Alzheimer Society
ALBERTA AND NORTHWEST TERRITORIES

First Link© Dementia Early Intervention Project

Final Evaluation Report

Presented to: Management Committee,
First Link © Dementia Early Intervention Project

Presented by: Alzheimer Society of Alberta and Northwest Territories

Insert Date: March 4, 2016, Final

"By building stronger relationships and collaborating with health care professionals we support coordination of care for our clients and contribute to a more efficient system. By proving ourselves to families, building a relationship based on trust and connecting care partners with one another, we walk the path with our clients. First Link® is the bridge." (First Link® Staff story sharing)

"Well I guess for me the main thing was that I felt really isolated when [name] was diagnosed… I wasn't surprised at the diagnosis, but I was surprised at the caring support we got from [the Alzheimer Society] … they're always so friendly… And I think our kids feel a lot safer having us here [as they are in different communities]." **(Client focus group)**

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Finding the solution is simple when you know how

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Acknowledgements

The Alzheimer Society of Alberta and Northwest Territories (ASANT) would like to thank Alberta Health for the funding provided to support the development and implementation of the *First Link®* Dementia Early Intervention Project including ASANT Café. Staff from Alberta Health, Alberta Health Services and ASANT provided guidance throughout the development and implementation of the project which has been a critical support. ASANT also thanks the front line providers from its organization as well as community based organizations/providers– without their support the outcomes achieved through *First Link®* would not be possible.

Executive Summary

Background

First Link® is a referral program/ process to assist physicians, health and community service providers to directly refer people living with Alzheimer Disease and Related Dementias (ADRD) and their care partners to the Alzheimer Society for services and support at the time of diagnosis and throughout the duration of the disease. Individuals and their care partners are linked to learning, services and support in their community as early as possible in the disease process.

The Alzheimer Society of Alberta and Northwest Territories (ASANT) received funding from an Alberta Health Continuing Care Initiatives Grant to implement the *First Link®* referral service across the province. The Project was launched in the fall of 2012 and the grant agreement was to end in March 2014. However, the project received an extension in early 2014 to December 2015. First *Link®* has been successfully operating for over ten years in other Canadian jurisdictions including Ontario, Saskatchewan, British Columbia and Nova Scotia. Prior to the grant, *First Link®* has been partially implemented in Edmonton in the North Region and Lethbridge in the South Region for a number of years.

Methods

An interim evaluation was completed March to May 2014 (covering fall 2012 to March 2014) and a final evaluation November 2015 to February 2016 (the current evaluation covering April 2014 to December 2015). The final evaluation is focused on outcome measures but also includes some process measures (e.g., a description of each component of the project as well as challenges/ satisfaction/effectiveness and suggested improvements).

Data collection methods used to evaluate the project include:

- A survey and focus groups with clients (primarily care partners but a few people with Alzheimer disease/dementia also participated);
- A survey with providers who refer clients through the *First Link*® referral process;
- Interviews, a survey and a story sharing process with *First Link*® staff (this included any staff that support the *First Link*® referral process);
- Interviews with Management Committee members;
- Synthesis of data from two databases - E-Tapestry and ASANT Café; and
- A review of selected project documents.

Findings and Recommendations

Community Outreach and Partnerships

The partnership between ASANT, Alberta Health and Alberta Health Services continues to be critical in helping to support the implementation of *First Link*®. Staff from Alberta Health and Alberta Health Services along with champions at the local level help to connect ASANT and *First Link*® to system level policies and strategies (e.g., the Alberta Dementia Strategy Action Plan) and problem solve issues/challenges. It is also important to further engage senior leaders from all three organizations to help strategize at higher levels.

Both community outreach and networking activities are helping to build awareness about *First Link*® and strengthening partnerships at the local level. In 2014 and 2015 approximately 150 outreach activities were done each year using a variety of strategies, most often face to face meetings with providers/ organizations, presentations, promotion through partnerships and health fairs. A variety of providers were targeted with primary care (family physicians, primary care networks and pharmacy), Community Care Access (Home Care) and police targeted by the majority of staff. Geriatric Assessment Units and nurse practitioners were also commonly reached. The findings from the referrer survey reveal that providers who have referred to ASANT feel a stronger connection with ASANT, and staff and Management Committee members

felt that the Alzheimer Society has gained recognition and credibility as a key partner in the health system including in policy development.

While outreach and networking are critical to building awareness about *First Link*® and connecting with potential referrers, they are time consuming activities. Staff turnover at ASANT and lack of internal human resource capacity remain challenges to doing outreach and networking activities, and may explain why the number of outreach and networking activities were approximately the same in 2014 and 2015, and why referrals have not increased overall.

Further challenging staff's ability to do outreach and networking is the increasing amount of time required to support clients. From 2014 to 2015, the number of contacts increased by 55% (4,585 to 7,103), the number of clients reached (unique cases) increased by 62% (1.538 to 2,499) and the number of communities served increased by 31% (179 to 235). Staff time has therefore focused on serving clients that have been referred to ASANT (both through *First Link*® and other means) as this is an immediate need and priority.

While the findings indicate that staff feel linkages with primary care have been strengthened and approximately one fifth of direct referrals come from primary care (20% in 2014 and 16% in 2015), engaging providers from this sector to make referrals remains a challenge. The informal connection of the health system to primary care may help to explain why it is more challenging to engage these providers (e.g., many family physicians remain as independent practitioners). Another reason may be because primary care physicians do not generally diagnosis someone with dementia or Alzheimer disease, and therefore may not be comfortable making a referral to ASANT. A recent survey by the Alberta Medical Association and Seniors Health Strategic Clinical Network that gathered feedback/perspectives on gaps in care of people living with dementia help to support this finding. Thirty-eight percent of the family physicians who responded to the survey felt that they did not have the necessary training or skills in the area of recognizing and providing care to people living with dementia[1].

[1] From Seniors Health Strategic Clinical Network Newsletter, November 2015

First Link® Referrals

The number of direct referrals to ASANT increased very slightly from 2014 to 2015 (496 and 537) and the primary source of referrals are Geriatric Assessment Units. As previously noted, the ability of staff to do outreach and networking has been challenged due to capacity of staff (i.e. turnover, not enough staff) and increasing demands for follow-up. These factors may help to explain the fact that there has not been a greater increase in referrals to ASANT.

Respondents to the referrer survey were satisfied with the referral process and clients in the focus groups consistently reported that the process worked well. Only a few referrers or clients noted challenges – most often noted was stigma associated with ADRD, which may prevent some providers from referring and/or clients from accepting the referral. This speaks to the importance of *First Link*®, and some clients discussed how essential the referral and contact from ASANT is as some people will not reach out, and therefore the referral process helps to connect people to much needed support sooner. A couple of other challenges noted by a few were lack of information about the referral process (referrers and clients).

ASANT Café

A number of activities have been done to support the implementation and uptake of ASANT Café including a public launch, creation and dissemination of a post card through various mechanisms, promotion through partner networks, creation of guidelines and tools, staff identified as Super Users to promote and encourage its use, and the availability of technical support. The findings reveal that all staff are using ASANT Café to some extent, however, generally not to its full capacity. Factors that appear to be challenges to the uptake of ASANT Café include lack of staff support to assist with implementation (the Super Users do provide support but their time to do so is limited because of other responsibilities), lack of awareness and understanding among some staff of the value of the resource and its potential to support their work and clients, and lack of computer skills among some staff as well as clients (given the age demographic of clients).

The client focus groups revealed that few people had used the resource, due to lack of awareness about ASANT Café, lack of computer skills, and lack of time. Although only a few had used ASANT Café, all of these people felt that it was useful and a valuable resource.

Since the launch of the ASANT Cafe on April 1, 2014 until December 31, 2015 there have been a total of 11,235 visits to ASANT Café with 7,989 unique visitors. In terms of members, over the same period, 542 people have become members.

Support from ASANT

The focus of the current evaluation was on *First Link*® rather than a comprehensive evaluation of ASANT programs and services. However, during the focus group with clients and on the survey, satisfaction with ASANT programs and services was explored. The findings reveal high levels of satisfaction with supports accessed including the information provided, the one on one support, and support groups. Clients consistently noted that ASANT staff were approachable, respectful, courteous, empathetic and understanding. Challenges were only noted by a few and most often discussed were challenges related to other parts of the health care system, and included issues with access and satisfaction with services provided.

Being connected to ASANT programs and services has resulted in people with dementia and care partners not only accessing ASANT programs and services, but also community supports (e.g., Home Care, Adult Day Programs, VON). ASANT staff have helped clients, care partners in particular, to navigate the health system and access required supports. Other benefits of being connected to ASANT programs and services through *First Link*® (for care partners in particular) include increased understanding about ADRD, gaining practical caregiving skills and tips in how to support a person with dementia, being better able to cope, and reducing stress. The ability of people with dementia and care partners to access programs and services through community – based organizations such as the Alzheimer Society helps to support efficient use of resources within the health care system.

Staff also spoke about the benefits that they have observed among their clients. They described *First Link*® as the foundation of the organization, and described themselves as advocates for people with dementia/ care partners. They see themselves as agents of change in the health system and community. The role of the Alzheimer Society in patient navigation was also highlighted by staff, as well as the important role the organization plays in helping to bridge community and health system programs and services.

Recommendations

Develop a comprehensive plan for *First Link*® that addresses outreach and networking, overall communication, provider engagement (particularly primary care) and uptake of ASANT Café. The following recommendations are suggested for incorporation within the plan:

- ***Continue outreach and relationship building*** and strategize how to effectively support these activities such as providing additional staff who could support program and service delivery (and free up the time of *First Link*® staff to do community outreach and partnership development);
- ***Develop strategies to facilitate the engagement of key stakeholders,*** notably primary care, and involve senior leaders and appropriate staff from Alberta Health, Alberta Health Services and ASANT to strategize (e.g., Primary Care branch at Alberta Health, CEO of ASANT, etc.);
- ***Continue to engage Home Care and Continuing Care*** to further build awareness and understanding about the *First Link*® referral process (e.g., connect with Zone leads for Continuing Care, continue to build awareness among front line staff, etc.);
- ***Continue to offer high quality programs and services through ASANT*** and periodically review to ensure continuous quality improvement and client satisfaction (e.g., review the amount of information distributed to clients to ensure it is not overwhelming, etc.)
- ***Explore strategies to increase efficiency*** of the *First Link*® referral process and the provision of programs and services (e.g., using ASANT Café more effectively to offer services such as support groups, creation of an online referral form, etc.)

- ***Develop strategies to facilitate the uptake of ASANT Café*** such as identifying audiences and channels to reach them, linking ASANT Café to the strategic direction and overall communication plan of the organization, engaging health professionals in online discussions, reviewing and updating resources and materials, working with phone support programs such as Health Link, 911 dispatch, etc. The strategies should include exploration of a staff position to manage/coordinate ASANT Café and support its full implementation.
- ***Continue providing supports for First Link® staff*** including networking opportunities among staff in various areas of the province to share and learn from one another; training and education in using ASASNT Café to facilitate its full implementation; and learning opportunities to support other roles and responsibilities (e.g., outreach, partnership building, etc.). The support should include recognition of the diverse knowledge and skills required of *First Link*® staff.
- ***Develop a communication strategy/ plan*** for the *First Link*® referral process and ASANT Café that helps to coordinate the various pieces of work of ASANT (both internally and externally); and identifies key audiences and communication mechanisms (e.g., using social media more effectively to communicate with the public, channels to communicate with health care providers, etc.). The plan should include a review and updating of existing promotional material (e.g., review of *First Link*® pamphlet, explore creating a video about *First Link*®, link *First Link*® to the ASANT website, and promote *First Link*® through national organizations such as the Canadian Medical Association), and involve ASANT staff with expertise in marketing/communications.

Introduction

Background

First Link® is a referral program/ process to assist physicians, health and community service providers to directly refer people living with Alzheimer Disease and Related Dementias (ADRD) and their care partners to the Alzheimer Society for services and support at the time of diagnosis and throughout the duration of the disease. Individuals and their care partners are linked to learning, services and support in their community as early as possible in the disease process.

The Alzheimer Society of Alberta and Northwest Territories (ASANT) received funding from an Alberta Health Continuing Care Initiatives Grant to implement the *First Link®* referral service across the province. *First Link®* has been successfully operating for over ten years in other Canadian jurisdictions including Ontario, Saskatchewan, British Columbia and Nova Scotia. Prior to the grant, *First Link®* has been partially implemented in Edmonton in the North Region and Lethbridge in the South Region for a number of years.

The long term/overall goal of *First Link®* is an *increased understanding of and effective reduction of the personal and social consequences of dementia*. The short term goal (and within the scope of the funding) is that *consenting individuals newly diagnosed with dementia, and their care partners, are referred by physicians and health and community service providers to ASANT via First Link®*. The key components of *First Link®*:

- Outreach and relationship building;
- *First Link®* implementation (formal referral, proactive contacts, connection to ASANT and community services, and intentional follow-up); and

- The development and implementation of an online environment called the ASANT Café (data base; information, support and education; E-Learning) – this is a unique feature of *First Link®* in Alberta;

Further details about each of the components are provided in the *Findings* section of the report. The Project was launched in the fall of 2012 and the grant agreement was to end in March 2014. However, the project received an extension in early 2014 to December 2015. An interim evaluation was completed March to May 2014 (covering fall 2012 to March 2014) and a final evaluation November 2015 to February 2016 (the current evaluation covering April 2014 to December 2015).

Findings from the Interim Report

An interim evaluation was conducted from January to April 2014 to help inform the ongoing development and implementation of *First Link®.* A summary of findings is provided below.

