



First Link[®] Care Navigation Program

Evaluation Report Year 2

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CENTRE FOR
COMMUNITY
BASED RESEARCH

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The purpose of this report is to provide evaluation results of the First Link® Care Navigation (FLCN) program using data gathered with Persons Living with Dementia, Care Partners, First Link® Care Navigators and System Partners between 2018 and 2019. This technical report summarizes the findings according to the evaluation's three data gathering methods.

1. Evaluation Framework

Purpose & Overview

As a part of Alzheimer Society of Ontario's (ASO) commitment to strengthening its First Link® Care Navigation (FLCN) program and Ontario's larger Dementia Strategy, robust monitoring and evaluation was a critical component. Evaluation methods were used in order to better understand the impact of the investment and to inform continuous improvement of the First Link® program and the role it plays in care navigation. The Centre for Community Based Research (CCBR) was engaged by ASO to create an evaluation framework.

The evaluation implements a community-based research approach. Community-based research is defined as: "a research approach that involves active participation of stakeholders, those whose lives are affected by the issue being studied, in all phases of research for the purpose of producing useful results to make positive changes" (Nelson, Ochocka, Griffin, & Lord, 1998, p.12). Community-based research is grounded in three hallmarks: community-driven, participatory and action-oriented (Ochocka & Janzen, 2014).

CCBR implements this approach using three main mechanisms:

The research team comprises the researchers from the Centre for Community Based Research (CCBR) and staff from the Alzheimer Society of Ontario (ASO). CCBR and ASO work closely together to create the program logic model, design and facilitate the implementation of evaluation tools and methods, collect and analyze all data, as well as draft evaluation reports and recommendations.

The steering committee comprises 8-12 members of stakeholder groups and meets regularly during the evaluation process. This steering committee's role is to guide the evaluation process and evaluation products. That is, the steering committee assists the research team to understand local Alzheimer Societies' contexts, review the program logic model, shape evaluation tools and methods, and review the evaluation report and recommendations (see Table 2)

Key representatives from the Ministry of Health and Long-Term Care were engaged to ensure that the evaluation framework, progress and learning are aligned with the overall objectives and evaluation of the Ontario Dementia Strategy.

Table 2. Roles of the Research Team and Steering Committee

Steering Committee “Guiders”	Research Team (CCBR & ASO) “Doers”
Assist CCBR to understand local Alzheimer Societies’ contexts	Design the Program Logic Model
Review Program Logic Model	Design and Facilitate the implementation of Evaluation Tools and Methods
Shape Evaluation Tools and Methods	Collect and Analyze Data
Review Evaluation Reports	Draft the Evaluation Reports and Recommendations

The evaluation framework that has guided the evaluation of the First Link[®] Care Navigation Program (2018-2020) has been collaboratively developed by CCBR in consultation with ASO and the steering committee. The evaluation has been implemented in three cycles. This report covers cycle two (2018-2019).

Evaluation Purpose

The purpose of the First Link[®] Care Navigation program evaluation is to collaboratively determine:

1. The impact of the First Link[®] Care Navigation program, especially on clients’ quality of life, and the extent to which the First Link[®] Care Navigation program was implemented successfully, and
2. The impact of this investment on the overall First Link[®] program over time.

To address the purpose of this evaluation, the four main research questions focused on: 1) Program Outcomes; 2) Program Implementation Processes; 3) Program Context; and 4) Program Improvements.

The Stakeholders

Several stakeholder perspectives were explored throughout the First Link[®] Care Navigation program evaluation. Below is a table, illustrating the various stakeholder perspectives considered:

Stakeholder Group	Stakeholder
Clients	Persons Living with Dementia (PLWD) Care Partners (CP)
Alzheimer Society in Ontario (ASiO)	First Link [®] Care Navigators (FLCNs)
System Partners	Primary Care Community Supports/Services

Research Questions

Research Question 1: Program Outcomes

How and to what extent has the First Link® Care Navigation program impacted clients and System Partners?

- What evidence is there that Persons Living with Dementia (PLWD) have improved client experience and engagement as a result of FLCN?
- What evidence is there that FLCN position impacted Care Partner (CP) stress and capacity?
- What evidence is there that shows strengthened linkages between primary care and community supports/services as a result of FLCN?
- What unanticipated impacts were found?
- To what extent have other external enablers contributed to the observed outcomes?
- How have outcomes changed over time? (year 2 and 3) Why?
- What stories serve to illustrate impact?

Research Question 2: Program Implementation Processes

To what extent has the First Link® Care Navigation program been implemented successfully?

- To what extent is the enhancement being implemented as expected and meeting targets?
- Who are the program clients, how are they referred into the program, what degree of interactions have there been, and how satisfied are clients with these interactions?
- Have specific diverse communities (Indigenous, remote/rural, Francophone, LGBTQ) been supported through this investment?
- What are the number, nature and perceived quality of Alzheimer Society (AS) services/supports and external referrals?
- What aspects of FLCN seem to be working well and not working well?
- What is facilitating and what is hindering effective implementation?

Research Question 3: Program Context

How has the First Link® Care Navigation program impacted the overall First Link® program and Care System over time (throughout 2018-2020)?

- In what ways has the overall First Link® program and care system changed as a result of FLCN? What need or gap was FLCN aiming to address initially? Has FLCN successfully addressed it?
- How and to what extent have FLCNs been integrated as part of local AS operations?
- How and to what extent have learnings from FLCN evaluation been incorporated into overall First Link® program and care system?
- To what extent has the reach and impact of the overall First Link® program and care system benefited from FLCN?
- How has First Link® training helped to build skills/expertise for FLCN's in their role, helped to enhance AS effectiveness in supporting clients?

- What is the relationship between FLCN, the overall First Link® program, and other contributing factors?

Research Question 4: Program Improvements

What would improve the First Link® Care Navigation program?

- What are we learning that would help to make FLCN more effective and impactful?
- What should be taken into consideration when expanding FLCN to other local Alzheimer Societies in subsequent years?
- To what extent are learnings about FLCN context-specific and what can be transferred to all communities?
- How can training be enhanced to improve the delivery and client outcomes related to FLCN?
- How should FLCN be better evaluated?
- What investments are required for long-term sustainability?

Methods

The FLCN program evaluation used several methods and gathered various stakeholder perspectives. The methods included:

1. Focus groups with clients
2. Key informant telephone interviews with System Partners
3. Surveys with clients and FLCN

All these methods were conducted in parallel in order to triangulate information providing both breadth (quantitative) and depth (qualitative) of program information.

