First Link Saskatchewan Demonstration Project: Final Evaluation Report

Submitted to: Alzheimer Society of Saskatchewan

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

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Glossary of Terms

ADL/IADL	Activities of Daily Living/ Instrumental Activities of Daily Living
ADRD	Alzheimer Disease and Related Dementias
AS	Alzheimer Society
ASO	Alzheimer Society of Ontario
CPAS	Client Patient Access Services
LTC	Long-term Care
OT	Occupational Therapy
SD	Standard Deviation[1]
SGS	Specialized Geriatric Services

[1] The average distance between individual scores from the overall average score.

EXECUTIVE SUMMARY

First Link Demonstration Project

Introduction: 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).

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 name 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.

First Link started in Ottawa, Ontario, as a coordinated support and education initiative led by the Alzheimer Society of Ottawa in collaboration with the Dementia Network of Ottawa. 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 (2007-2009). Shortly after the demonstration project launch in Ontario, Saskatchewan launched a demonstration project, operating out of Regina and Saskatoon. Funding for the evaluation was provided by an Alzheimer Society of Canada research grant. First Link in Saskatchewan was launched in 2007.

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 as implemented by the Alzheimer Society of Saskatchewan.

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)**.** The evaluation methods used in this evaluation were similar to those used in the evaluation of First Link in Ontario.

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 signed consent to share their name and contact information by telephone, fax, or email with the Alzheimer Society so the Society can contact them);
ii) a verbal recommendation by a health professional for the patient or caregiver to contact the Alzheimer Society; and
iii) independently, with no referral or recommendation.

For the purposes of this evaluation, 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. Note: The term "client" refers to an individual who registers with the Alzheimer Society, although this is most frequently caregivers of persons with dementia, occasionally the client is a person with dementia.

Sources of Information:

- ***Referral and Service Tracking*** data collected in e-tapestry (an electronic database) starting in October 2007[2] to December 31, 2010.
- ***Information, Education, and Awareness Raising Activities Tracking*** data collected by First Link Coordinators from April 2007 to December 31, 2010.
- ***Caregivers of Persons with Dementia*** who completed a baseline questionnaire (N = 43) 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 (19%); the response rate to the follow-up surveys tended to be higher, ranging from 9% to 72% per follow-up survey.
- ***Health Professionals*** (N = 19) 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 = 9) was interviewed to gather more in-depth information about these indicators.
- ***Alzheimer Society representatives*** (N = 4) 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 = 5) 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 = 13) associated with each provincial office 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 October 1, 2007 to December 31, 2010, 502 individuals were registered as Alzheimer Society of Saskatchewan clients as recorded in E-Tapestry.

- A significantly higher percentage of clients (61%) were registered with the Saskatoon office than the Regina office.
- The majority (78%) of clients were women and the average age of clients was 61 years, though they ranged in age from 22 to 100 years.

[2] Referrals to First Link were collected manually until April 2009 when an information system (E-Tapestry) was installed to track referrals. Direct referrals and some, but not all, self-referrals prior to April 2009 were entered into E-Tapestry retrospectively.

- Although some clients (2%) were the person with dementia themselves, the majority (94%) were either family members or friends of the person with dementia, the majority of these individuals being a child (54%) or spouse (31%) of the person with dementia.
- The majority of persons with dementia were female (52%). They ranged in age from 46 – 98 years, with an average age of 79 years. Although a large percentage of clients represented individuals diagnosed with Alzheimer Disease (27%) or with a related or unspecified dementia (51%), some were without diagnosis (27%).
- ***Referral Status:*** Overall, a significantly higher number of individuals were self-referred to the Alzheimer Society (61%) than those who were referred via First Link (24%), χ^2 (1) = 78.4, p = .001. There were significant differences in the percentage of referrals via First Link across the two provincial offices: a higher percentage of clients were referred via First Link through the Saskatoon office (33%) then through the Regina office (10%), χ^2 (1) = 29.9, p<.001.
    - The mean number of clients who were referred on a monthly basis via First Link, was significantly lower than the mean number of clients who were self-referred, $F(1,54) = 8.0$, p<.01. For those who were self-referred, the number of monthly referrals ranged from 1 (October, 2007, January, February, and October 2008) to 25 (January 2010), with the average being 8.2 (SD = 7.0). For those who were referred via First Link, the number of monthly referrals ranged from 0 (October, 2007, January, February, and October 2008) to 19 (January 2010), with the average being 4.0 (SD = 4.0). In 2009, referrals remained relatively consistent, with a few spikes in self-referrals (March, July and October), however in January 2010 there was a sharp increase in both self-referrals and referrals via First Link, after which time monthly self-referrals remained higher than in 2009 and referrals via First Link declined back to 2009 rates. The number of self-referrals and referrals via First Link dropped in November (4 and 2, respectively) and December (7 and 1, respectively).
    - The Alzheimer Society, telephone directory, friends and family and other sources (e.g., clergy, library, other organizations and groups) were the most frequently identified sources of information about the Alzheimer Society as reported by those who were self-referred to First Link. Although there were no significant differences between the provincial offices in the percentage of self-referred clients who heard about the Alzheimer Society from the various sources of information, more clients from the Saskatoon office (11%) heard about the services and supports available at the Alzheimer Society from the Regional Health Authority (via assessment agencies, home care, adult day programs, and LTC facilities) than those from the Regina office (4%).
    - Generally, there were few differences in demographic information between those self-referred and those referred via First Link. The mean age of clients referred to the Alzheimer Society via First Link was significantly higher (67 years) than those self-referred (59 years), $F(1, 201) = 11.7$, p<.000.
    - On average, those who were referred to the Alzheimer Society via First Link were referred sooner after the diagnosis of ADRD (6 vs. 17 months, respectively; or average 11 months sooner).

- Although a low percentage of clients were self-referred or referred via First Link to prior to the diagnosis of ADRD (4% and 8%, respectively), a greater percentage of those who were referred via First Link were referred within the same month of diagnosis (31%) and within one year of diagnosis (47%) than those who were self-referred (7% and 17%, respectively), χ^2 (1) = 201.2, p<.001). There were minimal differences in the percentage of self-referred clients and those referred via First Link that were referred later, in the first few years following the diagnosis (14% vs. 12%, respectively).
- In total, a small perception of contacts with First Link were considered a crisis (12%), however, a significantly higher percentage of clients who were self-referred to the Alzheimer Society (15%) perceived their contact as a crisis than those who were referred via First Link (3%), $\chi^2(2) = 15.5$, p<.001.

Information and Awareness Raising Activities:

- Alzheimer Society staff conducted 373 awareness raising presentations and 52 displays accessing 9,095 individuals in the process.
- Awareness raising activities included visits to family physicians, Memory Clinics and other specialized diagnostic and treatment services to provide information about the goals and objectives of First Link and services provided, 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.
- The First Link Coordinators provided or coordinated 444 hours of education with a total of 1,250 people in attendance. In total 34 Alzheimer Society volunteers spent 102 hours supporting the First Link Learning Series (Care Essentials and Options for Care).
- In terms of the number of contacts that First Link had made with Alzheimer Society clients (e.g., to share information, invite them to education series, respond to their queries), in total Alzheimer Society staff had 3,352 client contacts, with the number of contacts per fiscal year ranging from 800 – 892.

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

Nurturing Partnerships:

- In terms of referring practices, those involved in making referrals noted that they frequently recommend First Link, however, only a small proportion consent to being referred (interview participants reported that 40 – 99% of eligible clients do not provide consent for a referral to First Link). Potentials reasons for the limited consents for referral included: stigma and embarrassment at the diagnosis, denial or resistance to the diagnosis, feeling so overwhelmed at the time of diagnosis that they are unable to make a decision about the referral, and geographical distance for those in rural and remote areas of the province. It was also suggested that those diagnosed with dementia think, despite being told otherwise, that because they don't have Alzheimer Disease the services offered by the Alzheimer Society would not be relevant to them.

- Generally all of the health professionals noted that that referral process is extremely easy, straightforward, and user friendly and that communication with First Link to share or obtain information is very easy. Despite the ease with which referrals are made, the requirement for signed consent from the person with dementia was identified as a significant barrier to referral, particularly in cases where the recommendation for First Link is made over the phone. It was suggested that the acceptance rate for recommendations to First Link would be higher if verbal consent was acceptable for a referral.
- Interviewed health professionals described partnerships with the Alzheimer Society as significant as health care and service providers are limited in the education and support they can provide to persons with dementia and their families. Several key stakeholders noted that they are limited in the amount of time they are able to spend with persons with dementia and caregivers, so the Alzheimer Society provides a service that complements and supports the work that they do. Several health professionals involved in assessment and diagnosis acknowledged that at the time of diagnosis patients and caregivers are so overwhelmed by the diagnosis that their receptivity to information and education is limited. The Alzheimer Society is able to access people at time when they are more receptive to information and support.
- Alzheimer Society representatives identified partnerships with community services and assessment clinics as critical to the success of First Link and their ability to provide timely access to information and support to clients and to do so in a way that supports the work of health professionals.
- It was noted that partnerships with experts in the field and with Telehealth, have been critical to the quality and delivery of the Learning Series. The Alzheimer Society's partnership with Telehealth has allowed them to increase access to the Learning Series for people who live in rural and remote areas at no cost to the Society or participants. Similarly, the involvement of local experts in facilitating the Learning Series has increased the quality of the sessions and has further enhanced linkages with the Society.
- Health Professionals were very satisfied with the services provided by the First Link as reflected in the mean satisfaction rating of 4.2 (SD = .71; as rated on a 5-point scale: 1 = not at all satisfied; 5 = extremely satisfied). Many of the comments made about First Link reflect satisfaction with the services and supports provided to health professionals as well as to persons with dementia and their care partners.

Providing Progressive Education:

- ***Impact on Knowledge:*** Almost 85% 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.

- ***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.
    - Many survey respondents commented that many of the clients that they work with have already been diagnosed so they are unable to comment on the impact of First Link on increasing diagnoses. Others noted that health professionals responsible for diagnosis are skilled to do so and other respondents noted that individuals with memory concerns believe that this is inevitable so do not seek a diagnosis, or wait until the disease is advanced.
- ***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 (59%) and community support services (56%).
    - Although the majority of survey respondents (59%) 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; 31% reported that they are now referring more patients to community support services as a result of First Link.
- ***Impact on Dementia Care:*** While interview participants did not think First Link has had a direct impact on increased detection of ADRD, as expertise for assessment and diagnosis exists in the province and detection is primarily a function of access to assessment (e.g., Rural and Remote Memory Clinics), it was noted that First Link has been instrumental in reinforcing the need for early intervention and has provided a resource to ensure access to early intervention.
    - Many key stakeholders noted that First Link/ Alzheimer Society's provides information and support at a level that they are not able to provide, in terms of time, expertise and resources.
    - Alzheimer Society representatives identified a need for increased education among health professionals, particularly physicians. It was noted that many clients continue to struggle with difficulties getting a diagnoses, either because their physician attributes memory loss to normal aging or suggests that assessment is not necessary. Similarly, it was noted that some clients are receiving inaccurate information from their physicians regarding treatment for cognitive impairment. It was noted that access to early diagnosis is better in the Northern areas of the province due to access to diagnostic centres such as the Rural and Remote Memory Clinics and the Geriatric Evaluation and Management (GEM program.

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 the scores, ranging from 13 to 30 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). 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:*** Caregiver survey respondents' mean ratings of stress remained relatively consistent across survey times (ranging from 4.0 – 4.3 on a 5-point rating scale. There were no significant differences in ratings of caregiver stress across survey times or by referral status. Interviewed caregivers reported that their stress reduced with the services and supports provided by the Alzheimer Society.
- ***Helpfulness of First Link Information:*** Forty to 49% 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. Ratings of the usefulness of this information were moderate with ratings of usefulness generally decreasing over time.
- ***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. Keeping in mind the small size, paired t-tests revealed a significant difference in mean satisfaction scores between the first follow-up survey ($M = 4.2$, $SD = .75$, $N = 11$) and the second follow-up survey ($M = 3.5$, $SD = .82$, $N= 11$), $t\ (10) = 2.3$, $p < .05$, reflecting a decrease in satisfaction over time. There were no significant differences in satisfaction ratings by referral status (self-referred/ referred via First Link).
- ***Impacts as identified by caregivers and persons with dementia:*** Interview participants identified the following impacts associated with First Link:
    - Single entry point to information
    - Knowledgeable source of information
    - Access to information about ADRD
    - Access to information about community services and supports
    - Caregiver support (learning from each other, practical strategies, reduced isolation and burden)
    - Support for Persons with Dementia
- ***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 information about their disease**
  - Increased access to information earlier in the disease process
  - Increased access to information in rural and remote areas
  - Access to information when relevant
  - Access to accurate information not available elsewhere
- **Increased access to early intervention**
  - Potential for assessment early in the disease process
  - Increased access to system navigation support
  - Increased access in rural areas
  - Access to proactive supports
  - Access to support when needed
- **Increased access to caregiver support**
  - Increased caregiver capacity
  - Reduced stress
  - Increased access to caregiver supports in rural and remote areas
  - Reduced stigma associated with seeking support
- **Reduced crises**
  - Reduced Emergency Department visits

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; these included:
  - Consultation process: Support for First Link
  - Support from Ottawa First Link program
  - Support from Key Stakeholders
  - Support from Alzheimer Society staff
  - Funding support from ASC for outreach to rural communities
  - Financial Support from the Ministry of Health
  - Partnerships and Champions (Community agencies and organizations, Memory Clinics and assessment units)
  - Quality programming and resources
  - Easy referral process
- ***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 included:
  - Limited understanding of the concept of First Link
  - Raising awareness of First Link in rural and remote areas
  - Misunderstanding that the Alzheimer Society only serves those with Alzheimer's Disease

- Issues around obtaining consent for referral to First Link
- Inconsistency in rate of referrals across the province
- Labour intensive nature of relationship building with referral sources
- Lack of physician support for direct referrals to First Link
- Limited diagnosing and lack of information given to people about their diagnosis:
- Limited human resources
- Limited use of E-Tapestry to its full potential

- ***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 included:
  - Create partnerships upfront
  - Promote the program as a benefit to health care providers
  - Continuously promote First Link
  - Keep key stakeholders engaged
  - Create a mechanism for following up on clients
  - Consult and partner with other First Link Programs
  - Ensure consistent messaging for an accurate understanding of First Link
  - Time 'cold calls' (unscheduled visits) to needs of stakeholders
  - Use Telehealth videoconferencing to increase access to education

- ***Suggestions for improvements and Sustainability:***
  - ***Key Stakeholders:*** Provide feedback on referrals, allow for referrals based on verbal consent, promote First Link more broadly in the community, continue to promote First Link with physicians, provide opportunities for those who use Telehealth for education and support to meet together face-to-face , and take advantage of opportunities where seniors gather to share information.
  - ***First Link and Alzheimer Society Representatives:*** Increased resources to operate First Link, promoting First Link to all who have contact with seniors, revise curriculum to be more inclusive of other dementias, utilize E-tapestry to its full potential, maintain good relationship with Telehealth, develop strategies to engage physicians, build greater capacity among physicians for assessment and diagnosis, create a national network of First Link programs, and develop resource material at different literacy levels and for different cultural groups.
  - ***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: distribute newsletters on a regular basis, start programs later in the morning, encourage referrals to First Link prior to diagnosis and promote First Link to physicians to increase referrals. Many interview participants also identified suggestions for improvements to dementia care namely: increase physician capacity for assessment, diagnosis and management, increase opportunities for home visits for medical care, and increase number of assessment/ diagnostic services, respite/ friendly visiting opportunities, and

increase access to day programs and adult day programs targeted to younger adults.

- ***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:
    - Identify potential sources of sustainable funding
    - Expansion of First Link across the province
        - Explore potential for society staff within each regional health authority or every second health authority to be able to offer localized support and programs and services
    - Continue outreach and program promotion
    - Explore opportunities for partnerships in developing services and supports for persons with frontotemporal dementia
    - Increase number of caregiver support group participants and use of core basket of services
    - Increase number of participants in support groups for persons with dementia
    - Promote early intervention: increase early access to services and support groups
    - Standardize client records so any staff member can respond to a clients' request for support

Evaluation Limitations: E-Tapestry, the software used to maintain records on clients registered with First Link, was set up after (April 2009) First Link was launched, requiring staff to "back" enter those clients registered with the Alzheimer Society prior to April 2009. Given the time consuming nature of this task, emphasis was placed on entering the information of clients directly referred to the Society via First Link over those self-referred to the Society, thus leaving some gaps in our understanding of this group of clients. The number of clients registered in E-Tapestry may be an underestimation of the actual total number of clients served by First Link and the Alzheimer Society; this may explain, in part, why an increase in referrals overtime was not demonstrated. The response rate to the caregiver study component of the evaluation was low, but consistent with response rate of the evaluation of First Link in Ontario. 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 coping 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. Similarly, as information on participation in support groups was not collected on those who participated in the caregiver study, it is not possible to determine whether these findings are a function of lack of support group involvement. 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. 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 502 caregivers representing over 502 persons with dementia were served by the Alzheimer Society between October 1, 2007 and December 31, 2010. Limitations with information entered into E-Tapestry have contributed to an underestimation of the number of clients served.

- This evaluation has demonstrated that the objectives of First Link have partially been achieved. A significant finding is that those clients who were referred to the Alzheimer Society via First Link were referred, on average, 11 months earlier than those who self-referred to the Society; this finding is consistent with that of the evaluation of the Ontario First Link Program. Despite great efforts on the part of First Link Coordinators and Alzheimer Society staff to promote direct referrals to the Society via First Link, the majority of people connect with the Society via self-referrals. There are a number of barriers that contribute to this including issues associated with obtaining written consent for referral (including misunderstandings of whether or not signed consent is actually required), difficulties promoting the program over a large geography, and lack of support among family physicians for direct referrals to First Link. Although many health professionals support the work of First Link and the Alzheimer Society, their recommendations that patients contact the Society has impacted self-referrals but potentially leaves a large segment of the population with dementia without or delayed support. Regardless, the efforts of First Link to promote direct referrals has not been without benefit; there appears to be somewhat of an upward trend in direct referrals and with continued promotion and marketing, the potential exists for an increase in direct referrals over time. This 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) and has demonstrated its ability to ensure that caregivers and persons with dementia have access to information and support as soon as possible after diagnosis, which has demonstrated to reduce the number of contacts with the Alzheimer Society at times of crisis.

- A significant outcome of the First Link demonstration project was the development of linkages and partnerships with diagnostic and treatment services, and community resources and supports and some primary care physicians. First Link's efforts to encourage direct referrals through health professionals represent 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. While these efforts have largely been effective, as for example, with Memory Clinics and assessment units, there continues to be a need to promote the program with primary care physicians. It has also been suggested that the program be promoted to other services that work in the frontline with seniors (e.g., home care workers, assisted living facilities).

- Although the findings of the caregiver study did not support hypotheses related to reduced caregiver burden and increased coping effectiveness (see evaluation limitations for potential explanations for these findings), there is anecdotal evidence from caregiver interviews that First Link and the services and supports of the Alzheimer Society are critical to their ability to manage and survive the caregiving role. 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.

- Consistent with findings of the Ontario evaluation, First Link has had a more of 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, rather than on how health professionals assess and manage 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. 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. The engagement of physician champions to promote the service to primary care physicians has been identified as a potential engagement strategy.

- Suggestions made for improving and sustaining First Link have the potential for further capacity building and support for caregivers and health professionals. In addition to resource supports (funding, human resources 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 intervention and quality of dementia care across the province, within the constraints of limited services and supports (e.g., respite, adult day programming, home care), particularly in rural and remote areas.

Evaluation Limitations: E-Tapestry, the software used to maintain records on clients registered with First Link, was set up after (April 2009) First Link was launched, requiring staff to "back" enter those clients registered with the Alzheimer Society prior to April 2009. Given the time consuming nature of this task, emphasis was placed on entering the information of clients directly referred to the Society via First Link over those self-referred to the Society, thus leaving some gaps in our understanding of this group of clients. The number of clients registered in E-

Tapestry may be an underestimation of the actual total number of clients served by First Link and the Alzheimer Society; this may explain, in part, why an increase in referrals overtime was not demonstrated. The response rate to the caregiver study component of the evaluation was low, but consistent with response rate of the evaluation of First Link in Ontario. 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 coping 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. Similarly, as information on participation in support groups was not collected on those who participated in the caregiver study, it is not possible to determine whether these findings are a function of lack of support group involvement. 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. 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.

1.0 BACKGROUND AND INTRODUCTION

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).

A key objective 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;

(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 A.[3]

[3] All appendices are presented in a separate document available on the Alzheimer Society of Saskatchewan website (www.alzheimer.sk.ca).

First Link started in Ottawa, Ontario, as a coordinated support and education initiative led by the Alzheimer Society of Ottawa in collaboration with the Dementia Network of Ottawa. In 2007, 1the 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 (2007-2009). Shortly after the demonstration project launch in Ontario, Saskatchewan launched a demonstration project in 2007, operating out of Regina and Saskatoon. According to the 2006 Canadian census, Saskatoon had a population of 202,340 people and Regina 179,246 people. Funding for an evaluation was provided by an Alzheimer Society of Canada research grant. Evaluations of the initial Ottawa pilot project and Ontario First Link demonstration projects revealed the objectives of First Link were largely achieved. Direct referrals via First Link impacted earlier access to information and supports. First Link had a positive impact on increasing understanding and awareness among caregivers and persons with dementia about ADRD and available community resources (McAiney, Hillier, & Stolee, 2010; See Appendix B).

Alzheimer Disease and Related Dementias: Existing Care Gaps

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 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). 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).

Significant care gaps exist for persons with dementia living in the community and their caregivers, primarily related to:

- ***Limited use of available community supports:*** Most of the care 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). 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.

- ***Limited early detection and primary care support:*** 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). 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; Glasser & Miller, 1998).

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). There is much 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). 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).

