer Society.

> ***Hypothesis Supported:*** On average, those referred via First Link clients were referred sooner after diagnosis of ADRD (an average of 11 months sooner) than those who were self-referred.

Over time, the proportion of referrals to the Alzheimer Society from health professionals (i.e., as referred by primary care physicians, specialized geriatric and mental health services, and community service providers) will increase compared with the proportion of self-referrals to the Alzheimer Society.

> ***Hypothesis Supported:*** A significantly higher number of individuals referred to the Alzheimer Society were referred via First Link (65%) than those who were self-referred (35%). Across time, the mean number of monthly referrals via First Link was significantly higher than self-referrals (114 vs. 61 per month, respectively). This distribution of monthly referrals was consistent throughout the demonstration phase.

Health professionals will report that, compared with prior to the initiation of First Link, they:

a) have a greater awareness and knowledge of the assessment and management of dementia.

> ***Hypothesis Partially Supported:*** Although the majority of survey health professionals (57%) reported that they now understand managing seniors with dementia more, for the majority of health professionals their understanding of assessment has remained the same (62%). Consistent with this, average ratings of the impact of First Link on increasing the number of individuals diagnosed with ADRD and health professionals' ability to identify or recognize dementia sooner/ earlier were low (less than 2.4 on a 5-point rating scale: 1 = not at all, 5 = very much so), reflecting that survey respondents thought that First Link had minimal impact on increasing ADRD diagnosis or on early diagnosis. These survey

findings are consistent with the finding gathered in the interviews with Health Professionals.

b) **have a greater awareness of the role of the Alzheimer Society and the First Link program.**

Hypothesis Supported: The majority of health professionals (60%) reported that they now have a greater understanding of the role of the Alzheimer Society/ First Link. Health professionals' average ratings of their familiarity with the services of Alzheimer Society were moderately high (4.0, as rated on a 5-point scale: 1 = not at all, 5 = extremely familiar). Consistent with this, the majority of health professionals surveyed (68%) reported that they refer most or all of their patients to the Alzheimer Society. These survey findings are consistent with the finding gathered in the interviews with Health Professionals.

e) **have a greater awareness of other community resources for individuals with dementia and/or their caregivers; and**

Hypothesis Supported: The majority of health professionals (52%) reported that they now have a greater understanding of the supports and services available to those with dementia. Consistent with this, average ratings of their familiarity with community support services were high (4.2, as rated on a 5- point scale: 1 = not at all, 5 = extremely familiar). These survey findings are consistent with the finding gathered in the interviews with Health Professionals.

f) **use these other community resources for individuals with dementia and/or their caregivers.**

Hypothesis Partially Supported: Although the majority of health professionals surveyed (68%) reported that they refer most or all of their patients to local community support services, the majority (56%) reported that their referral rates have remained the same despite First Link.

Caregiver stress will change over time and differ between those individuals who are referred to the Alzheimer Society by via First Link and those who self-refer. Specifically:

a) **Individuals who are referred to the Alzheimer Society via First Link will have lower ratings of caregiver stress at the time of first contact with the Society than individuals who self-refer.**

Hypothesis Supported: Although there were no significant differences in caregiver stress as rated on a 6-point scale (6 = most stress experienced) on the baseline caregiver survey between those self-referred and those referred via First Link (average ratings, 4.57 and 4.81, respectively), there were significant differences in caregiver burden ratings (Caregiver Burden Inventory scores) based on referral status. Those referred via First

Link had a significantly lower caregiver burden ratings than those self-referred (average ratings of 28.6 and 44.8, respectively; maximum score = 100, higher scores reflect greater caregiver burden).

b) **Individuals who are referred to the Alzheimer Society by health professionals will have higher ratings of coping effectiveness at the time of first contact with the Society than individuals who self-refer.**

Hypotheses Not Supported: There were no significant differences between those self-referred and those referred via First Link in coping effectiveness as measured by the Coping Effectiveness Scale on the baseline caregiver survey. Consistent with this, there were no differences in caregiver self-efficacy (ability to manage the caregiving role) based on referral status; the percentage of caregivers that reported that they were currently more able to manage the caregiver role in comparison to when their caregiver was first diagnosed was low at baseline and decreased over time.

e) **Over time, caregiver stress will be lower among individuals who are referred to the Alzheimer Society via First Link compared with those who self-refer.**

Hypotheses Not Supported: There were no significant differences in ratings of caregiver stress (as measured on a 6-point rating scale) over time between those self-referred and those referred via First Link.

f) **Over time, coping effectiveness will be higher among individuals who are referred to the Alzheimer Society by health professionals compared with those who self-refer.**

Hypotheses Not Supported: There were no significant differences in ratings of caregiver coping effectiveness over time between those self-referred and those referred via First Link.