Project Structure and Resources

The findings revealed that the funding allowed ASANT to develop ASANT Café and to hire local staff to support community outreach and relationships building with providers and organizations. Structures created (e.g., Project Management Committee and Project Implementation Team) and tools/resources (e.g., communication plan, terms of reference, etc.) helped to clarify project expectations, accountability, roles and responsibilities and helped to build awareness and understanding about the project. Staff turnover within organizations such as Alberta Health posed challenges initially for the Project (e.g., confusion over roles and responsibilities).

ASANT Café

A key outcome at the interim evaluation was the creation of an online environment called ASANT Café (a database of community supports, a range of discussion forums, a community of members, an online meeting space and access to E-learning). The participatory processes that engaged a range of key stakeholders, coupled with the expertise of the consultant team were

key enablers to the development of the ASANT Café. The importance of communication and marketing ASANT Café to build awareness and developing a plan to help facilitate uptake were discussed, as well the need to regularly review and update the site.

Partnerships

The partnership between ASANT, Alberta Health and Alberta Health Services were identified as critical in helping to move *First Link®* forward. It was noted that through the project, relationships were strengthened between these organizations, and that other provincial Alzheimer Societies helped to support the project by sharing tools/resources and expertise. The interim evaluation highlighted the importance of having and facilitating connections with communities as well as linking the project to government policy to help support sustainability.

Community Outreach and Relationship Building

The interim evaluation revealed that community outreach and relationship building were helping to build awareness about the Project within communities and facilitating referrals by providers. ASANT staff learning from one another and the experience of other Alzheimer Societies, and using existing connections/relationships and Project tools helped to facilitate community outreach. The need to strengthen connections with primary care was noted.

Capacity and Capacity Building

The interim evaluation findings revealed the importance of capacity building within ASANT to help support the development and implementation of the Project. Although the funding allowed for ASANT to hire local Client Services Coordinators, when the Project was launched there was a lack of capacity (both staff and expertise) within the organization to manage the varied and complex aspects of the Project (e.g., online learning environment, E-Tapestry, community outreach, connecting with primary care, etc.). The evaluation findings reveal that when using a participatory approach, it is important to invest time and energy upfront in building capacity (and setting up the necessary project structures and processes). Learning/ training and sharing opportunities for staff helped to build awareness and understanding about the project as well as knowledge and skills to support implementation. The findings revealed that capacity was been

built within ASANT and that the organization beginning to link with and become an important resource for the health system.

Structure of the Report

This final evaluation report presents the evaluation methods and final evaluation findings for the *First Link®* Project. The final evaluation is focused on outcome measures but also includes some process measures (e.g., a description of each component of the project as well as challenges/ satisfaction/effectiveness and suggested improvements). An evaluation framework was developed for the project including a program logic model that describes the key activities of the project and associated outputs and outcomes. The evaluation framework also presents the indicators that were identified/ developed for the outputs and outcomes in the logic model and associated data collection methods. The logic model for the project is presented in Appendix 1 and the evaluation framework is available through ASANT. Following a description of the evaluation methods, the key findings are presented, and then the conclusions and recommendations.

Methods

An independent evaluator, Stephanie Heath, from Research Power Incorporated was engaged at the beginning of the initiative to support the development of the evaluation strategy, conduct the interim and final evaluations, and write the reports.

Data Collection

Data collection methods used to evaluate the project include:

- A survey and focus groups with clients (primarily care partners but a few people with Alzheimer disease/dementia also participated);
- A survey with providers who refer clients through the *First Link*® referral process;
- Interviews, a survey and a story sharing process with *First Link*® staff (this included any staff that support the *First Link*® referral process);
- Interviews with Management Committee members;
- Synthesis of data from two databases - E-Tapestry and ASANT Café; and
- A review of selected project documents.

This report provides a compilation of the findings from all data collection methods. A summary of each data collection method is provided below. (The instruments are available through ASANT).

Interviews and Focus Groups

Telephone interviews were conducted with Management Committee members and the two Super Users of ASANT Café (n=7) in January 2016 (one interview was done in December 2015 when this person left their job). In the report, the interviews with the Super Users are coded as Management Committee members to help ensure confidentiality. Interviews were conducted with staff who supported the implementation of *First Link*® twice throughout the last two years

(September 2014 and January/February 2015). Interview guides were developed to ensure the indicators identified in the evaluation framework were assessed and all areas of interest were covered, and copies of the instruments are available in Appendix 2.

Six focus groups were conducted with clients who had been referred through the *First Link®* referral process and used programs and services of ASANT. A focus group guide was developed to ensure the indicators identified in the evaluation framework were assessed and all areas of interest were covered and a copy of the guide is available in Appendix 2. Focus group participants were recruited by staff of the three regional offices and two focus groups were held at each office with a total of 36 participants (see Table 1). The majority of participants were care partners (81%, n=29).

Table 1: Focus Group Participants

Region	Number of Participants	
	Care Partner	Person with Dementia
South Region, held in Lethbridge	9	2
Central Region, held in Red Deer	14*	2
North Region, held in Edmonton	6	3
Total	**29**	**7**

*3 participated in individual telephone interviews as they could not attend the focus group and this data was added to the focus group data

Surveys

Client Survey

Twenty-eight *First Link®* clients who participated in the focus groups also completed a survey to share their experience of the *First Link®* program. Most of the survey participants were care partners of a spouse or partner who has ADRD (79%, n=22). Others were care partners for a parent or other family member (14%, n=4). Two respondents had memory loss or ADRD. The majority of survey respondents were female (71%, n=20), and half of respondents were over 75 years of age.

Referrer Survey

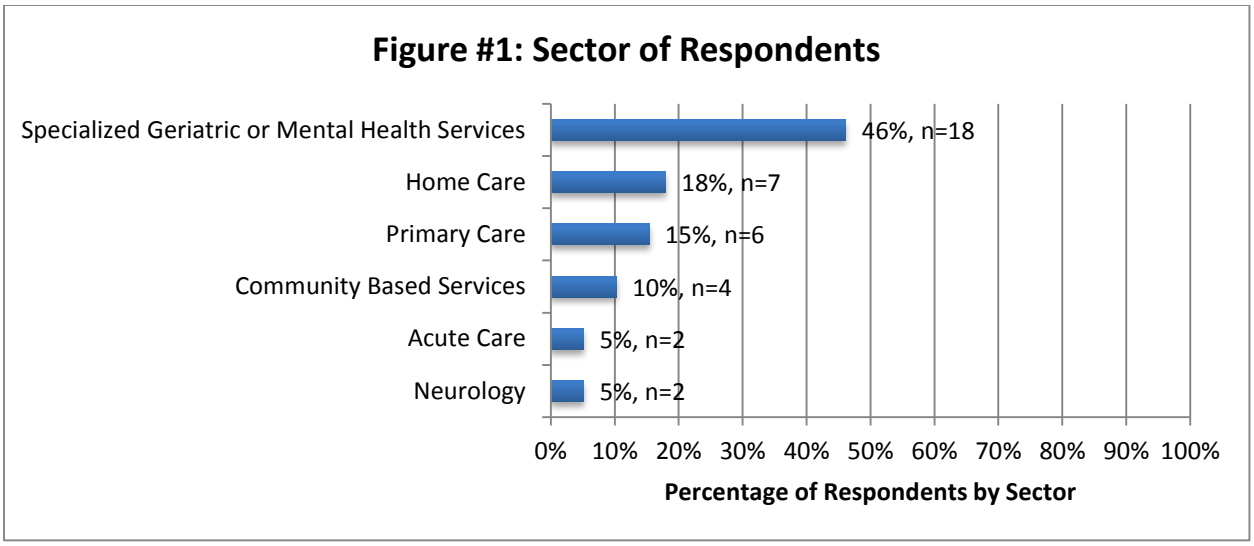
The three regional offices identified a list of providers who had referred a client to ASANT through the *First Link*® referral process in the last four years (from January 2012 to December 2015). As depicted in table two, a total of 123 referrers were identified across the regions. The referrer survey was developed based on a survey completed by the Manitoba *First Link*® program. Potential respondents were sent an invitation to complete the survey by the CEO of ASANT that contained an online link to the survey and a PDF version that could be printed, completed and faxed back to the evaluator. A total of 40 surveys were completed for a response rate of 33% (see Table 2).

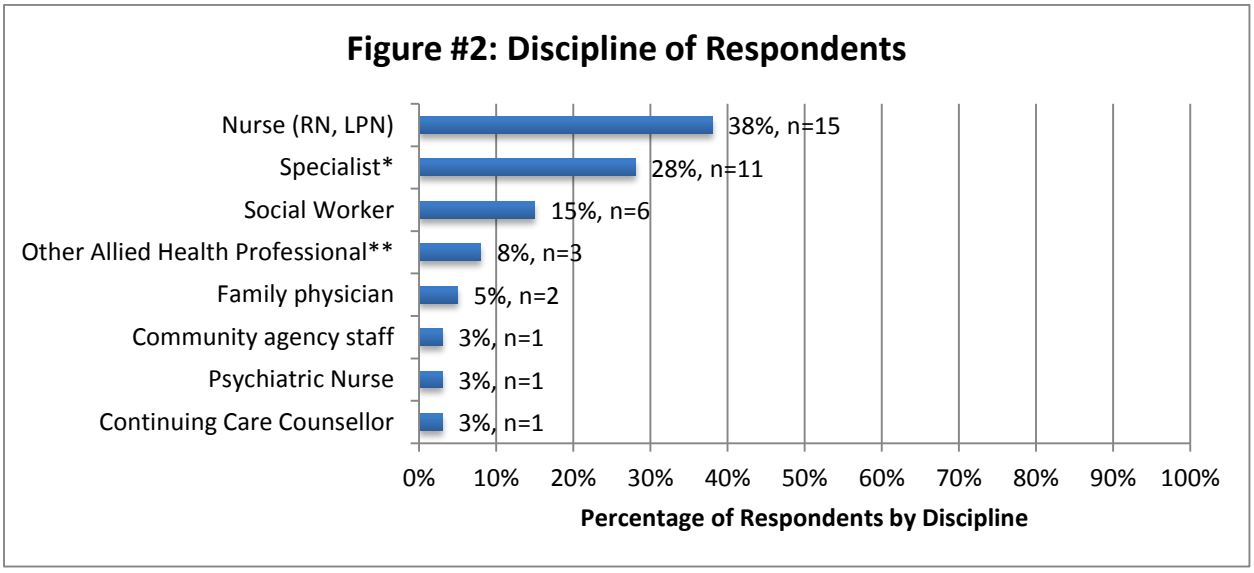
Table 2: Referrer Survey Response Rate

Region	Surveys Distributed	Surveys Returned	Response Rate
South Region	18	5	28%
Central Region	23	17	74%
North Region	82	18*	22%
Total	**123**	**40**	**33%**

*17 of these were from the Edmonton area

The following figures provide the sectors and disciplines of respondents to the referrer survey. Almost half of respondents were from specialized geriatric and/or mental health services (46%, n=18 as depicted in figure one). Over one third were nurses (38%, n=15) and just over a quarter were specialists (28%, n=11) (depicted in figure two).





*Geriatrician, Psychiatrist, Psychologist; **Recreation Therapist, Occupational Therapist, Physiotherapist, Speech Language Pathologist, Pharmacist, etc.

Document Review

Project documents such as the project status reports were reviewed and information/data that helped to describe the project were extracted. The information was then synthesized and is included in this report within the project description sections.

E-Tapestry

A data collection and management system called E-Tapestry, used in Alzheimer Societies in other provinces, was implemented within client services at ASANT. Staff enter data into the electronic database on a number of key variables to help monitor and evaluate *First Link®* implementation and outreach/relationship building (e.g., number and type of referrals, referrals sources, client contacts, etc.). For this evaluation the time period for data analysis was for the calendar years 2014 and 2015. Data from E-Tapestry is gathered and reported by the following locations: South Region, Central Region, Edmonton, and Northern Region.

ASANT Cafe

Data about the users of ASANT Café was collected through the ASANT dashboard, a data management system that tracks the use of the ASANT Cafe. The data collected through the dashboard provides accurate information for some variables (e.g., member characteristics) but not on others such as visits. Therefore, data related to number of visits was extracted from google analytics.

Data Analysis

The interviews and focus groups were audio recorded and then transcribed. Once transcribed the data was coded, that is, broken into meaningful pieces related to emerging themes and categories. Data were managed and coded using the qualitative software package NVivo. Verbatim quotations are used to illustrate and substantiate the theme/findings. Please note, strength of response is provided through the use of descriptors such as “consistently noted”/ “many”, “some” and “a few”.

Descriptive statistics were calculated for closed ended questions on the survey and cross tabulations completed for variables of interest. The data is presented in table format and using bar graphs - some of which are included in the body of the report with others provided in Appendix 3. Responses to open ended questions were coded and thematically analyzed.

Data from E-Tapestry was compiled and analyzed by ASANT staff in EXCEL and summary data provided to the evaluation consultant. Data from ASASNT Café was also completed by ASANT staff in table format and provided to the evaluation consultant. Descriptive statistics were calculated for both sets of data including frequencies and means.

Considerations

- A range of methods (e.g., interviews, focus groups, surveys, document review, E-Tapestry and ASANT Café databases) were used to evaluate the implementation of the *First Link®* project and data were gathered from the various stakeholders involved. This is strength in the methodology and the use of qualitative methods provides comprehensive data. While qualitative methods provide rich and valuable insight into peoples' views and reflections on their experiences, the results are not intended to be generalized or quantified.
- Quantitative analysis was performed using available data from the various surveys. The number of participants for which there is data may vary for different items/questions. This is due to missing data (i.e. a question on the survey not answered). The response rate on the referrer survey was relatively low at 33%, therefore caution should be used in generalizing the findings from this survey (although for a community-based survey this is a relatively good response rate).
- As noted, the E-Tapestry data is reported by the following four areas: South Region (staff located in Lethbridge and Medicine Hat), Central Region (staff located in Red Deer), Edmonton (staff located in Edmonton), and North region (staff located in Edmonton and travel to the Northern region, and staff located in Grand Prairie). The findings from the survey with referrers and *First Link®* staff are reported by the following areas: South Region, Central Region and North Region (includes Edmonton).

