



First Link® – Transforming the Dementia Experience in Alberta

Final Evaluation Report

Presented to: Alberta Health

Presented by: Alzheimer Society of Alberta and Northwest Territories

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Executive Summary

Background

First Link® is a referral process to assist physicians, health and community service providers to directly refer people living with dementia and their care partners and families 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 five key elements of First Link® include outreach and networking, a formal referral, proactive contact by Alzheimer Society staff, connection with programs and resources, and intentional follow-up.

The Alzheimer Society of Alberta and Northwest Territories (AS AB/NT) received funding from an Alberta Health Continuing Care Initiatives Grant to implement the First Link® referral service across the province between the fall of 2012 and December 2015. A grant from Alberta Health continued to fund First Link® from January 1, 2016 to December 31, 2018. The second phase of the initiative, *First Link® Transforming the Dementia Experience in Alberta*, has supported AS AB/NT to continue to implement First Link®, expand programs and services, and heighten awareness about dementia across Alberta. The funding also supported the expansion of First Link® in the Calgary Health Zone through a contractual agreement between AS AB/NT and the Alzheimer Society of Calgary (AS Calgary).

Methods

A final evaluation was completed to assess project impacts over the three years of the initiative (January 1, 2016 to December 31, 2018). The final evaluation is focused on outcome measures but also includes some process measures (e.g., a description challenges and enablers to implementation, reflections on sustainability).

Data collection methods used to evaluate the project include:

- A survey with clients (primarily care partners but a few people with Alzheimer disease/dementia also participated);
- Interviews with providers who refer clients through the *First Link®* referral process;
- A focus group with *First Link®* staff that support the *First Link®* referral process;
- Reflections of senior leaders;
- Synthesis of data from two databases - E-Tapestry and iCarol; and
- A review of selected project documents.

Conclusions

Findings

Enhanced Linkages and Increased Awareness and Understanding among Providers

Outreach and networking activities continue to help build awareness about First Link® and strengthen partnerships at the local level. The contract between AS AB/NT and AS Calgary to expand First Link® in the Calgary Region has increased the reach of the referral service and enhanced the relationship between the two organizations. Enhanced connections with various provider groups and increased awareness about First Link® is illustrated by a 206% increase in the number of direct referrals over the last five years (from 496 in 2014 to 1,517 in 2018).

While outreach and networking are important to help build awareness about First Link® and connecting with potential referrers, they are time consuming activities. Lack of human resources and the increasing amount of time required to support clients (i.e., the increasing number of client contacts and hours spent with clients) remain challenges to doing outreach and networking activities. In addition, many relationships have been established due to the outreach and networking that has been done, and therefore not as much effort is required in this area. To help ensure efficient use of resources, staff are becoming more strategic in outreach and networking activities (e.g., identify groups/audiences to focus on, doing less one on one and more group outreach, targeting leaders in organizations to obtain their buy-in, etc.)

The primary source for First Link® referrals continues to be specialist services (e.g., geriatric assessment units, geriatricians); however, significant growth has occurred in obtaining referrals from primary care and home care. This is due to focused efforts of First Link® staff over the last year and a half (since the interim evaluation) to reach these sectors through collaborative models of care and training other providers. The increasing number of referrals from primary care and home care indicate the benefits of this collaborative work, which is helping to provide comprehensive care to those living with dementia and their care partners.

Building relationships with various providers and organizations is key to supporting First Link®. Many stakeholders reach out to the Alzheimer Society for information, presentations and to participate on initiatives, illustrating that the Society is viewed as a credible source of information about dementia and dementia care, and a valuable partner. Feedback from referrers also illustrate the strong relationships that the Alzheimer Society has with providers and organizations, and that the Society is viewed as a vital part of the health care team.

In building awareness among providers, the focus is on First Link® and the supports available through the Alzheimer Society. This ensures that individuals and families are connected to programs and services as early as possible. The increasing number of direct referrals is a key indicator of the Society's success in building awareness in this regard. Outreach and networking, and training staff from other organizations also helps to build understanding among providers about other community supports and services, as well as dementia care. Knowledge and skills related to dementia care have been built among providers in other sectors such as home care and primary care. However, some providers have significant experience in the field and therefore already had high levels of knowledge and skills in the area.

Enhanced Connections with People with Dementia and Care Partners and Increased Awareness and Understanding

The number of clients reached has continued to increase since the interim report and overall there has been an increase of 312% from 1,538 in 2014 to 6,335 in 2018. This is a direct result of the increased number of referrals. The number of contacts with clients has more than tripled since 2014 from 4,585 to 16,815 in 2018, and the number of hours with clients has also increased. Staff time remains focused on serving clients as this is an immediate need and priority. There is also more individuals and communities being reached through programs such as the Learning Series, Support Groups, and First Link Connections.

Through First Link® and the provision of information, support and education, the Alzheimer Society is helping individuals with dementia and care partners to: connect to programs and services early in the disease process; become aware of available programs and services; understand ADRD; and better cope with the disease process. It appears that enhanced knowledge about dementia among clients living with dementia and their care partners and enhanced skills among care partners is helping clients to remain at home longer. It also appears that the knowledge and skills gained by care partners to better manage problem behaviours and cope with difficult situations is helping to avoid a crisis from escalating and unnecessary trips to the emergency department.

Coordination of Care

First Link® and the supports available through the Alzheimer Society are viewed as vital by both clients, and organizations and providers. The Society is viewed as a credible source of reliable and valid information and extends the health care services available to people, particularly psychosocial supports. A referral into the Society through First Link® also helps to connect people living with dementia and care partners with community resources as well as other people dealing with the disease and other dementias. This facilitates people learning from one another and connecting with people who may be experiencing similar challenges. The Alzheimer Society is viewed as a critical part of the care continuum and their programs and services are helping to provide continuity of care.

The partnership between AS AB/NT, Alberta Health and Alberta Health Services continues to be critical in helping to support the expansion of First Link®, ensuring quality care, and ultimately supporting people with dementia to remain at home and live well longer. Leaders/staff from Alberta Health and Alberta Health Services along with champions at the local level help to connect the Alzheimer Society and First Link® to system level policies and strategies (e.g., the Alberta Dementia Strategy) and problem solve issues/challenges.

Recommendations

Based on the findings from the final evaluation, the following recommendations are provided:

- **Continue to review quantitative and qualitative data** to assess outreach, networking, and program and service delivery (including First Link®) to ensure efficient use of resources and continuous quality improvement.
- **Continue providing supports to client services staff** including networking, training, education and team building opportunities to support First Link® implementation and sustainability.
- **Expand the First Link® service** of AS AB/NT into rural areas.
- **Expand use of technology (e.g., ASANT Café) and social media** to continue to raise awareness of First Link® and offer programs and services to help expand their reach.

- ***Continue to diversify mechanisms*** used to do outreach and build relationships (e.g., using technology for outreach, targeting groups of providers versus conducting one on one meetings, building champions/ambassadors for First Link®, etc.).
- ***Support AS Calgary to expand their reach*** to integrate rural communities within their service delivery model.
- ***Continue to build the relationship between AS AB/NT and AS Calgary*** to leverage opportunities to collaborate on initiatives that improve outcomes for Albertans living with dementia and their care partners.
- ***Together with AS Calgary explore strategies to work with partners*** to support initiatives related to First Link® support services (e.g. brain health awareness, dementia risk reduction factors, the promotion of dementia inclusive communities).

Introduction

1. Background

The mission of the Alzheimer Society of Alberta and Northwest Territories (AS AB/NT) is to alleviate the personal and social consequences of dementia, and to do this, information, education and support is provided to families affected by dementia. The Alzheimer Society is dedicated to helping people face dementia - to build their confidence and skills to maintain a good quality of life. Through six regional centres and a provincial office, AS AB/NT offers a provincial network of educational and support services for those with dementia and their care partners, builds partnerships with health professionals and the community, and advances research into effective treatments and finding a cure for this devastating disease.

First Link® is a referral process to assist physicians, health and community service providers to directly refer people living with dementia and their families to the Alzheimer Society for services and support at the time of diagnosis and throughout the duration of the disease. The following are the five overarching and standard key elements of First Link®:

- **Outreach and networking** to help build partnerships with physicians, other health professionals and community service providers to encourage them to proactively refer persons with dementia and their care partners to the Alzheimer Society.
- **Formal referral** of clients diagnosed by a health care professional of mild cognitive impairment, Alzheimer's disease or other dementia (includes a First Link® referral form that a physician, health professional or community service provider completes when referring a person diagnosed with dementia and/or care partner to the Alzheimer Society and acknowledgment of the referral)
- **Proactive contact** where the referral form gives the First Link® Intake Coordinator permission to make proactive contact with potential clients.
- **Connection** to Alzheimer Society information and supports (e.g., education, support groups) and other community supports/services as required.
- **Intentional follow-up** with individuals and families in a planned and consistent way following mutually agreed upon processes throughout the continuum of the disease process as desired by the client/family.

AS AB/NT received funding from an Alberta Health Continuing Care Initiatives Grant to implement the First Link® referral service across the province between the fall of 2012 and December 2015. First Link® has been successfully operating for over ten years in all Canadian provinces supported through government funding. Prior to the grant, First Link® had been partially implemented in Edmonton in the North Region and Lethbridge in the South Region for several years.

A grant from Alberta Health continued to fund First Link® from January 1, 2016 to December 31, 2018. The second phase of the initiative, *First Link® - Transforming the Dementia Experience in Alberta*, has supported AS AB/NT to continue to implement First Link®, expand programs and services and heighten

awareness about dementia across Alberta. The funding also supported the expansion of First Link® in the Calgary Health Zone through a contractual agreement between AS AB/NT and the Alzheimer Society of Calgary (AS Calgary).

The expected outcomes of *First Link® – Transforming the Dementia Experience in Alberta* are:

1. Enhanced linkages between AS AB/NT, AS Calgary and:
 - Primary Care Physicians diagnosing Alzheimer Disease and Related Dementias (ADRD)
 - Diagnostic and treatment services (specialized geriatric and mental health services)
 - Community service providers
2. Increased understanding and awareness among family physicians and allied health professionals of:
 - Assessment and management of ADRD
 - Role of AS AB/NT and the AS Calgary and the First Link® program, and
 - Other community resources for individuals with dementia and/or their caregivers/care partners
3. Increased understanding and awareness among individuals with dementia and family members/care partners of:
 - ADRD
 - Community resources
 - Coping strategies and care skills for caregivers/care partners
4. Improved coordination of care and linkages to community services for non-medical management issues from time of diagnosis through the duration of the disease for:
 - More families/care partners linked to AS AB/NT
 - Increased participation in AS AB/NT programs and community partners/resources
 - Reduced need for crisis intervention

2. Methods

A logic model and evaluation matrix were developed to guide the interim and final evaluation. The logic model identified high-level activities of the initiative and associated outputs and outcomes. Indicators and data collection methods were then mapped to the outputs and outcomes (the logic model is presented in Appendix 1). An Evaluation Framework report was produced and is available through the AS AB/NT. The data collection methods are described below including a description of data analysis.

Data Collection and Management Systems

Data collection and management systems are used by the Alzheimer Society to track activities (AS AB/NT uses E-Tapestry while the AS Calgary uses iCarol). Staff enter data into the electronic database on many variables to help monitor and evaluate First Link® implementation (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 to 2018.

Data from E-Tapestry and iCarol was compiled and analyzed by Alzheimer Society staff in EXCEL and summary data provided to the evaluation consultant. Descriptive statistics were calculated including frequencies and means.

Telephone interviews

Telephone interviews were conducted with a purposeful sample of referrers. Client services staff/managers supporting the implementation of First Link® identified referrers as potential interviewees and invited them to participate in an interview. First Link® staff ensured a range of referrers were identified including various disciplines as well as representatives from diverse organizations (e.g., primary care, community services, specialized services). Table 1 provides an overview of the respondents by region and type. Once the potential respondent agreed to participate, the evaluation consultant followed up to set up a time for the interview. An Interview guide was developed to ensure the all areas of interest were covered and a total of 14 interviews were completed.

Table 1: Interview Respondents

Region	Type	Number
Lethbridge Area	<ul style="list-style-type: none">• One from Community Services• Two from Specialized Geriatrics	3
Medicine Hat Area	<ul style="list-style-type: none">• One from Community Services• One from Specialized Geriatrics	2
Calgary Area	<ul style="list-style-type: none">• One from Primary Care• One from Community Services	2
Red Deer Area	<ul style="list-style-type: none">• Two from Primary Care• Two from Specialized Geriatrics	4
Edmonton Area	<ul style="list-style-type: none">• One from Primary Care• One from Specialized Geriatrics	2
Grand Prairie Area	<ul style="list-style-type: none">• One from Specialized Geriatrics	1
Total		14

The interviews were audio recorded and then transcribed. Once transcribed, the data were 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. Strength of response is provided using descriptors such as “consistently noted”/ “many” (n>10), “most” (n=8 to 10), some (4 to 7) and “a few” (<4).

Client Survey

A survey was developed and distributed to First Link® clients between January 1, 2018 to December 31, 2018. Staff developed a master survey list for each region of clients referred between January 1, 2016 to June 30, 2017. Staff then “cross referenced” the master survey list with their follow up call list and at the next follow-up call asked the client to complete the survey either through the online link (sent in an email) or through a paper copy (mailed). To capture clients referred from July 1, 2017 onward, the survey information was distributed at the 6-month follow up call (for direct referrals). Surveys were also administered through programs to clients who had been referred through First Link®.