Role of First Link in Enhancing Care for Persons with Dementia and their Caregivers

Nurturing Partnerships: 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, this would include nurturing partnerships with Client/ Patient Access Services (CPAS), 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, 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; 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.

Reaching Out to Families by 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. Consistent with privacy laws, all referrals require signed consent to share contact information with 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, CPAS, Memory Clinics, Geriatric Assessment Units, seniors' mental health programs, and other community support services. Persons with dementia (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, or directs them to the Society website or sends information by e-mail, 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 C). 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.

First Link/ Alzheimer Society of Saskatchewan Programming

In addition to the provision of the individual information, referral, and information provided on individual basis through offices in Regina and Saskatoon and a toll-free telephone number and information provided on the Alzheimer Society's website (www.alzheimer.sk.ca), First Link invites clients to attend the Learning Series that covers the following topics:

- Next Steps (8 hrs/ session)
- Next Steps Families (8 hrs/ session)
- Care Essentials (8 hrs/ session)
- Options for Care (6 hrs/ session)
- Care in the Later Stages (6 hrs/ session)

To increase access to the Learning Series to those living in rural and remote areas, First Link has partnered with Telehealth to deliver the Learning Series via Telehealth in various locations across the province. The sessions are designed to offer people information when they need it. For example, caregivers of persons in the early stages of their disease would attend the Next Steps session, which provides information aimed at the newly diagnosed. Caregivers of persons with mid to later stages of the disease would attend the Options for Care and Care in the Later Stages to obtain information about long-term care placement and end-of-life care. Occasionally, one time information sessions (2 hours in length) are offered on a specific topic outside of the learning series with the target audience being people who had previously attended one of the Learning Series.

In addition to the Learning Series, support is provided via:

- Coffee Club (social time for both persons with dementia and caregivers)
- Early Memory Loss Support Group
- Support Group for Caregivers

The Alzheimer Society also provides a *Safely Home* program, which assists police to locate missing or lost persons with dementia.

Evaluation: This report describes the methods and results of an evaluation of the First Link Demonstration Project as implemented by the Alzheimer Society of Saskatchewan.

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

The evaluation framework for First Link in Saskatchewan was based on that developed for the evaluation of First Link in Ontario. An Advisory Group was developed to focus the evaluation in Ontario consisting of representatives of from the ASO, the First Link Project Coordinators, and representatives from the First Link demonstration sites (4 in total). Caregivers of persons with dementia provided input into the development of the caregiver surveys. Joanne Michaels, [Program Services Manager, Alzheimer Society of Saskatchewan acted as an advisor to the application of the evaluation to the Saskatchewan First Link demonstration project.

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?

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 signed consent 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 or recommendation.

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 via First Link, i.e., from 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 ementia 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 via First Link and those who are self-referred. 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 are self-referred.
  b) Individuals who are referred to the Alzheimer Society via First Link will have higher ratings of coping effectiveness at the time of first contact with the Society than individuals who self-referred.
  c) Over time, caregiver stress will be lower among individuals who are referred to the Alzheimer Society via First Link compared with those who self-referred.
  d) Over time, coping effectiveness will be higher among individuals who are referred to the Alzheimer Society via First Link compared with those who self-referred.

- 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 D. 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

Information was collected on the number of referrals to the Alzheimer Society, population served (age, gender, diagnosis) and the services provided (information, education, support, number of contacts), as well as how clients accessed the Alzheimer Society: via First Link or self-referrals. This 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; data collection with E-Tapestry commenced in April 2009. All direct referrals prior to this date were entered; however, not all self-referrals prior to April 2009 were entered. A list of the data requested using E-Tapestry is presented in Appendix E.

Analysis of key outcome variable will explore differences between those individuals who access the Alzheimer Society via First Link and those self-referred.

2.4.2 First Link Information and Awareness Raising Activities Tracking

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) and volunteer activities (facilitation of Learning Series. For each of these activities, the number of direct hours (logged in 15 minute increments) involved in the activity and the 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 F.

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]. This survey is presented in Appendix G.

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 H).

These surveys were developed as part of the evaluation of the First Link demonstration project in Ontario. At the time that these surveys were developed, they were reviewed by the First Link Coordinators in Ontario 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 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 very 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 G). 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 January 2009; distribution of baseline surveys ended on April 30, 2010 and distribution of follow-up surveys ended on October 31, 2010.

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 I).

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 through the E-Tapestry database. 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). 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.

2.4.5 Interviews with Key Stakeholders

Of those individuals identified to receive an invitation to complete the Health Professional survey (described above), purposeful sample 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 J) 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.

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 K) 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

Although initially it was intended that Alzheimer Society clients (caregivers and persons with dementia) would be randomly selected to receive an invitation to participate in a group interview with other Alzheimer Society clients (caregiver/ individuals with dementia dyads), the experience with the Ontario First Link evaluation highlighted challenges with this methodology. Initial attempts to obtain a random sample were not possible as many of the persons with dementia selected to participate 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 and cited concerns 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). Thus, it was decided to recruit a purposeful sample of interview participants. First Link Coordinators from the Regina and Saskatoon offices, identified individuals willing to participate in the evaluation interviews.

A structured interview guide (presented in Appendix L) 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 provincial offices and referral status (self-referrals vs. those referred via First Link). 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 M and N. Responses to each question in the baseline and follow-up caregiver surveys and the health professional survey are located in Appendices O and P, respectively. Note: All appendices are presented in a separate document available on the Alzheimer Society of Saskatchewan website (www.alzheimer.sk.ca).

Generally, there were few significant differences between the two provincial sites (Regina and Saskatchewan) 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 October 1, 2007 to December 31, 2010, 502 individuals were registered as Alzheimer Society clients across the province as recorded in E-Tapestry (See Table 1). A significantly higher percentage of clients (61%) were registered with the Saskatoon office than the Regina office, χ^2 (1) = 23.2, p = .001.

Table 1: Number of Clients Registered with the Alzheimer Society Across Each Site (N = 502)

Demonstration Site	Percentage (#)
Regina	39.2% (197)
Saskatoon	60.8% (305)
Total Number in E-Tapestry	502

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 two provincial offices, as recorded in E-Tapestry. Overall, a significantly higher number of individuals were self-referred to the Alzheimer Society (61%) than those who were referred via First Link (24%), χ^2 (1) = 78.4, p = .001. There were significant differences in the percentage of referrals via First Link across the two provincial offices: a higher percentage of clients were referred via First Link through the Saskatoon office (33%) then through the Regina office (10%), χ^2 (1) = 29.9, p<.001.

Table 2: Distribution of Referral Status across Provincial Offices

	Percentage (#)	
Provincial Offices	Self-Referred	Referred Via First Link
Across both offices (N = 502)	60.7% (305)	24.3% (122)
Regina (N = 197)	69.0% (136)	10.1% (20)
Saskatoon (N = 305)	55.4% (169)	33.4% (102)

Figure 1 presents the number of monthly referrals to the Alzheimer Society from January 1, 2009 and December 31, 2010, by referral status (self-referrals vs. referrals via First Link) as recorded in E-Tapestry. Four clients were registered with Alzheimer Society prior to January 2009, as registered in E-Tapestry; all four of these clients were self-referred. The mean number of clients who were referred on a monthly basis via First Link, was significantly lower than the mean number of clients who were self-referred, $F(1,54) = 8.0$, p<.01. For those who were self-referred, the number of monthly referrals ranged from 1 (October, 2007, January, February, and October 2008) to 25 (January 2010), with the average being 8.2 (SD = 7.0). For those who were referred via First Link, the number of monthly referrals ranged from 0 (October, 2007, January, February, and October 2008) to 19 (January 2010), with the average being 4.0 (SD = 4.0). In 2009, referrals remained relatively consistent, with a few spikes in self-referrals (March, July and October), however in January 2010 there was a sharp increase in both self-referrals and referrals

via First Link, after which time monthly self-referrals remained higher than in 2009 and referrals via First Link declined back to 2009 rates. The number of self-referrals and referrals via First Link dropped in November (4 and 2, respectively) and December (7 and 1, respectively).

Figure 1: Referrals Recorded in E-Tapestry: January 1, 2009 - December 31, 2010

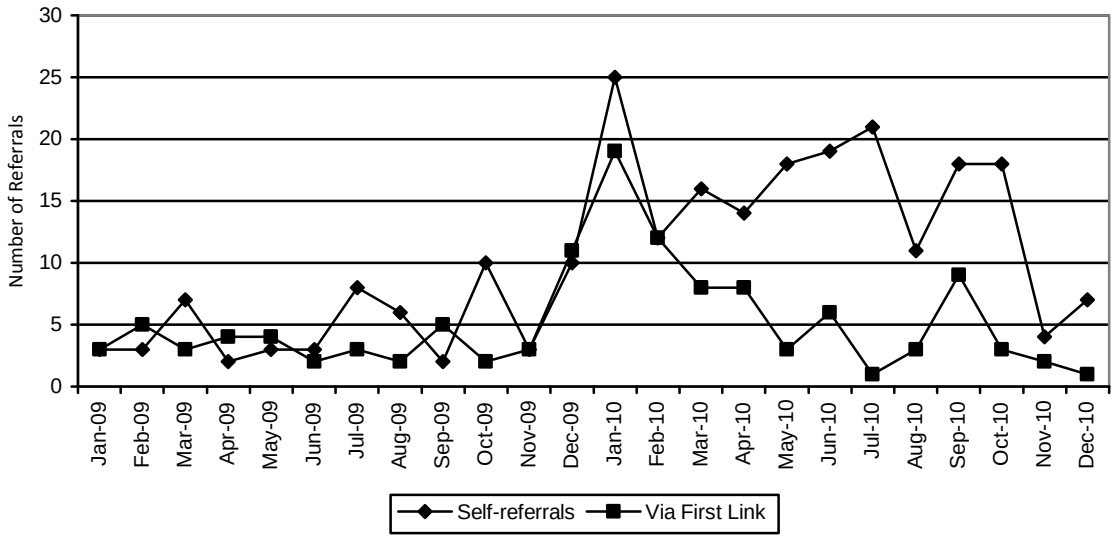


Table 3 presents demographic information across all clients and across those self-referred to the Alzheimer Society and those referred via First Link, as recorded in E-Tapestry. The majority (78%) of clients were women. The average age of clients was 61 years, though they ranged in age from 22 to 100 years. The mean age of clients referred to the Alzheimer Society via First Link was significantly higher (67 years) than those self-referred (59 years), $F(1, 201) = 11.7$, $p<.000$, reflecting the higher percentage of children of persons with dementia represented in those self-referred (57%) than those referred via First Link (44%). Although some clients (2%) were the person with dementia themselves, the majority (94%) were either family members or friends of the person with dementia, the majority of these individuals being a child (54%) or spouse (31%) of the person with dementia. A higher percentage of spouses (44%) of persons with dementia were referred via First Link than were self-referred (25%) and a higher percentage of children of persons with dementia were self-referred (57%) than referred via First Link (44%). For the majority of clients, English was their first language.

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

Demographic Information	All Clients (N = 427) % (#)	Self-Referrals (N = 305) % (#)	Referrals via First Link (N = 122) % (#)
Gender:			
Female	78.0% (238)	78.7% (96)	78.2% (334)
Male	19.0% (58)	19.7% (24)	19.2% (82)
Age (years):			
Mean (SD)	60.6 (14.6)	58.7 (14.2)	66.6 (14.5)
Range	22 – 100	22 – 100	33 – 87
Number	203	153	50
Relationship with Person with Dementia:			
Self	2.8% (12)	3.2% (10)	1.6% (2)
Child	53.6% (229)	57.4% (175)	44.2% (54)
Spouse	30.6% (131)	25.2% (77)	44.2% (54)
Relative	5.4% (23)	5.2% (16)	5.7% (7)
Sibling	3.5% (15)	4.3% (13)	1.6% (2)
Friend	1.9% (2)	2.0% (6)	1.6% (2)
First Language of Client:			
English	71.0% (303)	66.9% (204)	81.1% (99)
French	0.4% (2)	0.6% (2)	0
Other	0.7% (3)	1.6% (2)	0.7% (3)

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 46 – 98 years, with an average age of 79 years. Although a large percentage of clients represented individuals diagnosed with Alzheimer Disease (27%) or with a related or unspecified dementia (51%), some were without diagnosis (27%). A higher percentage of those self-referred (30%) to the Alzheimer Society represented individuals with Alzheimer Disease then those referred via First Link (18%) and a higher percentage of those self-referred (34%) represented individuals who were without diagnosis than those referred via First Link (9%), $\chi^2(7) = 60.0$, $p<.001$. Very few persons with dementia (2%) did not have a family physician. The majority of persons with dementia were identified as living with family (48%).

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 = 427)	Self-Referrals (N = 305)	Via First Link (N = 122)
Gender:	Female	51.8% (221)	51.5% (157)	52.5% (64)
	Male	38.6% (165)	36.4% (111)	44.3% (54)
Age (years):				
	Mean (SD)	79.2 (91)	78.6 (9.1)	80.6 (8.9)
	Range	46 – 98	46 – 98	55 - 96
	Number	244	174	70
Diagnosis				
	Alzheimer's Disease	26.6% (114)	30.1% (92)	18.0% (22)
	Frontotemporal Dementia	4.4% (19)	2.9% (9)	8.1% (10)
	Mixed Dementia*	3.0% (13)	2.6% (8)	4.1% (5)
	Lewy Body dementia	0.5% (2)	0.7% (2)	0
	Parkinsons	2.3% (10)	1.9% (6)	3.2% (4)
	Vascular dementia	5.9% (25)	3.9% (12)	11.4% (14)
	Dementia**	15.6% (67)	11.1% (34)	27.0% (33)
	Without diagnosis	26.9% (115)	34.0% (104)	9.0% (11)
	Other***	2.1% (9)	1.3% (4)	4.0% (5)
Does not have a Family Physician:		2.3% (10)	2.3% (7)	2.5% (3)
Living Arrangement:				
	Alone	13.1% (56)	151% (46)	8.2% (10)
	Institution	10.1% (43)	10.2% (31)	9.8% (12)
	With Care partner	48.0% (205)	44.9% (137)	55.7% (68)

Note: Percentages may not sum to 100% due to missing information.
* Mixed Dementia: Vascular and Alzheimer's disease
**Mostly unspecified: one case each of Ischemic, Binswanger, and Viral Dementia

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. The Alzheimer Society, telephone directory, friends and family and other sources (e.g., clergy, library, other organizations and groups) were the most frequently identified sources of information about the Alzheimer Society as reported by those who were self-referred to First Link. Although there were no significant differences between the provincial offices in the percentage of self-referred clients who heard about the Alzheimer Society from the various sources of information, more clients from the Saskatoon office (11%) heard about the services and supports available at the Alzheimer Society from the Regional Health Authority (via

assessment agencies, home care, adult day programs, and LTC facilities) than those from the Regina office (4%).

Geriatric Assessment Units and the Regional Health Authority were the most frequently identified referral sources for individuals referred via First Link. Very few referrals (less than 5%) came from family physicians, Memory Clinics, and specialists. A significantly higher percentage of clients from Saskatoon (65%) were referred to the Alzheimer Society by a Geriatric Assessment Unit than clients from Regina (5%) and a high percentage of clients from Regina were referred by the Regional Health Authority and specialists (45% and 25%, respectively) than clients from Saskatoon (31% and 0.9%, respectively), $\chi^2(6) = 64.5$, $p = .001$.

Table 5: Source of Information about First Link (N = 427)

Demographic Information	Percentage (Number)
Self-Referrals (N = 305)	
Source of Information about First Link:	
Alzheimer Society*	28.5% (87)
Friends/Family	19.0% (58)
Regional Health Authority**	7.8% (24)
Media***	5.5% (17)
Phonebook	23.6% (72)
Physician±	2.6% (8)
Self	1.3% (4)
Other±±	13.7% (42)
Referrals via First Link (N = 122)	
Referral Sources:	
Family Physician	4.9% (6)
Geriatric Assessment Unit	54.9%(67)
Memory Clinic	2.4% (3)
Regional Health Authority	33.6% (41)
Specialist	4.9% (6)
Other	0.8% (1)

Note: Percentages may not sum to 100% due to missing information.
*Alzheimer Society of Saskatchewan: AS Resource, pamphlet, poster, staff, support group, website.
**Regional Health Authority: Assessment agencies, home care, adult day support program, LTC facility.
***Media: Newspaper, radio, television, magazine.
± Physician: General practitioner, neurologist, geriatrician, Rural and Remote Memory Clinic.
±±Other: clergy, library, other organizations/ groups.

Time from Diagnosis to Referral: Across all clients for whom date of diagnosis was available, the average time from diagnosis to referral to (first contact) the Alzheimer Society was one year (See Table 6). On average, those who were referred to the Alzheimer Society via First Link were referred sooner after the diagnosis of ADRD (Mean = 6 months) than those who were self-referred (Mean = 17 months), F (1, 184) = 14.22, p=.001.

Table 6: Average Time from Diagnosis to Referral (First Contact) to Alzheimer Society

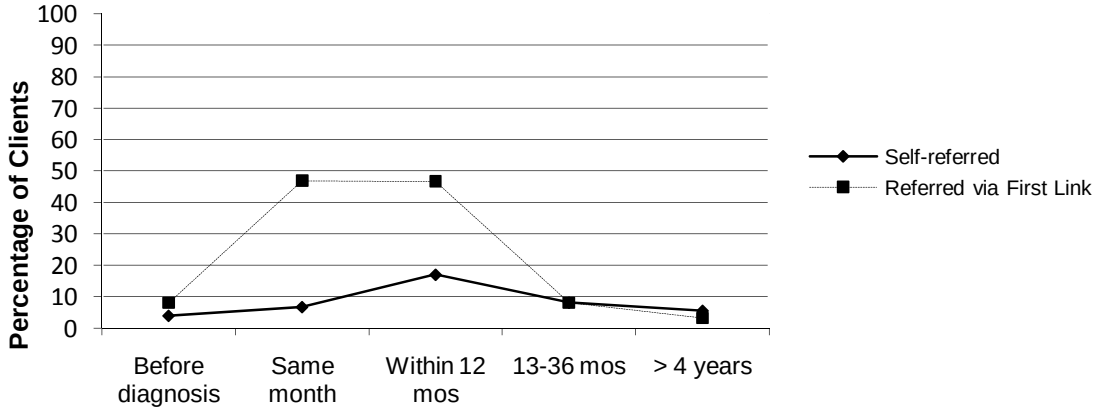
Time from diagnosis to referral	Self-Referred (N = 105)	Referred via First Link (N = 81)	*F*	Total (N = 186)
Mean (SD) months	17.3 (25.7)	5.7 (12.1)	14.22*	12.3 (21.6)
Range (months)	-7.0** – 137.00	-9.0 – 56.0		-9.0 – 137.0

* 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 a low percentage of clients were self-referred or referred via First Link to prior to the diagnosis of ADRD (4% and 8%, respectively), a greater percentage of those who were referred via First Link were referred within the same month of diagnosis (31%) and within one year of diagnosis (47%) than those who were self-referred (7% and 17%, respectively), χ^2 (1) = 201.2, p<.001). There were minimal differences in the percentage of self-referred clients and those referred via First Link that were referred later, in the first few years following the diagnosis (14% vs. 12%, respectively).

Figure 2: Time from Diagnosis to Referral by Referral Status



Perceptions of Contacts with First Link as Urgent/ Crisis:

When clients contacted First Link, they were asked whether they perceived the nature of the contact urgent or a crisis situation. In total, a small perception of contacts with First Link were considered a crisis (12%), however, a significantly higher percentage of clients who were self-referred to the Alzheimer Society (15%) perceived their contact as a crisis than those who were referred via First Link (3%), $\chi^2(2) = 15.5$, $p<.001$ (See Table 7).

Table 7: Perceptions of First Link as Urgent/ Crisis

Self-Referred (N = 305)	Referred via First Link (N = 122)	χ^2	Total (N = 502)
15.4% (47)	3.3% (4)	15.5*	11.9% (51)

* p<.001.

3.1.2 Information and Awareness Raising Activities

Table 8 presents the awareness raising, education, 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 per fiscal year (April 1 – March 31) are located in Appendix N.

Across the province (April 1, 2007 – December 31, 2010), Alzheimer Society staff conducted 373 awareness raising presentations and 52 displays accessing 9,095 individuals in the process. Awareness raising activities included visits to family physicians, Memory Clinics and other specialized diagnostic and treatment services to provide information about the goals and objectives of First Link and services provided, 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.

In total 63 Learning Series sessions were conducted. The number of sessions per topic ranged from 6 – 25; the most frequently delivered session being *Next Steps Families* (25 sessions). In addition, 4 information sessions were delivered on specific topics outside of the Learning Series with the target audience being people who had previously attended one of the Learning Series. The First Link Coordinators provided or coordinated 444 hours of education with a total of 1,250 people in attendance. In total 34 Alzheimer Society volunteers spent 102 hours supporting the First Link Learning Series (Care Essentials and Options for Care).

In terms of the number of contacts that First Link had made with Alzheimer Society clients (e.g., to share information, invite them to education series, respond to their queries), in total Alzheimer Society staff had 3,352 client contacts, with the number of contacts per fiscal year ranging from 800 – 892 (see Appendix N). It is anticipated the number of client contacts for the 2010-2011

fiscal year will exceed this range as 856 contacts have already been made in the first three quarters of the year.