Findings

The findings are drawn from all of the data sources (i.e., the client survey and focus groups; the survey with referrers; the interviews, survey and story sharing with *First Link®* staff; interviews with Management Committee members; the E-Tapestry and ASANT Café databases; and the document review); and the findings are organized according to the key project components:

- Community Outreach and Partnerships;
- *First Link®* Referrals;
- Supports from ASANT; and
- Implementation of ASANT Café.

Within each section there is a description of activities, followed by challenges, satisfaction/ effectiveness, and suggested improvements.

The findings conclude with an assessment of the outcomes of the project:

- Enhanced linkages between ASANT and diagnosing primary care physicians, diagnostic and treatment services (specialized geriatric and mental health services), community service providers and home care.
- Enhanced referral of individuals diagnosed with cognitive impairment and their families by physicians and health and community service providers to ASANT via *First Link®*.
- Improved linkages to community services for non-medical management of issues from time of diagnosis through the duration of the disease.
- ASANT Café is used as a resource by various audiences including people with dementia and their care partners and health care providers.
- Increased understanding and awareness, among individuals with dementia and care partners of: ASANT programs and services including *First Link®*; ADRD; community resources; coping strategies and care skills for care partners using current best practices.

Community Outreach and Partnerships

Description

Outreach

Community outreach is a key activity of the *First Link*® referral process to help build awareness and understanding about the program among various stakeholders, in particular, potential referral sources. The definition of outreach activities, as defined by ASANT, is provided in the following text box.

Outreach – Raising the profile of ASANT with an emphasis on promoting programs and services, specifically *First Link*®

-The goal of outreach is to raise the profile of and promote ASANT and its services. To inform potential referral sources of the programs and services available to clients. Outreach may also be targeted to engage specific client groups.

-Outreach activities are aimed at engaging new referral sources and might include: posters/brochures and newsletters; advertising; stalls and displays in local venues (e.g. libraries, community centres, markets etc.); marketing products and 'goodies'; open days; and sponsored events as well as face to face meetings. These products and events are used to maintain the profile of ASANT and our services and to encourage potential referral sources to connect clients to them…specifically *First Link*®.

Across the province the total number of outreach activities done was approximately 150 each year; 153 in 2014 and 150 in 2015 (from the E-Tapestry database). As depicted in figure three, presentations to organizations or groups of providers, face to face meetings, health fairs, and promotion through existing partnerships were the most common outreach activities done by staff (from the *First Link*® staff survey).

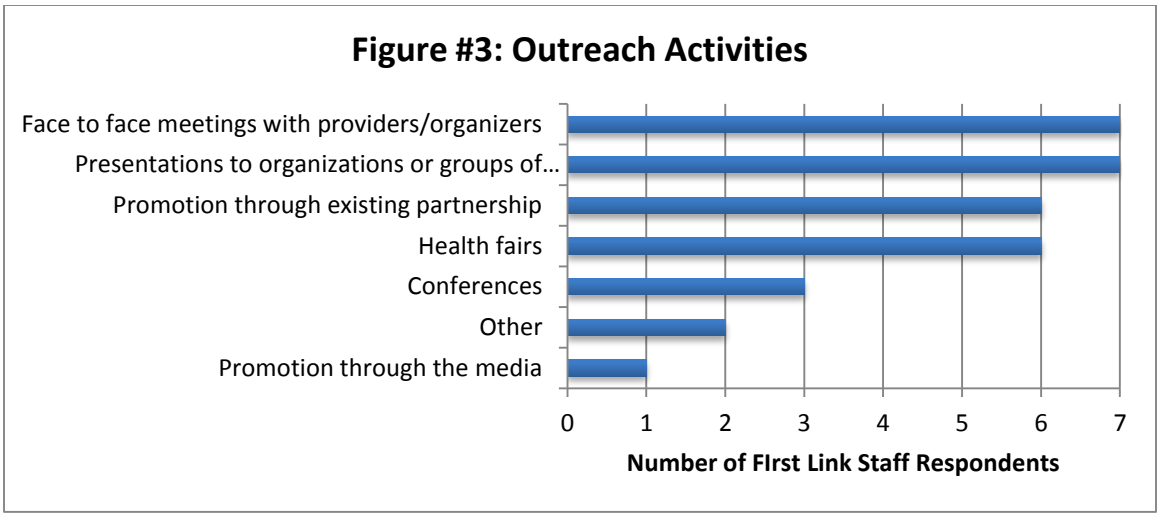
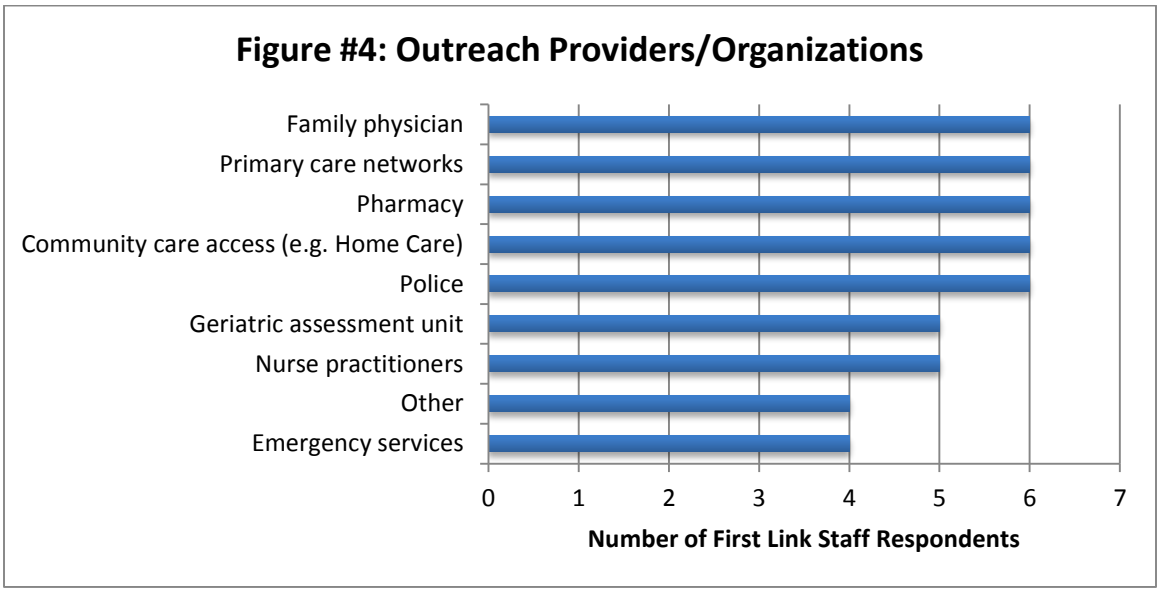


Figure four illustrates that outreach was done with a variety of providers with the majority of staff targeting primary care (family physicians and primary care networks, pharmacy), Home Care and police.



Relationships and Partnerships

Community Level

Another key activity of the *First Link*® referral process is networking. The definition of networking', as defined by ASANT, is provided in the following text box.

Networking - Building community relationships with an eye to improving systems of care – e.g. housing, transportation, elder abuse, public guardian etc.

-The goal of networking is to improve and build relationships that will ultimately improve the systems of care required by persons with dementia, their families and caregivers. This includes all service providers and organizations that enhance the well-being of persons with dementia, their families and caregivers.

-Networking provides the most productive, most proficient and most enduring tactic to build relationships. No one organization has a broad enough scope to address the complex issue of dementia in its entirety. A truly effective community response involves many stakeholders working in collaboration with each group building on its own unique strengths for a common purpose. A network is a partnership of these dedicated groups and networking is the process of the development of these relationships.

Across the province, 51 networking activities were done in 2014 and in 2015. In addition to referring patients with dementia and care partners to ASANT, the relationships and partnerships established through networking support ASANT by:

- Promoting *First Link*® to other organizations and providers;
- Distributing *First Link*® materials;
- Coordinating presentations and inviting *First Link*® staff to do presentations;
- Requesting *First Link*® staff to become members of committees related to seniors and senior's health; and
- Incorporating *First Link*® philosophy and language into programs and services (e.g., person-centred, using care partners versus care givers, etc.).

System Level

Management Committee members consistently discussed how partnerships between ASANT and, Alberta Health and Alberta Health Services have been strengthened. Engaging with both partners has been key in helping to move the work forward. Key supports provided through these partnerships include: linkages and connections to provincial level work where ASANT can have input and also build awareness about *First Link*® (e.g., the Dementia Strategy, Health Link Service, other grants); and problem solving issues (e.g., problem solving connections to Home Care in one Zone). Faculties of universities are also important partners for ASANT where linkages are made to research initiatives, academics, students, etc.

"At the system level, having Alberta Health Services at the table… is huge. A lot of programs and projects [funded through Alberta Health grants] don't have that engagement…so part of it is the dementia piece, it's very timely, it's a hot topic right now. Also, the fact that we've engaged the strategic clinical network, their level of engagement is different than other areas of AHS." (Management Committee interview)

"By virtue of those partners being part of the management committee, they're learning from each other about opportunities, they should be problem solving together, they're helping to explore opportunities to connect and connect each other into opportunities in the system that will support implementation of First Link®." (Management Committee interview)

Champions

Champions within government, communities and other organizations have been important in helping to build awareness and understanding about *First Link*® within their own organization as well as externally. These champions often have high profile and credibility in the community and promote *First Link*® through their networks, and are engaged by ASANT to provide presentations or as content experts. The following champions were consistently identified by Management Committee members and *First Link*® staff:

- Alberta Health (e.g., Management Committee member, Executive Director of Continuing Care);
- Alberta Health Services (e.g., Management Committee member);
- The Senior Medical Director of the Strategic Clinical Network;
- Gerontologists and other providers working with seniors/members of specialized geriatric teams (e.g., Geriatric Assessment Units, Senior's Consultation Teams, Senior's Mental Health, etc.);
- Community members including some Mayors, City Council members, families who have accessed supports through ASANT;
- Some providers from Primary Care and Home Care (early stages); and
- Academics within universities.

Communication Strategies

Various communication tools and strategies have been developed to support the implementation of the *First Link*® referral process. These communication strategies are listed below grouped by internal and external mechanisms. The external strategies are used at the community level, as well as at the system and provincial levels.

Internal

- A communication plan outlining communication processes between project partners;
- Quarterly status reports to provide an overview of project activities to the funder and internal partners; and
- Regular meetings between the Project Manager and the key contact from Alberta Health to provide updates on ongoing activities and issues.

External

- Communication tools that are shared/disseminated to help build awareness about the project (e.g., postcard, brochures, referral package, the USB stick/bracelet, presentations, press releases, etc.);
- Sharing information/presenting through project partner networks (e.g., presentation to Home Care staff from across the province, information shared about *First Link*® with Health Link staff (a 24/7 health information and triage service), presentations to Primary Care, presentations to Senior's Community Forum, presentations to local workplaces; and
- Presentations at conferences (e.g., Grey Matters, Canadian Association of Gerontology, Alberta Association of Gerontology, Alberta Senior's Housing conference).

Challenges

Challenges related to community outreach and partnership building were identified through the survey and story sharing with *First Link*® staff, and the Management Committee interviews. Challenges identified included: lack of capacity and staff turnover within ASANT, engaging primary care, the time consuming nature of the work, reaching smaller rural communities,

involving senior leaders, and the complexity of the continuing care system. Each of these themes is described below.

Capacity and Staff Turnover

In the interim evaluation report, a lack of capacity and competing priorities within ASANT were identified as challenges to the implementation of *First Link*®. During the final evaluation, Management Committee members and *First Link*® staff, again, consistently discussed staff turnover and capacity (in terms of lack of staff) as key challenges impacting the project. In the last two years, in particular, there have been a number of changes in staff within ASANT at both the senior level and among front line providers.

> *"I think that the first challenge has been the huge turnover. The organizational issues and challenges are realities ASANT has lived in the last two years with staff coming and going, new CEOs coming and going, and just entering into a project without really having the capacity to do it in the way that any of us would have liked…not having the marketing and communications capacity, for example. Not having the local capacity to do the outreach"* (Management Committee Interview)

In addition, the high number of referrals over the past two years has resulted in increasing demands to support clients (e.g., through one on one telephone calls or face to face meetings). The *First Link*® staff consistently discussed the challenge in trying to keep up with the demand of providing supports and also do outreach. Further, it was also noted that outreach, relationship building, and partnership development, while critically important, are time consuming. It was also noted that even when relationships are established (which is an enabler to the implementation of *First Link*®), connecting and linking with organizations and individuals is an ongoing process.

"Time required to do outreach [it is a] lower priority than contact with people with dementia and their care partners." (First Link® Staff survey)

"I think underestimating the time it would take to develop some of the relationships that we have, and that it would be an easier connect say, to the PCNs and all of those things. So that's a challenge, and maybe underestimating the staffing levels that it requires to deliver First Link® on all levels…." (Management Committee Interview)

"Difficulty building relationships with changing staff roles in stakeholder groups." (First Link® Staff survey)

Engaging Primary Care

Challenges in engaging primary care providers was discussed in the interim evaluation and was consistently discussed in this final evaluation by Management Committee members and *First Link*® staff. The lack of a formal connection of primary care to the health system and the fact that many family physicians are independent practitioners were cited as reasons for this challenge.