Paper copies of surveys sent to clients were returned to the Alzheimer Society office; and surveys were gathered and packaged together and couriered to the evaluation consultant at the end of each month.

A total of 197 surveys were completed. As depicted in Table 2, about two thirds of surveys (66%, n=130) were completed by clients referred within the last 12 months. Ninety-five percent of survey respondents were care partners.

Table 2: Time Period of Referral through First link

Time of Referral	Number	Percentage
Within 6 months	76	39%
Within 12 months	54	27%
Within 18 months	27	14%
Within 2 years	19	10%
More than 2 years	21	11%
Total	197	100%

Data from the survey was compiled and analyzed in EXCEL and descriptive statistics were calculated (e.g., frequencies).

Staff Focus Group and Leader Reflections

A focus group was conducted with client services staff/managers who support the implementation of First Link® and written reflections were provided by leaders from AS AB/NT to gather their feedback on both project implementation (e.g., adaptations made based on recommendations in the interim evaluation report, current challenges and enablers to the implementation of First Link®, suggestions for improvement, and observations related to project outcomes). Detailed notes were taken during the focus group which were thematically analyzed for common themes/threads, with findings incorporated throughout the report. The reflections of leaders were reviewed and incorporated into the findings.

Document Review

Status reports and First Link® Implementation Team (FLIT) meeting minutes 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 appropriate sections.

3. Considerations

- A range of methods (e.g., interviews, focus group, surveys, document review, E-Tapestry and iCarol) were used to evaluate the *First Link® - Transforming the Dementia Experience in Alberta* and data were gathered from the various stakeholders involved. This 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 on the survey data. 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).
- 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 Region (staff located in Edmonton), and Northern Region (staff located in Grand Prairie and Fort MacMurray). iCarol data is reported for the Calgary Region. Detailed data for each region is provided in tables in the appendices with provincial and summary data provided in the main body of the report.
- Close to 200 client surveys were received. However, the majority were from care partners given the difficulty for those with cognitive issues to respond to surveys. Given available resources for

the evaluation, implementing other methods to gather data from those living with dementia was not possible (e.g., longitudinal studies, case studies). To help illustrate the experience of those living with dementia, referrers and staff were asked to reflect on the impact on clients of being referred through First Link® – based on observations/stories. This data is included in the report findings.

This final evaluation report for *First Link® - Transforming the Dementia Experience in Alberta* presents the findings related to the outcomes in the grant agreement with Alberta Health. A description of key learnings (e.g. project challenges and enablers, adaptations made to continually improve program implementation, and alignment with Alberta Health priorities) are provided, followed by leader reflections on sustainability. The final section of the report provides conclusions and recommendations.

Findings – Progress on Outcomes

1. **Outcome: Enhanced linkages between AS AB/NT, AS Calgary and:**
 - **Primary Care Physicians diagnosing Alzheimer Disease and Related Dementias (ADRD)**
 - **Diagnostic and treatment services (specialized geriatric and mental health services)**
 - **Community service providers**

1.1 Relationship Between AS AB/NT and AS Calgary

Prior to 2004, there were several independent Alzheimer Societies in Alberta. In 2004, after months of negotiations and discussion, independent societies amalgamated to form the AS AB/NT. The Alzheimer Society of Calgary chose to remain independent and remains a separate entity today.

Although the Calgary Society is independent, the relationship between the two organizations is positive, and collaboration occurs whenever possible. An example of this collaboration is the successful expansion of the First Link® program into the Calgary Health Zone, something that was not considered feasible a few short years ago. Over the past three years, the CEO and Provincial Lead Client Services of AS AB/NT, working with the Executive Director and First Link® lead of AS Calgary to support First Link® processes, has resulted in greater collaborative efforts in other areas, for example, sharing best practice for programs and services, staff training in new programs such as “Opening Minds through Art”, and sharing political action strategies. However, the greatest benefit of the relationship between the two organizations is that today, all residents of Alberta now have the opportunity to access to First Link® referral and programs and support services.

The mandates of the two Societies remain distinct, but AS Calgary and AS AB/NT believe that both organizations work to improve the quality of life for those living with dementia, and to that end, the organizations cooperate on various initiatives including support of the Alberta Dementia Strategy and Action Plan, raising awareness of dementia, and other initiatives.

1.2 Referrals

The primary indicator of enhanced linkages is the number of direct referrals to the Alzheimer Society from providers including primary care, specialized geriatric services and community services. Direct

referrals are referrals that the Alzheimer Society receives directly from a health care professional or community partner, whereas self-referrals are when an individual finds the Society and its services on their own (e.g., through the phone book, from a friend, and calls or emails).

As depicted in Figure 1, the trend of an increasing number of direct referrals reported in the interim evaluation has continued. The number of direct referrals has consistently increased over the last five years from 496 in 2014 to 1,517 in 2018 representing a 206% increase. This increase would be expected with the addition of AS Calgary to the program. However, even with the Calgary Region removed, referrals consistently increased each year with 1,144 direct referrals made in 2018 (a 131% increase). Calgary Region direct referrals increased six-fold from 57 in 2016 to 373 in 2018. Edmonton Region continued to have the largest number of direct referrals (n=727) followed by Calgary (n=373), then central Region (n=223).

The number of self referrals has also increased over time with a dramatic increase in 2016 because AS Calgary was brought into the initiative. However, even when the Calgary Region’s numbers are excluded, self referrals have continued to rise (628 to 988). In the Calgary Region the number of self referrals has decreased from 1685 in 2017 to 1661 in 2018. Calgary Region continues to have many self referrals (many more than direct referrals compared to other regions in the province where direct referrals are higher than self referrals). This is because First Link® is much newer in the Calgary Region.

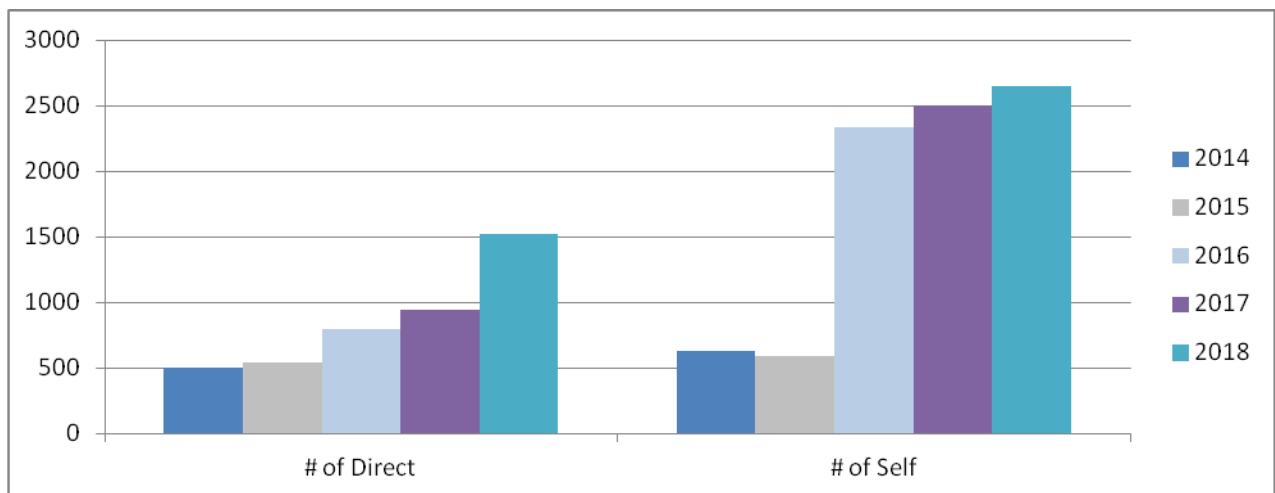


Figure 1: Number of Referrals by Type

The primary source of referrals continues to be specialized services, followed by community services and then primary care (see Table 3). Specialized services include geriatric assessment units (the majority within the category), specialists and nurse practitioners; primary care providers include both providers and primary care networks (PCN) (primary care networks are the majority within the category); and community services includes home care, (the majority in the category), dementia advice line, community residences/lodges, pharmacy, and emergency.

Specialized services have always been the primary source of referrals which is not surprising as the Alzheimer Society has strong relationships with geriatric assessment units and specialists that work with patients with dementia. Referrals from both primary care and community services have increased over time, with the number of referrals from community services more than tripling since 2017 due to an increase in referrals from home care.

The Alzheimer Society has been actively working to increase referrals from other sources, particularly primary care and home care. In the Edmonton Region where referrals from home care have increased significantly in the last year (n=61 in 2017 to n=246 in 2018), staff noted that Alberta Health Services was developing the home care program and linkages in 2017 were not possible, however, early in 2018 “the doors were opened” and Alzheimer Society staff were able to connect with 120 case managers with the results being a large rise in referrals in 2018. Other regions noted that they have been networking more with home care and continuing to build relationships which has resulted in more referrals from this sector.

In terms of primary care, in Central Region, AS AB/NT staff were invited to participate as a partner in the Primary Health Care Integrated Geriatric Initiative (PHC IGSI) in 2016. The goal of the PHC IGSI is to enhance capacity to recognize, diagnose and provide ongoing care and support for people living with dementia or other geriatric syndromes in community. The service is incorporated within PCNs in Central Region. A series of educational workshops were created aimed to increase capacity within primary health care (PHC) to support people living with dementia and their care partners. The education provides practical information covering dementia and frailty from timely recognition of dementia to end-of-life care, and focuses on proactive, personalized support throughout the dementia journey.

Central Region staff’s work with the PHC IGSI has demonstrated AS AB/NT as being an integral part of providing a more integrated model of care for seniors. As a result of this work, the credibility of the Society has increased in the eyes of Alberta Health Services and the communities where this service is offered, particularly related to supporting the psychosocial needs of people living with dementia and their care partners. The fact that there is growing willingness/readiness among primary care providers and PCNs to work in collaborative models has helped to increase the number of referrals from this group of providers.

Another enabler that has facilitated increased referrals is the establishment of program assistant positions in some regions, which has freed up staff time to do more outreach to promote First Link®.

Despite the gains made in reaching more primary care and community services, challenges in reaching these providers documented in the interim report continue in some regions (e.g., obtaining access to primary care providers is difficult due to their busy schedules; some primary care providers appear to be uncomfortable with referring potential clients as they do not diagnose patients and therefore refer to specialized services first).

Table 3: Source of Direct Referrals

	2014	2015	2016	2017	2018
Specialized Services	321	326	441	589	886
Primary Care Services	97	87	179	196	224
Community Services	28	48	153	110	341
Other/Missing/Unidentified	50	76	20	46	66
Total	496	537	793	941	1,517

During the past two years the First Link® referral form has been adapted and standardized across the province and First Link® materials updated to ensure consistency. In addition, website pages specific to First Link® have been created to ensure a “one stop” information centre related to First Link®.

1.3 Outreach

Outreach is a key activity of the First Link® referral process to help build awareness and understanding about the process among various stakeholders, in particular, potential referral sources. The definition of outreach is provided in the following text box.

Outreach – Promotion of First Link®

The goal of outreach is to raise the profile of and promote First Link®. 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 encourage potential referral sources to connect clients to the Alzheimer Society, specifically, First Link®.

As reported in the interim evaluation report, staff consistently discussed the importance of relationship building (described below within *Relationships and Partnerships*) with current and potential referral sources. Outreach activities increased significantly from 95 in 2016 to 251 in 2017 due to AS Calgary joining First Link®. In Calgary, outreach activities decreased from 78 in 2017 to 21 in 2018. Calgary Region was not surprised by this decrease as they reported that they had reached most of their targeted audience in 2017, and therefore had fewer places to go in 2018. Calgary also had some staff turnover in the position that had been leading this work in 2017, which may also explain this decrease. Outreach also fell in the Southern Region from 2017 to 2018 but increased in all other areas.

As reported in the interim evaluation report, conducting outreach and networking activities remains a challenge due to the increasing number of referrals (as previously described) and requirement to follow-up with all direct referrals within 2 weeks of receiving a referral and on an ongoing basis. As a result, staff are spending significant time and effort making follow up calls, connecting with clients through email and one on one visits, leaving less time for outreach and networking activities. Staff remain concerned that given finite human resources/capacity, it is challenging to adequately support clients if more outreach and networking is done.