2. Findings

Below, there are three separate sections summarizing the evaluation findings for each method. Each section describes the methodology, demographics, and research findings. The report starts with a presentation of focus group data, followed by key informant interviews with System Partners, followed by three surveys: (i) completed by PLWD, (ii) completed by CP, and (iii) completed by FLCN. Each survey included close-ended questions, presented below as quantitative analysis, and open-ended questions, presented below as qualitative analysis. Please see the report entitled, “Summary of Survey Findings by Evaluation Question,” to review the complete findings from the three surveys.

Report on Focus Groups

Methodology

Focus groups allow for in-depth understanding and description of the context and situations that underlie FLCN processes and outcomes. During focus groups, individuals discussed issues and explored subjective matters, such as expectations, attitudes, and experiences of the FLCN program. Focus groups were conducted with two stakeholder groups: (1) Persons Living with Dementia (PLWD) and (2) Care Partners (CP). CCBR provided training to local ASiO staff to facilitate two separate focus groups with PLWD and CPs.

The original protocol called for a minimum of one focus group (each for Care Partners and Persons Living with Dementia) to be conducted at nine ASiOs, with each group having 3-5 participants. ASiO staff recruited participants based on the following criteria:

(1) PLWD

- People who are cognitively able to answer focus group questions
- People who have generally longer experience with the First Link[®] Care Navigation Program
- People who have generally higher frequency of contact with their First Link[®] Care Navigator

(2) CP

- People who have generally longer experience with the First Link[®] Care Navigation Program
- People who have generally higher frequency of contact with their First Link[®] Care Navigator

Some ASiOs encountered difficulties recruiting participants, which resulted in some sites being limited to holding interviews only or none at all. Subsequently, eight focus groups and four interviews were scheduled with 13 PLWD and 18 CP between January 2019 and February 2019 at seven ASiO sites. Each focus group lasted approximately 60 minutes. The facilitator completed a “Note Taking Template” during the focus group, and audio recorded the entire session. Recordings were sent to CCBR and transcribed by hired staff. Information was later organized according to focus groups questions, and then coded through the identification of key themes relating to each of the four main research questions. Quotes from CP and PLWD were identified to illustrate and support key themes. These quotes are included in the sections below.

Demographics

As part of the First Link[®] Care Navigator evaluation, information was gathered from CP and PLWD from the following ASiO sites across Ontario:

- Toronto (1 CP, 3 PLWD)

- Niagara Region (4 CP, 3 PLWD)
- Brant, Haldimand Norfolk, Hamilton Halton (1 CP, 2 PLWD)
- Sault Ste. Marie & Algoma District (3 CP, 4 PLWD)
- Chatham-Kent (2 CP, 0 PLWD)
- York Region (3 CP, 0 PLWD)
- Simcoe County (4 CP, 1 PLWD)

PLWD and CP were not identified in the focus groups, nor was any identifying information collected.

Findings by Research Questions

Research Question 1: Program Outcomes

The first research question asks: how and to what extent has the First Link[®] Care Navigation program impacted clients and System Partners? More specifically, *what evidence is there that Persons Living with Dementia (PLWD) have improved client experience and engagement as a result of FLCN? And what evidence is there that the FLCN position has impacted care partner (CP) stress and capacity?* Information gathered through focus groups with PLWD and CP is divided into: (i) impacts on PLWD, and (ii) impacts on their CPs.

Information about the FLCN's impact on PLWD is divided into four key themes: (1) increased sense of comfort and safety; (2) decreased feelings of isolation & loneliness alongside an increased feeling of acceptance and support; (3) increased likelihood of engagement with ASO programs & services (4) increased quality of life & happiness. Information about the impacts on CPs is divided into three key themes: (1) FLCN provide guidance & coping strategies; (2) FLCNs provide support to CPs that reduces stress, anxiety & feelings of guilt; (3) FLCNs provide support that improves CP's relationships with the PLWD and their capacity to care.

The two sub-sections below provide more a detailed analysis of these themes.

Impacts on PLWD

Increased sense of comfort and safety

Many of the PLWD expressed a strong attachment or appreciation for the individual FLCN. Indeed, each participant did not refer to said individual as the "First Link[®] Care Navigator", but rather by their first name. This speaks to the close relationship that is often formed between clients and the FLCN, and further reflects a certain degree of comfort and safety that many PLWD expressed when speaking to the FLCN. PLWD often referred to the navigators in ways that spoke to their individual characteristics: that they are "easy to talk to", or they "feel very warm" because the individual is "using [their] heart to help me".

This sense of warmth, ease and comfort is reinforced by having FLCNs meet clients in their home. Being at home, and feeling comfortable, often made PLWD more open to communicating—something which was often highlighted by PLWD: "you feel comfortable so you relax and are able to say 'yes, no I felt this, I felt that way' and you're more at ease and you'll be able to answer the questions or give an answer" (PLWD). As clients in situations that can be extremely vulnerable, feeling safe and secure is of the utmost importance for all parties involved — as one PLWD noted, "before I used to be very scared" but now "I feel safe". Whether it is providing visits in the home, or simply interacting in a manner that is welcoming and warm, PLWD appeared to appreciate the comfortable approach and demeanor of the Navigators.

Decreased feelings of isolation & loneliness alongside an increased feeling of acceptance and support

The FLCN program provides opportunities for PLWD to build relationships and increase their social activity in two major ways. Firstly, PLWD build a personal relationship with a FLCN that provides medical and social supports. One PLWD reflected on the importance of his relationship with the FLCN, noting that he enjoyed speaking with her, and that conversing in ways that were not entirely "business-like" but addressed personal interests, such as cooking. PLWD expressed appreciation for having someone else to walk beside them in their dementia journey: "we are not doing it alone". Knowing that there is someone that accepts them for who they are and can provide support moving forward proved to be hugely beneficial for some PLWD. For some, this relationship allowed for greater confidence to move forward with their lives: "I am comfortable with it because I know what it is, and I know what's going on" (PLWD). One CP echoed this sentiment when she explained that the navigator helped their loved one feel accepted and empowered to lead their lives: "he had the ownership to say this is how I feel" (CP).

Secondly, through their connection with the FLCN, PLWD are connected to various ASO programs that enable them to interact with other PLWD, thereby increasing their social network and providing a sense of acceptance: "'I'm not alone, I know that someone else is in the same boat, and I try to learn to share my feelings".

Increased likelihood of engagement with ASO programs & services

Although most PLWD did not explicitly state that their engagement with ASO programs was a direct result of their interactions with the FLCN, one individual did note that he "wouldn't have been as motivated" without the FLCN. Instead, it was CPs that identified a link between the PLWD's involvement in ASO programming and the influence of the FLCN. One CP noted that their loved one was very resistant to attend certain programs prior to their interaction with the FLCN: "I never would have got her here without the Navigator". Some CP attributed this to the personal connection PLWD were able to build with the FLCN: "they identify the person involved in the activity...if the trust is built there, they're more inclined to try the activity, so that seems to be the connecting [part]" (CP). Further, CPs noted that having these interactions occur in intimate and relaxed environments (e.g. the home) "really made a difference" when convincing PLWD to participate. One CP further reiterated: "It's an invaluable program to be truthful, without the FLCN coming to the house, we wouldn't be here, she never would have given me permission to come and bring her here" (CP). Navigators appear to play a fundamental role not

only in informing PLWD and their CPs of programming and services, but encouraging and convincing PLWD to attend.