"One of the gaps I think is with the primary care, so trying to get the provider level involved is obviously something that we haven't been as successful at." (Management Committee interview)

"I think part of the issue is the physician piece, and the primary care, how they're all individual kind of businesses per se." (Management Committee interview)

"Accessing Primary Care doctors (GPs) [is a challenge]. I have been to doctor's offices and have done presentations but they do not make referrals. They will suggest that patients go to ASANT but do not make direct referrals." (First Link® Staff survey)

Lack of a Communication Plan and Promotion

Some Management Committee members and *First Link*® staff discussed the fact that there has been a lack of a communication plan for *First Link*® and a lack of strategic promotion at higher levels.

"We've had [some] communication, but as an Alzheimer's Society having now a communications person who actually started in the fall, and is really developing a First Link® communication strategy because before it's been hit and miss. So that's a piece that I feel that we've not really done a good job with." (Management Committee interview)

"First Link® is not marketed as a primary activity of the Alzheimer Society" (First Link® Staff survey)

Reaching Smaller Communities

Some of the *First Link®* staff discussed the challenge of reaching smaller rural communities – partly due to the large geographic area of the province and partly due to lack of staff.

"Not being able to hit as many rural areas due to capacity of staff" (First Link® Staff survey)

Involvement of Senior Leaders

Some Management Committee members noted a lack of involvement of senior leaders from the three organizations (i.e., ASANT, Alberta Health, Alberta Health Services). While it was noted that the staff involved from all organizations were champions for the project within their organization, it was felt that drawing in other senior leaders would help to further support the work including strategizing and problem solving.

"…for example, the issue of connecting with primary care networks, that should have been something at the management committee level at the system level where system thinkers and policy people were able to come together, toss that around, discuss it and give some guidance to ASANT. But we didn't really always have those higher level, systems and government level officials and thinkers at the table. So I think there was a gap in the level of partnerships that were active during the course of the project" (Management Committee interview)

"In the next steps we could engage the other area of AHS, so the seniors' health provincial team or the zone continuing care leads, get at the program services part, not just the initiatives piece." (Management Committee interview)

Complexity of Continuing Care System

Although it was consistently noted that inroads have been made in connecting with Continuing Care, particularly Home Care, the importance of continuing to link with this sector, given its size and complexity was noted by some (both Management Committee members and *First Link*® staff).

> *"… through links to continuing care, particularly to our home care system… that requires ongoing support because it's a huge system with a lot of staff in terms of the frontline staff that would have a relationship with their clients who could benefit from connecting with the Alzheimer's Society. There's turnover, there's very large teams all across the province… it's not exactly a gap, but an area where we need to be mindful of the need for continued effort…"* (Management Committee interview)
>
> *"Changing practice in Community Care Access to see ASANT as a resource on an organizational level. Often individual relationships are developed with Case Managers, and they will make a few referrals, however the entire organization has not accepted the services as part of their toolkit…"* (First Link® Staff survey)

Suggested Improvements

Management Committee members and *First Link*® staff discussed strategies to overcome the challenges with the following noted:

- ***Develop a communication strategy/ plan*** for the project (both the *First Link*® referral process and ASANT Café) that helps to coordinate the various pieces of work of ASANT (both internally and externally); and identifies key audiences and communication mechanisms (e.g., using social media more effectively to communicate with the public, channels to communicate with health care providers, etc.). Involve staff with expertise in communications from ASANT in the development of the plan/strategy.
- ***Review and update promotional materials*** (e.g., a resource is needed about early onset dementia); explore the creation of a video about *First Link*®; link *First Link*® to the ASANT website; and promote *First Link*® through national organizations such as the Canadian Medical Association.

- ***Develop a strategy or plan to facilitate the engagement of primary care*** and involve senior leaders and appropriate staff from the three organizations to strategize (e.g., Primary Care branch at Alberta Health, CEO of ASANT, etc.)
- ***Engage senior leaders*** and staff from other programs/branches from Alberta Health, Alberta Health Services and ASANT to strategize (e.g., problem solve issues, policy development, etc.).
- ***Continue to engage Home Care and Continuing Care*** to further build awareness and understanding about the *First Link*® referral process (e.g., connect with Zone leads for Continuing Care, continue to build awareness among front line staff, etc.)
- ***Continue outreach and relationship building*** and strategize how to effectively support these activities such as providing ***Program Assistants*** who could support program and service delivery (and free up the time of *First Link*® staff to do community outreach and partnership development – some noted that extra staff have been hired); develop a ***plan for outreach*** that includes strategies to provide programs and services more efficiently (e.g., using the online community resource more effectively, etc.)
- ***Continue to support First Link® staff*** including providing networking opportunities between staff in various areas of the province to share and learn from one another, and education and learning opportunities to build knowledge and skills and ensure a competent workforce.

First Link® Referrals

Description

As described above, outreach and networking are key components of the program as these activities help to build awareness and understanding about the *First Link*® Referral process. Potential referrers are provided with a referral package which includes a referral form, instructions about how to refer someone, and a permission to refer form. The referral form is completed by the providers and faxed into ASANT. Staff from ASANT then follow-up within two weeks unless the referral form indicates that an immediate response is required.

When asked on the referrer survey how they had heard about the *First Link®* referral process, most often noted was a presentation/meeting (69%, n=26); and about a quarter heard about *First Link®* from a colleague (26%, n=10). (Detailed findings in Table 1 in Appendix 2).

Respondents of the referrer survey were asked the main reason for referring people with the majority (75%, n=29) indicating "to connect them to initial and ongoing support and follow-up". Noted less often was to help people access information/materials (10%, n=4), to link to other community services/supports (10%, n=4), and to connect people to education opportunities (8%, =3). (Detailed findings in Table 2 in Appendix 2).

About three quarters of referrers (74%, n=29) indicated that there are times when they do not refer people with dementia or care partners through *First Link®*. The majority of these respondents noted that it is because the family member/care partner is not receptive to the referral (79%, n=23). (Detailed findings in Table 3 in Appendix 2).

Satisfaction with the Referral Process

Referrers was asked questions related to their satisfaction with the *First Link®* referral process. Almost all respondents (99%, n=38) agreed that they were satisfied with the *First Link®* referral process (one respondent was neutral), and all respondents agreed they would recommend *First Link®* to other health/community support professionals.

As illustrated in table three, the vast majority agreed that referring a patient was easy (92%, n=33). A high proportion of respondents also agreed that the referral package provided sufficient information (82%, n=32) and that the Alzheimer Society acknowledges the referral (84%, n=33).

Table 3: The Referral Process

Statements	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Referring a patient/client/care partner to the Alzheimer Society using *First Link®* is easy	3% (n=1)	0% (n=0)	5% (n=2)	30% (n=11)	62% (n=23)
The referral package provided sufficient information about *First Link®*	3% (n=1)	0% (n=0)	15% (n=6)	31% (n=12)	51% (n=20)
The Alzheimer Society acknowledges the referrals I have made to them	3% (n=1)	5% (n=2)	8% (n=3)	28% (n=11)	56% (n=22)

Challenges

In the client focus groups, participants consistently noted that the referral process worked well, and challenges were only identified by a few. Table four provides a summary of the few issues discussed.

Table 4: Challenges with the *First Link®* Referral Process (Client Focus Groups)

Theme and Description	Supporting Quotations
• ***Stigma Associated with Alzheimer Disease and other Dementias:*** The most often discussed challenge was the stigma associated with Alzheimer disease and other dementias (some focus groups). It was noted that many people are afraid of receiving a diagnosis of Alzheimer disease and this prevents some from seeking help. Participants also noted that the name of the Society does not encompass all clients with dementia and some may not seek help as they or their loved one has not received a diagnosis of Alzheimer disease.	*"…the name of the Society should be changed, and it should be all inclusive. It should be Dementia Society or something…I just think that because dementia truly is a catch all term, and as I said to the neuropsychologist, if somebody was 30 years old and they had a stroke and were left with memory issues, they would not be told they had dementia, they'd be told they had a brain injury. Which like it or not, has less stigma attached for the person that has the disease."*
• ***Lack of Referrals from Primary Health Care*:** In a couple of focus groups, some participants noted that referrals from family physicians may not be as high as they could be as they do not make a diagnosis, and therefore may be reluctant to refer; and a few participants noted that some family physicians may not take the symptoms seriously and think that memory loss is a normal part of aging.	I *feel it's kind of hard for a family doctor to really make a diagnosis of this at first because you know, it's sort of hard to pick up on…"*
• ***Lack of Information***: In a couple of focus groups, a few participants noted that a little more	

Theme and Description	Supporting Quotations
information could be provided about what to expect after the referral is made (e.g., what the Alzheimer Society provides, when to expect a call, etc.). [On the client survey 29% agreed with the statement "I was not given enough information on what to expect for services I would be able to receive from the Alzheimer Society."]	*"Well [name] who referred us, didn't give us any information except, can I give your name to the Alzheimer's Society"*

On the survey with *First Link*® staff, respondents were asked to identify the top three challenges related to the referral process. Most did not provide an answer or indicated the referral process worked well. The following challenges were identified by a few:

- Staff turnover and changing roles within some organizations (two respondents)
- Difficulty connecting with some of the individuals referred (one respondent)
- Willingness of some physicians and service providers to forward a referral and the need to build trust among referrers (one respondent)

When asked if they had encountered any obstacles in making a referral, 87% of referrers (n=34) indicated they had not. Of the five that had encountered obstacles, 2 indicated insufficient information, 2 indicated lack of time, and one indicated lack of a referral form.

Suggested Improvements

Few focus group participants could identify any improvements for the referral process. The one suggested improvement (discussed in a couple of focus groups) was the need for more promotion among providers and the public about *First Link*® and supports available through the Alzheimer Society.

On the *First Link*® staff survey, respondents provided the following suggestion to address challenges or improve the referral process: continue relationship building to engage more referrers and build relationships in communities so that *First Link*® gains a "presence" (three respondents)

When asked how the referral process could be improved, most referrers indicated that they had no suggestions or that the referral process worked well. However, the following suggestions were provided by a few:

- Develop an online referral form (versus paper); (n=3)
- Provide more information about the referral process in the pamphlet; (n=3)
- Shorten/revise the referral form; (n=2)
- Provide feedback to referrers (acknowledge referral received and client contacted, indicate what happened); (n=2)
- Promote the *First Link®* referral process to help increase uptake among providers; (n=1)
- Increase the number of staff at ASANT so they have capacity to respond to referrals. (n=1)

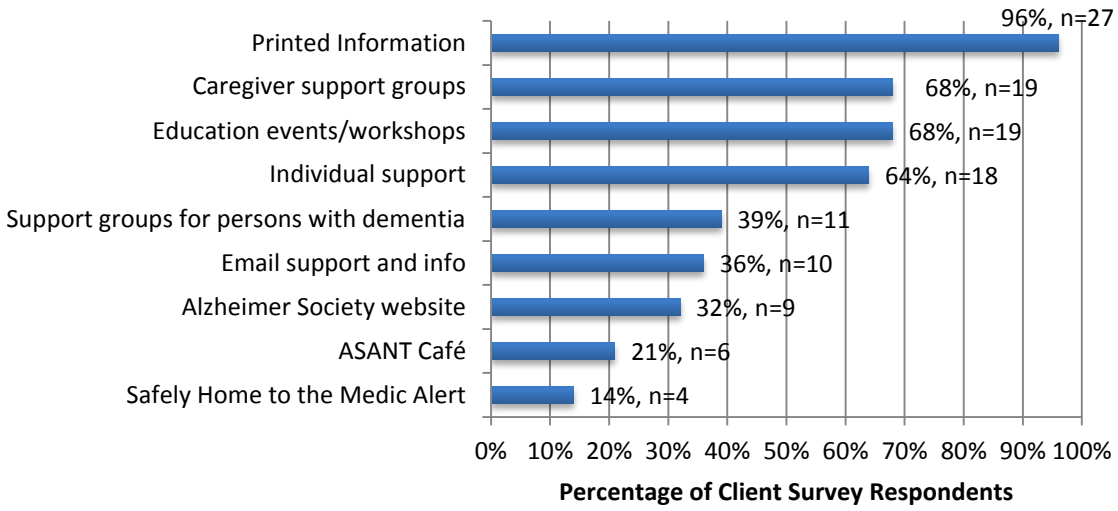
Supports from ASANT

Description

Once a client is referred to ASANT, staff reach out to the individual via telephone. Through this phone call, ASANT staff work collaboratively with the person to determine what information and supports are required. A variety of programs and services are available through ASANT and include: print information, education events/workshop, caregiver support groups, support groups for people with dementia, individual support (telephone or in-person), email support and information, the website, ASANT Café, and Safely Home Medic Alert.

As shown in the figure five, almost all of the client survey respondents have used or received printed information (brochures, fact sheets, etc.) since being referred through the *First Link®* referral process (96%, n=27). The majority of respondents also participated in education events or workshops (68%, n=19), caregiver support groups (68%, n=19), and received individual support through the telephone or one on one (64%, n=18).

Figure #5: Alzheimer Society Resources Used or Received



Satisfaction with ASANT Programs and Services

Focus group participants consistently report high levels of satisfaction with ASANT programs and services with the connection through the *First Link*® referral process described as a "lifeline" by some. The initial phone call from ASANT staff was important for many as it was someone to talk to, and through the connection, linkages to other supports were made. Focus group participants consistently discussed the usefulness of the information provided by ASANT staff. This included information on a variety of topics (e.g., legal issues such as power of attorney and personal directives, tips for care providers, etc.). On the client survey, all respondents (n=28) agreed that the information and support provided by the Society was practical and focused on their personal situation, and all agreed (two thirds strongly) that they would recommend the *First Link*® referral process to others.