Table 8: Summary of Public Awareness Raising and Education Activities: April 1, 2007 – December 31, 2010

Activities	TOTAL
Awareness Raising**	
Number of presentations	373
Number of people in attendance	9095
Number of displays	52
Learning Series: Number of Sessions	
Next Steps	8
Next Steps Families	25
Care Essentials	8
Options for Care	12
Care in the Later Stages	6
Information Sessions***	4
Total Number of Sessions	63
Learning Series: Attendance	
Next Steps	98
Next Steps Families	614
Care Essentials	202
Options for Care	104
Care in the Later Stages	95
Information Sessions	137
Total Attendance	1250
Learning Series: Hours	
Next Steps (8 hrs/ session)	64
Next Steps Families (8 hrs/ session)	200
Care Essentials (8 hrs/ session)	64
Options for Care (6 hrs/ session)	72
Care in the Later Stages (6 hrs/ session)	36
Information Sessions (2 hrs/ session)	8
Total Number of hours	444
Learning Series - Volunteer Hours‡	
Number of volunteers	34
Volunteers (# direct hours)	102

Activities	TOTAL
Client Contacts Number of client contacts‡‡	3352
Individual support and information (# direct service hours)	1385.5

*April 1, 2010 – December 31, 2010
**Community and General Public Awareness (understanding Alzheimer Disease/ Healthy Brain sessions.
***One time sessions (2 hours in length) on a specific topic outside of the learning series with the target audience being people who had previously attended one of the Learning Series.
‡Care Essentials and Options for Care
‡‡New (first time) contacts and repeat contacts with clients

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 (in E-Tapestry) during the demonstration project (N = 502), 230 (46%) agreed to receive further information about the study and were sent a survey package and invitation to participate in this component of the evaluation (49% through the Regina office and 44% through the Saskatoon office). In total 43 of the 230 baseline caregiver surveys distributed were completed (representing a 19% response rate).

Of those that received follow-up surveys, 72% (N = 31) of caregivers completed the first follow-up survey, 36% (N = 11) the second, and 9% (N = 1) the third follow-up survey. These response rates are generally consistent with those of the Ontario evaluation of First Link. 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, 72%% (31) of caregivers completed all of the surveys that were distributed to them, 26% (11) 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) and 2.3% (1) of caregiver discontinued participation in the study because their care-receiver had died.

Table 9: Response Rates across All of the Evaluation Components

Evaluation Component	Regina			Saskatoon			Total		
	# Distributed	# Completed	Response Rate**	# Distributed	# Completed	Response Rate**	# Distributed	# Completed	Response Rate**
Caregiver Surveys: Baseline	96/ 197 (48.7%)*	12	12.5%	134/ 305 (43.9%)*	31	21.1%	230/ 502 (45.8%)*	43	18.7%
Follow-up #1	12	11	91.7%	31	20	64.5%	43	31	72.1%
Follow-up #2	11	2	18.2%	20	9	45.0%	31	11	25.5%
Follow-up #3	2	0	0	9	1	11.1%	11	1	9.1%
Health Professional Survey	n/a***			n/a***			36	19	55.6%
Interviews: Health Professional	10	5	50.0%	13	4	30.7%	23	9	39.1%
AS Representatives	2			2			4		
Caregiver/ PWD Dyads	7 (5 caregivers, 2 PWD)			6 (5 caregivers, 1 PWD)			13 (10 caregivers, 3 PWD)		
First Link Coordinators	1			2			3		
Project Leaders	n/a			n/a			2		

AS = Alzheimer Society; PWD = Persons with dementia

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

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

***Health Professionals were identified across both provincial offices.

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. A significantly higher percentage of survey respondents (60%; N = 26) were self-referred than were referred via First Link (23%; N = 10), χ^2 (1) = 7.1, p<.01; referral status was not available for seven survey respondents. The only statistically significant difference in demographic information according to referral status was survey respondent relationship with the person with dementia: a higher percentage of spouses were referred to the Alzheimer Society via First Link (70%) than were self-referred (46%), χ^2 (2) = 15.2, p<.001.

Survey respondents ranged in age from 40 to 86 years, with a mean age of 65 years (SD = 14). A significantly higher percentage of survey respondents were female (81%) than male (19%, χ^2 (1) = 16.95, p<.001. A high percentage of survey respondents were spouses (44%) or children (33%) of the care receiver. Significantly more of their care receivers had a formal diagnosis of ADRD (78%) than those who have not been diagnosed with ADRD, but have experienced memory loss or other similar symptoms (22%), χ^2(1) = 12.9, p<.001. On average, at baseline, care receivers had 2.5 comorbid conditions (range = 0 – 6 conditions); 9% (N = 4) did not identify any comorbid conditions. A little over half (53%) of the care receivers had cerebrovascular disease (e.g., high blood pressure) or experienced a cerebrovascular event (e.g., stroke). Forty-seven percent had bone/ joint conditions such as arthritis or osteoporosis and 33% had depression. Fewer than 19% had the other comorbid conditions that are listed in Table 10. A significantly higher percentage of survey respondents were associated with the Saskatoon office the Alzheimer Society (72%) than the Regina office (28%), χ^2 (1) = 8.4, p<.01.

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

Demographic Information		Total (N = 43)	Self-Referred (N = 26)	Referred via First Link (N = 10)
Gender:	Male	18.6% (8)	15.4% (4)	20.0% (2)
	Female	81.4% (35)	84.6% (22)	80.0% (8)
Age (years):	Mean age (SD)	64.8 (14.1)	63.7 (14.8)	72.5 (13.3)
	Range	40 – 86	40 - 86	40 - 83
	Number	42	25	10
Relationship to Person with Dementia				
	Spouse	44.2% (19)	46.2% (12)	70.0% (7)
	Child	32.6% (14)	42.3% (11)	30.0% (3)
	Relative	2.3% (1)	3.8% (1)	0

Demographic Information	Total (N = 43)	Self-Referred (N = 26)	Referred via First Link (N = 10)
Diagnosis Status:*			
Formal diagnosis of ADRD	78.0% (32)	80.0% (2)	80.0% (8)
Memory loss or similar symptoms	22.0% (9)	20.0% (5)	20.0% (2)
Baseline Comorbid Conditions of the Persons with Dementia:			
Arthritis/osteoarthritis	46.5% (20)	50.0% (13)	50.0% (5)
Osteoporosis	18.6% (8)	19.2% (5)	20.0% (2)
Cancer	9.3% (4)	3.8% (1)	10.0% (1)
Cardiovascular disease (heart attack, angina)	18.6% (8)	11.5% (3)	40.0% (4)
Diabetes	25.6% (11)	23.1% (6)	40.0% (4)
Cerebrovascular disease/ event (hypertension, stroke)	53.5% (23)	53.8% (14)	50.0% (5)
Depression	32.6% (14)	19.2% (5)	60.0% (6)
Psychiatric disorders (psychosis or personality disorder)	2.3% (1)	0	0
Respiratory disease (COPD, emphysema, asthma)	9.3% (4)	7.7% (2)	20.0% (2)
Problems with drugs or alcohol	0	2.3% (1)	10.0% (1)
Other**	30.2% (13)	30.8% (8)	30.0% (3)
Baseline mean number of conditions per person (SD) Range Number	2.5 (1.4) 0 - 6 43	2.3 (1.4) 0 – 6 26	3.0 (1.3) 1 - 5 10
Provincial Office			
Regina Saskatoon	27.9% (12) 72.1% (31)	42.3% (11) 57.7% (15)	0 100% (10)

Note: Percentages do not sum to 100% due to missing values.
COPD = Chronic Obstructive Pulmonary Disease
**Other conditions are presented in Appendix M.
***Four individuals (9.3%) identified no health condition, three 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

(2.8, SD = 1.1, N = 36), as rated on a 5-point scale (1 = poor; 5 = excellent), reflected perceptions of their care receivers' health status as somewhat "good". There were no significant differences in this health rating by referral status.

At the time of the first follow-up survey, over half of the survey respondents (54%) reported that their care receivers' health had worsened over the previous 6 months. Similarly, by the time of the second follow-up survey, the highest percentage of survey respondents (14%) reported that their care receivers' health had worsened over the previous 6 months. The single caregiver who responded to the third follow-up survey reported that their care receiver's health had remained the same over the previous 6 months. At the time of the first follow-up survey a significantly higher percentage of self-referred survey respondents (62%) reported that their care receivers health had worsened than did survey respondents referred via First Link (20%), $\chi^2(3) = 9.0$, $p<.05$.

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

Referral Status	Second Survey (Follow-Up 1) N = 31			Third Survey (Follow-Up 2) N = 11			Fourth Survey (Follow-Up 3) N = 2		
	Worse	Same	Better	Worse	Same	Better	Worse	Same	Better
All (N = 43)	53.5% (23)	14.0% (6)	4.7% (2)	14.0% (6)	7.0% (3)	2.3% (1)	0	2.3% (1)	0
Self-Referred (N = 26)	61.5% (16)	23.1% (6)	0	15.4% (4)	3.8% (1)	3.8% (1)	n/a	n/a	n/a
Via First Link (N = 10)	20.0% (2)	0	10.0% (1)	0	10.0% (1)	0	n/a	n/a	n/a

n/a – not applicable: referral status unknown.*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

Fifty individuals were identified as referral sources; contact information (e-mail address) was not available for eight individuals. Forty-two invitations to complete the survey on-line were distributed; six were returned undeliverable so the final number of invitations distributed was 36. A total of 19 health professional surveys were completed (56% response rate). Table 12 presents demographic information for the health professional survey respondents. The majority of survey respondents were allied health professionals (68%). Survey respondents worked in a range of settings, with the highest percentage working in Client/ Patient Access (CPAS; 26%) and Specialized clinics (26%). A significantly higher percentage of survey respondents (58%)

affiliated themselves with the Regina office of the Alzheimer Society; 37% affiliated themselves with the Saskatoon office, $\chi^2(2) = 8.0$, $p<.05$. There was great variability in the percentage of individuals in the participants' practices over the age of 65 years (range = 40 – 99%), with the average being 83%, and in the estimated percentage of individuals in their practice diagnosed with ADRD (range = 3% - 100%), with the average being 60%. These estimated did not vary significantly by practice setting.

Table 12: Health Professional Survey Respondents: Demographic Information (N = 19)

Demographic Information	Percentage (#)
Discipline:	
Family Physician/ General Practitioner	0
Specialist: neurologist, geriatrician, geriatric psychiatrist	5.3% (1)
Allied health professional: Registered Nurse, Nurse Practitioner, Mental Health Counselor	68.4% (13)
Other*	26.3% (5)
Workplace Setting:	
Primary Care	10.5% (2)
Client/ Patient Access Services (CPAS)	26.3% (5)
Specialized Clinics/ Care Teams (e.g., geriatric medicine, geriatric psychiatry)	26.3% (5)
Other**	36.8% (7)
Provincial Office Link:	
Regina	57.9% (11)
Saskatoon	36.8% (7)
Both	5.3% (1)
Percentage of individuals in practice over 65 years of age (N = 10):	
Mean (SD)	82.7% (20.4)
Range	40% - 99%
Percentage of individuals in practice diagnosed with ADRD (N = 15):	
Mean (SD)	59.7% (15)
Range	3 – 100%

*Other disciplines: Administration/ Case Management (1), Assessor/ Coordinator (3), Home Care Assessor (1)
**Other workplace settings: SWADD (3), Rural Community (1), Home Care (1), Day Program (1), LTC (1)

3.2.3 Interviews with Key Stakeholders

Health Professionals: Interviews were conducted with 9 health professionals/ key stakeholders: four Long-Term Care representatives (one Director of Care and three front-line workers), three Memory Clinic representatives (two clinicians and one researcher), one representative from CPAC (home care coordination), and one representative from the Regional Health Authority (representing chronic disease management) These interviews ranged in length from 11 to 35 minutes (average = 26 minutes).

Three of the key stakeholders who were interviewed reported that they are not actively involved referring persons with dementia and family caregivers to First Link. One individual noted that although it is not his role to refer to First Link his organization has partnered with First Link to focus on strategic planning for dementia, and he is very familiar with the service that is provided through the Alzheimer Society. A second individual noted that although she does not directly refer clients to First Link she participates in the decision-making regarding referrals and a third individual is actively involved in research and evaluation with persons with dementia and their caregivers. A third individual noted that she was involved in research related to the assessment and diagnosis of dementia.

Four of those interviewed reported that they have attended Learning Series sessions, and three have been involved in delivering some of the sessions. Four of those interviewed learned about First Link through information/ promotional sessions that were conducted within their workplace; although they may have been previously encouraged their clients/ patients to contact the Alzheimer Society for information, this session provided them with more detailed information about how they could directly refer people to the Society. The remaining interview participants reported that their organization has had a long-standing relationship or partnership with the Alzheimer Society and were thus previously aware of the programs and services offered by the Society.

Alzheimer Society Representatives: Interviews were conducted with 4 representatives from the Alzheimer Society Chapters; two interviews per demonstration site. Interviews were conducted with Public Education Coordinators (N = 2), Support and Education Coordinator (N = 1), and Communications Manager (N = 1). These interviews ranged in length from 8 to 55 minutes (average = 28 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 First Link calls when the Coordinator was not available, providing information and referring clients to Alzheimer Society programs, and developing promotion information regarding First Link.

3.2.4 Interviews with Project Leaders and First Link Coordinators

Three First Link Coordinators participated in individual interviews, including one coordinator who had recently left the position. Two coordinators were interviewed in-person and one via telephone. These interviews ranged in length from 34 to 49 minutes (average = 43 minutes).

Two Project Leaders participated in individual, in-person interviews. These interviews were 42 and 82 minutes in length.

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

A total of 10 caregivers and three persons with dementia participated in these interviews; four were conducted as group interviews, with the number of participants ranging from 2 to 4. One individual telephone interview was conducted. Half of the caregivers (N = 5) reported that they were referred to the Alzheimer Society via First Link, the remaining (N = 5) were self-referred having heard about the Alzheimer Society from friends, church representatives and the media. Those referred to the Alzheimer Society via First Link were referred by their family physician (N = 2), neurologist (N = 1), home care coordinator (N = 1) and through Alzheimer Society information sessions (N = 1). The group interviews ranged in length from 49 to 82 minutes (average = 59 minutes). The one individual telephone interview was 21 minutes in length. Participants represented both of the provincial offices (Regina: N = 7; Saskatoon: N = 6).

All of the group interviews were conducted in-person at the offices of the Alzheimer Society in Regina and Saskatoon. These interviews were conducted on September 13 and 15, 2010, respectively. The individual telephone interview was conducted on September 28, 2010.

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 (health professionals that refer to First Link; N = 6) were asked to provide the criteria they used to make referrals to First Link (types of patients referred, when they make the referral, circumstances/conditions under which they are referred). It was noted that referrals to First Link were made under the following circumstances (number in brackets represents the number of interview participants who identified this criteria):

- Individuals, and their caregivers, newly diagnosed with ADRD (4)
- Caregivers of persons with dementia in the later stages, who have not previously been involved with the Alzheimer Society (1)
- Families of persons with dementia living in long-term care who require support or information (1).

In terms of referring practices, those involved in making referrals noted that they frequently recommend First Link, however, only a small proportion consent to being referred. One health professional noted that in the past year their clinic has only been able to refer about 1% of those who would be eligible for a referral. Another key stakeholder noted that in their clinic about 40% of patients refuse a referral at their first appointment; in the cases where patients are seen for a follow-up appointment they tend to be more receptive at that time. Potentials reasons for the limited consents for referral included: stigma and embarrassment at the diagnosis, denial or resistance to the diagnosis, feeling so overwhelmed at the time of diagnosis that they are unable to make a decision about the referral, and geographical distance for those in rural and remote areas of the province. It was also suggested that those diagnosed with dementia think, despite being told otherwise, that because they don't have Alzheimer Disease the services offered by the Alzheimer Society would not be relevant to them.

> *"I see people in the later stages, it could be, I'm guessing and I don't know if it's because they're embarrassed or if it's because, they think they got through the worst and the person is placed already."* [KSID6]

> *"Well I try to make a referral, that being said, recently I've had a lot of people just not want that referral, but they'll take the First Link pamphlet with the contact information, but they want to be the ones to decide when they want to make that first contact. So probably I think probably within the last year I have been successful at making one or two actual referrals. They're just not ready for it at that time, whether they're still in a state of denial or they're just not ready to face it.*" [KDID8]

> *"What actually happens with a few of our families is they say that their spouse is so terrified by the fact that they've been diagnosed, that anything that says Alzheimer's Society on it, they throw out, they get very upset, or if the phone displays it. So I think it's maybe not so much the stigma from others, but the fact that it's rather terrifying to get that diagnosis. And the fear of that."* [KSID9]

> *"So there is still a barrier that because of our name that a lot of people think we just help people with Alzheimer's disease and for some of them that's a barrier."* [FLREPID6]

Several key stakeholders suggested that the Alzheimer Society should address the stigma and fear of the diagnosis and connection with the Society through their public awareness campaigns and should consider a name change that would be less alienating.

> *"I don't know what the name could be… but I just wonder if the Society does need to consider a name change because certainly people get pretty terrified when you say Alzheimer's Society."* [KSID9]

> *"Hearing the name 'Alzheimer Society' is a big shock to people. They don't want it because of what they think it represents."* [KSID2]

Satisfaction with the Referral Process: Generally all of the health professionals noted that the referral process is extremely easy, straightforward, and user friendly and that communication with First Link to share or obtain information is very easy, as reflected in the following comments:

> *"It's so easy to refer. I just fill out their form and fax it in. Done."* [KSID1]

> *"One of the really great things is that I feel comfortable doing it* [making referrals]. *I would say really, that's the really great point of the First Link program is that the people on their end are very willing to help."* [KSID5]

> *"When I had the contact through the Coordinator, it's been fantastic. They're available on very short notice. All of my contact would be by phone. I've also had meetings at their request with the Coordinator and I've also asked for meetings, just over various issues, I've helped them you know, it might be on developing the education, that sort of thing and they've also helped me with resources."* [KSID6]

Despite the ease with which referrals are made, the requirement for signed consent from the person with dementia was identified as a significant barrier to referral, particularly in cases where the recommendation for First Link is made over the phone. It was suggested that the acceptance rate for recommendations to First Link would be higher if verbal consent was acceptable for a referral.

> *"Once you ask people to sign something, it seems to change things. They just don't want to commit. Maybe they don't want to commit at that time. I don't know. It just seems that asking for that turns people off. I just end up giving them the information and tell them they should contact them. But really, that's not working the way it should be. I'd like it better if I referred and then First Link called them. That way I'd be sure that someone was following up with them."* [KSID1]

> *"This guy that I referred, we had a chat with him [on the phone]. So then I actually think I contacted the Alzheimer's Society and then I was asked to take the form and get his actual written consent. Then that was quite time consuming because I had to find him at home when I was free, which isn't a lot of time, and then try to get him to do the next step, so that was quite time consuming because I find when I have conversation with people and the moment is right, that's the time, when they are willing to be called… it probably took me another month to track him down…. I think it would be really nice if we could do the verbal consent, you know, like: "Would it be okay if I take your name and number and give it to the Alzheimer's Society?' Just verbal."* [KSID6]

Generally, many interview participants commented on the appropriateness of and importance of having health professionals refer patients to First Link to ensure that contact is made as early as possible in the disease process. There was much support for this process as a way to ensure that persons with dementia and their caregivers receive information and support, as reflected in the following comments:

"Well I think it's critical and I think that this is an important program to make those linkages early on with community supports and having someone that they can contact and who helps sort of walk them through resources that are out there when they need them. I think our patients at the end of the day are pretty tired and overwhelmed and it's really hard to absorb even just the diagnosis, let alone you know think about what they might need at that time, what they might need you know, in the next weeks and months and so on. So having someone proactively contact them a little bit later I think is really important because from our research, I'm pretty sure that very few of these patients and their caregivers self refer for services. They're just so busy just trying to cope with the day to day reality that they don't reach out for services… very few patients and caregivers self refer and unless there's some kind of a system in place, like a case management type of a system where people are linked up with someone in the community who is a navigator and can work with them throughout the trajectory of the dementia and the caregiving, they're pretty lost. They fall through the cracks and aren't getting the services that they might need or would find helpful, and unless that happens proactively like First Link, I'm afraid that people aren't getting services that are available to them, so I think it's really important." [KSID4]

"*Well I think this is good because well as you know, as research has shown that most people or families or patients they may be scared or too leery to phone, or overwhelmed with their diagnosis. So I think this is good because then the onus isn't on them to try and phone. They* [First Link] *contact them and I think that's really important, early access is important as well. They're overwhelmed at the end of the day and we don't get a lot of time to sit down with them and explain or they have that little bit of time to absorb what's been given to them, their diagnosis and such. So I think it will give them a little bit of time to absorb, but then they'll have questions. So in a couple weeks time if somebody phones them and says: "Okay, do you need any other information other than what the doctor has provided, what we provide in the package.' I think that's important. "* [KSID7]

"But the other aspect about it, that I think is crucial, I certainly refer for family members struggling with the shock of the diagnosis, is having someone phone you, as opposed to you having to pick up the phone when you're absolutely devastated. That part of the First Link is very good." [KSID9]

Perceptions of Increased Linkages and Partnerships for Dementia Care:

Interviewed health professionals described partnerships with the Alzheimer Society as significant, as health care and service providers are limited in the education and support they can provide to persons with dementia and their families. Several key stakeholders noted that they are limited in the amount of time they are able to spend with persons with dementia and caregivers, so the Alzheimer Society provides a service that complements and supports the work that they do. Several health professionals involved in assessment and diagnosis acknowledged that at the time of diagnosis patients and caregivers are so overwhelmed by the diagnosis that their receptivity to information and education is limited. The Alzheimer Society is able to access people at a time when they are more receptive to information and support.

