

First Link Demonstration Project: Final Evaluation Report Executive Summary

Submitted to: Alzheimer Society of Ontario

Submitted by: Carrie A. McAiney, PhD
Loretta M. Hillier, MA
Paul Stolee, PhD

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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 2007¹ 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%);

¹ 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%), $\chi^2 (1) = 303.7, p = .001$.
 - 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 an 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) AD/DRD. 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 AD/DRD (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 AD/DRD 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.