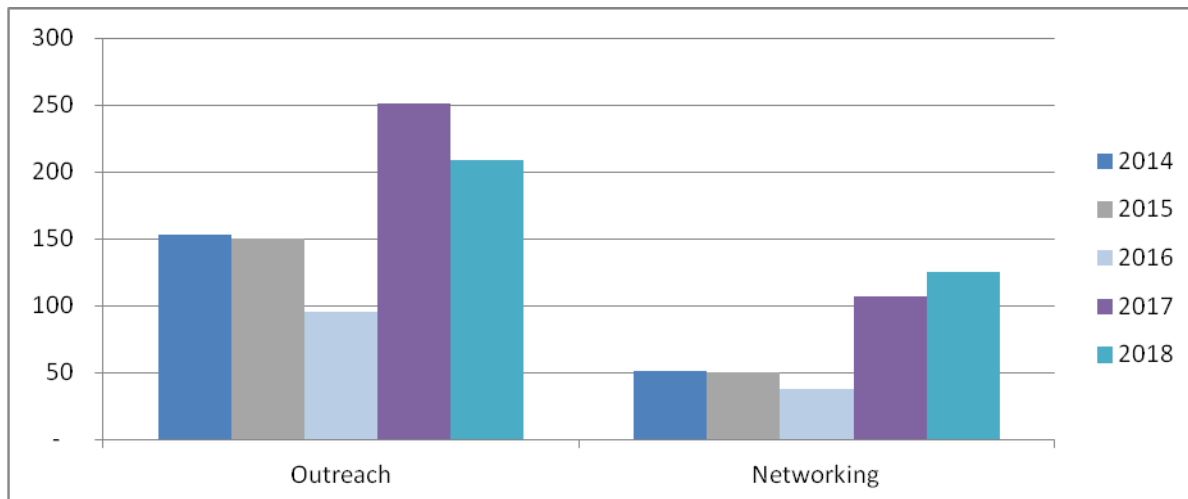


Figure 2: Number of Outreach and Networking Activities

The activities done to promote First Link® and do outreach to build linkages with various provider groups remain the same as reported in the interim report:

- **One to one meetings, emails and/or telephone calls** with diverse stakeholders and organizations who support and connect with seniors and/or people with dementia (e.g., specialized clinicians/units such as geriatricians, senior’s mental health teams.; providers from home care, long term care, FCSS services, supportive living, etc.; rehabilitation services; primary care providers and networks; pharmacists; recreation therapy; First Nation communities, academics and researchers).
- **Presentations** at various venues and to various stakeholders (e.g., specialized clinicians/units such as geriatricians, seniors mental health teams through rounds, conferences, etc.; providers from home care, long term care, FCSS services, adult day programs, discharge/transition planning, supportive living, etc.; primary care providers and networks; students at universities and community colleges from various disciplines such a nursing, medicine, recreation therapy; police; community groups (e.g., religious groups, Salvation Army, senior’s groups, support groups, advocacy groups); First Nation communities; academics and researchers; other not for profit groups; other organizations (e.g., Canada Revenue Agency, Handicapped Bus Services, dementia advice line, Chamber of Commerce).
- **Attending events** (e.g., health fairs, conferences [e.g., Lifeline, integrated primary care]).
- **Promotion through existing partnerships** (e.g., at existing meetings with interagency partners, existing committees, etc.).
- **Distribution of materials** such as the First Link® referral pad, postcard and brochures; information packages about the Alzheimer Society including First Link®; newsletters.

In the focus group, staff noted that while many of the outreach activities have remained the same, they are attempting to be more strategic in their approach (e.g., reaching out to groups of primary care providers versus doing one on one meetings, identifying potential referral sources through current referrers, ensuring that First Link® is woven into all conversations with providers).

1.4 Networking

Another key activity of the First Link® referral process is networking. The definition of networking is provided in the following text box.

Networking - Building relationships to help improve systems of care

The goal of networking is to build and improve 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. 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.

As with outreach, the number of networking activities increased in 2017 as a result of the AS Calgary joining the initiative in 2016 (from 38 in 2016 to 107 in 2017). Networking activities continued to increase in 2018 to 125. During the focus group, it was noted that networking activities help to open the door to promote First Link®.

1.5 Relationships and Partnerships

During the focus group and through the document review, staff were asked to describe enhanced linkages with various provider groups including geriatric services, primary care, and community services. In addition to the enhanced linkages previously described, staff also noted that they continue to receive requests from various organizations and providers (e.g., asked to join groups, do presentations, etc.) which they believe are an indication of enhanced linkages with these groups. Staff also described trying to enhance linkages with more communities, particularly more rural areas, however, they reported lacking the time and resources to do so.

Referrers also described linkages with the Alzheimer Society and the fact that the Society is viewed as a key partner in providing supports for people living with dementia and their care partners. The majority of referrers interviewed described Alzheimer Society staff as key members of the care team.

"I think it's our relationship that's really helped—it's been built by this First Link referral formal process for me, in reaching out to them and using them more than I ever have." (Referrer Interview)

"...in the beginning before we had our elder care program, really our knowledge on dementia and dementia care was pretty minimal. Now, in the last few years we've built our elder care assessment clinic; in partnership [with the Alzheimer Society] we really worked in the beginning with them a lot to build our program. So, our awareness of everything they do has just been so heightened, I just feel like they've really benefited our program, and now we're partners in this going forward." (Referrer Interview)

Specialized Geriatrics

Most of the sites discussed continued building of relationships with specialized geriatrics and noted that these providers are the primary source of referrals. Some sites noted that they have had strong relationships with this sector of providers for many years.

"I have continued to enhance linkages with the Geriatric Acute Care Unit, Recreation Therapy at Alberta Health Services and with the Seniors Best Practice Team." (Document Review)

"We are working with the Seniors Mental Health Team and involving and building relationships with Psychiatrists." (Document Review)

Primary Care

As previously described, in some regions, relationships have been enhanced significantly over the last two years with primary care. For example, participation in the PHC IGSI in Central Region. Other regions also discussed enhanced relationships with primary care and during the interviews with referrers, respondents from this sector noted the importance of their partnership with the Alzheimer Society.

"Another good part I would like to say about the First Link and the Alzheimer's is...it's come back this way as well because they've had people there and then referred to us, which we've been able to take because they've been part of our primary care network... So, it's worked both ways for us, which has been really good, that collaboration and partnership." (Referrer Interview)

Community Services

As previously described, staff in some regions are building relationships with community providers, particularly home care – and the result is an increase in the number of referrals from this sector. In addition to the work done in Edmonton (previously described), Calgary Region has also made inroads in reaching home care. First Link® staff have worked with a Dementia Care Team and Home Care to support a rural home care service. The process began with the Alzheimer Society providing training on dementia and dementia care to the home care staff, followed by monthly meetings to present and review complex cases.

“The overall process [with the Dementia Care Team and Home Care] created opportunities for better understanding of the role of all three services [Alzheimer Society, Dementia Care Team and Home Care] and how they could work together to support clients, as well as providing ongoing information about dementia, dementia care, and resources available to better support people impacted.” (Document Review)

Partnership Requests

It was consistently indicated in the document review that staff continue to receive many requests from a variety of organizations and providers to participate on partnership initiatives, provide presentations, participate in events and conferences, etc. During the focus group, staff noted that given the growing number of requests, they are now ensuring they are strategic in their partnership building (i.e., assessing pros and cons to ensure alignment of goals, etc.)

“We are now assessing partnerships before we participate to evaluate the benefits as partnerships take a lot of time.” (Staff Focus Group)

Increased Linkages in Rural and Remote Areas

Some of the regions discussed continued work to enhance linkages in rural areas, although having time and capacity to reach rural communities was consistently noted as a challenge in the document review and in the focus group with staff.

“Focused efforts on a certain geographic area that had not traditionally been targeted or received fewer referrals.” (Document Review).

Dementia Advice Line

In the last two years, work has been done to strengthen the relationship with the dementia advice line, which was launched in May 2016 to support Albertans living with dementia and for those caring for someone who has dementia including Alzheimer’s disease. Dementia advice is available through Health Link and can be accessed by dialing 811. This has resulted in a growing number of referrals from this service. During the interview with the dementia advice line staff, the importance of this relationships/ partnership was discussed.

“When I make referrals to First Link, I really believe that they’re going to be well cared for.” (Referrer Interview)

2. Outcome: Increased understanding and awareness among family physicians and allied health professionals of the:

- Assessment and management of ADRD
- Role of AS AB/NT and the AS Calgary and the First Link® program, and
- Other community resources for individuals with dementia and/or their caregivers/care partners

2.1 Increased Awareness and Understanding – Providers

The document review revealed the various activities that were conducted to build awareness among providers about the role of the Alzheimer Society and First Link® program and community resources available, and to increase understanding of dementia care. These activities included outreach and networking, presentations provided to various groups and providers about available supports and dementia care (e.g., tips and techniques for working with people living with dementia and their care partners), provision of resources to providers, meeting with and participation on various groups (e.g., interagency committees, meetings with PCNs, etc.), participating in conferences and workshops, and provision of training for some provider groups (e.g. home care) – which was previously described.

Although evaluations of training programs were not part of the current evaluation, staff shared that anecdotally they receive positive feedback from providers who have participated in training. For example, In Edmonton where staff offered 12 education sessions to home care, it was noted by participants that the training had helped to build their awareness and knowledge about dementia care. In Calgary Region, home care staff who participated in the training provided by Alzheimer Society staff were surveyed at the end of the session. There was a total of 45 participants in the training with 44 surveys completed. Eighty five percent of participants indicated that their knowledge of Alzheimer’s disease and other dementias had increased and 83% indicated they had increased their knowledge of strategies for caring for someone with Alzheimer’s disease or other dementias.

The interviews with referrers also helped to assess whether awareness and understanding of available resources (from the Alzheimer Society and other community organizations) had improved. Just over half of respondents indicated that through the First Link® process, they had increased their understanding of the role of the Alzheimer Society and its resources, as well as available community resources for individuals living with dementia and care partners. For those who indicated that their awareness had not increased, the primary reason was that they were already aware of available resources given that they had been working in the field of dementia care for many years.

“I wasn’t familiar with anything more than what I saw on the website when it came to what they offered for services, until I went actually to the Alzheimer’s Society and went to shadow one of the employees who works there, and their process of receiving the referrals that they get from us, and the follow up calls that they do, and what that looks like when they have people that come in and discuss things like power of attorney and personal directives.” (Referral Interview)

“Yes, it did for sure [build awareness of Alzheimer Society programs and services] ...in terms of the ASANT Café...the online services, some of the blogs, the videos the families can watch, different things like that...I think it’s broadened our practice and also helped us in terms of when we talk to people, there’s so many resources that people have in the community. Some of them are small or support groups, or volunteers driving seniors that people

are aware of, not just through the First Link, but through the groups of the Alzheimer's Society. And the people come and tell us, oh by the way, do you know there's this group they have set up in this small community? And we'll say, oh, well we'll look into that..." (Referral Interview)

"I would say that I had a fairly, not quite robust, but a fairly decent awareness of the various programs available, both through the Alzheimer's Society and the community-at-large. I would not say First Link changed that substantially..." (Referral Interview)

Referrers were also asked if their knowledge about dementia care had increased as a result of their interactions with the Alzheimer Society through First Link®. About half of the respondents indicated that they had increased their knowledge about dementia care because of their connection to the Alzheimer Society. Similar to the findings about increases in awareness of resources, those who indicated that their knowledge of dementia care had not increased, noted that this was because they already had significant knowledge and expertise given their education and work in the field.

"Yes, and so then just increasing my knowledge and in turn, I'm able to share that with clients. And in particular, just quickly thinking, I know that the one thing they helped with was behavior management strategies and providing me with worksheets, and then just talking to me about it, what their experience has been, what's worked and why. So, that was very helpful..." (Referrer Interview)

"...I think that on our unit, we have four physicians, and we have some behavioral specialists, and so they are very up to speed on disease and symptoms, and all of that. So, they're very forthcoming on that, so I don't typically look to the Alzheimer's Society for that information. It's more, how can you help people understand this and work through this?" (Referrer Interview)

During the focus group, staff noted that the increased number of direct referrals that they are receiving is a sign of increased awareness and understanding of Alzheimer Society programs and services, and that the Society is viewed as a credible source of information and support. This assertion was affirmed in the interviews with referrers, as some respondents indicated that they refer their patients and care partners to the Alzheimer Society to ensure they receive credible and consistent information.

"There's a lot of information out on the internet and things like that, and sometimes families and patients ask if they should do their own research. But I always push evidence-based research and things that are valid. So, the Alzheimer's Society is a resource they can use where, what information they're getting is factual and useful." (Referrer Interview)

"I like them to get credible information and make sure that they're connected to the best resource to answer questions and provide connection to somebody who has experience, or more knowledge than they currently do." (Referrer Interview)

The fact that providers and other stakeholders reach out to the Alzheimer Society for information, as well as to participate on partnerships/initiatives (previously described in the section on *Relationships and Partnerships*) is another sign that the Society is viewed as a valuable partner and helping to contribute to increased awareness and understanding about dementia care in the province. The interviews with referrers confirm this as respondents consistently noted that referring clients to the

Alzheimer Society is of great benefit to their practice as it gives them “peace of mind”. The Alzheimer Society is contributing to comprehensive and effective care for patients and providing invaluable supports for care providers.

“I send the referral, and then I am able to go check and move onto the next task that I have to complete. So, just knowing that they are going to take that ball and run with it is a relief to me, knowing that the family member is going to have whichever support they choose to have—whether it’s none or whether it’s a whole bunch. And I know that that’s being assessed by the folks that do the First Link program, right, so it’s an area that I can cross off my list of things to do.” (Referrer Interview)

“I just get follow up through the Alzheimer’s Society saying, hey, we’ve connected with so and so, and we’ve got them coming to this program and that program. And it’s like, oh thank goodness, I know they aren’t sitting at home anymore, and that care partner has relief...” (Referrer Interview)

2.2 Community Partners Engaged

As in the interim report, staff consistently described how they work with interdisciplinary providers from a variety of organizations/ sectors (e.g., specialized clinicians, primary care, long term care, community organizations) to support Alzheimer Society programs and, also to build their awareness and understanding about available services/supports through the Society. For example, partners are engaged to help with programs such as Seeds of Hope and Support Groups, and staff have worked with PCNs to host First Link® Connections.