Increased quality of life & happiness

Although PLWD did not explicitly state an increase in their quality of life or happiness, some CPs observed that their loved one was much happier and joyful after talking with the Navigator or attending one of the programs. A CP recalled: “he always seems happier afterwards”. One CP explained that the FLCN was able to identify their needs and interests, which resulted in a positive and enjoyable experience for the PLWD: “I’m telling you it’s the best thing we ever did, like I’m telling you I didn’t know what her needs were...[she’s] been in programs where there is art, where there is music, where there is games, where there is exercise and she has loved every part of it”. The impact the programs have had on one’s quality of life is not limited to PLWD, indeed one CP noted that their own life was hugely impacted by her involvement with the FLCN program: “my quality of life is much better because I’m able to engage my mom in programs and also engage myself, which is amazing because I’ve met some wonderful people and so has my mom” (CP).

Impacts on Care Partners

Many of the relational qualities between FLCNs and PLWDs were also evident in the relationships between FLCNs and CPs. How the relationship seems to differ is that CPs describe their relationship to FLCNs as more akin to counselling relationships. FLCNs provide guidance, help CPs navigate complex emotions, and provide strategies for increasing their capacity.

FLCN provide guidance & coping strategies

While navigators play a key role in providing care and support to PLWD, CPs are impacted by the disease second hand and require guidance to navigate the challenges they face along the journey. Some CPs noted that the navigator helped them foresee and plan for the steps ahead, to “keep track of what’s going on”, and help them navigate the “big mystery” that is dementia. One CP specifically noted that she found comfort in the guidance provided by the FLCN program: “I find it comforting having these supports with all these people around who’ve been where you’ve been, and to see where you’re heading. It can be a little frightening but at least you know what’s coming” (CP).

Navigating the system and trying to support your loved one, all the while attempting to live out one’s own life, is certainly a challenge. One CP explained that the Navigator “gives us the right of passage to the disease [...] she opens that window to acceptance and knowledge” (CP). Another CP echoed this sentiment, noting that they were provided with a “forward projection” and given the tools and strategies to prepare them for taking the next steps. Overall, many CPs suggested that the Navigator was able to direct them onto a path that would best suit their needs and inform them about what to expect—and what to take with them—on the journey.

FLCNs provide support to CPs that reduces stress, anxiety & feelings of guilt

One of the primary findings that came out of the focus groups with CPs was the amount of emotional support and counsel that the navigator provided for CPs. CPs expressed a wide array of emotions that impact their day-to-day lives as a result of their caring role. The most frequently mentioned emotions were stress, anxiety and guilt. Some CPs indicated that the Navigator helped them to ride this range of emotions. One CP noted that the FLCN “navigated me through my own emotions”, while another stated that the FLCN “helped remind me that it's ok to feel that way in [my] own home”.

When it comes to stress, most CPs reported feeling overwhelmed with the reality of having “a gazillion things going on in your mind that you've got to deal with”. For these individuals, the FLCN provided a degree of support and informal counselling that reduced their stress. As one CP explained, their time with the FLCN “settles you down” (CP). This sense of feeling “settled” or “at ease” was generally attributed to knowing another individual was there to walk alongside them, or as one CP explained: there is “someone watching out for both of you along the journey” (CP).

CPs are often the sole support for their loved one, and therefore must take on an inordinate amount of responsibility. When much of one's day is devoted to the caring of their loved one, having another individual bear some of that weight—in addition to looking after the CP's emotional needs—appears to have a profound impact on CPs wellbeing. One CP recalled a time when she was overwhelmed by the prospect of having to leave her loved one for a short trip. The FLCN responded by encouraging her to go to her car, “sit and take a few breaths” and reminded her “you have to live your life”. The CP noted that this moment taught her to “take a big breath and try and let the frustration get out”. For another CP, being in touch with the FLCN appeared to provide them with some of the care and support that they provide to their loved ones, but CPs do not always receive in return. The CP remarked, the FLCN “makes you feel somebody out there cares” (CP).

In addition to stress and anxiety, CPs often noted that they feel guilty or “to blame”. Some explained that certain decisions, such as moving their loved one into a home, or taking away their car keys, was accompanied with self-deprecating feelings. Further, CPs expressed sometimes feeling that they were to blame for how their loved one was behaving or feared that they were somehow providing incorrect or improper care. The Navigator's role appeared to reduce these feelings by helping CPs gain a more accurate perspective on their role as a CP and the realities of the disease. As one CP noted: “the big thing for me is not to feel guilty, it's not my fault”, while another furthered that “[dementia] has its stages...we've learned to accept it and there's nothing that we did wrong”.

Although the Navigators were not expected to completely erase their anxiety or stress, they appeared to have assisted in reducing or stabilizing CPs emotions: “It's just trying to keep our levels stable so at least we can manage and control what our [PLWD] is going through”. FLCNs were identified as being key players in reducing CPs intense negative emotions. FLCN play a quasi-counselling role which enables CPs to better care for the Person Living with Dementia, and ultimately, to take better care of themselves.

FLCNs provide support that improves CP's relationships with PLWD and increases their capacity to provide care

Many CPs have lived through the reality of having their loved one's personality shift and destabilize over the years. This reality, from a practical and emotional standpoint, is extremely challenging. CPs reflected on their personal interactions with their loved ones, sometimes questioning "what in the world is the matter with me?" when they became angry or frustrated. The Navigator's ability to provide "options of communication" (CP) was seen as a way of "changing the dynamics" (CP) between CPs and their loved ones. One CP explained that it was helpful to have someone navigate the relationship, and act as a third party to communicate with the PLWD and take pressure off their relationship

"Somebody else kind of navigating that direction, taking the pressure off the care provider...even though you think as the care-provider you're doing such a great job—you're finding all these things, you're finding all these programs—in their eyes, it's not".

The realities of the disease can result in interactions that leave CPs feeling frustrated, unappreciated, and even hated by their loved ones. FLCNs help CPs alter this dynamic and assure CPs that "your feelings are OK", which has enabled CPs to continue caring in a way that is healthy for all parties involved. For some, this has meant a profound increase in their capacity to care: "without the extra help they set me up with, I don't think I would have been able to deal with it as long as I did" (CP).