First Link Program will have an impact on caregivers' knowledge of ADRD and use of available resources. Specifically:

a) **Caregivers' self-reported ratings of knowledge of ADRD and available resources will increase over time.**

Hypotheses Supported: Over time a higher percentage of survey respondents reported that they were currently more knowledgeable of ADRD and familiar with community resources in comparison to when their care receiver was first diagnosed than reported no changes in knowledge of ADRD and available resources.

b) **The number of resources/services/supports accessed by caregivers will increase over time.**

Unable to determine: Due to limitations with the way in which data were collected, it is not possible to verify whether there has been an increase in the number of resources / services/ supports accessed by caregivers. However, there is anecdotal information (derived from interviews with key stakeholders, persons with dementia, and caregivers) that First Link has resulted in increased access to both the services and supports available through the Alzheimer Society as well as support services (e.g., home care, Meals on Wheels, safety programs) available within the community.

First Link Program will have an impact on coordination of care and linkages to community services for non-medical management issues. Specifically:

a) The number of First Link clients/families participating in Alzheimer Society programs will increase over time, and,

b) The number of First Link referrals to community resources, supports, and services will increase over time.

Unable to determine: Due to limitations with the way in which data were collected, it is not possible to verify whether there has been an increase in the number of First Link clients participation in Alzheimer Society programs over time or whether referrals to available resources, services, and supports have increased. However, there is anecdotal information (derived from interviews with key stakeholders) that there has been an increase in the need/ demand for Alzheimer Society programs/ services as a result of the referrals generated via First Link and, similarly, and an increase in the referrals made by the Alzheimer Society to community resources, supports, and services.

4.3 Conclusions

Based on the findings of this evaluation, the following conclusions can be made:

- At a minimum 3600 caregivers representing over 3600 persons with dementia have been served by the Alzheimer Society during this demonstration project. Challenges associated with data collection, entry, and maintenance has most likely contributed to an underestimation of the number of clients that have been served.

- The evaluation has demonstrated that the objectives of First Link have largely been achieved. The new model of service access as facilitated by First Link represents a major move towards filling dementia care gaps that are well documented within the literature (Pratt et al., 2006). The new referral process ensures caregivers and persons with dementia have the opportunity to be supported as soon as possible after diagnosis and, thus, as commonly occurs, reduces first time contact with the Alzheimer Society at times of crisis. Since the inception of First Link, there have been increasing demands for Alzheimer Society services; while people are 'reached' sooner in the disease process, a large of number of individuals continue to be linked into the services and supports later in the disease process. For some of these families this occurs because they were not connected to the Alzheimer Society at the time of diagnosis (and thus the Alzheimer Society is "catching up" to reach these individuals), for others it is because they were diagnosed later in the disease process.

- The number of referrals to the Alzheimer Society via First Link were higher than self-referrals and this trend remained consistent throughout the demonstration project. It was expected that the number of referrals via First Link would have increased as the awareness of the program grew. It is not clear why this increase did not occur. It may perhaps have been due to how the program was initially marketed, or errors in how referrals were recorded. It might also be that this initial trend was missed because e -tapestry was not in place at the time the program was initiated. The data presented in this report are only those recorded in e-tapestry starting in November 2007.

- Significant headway has been made in the development of linkages and partnerships with primary care physicians, diagnostic and treatment services, and community resources and supports. Ottawa, by virtue of its history with First Link, likely has the strongest links within the local health system, but with continued efforts over time the other demonstration sites will most likely achieve the same level of health system relationships; a strong foundation to do so has been laid. Already, across sites, there are a higher percentage of referrals from physicians in comparison to earlier evaluation reports of the Ottawa pilot project. It needs to be acknowledged that First Link's foray into providing assessment and intervention services with the aim of enhancing system navigation and care coordination and the process in which this occurs represents a significant change in the Alzheimer Society's service provision and generally how they do business. This change has resulted in the need for frontline staff to change how they market and promote ('brand') themselves to effect a change in how they are perceived within the health system. The uptake of the referral process provides evidence that they have been able to do this, however this has been time-consuming and not without challenge.