“We have connected with recreation centres and fitness instructors to offer the Minds in Motion program...we are connected with a PCN to delivery First Link Connections and plan to connect with additional PCNs for this purpose.” (Document Review)

“Relationship enhanced with [name of senior’s group] through conference and First Link® co-facilitation of 8-week COMPASS support group. Staff also provided with Navigator Training through Caregivers Alberta and linkages established with this organization.” (Document Review)

3. Outcome: Increased understanding and awareness among individuals with dementia and family members/care partners of:

- **ADRD**
- **Community resources**
- **Coping strategies and care skills for caregivers/care partners**

3.1 Follow-up and Contacts

A key feature of First Link® is the follow-up provided by Alzheimer Society staff after receiving a direct referral. The first contact is provided within two weeks of receiving a referral and at points in time thereafter. Through these contacts, clients (people with dementia and care partners) are provided with information and education and linked to other supports and services (both Alzheimer Society and other community supports). The staff also help clients to plan and problem solve issues throughout their dementia journey.

As reported in the interim evaluation, the number of contacts (includes phone, visit, email support and follow-up attempts) has continued to increase over the four years. Figure 3 illustrates that the number of contacts has more than tripled since 2014 from 4,585 to 16,815, representing a 267% increase (n=12,230). The number of clients reached (unique cases) also increased from 1,538 to 6,335 between 2014 and 2018, which is a 312% increase (n=4,797), as has the number of hours spent with clients. The addition of the Alzheimer Society of Calgary in 2016 to the program is one reason for the increase, however, even with Calgary numbers removed, there were increases in all areas (e.g., an increase in contacts from 4,585 to 12,248; an increase in individuals reached from 1,538 to 4,993; and an increase in hours spent with clients from 1,818 to 4,370)

The number of communities reached increased from 179 in 2014 to 304 in 2018. Regions have continued their efforts to reach rural and remote areas of the province, but as previously noted, given available time and resources, it is challenging to expand current work in this area. In addition, as previously described, the Alzheimer Society of Calgary was brought into the initiative in January 2016 and has progressively worked to reach communities outside of the urban core of Calgary.

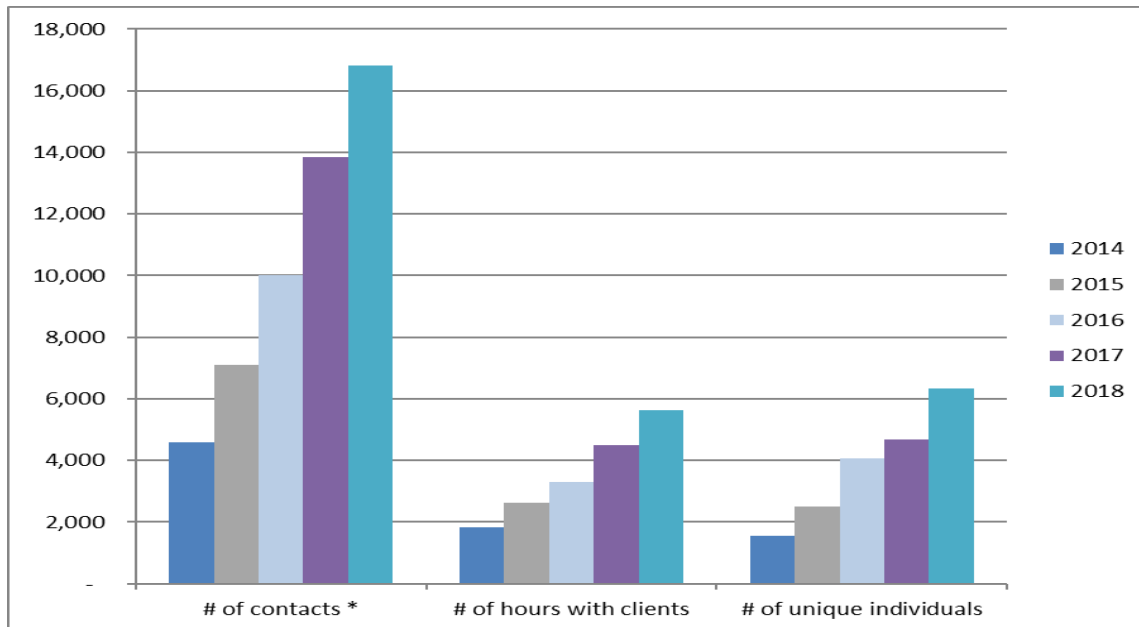


Figure 3: Client Contacts

As depicted in Figures 4 and 5, most clients are care partners (80% to 90%) and female (about three quarters) - and these trends have continued since 2014.

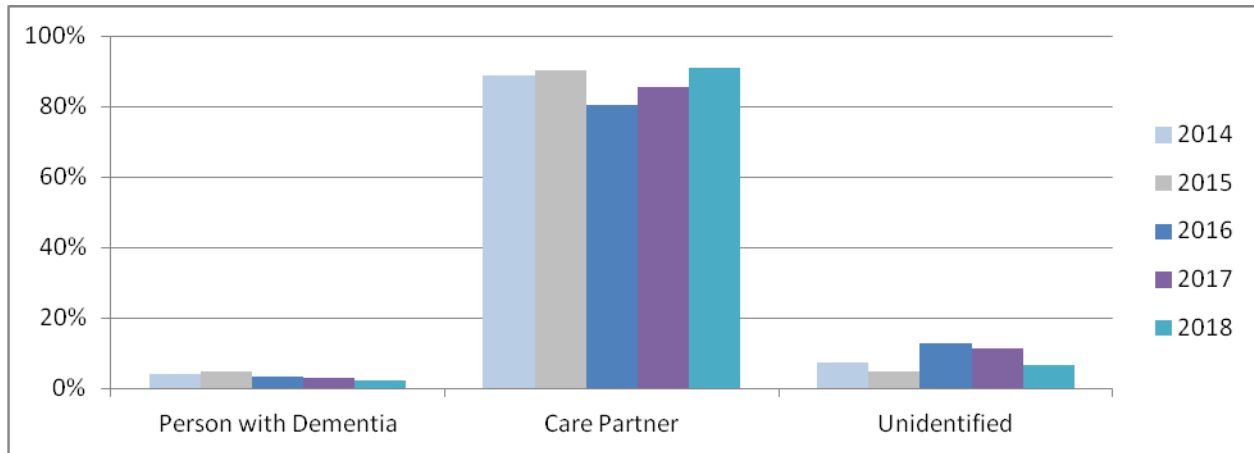


Figure 4: Types of Clients

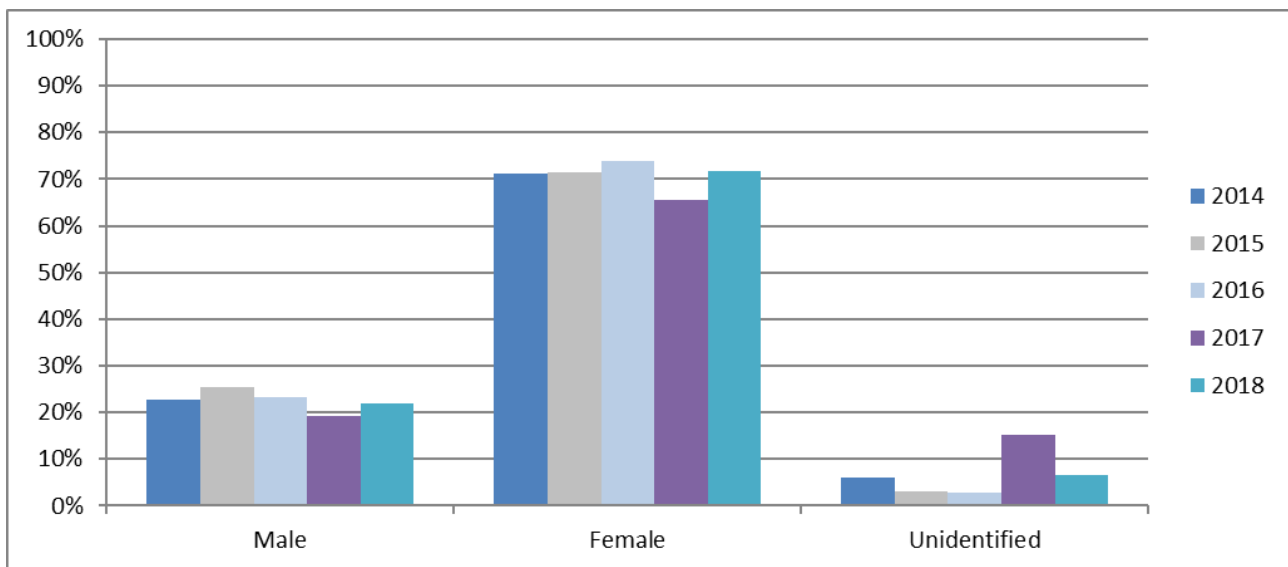


Figure 5: Client by Gender

3.2 Programs

Once a client is referred to the Alzheimer Society, staff reach out to the individual and work collaboratively with the person to determine what information and supports are required. The Alzheimer Society also reaches the broader community and public through presentations, newsletters, community events, and social media.

Tables 4 and 5 provide the number of learning series and support groups offered by AS AB/NT from 2015 to 2018, including number of unique individuals and communities reached. As illustrated, the numbers increased significantly in 2017 after the Alzheimer Society of Calgary joined the program. In 2018, the number of learning series and communities reached was about the same, although more individuals were reached. The number of support groups increased slightly in 2018 as did the number of individuals and communities reached.

Table 4: Learning Series

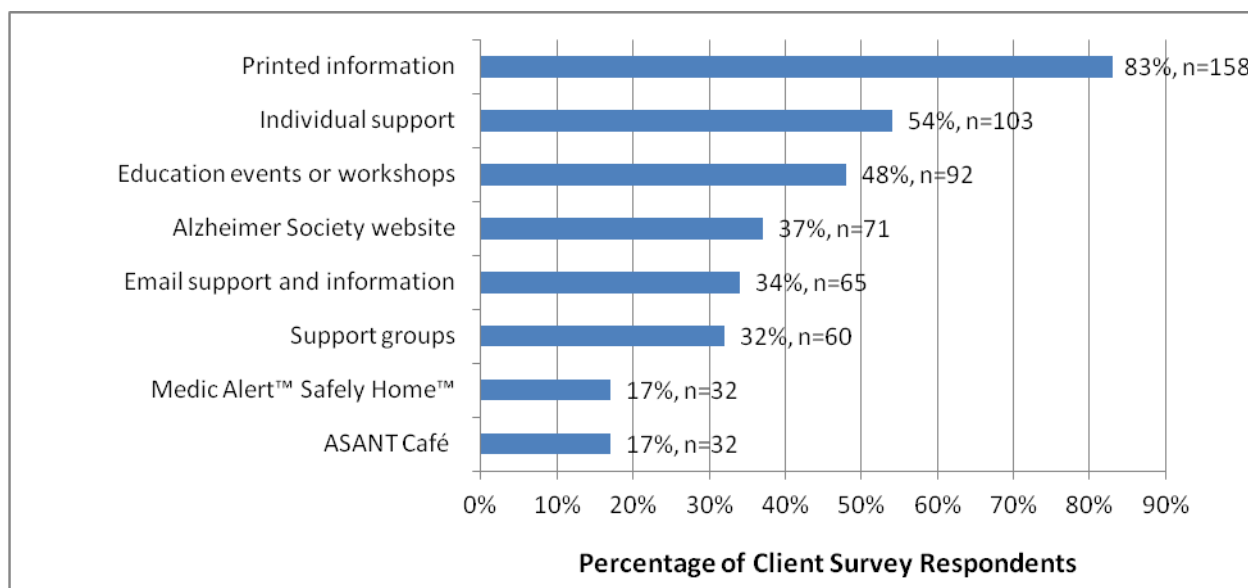
	2015	2016	2017	2018	Total
# of Learning Series	10	9	33	35	87
# of Unique Individuals	73	110	223	404	810
# of Communities Represented	8	17	28	29	82

Table 5: Support Groups

	2015	2016	2017	2018	Total
# of Unique Support Groups	29	39	52	59	179
# of Unique Individuals	524	598	920	1,040	3,082
# of Communities Represented	58	63	92	98	311

Another program offered by AS AB/NT is First Link Connections, provided in two regions of the province. The number of unique individuals reached continued to increase - **306 in 2015 to 618 in 2018** through this service.

On the client survey, participants were asked what resources they had used since being referred to the Alzheimer Society. As illustrated in Figure 6, printed information was most often used followed by individual support groups and education events or workshops. The Medic Alert Safety Home and ASANT Café were used least often.

**Figure 6: Resources Used**

On the client survey, respondents were asked about the usefulness of the information provided with 91% agreeing (40%, n=75) or strongly agreeing (51%, n=97) that the information and support provided by the Alzheimer Society were practical and focused on their personal situation.

During the referrer interviews, respondents were asked about the benefits of referring patients and care partners through First Link® to the Alzheimer Society. All respondents indicated that the wealth of resources available through the Alzheimer Society are in invaluable support (e.g., support groups, print information, individual sessions and online supports). As previously noted, the information provided through the Alzheimer Society is credible and consistent. Further, the supports connect patients and

care partners with others experiencing similar issues and fill a gap in service given that many providers do not have the time to address - the psychosocial needs of patients and families.