Research Question 2: Program Implementation

The second research question asks: To what extent has First Link[®] Care Navigation been implemented successfully? Focus groups with PLWD and CP provide information that can be grouped into six key themes: (1) First Link[®] Care Navigators connect CP and PLWD with community supports and programs; (2) First Link[®] Care Navigators provide useful information and guidance for PLWD and their CPs; (3) First Link[®] Care Navigators are supporting CPs in ways that increase their capacity to care; (4) PLWD and CP feel comfortable and safe with First Link[®] Care Navigators; (5) PLWD and CPs living in remote or rural areas face challenges accessing First Link[®] Care; (6) Limited capacity and availability of the FLCN program decreases the number of face-to-face encounters. The section below provides a more detailed analysis of these themes.

FLCN connect CPs and PLWD to community supports and programs

Both CP and PLWD spoke highly of specific programs they were connected to at the ASiO, such as the Minds in Motion program. While PLWD often referred to programs they enjoyed, they were not clear about how they were connected to those programs, whereas CPs were more explicit that the FLCN helped CPs increase their awareness of possible programs and services, which was paramount in making the arrangements: "everything goes through [her], she sets you up—she's a one stop shop!".

CPs also spoke about FLCNs connecting them to medical services, helping with medical paperwork, referrals, or visiting the client alongside a nurse. CPs noted being connected to medical services, such as cognitive assessments, the LHIN, in home support and medical professionals (e.g. occupational therapists). This connection between the navigator and the medical system also depends on medical professionals referring recently diagnosed individuals to the FLCN program. Several CPs expressed complete satisfaction with the quick response rate of the FLCN after the referral was made. Some said that it took anywhere from 48 hours to a week. Ultimately, CPs appeared to recognize that the FLCN connected them to the larger ASO system and medical services and felt that the FLCN program and larger community of supports was able to “share information...[and] really work together” (CP).

FLCN provide useful information & guidance for PLWD and their CPs

CPs and PLWD were quick to emphasize how much they learned from the FLCN, with some noting that they had *exclusively* received information on the disease, programming and supports from the FLCN and their local ASiO. One PLWD noted that the information they received was useful and helped them grow in their understanding of the disease: “[I’ve] learned so much from [her] and the society [...] I feel that I’ve come a long way”. CPs echoed that they too increased their knowledge due to the resources they were given. A CP explained that they “knew nothing at the beginning” but due to their involvement in the FLCN program “our knowledge now has increased thousand-fold”. CPs indicated that the resources provided to them “has been vital” and that the navigators have been “extremely good” at explaining information to CPs and PLWD. In this respect, FLCN not only connected CPs and PLWD to supports and services but were a necessary resource in and of themselves. When referring to their local FLCN, one CP noted: “[knowledge] is at her fingertips, she can suggest and recommend what may help us and inevitably will help us, cause we don’t know what side to see at the end”. FLCNs appear to be successfully providing the necessary information and guidance that helps PLWD and their CPs effectively navigate the disease, and the larger system of community supports.

FLCN are supporting CPs in ways that increase their capacity to provide care

A number of CPs noted that the navigator’s support enabled them to provide better care for their loved ones. CPs repeatedly identified that dementia is a disease that impacts both the PLWD and their CP: “we’re both living it, [she’s] dealing with it [...] she’s living with it and I’m dealing with it” (CP). Or in the words of another CP: “it’s a journey that’s made with two people” (CP). Therefore, CPs require a similar degree of support and attention in order to properly care for their loved one. In the words of one CP: “[It’s] just us here, just moving forward, because we are known as the support and we need support too... that’s what we get, thankfully from [the FLCN] and, as I said about the other programs, it helps moving forward”. Further, CPs appeared to understand this connection between *their* care and their *ability* to care—in the words of one CP: “taking care of me helps to take care of him” (CP). FLCNs appear to provide CPs with the support that is much needed in their busy lives—support to better care for themselves, which in turn enables them to better care for their loved one.

PLWD and CP feel comfortable and safe with FLCN

Due to the intimate and direct role of the FLCN, interacting with clients in a manner that ensures feelings of comfort and safety is fundamental to providing successful and impactful care. FLCN can visit clients in their own homes, which ensures a certain level of comfort, but also requires a degree of trust and security. Information from focus groups suggest that FLCNs have been successful in creating spaces and interactions that are safe and comfortable. PLWD often expressed that it was easy to speak with the FLCN, they enjoyed their conversations, and appreciated having the time to communicate their thoughts and feelings. For PLWD, effective conversations occurred when questions were asked sensitively and respectfully—as one PLWD noted: “a person can ask questions that upset you sometimes, but [the FLCN] doesn't do that”. Ensuring a calm and safe interaction between clients and the FLCN appears to be a necessary foundation for effective and supportive care.

CPs similarly noted that they felt FLCNs to be open and welcoming. Similar to PLWD, CPs noted that speaking with FLCN at their homes created a “calming” and “non-threatening” environment. CPs repeatedly expressed this sense of calm and warmth when it came to interacting with the FLCN; one CP noted the FLCN has a “very calm demeanor in her approach in the sense that she actually listens to you”, while another compared the individual to “the calming seas, the safe weather at port”. Further, CPs appreciated that there was “no judgement, there was no criticism” on the part of the FLCN and felt free to speak candidly about their concerns and experiences. Given the stress and challenges many CP carry, there was a significant amount of focus placed on the importance of having the interaction with the FLCN be one where they felt calm, secure and listened to.

PLWD and CPs living in remote or rural areas face challenges accessing First Link® Care

While discussions with PLWD and CPs were largely positive, much of the criticism around the implementation of the FLCN program was expressed by those living in more remote or rural areas where access to programming was more difficult, and FLCN visits were less frequent. One PLWD expressed an awareness of the multitude of programs available; however, they could not easily access their local ASiO due to their location: “we just can't get [there]...when we do, there's so many other things” (PLWD). Others suggested that FLCN programming could be expanded to reach to more people or provide more transportation options for those living further afield. Some CPs echoed this concern and expressed that it was quite difficult to access certain programs, and although some transportation existed (ex. RIDE program), they did not sufficiently cater to their particular area.

Limited capacity & availability of the FLCN decreases the number of face-to-face encounters

FLCNs client load can include up to hundreds of clients, which can be a challenge when it comes to ensuring frequent visits and meaningful relationships. Indeed, a number of PLWD and CPs were surprised by the number of clients served by the FLCN and the weight of their role with the ASiO. Due to this, participants frequently raised the concern that there was the need for more FLCNs in order to ensure their quality of care and the number of home visits.