"We're really limited in what we can do here so it's really good for us to be able to refer to First Link, especially since this is a chronic disease and people need a lot of information and support in the long-term, not just the one time that we see them." [KSID1]

"Well I think just in the fact that I feel more comfortable now that there's some follow-up with our patients. That if they agreed to being contacted, that there's something there for them because we don't at the clinic phone them in a few weeks and say: 'how's it going?' it's nice to know that somebody will do that. Before we used to give the [information] package, but that's it so we didn't have any follow-up. This way I'm kind of thinking hopefully there will be some follow-up, so I think in that way it's definitely helped us." [KSID7]

"I really think that we have a good partnership with the First Link and the Alzheimer Society. They not only provide a vital service to our patients, doing what we don't have the resources to do, or even the mandate but what people really need when they get that diagnosis. It really enhances the system of care by providing that continuity. They get diagnosed and then First Link can step in to make sure they get all the information they need and the making sure they know what is available. And too making sure all services know what is available, because you can advise people about where to go when you don't know yourself." [KSID2]

Similarly, Alzheimer Society representatives identified partnerships with community services and assessment clinics as critical to the success of First Link and their ability to provide timely access to information and support to clients and to do so in a way that supports the work of health professionals, as reflected in the following comments:

"Well I think we did a really great job of partnerships. I think to make this program successful even in other health authorities here in the province or if another province would be doing it, it would be partnerships… I think as well too, that we have a lot of common goals that we're looking at achieving in different ways. The benefits to health care professionals is often their primary relationship is with the patient or the resident and not so much with the family, but recognizing family caregivers are engaged, and you know in a lot of cases with physicians, family caregivers can take lots of their time, and when they recognize what we can do it can save them time, so I think really understanding the relationship and how we can all work together to better serve that patient and the broader community of that patient."[ASREPID2]

"I think a lot of health care professionals don't really know what we do either, and by linking them with the program and having that relationship, its again, it's just closing those gaps and its working better together and we get to know the physicians and we get to know the personnel who are directly making the diagnoses, and it's definitely making I think everybody's job a little bit easier." [ASREPID3]

It was noted that partnerships with experts in the field and with Telehealth, have been critical to the quality and delivery of the Learning Series. The Alzheimer Society's partnership with Telehealth has allowed them to increase access to the Learning Series for people who live in rural and remote areas at no cost to the Society or participants. Similarly, the involvement of

local experts in facilitating the Learning Series has increased the quality of the sessions and has further enhanced linkages with the Society.

> *"[Learning Series] are extremely well attended and we're really fortunate that with our telehealth program that its one of our partnership pieces with the ministry I guess you would say, that we're not having to pay for any of those telehealth services, that that is offered to us and to the clients at no charge."* [FLREPID1]

> "*We keep building strong relationships with pharmacists that we hadn't ever connected with and with nurse practitioners. We had representation at the OT conference in the last couple of years and had we not been displaying First Link, I don't think we would have been there. Definitely, there's been definitely linkages made, particularly with the kind of less obvious connections, the OTs, pharmacists." [*FLREPID4]

As will be discussed further the lessons learned section, partnerships are important to the success of First Link and is very time consuming as nurturing of these partnerships needs to be ongoing.

Health Professional Satisfaction with First Link: Health Professional Survey Results

Health Professionals were very satisfied with the services provided by First Link as reflected in the mean satisfaction rating of 4.2 (SD = .71; as rated on a 5-point scale: 1 = not at all satisfied; 5 = extremely satisfied). Many of the comments made about First Link reflect satisfaction with the services and supports provided to health professionals as well as to persons with dementia and their care partners, as illustrated in the following comments:

> *"I find that the staff at First Link and the Alzheimer Society are very approachable and helpful. I never hesitate to call on them if I have any questions or need to "brainstorm". I am very comfortable knowing that help is only a phone call away."*

> *"Thank you for your much needed services and supports to the patient and their families. They are so much better off for it!!"*

> *"I find that First Link has been instrumental in helping me deal with the various stages of Alzheimer/Dementia. There have been many pointers that I have been able to pass along to my staff."*

> *"First Link is best educational and emotional support for the caregivers and family."*

> *"This is an extremely helpful service for those in rural areas to have this type of connection."*

3.3.2 Providing Progressive Education

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

Impact on Knowledge: Almost 85% 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	84.2% (16)	4.1 (.77) Range: 3 - 5
Material on available community support services/ resources	84.2% (16)	4.1 (.73) Range: 2 - 5

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

The majority of survey respondents indicated that their understanding of dementia in general and of identifying seniors with dementia has not changed as a result of First Link (63% and 74% 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 (63%), the role of the Alzheimer Society (68%), and of available community resources (53%).

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	5.3% (1)	63.2% (12)	31.6% (6)
Identifying seniors with dementia	5.3% (1)	73.7% (14)	21.1% (4)
Managing seniors with dementia	10.5% (2)	26.3% (5)	63.2% (12)
Role of the Alzheimer Society	5.3% (1)	26.3% (5)	68.4% (13)
Available community resources	5.3% (1)	42.1% (8)	52.6% (10)

*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. While one respondent commented on learnings related to the variability in how dementia is manifested, all of the survey respondents commented on learnings related to available services and supports provided by First Link/ Alzheimer Society, as illustrated in the following comments:

"Learned about the variety of education sessions through Alzheimer Society. Learned about the process by which First Link Coordinator handles the referrals and makes contacts with patients and families."

"That help is out there for clients and families, -to refer early in dementia -about Picks disease -First Steps gives info and sets up contacts for individuals needing support and info to plan ahead and make good choices."

"Learning the available resources is invaluable as I then pass this information on to families."

"Upcoming Learning Series, which is helpful when educating clients, encouraging them to consider these services."

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 (<2 on a 5-point rating scale), reflecting that survey respondents thought that First Link had minimal impact on increasing ADRD diagnosis or on early diagnosis (See Table 15).

Table 15: 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 = 17)	1.7 (1.1) Range: 1 - 5
Ratings* of impact on health professionals' ability to identify ADRD early (N = 17)	1.9 (1.1) Range: 1 - 4

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

Many survey respondents commented that many of the clients that they work with have already been diagnosed so they are unable to comment on the impact of First Link on increasing diagnoses, as reflected in the following comments.

"The diagnosis is made prior to our agency becoming involved with patient."

"In order to attend our program, a diagnosis of irreversible memory loss is required. Our Participants are referred to us by CPAS . Their diagnosis would already have been made."

"I am not aware of patients getting diagnosed; most of the people I work with are already diagnosed."

Several respondents noted that health professionals responsible for diagnosis are skilled to do so and other respondents noted that individuals with memory concerns believe that this is inevitable so do not seek a diagnosis, or wait until the disease is advanced:

"I have found in my practice that very few clients are actually given a diagnosis of Alzheimer Disease or any dementia. Families are aware of the client's memory loss, but feel that there is nothing that can be done about it, so don't pressure physicians to give a diagnosis or explore treatments."

"In my role, families are usually approaching their breaking point before referring the client, so often times client's dementia is advanced to the point where it is affecting their daily lives and ability to complete ADLs and IADLs."

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). Overall, the mean ratings of familiarity with the services of Alzheimer Society and community support services were moderately high (3.7 and 4.3, respectively; See Table 16).

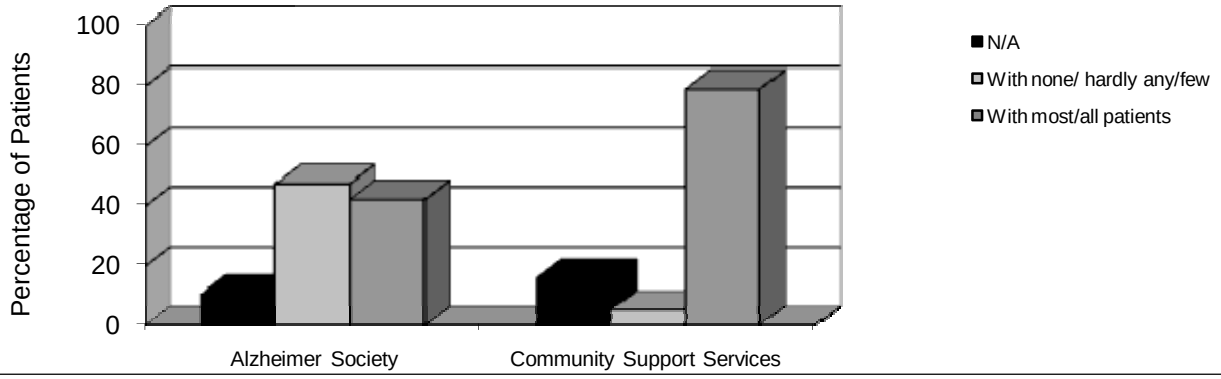
Table 16: Health Professionals' Ratings of their Familiarity with the Alzheimer Society and Available Community Services

	Mean (SD)
Familiarity with services and supports provided by Alzheimer Society (N= 19)	3.7 (.65) Range: 3 – 4
Familiarity with available community supports (N = 19)	4.3 (.89) Range: 2 - 5

Figure 3 presents the frequency with which Health Professionals' referred patients to the Alzheimer Society and to community support services. An almost equal percentage of Health Professionals reported referring none/ few of their patients to the Alzheimer Society (48%) as did

those who reported referring most/ all of their patients (42%). The majority of survey respondents reported that they refer most or all of their patients to the community support services (79%).

Figure 3: Frequency* of Health Professionals' Referrals to the Alzheimer Society and Community Support Services



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 (59%) 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; 31% reported that they are now referring more patients to community support services as a result of First Link (See Table 17).

Table 17: Ratings* of Changes to Referrals to Alzheimer Society and Community Support Services as a Result of First Link (N = 17)**

	Now Referring Less***	The Same	Now Referring More*
Referrals to Alzheimer Society	0	35.3% (6)	58.8% (10)
Referrals to Community Support Services	6.3% (1)	56.3% (9)	31.3% (5)

* Does not include those who reported that it is not their role to patients to these types of services
**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

Generally, key stakeholders (health professionals) did not think that First Link has had a direct impact on increased detection of ADRD, as expertise for assessment and diagnosis exists in the province and detection is primarily a function of access to assessment (e.g., Rural and Remote Memory Clinics). It was noted that First Link has been instrumental reinforcing the need for early intervention and has provided a resource to ensure access to early intervention.

> *"Well, I don't think First Link impacts that* [increased capacity for detection] *at all. Assessment and diagnosis is what I do. I should already have that expertise. The Alzheimer Society won't change that. I think it has really stressed the importance of getting people hooked up with services as early as possible. I don't think anyone would argue with that, but now people have a resource they can refer to, to make sure those diagnosed are followed and don't get lost." [KSID1]*

Almost all key stakeholders commented on the important role that First Link plays in increasing access to early intervention.

> *"I think a really key role that First Link plays is making sure that people have access to support, especially in rural and remote areas. They really help with navigating the system. How to access different services. So doing that and doing that early is something that they are really good at."* [KSID2]

> *"I think early intervention by First Link is encouraging families to get help early, don't wait for a crisis, it's also informing families of what are the resources that are out there and what, what is going to happen in the progression of this disease."* [KSID3]

As described earlier, many key stakeholders noted that First Link/ the Alzheimer Society provides information and support at a level that they are not able to provide, in terms of time, expertise and resources.

> *"I'm not sure a lot of agencies really know how we fit in to the health care picture, but when they get engaged with us, they really see the benefits of linking with the Alzheimer's Society because often it's a service that they can't provide to care givers because they don't have the time. And many of them feel like: 'Oh we're just putting them off and they're so desperate for help, but if we can refer them to the Alzheimer's Society we know they're getting a good service from you. I can't help you with this, but I can refer you to the Alzheimer's Society.' I think it's a real benefit to them that they have a place to refer people."* [FLREPID2]

> *"So hooking them* [person with dementia/ caregiver*] up with the organization through First Link, would give the person the ability to just talk to somebody and then it relieves the health care providers as well."* [ASREPID4]

Although key stakeholders tended to emphasize the role that First Link plays in supporting persons with dementia and their caregivers rather than capacity building among health professionals, Alzheimer Society representatives identified a need for increased education among health professionals, particularly physicians. It was noted that many clients continue to struggle with difficulties getting a diagnoses, either because their physician attributes memory loss to normal aging or suggests that assessment is not necessary. Similarly, it was noted that some clients are receiving inaccurate information from their physicians regarding treatment for cognitive impairment. It was noted that access to early diagnosis is better in the Northern areas of the province due to access to diagnostic centres such as the Rural and Remote Memory Clinics and the Geriatric Evaluation and Management (GEM) program, as reflected in the following comment:

> *"So access to early diagnosis is a real barrier here and so I notice a very different, a very different client group in our Saskatoon office than in our Regina office. In our Regina office we still have a lot of people struggling with the diagnosis, struggling to get doctors to recognize their problems, especially if they're younger, that it could be a dementia of some type. So really physicians are the gatekeepers and if you don't get diagnosed, you don't get referred. You can't come to grips with your diagnosis. You can't make those life decisions. So that area I still see as problematic in the south part of the province, so we still have some barriers to diagnosis. So if you're having trouble getting physicians to recognize dementia, what are the chances that they're going to recognize the Alzheimer's Society as a valuable service? So I still think we have some barriers there."* [FLREPID2]

> *"I think one of the stumbling blocks too is a lot of the physicians went to medical school a long time ago, and a lot has changed since then. I just heard from a client on the phone Friday, his family physician was diagnosing his mom and said: 'Well we shouldn't prescribe this Alzheimer's medication now. We should wait later on in the disease process so you get more bang for your buck.' And I was kind of just shocked to hear that because we know that the earlier you administer the medications, the more likely they are to work."* [ASREPID3]

> *"Some of the things that we continue to hear, that physicians are telling clients about the medications, when they should be taking the medications, when they should be starting the medications, all of those types of things, aren't evidence based. And this continues to be a frustration."* [ASREPID1]

> *"We do our best to educate families, but there's limited opportunities I would say in terms of educating health care professionals."* [FLREPID4]

It was noted that physicians would respond to capacity building efforts more if they were led by other physicians rather than Alzheimer Society staff. It was suggested that greater efforts are needed to target physicians to increase referrals to First Link.

> *"Physicians will only listen to other physicians. So there are barriers there... We're not necessarily getting referrals from physicians."* [FLREPID1]

"My biggest concern in all the time that I've spent here is with the physicians, and my biggest recommendation for a provincial and national level is more work at the physician level… with interprofessional, interdisciplinary training sessions right from year one…and certainly by targeting the medical schools with presentations, so that we're getting the ongoing physicians in training and by figuring out a way to target the physicians… but we have to find a way to target the physicians and really get through to them, to really blitz them." [FLREPID3]

Increased awareness of First Link, the Alzheimer Society and other community resources: Interview participations credited First Link with increasing health professionals' knowledge about what services and supports are available for persons with dementia and their caregivers and by doing so has increased early access to these services and supports.

"It [First Link] *did change was what I know about what they do. The education sessions they give and all about the support groups and how they contact people and how they link people with the services they need. I didn't really know that before. And I think too, I learned about some new services available locally that I didn't know about before. But in terms of expertise we're pretty well situated here in Saskatchewan with the assessment units and Rural and Remote Memory Clinics."* [KSID1]

"I think it opens their [health professionals] *eyes to what is available, because I can tell you I was astonished with the amount of stuff that the Alzheimer's provides, that I wasn't aware of that would have been beneficial when I was in my other position."* [ASREPID4]

3.3.3 Reaching out to Families

Education to First Link Clients: Learning Series Attendance

Overall, 21% (N = 106) of registered Alzheimer Society clients were identified as having attended at least one learning series (See Table 18), 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 provincial offices was evenly distributed, as was attendance by referral status. Attendance was highest at the Next Steps Families sessions. Attendance patterns were similar across provincial offices and referral status (self-referred vs. via First Link; See Appendix N).

Table 18: Learning Series Attendance*

Learning Series Attendance	Attendance Percentage (#)
Across all First Link Clients (N = 503)	21.1% (106)
Provincial office (N = 502)	
Regina (N= 197)	20.8% (41)
Saskatoon (N = 305)	21.3% (65)
Referral Status (N = 427)	
Self-referred (N = 305)	21.0% (64)
Referred via First Link (N = 122)	18.0% (22)
Learning Series (N = 106)*	
Next Steps	16.0% (17)
Next Steps Families	69.8% (74)
Care Essentials	16.9% (18)
Care in the Later Stages	2.8% (3)
Options for Care	4.7% (5)

*At least one learning series
**Percentage exceed 100% because people attended more than one of sessions

Provision of Information (Contact Outcome): Table 19 presents the outcome of clients' contact with the Alzheimer Society in terms of the provision of information. A small percentage of clients did not request or require information. Most frequently (57%) caregivers were sent an information package. A smaller percentage of clients were referred to the website for information (17%) or were sent information via e-mail. There were some significant differences in the provision of information based on referral status. More self-referred clients (23%) were referred to the information on the website than those referred via First Link (2%), $\chi^2(1) = 27.7$, p= .001. More self-referred clients (21%) were sent information via email than those referred via First Link (7%), $\chi^2(1) = 13.4$, p< .001 (See Appendix N). Similarly, there were several significant differences in the provision of information based on which provincial office clients were associated with. More clients from Saskatoon (21%) were sent information via email than those from Regina (8%), $\chi^2(1) = 15.4$, p= .001. More caregivers from Saskatoon (63%) were sent an information package than those from Regina (49%), $\chi^2(1) = 9.4$ p <.01.

Table 19: Provision of Information (N = 502)

Provision of Information	Attendance Percentage (#)
Information on website	17.1% (86)
Information sent via e-mail	16.1% (81)

Provision of Information	Attendance Percentage (#)
Information package sent to caregiver	57.1% (287)
Information package sent to PWD	3.9% (20)
No information requested/ required	7.1% (36)

Recommendations for Services and Supports

Table 20 presents the services and supports that clients participated in and those that were recommended by referral status, as listed in E-Tapestry. The highest percentage of individuals received individual support and information (26%). There were significant differences in the provision of individual support and information by provincial office and by referral status. A higher percentage of clients from Saskatoon (38%) received individual support and information than those from Regina (8%), $\chi^2(1) = 54.3$, $p = .001$ (See Appendix M). A higher percentage of clients referred via First Link (50%) received individual support and information than those self-referred to the Alzheimer Society (21%), $\chi^2(1) = 36.6$, $p = .001$.

Table 20: Services and Supports: Participation and Recommendations (N = 427)

Services and Supports	Self-referred (N = 305)	Referred via First Link (N = 122)	Total (N = 427)
Participation in: Individual Support/ Information	20.9% (64)	50.0% (61)	29.2% (125)
Coffee Club	.07% (2)	0	0.5% (2)
Early Memory Loss Support Group	0.3% (1)	0	0.2% (1)
Support Group for Caregivers	0.7% (2)	0.8% (1)	0.7% (3)
Safely Home	1.0% (3)	0	0.7% (3)
Recommendations for: Regional Health Authority Assessment	24.4% (48)	21.3% (65)	22.5% (113)
Adult Day Program	9.6% (19)	10.5% (32)	10.2% (51)
Respite	5.1% (10)	6.9% (21)	6.2% (31)
Placement	4.1% (8)	3.0% (9)	3.4% (17)

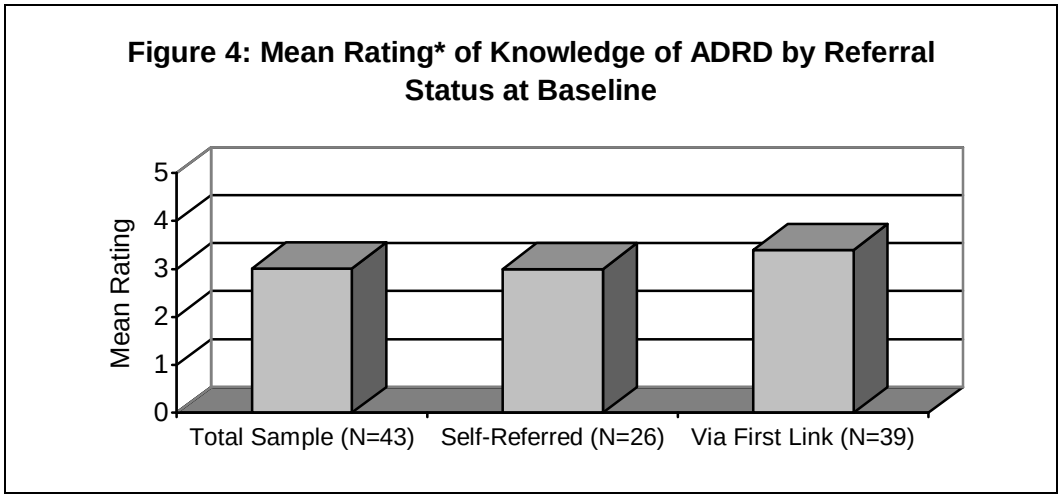
Changes in caregiver competency over time: Results of the Caregiver Survey

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 4 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 36 of the 43 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 = 3.00; SD = .75, and Mean = 3.4, SD = .52, respectively).

Figure 4: Mean Rating* of Knowledge of ADRD by Referral Status at Baseline



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

Table 21 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 21: Ratings* of Changes in Knowledge of ADRD across Surveys and Referral Status

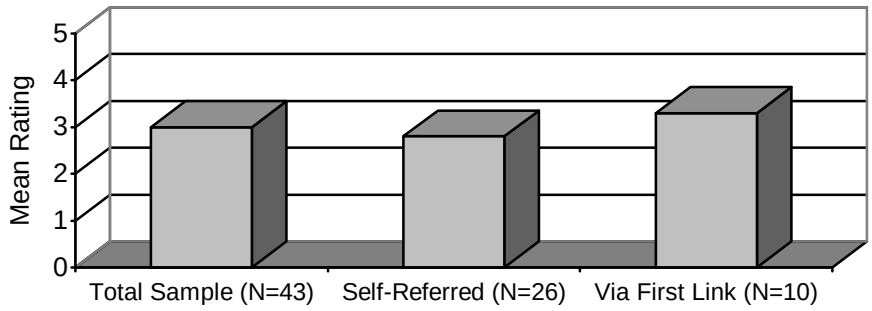
Survey Referral Status	Less knowledgeable Now	About the same	More knowledgeable now
Second Survey (Follow-Up 1) Total Sample (N = 43)	3.2% (1)	7.0% (3)	62.8% (27)
Self-Referred (N = 23)	0	13.0% (3)	87.0% (20)
Referred via First Link (N = 3)	0	0	100% (3)

Survey Referral Status	Less knowledgeable Now	About the same	More knowledgeable now
Third Survey (Follow-Up 2) Total Sample (N = 31)	0	6.5% (2)	29.0% (9)
Self-Referred (N = 6)	0	16.7% (1)	83.3% (5)
Referred via First Link (N = 1)	0	0	100% (1)
Fourth Survey (Follow-Up 3)** Total Sample (N = 11)	0		9.1% (1)

*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.
**The referral status of the individual who completed the fourth survey is not known.