- First Link has had a positive impact on increasing understanding and awareness, among health professionals, and particularly physicians regarding the role of First Link and the Alzheimer Society and other community resources available to support those with dementia and their caregivers. As well, it has positively influenced how health professionals manage dementia (from the perspective that increased partnerships with and timely referrals to First Link represents a change in how dementia is managed and impacting early intervention). First Link has had less of impact on how health professionals assess dementia. This is not surprising given that the emphasis of educational activities has focused on persons with dementia and their families and less on education for health professionals. Larger scale efforts would be required to impact health professional knowledge and practice related to assessment. Although specialists and specialized services have the expertise required for optimal screening and assessment of dementia, primary care settings have been described in the research literature as less able to do so (Callahan et al., 2006; Sachs et al., 2004). There are anecdotal reports to support this; many caregivers as well as Alzheimer Society representatives have experienced situations where primary care providers have negated the relevance of memory and behavioral concerns thus delaying the diagnosis of (and intervention for) ADRD. Related to assessment, First Link has had a significant impact on educating the general public about ADRD and providing them the knowledge and skills needed to advocate for screening and assessment on the behalf of themselves or their loved ones; increased public awareness may bring them to their care providers for screening earlier than otherwise (as evidenced by those who access First Link prior to diagnosis). Similarly, in areas where there are limited specialists and specialized assessment services (e.g., Sudbury/Timmins), the Alzheimer Society plays a significant role in the assessment of ADRD (in-home comprehensive assessments conducted by trained registered nurses); this service is welcomed by health providers who are unable to provide the same level of outreach service due to time constraints, competing priorities for health system resources, and in some cases limited resources and expertise. Clearly, physicians play a key role in facilitating referrals to First Link; a higher percentage of those referred to the Alzheimer Society via First Link had a family physician than those self-referred and those referred via First Link are referred earlier in the disease process than those who are self-referred. Continued efforts to identify optimal strategies to engage, educate and support family physicians, should yield positive results in this respect.

- First Link and the Alzheimer Society has had a positive impact on increasing understanding and awareness among caregivers and the persons they care for about ADRD and available community resources as well as on increasing their confidence in their ability to manage the disease. Although interviewed caregivers (in addition to interviewed health professionals and Alzheimer Society representatives) reported that the information and supports provided by First Link and the Alzheimer Society has reduced their stress and improved their ability to cope with the disease, the results of the caregiver surveys do not support these findings. There are most likely several reasons for this: the sample size was not large enough to detect significant differences over time, the sample may not have been representative of all caregivers, and as caregiver stress and burden were not particularly high at baseline changes may not have been easily detectable. Despite the limited data available on the Caregiver Burden Inventory (completed at baseline, but later removed from the survey), there is at least some evidence of lower caregiver burden among those referred via First Link than those self-referred, suggesting that early connections with the Alzheimer Society can impact caregiver coping. This is a significant finding as caregiving becomes increasing difficult as the disease progresses; in this study the percentage of caregivers who reported that they were currently more able to manage the caregiver role in comparison to when their care receiver was first diagnosed was low at baseline and decreased over time.

- Health professionals and other key stakeholders believe that the education and support provided by the Alzheimer Society better prepares caregivers to understand and manage the psychological and behavioral symptoms that typically result in visits to the Emergency Department and crisis-related long-term care placements, though much of the evidence on health system impacts as a result of First Link and Alzheimer Society is anecdotal. Potentially these supports may ensure an appropriate use of health system resources through the reduction of avoidable visits to the Emergency Department.

- There is much support for First Link, particularly its role in reaching out to families as soon as possible after diagnosis and throughout the disease process. It has been well received by caregivers and key stakeholders. Caregivers described the services and supports of the Alzheimer Society as a "*lifeline*" and expressed their gratitude that First Link has facilitated their participation in education sessions, support groups and for assisting them to access the resources and supports that have become essential for helping them to keep their loved one at home for as long as possible.

- One of the key elements of the First Link's success is that it builds upon existing capacity for dementia care within the community. Increased engagement of and collaboration with primary care, diagnostic and treatment services and community resources and services is a significant outcome impacting the Alzheimer Society's success. Suggestions made for improving and sustaining First Link have the potential for further capacity building. In addition to resource supports (funding, information systems, enhanced programming), opportunities for health professional support and continued promotion/ marketing of First Link will strengthen its ability to achieve its objectives.

- Further development, implementation, and expansion of First Link have the potential to significantly impact early detection and quality of dementia care. First Link is a model of optimal service access and delivery for other regions in the province, as well as other disease-specific organizations/agencies aimed at improving chronic disease management. Lessons learned in developing and implementing First Link in this demonstration project can be used to inform the development of First Link in other areas.

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