“I have grown to appreciate so much more what those specific workers there do behind the desk when they make that phone call out. Listen to them compassionately, very unrushed—they have only one thing in mind, and that’s just to be the detective, to find out how it is that they can help. And sometimes, they like us, when they talk to that caregiver, they don’t know, the caregiver doesn’t even know what they need. And so, the team working at First Link, they’re very good at what they do in streamlining specific, individualized care for that caregiver. And yeah, I think that they’re an amazing group. I really and truly do.” (Referrer Interview)

“I don’t know where we’d be without First Link and the Alzheimer’s Society. They are absolutely essential. We’ve got great people here... They just are excellent with families, and you see it because the families just, once they go there, they’re hook, line and sinker. Then they realize, this is their support system, and this is where their people are. And they’re just a great group of people. They’ve got great staff, and it’s an essential service.” (Referrer Interview)

“...from a clinic standpoint it just helps fill that gap, and just really takes some of the management piece off of our shoulders because we’re already managing many other things, specifically the medical issues that are going on. So, that really helps with the psychosocial aspect of the patients’ care.” (Referrer Interview)

3.3 Increased Awareness and Understanding – People with Dementia and Care Partners

Awareness of Supports and Services

On the client survey, respondents were asked questions related to their awareness of supports and services and as illustrated in Table 6, overall there was high level of awareness of support and services available through the Alzheimer Society (95%, n=174). There was also high awareness about supports and services in the community (92%, n=169) and how to access the supports (89%, n=165).

Table 6: Awareness of Supports and Services

Statement	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Through being referred to the Alzheimer Society, I feel I have increased my knowledge about supports and services available through the Alzheimer Society.	1.1% (n=2)	0.5% (n=1)	3.3% (n=6)	40.4% (n=74)	54.6% (n=100)
Being referred to the Alzheimer Society has made me aware of available supports and services in my community.	2.7% (n=5)	1.1% (n=2)	4.9% (n=9)	28.6% (n=53)	62.7% (n=116)
Being referred to the Alzheimer Society has provided me with information about how to access available supports and services in my community.	2.7% (n=5)	1.1% (n=2)	7.0% (n=13)	31.9% (n=59)	57.3% (n=106)

* N/A removed as very small #

Referrers were asked to describe any impacts of the First Link® referral process, with some describing how being linked with the Alzheimer Society had helped clients learn about available supports as well as providing care partners with strategies for managing their loved ones with dementia.

“...just knowing more of the ins and outs of the disease process. Knowing what supports are available, and just linking other people up with the caregivers. I think those are probably the main points that I think are the most helpful because again, things crop up that you don’t actually expect, or family members of other patients will have a different perspective on how to help manage patients with dementia. And so, I think that’s what people get the most benefit from.” (Referrer Interviews)

“I know at the Alzheimer’s Society, sometimes people come back and they’ll say you know, the Alzheimer’s Society asked us whether we could get the social worker or somebody to help with exploring access to other benefits, like through the veteran’s groups, Veteran’s Affairs, or also there are some benefits that people in Alberta are entitled to, and many people do not know the special needs assistance to get some adaptive aids.” (Referrer Interviews)

Enhanced Coping and Reduced Stress

The client survey revealed the being referred to the Alzheimer Society has helped them to cope with their situation (85%, n= 157 agreeing). There was slightly less agreement from respondents that they had learned new coping skills that reduced their stress (70%, n=125) and that they had become more at ease in asking for support from family members or friends (71%, n=126).

Table 7: 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, I feel I am better able to cope with my situation.	2.7% (n=5)	2.7% (n=5)	9.2% (n=17)	36.4% (n=67)	48.9% (n=90)
Through being referred to the Alzheimer Society, I have learned new coping skills that have reduced my stress level	1.1% (n=2)	2.8% (n=5)	25.8% (n=46)	33.7% (n=60)	36.5% (n=65)
Through being referred to the Alzheimer Society, I have become more at ease in asking for support from family members or friends.	1.7% (n=3)	2.8% (n=5)	24.3% (n=43)	40.7% (n=72)	30.5% (n=54)

Providers who have referred to the Alzheimer Society through First Link® described how the supports/services had helped their clients and their families to cope with the disease and decrease their stress levels. Some described how the connection to the Alzheimer Society was helping families keep their loved ones at home longer.

“And we find the stress level goes right down [after being referred to the Alzheimer Society]. A lot of people who we talk to, their stress and their depression scores are so high at this first point of contact, that by giving them some hope through the staff at First Link, knowing that that’s just going to be an ongoing dialogue with them as well as with us, we can sense that their stress is down and that they feel more and more supported through the journey.” (Referrer Interview)

“...90 percent of the referrals that come in and people that we assess have some sort of either cognitive impairment, diagnosed dementia, or we’re diagnosing dementias, and that support that is provided by First Link is

very vital in our view of keeping seniors well and at home, and as independent as long as it is safe to do so. And so, that source of support to both the client, and more so the family or the caregivers, is what's really important.”
(Referrer Survey)

“I think in some cases, they're able to manage their loved one better at home. So, they're really looking into, like some of my families have really looked into what is the best approaches that they need to be taking for their loved one that is still living in the home. And then they're modifying their own sort of approaches to their loved ones to make things better, reduce agitation and that sort of thing...and then there's less medication maybe being used because they're doing as much as they can to support the person at home. And this is with the better understanding of the whole dementia process. I think they're able to last longer in the home.” (Referrer Interview)

A few referrers shared stories of the significant impact that being referred to the Alzheimer Society had on both those living with dementia and care partners including giving them confidence to manage their illness as well as hope for the future.

“...the wife with the early onset dementia is one of the people that I ended up talking to, and she understood the diagnosis meant that this was a terminal brain failure that she was having, and it was going to get worse. And her husband then learned what the Alzheimer's Society was all about, and how through the journey no one knows how fast things will progress, or the direction of situations are going to take them down certain roads. So, I reassured them that the Alzheimer's Society could be utilized in whatever capacity they needed along the way...And when I had called back 30 days later, they said that somebody from First Link had contacted them, and they were both very excited. And from the sweet woman with dementia, she had said to me, you would not believe, they're going to ask me to speak in front of other people, and she had a teaching background, and I'm going to be able to tell them where I'm at with this diagnosis, with living with dementia. And it gave her such confidence, such empowerment, that she isn't a write-off, as she thought she was. She thought that this was the end of the road. She was reaffirmed that she would be okay to be playing with her grandchildren at family gatherings... when I make referrals to First Link, I really believe that they're going to be well cared for...” (Referrer Interview)

“...she's had one-on-one help, she's gone to all kinds of classes and in-services, and she's got one-on-one assistance from them. And she's come from someone who, all she does is cry, to becoming now able to laugh and cope, and is now extending her help to other people. So, I mean, the resource is wonderful.” (Referrer Interview)

“It's a young lady whose mother has early onset Alzheimer's disease, and this young lady was involved with the Alzheimer's Society I think fairly early on in the diagnostic and evaluation process. And tragically the patient, this young lady's mother has a genetic mutation which this young lady herself has now been found to have, and she's gone from, with the support, she's basically a poster child for the Alzheimer's Society ...She's gone from being seemingly quite overwhelmed, distraught, completely helpless and powerless, and at a loss to not only deal with her mom's very challenging behaviors and the changes in her mom's cognition, but also the writing being on the wall for her as well, which is quite heart-wrenching and devastating. She's gone from that to being somebody who seems fully accepting of the fact that nothing is set in stone, or that everything is fleeting. She's more confident, she's more assured, she's more at peace, and I mean, I shudder to think what would have happened to her without the Alzheimer's Society.” (Referrer Interview)

Knowledge and Skills

The vast majority of respondents indicated that the referral to the Alzheimer Society had increased their knowledge about dementia (95%, n=172). Eighty-three percent (n=144) of caregivers indicated that they had learned new caregiving skills as a result of being referred to the Alzheimer Society.

Table 8: Knowledge and Caregiving Skills

Statement	Level of Agreement				
	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
Through being referred to the Alzheimer Society, I feel I have increased my knowledge about dementia	1.1% (n=2)	0.6% (n=1)	3.3% (n=6)	40.9% (n=74)	54.1% (n=98)
Through being referred to the Alzheimer Society, I feel I have learned new caregiving skills	1.1% (n=2)	1.1% (n=2)	14.9% (n=26)	38.5% (n=67)	44.3% (n=77)

Some referrers described improvements in knowledge among patients and care givers as a result of being referrer to the Alzheimer Society.

“...care partners, even people living with dementia are coming to us with more insight and knowledge because they’ve received it through them, or they come in with slightly different questions because whatever they’ve heard, they have another take on it and have another question for a physician.” (Referrer Interview)

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

- More families/care partners linked to AS AB/NT
- Increased participation in AS AB/NT programs and community partners/resources
- Reduced need for crisis intervention

4.1 Collaboration to Support Dementia Care

As was reported in the interim evaluation, staff continue to work collaboratively with organizations and providers to support dementia care.

“We work collaboratively to host support groups in organizations that support seniors...we are coordinating to offer this support.” (Staff Focus Group)

“Working together [with AHS] on complex cases, assisting families to get linked to the right group at the right time...seek clarification on cases, assist each other with education.” (Document Review)

Referrers also consistently discussed how the Alzheimer Society collaborates with an array of providers and organizations and is an integral part of the care team. The referrers consistently indicated that the Alzheimer Society is helping to improve care coordination for their clients.

“...it significantly benefits our team and our extended team, our family nurses in the community because they just give that added support of what is the next step, what is the next step for our patients, and where can they get support?” (Referrer Interview)

“They’re absolutely part of our care team. I don’t think we’d have—well, we’d have to add something onto our program because there’s no educational piece for the family in our program, because we depend on them for that.” (Referrer Interview)

“I feel that it benefits the families certainly in that way, that there’s continuity of care.” (Referrer Interview)

“...or myself as a partner, just having that go to, that information. The staff that I deal with has been amazing, and we’ve developed quite a rapport, which has been very fortunate because that trickles down when you’re dealing with the actual clients as well.” (Referrer Interview)

As previously noted, many referrers discussed how through First Link® their patients and families have greater access to services and that the Alzheimer Society is filling a vital need on the health system and community.

“...you could spend several hours if not days discussing the course of the disease, the prognosis, what to expect going forward, what are some of the management difficulties and the caregiving difficulties that can happen as the disease progresses? And so, the main reason why I refer to the Alzheimer’s Society or the First Link program, is that they can fill in the gap that we have in our clinic setting where we have a limited amount of time spending with patients. The Alzheimer’s Society and First Link, they can spend much more time delving into what the disease is, what to expect going forward, what resources are available in the community, and then specifically supporting caregivers and loved ones of people with dementia.” (Referrer Interview)

“...while there is a fair amount that I try to do myself in the office in the time that I have with my patients and their family members, there’s only so much of me to go around and there’s only so much that I can handle myself in terms of providing that critical piece—like, not just diagnosis and management, but also asking how are you doing with this diagnosis, or what are some actual very practical strategies that they could benefit from to more cope with some of the day-to-day concerns or challenges that they have as the person with the condition or their family members. That’s where I sometimes have some ideas, but really the Alzheimer’s Society is I think in a much better position, better suited and they have the time and the personnel to do a lot better job, and deliver that education and support that I just can’t full stop...” (Referrer Interview)

4.2 Linkages to Community Supports and Services

Respondents to the client survey were asked if they had learned about various support/services through the Alzheimer Society. As depicted in the following bar graph home care, adult day programs and recreation programs were the services that clients most often learned about through the Alzheimer Society.

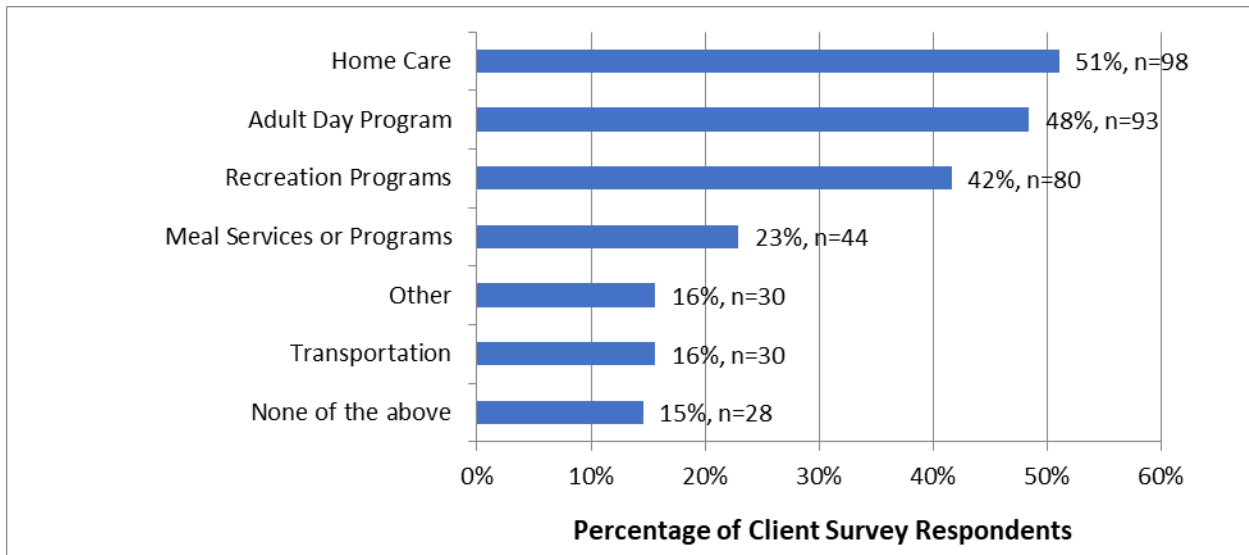


Figure 7: Supports/Services Clients Learned About

Forty five percent (n=63) of respondents to the client survey indicated that they used the community supports/services that were suggested, while 55% indicate they had not (n=76). As illustrated in the following figure, 65% (n=55) of those who did not use the service indicated that they did not currently need it.