Figure 5 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 = 2.8; SD = .75, and Mean = 3.3, SD = .94, respectively).

Figure 5: Mean Rating* of Familiarity with Community Resources by Referral Status at Baseline



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

Table 22 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.

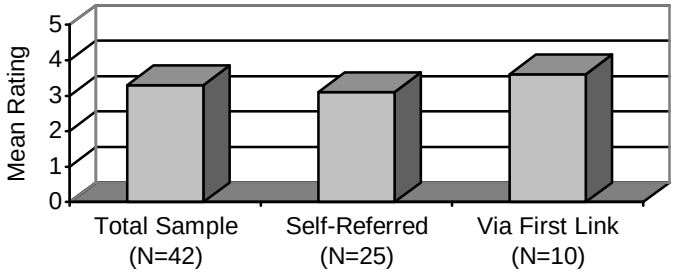
Table 22: Ratings* of Changes in Familiarity with Community Resources across Surveys and Referral Status

Survey Referral Status	Less familiar Now	About the same	More familiar now
Second Survey (Follow-Up 1) Total Sample (N = 43)	0	16.3% (7)	55.8% (24)
Self-Referred (N = 23)	0	17.4% (4)	82.6% (19)
Referred via First Link (N = 3)	0	0	100% (3)
Third Survey (Follow-Up 2) Total Sample (N = 31)	0	12.9% (4)	22.6% (7)
Self-Referred (N = 6)	0	33.3% (2)	66.6% (4)
Referred via First Link (N = 1)	0	0	100% (1)
Fourth Survey (Follow-Up 3)** Total Sample (N = 11)	0	0	9.1% (1)

*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.
**The referral status of the individual who completed the fourth survey is not known.

Figure 6 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 = 3.1; SD = .86, and Mean = 3.6, SD = 1.1, respectively).

Figure 6: Mean Rating* of Confidence in Ability to Manage the Caregiver Roleby Referral Status



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

Table 23 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 26% to 35%.

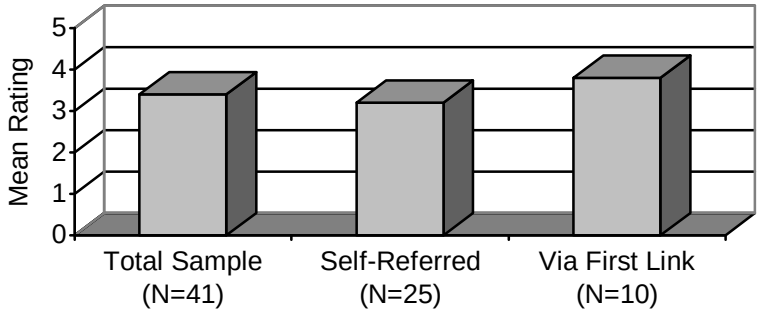
Table 23: Ratings* of Changes in Confidence in Ability to Manage the Caregiver Role across Surveys and Referral Status

Survey Referral Status	Less confident Now	About the same	More confident now
Second Survey (Follow-Up 1) Total Sample (N = 43)	7.0% (3)	27.9% (12)	34.9% (15)
Self-Referred (N = 23)	13.0% (3)	43.5% (10)	43.5% (10)
Referred via First Link (N = 3)	0	33.3% (1)	66.6% (2)
Third Survey (Follow-Up 2) Total Sample (N = 31)	0	6.5% (2)	25.8% (8)
Self-Referred (N = 6)	0	16.7% (1)	83.3% (5)
Referred via First Link (N = 1)		0	100% (1)
Fourth Survey (Follow-Up 3)** Total Sample (N = 11)	0	100% (1)	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.
**The referral status of the individual who completed the fourth survey is not known.

Figure 7 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 = 3.2; SD = .93, and Mean = 3.8, SD = .92, respectively).

Figure 7: Mean Rating* of Self-Efficacy by Referral Status at Baseline



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

Table 24 presents changes in self-efficacy in the caregiver role (ability to manage the role) by referral status. There were no significant differences 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 47%) and decreased over time.

Table 24: 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 = 43)	4.6% (2)	20.9% (9)	46.5% (20)
Self-Referred (N = 23)	0	30.4% (7)	69.6% (16)
Referred via First Link (N = 3)	0	33.3% (1)	66.7% (2)
Third Survey (Follow-Up 2) Total Sample (N = 31)	0	9.7% (3)	22.6% (7)
Self-Referred (N = 6)	0	33.3% (2)	66.7% (4)
Referred via First Link (N = 1)	0	0	100% (1)
Fourth Survey (Follow-Up 3)** Total Sample (N = 11)	0	9.1% (1)	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.

**The referral status of the individual who completed the fourth survey is not known.

Coping Effectiveness: At each survey time, survey respondents completed the Coping Effectiveness Scale (Gottlieb & Rooney, 2004), the results of which are presented in Table 25 (Higher scores reflect greater coping effectiveness; maximum score = 35.) Although there was some variability in the scores, ranging from 13 to 30 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 25: Mean Coping Effectiveness Scale Scores* Across Survey Times

Survey Time	Mean (SD)	Range
First Survey		
Total Sample (N = 42)	21.5 (3.1)	15 – 28
Self-Referred (N =25)	21.2 (3.2)	16 – 28
Referred via First Link (N = 10)	21.0 (2.7)	15 - 25
Second Survey (Follow-Up 1)		
Total Sample (N = 29)	21.5 (3.9)	13 – 31
Self-Referred (N = 21)	21.9 (4.2)	13 – 31
Referred via First Link (N = 3)	20.3 (3.1)	17 – 23
Third Survey (Follow-Up 2)		
Total Sample (N = 11)	21.3 (4.3)	16 – 30
Self-Referred (N = 6)	20.2 (3.6)	16 - 25
Referred via First Link (N = 1)	30.0 (.)	30
Fourth Survey (Follow-Up 3)**		
Total Sample (N = 1)	17.0 (.)	17

*Higher scores reflect coping effectiveness; Maximum score = 35.
**The referral status of the individual who completed the fourth survey is not known.

Caregiver Stress: Survey respondents were asked to rate the amount of caregiver stress they experience related to caregiving using a 6-point scale (1 = not at all; 6 = the most stress I've ever experienced related to this person). There were no significant differences in ratings of caregiver stress across survey times or by referral status: mean ratings of stress remained relatively consistent across survey times and between those self-referred to the Alzheimer Society and those referred via First Link (See Table 26).

Table 26: Ratings* of Stress Scores across Survey Times

Survey Time	Mean (SD)	Range
First Survey (Follow-Up 1)		
Total Sample (N = 42)	4.2 (1.1)	1 – 6
Self-Referred (N = 25)	4.4 (1.2)	1 – 5

Survey Time	Mean (SD)	Range
Referred via First Link (N = 10)	4.0 (1.3)	2 – 6
Second Survey (Follow-Up 2) Total Sample (N = 31)	4.2 (1.3)	1 – 6
Self-Referred (N = 23)	4.1 (1.3)	1 – 6
Referred via First Link (N = 3)	4.3 (1.2)	3 – 5
Third Survey (Follow-Up 3) Total Sample (N = 11)	4.3 (1.1)	3 – 6
Self-Referred (N = 6)	4.2 (1.2)	3 – 6
Referred via First Link (N = 1)	3.0 (.)	3
Fourth Survey (Follow-Up 4)** Total Sample (N = 1)	5.0 (.)	5

* 6-point rating scale: 1 = no stress at all; 6 = the most stress I've ever experienced related to this person.
**The referral status of the individual who completed the fourth survey is not known.

Helpfulness of First Link Information: Table 27 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. Almost half of the survey respondents (49%) had received information from First Link about ADRD at the time of the first follow-up, with the number of respondents receiving information over time (i.e., in subsequent follow-up surveys) decreasing. The usefulness of this information was high (mean ratings ranged from 3.5 – 4.0 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 survey times or by referral status (self-referred/ referred via First Link).

Table 27: 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 = 43)	48.8% (21)	4.0 (.59) N = 21
Self-Referred (N = 23)	69.6% (16)	3.9 (.62) N = 16
Referred via First Link (N = 3)	100% (3)	4.0 (.) N = (3)

Survey Time	Percentage (#) Information Received	Rating of Helpfulness Mean (SD)
Third Survey (Follow-Up 2) Total Sample (N = 31)	12.9% (4)	3.5 (.58) N = 4
Self-Referred (N = 6)	50.0% (3)	3.7 (.58) N = 3
Referred via First Link (N = 1)	0	n/a
Fourth Survey (Follow-Up 3) Total Sample (N = 11)	0	n/a

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

Table 28 presents the percentage of survey respondents that received information about community resources or services from First Link/ Alzheimer Society (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. Forty percent of the survey respondents had received information about community resources or services at the time of the first follow-up, with the number of respondents receiving information over time (i.e., in subsequent follow-up surveys) decreasing. Ratings of the helpfulness of this information was moderate (Mean = 3.4 the first and second follow-up). There were no significant differences in ratings of helpfulness of this information across the survey times or by referral status (self-referred/ referred via First Link).

Table 28: 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 = 43)	9.3% (4)	39.5% (17)	3.4 (.94) N = 17
Self-Referred (N = 23)	9.5% (2)	61.9% (13)	3.2 (.93) N = 13
Referred via First Link (N = 3)	0	100% (3)	3.7 (.58) N = 3

Survey Time	Percentage (#) Received Information But Did Not Contact Them**	Percentage (#) Information Received and Used the Resources/ Services	Rating of Helpfulness Mean (SD)
Third Survey (Follow-Up 2) Total Sample (N = 31)	0	19.3% (6)	3.4 (.89) N = 5
Self-Referred (N = 6)	0	83.3% (5)	3.3 (.96) N = 4
Referred via First Link (N = 1)	0	0	n/a
Fourth Survey (Follow-Up 3)* ** Total Sample (N = 11)	9.1% (1)	0	n/a

n/a = not applicable

* 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.

***The referral status of the individual who completed the fourth survey is not known.

Table 29 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. Forty-four percent 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 12% across survey times). The usefulness of the education/ information was consistently high across survey times (Mean = 4.0 at the time of the first and second follow-up survey). There were no significant differences in ratings of helpfulness of this information across the survey times or by referral status (self-referred/ referred via First Link).

Table 29: 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 = 43)	11.6% (5)	44.2% (19)	4.0 (.71) N = 19
Self-Referred (N =23)	14.3% (3)	66.7% (14)	3.8 (.70) N = 14

Survey Time	Percentage (#) Received Information But Did Not Attend	Percentage (#) Received Information and Attended the Sessions	Rating of Helpfulness Mean (SD)
Referred via First Link (N = 3)	0	100% (3)	4.0 (.) N = 3
Third Survey (Follow-Up 2) Total Sample (N = 31)	3.2% (1)	16.1% (5)	4.0 (.71) N = 5
Self-Referred (N = 6)	16.7% (1)	66.7% (4)	4.0 (.82) N = 4
Referred via First Link (N = 1)	0	0	n/a
Fourth Survey (Follow-Up 3)** Total Sample (N = 11)	0	0	n/a

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

**The referral status of the individual who completed the fourth survey is not known.

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 30). Paired t-tests revealed a significant difference in mean satisfaction scores between the first follow-up survey (M = 4.2, SD = .75, N = 11) and the second follow-up survey (M = 3.5, SD = .82, N= 11), $t(10) = 2.3$, $p < .05$, reflecting a decrease in satisfaction over time. There were no significant differences in satisfaction ratings by referral status (self-referred/ referred via First Link).

Table 30: 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 = 27)	3.9 (.92)	1 – 5
Self-Referred (N = 19)	4.0 (.75)	3 - 5
Referred via First Link (N = 3)	4.0 (.82)	4
Third Survey (Follow-Up 2) Total Sample (N = 11)	3.5 (.82)	2 – 5
Self-Referred (N = 6)	3.5 (.84)	2 - 4
Referred via First Link (N = 1)	3.0 (.)	3
	3.0 (.)	3

Survey	Mean (SD)	Range
Fourth Survey (Follow-Up 3)** Total Sample (N = 1)		

* 5-point rating scale: 1 = no at all satisfied; 5= extremely satisfied.
**The referral status of the individual who completed the fourth survey is not known.

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

Health professionals were very satisfied with the services provided by First Link (as described earlier). Generally, many survey respondents commented on the importance of the services and supports provided to persons with dementia and their caregivers, particularly as this level of support is not available elsewhere and is beyond the scope of many health professionals to provide, as illustrated in the following comments:

> *"The education and support to families or Informal Care Providers is invaluable to help them cope with the changes in the patient and helps to reduce care giver burn out and depression. Prior to my awareness of the programs through the Alzheimer's society, I (an RPN) provided that education and support to the family, so AS of S has reduced my work load. More significantly, First link does a better job of education and support than I was able to do re time/availability resources and peer support."*

> *"I have found any dealings that I have made with the First Link Co-ordinator (on behalf of clients/families) has always been met with openness and willingness to be of assistance. This is very appreciated as I feel like I can count on this agency to provide the support I can't provide to the families of my clients."*

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 31.

Table 31: Summary of Client and Caregiver-Related Impacts Associated with First Link

Client and Caregiver Related Impacts:

- **Increased access to information about their disease**
  - Increased access to information earlier in the disease process
  - Increased access to information in rural and remote areas
  - Access to information when relevant
  - Access to accurate information not available elsewhere

- **Increased access to early intervention**
  - Potential for assessment early in the disease process
  - Increased access to system navigation support
  - Increased access in rural areas
  - Access to proactive supports
  - Access to support when needed

- **Increased access to caregiver support**
  - Increased caregiver capacity
  - Reduced stress
  - Increased access to caregiver supports in rural and remote areas
  - Reduced stigma associated with seeking support

- **Reduced crises**
  - Reduced Emergency Department visits
  - LTC avoidance: Increased capacity to remain at home

Increased access to information about their disease

Almost all of the key stakeholders interviewed (health professionals, Alzheimer Society Representatives, and project leaders) noted that a significant role of First Link and the Alzheimer Society has been the provision of accurate and detailed information about ADRD that is not usually available elsewhere, early in the disease process and the provision of this information when it is most relevant to the person with dementia and their families. It was also noted that the Alzheimer Society plays a key role in ensuring that this information is available to people living in rural and remote areas of the province.

- ***Increased access to information earlier in the disease process:*** It was noted that First Link ensures that people have access to information about their disease early in the disease process and that for those who are diagnosed in the later stages of the disease it provides timely access to information. It was generally accepted that early access to information is critical for person with dementia and their families to assist them to understand and manage the disease and to plan for the future.

  "The more people know early the better. It's just so important for how they handle what happens next." [KSID1]

  "Well one of the major benefits I think to First Link is what you're going through. You're not all alone and that some of the things that you may be experiencing in the evenings or in the middle of the night are typical of the disease, I think helping families understand that this person has a disease process, their behaviours aren't meant to attack anyone in the family personally. I know a lot of times people are struggling with why is dad doing this, doesn't he know better?" [KSID3]

It was noted that access to information is increased with First Link making the first connection with those newly diagnosed, a time described as overwhelming and a time when people are least likely to call First Link, despite it being the time when they need information the most.

> *"Most people or families or patients they may be scared or too leery to phone, or overwhelmed with their diagnosis. So I think this is good because then the onus isn't on them to try and phone. They* [First Link] *contact them and I think that's really important, early access is important."* [KSID7]

> *"The other aspect about it that I think is crucial, I certainly refer for family members struggling with the shock of the diagnosis, is having someone phone you, as opposed to you having to pick up the phone when you're absolutely devastated. That part of the First Link is very good."* [KSID9]

- ***Increased access to information in rural and remote areas:*** It was noted that generally in rural and remote areas of the province, persons with dementia and their families have limited access to information and services. With the introduction of Telehealth Network video-conferencing for the Alzheimer Society Learning Series, people in rural and remote areas now have access to information that was not available to them before.

- ***Access to information when relevant:*** First Link offers learning series sessions that provide information to specific stages of the disease, so that people can access information as it becomes relevant for them. Similarly, First Link follows up with people to remain connected so that while someone may indicate when first contacted that they are not interested in any information or assistance, they are contacted at a later time as an opportunity to identify a change in needs.

> *"They* [First Link] *actually do follow up, so if they call in two weeks and say: 'Do you want more information? Do you want to come to the learning series?' and they* [First Link client] *say no, First Link actually do call them back in six months. Because the whole premise is that people need information when they're ready for it, and two weeks after the diagnosis, they might not be ready for it. Sometimes people actually call before then and say I wasn't ready then, but I'm ready now."* [KSID7]

- ***Access to accurate information not available elsewhere:*** It was noted that when persons with dementia are diagnosed in Memory Clinics and assessment units they are referred back to their family physicians for follow-up and are usually not seen again. Although professionals in Memory Clinics and assessment units are knowledgeable about Alzheimer Disease and dementias it is beyond their scope of practice to provide education and information on a longer term basis. Similarly, family physicians are too busy to assume this role. First Link and the Alzheimer Society play an important role in providing persons with dementia and caregivers accurate and reliable information that they would not be able to get elsewhere. It was noted that although there is a lot of

information about ADRD on the internet, persons with dementia and caregivers often need to speak to someone directly about this information to determine its relevance and applicability to their situation. It was also noted that there is a lot of misinformation about ADRD on the internet.

> "*I feel comfortable in referring to the First Link because I think the coordinators are very knowledgeable and have such a wealth of information that I've learned from even just talking to them about it, it's a wealth of information that they* [families] *need to have."* [KSID5]

Increased access to early intervention

First Link was credited with increasing access to early intervention through its role in providing system navigation support, increasing access to intervention in rural and remote areas, increasing access to proactive supports rather than access at the time of crisis and increasing access to supports when needed. Similarly, it was noted that as a result of information provided on dementia, some people are seeking assessment and diagnosis earlier in the disease process.

- ***Potential for assessment early in the disease process:*** It was noted that there are an increasing number of people contacting First Link for information regarding their memory concerns. As a result of the information that they received, they seek out assessment so that potential exists for early diagnosis and intervention.

  > *"Clearly there's a lot of people that are calling the Alzheimer's Society because they've got some concerns and they want to start to sort it out, which I think is fabulous because we have all that information that we can give people to help them and not have happen that they go to the doctor and get patted on the head and say: 'Well, you're fine, I don't know what you're doing here.' because that's a problem...They can get information to help them to get to the right diagnosis and to get help rolling."* [ASREPID5]

- ***Increased access to system navigation support:*** It was noted that an important role of First Link is to help connect people to services and resources that could be of benefit to them. Identifying what services are available and how to contact them is a valuable service that is not provided by healthcare providers. Many stakeholders identified the system navigation role of First Link as particularly important in rural and remote areas as a challenge, as reflected in the following comment:

  > *"Some of our patients have told us that, and this is a frontal temporal patient's husband, they're in a rural community, you think it would be easy to know who to contact when you needed help. The spouse made four phone calls before he got connected with somebody who could possibly help him. He kept getting voice mail and getting you know, press this and press that, and then there would be nobody at the end, and just leaving a voice message, and this is a person who was in a crisis and needed help now and didn't know how to find out help because everywhere they*

phoned there was nobody they could talk to. So they said: 'That's not our thing. You need mental health or try this." It was heartbreaking to hear the story. It's not obvious even in small communities where you phone to get help." [KSID4]

An Alzheimer Society representative who once worked in a private sector organization commented on how overwhelmed people were at the time of diagnosis and how, at the time, people could have benefited from First Link:

"We used to have people who say: "I was just at the doctor, I got a diagnosis of Alzheimer's, I don't know what to do. I don't know where to go. They gave me all these numbers. What do I do? …Because when you get the diagnosis you're given all this information, 'You should phone here, and you should phone there and you should phone this. It's overwhelming, so for me to say, you know what, give me your name and number, I'll get somebody to call you, would have been a huge relief for them." [ASREPID4]

- ***Increased access in rural areas:*** Increased access to information about ADRD and available community resources, as well as system navigation support has increased access to intervention and support, particularly in rural and remote areas where access to intervention has been a challenge.

  "I think it's very positive what they're doing, the fact that they're advertising and people are becoming aware that there is a service, because I'm always surprised at how people are struggling without resources so and it's not just something that's happening in Regina, they're also out and about in the rural area of Saskatchewan trying to provide resources to families." [KSID3]

- ***Access to proactive supports:*** First Link was credited with ensuring that people have information about and access to supports and services before the need for these services becomes critical. Learning Series focused on Care in the Later Stages ensures that people know what is available to them, and the Society will work with them to put these services in place before a crisis situation occurs.

  "I think early intervention by First Link is encouraging families to get help early, don't wait for a crisis, it's also informing families of what are the resources that are out there and what is going to happen in the progression of this disease." [KSID3]

- ***Access to support when needed:*** It was noted that one of the key benefits of First Link and the Alzheimer Society is their availability when support is needed. Not all persons with dementia and their caregivers require assistance when they are first diagnosed or first learn about the Society, but the connection with First Link informs them of what is available and how to access it when it needed. Follow-up contact by First Link ensures that people are reminded that supports are available to them. It was noted that although Memory Clinics and assessment units provide family physicians with recommendations regarding referrals to community services that should be made for patients, many

physicians are not in a position to assume a case management role and many referrals for services are left unmade.