"They gave us all kinds of information, and they told us where we should go to look for extra help. And they supplied the support groups, which were really, really helpful in understanding what's going on." (Client focus group)

"I sort of felt like someone had thrown out a life preserver and held the rope." (Client focus group)

"Well I guess for me the main thing was that I felt really isolated when [name] was diagnosed… I wasn't surprised at the diagnosis, but I was surprised at the caring support we got from [the Alzheimer Society] … they're always so friendly… And I think our kids feel a lot safer having us here [as they are in different communities]." (Client focus group)

On the client survey, respondents were asked about their experience when they were first contacted by the Alzheimer Society. As depicted in table five, all respondents agreed that staff were approachable, respectful and courteous and that they received an appropriate amount of clear and practical information. The majority (88%) also agreed that it was helpful to receive the call rather than having to make it themselves (referrers also noted the importance of this as reported below). Further, the majority (89%, n=25) either disagreed or were neutral when asked if they could manage without follow-up.

Table 5: Experience when Contacted

Statement	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
The staff member was approachable, respectful and courteous in the conversation with me.	0%	0%	0%	18% (n=5)	82% (n=23)
I received an appropriate amount of clear and practical information about dementia and/or caregiving skills.	0%	0%	0%	57% (n=16)	43% (n=12)
It was helpful for me to receive the call from the Alzheimer Society instead of having to make the call myself. *	0%	0%	11% (n=3)	41% (n=11)	48% (n=13)
I received enough information and would be able to manage without a follow-up call and would prefer to call on an 'as needed' basis.	18% (n=5)	32% (n=9)	39% (n=11)	7% (n=2)	4% (n=1)

*One missing response.

Client survey respondents were also asked how they found their interaction with Alzheimer Society staff. As depicted in table six, almost all respondents agreed that staff were empathetic and understanding, respectful of client time and that timely follow-up was provided.

Table 6: Client Experience with Interaction with Staff

Statement	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Empathetic and understanding of my concerns.	0%	0%	4% (n=1)	29% (n=8)	68% (n=19)
Respectful of my time.	0%	0%	0% (n=0)	39% (n=11)	61% (n=17)
Follow-up has been provided in a timely manner*	0%	0%	0% (n=0)	52% (n=14)	48% (n=13)

*One missing response.

Although the various programs and services provided through ASANT (e.g., information packages, one on one supports, learning series) were discussed positively by focus groups participants, supports groups were most often discussed as a key support and valued most highly. Some indicated that they and/or people they know have continued with support groups after the person they are caring for is transferred to a facility such as a nursing home or passes away.

> *"…the real understanding was coming in, learning, but also listening to everybody else and having the same story or the same symptoms. The support group for me, I enjoyed that because then I wasn't alone. I know that that one is going through the same as me, so you know, to have the similarities*." (Client focus group)
>
> *"… that's the advantage of getting together with other people that are going through it because you get so many different ideas of, this worked for me, but this sure as heck didn't, and try it this way, or other stuff that you don't even think about. Because everybody is unique and everybody tries different things, it depends on where their background came from or whatever. So you can get some really different and creative approaches that you never really thought of."* (Client focus group)

Challenges and Suggested Improvements

As noted, generally, focus groups participants reported being very satisfied with ASANT programs and services. Just three challenges were identified in a couple of focus groups.

- The need for ***more supports groups*** as they are continuing to grow in popularity and some now have too many participants;
- While the information provided was consistently noted as valuable and informative, a few were ***overwhelmed with the amount of material*** provided. On the client survey nine respondents (of 28 who completed it) indicated that they were overwhelmed with the amount of information provided; and
- ***Lack of transportation*** to get to support groups, particularly for those living in rural areas.

The number one complaint of focus groups participants (discussed in all focus groups) was related to other parts of the health care system, most often gaining access to programs and services. Some care providers discussed dissatisfaction with some of the care provided, particularly through Home Care and some Long Term care facilities.

> *"… A lot of it is healthcare system being so busy, that it takes months to get in to see these people. And more and more of us baby boomers are getting this disease, so it's even longer…"* (Client focus group)
>
> *"… We found that that didn't help us in the long term because we couldn't seem to get through that we needed the same person on an ongoing basis, because change for Mom is extremely difficult. And so we made the difficult decision to actually hire our own caregiver, and make her our employee, and pay for that out of our own pocket for that reason. Because what we were getting from them was not working for Mom… a lot of the people that were sent to help us from the homecare program had no education around dementia."* (Client focus group)

Implementation of ASANT Café

Description

ASANT Café, a community online resource, was developed in the first two years of the project and launched in April 2014. ASANT Café is comprised of a number of key components that enable the sharing of information, education and support including:

- ***A database of all community supports*** currently recommended by ASANT in Alberta and all core literature available via the Alzheimer Society of Canada for people living with dementia and their care partners.
- ***A range of discussion forums*** to enable the community to connect on a variety of key topics.
- ***A community of members*** who can interact privately through messaging, share content with each other and plan for group interactions through a calendar of online and 'on the ground' events.
- ***An online meeting space***, which will enable both audio and video connectivity for small group meetings, workshops and support groups.
- ***Access to E-learning***, starting with the ASANT *Seeds of Hope* Family Learning Series, which is designed to offer care partners the opportunity to gain understanding and develop skills related to best practice in caring for a person living with dementia. It will include a video series and range of printable resources to support learning.

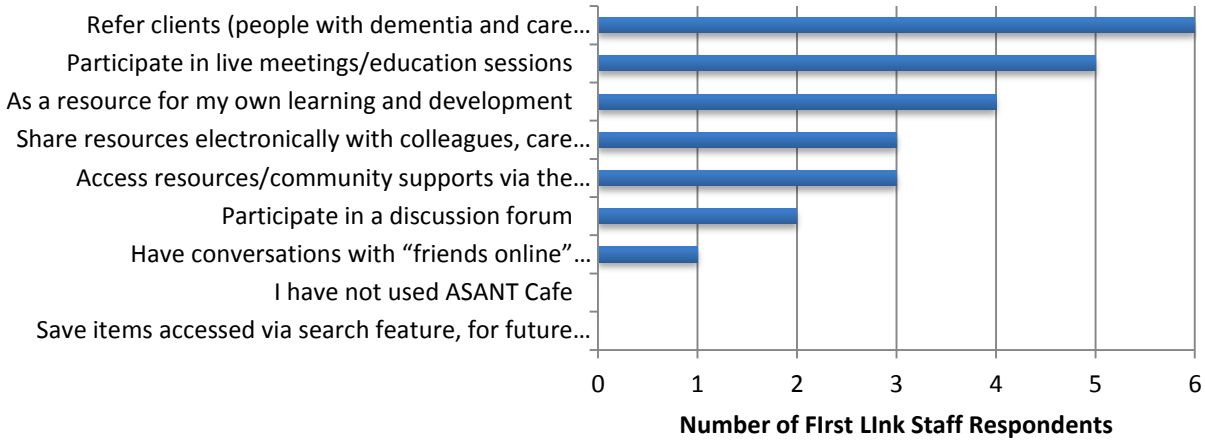
To following activities were done/are being done to help support the implementation and uptake of ASANT Café:

- Hosting of a ***public launch*** of the Café in April 2014.
- Creation of a ***post card*** (and subsequently a poster) to help build awareness and understanding about ASANT Café. This post card is shared and disseminated by ASANT staff at presentations, outreach, partnership meetings etc. Management Committee members from Alberta Health and Alberta Health Services also noted how they have shared the post card through their networks.
- **Promotion of ASANT Café** through partner networks, conferences, presentations to various organizations and communities, and health fairs and booths.
- ***Creation of guidelines and tools*** to support use of the resource (e.g., branding guidelines, policies around privacy, collaboration approval form to document and review requests for partnership or collaboration, task descriptions for super users, user guide, training outline).

- ***Staff identified to be "Super-Users***" to promote and encourage the use of ASANT Café internally and externally, support content, monitor use, problem solve issues, etc.
- Availability of ***technical support*** through the creators of ASANT Café.

On the survey, the *First Link*® staff were asked how they had used ASANT Café. As noted in figure six, all six who responded indicated that they referred clients and health care providers to the online community, and all but one person had participated in live meetings/ education sessions. Fewer had used other features of the resource such as participating in a discussion forum (n=2), using the community database (n=3) and sharing resources electronically (n=3).

Figure #6: ASANT Cafe Use



Effectiveness

First Link® staff were also asked how helpful ASANT Café is for them in their work, for people with dementia and care partners, and for health care providers. As depicted in table seven generally staff viewed the community online resource as just somewhat helpful; and in terms of health care providers, two indicated it was not helpful (i.e., rated a 2 on a five-point Likert scale).

Table 7: Helpfulness of ASANT Café

Audience	Rating					Mean
	1	2	3	4	5	
	Not at All Helpful		Somewhat Helpful		Very Helpful	
Staff	0%	0%	50% (n=3)	17% (n=1)	33% (n=2)	3.8
Client and Care Partners	0%	0%	67% (n=4)	33% (n=2)	0%	3.3
Health Care Providers	0%	40% (n=2)	20% (n=1)	40% (n=2)	0%	3

When asked to explain their rating those who rated ASANT Café lower in terms of helpfulness indicated that the site was not used or not being used to its full capacity.

Management Committee members and Super Users also felt that ASANT Café is an under-utilized resource. These respondents noted the lack of uptake is probably due to a number of factors including:

- Lack of staff support to assist with implementation of ASANT Café as the Super User has many other responsibilities within the organization and therefore does not have enough time to effectively support its implementation;
- Lack of awareness and understanding among some staff about ASANT Café and its potential (perhaps due to a lack of computer skills and confidence among some as well as staff turnover); and
- Lack of computer skills among some clients given the age demographic (while some felt this was an issue, others did not perceive this as a challenge).

"[ASANT Café is] underutilized somewhat by staff, but as well somewhat just by the organization as a whole… it was timing lost I felt like, where momentum was just kind of slowly dwindling, where we could have been gaining more members and gaining a little bit more of an online presence to make it a little bit more of a self-sufficient community…I just didn't feel like it was given enough quality attention, so I feel like we lost a year and that to me was challenging because it was hard to try and do something with a really great site and a really great piece of technology that is very exclusive to Alberta and to Canada. For us, I just felt like it was being very underutilized,

and that was a little hard to continue going forward with it…" (Management Committee interview)

Some of the respondents did feel that with the recent hiring of staff (e.g., CEO, Director of Communication), dialogue and planning about how best to support the use of ASANT Café is beginning to happen.

"The café does have so much potential to do a lot of different things… we are starting to… see it being promoted more now, we are doing more things. We are hosting more of our education series on there, so for example, in the fall we did our first webinar version of our Seeds of Hope with our speakers. So now it's recorded and can be viewed at any time, so there's many things like that... we'd have other physicians come in to present about a specific topic and record that, so it's readily available for other family members to view as well. So different things, and now with this whole adding more awareness, events in news to the café, where families can just quickly link there and view all that information. I think we are using it more and again, there's just still so much more potential for the café…" (Management Committee interview)

Suggested Improvements

Management Committee members and *First Link*® staff offered suggestions to help improve the promotion and uptake of ASANT Café:

- ***Create a comprehensive plan*** that outlines actions and supports required to ensure the uptake of ASANT Café (e.g., identify potential audiences and channels to reach them, link the Café to other ASANT communication strategies such as Dementia Month and to the overall strategic plan of the organization, engage health professionals in online discussions, etc.).
- ***Explore the creation of a staff position*** to manage/coordinate ASANT Café and support its full implementation and use. As noted "*we just really need a dedicated person to just do the café and café only. It can't be latched onto anybody else's role. I think it just needs to be a role for someone to just completely take on and immerse in it*."
- ***Provide training and education*** for staff in how to use ASANT Café so they understand and are able to fully use the resources; and so that they can more effectively support

others to use the Café. As noted, staff need to be "*supported to think about ASANT Café as not another program, but it's a way to support all that they're trying to accomplish in client services by providing information, support and education. So whenever they're talking to a client or whenever they're doing outreach, or developing a partnership with an organization or attending committee meetings, they've always got ASANT Café in their back pocket.*"

- Continually ***review and update*** ASANT Café (all elements including the guidelines, resources, etc.).
- Ensure continued ***support to address technical issues/glitches*** that emerge.

Project Outcomes

The following section provides an assessment of the outcomes of the *First Link*® referral process. The outcome is provided followed by the findings.

Outcome: Enhanced linkages between ASANT and diagnosing primary care physicians, diagnostic and treatment services (specialized geriatric and mental health services), community service providers and home care.

When *First Link*® staff were asked (on the survey) about strengthening linkages with various providers, as depicted in table eight, all agreed that they had strengthened linkages with Primary Care Networks (3 indicated strong agreement). *First Link*® staff generally agreed that linkages had been strengthened with family physicians (although one respondent disagreed and only one strongly agreed). Respondents were more neutral in terms of linking/engaging with pharmacy, nurse practitioners and emergency services.

Table 8: Strengthened Linkages

Provider/ Organization	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Primary Care Networks	0%	0%	0%	57% (n=4)	43% (n=3)
Family Physicians	0%	14% (n=1)	0%	71% (n=5)	14% (n=1)

Provider/ Organization	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Geriatric Assessment Units	0%	0%	14% (n=1)	43% (n=3)	43% (n=3)
Community Care Access	14% (n=1)	0%	14% (n=1)	43% (n=3)	29% (n=2)
Specialists	0%	0%	29% (n=2)	43% (n=3)	29% (n=2)
Police	0%	0%	33% (n=2)	67% (n=4)	0%
Emergency Services	0%	14% (n=1)	29% (n=2)	57% (n=4)	0%
Nurse Practitioners	0%	0%	43% (n=3)	43% (n=3)	14% (n=1)
Pharmacy	0%	0%	71% (n=5)	29% (n=2)	0%

First Link® staff were asked about their greatest successes in terms of outreach and partnership development. Respondents consistently discussed the importance of the connections that had been made with a variety of organizations and individuals, and the increasing buy-in to the referral process.