By having the FLCN as their main contact person, CPs expressed this was “a very valuable” component which enabled PLWD to place a face to the program—therefore increasing the likelihood that they would be receptive to suggestions and participate in programming. In the case of one PLWD, he noted having difficulty recalling certain individuals when speaking on the phone, and therefore emphasized why it was important for him to have frequent visits with the FLCN to maintain a degree of recognition. Further, one CP noted: “because of the distance between appointments...there's not a connection there for my mom to [her]” (CP). With less frequent visits, some CPs were concerned that this relationship was not as strong as it could be, which would risk the likelihood that their loved ones would know and trust the Navigator, and by extension the information or programming they recommend. In addition to increasing the number of FLCN, one CP suggested increasing face-to-face interactions between PLWD and FLCN by involving FLCN in ASO programming (e.g. Minds in Motion) and have them “make more of a connection” (CP).

Research Question 3: Program Context

The third research question asks: how has the First Link[®] Care program impacted the overall Care System over time (throughout 2018-2020)? In response to this question, information from focus groups can be grouped into two key themes: (1) FLCNs connect PLWD and CPs to medical professionals & larger medical system; (2) FLCNs bring CPs together to better support each other, and PLWD within the community. The section below provides more of a detailed analysis of these themes.

FLCNs connect PLWD and CP to medical professionals & larger medical system

A number of PLWD and their CPs recalled being connected to the Alzheimer Society after a diagnosis or specific appointment with a medical professional. Indeed, for most individuals living with the dementia, their world fits within a larger medical system they must learn to navigate. Similar to CPs recognizing FLCNs as a “third party” in their relationships with their loved ones, this dynamic position exists within the larger medical system when navigators inform and connect PLWD to medical supports. One PLWD noted that the FLCN “complemented what I was talking with the professionals about” and helped to “map out specific things that I could focus on” (PLWD), while another recounted a nurse that accompanied the FLCN during one of their visits. CPs also noted the role FLCN played in connecting them to medical services, such as assisting with setting up cognitive assessments, providing information on the LHIN, and other medical services (e.g. occupational therapists). FLCN appear to be assisting PLWD and their CP with access medical information and services more easily, and in a comfortable manner.

FLCNs bring CPs together to better support each other and PLWD within the community

One of the main themes that came out in discussions with CPs was an appreciation for the support and acceptance received during meetings with other CPs. The program’s ability to engage CPs within the community and hold monthly meetings to support one another has been an impactful and meaningful part of the FLCN program. For one CP, the ability to connect with other CPs helped to reduce the stigma they felt around the disease: “you take the label off and all these people are real in these groups...they're not the diagnosis” (CP). Further, the reality

that “you're not dealing with this alone” (CP) was a comfort to many CPs, as meetings provided them with a space to share, console one another, and build a larger caring community. The FLCN program has enabled CPs to come together and reap the benefits that comes with building relationships of support within the community.

Research Question 4: Program Improvements

The fourth research question asks: what would improve the First Link[®] Care Navigation program? There were a few recommendations that were consistent throughout the focus groups with CPs and PLWD. Recommendations can be broken down into four main areas: (1) improved information and supports in relation to a) specific challenges identified by CPs and b) specific types of dementia; (2) improved communication and information about the FLCN program; (3) increased number of FLCNs & CP support groups; (4) greater advocacy efforts. These will be briefly discussed in the section below.

Improved information and supports in relation to ... specific challenges identified by CPs

Focus groups with CPs identified a few major events which proved to be incredibly stressful for Care Partners to navigate. These included: the revoking of ones driving license, transitioning to a care home, introducing a personal support worker into the home, and life after the PLWD has passed away. CPs expressed a degree of anxiety and frustrations when it came to navigate these difficult situations and conversations with their loved one—how does one receive consent from the PLWD to move into a care facility? How does one navigate the vast array of waitlists and applications? How does one tell their loved one they can no longer drive without being vilified? As one CP questioned, would it be better if doctors were the ones to take away drivers licenses instead of CPs? The supports navigators provide would be improved if they were better prepared with information and strategies for tackling these challenges. With helpful strategies or solutions to navigate these unique circumstances, navigators could lessen the stress incurred by CPs and better prepare for what may lay ahead.

Improved information and supports in relation to ... specific types of dementia

Another common concern expressed by CPs was a lack of distinction and information between Alzheimer's and other forms of dementia. With regards to the broader community, there was agreement among Care Partners that more could be done to spread public awareness that dementia is not “just an old-person's disease”. While with regards to individual support and care, some expressed the challenge of encouraging their loved one to participate in groups or programs that were labeled as “Alzheimer's”, as they may not have that particular type of dementia or feel hesitant to associate themselves with the label. Further, one Care Partner stressed the importance of isolating the different forms of the disease, akin to various types of cancer. Enabling greater awareness and information of these different forms of dementia would improve the degree of individualized care provided to Persons Living with Dementia, increase program accessibility, and promote a positive community awareness around the disease.

Improved communication and information about the FLCN program

Although most PLWD and CPs were positive about their experience with the FLCN program, there were a handful of individuals who expressed a lack of clarity around the roles, responsibilities and services offered in the FLCN program. One person living with dementia

expressed difficulty contacting the FLCN over the phone, which was largely a result of calling during times when the Navigator was not working. This individual expressed his frustration, noting: “they have very little time, but they do not tell us this—they should be upfront with their restrictions”. Providing more clear, accessible information around the exact availability and limitations of the FLCN might help PLWD remember when they can contact the FLCN and know exactly the types of services that can be provided to them. Another person living with dementia suggested creating a brochure “that tells us what we can expect and what kind of help we could get”. Similarly, several Care Partners expressed a lack of clear, concise information about the program and the larger system of support provided at the ASiO. Some suggested an information package to be sent in the mail, or webinar to assist those who are not able to attend an information session. Without clear and accessible information, one runs the risk that clients are not accessing the full breadth of supports available or may become frustrated simply because they are unaware of the program’s capacity.

Increased number of FLCNs & CP support groups

A common recommendation that came up in focus groups, and was reflected upon earlier, was the need for more FLCNs and care partner support groups. Many of the issues facing the program, such as minimal face-to-face interactions, difficulties accessing clients in remote areas or limited hours of availability, would be addressed with the addition of more FLCNs. Further, Care Partners repeatedly noted the importance of their support groups and stressed that they would benefit from more than one meeting a month. One CP suggested that a virtual community, similar to a Facebook group, could also provide a space for Care Partners to post questions and support each other on an online platform. The program would significantly improve its capacity to support its clients with the addition of more navigators and support groups for Care Partners.

Greater advocacy efforts

As a government-funded body, The Alzheimer Society is in a difficult position to challenge the current system and push for larger change; however, PLWD and CP expressed a desire to see FLCN and the larger ASO system take on a stronger advocacy role. One PLWD noted that he was unable to properly express himself due to the disease, and similar to many others living with the condition, rely on “someone to advocate for us”. Although the Navigator could potentially fill this advocacy role, one care partner noted that the responsibility of making broader changes cannot solely lie on the ASO, but it is up to the larger system to be responsive and change: “next would be not to make poor [FLCN] work any harder...we need [other] folks navigating physicians into the system, so it becomes a holistic piece” (CP).