> *"Well I think it's critical and I think that this is an important program to make those linkages early on with community supports and having someone that they can contact and who helps sort of walk them through resources that are out there when they need them. I think our patients at the end of the day are pretty tired and overwhelmed and it's really hard to absorb even just the diagnosis, let alone to think about what they might need at that time. What they might need in the next weeks and months and so on. So having someone proactively contact them a little bit later I think is really important. I'm pretty sure that very few of these patients and their caregivers self refer for services, they're just so busy just trying to cope with the day to day reality that they don't reach out for services… very few patients and caregivers self refer and unless there's some kind of a system in place, like a case management type of a system where people are linked up with someone in the community who is a navigator and can work with them throughout the trajectory of the dementia and the caregiving, they're pretty lost. They fall through the cracks and aren't getting the services that they might need or would find helpful, and unless that happens proactively like First Link, I'm afraid that people aren't getting services that are available to them, so I think it's really important."* [KSID4]

> *"The fact that information keeps coming and it's not just, we talked to you once. In hearing from some of my staff , when they did some of the follow up phone calls it was like: "Oh, it's just so nice to know that you're still out here and no we don't need anything, but you know it was just nice to know that you're there and you are going to check in. And I think for them too it's just reassurance that they can call the Alzheimer's Society back when they need us."* [ASREPID2]

It was noted by an Alzheimer Society representative, that increased access to information and support is evidenced by the increase in the number of people who have registered with the Alzheimer Society:

> *"I think that with the marketing that we have done about First Link that there are more people that have come out, from around Saskatchewan, I think that that has been greater awareness of what we do. I think we've been well connected with the society, doing direct referrals and I think there has been an increase in the folks that have connected with the society that reached out."* [ASREPID6]

Increased access to caregiver support

Almost all of the key stakeholders interviewed commented that First Link has been critical in increasing caregiver awareness of and access to information and support to assist them in their caregiver role.

There's a two-fold thing going on here. One is getting people connected, but it's the broader issue and we've always been aware of raising the profile, making people believe that we can do something for them. Really giving them a sense that of hope, that if I do call there can be some positive change in my life." [ASREP]

- ***Increased caregiver capacity:*** Information and support provided via the First Link and the Alzheimer Society to caregivers were credited with increasing their capacity and confidence in their caregiver role.

  "And so really validating their coping strategies, because you can be coping 80% of the way and you're so fixated on that 20% you don't realize that this is good and if somebody strokes you for it, then you can just relax a little bit and say: 'Okay, I am doing a good job.", so those are all things that I think really go under support. Support in terms of mentally knowing that you understand and getting the information you might need for the stuff that you're not doing." [ASREPID3]

  "Some of the benefits is the amount of information that's available. If you look at the information that's available through First Link, like the learning series and the support groups, I think those make a huge difference with how a spouse or a child deals with the disease, because anything is a lot easier to deal with when you know the information and also too when you can sit down with somebody that's going through the same thing…. Because as much information as we can provide, we can't list everything that works. Whereas if you sit down with somebody and you go: Oh my God, I'm trying to do this and it's just not working and mom's really argumentative, or my spouse is really argumentative', and they go: 'Oh well you know what, I did that, I went through that last month and this is what I tried.' It is so beneficial." [ASREPID4]

- ***Reduced stress:*** Caregiver supports provided via First Link and the Alzheimer Society have had an impact on reducing caregiver stress.

  "Benefits of First Link? I would say alleviating the emotional distress of family members and giving them support." [KSID5]

  "And when that phone call comes in, it's an opportunity to learn about it because I think there's so much misinformation still out there about Alzheimer's disease and dementia. And for caregivers, this diagnosis, it affects people in such a profound way that it really helps them to understand the disease and to come to terms with it, for some it's the ability to meet other people who are going through the same thing and to be able to talk about that with someone who truly understands, as well too." [ASREPID2]

- ***Increased access to caregiver supports in rural and remote areas:*** Videoconferencing and system navigation support has increased access to supports for caregivers in rural and

remote, who have primarily had to manage the disease in isolation with minimal supports.

> *"There is nothing around in rural Saskatchewan to support caregivers. They tend not to go south for things like this so First Link has definitely been a way to get more people connected."* [KSID2]

- ***Reduced stigma associated with seeking support:*** It was noted that access to emotional supports continue to be a challenge not only for those in rural and remote areas, but also for those of a generation where seeking emotional support is viewed as not socially acceptable. First Link was credited with breaking down some of the barriers that prevent people from seeking support.

> *"That's a very different generation than what you and I might have grown up with, and* [caregivers] *were very reluctant to go to a counsellor. They would go see their minister for counselling, but they would not go outside the family… If people are open to the support, I see it as a really good tool and it gets people in the door sort of to an organization that can continue to provide support."* [KSID8]

> *"It's partly the stigma. What actually happens with a few of our families is they say that their spouse is so terrified by the fact that they've been diagnosed, that anything that says Alzheimer's Society on it, they throw out, they get very upset, or if the phone displays it. So I think it's the fact that it's rather terrifying to get that diagnosis, the fear of that… We diagnose and communicate the diagnosis. But certainly people get pretty terrified when you say Alzheimer's Society."* [KSID9]

Reduced crises

It was noted that information and supports received from First Link/ Alzheimer Society can serve to reduce the incidence of crises created by failure to cope, escalating behaviors, and ineffective management. This in turn serves to reduce the number of visits to Emergency Departments and may increase caregiver's capacity to manage the person with dementia at home, thereby delaying or avoiding long-term care placement.

> *"I think early intervention by First Link is encouraging families to get help early, don't wait for a crisis, it's also informing families of what are the resources that are out there and what, what is going to happen in the progression of this disease…I have no information that would say that it reduces the number of people that show up in the emergency department, but I would think it would have to impact that because if families are understanding about walk away, don't try and push an issue, it's one of the ways you keep the person calm and you're not frightening them and therefore there maybe wouldn't be some of those episodes occurring."* [KSID3]

> *"I think we could avoid a lot of crises…if there was someone working with this family right from the beginning, that could stay in touch with them, develop a relationship and trust, just gently suggest some things that are out there when they're ready, that they can*

start you know, mentally processing that before it gets to be a crisis. So I think it really could reduce use of resources [health system] *and provide support to caregivers. I think its supporting caregivers so that they can continue to care as long as they want to, and they can do that if they have the right supports in place."* [KSID4]

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 caregivers and persons with dementia who were directly referred to the Alzheimer Society via First Link reported that accessing First Link and the services of the Alzheimer Society was extremely easy, requiring no effort as they were contacted by the First Link Coordinator. Several of the caregivers who were referred to First Link by their physicians commented on their satisfaction with their physicians' foresight to make the referral.

"For us we were referred through my mother-in-law's doctor and I was just delighted to have him be so positive about having his patients or in our instance, caregivers, be in touch with the Society." [CG1]

"He was her primary caregiver and he knew that the situation was bad, we didn't realize to the extent and so then it became the responsibility of family to take her to the doctor and her family doctor has been excellent, I was very impressed and he was very proactive in, he is very proactive in getting his patients or their caregivers to be involved with the Society." [CG2]

In contrast, those who self-referred to the Alzheimer spoke about their frustrations and struggles in seeking assistance and dissatisfaction with their physician's lack of awareness of resources available to support their patients.

"We went into drug trials, different drug trials and we were on our own and I'm searching and wondering: 'What can I do?' And when we'd go to the doctor all he wants to go do is give us pills and say: 'Come back in four months and we'll do it again.' So I was really sort of at my wit's end, but we, we are dumb I guess, we didn't start looking on our own for a while." [CG4]

"I was very disappointed with [family physician], [specialist], why haven't they got pamphlets or why don't they suggest we do this? And one of my visits when I did finally get in contact with the Alzheimer's Society I said we're going to go to what they call a coffee club, he said: 'Oh that's good, you should be going there.' Well why hadn't he told us before that?" [CG2]

"Well as I was telling you, we had absolutely no information given to us from the neurologist's office or from our family doctor when he was originally diagnosed. So, I just started asking where can I get some help... so I asked some friends, some were ministers, and they told me about Oliver Lodge and the Alzheimer's Society and they had a couple of names for me, so I just started phoning. But I didn't get any information from my family doctor and that really bothered me." [CG3]

One caregiver commented that although she was aware of the Alzheimer Society and had attended a Learning Series session, the lack of a diagnosis prevented her from getting actively involved in the services that were available or from getting the person with dementia to attend programming.

> *"We suspected Alzheimer's, but didn't know for sure. But I found initially the times I came to get information* [from Alzheimer Society], *the people were really helpful, as far as like finding out about any of the courses and stuff like that. I didn't really, really get involved until I had the diagnosis, and getting a diagnosis is a very long process.... I've actually just talked to him about coming to the learning series next, but because we don't have a specific diagnosis, even though we have a diagnosis of early dementia, it's really difficult to get him to buy in to the fact that anything is wrong when he feels fine, in the moment."* [CG1]

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 32.

Table 32: Summary of the Ways in Which First Link has been Helpful to Caregivers and Persons with Dementia

Caregiver/ Person with Dementia Related Impacts

- Single entry point to information
- Knowledgeable source of information
- Access to information about ADRD
- Access to information about community services and supports
- Caregiver support
  - Learning from each other
  - Practical strategies
  - Reduced isolation and burden
- Support for Persons with Dementia

- ***Single entry point to information:*** First Link and the Alzheimer Society were noted to be a single entry point to information and support regarding ADRD. This was described as significant as it does not require people to search out information at a time that they are extremely overwhelmed.

  > "All that information is very essential, and it was one place to come and get it, where you didn't have to search... you just go to one place and you got it all." [CG3]

- ***Knowledgeable source of information:*** First Link and the Alzheimer Society were described as knowledgeable and reliable sources of information. Almost all of the caregivers noted that they found the Alzheimer Society to be more knowledgeable and better able to manage ADRD than health professionals.

"I find that the people here are more knowledgeable than the people in the medical profession, even people you know that are specialists that I would expect to know this...Maybe like as far as for what both the person with the illness as well as the people, like the family members and the care givers, what they're going through. We had a situation where dad got sent for blood tests, but how is he to remember that he got sent for blood tests, so we had to go back and find out from the doctor what happened. It's like you can't just send him out for an appointment without telling someone that has no short term memory what it is that has to happen next, So I found dealing with the doctors extremely frustrating sometimes." [CG1]

- ***Access to information about ADRD:*** Many caregivers noted that the information about ADRD that they received from the Alzheimer was information that they would not have otherwise had access to and that they would not get elsewhere. The information was described at a level that was understandable and useful, as for example, in preparing for doctor's appointments, learning what questions to ask of health professionals, and in understanding the person with dementia's behaviour.

  "There was so much information... I remember there was a video that was shown on like things that people would take for granted, I think it was making a cup of coffee...you don't really realize how many different areas of the brain are required to all be working together and that its actually quite a multi step process as far as where are the cups, and what does a cup look like and where are the cups...it was really interesting, it just gave me insight and then the following week, actually right after I saw that video my dad tried to make toast on his own and I saw him mix up the steps and it really gave me like insight into what he was doing." [CG1]

  "I found the information was very good, particularly about the disease, so we learned more about what happens with the disease. The financial information was tremendous for me as a care giver to know what I needed to do financially, I hadn't even thought about that kind of stuff." [CG3]

  "And it also prepares you better for the doctor's appointments because you find out what kind of tests they do, and then you're able to recognize whether or not the doctor is willing to do some of those tests...it [information] was helpful because even then it gave me information on what type of questions to ask." [CG1]

  "I do plan to go because I still need the support and I need to learn some more. The doctors, they say: 'Well too bad, that's the way it is. There's no magic pill.'" [CG1]

- ***Access to information about community services and supports:*** Caregivers and persons with dementia learned new information about community services and supports, such as day programs, friendly visiting programs, and respite that were not previously aware of. This system navigation role was described as extremely significant as there are few other sources for this type information.

"I had no idea how you would access services. So it was great...it was excellent because that gives you access to everything then and they can recommend it." [CG3]

"We were really struggling on our own. I had no idea of what help was there for us. Nobody told us. Until First Link called us, we had no idea of where to go." [CG5]

"I had no idea how you would access services. So it was great...it was excellent because that gives you access to everything then and they can recommend it." [CG3]

"They [Alzheimer Society] made information available of where we can go for that extra help, which is a very, very important thing. Without it, people don't know where to go." [CG2]

- ***Caregiver support:*** Almost all of those interviewed reported that they had attended Learning Series sessions, support groups and coffee hour programs. Those who reported that they had not attended support groups were openly encouraged by other interview participants to do so because it is a significant source of emotional and informational support. Interview participants described how the relationships formed with other support group members have been meaningful and long-lasting. The Learning Series sessions, support groups and individual contacts with First Link Coordinators were described as an opportunity to share experiences and learn from each other, learning practical strategies and were credited with reducing caregiver feelings of isolation and burden.

  "I'm not really sure what I thought when went I to that first group…they've become my lifeline… best of friends." [CG4]

  "I find there, I think there's three different support groups that I'm aware of ... it has been invaluable, and it was from the Alzheimer's Society that I was able to you know find out about that, and that's where because it's a confidential setting, that's where the participants can exchange that type of information as far as what people are doing." [CG1]

  "I think we're getting to know everybody. We're made a whole new circle of friends with the support group and everybody, so that's been good. ... It's good to go to a place with the support group that you can talk and where people are on that same journey, and a lot of them are a lot further along with their journey that we are, some have spouses in long term care, so just that wisdom, that collective wisdom is great." [CG3]

Learning from each other

"It [Learning Series] was fabulous. Even just getting experiences from everyone, because all the different participants were in different stages so not only did I get to find about the day program, but say the one lady, her husband actually went to the day program so I kind of got to know a bit about like what those different experiences were like and what services were out there." [CG1]

"I was having trouble about 3 or 4 months ago with him sleeping. Not sleeping, all night long, he still does that sometimes. But I had talked with the support group about it and then I got to our family doctor and he was able to give him some medication that helps considerably... I find sleep is the biggest thing, I can cope with everything else as long as I'm able to sleep, but if I can't get sleep then I'm not very good at coping... so it was helpful to have the group to talk to about that." [CG3]

Practical strategies

"Well I'd say the one thing is you know the counsellors that you can call in if you're having a bad day or you're having a struggle with something. One of the things that we were having difficulty with and it was partly because dad thought he had just done it, was getting him to go and have a shower. I remember calling in and talking about different ways that I could try and encourage him. You always feel better at the end of the phone call than you did at the beginning of the phone call." [CG1]

Reduced isolation and burden

"*I don't feel so alone."* [CG3]

"I think it's a very important program because it's really kept me from going crazy." [CG1]

"What I've learned too in coming here is that I'm not the only one in that situation, and so there are groups that we can go to who can give us assistance or we can just sit down over a cup of coffee and say: 'This is my situation.' and [caregiver] over there is going to say: 'And this is my situation' and you can talk about how you can make it better." [CG2]

"But you know, it's having as much information as possible just eases the load, it gives us confidence in what we're doing, and it helps us to understand the situation we find ourselves in." [CG2]

- ***Support for persons with dementia:*** Interactions with other caregivers and persons with dementia were viewed as beneficial for persons with dementia as opportunities to improve mood, reduce social isolation and provide encouragement.

"[Person with dementia] *had already tried the day program and he went one day and it was a disaster. He came home, he was upset. He was never going back, he cancelled it... Then we came to a coffee club in March and one of the ladies said: '[Persons with dementia] would you consider going to the day program because my husband's going to start going?' and* [persons with dementia] *said sure. He had some help with that and he went because he had someone to go with and that was some encouragement."* [CG1]

"We're going to that group [group for persons with dementia and caregivers] next time. It will help me, because I am getting down." [PWD2]

Satisfaction with First Link: There was general consensus among the caregivers and persons with dementia that First Link and the Alzheimer Society plays a critical role in management of ADRD, in terms of its role in providing information, system navigation support, and provision of emotional support. All of those interviewed were very satisfied with their involvement with First Link and the Alzheimer Society and many expressed gratitude for services and supports received, and in particular commented on how there was always someone available to speak with them whether in crisis or not. It was also noted that with the aging of the population and expected increase in ADRD, the Alzheimer Society will continue to be a much needed resource. There was much support for continued government funding for the Alzheimer Society.

"Well I know everybody here, you've all heard me say this before, but to me when I hooked up with the Alzheimer's Society I felt like they had thrown me a life line, I really thought I was drowning." [CG4]

"The Alzheimer's Society definitely is needed and has a place in our society, particularly going in to what we're going in to, as I mentioned, there are so many baby boomers and this is a generation of people who dementia and Alzheimer's is affecting… I definitely want to see them continue in the community and I definitely want to see federal government money coming here to keep on working. We're evidence of the fact that they've had an impact. I think that is crucial."
" [CG2]

"They are so accessible. I found like with my mom, I spent an hour on the phone with [First Link Coordinator], *she's never said: 'I'm too busy or I'll call you back or anything.' I just got so much support from them."* [CG4]

Suggestions for Improvements: Interview participants indicated that they were satisfied with their involvement with First Link and the Alzheimer Society and had few suggestions for improvements. Of greatest significance were suggestions highlighting the need for physicians to make referrals to First Link. Caregivers identified a number of suggestions for improving the system of care for persons with dementia, most significantly the need to increase physician capacity for assessment, diagnosis and management of ADRD. Suggestions for improvements to First Link and to dementia care in general are summarized in Table 33.

Table 33: 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
• Distribute newsletters on a regular basis
• Start programs later in the morning
• Encourage referrals to First Link prior to diagnosis

- Promote First Link to physicians to increase referrals

Improvements to Dementia Care

- Increase physician capacity for assessment, diagnosis, and management
- Increase opportunities for home visits for medical care
- Increase number of assessment/ diagnostic services
- Increase respite/ friendly visiting
- Increase access to day programs
- Increase adult day programs targeted to younger adults

- ***Distribute newsletters on a regular basis:*** It was suggested that the First Link and Alzheimer Society distribute newsletters, as they have in the past, on a more frequent and regular basis.

  "They had one newsletter out, I don't know if they've added another one this year, but there was some good information in it. It's a whole year ago since we got it, about research in Saskatoon, but I don't know if they sent out another one. It would be nice to get an up to date newsletter once in a while." [CG3]

- ***Start programs later in the morning:*** As attendance at programs before 11am is difficult given persons with dementia requirements for assistance with bathing and dressing and travel time for those living out of town. It was suggested that programming not be scheduled earlier than 11:00am.

- ***Encourage referrals to First Link prior to diagnosis:*** Given the significant role that First Link plays in assisting caregivers and persons with dementia to access information and support, and to navigate the system of care, it was suggested that referral sources be encouraged to refer people to First Link even before a diagnosis is finalized.

  "Just that one about being connected prior to the diagnosis, because then at least even if they [physicians] *can't tell you what it is, at least you can start getting connected with the other people and getting the information that is so helpful."* [CG4]

- ***Promote First Link to physicians to increase referrals***: Many caregivers stressed the importance of being connected with First Link as soon as possible after the diagnosis is made and suggested that First Link be promoted to physicians to increase access to the Alzheimer Society.

  "I don't know how you can do it, but somehow to get the neurologists, the family doctors, those places to be able to point you in the right direction, even if it's just giving you an information pamphlet saying this is who you need to contact, it would be amazingly wonderful. I would have been happy to have been handed a pamphlet to say this is who you need to contact. It would have been so helpful and save me a lot of running around, trying to find out where I needed to go and who I needed to talk to

and I don't know how that happens, you can't force them, but darn, I wish you could, because that was probably the biggest thing, was the access." [CG3]

"I think that's what we need our physicians educated to do, is that when this diagnosis has been made, that they then take that step of referring us to the Alzheimer's Society and we can avail ourselves of so much information. So that's what they need to be educated about is the referring." [CG2]

Improvements to Dementia Care

- ***Increase physician capacity for assessment, diagnosis, and management:*** Almost all of the caregivers interviewed described the need to increase physician capacity for assessment, diagnosis and management of ADRD. Many described being dissatisfied with the care that they and their loved one had received from health professionals, specifically the lack of attention to concerns about memory loss, lack of a clear diagnosis, lack of information about the disease and strategies for management and about available community supports, including the Alzheimer Society.

  "Actually dad's original doctor who has as much said we didn't need to say anything to him. Well, I don't believe in lying to my father... but he just called it normal aging. And it is not, not at all.... So there is a lot of frustration with the medical system that they're not well informed, not only about the disease, but not well informed about what supports are available in the community.... He kept saying it was just normal aging. My mother contacted the doctor. My sister contacted the doctor; my sister is a nurse. She went in and had a meeting and he would not listen to her what so ever! Now with a new doctor, he has a general diagnosis and here's information on six different dementias that you might have... so it leaves a really bad taste in my mouth because that's like telling someone they have cancer, but we're not going to tell you where it is, and that would never happen." [CG1]

  "We were struggling with all the changes happening in our lives. When we'd ask [physician] questions, he more or less said: 'Well this is the way it is.' and there was not much anyone could do about it. He could give pills but that was it. I needed to talk to about my frustrations, and new changes happening every day." [CG1]

  "It [assessment] *was scary."* [PWD3]... *"It was a terrible, actually it was an awful experience for him and for me, but for him particularly, because they gave him that test where they ask the questions, see what they can remember and all that, and he* [person with dementia] *wasn't expecting it and he gets, of course you get flustered and he got all these questions thrown at you and he* [physician] *was very abrupt and just threw him off completely... It was disrespectful."* [CG3]

  "Because my mom had Alzheimer's I started to notice things a good two years before [Person with dementia] *ever got diagnosed. I finally convinced him he needed to go in for an annual check-up and he went in and now I didn't talk to the doctor, he told the doctor that his wife said he was having trouble remembering things, and the doctor*

apparently said to him: 'Oh yea, well you know, I have that too, I forget things at home' and just brushed him off. That was the first year. The next year, [PDW] said he forgot to tell the doctor that he was forgetting things. The following year he was diagnosed" [CG4]

- ***Increase opportunities for home visits for medical care:*** It was suggested that accessing medical care is often difficult for persons with dementia, due to either denial or anxiety. One caregiver noted that her care receiver had 19 cancelled medical appointments because he would have an anxiety attack prior to the appointment and would be unable to leave the house. Other caregivers also noted increased agitation and behaviors associated with medical appointments. It was suggested that physicians do home visits in these types of situations to ensure that persons with dementia have timely access to medical care and assessment.