> *"Buy-in from physicians in rural areas that could really use our programs and services for their patients… buy-in from the community… maintain those links/connections to further work with each other in the future to provide the best possible support for families."* (First Link® Staff survey)

During the story sharing session, *First Link*® staff discussed that through their networking and relationship building ASANT is: addressing gaps in the health care system, helping families to navigate the health care system, supporting coordination of care and the provision of consistent care for those with Alzheimer disease and their care partners.

> *"By building stronger relationships and collaborating with health care professionals we support coordination of care for our clients and contribute to a more efficient system. By proving ourselves to families, building a relationship based on trust and connecting care partners with one another, we walk the path with our clients. First Link® is the bridge."* (First Link® Staff story sharing)
>
> *"First Link® attempts to fill gaps by completing outreach in rural areas to provide consistent services across the province."* (First Link® Staff story sharing)

When asked about key project accomplishment/successes, Management Committee members consistently discussed how through *First Link®*, the Alzheimer Society has gained recognition and credibility as a key partner in the health system. The contributions of the Alzheimer Society to the development and support of policy such as the Dementia Strategy was also highlighted.

> *"The fact that we're building relationships not just with individuals, but also at a higher level, the partnerships and the relationships that are now happening within and across those organizations to the extent that… ASANT is being sought out more and being included and invited to different tables and more tables, particularly around the dementia strategy work. So outside of the fact that we've created ASANT Café and we've increased reach around First Link® the value adds… is the fact that [ASANT is] now perceived as a player within dementia and dementia care in Alberta"* (Management Committee Interview)

Three quarters of respondents to the referrer survey (75%, n=30) indicated they were more aware and knowledgeable about the services and programs offered by the Alzheimer Society and 74% (n=29) indicated that they felt they had a stronger connection with the Alzheimer Society. Ninety-two percent (n=36) agreed that the *First Link®* referral process had benefited their practice/service. In addition, the vast majority agreed that they were more confident that the information and support needs of their clients with dementia and care partners were being met (98%, n=39). (Detailed findings in Tables 4 and 5 in Appendix 2).

Outcome: Enhanced referral of individuals diagnosed with cognitive impairment and their families by physicians and health and community service providers to ASANT via *First Link®*.

Number, Type and Source of Referrals

The number of direct referrals (which represents referrals through *First Link®*) was 496 in 2014 and 537 in 2015. The total number of referrals (includes direct, instructed and self-referrals) was essentially the same in both years – 1124 in 2014 and 1130 in 2015 (direct referral – the Alzheimer Society receives a referral form directly from a health care professional or community

partner; self-referral – an individual finds the Society and its service on their own (through the phone book, from a friend, and calls or emails); instructed referral – a health care professional or community partner suggest or instructs an individual to call the Alzheimer Society but does not send a referral form to the Society).

The majority of direct referrals came from Edmonton in both years – 58% (n=288) in 2014 and 64% (n=342) in 2015; followed by Central Region – 19% (n=96) in 2014 and 20% (n=106) in 2015. In both Edmonton and Central regions, the number of direct referrals increased (from 288 to 342 in Edmonton and from 96 to 106 in Central Region) as did the total number of referrals (from 659 to 666 in Edmonton and from 183 to 195 in Central region). In the North and South regions both the direct and overall referrals decreased from 2014 to 2015 (in the North region direct referrals decreased from 40 to 26 and overall referrals from 104 to 97; in the South direct referrals decreased from 60 to 49 and overall referrals from 130 to 120). The detailed information about the number of referrals including by type and region is provided in tables 6 and 7 in Appendix 2.

The primary source of referrals in all regions both years was Geriatric Assessment Units (48%, n=240 in 2014; 44%, n=234 in 2015). In terms of referrals from primary care (categorized as Primary Care Networks and family physicians), 20% (n=97) were from this sector in 2014 and 16% (n=87) in 2015. (Detailed data provided in figures 1 and 2 in Appendix 2)

Reaching Out and Early Contact Important

In some of the focus groups, clients discussed that the referral by a service provider and ASANT reaching out is important as some people will not contact the Alzheimer Society on their own. Therefore, that first call is critically important as it connects people to support sooner.

> *"And I wouldn't have called them, I would have just gone on my own, and I have no family here in town, so it was a lifeline for us."* (Client focus group)
>
> *"I probably wouldn't have contacted the Society… certainly not as soon as I did because things were still quite cope-able here… I probably would have put it off for a long time until someone,*

probably another doctor or something might have mentioned maybe a year later, but as far as I'm concerned, the sooner the better." (Client focus group)

Referrers also highlighted the importance of ASANT reaching out as some people may not make contact or seek help on their own (10 referrers noted this in response to an open ended question about how the referral process was most helpful).

"Someone knowledgeable and friendly is phoning them directly; they do not have to make another call to the 'unknown'" (Referrer survey)

"The first contact with a support service is often very difficult for both those with dementia and the care partners. Being contacted by the Alzheimer Society opens that door to support in a non-threatening way. Follow-up is essential as it may take time to recognize a need for support." (Referrer survey)

On the client survey respondents were asked how they felt when the doctor or health/ community care provider asked them if they could refer them to ASANT. The majority of respondents agreed or strongly agreed that they were relieved to be connected with further support and information about dementia (88%, n=22) and less overwhelmed knowing that they did not have to make the phone call (67%n n=16, 33% were neutral). Just 17% (n=4) of respondents agreed that they did not need the support and could have made the call themselves. (Detailed findings in Table 17 in Appendix 2)

Clients and Contacts

In the E-Tapestry database, clients are classified as a person with dementia, care partner or both. In both years the vast majority of clients were care partners – 89% (n=997) in 2014 and 90% (n=1021); and close to three quarters were female – 71% (n=799) in 2014 and 72% (n=808) in 2015. (Tables 8 to 11 in Appendix 2 provide the detailed findings).

As depicted in table nine, the number of contacts (includes phone, visit, email support and follow-up attempts) increased from 4,585 to 7,103 from 2014 to 2015. There were 2,518 more

contacts made, which is a 55% increase. The number of clients reached (unique cases) also increased from 1,538 to 2,499 between 2014 and 2015, which is a 62% increase (n=961). The number of communities reached increased by 56 from 179 in 2014 to 235 in 2015, which represents a 31% increase.

Table 9: Client Contacts

Client Contacts	Number	
	2014	**2015**
Number of Contacts	4585	7103
Number of hours with Clients	1818	2611
# of clients* (represents unique cases)	1538	2499
# of Communities	179	235

*# of clients does not equal # of referrals as the # of clients includes new clients (i.e.., referrals) as well as existing clients.

Outcome: Improved linkages to community services for non-medical management of issues from time of diagnosis through the duration of the disease.

In all focus groups, participants consistently described how they were connected to community supports such as Home Care, Adult Day Programs, Victorian Order of Nurses (VON), and Primary Care as a result of their referral to ASANT. They learned about these important supports through ASANT staff as well as through support groups. Participants also discussed how the Alzheimer Society has played a navigator role, helping them to understand and connect to the health care system – "*they have been very instrumental to us in terms of how to negotiate the health care system. And so we looked to them for guidance in that respect*."

> *"She [ASANT staff] found a temporary doctor and through her connection with that doctor, we found a female doctor… where we were told it was impossible… I really felt that if it wasn't for her indirectly… we would not have had a female family doctor, which was very important to [my wife]."* (Client focus group)

"I got connected to homecare. And that was tremendous and it grew over time as well, and was extremely helpful. They connected me to homecare and then an RN from Alberta Health Services came and interviewed us" (Client focus group)

All respondents to the client survey agreed that through the *First Link*® referral to the Alzheimer Society that they had become more aware of community services/resources (100%, n=28), and 90% (n=25) agreed they were provided with information about how to access available supports and services in the community.

Outcome: ASANT Café is used as a resource by various audiences including people with dementia and their care partners and health care providers.

Since the launch of the ASANT Care on April 1, 2014 until December 31, 2015 there have been a total of 11,235 visits to ASANT Café with 7,989 unique visitors (there is a small margin of error in these numbers as there are times when not all information is available to track individuals using the Café). Visitors to the ASANT Café have the opportunity to sign in and become members where they are registered within the online community and create a personal profile. By becoming a member an individual has access to more features of the Café such as the chat rooms, etc. Over the same period (April 1, 2014 to December 31, 2015), 542 people have become members. Eighty percent (n=434) are female and 93% are care partners of people living with dementia. The average number of visits per member was 7. (More detailed data related to the demographics of members are provided in Tables 18-20 in Appendix 2).

Only six of 28 respondents (21%) to the client survey reported that they had used ASANT Café. In the focus groups, clients were asked why they did not use the site and most often noted were lack of awareness about the online resource, lack of computer skills, and lack of time (due to the demands of caring for someone with dementia). Also noted by a few was not wanting to become consumed with the disease and always seeking out information.

> *"…well it looked very impressive. They have a chat room, and they had a lot of resources that you could link onto. I must admit that I did look at it, but I didn't [use it that much] …for me personally, I don't want dementia to become my next career path. So it's good to have knowledge and I do read… but for me it's easy to get totally immersed in it… but it certainly had a lot of resources."* (Client focus group)

Of the six respondents who indicated they used the ASANT Café, five respondents provided a rating regarding how useful the online resource has been in supporting their journey with dementia, all of whom indicated it was useful (60% indicated it was somewhat useful, and 40% indicated it was very useful). The focus group participants who had used ASANT Cafe indicated that it is a valuable resource.

> *"Helpful discussions and webinars*" (Client survey)
>
> *"Lots of excellent info and chat rooms"* (Client survey)

Outcome: Increased understanding and awareness among people with dementia and care partners of: ASANT programs and services; ADRD; community resources; coping strategies and care skills for care partners using current best practices.

Increased Awareness of and Connected to ASANT Programs and Services

In all focus groups, participants consistently discussed how being referred to ASANT through *First Link*® increased their knowledge about not only community supports but also about the programs and services available through the Alzheimer Society such as support groups, information, one on one support in person or through telephone, etc. Many people indicated that they did not know about the wealth of support available through ASANT or other community resources.

"I have friends that are going through it as well, and I talked to them and said, you've got to get in touch with the Alzheimer's Society, it's so beneficial and talk to them about it. But before this, I never knew anything about it." (Client focus group)

"I had no idea this existed. And I knew I was going to have to start looking for something, but I didn't know where to start, I didn't know anything. So that link from when she was diagnosed in the hospital to the Society, that is very important. And I think there's a lot of people that are struggling. I was fortunate in that she agreed to go to the hospital. Some of these people can't get their spouses to go to the hospital, they have to have them physically picked up by ambulance or somebody, and taken. You know, that's a terrible situation to be in, and they struggle. And I think a lot of times they don't know. I think there's a lot of people out there that don't know what is available for them." (Client focus group)

An open ended question on the referrer survey asked respondents how the *First Link®* referral process was most helpful to clients and care partners. Noted most often (n=23 of 33 who responded to the question) was the importance of connecting patients and care partners to credible community support and information to help them cope with their disease.

"It opens up conversation to acknowledge there is a memory problem that is real and to not pretend it is a normal part of aging. Gives the client room to talk openly about the problem and for family to gain an understanding about dementia and ways to cope. Provides support." (Referrer survey)

"The way the support and education is provided to the client/family is wonderful, caring and very useful." (Referrer survey)

Increased Knowledge and Skills (knowledge about ADRD, coping skills)

During the focus groups, care partners consistently discussed how their understanding about ADRD had increased because of the ASANT programs and services. They described how they learned to better support their family member/friend with dementia including gaining practical tips and coping strategies.

"You learn, you get from how other people in the group have dealt with it. Like I know with my mom, she crocheted for years and years. Well she can't crochet anymore, she's forgotten. And so, I crochet and then I give her the crocheting, and then I get her to undo it, to make the ball. So then she thinks she's doing it. Or people that they say, well yeah, you know, my wife used to do a lot of cooking, so they give them a bowl with flour and say, here's a fork, just mix. So it's those kinds of tools that make the day-to-day life a little bit easier." (Client focus group)

"I think [name] at one point sent me a list of 101 things to do with people with dementia. You know, even small things like not correcting them, is huge for us because we had absolutely no idea. Things to do with her that she's actually capable of doing, that she really enjoys like little small projects, you know, all those kinds of things came directly from our connection with the Alzheimer's Society." (Client focus group)

The findings from the client survey also illustrate increases in knowledge and skills for both those with dementia and care partners. As depicted in table ten, over 90% of respondents reported increases in knowledge about dementia (96%, n=27), learning new coping skills that reduced stress (96%, n=25), and learning new caregiving skills (caregivers) (96%, n=24). About three quarters (73%, n=16) agreed that they were more at ease in asking for support from family and friends.

Table 10: Value of Referral to the Alzheimer Society

Statement	Level of Agreement					
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
Increased my knowledge about dementia.	0%	0%	4% (n=1)	32% (n=9)	64% (n=18)	(n=0)
Learned new caregiving skills.	0%	0%	4% (n=1)	58% (n=14)	38% (n=9)	(n=4)
Learned new coping skills that have reduced my stress level. *	0%	0%	4% (n=1)	65% (n=17)	31% (n=8)	(n=1)
Become more at ease in asking for support from family members or friends,			27% (n=6)	50% (n=11)	23% (n=5)	(n=6)

*One missing response

Enhanced Coping and Reduced Stress

As noted in the above section*, Increased Knowledge and Skills*, clients (mainly care partners) consistently reported learning new coping strategies to help support their family member. In addition, as illustrated in table 11, the vast majority of respondents to the client survey (93%, n=23) agreed that as a result of the referral through *First Link®* to the Society, they are better able to cope with their situation. About three quarters reported feeling more accepting of their situation (79%, n=22) and less stressed (75%, n=21) as a result of the referral.