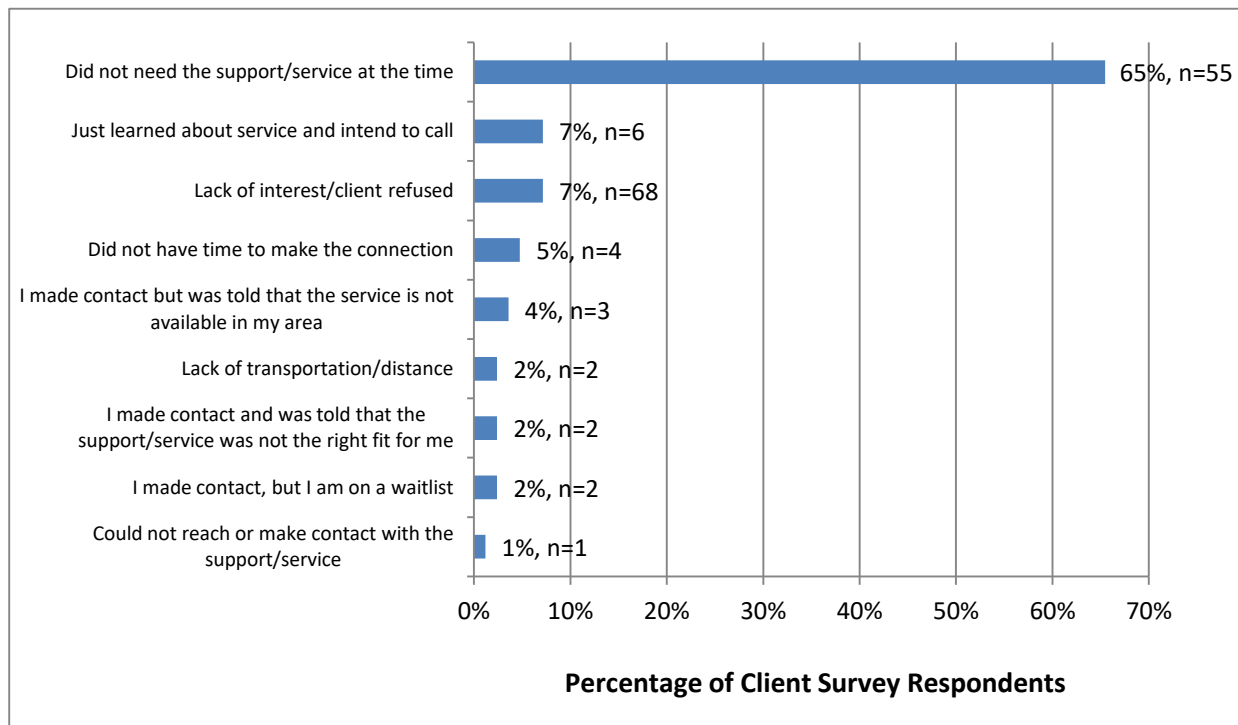


Figure 8: Reasons Clients Did Not Use Suggested Supports/Services

Many of the referrers also described how the referral through First Link® had helped to connect their clients and care partners to community resources/supports.

"...if I make the referral to First Link...I know that other links are made through them, which it's so nice as opposed to me contacting Homecare, me contacting First Link, me contacting adult day support program. Because I know if I get them to First Link, it all disseminates from there." (Referrer Interview)

4.3 Crisis Intervention

On the client survey, respondents were asked if the information and support received from the Alzheimer Society had helped to keep them or their relative from visiting the Emergency Department due to being overwhelmed and not knowing what to do. Close to half (49%, n=88) indicated "yes", 38% (n=68) said they were not sure and 14% (n=26) indicated "no".

Those who indicated yes, were asked to explain, with respondents consistently noting that they had gained knowledge and skills to help them better cope and manage the disease process (e.g., increased their understanding of dementia, increased knowledge about how to better manage behaviours, etc.). It was also noted that knowing that being able to connect with Alzheimer Society staff to problem solve issues has helped to avoid situations escalating into a crisis.

"Instead of panicking, I can use the tools I've learned to cope or alleviate problems." (Client Survey)

"I know that certain concerns and/or situations are not emergencies but only part of the dementia." (Client Survey)

"With the knowledge and information that I have received through various means, I am more confident in my ability to cope and deal with my situation and if I have difficulties for whatever reason, I know I have the support of the Alzheimer Society to help guide and direct me." (Client Survey)

5. Learnings

The following section describes the learnings related to the implementation of *First Link® - Transforming the Dementia Experience in Alberta* as identified through the document review, focus groups with staff and leader reflections. Enablers and challenges are described, as well as adaptation made to continuously improve implementation and/or address the challenges, and work done to ensure alignment with government priorities is also described.

5.1 Enablers

Established Relationships and Credibility

In the focus group with staff and reflections provided by leadership it was consistently noted that the relationships that have been cultivated over the last few years since First Link® was launched, as well as the Alzheimer Society's history with partnership building over many years has been a key enabler to the work of First Link® (this was also reported in the interim report). Staff and leaders indicated that the Society has built credibility and is viewed as a valuable partner in dementia care, which was also affirmed during the interviews with referrers. This is part of the reason that the Society is frequently invited to participate on existing partnerships and initiatives (previously described) which helps to advance their work including First Link®. Staff make every effort to participate on these partnerships/initiatives, and as previously discussed – these relationships are key to achievement of the project outcomes.

“Developing relationships with the other agencies is crucial, through interagency meetings, public presentations, and collaboration on projects. It is all about the relationships!!...and seizing the opportunities. Few relationships are developed over email.” (Document Review)

Other

Other enablers that were identified include:

- **Champions** within government, communities and other organizations who have been important in helping to build awareness and understanding about First Link® within their own organization as well as externally, and are helping to increase the number of direct referrals (e.g., gerontologists, directors in home care and long-term care, academics, etc.) These champions often have high profile and credibility in the community and promote First Link® through their networks and are engaged by the Alzheimer Society to provide presentations or as content experts.
- **Provincial approach** which means that First Link® is accessible to all Albertans who can benefit from the supports. The importance of contracting the Alzheimer Society of Calgary to ensure the service is available across the province was highlighted, however, it was also noted that there is a need to continue to build the relationships given there are two separate organizations.
- **Increased readiness** within communities as some referrers and staff noted that there appears to be less stigma related to dementia and greater interest in the issue and receiving support.

5.2 Challenges

The document review and focus group with staff revealed that some of the challenges reported in the interim report remained the same over the past two years including:

- **Limited human resources/capacity** to keep up with the follow up contacts due to the increasing number of referrals, and competing priorities, particularly for smaller offices that have fewer staff. Further, it is time consuming to network to build relationships and partnerships, and multiple meetings/presentations are required to help build understanding about First Link® and maintain relationships. In addition, there was staff turnover within some regions and staff are more isolated in rural areas.
- **System or partner challenges** such as staff turnover which requires time to build awareness and understanding with new staff and can lead to changing expectations; difficulty engaging some providers/sectors such as primary care and home care due to busy schedules, fear of working in new ways/changing practice, lack of readiness for or awareness of First Link®; lack of support from leadership within some partner organizations; lack of coordination within the system and a provincial network for dementia care
- **Large geography** to serve which is a challenge given the time required to reach rural and remote communities

5.3 Addressing Challenges and Adaptations Made

Strategies were developed to address the challenges identified as outlined in Table 9.

Table 9: Challenges and Strategies to Address

Challenges	Strategies to Address
Lack of Human Resources and Capacity in the Alzheimer Society	<ul style="list-style-type: none"> • Analysis of client services staffing component and adaptations to staff position descriptions to support maximizing the skill sets of staff and ensuring efficient use of resources

Challenges	Strategies to Address
	<ul style="list-style-type: none"> • Adding staff positions to some regional offices to support First Link® • Training sessions for new or junior staff with more senior, experienced staff in regional centres • Yearly all staff in person meetings to build capacity to support implementation of First Link® • Project Implementation Team membership expanded to include all regional leads and the name changed to the First Link® Implementation Team (FLIT), which meets monthly to share learnings including reviewing status reports with summaries of E-Tapestry and iCarol data to problem solve challenges/issues and brainstorm opportunities for improvement • Conducting reviews of client files/accounts to ensure efficiency in follow-up (i.e., removing clients files who had moved or were deceased) • Adapting hours when follow-up calls are completed to include evenings to minimize the number of attempts to reach clients
<p>System or Partner Challenges (turnover, difficulty engaging due to busy schedules, lack of readiness, lack of coordination with the system)</p>	<ul style="list-style-type: none"> • Continuing networking and outreach to potential referrals to promote First Link® given staff turnover in organizations • Implementing regular updates and visits from First Link® staff and provision of presentations to referral sources (e.g., PCNs, Home Care, Dementia Advice Line staff) • Ensuring consistent messaging about the value of First Link® and how referring can save health care professional time and energy (e.g., the Alzheimer Society can support the non-medical issues such as dealing with incontinence, driving cessation, educating about the stages of dementia and how to plan for the future, care partners supports, etc.) • Identifying and connecting with key leaders in referring organizations to build understanding and buy-in • Engaging champions to build understanding about First Link® and the Alzheimer Society and the value of the service and supports (e.g., current and former leaders in Seniors Health Strategic Clinical Network and Alberta Health Services, senior leadership in Alberta Health, regional physicians including geriatricians, dementia researchers in Alberta’s three neuroscience institutes, leaders and key staff in Translating Research in Elder Care, Executive Directors of other neuro-based organizations (e.g., Parkinson Alberta) • Establishing mechanisms for staff to share and discuss strategies to problem solve issues and overcome challenges – First Link® Implementation (FLIT) meetings
<p>Large Geographic Area</p>	<ul style="list-style-type: none"> • Recruiting and training a cadre of volunteers and providing oversight to help grow the number of support groups in areas outside of regional centres • Identifying areas where there are fewer referrals and strategically targeting with outreach • Leveraging available technology, specifically the ASANT Café, to augment program delivery • Creating a lead position for the ASANT Café to grow Café use (webinars,

Challenges	Strategies to Address
	education, live meetings) specific to First Link® programs. <ul style="list-style-type: none"> <li data-bbox="586 268 1406 331">• Leveraging social media to raise awareness of First Link® program opportunities

As previously reported, challenges related to lack of referrals from home care and primary care were addressed over the last two years by focused efforts to partner and connect with these sectors (e.g., PCNs, primary care providers, PHC IGSI, education/training with home care staff, etc.)

Another challenge identified during the interim report was lack of consistency in data entry among staff and data entry errors which posed challenges in terms of using the data to review and improve program processes. Since the interim report, improvements have been made to First Link® data collection, entry and retrieval including consolidating initial client data entry to one person for the province. This staffing change has helped to reduce data entry errors and has also freed up client services staff time to focus on referral follow-ups. In addition, E-Tapestry entry standards learning videos have been created to help build staff capacity. During the focus group, staff described how they are using data from E-Tapestry and iCarol to help plan outreach and networking and to support programming (e.g., sending reminders to those who have not been participating in programs).

During the focus group, staff discussed continued and/or additional supports to facilitate the implementation of First Link® including:

- **Continue to provide opportunities for staff networking and team building** to facilitate sharing of expertise, best practice strategies, ideas, and materials (e.g., presentations, local material resources, etc.); to help problem solve issues; and to support team functioning and building a collaborative culture with staff across the organization and province.
- **Continue to share and utilize reports from E-Tapestry and iCarol** with staff for continuous quality improvement (i.e. so staff can review the data/information to assess their work and continuously improve implementation of First Link® and other work).
- **Continue to promote First Link® at the provincial level** (e.g., place an article in association newsletters such as the Alberta Medical Association, College of Family Physicians, Alberta College of Social Workers, Alberta College of Pharmacists, Alberta College of Occupational Therapists, Alberta College of Speech Language Pathologist and Audiologists, Nurse Practitioner Association of Alberta, etc.; create provincial communication materials, etc.)
- **Expand use of technology** to support follow-up and program implementation (e.g., continue to expand the number of programs provided through ASANT Café, promoting the Café through social media, encouraging staff to promote the Café and documenting how they will incorporate the Café within workplans, explore the use of Telehealth to provide programs and services, etc.).

5.4 Alignment with Government Priorities

The AS AB/NT and AS Calgary have worked to ensure alignment with the Alberta Dementia Strategy and Action Plan (ADSAP). The education, information and services the Society provides to persons living with dementia and their care partners, and to the general public through awareness raising, support the outcomes of the ADSAP. First Link® is the “gateway” to AS AB/NT programs which are designed to support those living with dementia (the diagnosed, their care partner and family) from the time of diagnosis and throughout the progression of the disease. The aim of First Link® is to enable persons to plan for each stage of the disease, live well for as long as possible with dementia, and ultimately to remain in their homes and community longer. These are also aims of the ADSAP – to support individuals impacted by dementia to live well.

Another example of alignment with government priorities is the work with the PHC IGSI in the central health zone, previously described. Recently the AS AB/NT has been contacted by the Westlock PCN to be involved in establishing the first geriatric assessment clinic in that health zone, based on the PHC IGSI model. The partnership with the PHC IGSI has strengthened relationships with PCNs which will continue to expand across Alberta.