- ***Increase number of assessment/ diagnostic services:*** There was much support among caregivers, particularly those from southern regions of the province for more assessment units and Memory Clinics, and particularly for assessment programs that provide same day assessment and diagnosis.

  "The memory centre in Saskatoon they do everything in one day. I'd love to have something like this locally." [CG1]

- ***Increase respite/ friendly visiting:*** It was noted that there is a severe lack of respite across the province, particularly in-home respite. Although in-home respite is available through community service provider agencies, it was noted that this is type of private respite is not generally affordable, particularly when needed frequently. It was also suggested that more opportunities for in-home friendly visiting with persons with dementia were needed.

  "And when you're in this situation, you deal with this 24/7, respite is really important. You need that break in order to avoid having that fuse come to the end of its line. We also are aware that respite for various types of needs, those beds just aren't available. [CG2]

  "I went to a group… he stayed home on this own… and he called me three times and then he called 9-1-1. And we had had 9-1-1 a couple of weeks before that, or I'd had to phone, had the firemen come to help me get him up and the reaction of one fireman was not very positive. He said I would have to look for alternatives. He said: 'Don't you have any family in town?' And I said: 'Yea, I've got an 80-year-old sister' and that ended that conversation." [CG4]

  "You know what I really miss? I miss sewing. I used to sew a lot of clothes for my grandchildren and I'd do their Halloween costumes. But you really have to concentrate on it and you can't keep getting interrupted and really need to do it in stretches of time. You can't just do a little bit here and there. I'd love to just have a

day of quiet sewing. I can't do that. He'd either be wanting me all the time because he's become glued to my side or he'd be off somewhere in the house about ready to burn it down. It would be nice if someone could come stay with him or take him out for the day so I could just sew. Just sew. That's all I'd want to do. That would make me happy. Now I could get someone to come for a few hours, but it would have to be a good reason, like when I go to the doctor or when I had my teeth done. But not because I just want to sew." [CG7]

- ***Increase access to day programs***: Although day programs are available, it was noted that there are generally long-waiting lists for spaces. Caregivers noted that while there are many benefits associated with participation in day programs, persons with dementia often decline while waiting for a space and the lose the opportunity to benefit from the program.

  "Well I wish they had more spaces in like, he's been accepted into the day program, but there's no space right now so we're going to have to sit and wait for a space to come up. I'm hoping the wait won't be too long, and the same when you want to go into long term care, when you're ready for that, you wait till there's a space, so I think the overcrowding, but that's true I think across Canada and as our population ages, it'll be more so. It would be nice if he could be in a day program now a couple days a week, but we'll sit and we'll wait." [CG3]

- ***Increase adult day programs targeted to younger adults:*** There is a need for more day programs targeted to younger adults as most are currently geared to the needs and interests of older adults.

  "[Person with dementia] *was 62 when he was diagnosed. …He did come to* [day program] *for one day and at that point he could still use his cell phone and he phoned me at noon and said: 'Come and get me, they've got me in here with a bunch of old people."* [CG4]

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.

Educating Caregivers

"I remember this woman, whose husband was in a care home. He was in the late stages and she had tried to keep him at home as long as she could but it was a real struggle. She had become sick herself and really looking back at some of the things she had told me about, she had not coped well at all. It really aged her. And she was doing it all on her own, out in the middle of nowhere. Now even though her husband was in a facility, I thought it would be good for her to talk to somebody, so I referred her to First Link.... The next time I saw her, probably a couple of months later, she looked so different. She said she met with someone from the Alzheimer Society and had gone out to some of their groups and she was shocked at what she had learned. Things

that she had no idea about when she was going through them, like why he was doing the things he was doing. She kept saying she wished she known about this before because it would have made things so much different for her. But I think what she learned made it so much easier for her to have him in the facility and she could deal with that better. She understood it better." [KSID1]

Supporting Caregivers

"I had referred a family that was very supportive of their mother, who has, I'm not sure if it was dementia or Alzheimer's, because they were dealing with the progression of the disease, and the willingness of the coordinator to actually sit down and meet with them and talk about what was happening. That's where I think the family said it was very helpful. They didn't go into detail, but they felt, I mean they made comments that it was helpful." KSID5]

"We had man that has dementia and some erratic behaviour, a very over stressed family system, and absolutely no money...the police put out an APB on him about 2, 3 weeks ago. I had told them to get a safely home when I first saw them last summer some time. It turns out money is an issue. So he doesn't have the bracelet... because his behaviour can be quite erratic. When the police pick him up, he's not a cute little old lady. He's been brought up to fight and he's tough, so if he had the bracelet that would have really helped. But the family phoned yesterday. They went into the GEM program and asked if they could get Safely home. So you know, that's an example of where the program can really, really help somebody from coming in to harm." [SKFLID3]

"We've been working with this particular doctor for a long time to get him to make referrals and keep it top of mind. [First Link Coordinator] had a relationship with this doctor ... After seeing her at a conference we finally got that first referral from him and it worked out that this person that he referred, this particular woman came to a learning series. She was just relieved that it worked out to come, and she said; 'I'm going back to him and telling him this was great.' I talked to her again last week and she said her mother had since gotten settled into a personal care home and was doing quite well and she said: 'I just know how to visit with her now and now I'm going through it with dad, and I feel better about it and I want to know what other series you have.' She was very positive about the Society and about her experience and was willing to speak to that." [FKREPID4]

Reaching out to Families

"When we first were implementing First Link we received a direct referral from the geriatric assessment unit at the hospital. I had called the person that was listed as the person to call, which was the wife, the gentleman had the diagnosis and so I gave her a call. She said something like: 'This is all so new, and I'm just trying to get my head wrapped around the diagnosis and all the changes, it's all just so new.' And so I asked her if I could give her a call in a couple of month's time, just give her some time to think through, to absorb the news that they had received and she said: 'Yes, by all means, give me a call back and I also provided her with my contact information as well.' And you know, she called me back before the two months was up, three weeks later and said: 'You know what, I am now ready to hear, that you're able to help us.' And so we chatted about the diagnosis and about why some of the changes were happening and told her about the learning series and about counselling, support services and they actually did

become quite involved with us. She attended a care giver support group, she also attended our learning series, and then after that learning series they attended the monthly groups, and she advocated on behalf of the Alzheimer's Society to her family, to her other support groups, support networks, like to her church community and things like that.... if we wouldn't have received the direct referral, we don't know if she would have connected with the Alzheimer's Society." [FLREPID6]

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, First Link Coordinators, and Alzheimer Society representatives identified a number of factors that facilitated the development and implementation of First Link; these factors are summarized in Table 34.

Table 34: Summary of the Factors Facilitating the Development and Implementation of First Link

Facilitating Factors:

- Consultation process: Support for First Link
- Support from Ottawa First Link program
- Support from key stakeholders
- Support from Alzheimer Society staff
- Funding support from ASC for outreach to rural communities
- Financial Support from the Saskatchewan Ministry of Health
- Partnerships and Champions
    - Community agencies and organizations
    - Memory Clinics and assessment units
- Quality programming and resources
- Easy referral process

- ***Consultation process:*** It was noted that prior to the creation of First Link, consultation with persons with dementia, caregivers and other key stakeholders identified the need for a program where physicians would refer newly diagnosed individuals for information and support. Their descriptions of this program were consistent with First Link, so that once developed, people were supportive because it met their needs and was consistent with their recommendations.

    "Prior to the development of First Link we were putting together an Alzheimer's strategy where we talked to people with the disease, caregivers, stakeholders, really about what they saw key issues were in the province, and so they named their key

issues and then we asked them to define solutions that they felt would help us to address the key issues, and they talked about a program where after you were diagnosed, that your doctor would refer you to an organization like the Alzheimer's Society so little did they know, but they were describing First Link." [FLREPID2]

- ***Support from Ottawa First Link program:*** The First Link program in Saskatchewan was built on the program developed in Ottawa, capitalizing on processes, Learning Series curriculum and materials that were successful in that program. Staff from the Ottawa program provided mentorship support, including facilitating a workshop on First Link in Saskatchewan.

  "Some of the things that I consider to be key successes of the program was we had a model to build on, very grateful for the Alzheimer's Society of Ottawa Carleton and the partnership with the Alzheimer's Society of Ontario, to work together to develop the program, to have a framework to work with." [ASREPID1]

- ***Support from Key Stakeholders:*** It was noted that once people learned about First Link and the services that it provides, there was much interest and support for the program.

  "I think a lot of people were surprised, they, especially in rural Saskatchewan. I think the people have a perception that the Alzheimer's Society is 2 or 3 people who work kind of out of somebody's basement, so when you talk about all these programs, they're quite surprised that we do so much. So it was definitely a positive: "oh wow, I didn't know you do that. That sounds great.' That made a difference." [ASREPID3]

- ***Support from Alzheimer Society staff:*** It was noted that staff were enthusiastic about the potential of the program to increase access and improve quality of life for persons with dementia and their caregivers so they were very supportive of efforts to develop and grow First Link.

  "Overall, I think that they [Alzheimer Society staff] had passion and a lot of staff were on board and I think that helped." [ASREPID6]

- ***Funding support from ASC for outreach to rural communities:*** Support from the Alzheimer Society of Canada for further outreach to rural communities has been met with much support from the affected communities.

  "And we're doing right now with the ASC has gotten some, a grant from Pfizer so we got some additional funding to do specific outreach into three health regions, three cities and so especially in those three communities of North Battle, Swift Current and Estavan doing those really targeted pieces and the response that we're getting in those communities, even from the telehealth coordinators with regards to this, is they're on board." [ASREPID1]

- ***Financial Support from the Saskatchewan Ministry of Health:*** The provincial Ministry of Health has provided some funding support and financial support for the use of the

telehealth videoconferencing, which has allowed the Alzheimer Society to increase access to the Learning Series in rural and remote areas of the province, where they would otherwise be unable to access this type of education.

- ***Partnerships and Champions:*** It was noted that partnerships with various community organizations have helped to increased access to education. As an example, a long-term care home in a rural area recently hosted a learning series session (Care in the Later stages) with over 40 people in attendance. It was noted that attendance is much lower when held at the Alzheimer Society. Similarly, it was noted that partnerships with referring agencies (e.g., assessment units) has facilitated an increase in referrals to the Alzheimer Society.

  "I think that in terms of the development in Saskatoon and the ongoing support, we've been very fortunate to have the support of the rural and remote memory clinic, as well as the geriatric evaluation and management program, GEM for short, and so we've been very fortunate to have those two organizations as champions." [FLREPID4]

- ***Quality programming and resources:*** The high quality of the programs and materials offered by the Alzheimer Society contribute to the success of First Link. People are responsive to First Link because the Alzheimer Society has become a trusted resource for information and support.

  "I think the strong learning series. I think that the development of the learning series and the strength of the presenters that we had have really helped." [FLREPID4]

- ***Easy referral process:*** The user-friendly nature of the referral process through First Link has contributed to its success.

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 35.

Table 35: Summary of the Factors Challenging the Development and Implementation of First Link

Challenges:

- Limited understanding of the concept of First Link
- Raising awareness of First Link in rural and remote areas
- Misunderstanding that the Alzheimer Society only serves those with Alzheimer's Disease
- Issues around obtaining consent for referral to First Link
- Inconsistency in rate of referrals across the province

- Labour intensive nature of relationship building with referral sources
- Lack of physician support for direct referrals
- Limited diagnosing and lack of information given to people about their diagnosis:
- Limited human resources
- Limited use of E-Tapestry to its full potential

- ***Limited understanding of the concept of First Link:*** The development and implementation of First Link was challenged by struggles around the concept of what First Link was in terms of its role as a referral process.

  "I think one of the challenges is really understanding First Link, and to me First Link is really the referral program, that formalizing of the direct referral program…When we talked about First Link people didn't really understand what that was and some people felt it was the core services and some people felt it was the referral piece. So it was almost like it was an abstract idea, and as we worked together as an Alzheimer's Society to define what First Link was, and we were able to articulate here's some pre-requisites to implementing the program and then it's really the referral piece that is the First Link piece, and I think for a lot of people it was until they could sort of see their way through that, it was like people didn't really understand the concept of First Link." [FLREPID2]

- ***Raising awareness of First Link in rural and remote areas:*** Given the large geography of the province, it has been a challenge to ensure consistent awareness-raising across the province. Although telehealth has increased awareness of First Link and the Alzheimer Society in many areas of the province, there are still communities that have not yet been reached. Turnover in physicians has also challenged First Link to ensure that all health care providers are aware of the program. The large geography also poses a challenge to ensure that people have access to the supports and services needed.

  "We've definitely seen the referrals increase which is great, and we hope that they increase more, but I still think especially in Saskatchewan because people are disconnected, they're living 3 or 4 hours from the nearest city, they don't know that that program exists. So they haven't heard about it and in Saskatchewan too, we're having a lot of doctor changes, so you may get one physician who buys into it, but they're not in that community for very long. So it's been a bit of a stumbling block there, but I think once people sort of see the direct benefit from the program, I think that their sold, and it's not a very hard sell." [ASID3]

- ***Misunderstanding that the Alzheimer Society only serves those with Alzheimer's disease:*** Many people, both health care professionals and consumers, assume that the Alzheimer Society cannot be of benefit to them unless they have Alzheimer's disease or they have memory concerns but no diagnosis.

"The other challenge is, and is, probably has something to do with our name, is that understanding that although we're the Alzheimer's Society and that's the part, that's the dementia we know most about, that we can provide and try to provide support and information to the other dementias as well." [FLREPID1]

"Sometimes I think as well some of the barriers that have been is that people don't understand who we are and what we do, and how we can benefit the client and how it's going to benefit them, what role we ask them to take on, and what role we can do and how in that partnership together we can support the client but we're all working smarter, not harder." [FLREPID1]

- ***Issues around obtaining consent for referral to First Link:*** There is inconsistent understanding of what type of consent, verbal or written, is required for health professionals to refer patients to First Link. The requirement for written consent may be negatively impacting referral rates.

  "I think it can be a challenge. Because in some places we're considered to be an official part of the circle of care and others were outside the circle of care. When we first started this one health region said we didn't even need to have that consent piece on, and the other said they couldn't do anything without it. We're saying as long as there is some sort of consent, whether it's documented or verbal consent, that its verbal consent by this and you've documented it within your particular client records, we're fine with that." [ASREPID3]

- ***Inconsistency in rate of referrals across the province:*** Direct referrals to First Link are greater in the northern than southern regions of the province. It has been suggested that this is directly because of the Memory Clinics and assessments units (Geriatric Evaluation and Management programs) in the northern regions, which are major referral sources. The limited number of similar programs in the southern regions has resulted in fewer referrals to the Alzheimer Society via First Link. Generally, direct referrals via First Link are lower than anticipated.

  "Numbers, I think that's probably the thing that we didn't get to and that's why I said I wish we had another year, another two years because our numbers are starting to come." [FLREP1]

- ***Labour intensive nature of relationship building with referral sources:*** First Link coordinators described the time and labour intensive nature of raising awareness about the Alzheimer Society and building partnerships and relationships with referral sources. They had underestimated the amount of time and effort that this would require and suggested that it takes several years to get to a point where direct referrals via First Link become a standard best practice.

  "In some of the relationships with some of the community partners and the referral sources, I've met with them so I could tick them off the list, but what we realized was

there's lots of staff turnover, you can go up to people once and maybe some people would respond to a letter, maybe some people would respond to a phone call, but really what we realized and I think this is lessons learned again, when we went to the work shop in Ontario is sometimes it takes 8 visits to a referral source before they refer, and then even though you get them referring, then you have to continue to reach out to them to keep the Alzheimer's Society First Link program top of mind with them… I think for some staff they didn't realize how labour intensive that was going to be." [FLREPID2]

"I think it, we didn't understand and appreciate the length of time that it would take to develop everything, as well as the amount of times that it would take initially, we're learning this now, that we thought if you went in once we'd get all these referrals and be flooded with the referrals, the importance of going back as well as the importance of keeping the First Link program and the referral process top of mind to people who refer all the time, as well as to the people who refer sporadically. As well as making sure that people really understand the process and the importance of the paper referral." [FLREPID1]

- ***Lack of physician support:*** It was noted that there is limited physician support for referrals to the Alzheimer Society. It has been suggested that this is because they of limited understanding of what the Society can provide to their patients; physician lack of awareness has been attributed, in part, to the fact that physicians, particularly in rural and remote areas are extremely busy and unable to take advantage of opportunities to learn more about these types of resources for their patients. Because of limited physician response, some Alzheimer Society staff are not supportive of "cold calls" (unscheduled visits) to promote the program with physicians and have not conducted the outreach needed to gain their support.

  "Well I think the big challenge is making them somehow believe that it'll make a difference. The other big challenge is connecting with the, the existing systems like the physicians, like the coordinators that are working for health,… the selling of our services to the existing systems so that they also believe in us, that they understand what role we play." [ASREPID5]

  "It's extremely challenging, like doctors, I would venture to say that doctors in rural Saskatchewan are barely keeping their heads above water in terms of getting the basics done." [FLREPID4]

- ***Limited diagnosing and lack of information given to people about their diagnosis:*** Alzheimer Society staff noted a significant challenge related to people not being diagnosed or given limited information about their diagnosis. This challenges their ability to provide appropriate information and supports when it is not clear what they are dealing with. Similarly, it was suggested that referrals to the Society would be higher if people had a clearer understanding of their condition.

"It's not uncommon for people to not have a diagnosis, to being just told they have dementia. Somebody said yesterday it's like telling somebody they have cancer, but not telling them what kind. Nor do they tell them what those terms mean…So not only are they you know, not diagnosing, and here's another conundrum, just on the phone with a client who has been told they have dementia. That's the diagnosis, that's what they've been told." [ASREPID5]

"I came to realize quite quickly how limited the diagnosing is in Regina and rural Saskatchewan, southern and rural Saskatchewan, a lot of people aren't getting specific diagnosis, they're getting a diagnosis of dementia, there's still a lot of misinformation even among medical professionals about how to diagnose, when to prescribe the medications, and I think that's, that's the biggest challenge is the actual diagnosis at this point. I think that we would get more referrals if diagnoses were being properly made and were being made more frequently." [FLREPID4]

- ***Limited human resources:*** The Alzheimer Society is challenged to meet the increasing interest in the Learning Series and in-services and supports by limited human resources. Moreover, given the large geography of the province, outreach is very time consuming and required dedicated resources.

  "Human resources, we could use like three more staff, and human resources and geographical challenges. You know, we want to expand this First Link program province wide, but if we're looking at the three communities that we have chosen, they're an hour and a half to two hours one-way drive to go out and do that physical outreach from the offices, so it definitely takes a dedication, it requires organization and it requires a deliberate, even more of a deliberate effort to be in that community so it's not only just doing the outreach in that community, but it's doing the follow-up, doing the learning series, and working with our volunteers and our facilitators to be able to offer you know, the programming in that area, as well, so it definitely requires some dedicated pieces." [FLREPID1]

- ***Limited use of E-Tapestry to its full potential:*** While there is much satisfaction with the E-Tapestry database to maintain records on clients, it was noted that E-Tapestry is currently not being used to its full potential. It was suggested that the database could be used to identify those clients requiring a follow-up contact and to gather information on support group attendees. Time constraints were identified as a key reason for the limited use of E-Tapestry.

  "There's still lots of information that I would still like to capture within e-tapestry, as we haven't been capturing the individual clients that have been attending our various support groups so I mean those are things that I still want to capture so that we have a much richer picture of client involvement with society programs." [FLREPID1]

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 36.

Table 36: Summary of the Key Lessons Learned in the Development and Implementation of the First Link

Lessons Learned: • Create partnerships upfront • Promote the program as a benefit to health care providers • Continuously promote First Link • Keep key stakeholders engaged • Create a mechanism for following up on clients • Consult and partner with other First Link Programs • Ensure consistent messaging for an accurate understanding of First Link • Time 'cold calls' (unscheduled visits) to needs of stakeholders • Use Telehealth videoconferencing to increase access to education

- ***Create partnerships upfront:*** To maximize efforts at delivering a First Link program, it was suggested that partnerships be created up front, with partners being actively involved in the development and implementation in the program.

  > *"Well I think we did a really great job of partnerships, when we were talking about the program and talking about implementation, but I think to make this program successful even in other health authorities here in the province or if another province would be doing it, it would be partnerships and partnership agreements before the program gets started because we really rely on one another to make this a success."* [FLREPID2]

- ***Promote the program as a benefit to health care providers*:** Referral sources will be more willing to refer patients to First Link when they clearly understand that doing so will have a direct benefit for them, in terms of lessening the burden for care.

  > *"I think as well too, that we have a lot of common goals that we're looking at achieving in different ways, and the benefits to health care professionals is often, their primary relationship is with the patient or the resident and not so much with the family, but recognizing family caregivers are engaged, and in a lot of cases with physicians, family caregivers can take lots of their time, and when they recognize what we can do it can save them time. So I think really understanding the relationship and how we can all work together to better serve that patient and the broader community of that patient."* [FLREPID2]

- ***Continuously promote First Link***: An increase in referrals via First Link was attributed to ongoing promotion of the program. It was noted that one-time only promotion of the program will not likely lead to an increase in referrals. The labour intensive nature of the marketing and promotion requires dedicated resources, both time and human resources, for this type of outreach.