Table 11: Coping and Reduced Stress

Statement	Level of Agreement				
	Strongly Disagree	**Disagree**	**Neutral**	**Agree**	**Strongly Agree**
As a result of being referred to the Alzheimer Society through *First Link®*, I feel I am better able to cope with my situation.	0%	0%	7% (n=2)	57% (n=16)	36% (n=10)
As a result of being referred to the Alzheimer Society through *First Link®*, I feel more accepting of my situation.	0% (n=0)	4% (n=1)	18% (n=5)	43% (n=12)	36% (n=10)
As a result of being referred to the Alzheimer Society through *First Link®*, I feel less stressed about my situation.	0%	11% (n=3)	14% (n=4)	54% (n=15)	21% (n=6)

Other Benefits to Clients and Communities

Referrers were asked if they believed that the Alzheimer Society had met the information and support needs of their clients they had referred, with 88% (n=34) indicating that they agreed the Society had met their clients' needs. Eighty-eight percent (n=34) also agreed that their clients had benefitted as a result of the referral.

First Link® staff were asked to rate the benefit of the *First Link®* referral process on a five point Likert scale for people with dementia and care partners. In terms of benefits for care partners, the average rating was five (all respondents indicated it was "very helpful).

"Many say they cannot imagine what they would do without our services." (First Link® staff survey)

"Caregivers are often stressed and not able to make the phone call to get support, and First Link® provides this easier link. Caregivers say this referral and relationship developed subsequently with ASANT has saved their lives." (First Link® Staff survey)

In terms of how beneficial *First Link®* is for people with dementia the average rating was 4.2. It appears that this rating was slightly lower as people feel the referral process and supports are more useful for care partners, and that contact with people with dementia is sometimes more sporadic.

"… It's mostly helpful for families who have a family member who has dementia. However, we do advocate for people with dementia and provide different resources to those who have been diagnosed…" (First Link® Staff survey)

During the story sharing session, *First Link®* staff spoke about the benefits of the *First Link®* referral process to individuals and communities, and described *First Link®* as the foundation of the Alzheimer Society.

"First Link® has become the way we interface with clients, no longer just a program… it is a door of hope. First Link® is more than a referral process and is an under-utilized gem. The Alzheimer Society needs full buy-in to First Link® and to acknowledge it as the interface, not only with ASANT clients, but also with health care providers/stakeholders." (First Link® Staff story sharing)

First Link® staff also spoke about the importance of *First Link®* in not only linking clients to much needed programs and services, but also the role staff play in advocacy and as agents of change in the health system and community.

"At a client level we assess and identify client needs and help advocate for services that will address gaps in an individual's ability to cope. At an organization level, we are agents of positive system change for families impacted by Alzheimer disease and related dementias." (First Link® Staff story sharing)

"A key function of First Link® is to provide education and build awareness of families, persons diagnosed with dementia, health care professionals and community. This helps to de-stigmatize Alzheimer disease and related dementias; and is supporting shifting language and attitudes towards a person-centred approach." (First Link® Staff story sharing)

Conclusions & Recommendations

Community Outreach and Partnerships

The partnership between ASANT, Alberta Health and Alberta Health Services continues to be critical in helping to support the implementation of *First Link*®. Staff from Alberta Health and Alberta Health Services along with champions at the local level help to connect ASANT and *First Link*® to system level policies and strategies (e.g., the Alberta Dementia Strategy Action Plan) and problem solve issues/challenges. It is also important to further engage senior leaders from all three organizations to help strategize at higher levels.

Both community outreach and networking activities are helping to build awareness about *First Link*® and strengthening partnerships at the local level. In 2014 and 2015 approximately 150 outreach activities were done each year using a variety of strategies, most often face to face meetings with providers/ organizations, presentations, promotion through partnerships and health fairs. A variety of providers were targeted with primary care (family physicians, primary care networks and pharmacy), Community Care Access (Home Care) and police targeted by the majority of staff. Geriatric Assessment Units and nurse practitioners were also commonly reached. The findings from the referrer survey reveal that providers who have referred to ASANT feel a stronger connection with ASANT, and staff and Management Committee members felt that the Alzheimer Society has gained recognition and credibility as a key partner in the health system including in policy development.

While outreach and networking are critical to building awareness about *First Link*® and connecting with potential referrers, they are time consuming activities. Staff turnover at ASANT

and lack of internal human resource capacity remain challenges to doing outreach and networking activities, and may explain why the number of outreach and networking activities were approximately the same in 2014 and 2015, and why referrals have not increased overall.

Further challenging staff's ability to do outreach and networking is the increasing amount of time required to support clients. From 2014 to 2015, the number of contacts increased by 55% (4,585 to 7,103), the number of clients reached (unique cases) increased by 62% (1.538 to 2,499) and the number of communities served increased by 31% (179 to 235). Staff time has therefore focused on serving clients that have been referred to ASANT (both through *First Link*® and other means) as this is an immediate need and priority.

While the findings indicate that staff feel linkages with primary care have been strengthened and approximately one fifth of direct referrals come from primary care (20% in 2014 and 16% in 2015), engaging providers from this sector to make referrals remains a challenge. The informal connection of the health system to primary care may help to explain why it is more challenging to engage these providers (e.g., many family physicians remain as independent practitioners). Another reason may be because primary care physicians do not generally diagnosis someone with dementia or Alzheimer disease, and therefore may not be comfortable making a referral to ASANT. A recent survey by the Alberta Medical Association and Seniors Health Strategic Clinical Network that gathered feedback/perspectives on gaps in care of people living with dementia help to support this finding. Thirty-eight percent of the family physicians who responded to the survey felt that they did not have the necessary training or skills in the area of recognizing and providing care to people living with dementia[2].

First Link® Referrals

The number of direct referrals to ASANT increased very slightly from 2014 to 2015 (496 and 537) and the primary source of referrals are Geriatric Assessment Units. As previously noted, the ability of staff to do outreach and networking has been challenged due to capacity of staff (i.e.

[2] From Seniors Health Strategic Clinical Network Newsletter, November 2015

turnover, not enough staff) and increasing demands for follow-up. These factors may help to explain the fact that there has not been a greater increase in referrals to ASANT.

Respondents to the referrer survey were satisfied with the referral process and clients in the focus groups consistently reported that the process worked well. Only a few referrers or clients noted challenges – most often noted was stigma associated with ADRD, which may prevent some providers from referring and/or clients from accepting the referral. This speaks to the importance of *First Link®*, and some clients discussed how essential the referral and contact from ASANT is as some people will not reach out, and therefore the referral process helps to connect people to much needed support sooner. A couple of other challenges noted by a few were lack of information about the referral process (referrers and clients).

ASANT Café

A number of activities have been done to support the implementation and uptake of ASANT Café including a public launch, creation and dissemination of a post card through various mechanisms, promotion through partner networks, creation of guidelines and tools, staff identified as Super Users to promote and encourage its use, and the availability of technical support. The findings reveal that all staff are using ASANT Café to some extent, however, generally not to its full capacity. Factors that appear to be challenges to the uptake of ASANT Café include lack of staff support to assist with implementation (the Super Users do provide support but their time to do so is limited because of other responsibilities), lack of awareness and understanding among some staff of the value of the resource and its potential to support their work and clients, and lack of computer skills among some staff as well as clients (given the age demographic of clients).

The client focus groups revealed that few people had used the resource, due to lack of awareness about ASANT Café, lack of computer skills, and lack of time. Although only a few had used ASANT Café, all of these people felt that it was useful and a valuable resource.

Since the launch of the ASANT Cafe on April 1, 2014 until December 31, 2015 there have been a total of 11,235 visits to ASANT Café with 7,989 unique visitors. In terms of members, over the same period, 542 people have become members.

Support from ASANT

The focus of the current evaluation was on *First Link*® rather than a comprehensive evaluation of ASANT programs and services. However, during the focus group with clients and on the survey, satisfaction with ASANT programs and services was explored. The findings reveal high levels of satisfaction with supports accessed including the information provided, the one on one support, and support groups. Clients consistently noted that ASANT staff were approachable, respectful, courteous, empathetic and understanding. Challenges were only noted by a few and most often discussed were challenges related to other parts of the health care system, and included issues with access and satisfaction with services provided.

Being connected to ASANT programs and services has resulted in people with dementia and care partners not only accessing ASANT programs and services, but also community supports (e.g., Home Care, Adult Day Programs, VON). ASANT staff have helped clients, care partners in particular, to navigate the health system and access required supports. Other benefits of being connected to ASANT programs and services through *First Link*® (for care partners in particular) include increased understanding about ADRD, gaining practical caregiving skills and tips in how to support a person with dementia, being better able to cope, and reducing stress. The ability of people with dementia and care partners to access programs and services through community – based organizations such as the Alzheimer Society helps to support efficient use of resources within the health care system.

Staff also spoke about the benefits that they have observed among their clients. They described *First Link*® as the foundation of the organization, and described themselves as advocates for people with dementia/ care partners. They see themselves as agents of change in the health system and community. The role of the Alzheimer Society in patient navigation was also

highlighted by staff, as well as the important role the organization plays in helping to bridge community and health system programs and services.

Recommendations

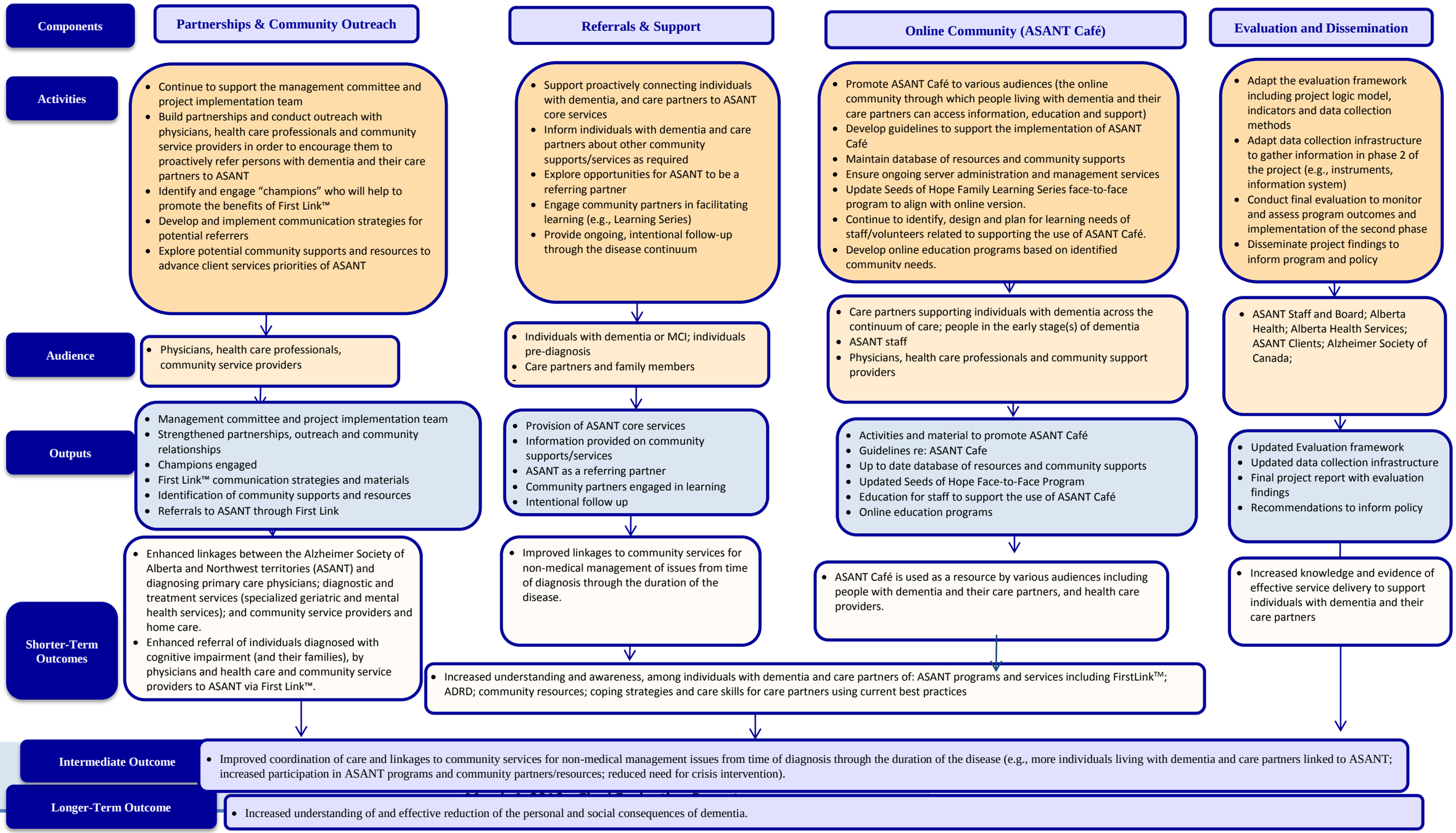
Develop a comprehensive plan for *First Link*® that addresses outreach and networking, overall communication, provider engagement (particularly primary care) and uptake of ASANT Café. The following recommendations are suggested for incorporation within the plan:

- ***Continue outreach and relationship building*** and strategize how to effectively support these activities such as providing additional staff who could support program and service delivery (and free up the time of *First Link*® staff to do community outreach and partnership development);
- ***Develop strategies to facilitate the engagement of key stakeholders,*** notably primary care, and involve senior leaders and appropriate staff from Alberta Health, Alberta Health Services and ASANT to strategize (e.g., Primary Care branch at Alberta Health, CEO of ASANT, etc.);
- ***Continue to engage Home Care and Continuing Care*** to further build awareness and understanding about the *First Link*® referral process (e.g., connect with Zone leads for Continuing Care, continue to build awareness among front line staff, etc.);
- ***Continue to offer high quality programs and services through ASANT*** and periodically review to ensure continuous quality improvement and client satisfaction (e.g., review the amount of information distributed to clients to ensure it is not overwhelming, etc.)
- ***Explore strategies to increase efficiency*** of the *First Link*® referral process and the provision of programs and services (e.g., using ASANT Café more effectively to offer services such as support groups, creation of an online referral form, etc.)
- ***Develop strategies to facilitate the uptake of ASANT Café*** such as identifying audiences and channels to reach them, linking ASANT Café to the strategic direction and overall communication plan of the organization, engaging health professionals in online discussions, reviewing and updating resources and materials, working with phone support

programs such as Health Link, 911 dispatch, etc. The strategies should include exploration of a staff position to manage/coordinate ASANT Café and support its full implementation.