All these improvements and suggestions could help make the FLCN program more effective and impactful. Further, by addressing these weaknesses, the program is more likely to be sustainable and meet the growing needs of those affected by dementia. Of course, this is dependent on increased funding and support by the government, which requires the overseers to recognize the importance and role the FLCN program has on the lives of those living with dementia and their Care Partners.

Challenges and Data Limitations

Challenges and limitations will always be a reality of focus groups, especially when working with a population that may have cognitive or behavioral challenges. With regards to focus groups conducted with Persons Living with Dementia, feedback was limited to those who were cognitively able to participate, of which some individuals still encountered difficulties fully expressing themselves. However, it remains a key hallmark of community-based evaluation that the voices of those who are impacted by the program are heard, and therefore the comments brought forward by Persons Living with Dementia remain fundamental to the integrity of this evaluation. In a similar vein, the data is somewhat limited with regards to representing the voice of Persons Living with Dementia from all ASiO sites (one ASiO was unable to arrange a focus group, while another was required to include one person living with dementia in their care partner focus group).

Further challenges were encountered with regards to sampling, as those able to attend were Care Partners and Persons Living with Dementia who were already well connected with the FLCN program and able to travel to the local ASiO (where the focus group was held). This likely impacted the number and type of participants each ASiO was able to recruit, and potentially provides responses that are slightly biased and more positively skewed.

Finally, it is important to recognize that any findings from the focus groups in relation to the FLCN are highly personal and individualized. Due to the reality that most clients will form a close relationship with one FLCN, who then becomes the “face” of the FLCN program, it can be challenging to separate the personal qualities of the Navigator from the program as a whole. What one individual does for a client may not be a realistic exception for the entire program (e.g. one Care Partner noted that they appreciated when the FLCN attended the funeral of their loved one). This reality goes hand-in-hand with an overall understanding that each CP and PLWD has a unique experience and reality; any story, suggestion, criticism or accolade is possibly reflective of a larger theme or pattern, but ultimately needs to be recognized as a byproduct of each individual’s lived experience.

Report on System Partner Interviews

Methodology

The evaluation of the First Link® Care Navigator role included interviews with System Partners. Interviews allow for in-depth probing, clarification, and flexibility in gathering information. Limitations include low numbers of people and the potential for a non-diverse sample because of such low numbers. Similar to focus groups, the facilitator needs to be highly skilled to conduct interviews, and researchers have less control over the discussion. Interviews are also time-consuming to transcribe and analyze.

The System Partner interviews included 15 telephone interviews with community service providers and Medical Professionals who work in partnership with the Alzheimer Society and the First Link® Care Navigators in particular. It was important to obtain a diversity of perspectives on the First Link® Care Navigator role in order to understand a wide range of interactions and relationships between System Partners and First Link® Care Navigators across Ontario, and to gain insight into the impacts of the First Link® Care Navigator role on Persons Living with Dementia and their Care Partners, System Partners, and the Healthcare System more broadly.

In order to recruit System Partners, the Alzheimer Society of Ontario sent an email to all participating local Alzheimer Society organizations explaining that the Centre for Community Based Research would be hosting interviews with key external stakeholders from community partner organizations and primary care providers. Further, it asked local organizations to submit the names of 1-3 key stakeholders that they thought would be able to speak to the impact of First Link® Care Navigation. Based on this request, CCBR received a total of 84 System Partner names from 25 local organizations. CCBR then randomly selected a sample of 25 names from the list by selecting one person from each of the 25 sites, with as equal as possible representation of community service providers and Medical Professionals.

Subsequently, a CCBR Researcher scheduled interviews with 16 System Partners. A total of 15 telephone interviews took place with 8 community service providers and 7 Medical Professionals between March 4, 2019 and March 20, 2019. Each interview lasted between 30-40 minutes. The Researcher took detailed notes during the interviews, which were not audio recorded. The interview notes were subsequently coded through the identification of key themes relating to each of the four main research questions. In order to center the voices of System Partners, quotes were identified that illustrate and support each of the key themes. These quotes are included in the sections below.

Demographics

As part of the First Link® Care Navigator evaluation, 15 System Partner Interviews were conducted with System Partners in 15 different sites across Ontario. Of these partners, eight are community service providers in roles such as Care Planner, Central Intake Coordinator, Social Worker, and Geriatric Assessor. In addition, seven of the partners interviewed are Medical

Professionals including a Pharmacist, Registered Nurse, Geriatric Resource Nurse, Occupational Therapist and Geriatric Emergency Management Nurse.

Findings by Research Questions

Research Question 1: Program Outcomes

The first research question asks: how and to what extent has First Link[®] Care Navigation impacted clients and System Partners? Information gathered through interviews with System Partners is divided into: (i) impacts on Persons Living with Dementia and their Care Partners, and (ii) impacts on System Partners. Information about the impacts on Persons Living with Dementia and their Care Partners is grouped into four key themes: (1) providing better support to Care Partners and reducing crises for Persons Living with Dementia; (2) Persons Living with Dementia enjoy better health outcomes and improved quality of life; (3) Care Partners understand dementia better and are more empowered, reducing abuse; and (4) First Link[®] Care Navigators support Care Partners to support one another. Information about the impacts on System Partners is grouped into five key themes: (1) System Partners appreciate that First Link[®] Care Navigators are dementia experts providing consistent, long-term support; (2) First Link[®] Care Navigators are experts in community supports, extending the services of System Partner teams; (3) First Link[®] Care Navigators help System Partners to prevent crises; (4) First Link[®] Care Navigators help System Partners to access more information in order to provide more targeted supports; and (5) First Link[®] Care Navigators are colleagues and team members of System Partners. The two sub-sections below provide more a detailed analysis of these themes.

Program Outcomes for PLWD and CP

Providing better support to Care Partners and reducing crises for PLWD

System Partners emphasize the fact that First Link[®] Care Navigators play a key role in the early identification of dementia, as well as changes in a person's health over time. Due to the fact that First Link[®] Care Navigators are the first point of contact for people with a new dementia diagnosis, and also the people who are in regular contact with families over the long-term, the Navigators understand what supports Persons Living with Dementia and their Care Partners need and what is the appropriate time to implement those supports.

“I get a chance not only to see the clients who come through the early stage programs but get to know them well. What they will tell me is, “coming to the Society as early as we did, gave us our lives back.” I see this in our clients that come to the Society early and take advantage of some of the programs we have and continue to follow-through on other programs. They say, “I don’t know how I coped without you.” A couple moved to another province, and before they left they said, “you are like family to us here. You have become our family.” They talk about feeling respected. Not just about coping... The Navigator, she will come and say hello to put a face to the name so people know she is

the one who is calling, who is following-up. They say, “when we come here we feel normal. We feel like we belong. We feel safe.” The impact is tremendous” (Community Service Provider, Urban/Rural, Southeastern Ontario).