6. Project Sustainability

Leaders reflected that the key to sustainable programming is predictable, stable funding. An organization which relies on donations and fund raising to carry out its operations has a difficult time assuring program sustainability. However, throughout the life of the First Link® grant, and as previously mentioned, both Societies have gained insight through experience, and have refined or created new strategies to improve efficiencies and productivity including:

- Continuous outreach to new potential referrers; regular “check in” contact with experienced referrers.
- Creation of standardized materials and forms.
- Creation of a “one-stop” place where First Link® information is available and accessed by referrers and families.
- Flexibility in connecting with stakeholders and use of a variety of methods to engage them in First Link® activities/work.
- Marketing First Link® programs and support services to donors; developing promotion materials for fundraisers and donors specific to First Link®.
- Enhancing the use of technology, especially leveraging the ASANT Café to support First Link® programming
- Using social media to raise awareness of First Link® programs and services
- Increasing the number of grant applications targeted to First Link®

During this grant cycle, some donors (recipients of First Link® programs themselves) asked if their funds could be specifically put toward supporting First Link® programs. The Society is planning to develop a targeted First Link® marketing plan to intentionally seek “First Link®” donors. A focused and targeted plan will ensure donated funds will intentionally assist program sustainability in the future.

Conclusions

1. Enhanced Linkages and Increased Awareness and Understanding among Providers

Outreach and networking activities continue to help build awareness about First Link® and strengthen partnerships at the local level. The contract between AS AB/NT and AS Calgary to expand First Link® in the Calgary Region has increased the reach of the referral service and enhanced the relationship between the two organizations. Enhanced connections with various provider groups and increased awareness about First Link® is illustrated by a 206% increase in the number of direct referrals over the last five years (from 496 in 2014 to 1,517 in 2018).

While outreach and networking are important to help build awareness about First Link® and connecting with potential referrers, they are time consuming activities. Lack of human resources and the increasing amount of time required to support clients (i.e., the increasing number of client contacts and hours spent with clients) remain challenges to doing outreach and networking activities. In addition, many relationships have been established due to the outreach and networking that has been done, and therefore not as much effort is required in this area. To help ensure efficient use of resources, staff are becoming more strategic in outreach and networking activities (e.g., identify groups/audiences to focus on, doing less one on one and more group outreach, targeting leaders in organizations to obtain their buy-in, etc.)

The primary source for First Link® referrals continues to be specialist services (e.g., geriatric assessment units, geriatricians); however, significant growth has occurred in obtaining referrals from primary care and home care. This is due to focused efforts of First Link® staff over the last year and a half (since the interim evaluation) to reach these sectors through collaborative models of care and training other providers. The increasing number of referrals from primary care and home care indicate the benefits of this collaborative work, which is helping to provide comprehensive care to those living with dementia and their care partners.

Building relationships with various providers and organizations is key to supporting First Link®. Many stakeholders reach out to the Alzheimer Society for information, presentations and to participate on initiatives, illustrating that the Society is viewed as a credible source of information about dementia and dementia care, and a valuable partner. Feedback from referrers also illustrate the strong relationships that the Alzheimer Society has with providers and organizations, and that the Society is viewed as a vital part of the health care team.

In building awareness among providers, the focus is on First Link® and the supports available through the Alzheimer Society. This ensures that individuals and families are connected to programs and services as early as possible. The increasing number of direct referrals is a key indicator of the Society's success in building awareness in this regard. Outreach and networking, and training staff from other organizations also helps to build understanding among providers about other community supports and services, as well as dementia care. Knowledge and skills related to dementia care have been built among

providers in other sectors such as home care and primary care. However, some providers have significant experience in the field and therefore already had high levels of knowledge and skills in the area.

2. Enhanced Connections with People with Dementia and Care Partners and Increased Awareness and Understanding

The number of clients reached has continued to increase since the interim report and overall there has been an increase of 312% from 1,538 in 2014 to 6,335 in 2018. This is a direct result of the increased number of referrals. The number of contacts with clients has more than tripled since 2014 from 4,585 to 16,815 in 2018, and the number of hours with clients has also increased. Staff time remains focused on serving clients as this is an immediate need and priority. There is also more individuals and communities being reached through programs such as the Learning Series, Support Groups, and First Link Connections.

Through First Link® and the provision of information, support and education, the Alzheimer Society is helping individuals with dementia and care partners to: connect to programs and services early in the disease process; become aware of available programs and services; understand ADRD; and better cope with the disease process. It appears that enhanced knowledge about dementia among clients living with dementia and their care partners and enhanced skills among care partners is helping clients to remain at home longer. It also appears that the knowledge and skills gained by care partners to better manage problem behaviours and cope with difficult situations is helping to avoid a crisis from escalating and unnecessary trips to the emergency department.

3. Coordination of Care

First Link® and the supports available through the Alzheimer Society are viewed as vital by both clients, and organizations and providers. The Society is viewed as a credible source of reliable and valid information and extends the health care services available to people, particularly psychosocial supports. A referral into the Society through First Link® also helps to connect people living with dementia and care partners with community resources as well as other people dealing with the disease and other dementias. This facilitates people learning from one another and connecting with people who may be experiencing similar challenges. The Alzheimer Society is viewed as a critical part of the care continuum and their programs and services are helping to provide continuity of care.

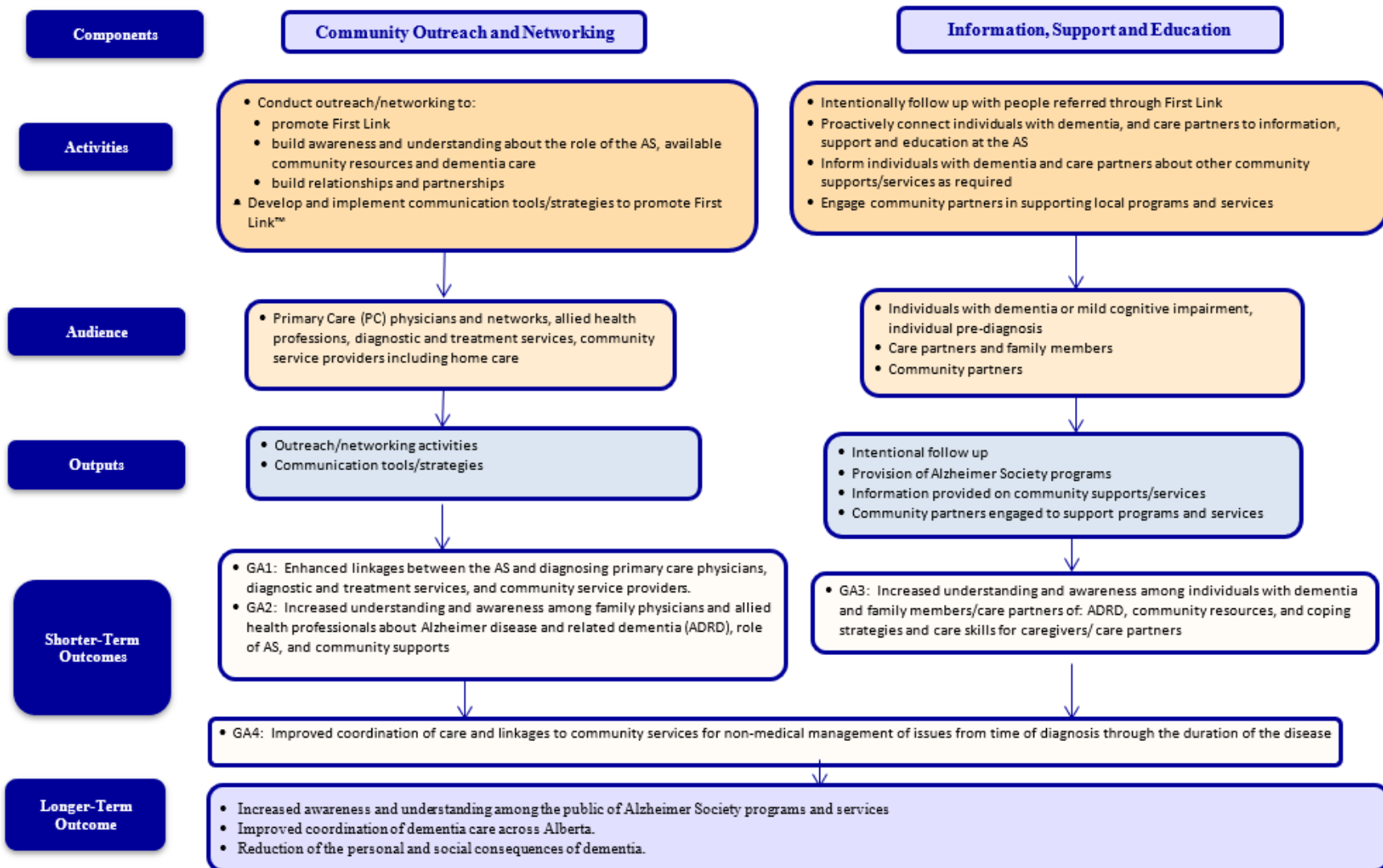
The partnership between AS AB/NT, Alberta Health and Alberta Health Services continues to be critical in helping to support the expansion of First Link®, ensuring quality care, and ultimately supporting people with dementia to remain at home and live well longer. Leaders/staff from Alberta Health and Alberta Health Services along with champions at the local level help to connect the Alzheimer Society and First Link® to system level policies and strategies (e.g., the Alberta Dementia Strategy) and problem solve issues/challenges.

4. Recommendations

Based on the findings from the final evaluation, the following recommendations are provided:

- **Continue to review quantitative and qualitative data** to assess outreach, networking, and program and service delivery (including First Link®) to ensure efficient use of resources and continuous quality improvement.
- **Continue providing supports to client services staff** including networking, training, education and team building opportunities to support First Link® implementation and sustainability.
- **Expand the First Link® service of AS AB/NT into rural areas.**
- **Expand use of technology (e.g., ASANT Café) and social media** to continue to raise awareness of First Link® and offer programs and services to help expand their reach.
- **Continue to diversify mechanisms** used to do outreach and build relationships (e.g., using technology for outreach, targeting groups of providers versus conducting one on one meetings, building champions/ambassadors for First Link®, etc.).
- **Support AS Calgary to expand their reach** to integrate rural communities within their service delivery model.
- **Continue to build the relationship between AS AB/NT and AS Calgary** to leverage opportunities to collaborate on initiatives that improve outcomes for Albertans living with dementia and their care partners.
- **Together with AS Calgary explore strategies to work with partners** to support initiatives related to First Link® support services (e.g. brain health awareness, dementia risk reduction factors, the promotion of dementia inclusive communities).

Appendix 1: Logic Model



Appendix 2: Instruments

Client Survey

Alzheimer Society Programs and Services Client Feedback Survey

As someone who was referred to the Alzheimer Society, we would like your input on our programs and services, so we can improve the way we help people living with dementia and their family members or care partners. The following questions ask about your experiences since being referred to the Alzheimer Society. The questions should only take 10 minutes of your time to complete. Your answers will be combined with the responses we get from other individuals and shared with the Alzheimer Society staff in grouped form. Your name will not be used in any report.

Your input is very important to us. Thank you for helping us to improve our programs and services!

1. I am a: (choose one)

- Person with memory loss, Alzheimer disease or another dementia.
- Care partner and/or family member of a person with memory loss, Alzheimer disease or another dementia.
- Other - please describe: _____

2. I, or the person I am caring for, was referred to the Alzheimer Society within the last (choose one):

<input type="checkbox"/> 6 months	<input type="checkbox"/> 12 months	<input type="checkbox"/> 18 months	<input type="checkbox"/> 2 years	<input type="checkbox"/> More than 2 years
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Since being referred to the Alzheimer Society, I have USED OR RECEIVED the following resources: (choose all that apply)

- Printed information (brochures, fact sheets, etc.)
- Education events or workshops
- ASANT Café (www.ASANTCAFE.com)
- Support groups
- Individual support (telephone or office visit)
- Email support and information
- Alzheimer Society website
- Medic Alert™ Safely Home™

3. Please indicate how much you agree or disagree with each statement:

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
a)	The information and support provided to me by the Alzheimer Society were practical and focused on my personal situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Being referred to the Alzheimer Society has made me aware of available supports and services in my community.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Being referred to the Alzheimer Society has provided me with information about how to access available supports and services in my community.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	As a result of being referred to the Alzheimer Society, I feel I am better able to cope with my situation.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4. Through being referred to the Alzheimer Society, I feel I have...

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
a)	Increased my knowledge about dementia.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Increased my knowledge about supports and services available through the Alzheimer Society.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Not Applicable
c)	Learned new caregiving strategies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Learned new coping skills that have reduced my stress level.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Become more at ease in asking for support from family members or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f)	Become more aware of available community services or resources.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Sometimes people go to the Emergency Department because they are overwhelmed with their caregiving situation and don't know what else to do. Do you think that the information and support you have received from the Alzheimer Society has helped to keep you or your relative from visiting the Emergency Department for these reasons?

- No
 - I'm not sure
 - Yes - please explain: _____
- _____
- _____
- _____

6. Did you LEARN about any of the following community supports/services from Alzheimer Society staff? (choose all that apply)

- Home Care
- Adult Day Program
- Meal Services or Programs
- Transportation
- Recreation Programs
- Other - please describe: _____
- None of the above – You can skip questions 8 and 9 and are done the survey.

7. Have you used the community support(s)/service(s) that were suggested?

Yes

No

8. If no, why did you not use the support/service? (choose one)

Did not need the support/service at the time

Did not have time to make the connection

Could not reach or make contact with the support/service

I made contact, but I am on a waitlist

I made contact and was told that the support/service was not the right fit for me

I made contact but was told that the service is not available in my area

Other - please describe: _____

Thank you for completing this survey!