- ***Continue providing supports for First Link® staff*** including networking opportunities among staff in various areas of the province to share and learn from one another; training and education in using ASASNT Café to facilitate its full implementation; and learning opportunities to support other roles and responsibilities (e.g., outreach, partnership building, etc.). The support should include recognition of the diverse knowledge and skills required of *First Link*® staff.
- ***Develop a communication strategy/ plan*** for the *First Link*® referral process and ASANT Café that helps to coordinate the various pieces of work of ASANT (both internally and externally); and identifies key audiences and communication mechanisms (e.g., using social media more effectively to communicate with the public, channels to communicate with health care providers, etc.). The plan should include a review and updating of existing promotional material (e.g., review of *First Link*® pamphlet, explore creating a video about *First Link*®, link *First Link*® to the ASANT website, and promote *First Link*® through national organizations such as the Canadian Medical Association), and involve ASANT staff with expertise in marketing/communications.

Appendix 1 - First Link™ Dementia Early Intervention Project Logic Model



Appendix 2: Tables

Referrer Survey

Table 1: How did you hear about the First Link® referral process?

Response	% (n)
ASANT website	8% (n=3)
Courtesy call from an Alzheimer Society staff	10% (n=4)
From a colleague	26% (n=10)
Presentation/meeting	69% (n=27)
Referral package mailed/dropped off	5% (n=2)

**Respondents could select more than one response, so the total responses will add up to more than 40.*

Table 2: What is your primary reason for referring individuals through First Link® to the Alzheimer Society?

Primary Reason	% (n)
To connect people to initial and ongoing support and follow-up	73% (n=29)
To help people access information or materials	10% (n=4)
To link people to other community services and supports	10% (n=4)
To connect people to education opportunities (e.g., face to face, online learning, etc.)	8% (n=3)
Total	**100% (n=40)**

Table 3a: Are there times when you don't' refer people with dementia or cognitive impairment or their family members/care partners through First Link® to the Alzheimer Society?

Response	% (n)
Yes	74% (n=29)
No	26% (n=10)
Total	**100% (n=39)**

Table 3b: If yes, why?

Reason	% (n)
May not make referral at first contact but later	0% (n=0)
The family member/care partner is not receptive to the referral	79% (n=23)
The person with dementia is not receptive to the referral	14% (n=4)
Other: • The patient / family member want to first read the Alzheimer's Society materials that I provide. (3%, n=1) • If the Individual or family are not receptive, or they already have a strong knowledge base with regards to dementia, and resources. (3%, n=1)	6% (n=2)

Reason	% (n)
Total	**100% (n=29)**

Table 4: As a result of my interactions with First Link®

Statements	Level of Agreement				
	Strongly Agree	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
I am more aware and knowledgeable about the services and programs offered by the Alzheimer Society	20% (n=8)	55% (n=22)	18% (n=7)	8% (n=3)	0% (n=0)
I am more confident that the information and support needs of my patients with dementia and their family/care partners are being met	38% (n=15)	60% (n=24)	3% (n=1)	0% (n=0)	0% (n=0)
I feel I have built a stronger connection with the Alzheimer Society	23% (n=9)	51% (n=20)	26% (n=10)	0% (n=0)	0% (n=0)

Table 5: I believe that

Statements	Level of Agreement				
	Strongly Agree	**Agree**	**Neutral**	**Disagree**	**Strongly Disagree**
The Alzheimer Society has met the information and support needs of the patient/client/care partner I have referred through the First Link® referral process	40% (n=16)	48% (n=19)	13% (n=5)	0% (n=0)	0% (n=0)
My clients/patients have benefitted from being referred through the First Link® referral process	48% (n=19)	40% (n=16)	10% (n=4)	3% (n=1)	0% (n=0)
The First Link® referral process has benefited my practice/service.	59% (n=23)	33% (n=13)	8% (n=3)	0% (n=0)	0% (n=0)

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Table 6: 2014 Referrals

Region	Type of Referral		
	Direct	**Instructed**	**Self**
Calgary	3	1	12
Central	96	3	84
Edmonton	288	45	326
North	40	16	48
South	60	3	62
Other	9	5	23
Total	496	73	555

Table 7: 2015 Referrals

Region	Type of Referral			
	Direct	Instructed	Self	Unidentified
Calgary	5	5	14	0
Central	106	24	64	1
Edmonton	342	40	284	0
North	26	30	41	0
South	49	7	64	0
Other	9	4	15	0
Total	537	110	482	1

Figure 1: Source of Direct Referral 2014

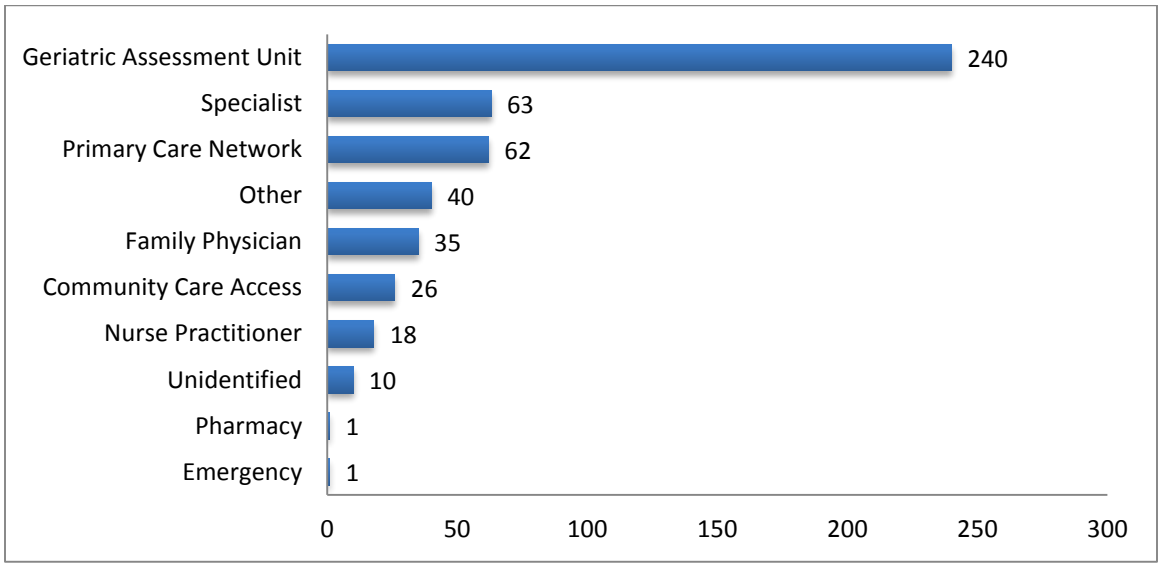

Figure 2: Source of Direct Referral 2015

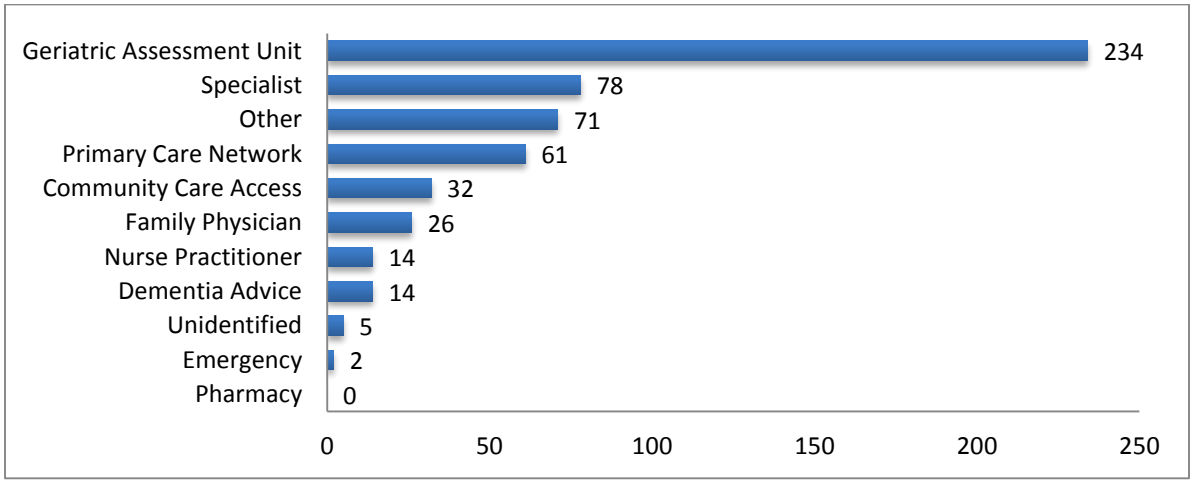

Table 8: 2014 Type of Clients by Region

Region	Type of Clients			
	Person with Dementia	Care Partner	Both	Unidentified
Calgary	1	13	0	2
Central	10	159	5	10
Edmonton	24	601	13	22
North	2	92	5	5
South	6	106	3	10
Other	2	26	0	7
Total	45	997	26	56

Table 9: 2015 Type of Clients by Region

Region	Type of Clients			
	Person with Dementia	Care Partner	Both	Unidentified
Calgary	2	22	0	0
Central	11	178	5	2
Edmonton	27	620	8	11
North	5	86	4	1
South	7	90	3	19
Other	1	25	0	3
Total	53	1021	20	36

Table 10: 2014 Gender of Client

Region	Gender of Client			
	Male	Female	Both	Unidentified
Calgary	5	9	0	2
Central	36	137	2	9
Edmonton	147	474	5	34
North	17	83	1	3
South	45	79	0	1
Other	6	17	1	11
Total	256	799	9	60

Table 11: 2015 Gender of Client

Region	Gender of Client			
	Male	Female	Both	Unidentified
Calgary	10	14	0	0
Central	45	146	3	2
Edmonton	170	469	5	22
North	24	74	0	1
South	34	84	1	0
Other	6	21	0	2
Total	286	808	9	27

Table 12: 2014 Client Contacts

Region	Client Contacts			
	Number of Contacts	Number of Hours with Clients	Number of Unique Individuals	Number of Communities
Calgary	36	15	16	2
Central	266	137	160	32
Edmonton	2850	871	947	46
North	251	94	124	47
South	1085	667	245	37
Other	97	35	46	15
Total	4585	1819	1538	179

Table 13: 2015 Client Contacts

Region	Client Contacts			
	Number of Contacts	Number of Hours with Clients	Number of Unique Individuals	Number of Communities
Calgary	51	21	22	4
Central	715	244	380	66
Edmonton	4542	1335	1559	55
North	369	192	180	49
South	1384	797	331	42
Other	41	22	26	18
Total	7102	2611	2498	234

Table 14: 2014 Who Initiated Contact

Region	Who Initiated Contact			
	Client	Staff	Both	Unidentified
Calgary	15	19	0	2
Central	38	57	2	169
Edmonton	599	1980	20	251
North	46	185	2	18
South	152	907	0	26
Other	46	36	0	15
Total	896	3184	24	481

Table 15: 2015 Who Initiated Contact

Region	Who Initiated Contact			
	Client	Staff	Both	Unidentified
Calgary	11	37	0	3

Region	Who Initiated Contact			
	Client	Staff	Both	Unidentified
Central	109	322	2	282
Edmonton	524	3667	19	346
North	72	283	0	14
South	266	1098	3	17
Other	15	3	0	9
Total	997	5410	24	671

Table 16: Outreach and Networking

Region	Outreach		Networking	
	2014	2015	2014	2015
Calgary	0	0	0	0
Central	44	34	16	26
Edmonton	23	14	8	0
North	66	83	5	13
South	20	0	22	0
Other	0	19	0	11
Total	153	150	51	50

Client Survey

Table 17: How did you feel when the doctor or health/ community care provider asked you if they could refer you to ASANT

Statements	Level of Agreement				
	Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
Relieved to be connected with further support and information about dementia. *	0% (n=0)	0% (n=0)	12% (n=3)	60% (n=15)	28% (n=7)
Less overwhelmed knowing that I did not have to make the phone call. **	0% (n=0)	0% (n=0)	33% (n=8)	46% (n=11)	21% (n=5)
I did not need the support and could have made the call myself. **	25% (n=6)	33% (n=8)	25% (n=6)	13% (n=3)	4% (n=1)
I was not given enough information on what to expect for services I would be able to receive from the Alzheimer Society. **	17% (n=4)	42% (n=10)	13% (n=3)	25% (n=6)	4% (n=1)

** Three missing responses; ** Four missing responses*

ASANT Café

Table 18: Session Type

Session Type	New	Returning	More than 1 Visit	All
PWD	34	2	18	36
Care Partners	483	22	318	505
Undisclosed	0	0	0	0
TOTALS	517	24	336	541

Table 19: Gender Breakdown

Gender	Members	Visits
Male	95	1171
Female	434	2486
Unknown	0	0

Table 20: Member Type vs. Visit Breakdown

Type	Visits
PWD (1)	225
CP (2)	3571
Unknown	0