“Probably a lot of people wouldn’t access the Alzheimer Society if it wasn’t for the First Link® Care Navigator. And if people wouldn’t access the services, this would lead to poorer outcomes for their health. Not everybody wants to access it. The ones that do are better supported, better understand what is going on with their own health, get put in the places where they need to be – supportive housing, Long-Term Care. The timing seems to work out better when they have the support of the Alzheimer Society and the First Link® Care Navigator. They are frequently seeing them also. She knows them better than we do. She can tell us about the progress or decline that she has seen. Having somebody that is following their story and sticking with them, they have that person advocating for them, for the services, that makes a difference for them” (Medical Practitioner, Urban/Rural, South Central Ontario).

As a result of implementation of the First Link® Care Navigator role, Persons Living with Dementia are getting more help earlier, which allows them to better participate in their own care plans while they are still able to make decisions about care. Caregivers feel better supported because they know that there is one person they can trust and rely on for help. They also know that they can drop-in to the office or request a home visit, depending on what is right for their own situation. One System Partner, a community service provider in an urban center in the north, reported that for many families, the First Link® Care Navigator is their only source of support: “A lot of people don’t share the fact that they are living with a person with dementia. They hide this fact, and so they don’t reach out for or get help. Often, the First Link® Care Navigator is the only support they have.”

“I think it makes a difference because these patients and families aren’t alone. Even if they don’t access the services it can prevent a crisis situation because they know what’s available and if they have the resources they can reach out when they’re ready” (Community Service Provider, Urban/Rural, Southwestern Ontario).

“The support is for the caregiver and not the patient as much. The First Link® Care Navigator supports the caregivers even more than they do the patients. It’s important because when it comes to cognitive impairment, without a caregiver it’s way harder to manage. It happens sometimes. If a caregiver understands the disease and understands what’s going on with a patient, they will do much better. A caregiver needs support and care. Their physical and mental health is at stake...knowing where to go, maybe needing PSW support, moving to a different spot, the Navigator does that for them. They help guide, “this is what’s available. This is how you access this, get on a list for this.” Without the First Link® Care Navigator, it contributes to burden, burnout. In those cases, hopefully you can work with other family members, people living in the community, friends, community supports...There are long waiting lists and not a lot of care available” (Medical Practitioner, Urban/Rural, South Central Ontario).

The First Link® Care Navigators’ expertise in both dementia and available community supports and services allows the Navigators to help families to identify, connect with, and put in place

these supports. One System Partner emphasized that if the Navigator wasn't there, there would be an increased risk level for some Persons Living with Dementia because they would not have access to services they are eligible for (Community Service Provider, Urban, Northern Ontario). Ensuring that the right supports are in place at the right time prevents crisis situations such as the person with dementia wandering outside the home. It also reduces hospitalization, allows Persons Living with Dementia to stay in their homes longer and access Long-Term Care only when all community-based options are no longer sufficient to provide effective care.

“With the First Link® Care Navigator, we can make the referrals early. So that they can have supports and education through the process right until they can no longer live at home. It helps them stay at home longer...it reduces crisis situations, and if they can understand dementia and what to expect, they have increased coping and can manage in the home for longer. A crisis means: I can't do this any longer and I leave, or drop the person at Emergency and say, “I can't handle this anymore.” They get admitted as “failure to thrive and cope.” Or the Coordinator, like me, goes out and expedites a Long-Term Care application and advocates for them to go in front of many others in the community because they have exhausted informal supports and because the family can't care for them any longer...The goal for everyone is to keep them in the home” (Medical Practitioner, Urban, Northeastern Ontario).

“There have been situations where I have seen families not have the support of the Alzheimer Society. And I have seen fractured relationships with family. And I have seen some very lonely patients who families detach from because they are frightened and unaware of what's normal. I have seen other family members desperately thinking they are doomed because of diagnosis without education. From a doctor you get 15 minutes or 30 minutes maximum of discussion and then the family is back on their own. And I have definitely heard stories...and have seen people living at risk with dementia. I have heard of paramedics going out and finding people without food and water and half-frozen and terrible stories. That's because there wasn't the communication and the stop-gaps that the Alzheimer Society fills...The risk is that people go out looking for the voices or the music or something else in the middle of the night and it's freezing cold and they are found by the police two days later. Because families didn't know or were afraid and thought the family member was just being difficult” (Medical Practitioner, Rural, Central Ontario).

PLWD enjoy better health outcomes and improved quality of life

The First Link® Care Navigators effectively connect Persons Living with Dementia and their Care Partners to a wide range of available community services and supports, including the Alzheimer Society's programs and services. One System Partner, a Medical Practitioner providing care in rural areas in Southern Ontario, said: “I refer people right away because I think that Persons Living with Dementia stand a better chance of having a better quality of life if they are more involved in community programs...I think there is a potential to have a higher functioning, more socialized person if they are involved right at the beginning.”

All System Partners reported that PLWD and their CPs are satisfied with the supports they receive from the First Link® Care Navigators. They use words such as, “100% satisfaction,”

“extremely grateful,” “extremely satisfied,” and “I think they love it!” According to one System Partner, a Community Service Provider providing support in both urban and rural areas in Southeastern Ontario, “people with dementia and their caregivers will tell others in the community, “you need to call this Navigator person. She will set you up or will give you information about it.” As a result of being connected with community supports, PLWD and their CPs experience better health outcomes and increased quality of life.

“Families are better able to cope because caregivers understand what is happening to the person they are caring for. They feel more supported because now they have a few options; people they can rely on if stressed or in need. For the person with dementia, it’s the programs they can get out there and engage in which improve their quality of life.” (Medical Practitioner, Rural, Eastern Ontario).

“Improved quality of life, from a caregiver perspective. Dementia is 24/7. The caregivers are trying to manage all the time. In rural Ontario, families are spread out and it’s just the caregiver in contact with that person living with dementia. That’s a very poor quality of life situation where they are managing 24/7. If can get the person with dementia into an adult day program or respite, this will definitely improve their quality of life and prevent illness and burnout. When the person with dementia is working with the Navigator, if there are behaviours in play, the caregiver can work with the Navigator to help have appropriate responses to behaviours or manage them. And if there is someone with nonacceptance, having the FLCN in place she understands what stage they are at and she can identify the care needed at that time because she understands the whole situation and what is needed. It improves quality of life” (Community Service Provider, Rural, Southern Ontario).