Referrer Interview Guide

First Link™ Transforming the Dementia Experience in Alberta Project Final Evaluation - Interviews with Providers who have Referred through First Link™

Interview Questions

Introduction and Purpose

A financial grant from Alberta Health is funding First Link®-Transforming the Dementia Experience in Alberta to support the Alzheimer Society of Alberta and Northwest Territories (Alzheimer AB and NT) to expand programs and services and heighten awareness about dementia in more communities in the province of Alberta. Alzheimer AB and NT is partnering with the Alzheimer Society of Calgary to implement First Link® in the Calgary Health Zone.

First Link®-Transforming the Dementia Experience in Alberta is being evaluated to assess the outcomes and to gather feedback about the challenges and facilitators to implementation, and suggestions for improvement.

As a provider who has referred clients (individuals living with dementia and care providers) to First Link®, we value your feedback about First Link®. To help with the analysis of the information, I would like to tape record this interview. The transcript from your interview will be kept confidential (i.e., only consultants from the evaluation firm who is conducting the evaluation will see them). The responses that you provide will only be reported in aggregate (summed together) in the evaluation report, and although individual responses may be used as quotations in the final report, you will not be personally identified.

Do you have any questions?

Do you consent to participate in the interview?

Yes No

Questions

1. Please tell me a little about yourself: where you work (sector and location), your current role, how long you have been referring clients to the Alzheimer Society through First Link?
2. How did you hear about the First Link ® referral process?

3. Why do you refer individuals through First Link® to the Alzheimer Society?

4. In your opinion, how is the First Link® referral process most helpful to patients/clients/care partners? Please describe.
Probes:
 - How has the First Link® referral process benefitted patients/clients/care partners?
 - What impacts, or outcome have you seen as a result of patient/clients/care partners being referred to the Alzheimer Society?

5. How, if at all, has the First Link® referral process benefitted you and/or your practice? Please describe.
Probes:
 - Has the First Link® referral process changed your awareness and/or knowledge about the services and programs offered by the Alzheimer Society? Other community resources available for individuals living with dementia and their care partners?
 - Has the First Link® referral process (or your interactions with the Alzheimer Society) changed your awareness/understanding about the assessment and management of ADRDs? Or build your capacity in dementia care in other ways?

6. In your opinion, how well is the referral process working?
Probes:
 - What is working well?
 - What are the challenges with the referral process/making a referral?
 - How could the referral process be improved?
 - Note for interviewer - areas to explore: the referral package, the referral form, is there enough information, time required to make a referral, acknowledgement of the referral by the Alzheimer Society, overall ease of the process.

7. Do you have any other comments or feedback to help inform the evaluation of the First Link™ Transforming the Dementia Experience in Alberta Project?

Thank you for your time and feedback

Appendix 3: Tables

Client Survey

Table 1: I am a:

Response	% (n)
Person with memory loss, Alzheimer disease or another dementia	4.0% (n=8)
Care partner and/or family member of a person with memory loss, Alzheimer disease or another dementia	94.9% (n=188)
Other	1.0% (n=2)
Total	100.0% (n=198)

Table 2: I, or the person I am caring for, was referred to the Alzheimer Society within the last:

Response	% (n)
6 months	38.6% (n=76)
12 months	27.4% (n=54)
18 months	13.7% (n=27)
2 years	9.6% (n=19)
More than 2 years	10.7% (n=21)
Total	100.0% (n=197)

Table 3: Since being referred to the Alzheimer Society, I have USED OR RECEIVED the following resources

Response	% (n)
ASANT Café	17% (n=32)
Medic Alert™ Safely Home™	17% (n=32)
Support groups	32% (n=60)
Email support and information	34% (n=65)
Alzheimer Society website	37% (n=71)
Education events or workshops	48% (n=92)
Individual support	54% (n=103)
Printed information	83% (n=158)
Total Respondents	n=190

**Respondents could select more than one response.*

Table 4: Please indicate how much you agree or disagree with each statement:

	Statement	Level of Agreement				
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a	The information and support provided to me by the Alzheimer Society were practical and focused on my personal situation.	2.7% (n=5)	0.5% (n=1)	4.8% (n=9)	39.7% (n=75)	51.3% (n=97)
b	Being referred to the Alzheimer Society has made me aware of available supports and services in my community.	2.7% (n=5)	1.1% (n=2)	4.9% (n=9)	28.6% (n=53)	62.7% (n=116)
c	Being referred to the Alzheimer Society has provided me with information about how to access available supports and services in my community.	2.7% (n=5)	1.1% (n=2)	7.0% (n=13)	31.9% (n=59)	57.3% (n=106)
d	As a result of being referred to the Alzheimer Society, I feel I am better able to cope with my situation.	2.7% (n=5)	2.7% (n=5)	9.2% (n=17)	36.4% (n=67)	48.9% (n=90)

Table 5: Through being referred to the Alzheimer Society, I feel I have...

	Statement	Level of Agreement				
		Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
a	Increased my knowledge about dementia	1.1% (n=2)	0.6% (n=1)	3.3% (n=6)	40.9% (n=74)	54.1% (n=98)
b	Increased my knowledge about supports and services available through the Alzheimer Society.	1.1% (n=2)	0.5% (n=1)	3.3% (n=6)	40.4% (n=74)	54.6% (n=100)
c	Learned new caregiving skills	1.1% (n=2)	1.1% (n=2)	14.9% (n=26)	38.5% (n=67)	44.3% (n=77)
d	Learned new coping skills that have reduced my stress level	1.1% (n=2)	2.8% (n=5)	25.8% (n=46)	33.7% (n=60)	36.5% (n=65)
e	Become more at ease in asking for support from family members or friends.	1.7% (n=3)	2.8% (n=5)	24.3% (n=43)	40.7% (n=72)	30.5% (n=54)
f	Become more aware of available community services or resources.	0.6% (n=1)	0.6% (n=1)	11.1% (n=20)	40.0% (n=72)	47.8% (n=86)

Table 6: Sometimes people go to the Emergency Department because they are overwhelmed with their caregiving situation and don't know what else to do. Do you think that the information and support you have received from the Alzheimer Society has helped to keep you or your relative from visiting the Emergency Department for these reasons?

Response	% (n)
Yes	49% (n=88)
No	14% (n=26)
I'm not sure	38% (n=68)
Total	100% (n=182)

Table 7: Did you LEARN about any of the following community supports/services from Alzheimer Society staff?

Reason	% (n)
None of the above	15% (n=28)
Transportation	16% (n=30)
Other	16% (n=30)
Meal Services or Programs	23% (n=44)
Recreation Programs	42% (n=80)
Adult Day Program	48% (n=93)
Home Care	51% (n=98)

Table 8: Have you used the community support(s)/service(s) that were suggested?

Response	% (n)
Yes	45% (n=63)
No	55% (n=76)
Total	100% (n=139)

Table 9: If no, why did you not use the support/service?

Response	% (n)
Could not reach or make contact with the support/service	1.2% (n=1)
I made contact, but I am on a waitlist	2.4% (n=2)
I made contact and was told that the support/service was not the right fit for me	2.4% (n=2)
Lack of transportation/distance	2.4% (n=2)
I made contact but was told that the service is not available in my area	3.6% (n=3)
Did not have time to make the connection	4.8% (n=4)
Lack of interest/client refused	7.1% (n=6)
Just learned about service and intend to call	7.1% (n=6)
Did not need the support/service at the time	65.5% (n=55)

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Table 10: 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 11: 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

Table 12: 2016 Referrals

Region	Type of Referral	
	Direct	Self
Calgary	57	1576
Central	124	97
Edmonton	510	378
North	27	31
South	55	47
Total	773	2129

Table 13: 2017 Referrals

Region	Type of Referral	
	Direct	Self
Calgary	181	1685
Central	194	156
Edmonton	444	551
North	10	8
South	112	104
Total	941	2504

Table 14: 2018 Referrals

Region	Type of Referral	
	Direct	Self
Calgary	373	1661
Central	223	193
Edmonton	727	667
North	25	41
South	169	87
Total	1517	2649

Table 15: Source of Direct Referrals

	2014	2015	2016	2017	2018
Specialized Services	64.7% (n=321)	60.7% (n=326)	55.6% (n=441)	62.6% (n=589)	58.4% (n=886)
Primary Care Services	19.6% (n=97)	16.2% (n=87)	22.6% (n=179)	20.8% (n=196)	14.8% (n=224)
Community Services	5.6 (n=28)	8.9% (n=48)	19.3% (n=153)	11.7% (n=110)	22.5% (n=341)
Other/Missing/Unidentified	10.1% (n=50)	14.2% (n=76)	2.5% (n=20)	4.9% (n=46)	4.4% (n=66)
Total	100.0% (n=496)	100.0% (n=537)	100.0% (n=793)	100.0% (n=941)	100.0% (n=1,517)

Table 16: 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 17: 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 18: 2016 Type of Clients by Region

Region	Type of Clients			
	Person with Dementia	Care Partner	Both	Unidentified
Calgary	69	1,290	0	274
Central	9	193	5	14
Edmonton	18	845	11	14
North	1	54	1	2
South	2	93	2	5
Other	4	38	2	3
Total	103	2,513	21	312

Table 19: 2017 Type of Clients by Region

Region	Type of Clients		
	Person with Dementia	Care Partner	Unidentified
Calgary	61	1,564	214
Central	18	308	24
Edmonton	20	837	138
North	1	13	4
South	6	200	10
Total	106	2,922	390

Table 20: 2018 Type of Clients by Region

Region	Type of Clients		
	Person with Dementia	Care Partner	Unidentified
Calgary	33	1,771	230
Central	12	382	22
Edmonton	35	1,335	24
North	3	59	4
South	7	245	4
Total	90	3,792	284

Table 21: 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 22: 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	21	74	0	1
South	34	84	1	0
Other	6	21	0	2
Total	286	808	9	27

Table 23: 2016 Gender of Client

Region	Gender of Client			
	Male	Female	Both	Unidentified
Calgary	0	0	0	0
Central	41	169	0	11
Edmonton	237	638	5	8
North	8	48	0	2
South	27	75	0	0
Other	12	27	0	9
Total	325	957	5	30

Table 24: 2017 Gender of Client

Region	Gender of Client			
	Male	Female	Both	Unidentified
Calgary	372	1447	0	20
Central	79	185	1	85
Edmonton	155	464	1	375
North	3	11	0	4
South	50	137	0	29
Total	659	2244	2	513

Table 25: 2018 Gender of Client

Region	Gender of Client			
	Male	Female	Both	Unidentified
Calgary	370	1646	0	18
Central	98	258	0	60
Edmonton	366	882	1	145
North	15	46	0	5
South	60	155	0	41
Total	909	2987	1	269

Table 26: 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 27: 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 28: 2016 Client Contacts

Region	Client Contacts			
	Number of Contacts	Number of Hours with Clients	Number of Unique Individuals	Number of Communities
Calgary	1622	466	1069	0
Central	1252	471	547	70
Edmonton	5334	1514	1939	70
North	262	83	138	37
South	1398	689	303	35
Other	137	68	62	24
Total	10005	3290	4058	236

Table 29: 2017 Client Contacts

Region	Client Contacts			
	Number of Contacts	Number of Hours with Clients	Number of Unique Individuals	Number of Communities
Calgary	4341	1221	1139	6
Central	1746	771	650	74
Edmonton	6262	1,831	2412	113
North	87	38	45	8
South	1420	620	418	46
Total	13856	4481	4664	247

Table 30: 2018 Client Contacts

Region	Client Contacts			
	Number of Contacts	Number of Hours with Clients	Number of Unique Individuals	Number of Communities
Calgary	4,567	1,274	1,342	13
Central	2,504	1,150	932	84
Edmonton	8,339	2,505	3,376	115
North	292	106	136	33
South	1,113	610	549	59
Total	16,815	5,644	6,335	304

Table 31: 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 32: 2015 Who Initiated Contact

Region	Who Initiated Contact			
	Client	Staff	Both	Unidentified
Calgary	11	37	0	3
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 33: 2016 Who Initiated Contact

Region	Who Initiated Contact			
	Client	Staff	Both	Unidentified
Calgary	405	1347	55	0
Central	160	881	2	208
Edmonton	583	4485	8	257
North	26	219	0	17
South	162	1223	0	13
Other	44	83	0	10
Total	1380	8238	65	505

Table 34: 2017 Who Initiated Contact

Region	Who Initiated Contact		
	Client	Staff	Unidentified/Both
Calgary	744	249	0
Central	205	1218	323
Edmonton	897	5101	264
North	12	69	0
South	220	1027	0
Total	2078	7664	587

Table 35: 2018 Who Initiated Contact

Region	Who Initiated Contact		
	Client	Staff	Unidentified/Both
Calgary	0	0	0
Central	377	2079	64
Edmonton	1072	7263	56
North	32	265	0
South	277	840	0
Total	1758	10447	120

Table 36: Outreach

Region	Outreach				
	2014	2015	2016	2017	2018
Calgary	0	0	7	78	21
Central	44	34	31	80	76
Edmonton	23	14	10	46	65
North	66	83	41	0	24
South	20	0	6	47	23
Other	0	19	0	0	0
Total	153	150	95	251	209

Table 37: Networking

Region	Networking				
	2014	2015	2016	2017	2018
Calgary	0	0	15	58	61
Central	16	26	14	12	52
Edmonton	8	0	0	1	2
North	5	13	3	0	4
South	22	0	6	36	6
Other	0	11	0	0	0
Total	51	50	38	107	125