  > *"You need to promote First Link repeatedly, that you can't go in to a health team or physician once and expect the referrals to suddenly go up. You have to keep going back and back and keeping it in the front of their minds… and the importance of making sure that that time is dedicated and allocated for outreach."* [FLREPID1]

  > *"You need to get out of the chair and hit the pavement. You can't do this work without getting out of the office, and convincing them that it's okay to just show up…its cold calls and a lot of people aren't comfortable with that, and I found it was a lot of convincing of we just got to get out there. We just got to get out there, we've got to get the packages out there. We've never, as far as I know, ever been booted to the curb, but you just have to get out there. You have to go talk to people. You have to be promoting it…."Be patient. Be patient. It'll come, you're not going to create champions with one client. Know that you're doing good work and be passionate about it."* [FLREPID4]

- ***Keep key stakeholders engaged:*** It was noted that it is important to keep key stakeholders engaged with First Link and the Alzheimer Society. Key stakeholder meetings, conferences and evaluation efforts designed to obtain feedback on challenges and needs were identified as potential ways to engage stakeholders and to promote First Link and the services offered by the Alzheimer Society.

  > *"I think there's value in bringing people together, so maybe at the end of every year, you know, just bringing all of our stakeholders back in and maybe doing an evaluation, like a focus group and just to talk about what were the challenges, what were the successes, so that every year again you're building on that community and your listening to everybody else's input to move forward."* [FLREPID2]

- ***Create a mechanism for following up on clients:*** An important aspect of First Link is the follow-up with clients to ensure that their needs for information and support are being met. This requires a mechanism for ensuring that clients in need of follow-up are identified and contacted on a regular basis.

  > *"The other lesson that we're still trying to figure out is figuring out that mechanism for that intentional follow-up. How can we utilize those systems, the database that we have, to whether it's to pull reports or those kind of things, to of who needs to be followed up and we haven't had any contact?"* [FLREPID1]

- ***Consult and partner with other First Link Programs***: Established First Link Programs were identified as an important source of advice, information and resources. It was

suggested that partnering with established programs provides an opportunity to share common program components and resources, learnings, and for brainstorming solutions to challenges. For Saskatchewan, opportunities for consulting with the Ottawa First Link program were described as invaluable.

> *"This is truly one of those pieces that is a federation partnership. I think with some of the things that are happening at the federation level with this money that has been received from Pfizer and the grant so Nova Scotia has gotten some money, Ontario has gotten a little bit of money, we have and Manitoba and BC, that we're meeting quarterly to discuss how we're all doing with our different projects and different people are sharing things and so even on those teleconferences someone will say something and someone will go: 'Well I have this resource that I can send to you. The sharing piece."* [FLREPID1]

> *"Consult with people who have already done it. Don't work in that isolation. As we continue to move forward, even as we look at doing different pieces, I'm continually saying, contact* [Ontario First Link], *see what they might have done."* [FLREPID1]

- ***Ensure consistent messaging for an accurate understanding of First Link:*** To minimize confusion created by misunderstandings of what First Link is, it was suggested that there be consistent messaging about First Link.

- ***Time 'cold calls' to needs of stakeholders:*** To promote and market the program efficiently is was suggested that the timing of visits ('cold calls') to potential referral sources meet their needs (e.g., avoiding visits to physicians offices after long weekends, and avoiding visits to pharmacies during peak busy times). Similarly, it was suggested that messages and resources left during visits be simple and not overwhelming and that visits be targeted to those individuals who make referrals, as for example, nurses working in physicians' offices.

> *"I think that what I've learned in terms of marketing is timing is key, for instance, I learned in August you don't show up the Tuesday after a long weekend. They're swamped. The phone is ringing. And don't show up to a pharmacy after 11:30, again, everyone that's had their appointment all morning has been showing up with their prescription and they're swamped. So your key time for pharmacy is from the time they open the doors until 11:30. One of the lessons we learned through one of the drug companies was don't overwhelm them with material. Keep what you give on any given time very simple. You know, if, you don't want to overwhelm them with stuff. You don't want your message to get lost. Take one thing, right now I'm distributing the physician's flyer, that's it… It's a reason to go back, you want to keep generating reasons to go back….. I guess the other things we learned, you know, know who to ask for who's making the referral. Is there nurses in the office? You don't necessarily have to speak with the doctor... everyone has the potential to influence that doctor, whether it's the nurse he works with, whether it's the receptionist."* [FLREPID4]

- ***Use Telehealth videoconferencing:*** Access to education, particularly in rural and remote areas, can be increased with the use of telehealth videoconferencing.

  > *"I think one other lesson that we learned is developing the learning series via telehealth. And that's been another positive thing. The way that we have been able to provide the learning series in other communities around the province."* [FLREPID6]

3.4.4 Suggestions for improvements and Sustainability

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 37).

Table 37: Suggestions for Improving and Sustaining the Services and Supports Offered by First Link and the Alzheimer Society

Improvement/ Sustainability Strategies…

Identified by Alzheimer Society and First Link Representatives:

- Increased resource to operate First Link
- Promoting First Link to all who have contact with seniors
- Revise curriculum to be more inclusive of other dementias
- Utilize E-tapestry to its full potential
- Maintain good relationship with Telehealth
- Develop strategies to engage physicians
- Build greater capacity among physicians for assessment and diagnosis
- Create a national network of First Link programs
- Develop resource material at different literacy levels and for different cultural groups

Identified by Key Stakeholders:

- Provide feedback on referrals
- Allow for referrals based on verbal consent
- Promote the First Link more broadly in the community
- Continue to promote First Link with physicians
- Provide opportunities for those who use Telehealth to meet face-to-face
- Take advantage of opportunities where seniors gather to share information

Suggestions for Improvements and Sustainability

Identified by Alzheimer Society and First Link Representatives:

- ***Increased resource to operate First Link:*** Greater funding and human resource support is needed to continue to operate First Link, particularly as outreach and promotion are extremely time and labour intensive.

  "More money, more personnel to promote it… It's more just the human and financial resources. Just so that the people who are out there walking in to the doctor's offices and promoting the program and following-up with clients have the support that they need so they can do their job." [ASREPID3]

- ***Promoting First Link to all who have contact with seniors:*** It was suggested that although promotion to health care providers is very important, the program should be promoted to all professionals that work closely with seniors, as for example, those working in enriched/ supportive housing, and are in a position to identify early signs and symptoms of ADRD and to make and support a referral to First Link.

  "Promoting it to everybody. Seeing not just the health care providers but promoting it out to the enriched housing I think would make a huge difference. I think there would be a lot of vital information that could come from that." [ASREPID4]

- ***Revise curriculum to be more inclusive of other dementias:*** It was suggested that although the Learning Series is marketed as applicable to Alzheimer Disease and related dementias, the emphasis is primarily on Alzheimer Disease. It was noted that some clients have left sessions because they felt the information was not applicable to their type of dementia.

  "I would probably want to take another crack at the learning series…We've put in the language of you can come for any dementia and certainly we try…I don't think we've done a very good job at marketing it, at pointing it out, because it says or related dementia, but if you come to the learning series the focus is Alzheimer's disease." [ASREPID5]

- ***Utilize E-tapestry to its full potential:*** It was recognized that the E-Tapestry data could potentially be a significant source of information that could inform a number of decisions that need to be made around programming, however it is currently not being used to its full potential. It was suggested that dedicated IT support may be required to assist this.

  "It's the whole data record piece, the data management, client record piece. We need to make sure that we're staying on top of and utilizing that information." [FLREPID1]

- ***Maintain good relationship with Telehealth:*** It was acknowledged that the partnership with Telehealth is critical to ensuring access to education across the province; given the significance of this relationship, it was suggested that the Alzheimer Society needs to be cautious about not compromising that relationship.

  "We want to be really conscious of our relationship with telehealth that we're not trying to over utilize time available because we don't want that to be, it's a delicate relationship for us, we're very grateful for that, but we're not wanting to over extend our welcome with that program." [FLREPID1]

- ***Develop strategies to engage physicians:*** Given the limited support to date from physicians it was suggested that strategies are needed to better engage physicians, as for example, with the use of physicians to act as champions to promote First Link to other physicians.

  "We have a figure out a way to target the physicians... its absolutely critical because when I go to do outreach at physician's office I'm quite successful in talking to the office managers. They're very receptive, they say they'll pass the information on to the physicians or to all of the staff during their staff meetings, but the doctors won't even talk to me…. for them we need to do a better sales job of showing them how this [First Link/ Alzheimer Society] can augment their service." [FLREPID3]

- ***Build greater capacity among physicians for assessment and diagnosis:*** To respond to challenges related to difficulties with assessment and diagnosis, it was suggested that greater efforts are needed to build physician capacity for diagnosis.

  "Suggestions for improving First Link? I think is figuring out how to get the diagnosis, we're missing, in my opinion we're missing a key piece by not having proper diagnosis happening in this province and in this country. I think that's the biggest missing factor is we've got this great program, and we don't have people being properly diagnosed to get them to the program they need…. physicians, they're not comfortable talking about mental health. They're not comfortable talking about Alzheimer's disease either. I think it always comes back to they can't run a blood test so therefore it's very difficult to diagnose, if we get to that point where we had a blood test, oh my goodness the phones will be ringing off the hook." [FLREPID4]

  "The minute you give more work to doctors, and more speciality work, they need more training… and that's what we've done to them, so somehow training about the actual assessment." [FLREPID3]

- ***Create a national network of First Link programs:*** It was suggested that a national network of First Link programs be created as an opportunity to support and mentor each other and to share resources.

"Opportunities to continue to network with Ontario. And you know there are other provinces that are getting on board as well, anyone that's connected with First Link. Almost like having a national network, because there's so much we can learn from each other about what works. Even things to try, just something that we tried and it didn't work for us here, or something that worked really well they can try." [FLREPID6]

- ***Develop resource material at different literacy levels and for different cultural groups:*** Given diversity in the province in terms of language, ethnicity, culture, and literacy levels, it was suggested that written information about the Alzheimer Society and about dementia be created to target different literacy levels, languages, and cultural groups. As an example, it was suggested that there is a need for materials targeted to Aboriginal communities.

  "When I showed [potential referral source] a couple of sample things she said: 'Do you have anything with a lower literacy because that's actually a very high literacy rate.'… there is also a low literacy rate from further north where people are very good verbally but in terms of written material, our literacy rate is actually quite high…I would want to have both types of pamphlets, the high school level literacy, but also something that's very, very plain English, and translation perhaps in a couple of the aboriginal languages, and that's coming up a lot, with U of S they're doing a fair bit of work with their memory clinic in terms of cultural diversity ." [FLREPID3]

Identified by Key Stakeholders:

- ***Provide feedback on referrals:*** Referral sources noted that it would be helpful to get feedback on the referrals they made to First Link, in terms of whether contact with the client was made and what the outcome was of the contact.

  "It would be really helpful to know what's happened after we refer. Did they get in touch? Is the patient or their spouse going to the support groups? Did they go the education? If I know that they didn't go then I could reinforce the importance of it." [KSID1]

- ***Allow for referrals based on verbal consent:*** Given the challenges associated with obtaining written consent, it was suggested that verbal consent be allowed for referrals.

  "I think it would be really nice if we could do the verbal consent, like: 'Would it be okay if I take your name and number and give it to the Alzheimer's Society?' Just verbal, because I don't know if having to the find the paper it might be a bit of a problem… so if there was a way to make it a little bit more verbal, I think that would be better." [KSID6]

- ***Promote the First Link more broadly in the community:*** While it was acknowledged that promotion with health professionals in primary care and assessment units is

important, it was also noted that promotion with other community agencies and care providers can provide a significant source of referrals. For example it was suggested that home care workers are in a position to identify the early signs and symptoms of cognitive impairment. Similarly, it was suggested that the program be promoted with all community groups and organizations that deal with seniors.

> *"They should really promote the program with CPAS, with the home care workers because they are often the first line with people with dementia. They can link the person early to First Link."* [KSID2]

- ***Continue to promote First Link with physicians:*** As physicians are usually the first professional that patients turn to with memory concerns, it was suggested that First Link continue to promote the program with physicians, even if they have to do this repeatedly, as eventually referrals will increase.

> *"I know from the Alzheimer's Society that they're targeting the physicians which again is very, very important because it could be nobody has gone to the Alzheimer's Society but they start with the physician and as long as the physician is saying: 'Here's a resource, I would encourage you to go that way.' So as long as the Alzheimer's Society keeps lobbying with the physicians, that they're there and they're doing a good job, First Link can only grow."* [KSID3]

- ***Provide opportunities for those who use Telehealth to meet face-to-face:*** Although there was much support for the use of Telehealth videoconferencing for Learning Series sessions, it was suggested that this be augmented with opportunities for face-to-face contact. This was thought to increase the likelihood that people would ask questions about issues that they may not be comfortable discussing via videoconferencing.

> *"I know in order to get as many people as you can that Telehealth was a good way to do it, because people are all over the province, but at the same time, I think trying to have a discussion and support people where they live, Telehealth is not necessarily the way to do it. There needs to be face-to-face contact and for people to ask questions when they have to go on the video and have their questions responded to. If you want people to ask questions or to discuss sensitive issues, it's really hard for them to do that on Telehealth."* [KSID3]

One interview participant suggested the need for a face-to-face education and support group session in Prince Albert, indicating that while telehealth has been a great benefit to that community, there is also a great need for more personal contact.

> *"I wish we had a system right in Prince Albert that makes it easier for people. Right in Prince Albert. This teleconference thing, I think it's a great idea, but I think just to have a person here, more personal contact would be really good."* [KSID5]

- ***Take advantage of opportunities where seniors gather to share information:*** It was suggested that information about First Link be disseminated where ever seniors gather, as for example, senior centers, day programs, long-term care homes, 'Seniors' Day at local drug and grocery stores.

> *"If it was something that was in people's homes that was readily available, like a flyer that came with the newspaper, because that group, almost all of them still read the newspaper, so I'm thinking if there was a way to get the information out that way, or through the community care coordinator, that information, the brochure, could be given at admission. Or admission to other services or long term care. So it just sort of reinforces it so they may have heard it other places, so you hear it enough times you*

3.4.5 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:

- Increased access to early identification (Memory Clinics, Geriatric Evaluation and Management) consistently across the province (increased number of assessment clinics in the southern region of the province)
    - Reduced wait times for assessment
- More geriatricians in the province
- Increased access to services (respite, day programs) and support groups in rural communities
- Greater opportunities/ increased access to respite:
    - Short-term
    - Longer-term
    - Weekends
    - In-home
    - Emergency/ crisis
- Increased access to transportation to attend support groups, day programs
    - Consistent service – familiar driver
- Increased day programs specifically targeted to those in early stages and those who are young (under 65 years of age)
- Improved programming in day programs to encourage greater attendance
- Increased opportunities for social programming
    - Day programs
    - Exercise programs
- Specialized/ dementia-friendly long-term care facilities
- Access to flexible home care services to meet the unique needs of the person with dementia and their caregivers to avoid long-term care
    - amount of time offered
    - times offered

    - variety of services offered (personal care, homemaking, home maintenance)
    - friendly visiting targeted to males (males visiting males)
- More supportive housing with in-home services to avoid long-term care
- Better system capacity for dementia
    - Identification (e.g., family physician and home care provider ability to recognize early signs and symptoms)
    - Management
- Specialized/ separate support services for those with frontotemporal dementia
    - Separate support group for spouses and children
- Establishment of an Alzheimer Society office in Prince Albert (Regina to handle southern region of the province, Saskatoon the central region, and Prince Alberta the northern region of the province).

3.4.6 Next Steps: Future Goals and Objectives for First Link

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

- Identify potential sources of sustainable funding
- Expand of First Link across the province
    - Explore potential for society staff within each regional health authority or every second health authority to be able to offer localized support and programs and services
- Continue outreach and program promotion
- Explore of opportunities for partnerships in developing services and supports for persons with frontotemporal dementia
- Increase number of caregiver support group participants and use of core basket of services
- Increase number of participants in support groups for persons with dementia
- Promote early intervention: increase early access to services and support groups
- Standardize client records so any staff member can respond to a clients' request for support.

4.0 CONCLUSIONS

4.1 Evaluation Limitations

Evaluation Limitations: E-Tapestry, the software used to maintain records on clients registered with First Link, was set up after (April 2009) First Link was launched, requiring staff to "back" enter those clients registered with the Alzheimer Society prior to April 2009. Given the time consuming nature of this task, emphasis was placed on entering the information of clients directly referred to the Society via First Link over those self-referred to the Society, thus leaving some gaps in our understanding of this group of clients. The number of clients registered in E-Tapestry may be an underestimation of the actual total number of clients served by First Link and the Alzheimer Society; this may explain, in part, why an increase in referrals overtime was not demonstrated. The response rate to the caregiver study component of the evaluation was low, but consistent with response rate of the evaluation of First Link in Ontario. 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 coping 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. Similarly, as information on participation in support groups was not collected on those who participated in the caregiver study, it is not possible to determine whether these findings are a function of lack of support group involvement. 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. 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. The Alzheimer Society of Saskatchewan 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 (mean time to referral = 17 months) after diagnosis of ADRD (an average of 11 months sooner) than those who were self-referred (mean time to referral = 6 months).

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 Not Supported: A significantly higher number of individuals referred to the Alzheimer Society were self-referred (61%) than those referred via First Link (24%), though over the past two years there has been somewhat of upwards trend in referrals via First Link. Generally, the average number of monthly self-referrals (Mean = 8; SD = 7.0) is double that of referrals via First Link (Mean = 4; SD = 4).

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 (63%) reported that they now better understand managing seniors with dementia, for the majority of health professionals their understanding of assessment has remained the same (63%). 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 very low (less than 1.9 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 (68%) 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 moderate (3.7, as rated on a 5-point scale: 1 = not at all, 5 = extremely familiar). Consistent with this, the majority of health professionals surveyed (59%) reported that as a result of First Link they are now referring more 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 (53%) 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 (4.0, 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 (79%) 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 Partially Supported: Although average ratings of caregiver stress, as rated on a 6-point scale (6 = most stress experienced) on the baseline caregiver survey were slightly lower for those referred to the Alzheimer Society via First Link (Mean = 4.0; SD = 1.3) than those self-referred (Mean = 4.4; SD = 1.2), this difference is not statistically significant. Similarly, there were no significant differences in caregivers' rating of stress across survey times. However, this is inconsistent with reports of caregivers who participated in the evaluation interviews; interview participants reported reduced caregiver burden associated with receipt of information and participation in Alzheimer Society support groups.

Crisis contacts with the Alzheimer Society may be considered a proxy indicator for caregiver stress. A significantly higher percentage of clients who were self-referred to the Alzheimer Society (15%) perceived their contact as a crisis than those who were referred via First Link (3%), $\chi^2(2) = 15.5$, $p<.001$.

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 Partially Supported: Although average ratings of caregiver self-efficacy (ability to manage the caregiving role), as rated on a 5-point scale (5 = extremely capable) on the baseline caregiver survey were slightly higher for those referred to the Alzheimer Society via First Link (Mean = 3.8; SD = .92) than those self-referred (Mean = 3.2; SD = .93), this difference is not statistically significant. The percentage of caregivers (46%) that reported that they were currently more able to manage the caregiver role in comparison to when their caregiver was first diagnosed was moderate at the first follow-up survey and decreased over time. However, these findings are inconsistent with reports of caregivers who participated in the evaluation interviews; interview participants reported increased capacity to manage the caregiving role as a result of the information and support provided by the Alzheimer Society.

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., day programs, home care, respite) 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 502 caregivers representing over 502 persons with dementia were served by the Alzheimer Society between October 1, 2007 and December 31, 2010. Limitations with information entered into E-Tapestry have contributed to an underestimation of the number of clients served.

- This evaluation has demonstrated that the objectives of First Link have partially been achieved. A significant finding is that those clients who were referred to the Alzheimer Society via First Link were referred, on average, 11 months earlier than those who self-referred to the Society; this finding is consistent with that of the evaluation of the Ontario First Link Program. Despite great efforts on the part of First Link Coordinators and Alzheimer Society staff to promote direct referrals to the Society via First Link, the majority of people connect with the Society via self-referrals. There are a number of barriers that contribute to this including, issues associated with obtaining written consent for referral (including misunderstandings of whether or not signed consent is actually required)), difficulties promoting the program over a large geography, and lack of support among family physicians for direct referrals to First Link. Although many health professionals support the work of First Link and the Alzheimer Society, their recommendations that patients contact the Society has impacted self-referrals but potentially leaves a large segment of the population with dementia without or delayed support. Regardless, the efforts of First Link to promote direct referrals has not been without benefit; there appears to be somewhat of an

upward trend in direct referrals and with continued promotion and marketing, the potential exists for an increase in direct referrals over time. This 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) and has demonstrated its ability to ensure that caregivers and persons with dementia have access to information and support as soon as possible after diagnosis, which has demonstrated to reduce the number of contacts with the Alzheimer Society at times of crisis.

- A significant outcome of the First Link demonstration project was the development of linkages and partnerships with diagnostic and treatment services, and community resources and supports and some primary care physicians. First Link's efforts to encourage direct referrals through health professionals represent 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. While these efforts have largely been effective, as for example, with Memory Clinics and assessment units, there continues to be a need to promote the program with primary care physicians. It has also been suggested that the program be promoted to other services that work in the frontline with seniors (e.g., home care workers, assisted living facilities).

- Although the findings of the caregiver study did not support hypotheses related to reduced caregiver burden and increased coping effectiveness (see evaluation limitations for potential explanations for these findings), there is anecdotal evidence from caregiver interviews that First Link and the services and supports of the Alzheimer Society are critical to their ability to manage and survive the caregiving role. 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.

- Consistent with findings of the Ontario evaluation, First Link has had a more of 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, rather than on how health professionals assess and manage 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. 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. The engagement of physician champions to promote the service to primary care physicians has been identified as a potential engagement strategy.

- Suggestions made for improving and sustaining First Link have the potential for further capacity building and support for caregivers and health professionals. In addition to resource supports (funding, human resources 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 intervention and quality of dementia care across the province, within the constraints of limited services and supports (e.g., respite, adult day programming, home care), particularly in rural and remote areas.

5.0 References

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