CP understand dementia better and are more empowered, reducing abuse

The First Link® Care Navigator equips Care Partners with information about dementia, including what may happen as the disease progresses, possible changes in behaviour over time and what they may signal, and what “responsive behaviours” look like for PLWD. As one System Partner, a Medical Practitioner providing care in rural areas in Central Ontario, explained: “Most people don’t really know what dementia is.” When Care Partners understand that particular behaviours are the result of dementia, rather than perceiving their loved one as uncooperative or aggressive or disrespectful, they are more likely to reach out for help. The First Link® Care Navigator can then help Care Partners to put strategies in place to manage those behaviours, such as helping the PLWD to move to a different activity or putting bells on the doors to signal when a loved one may start wandering. This also helps Care Partners to avoid inadvertently escalating the behaviours.

“Caring for someone with dementia at home can be extremely difficult and wearing. We know that the Alzheimer Society is there to provide that support about, “what do I do now? Mom is wandering outdoors. What do I do?” They provide strategies around the best care at home. And sometimes also around the transition to Long-term Care; support people in that difficult decision” (Medical Practitioner, Rural, Southern Ontario).

“Care Partners are learning those things: what to expect, the progression of the disease, learning coping strategies or effective communication strategies for engaging with the person with dementia or how to deal with responsive behaviours. It increases their toolkit to respond in a more effective way; to respond to any number of situations: responsive behaviours, verbally expressive, physically expressive, wandering, exit-seeking, resistant to care, exhibiting signs of depression. If the care partner does not respond in an appropriate way or provide feedback, they may escalate; become more verbal, violent, exist-seeking. The First Link® Care Navigator helps the care partner figure out why and then come up with the appropriate response to validate how they’re feeling and help them move to another behaviour so they’re not threatening” (Community Service Provider, Urban, Northern Ontario).

“For the caregiver specifically, the FLCN helps them to understand the diagnosis. The loved one isn’t behaving differently on purpose. The spouse is usually the trigger. The one they love is the one they tend to be mean with. If the caregiver understands, they will know how to talk with the person with dementia. They will have a Behaviour Care Plan with strategies or interventions that work based on the Navigator’s observations and advice. If the caregiver knows the signals of when the disease is progressing, then they can reach out for help. When they become incontinent, start wandering, they are on that line with them and can help them. It increases their coping skills and confidence to take care of them. They are not alone” (Medical Practitioner, Urban, Northeastern Ontario).

Because Care Partners are better supported, they have better physical and mental health and are less likely to experience burnout. In addition to allowing Care Partners to stay in the home longer with their loved one who is living with dementia, supports provided by the First Link® Care Navigator also prevent abuse. This happens both because Care Partners have a better understanding of what constitutes abuse and because Care Partners experience less frustration and stress due to increased connections with community supports such as Adult Day Programs, in-home respite care, and regular, consistent follow-up by the First Link® Care Navigators themselves.

“Having the FLCN in place is helping to prevent further abuse. And sometimes caregivers don’t know that what they are doing is abusive. Or could be abusive. So, having the programs and then the FLCN involved in the Circle of Care is helping out with that by helping caregivers to be aware of their behavior; what it means to be abusive, respectful care behaviours...It’s easier to catch situations of abuse when they happen” (Community Service provider, Urban/Rural, Southeastern Ontario).

“I make the referral to the First Link® Care Navigator to provide the family access to the respite program, the day program, the caregiver education series, the caregiver support group. The respite program and day program allow caregivers to have time for themselves as well as providing the patient with meaningful activities. There is a lot of caregiver burnout. So, it’s important to get a break. Linking with the caregiver support group is important so that they know they’re not the only one going through this. A lot caregivers find this beneficial; to learn from each other, support each other. The same with the education series. Everyone thinks they have an understanding of dementia until

you are living it and experience it. Through the programs, you have more knowledge to better deal with it. Caregiver burnout is occurring in the home. Before any supports are available, the caregiver can start to have health problems, and this also affects their ability to care for the person with dementia. As we provide them with more resources, they can take care of themselves better and care for their loved one better. If they do not get help, it often leads to a Long-Term Care placement or hospitalization for either the caregiver or the individual. The caregiver can also have health problems. There is a cardiac component to caregiver burnout. Or they themselves start to experience cognitive impairments because of the level of stress” (Community Service Provider, Urban/Rural, Southwestern Ontario).

FLCN support Care Partners to support one another

In addition to connecting Persons Living with Dementia and their Care Partners to community supports and services, the First Link® Care Navigator connects people with one another. This creates situations in which peer support happens organically. Families meet at the Alzheimer Society and talk with one another about their experiences. Through these conversations, they provide one another with emotional support, share stories of similar experiences, and reduce their isolation through continued connection over weeks and months. Through these longer-term connections, PLWD and their CPs feel less alone and are better able to cope.

“Because often when we see people earlier in particular, they have a lot of grief and don’t recognize that’s what they are dealing with. They have a place to discuss grief, learn about it through educational programs, and develop a lot of strategies. They have a lot of caregiver wellness strategies. What they are able to do is work together to develop strategies. They attend the social programs and will tell us that they now have peers to call in the evenings when things are difficult. They problem-solve together as peers, both clients and Care Partners. If the Navigator hadn’t made that first phone call, they wouldn’t have known about drop-in counselling. Coping, quality of life has improved. It’s still difficult but they tell us consistently, “we know we are not alone.” And that’s huge” (Community Service provider, Urban/Rural, Southeast).

Program Outcomes for System Partners

System Partners appreciate that FLCN are dementia experts providing consistent, long-term support

First Link® Care Navigators are respected by System Partners as the service providers who have the most consistent relationships with PLWD and their CPs. These relationships, over time, become relationships of mutual trust and respect. This allows First Link® Care Navigators to learn information about the everyday struggles of PLWD and their CPs that people may choose not to share with service providers they only meet with once or once every six months. First Link® Care Navigators can then act on this information by supporting PLWD and their CPs to connect with the most appropriate community supports based on the most accurate and specific knowledge of the impact’s dementia is having on the family.

“It’s more support than I can provide. They can have a longer-term relationship with the family and the person with dementia than I can. It’s a disease...that becomes more and more challenging to manage. So, families and caregivers need that support from someone they trust who has the knowledge and expertise to support them in some of the most difficult situations they will ever experience. And there is a benefit to that consistency; not having to tell “my story” over and over again. The Alzheimer Society is good at advocating for patients and helping them navigate” (Medical Practitioner, Rural, Southern Ontario).

“What has worked really well for me, personally, has been identifying those individuals that I may never get to meet. It’s that person who says, “I want some information and I will call you back.” The FLCN will say, “how about I call you back in 3 months?” This is a direct connection to someone we are hoping we can support sooner. You get so much information as a family. The FLCN can say, “let’s break some of this information down.” She will say, “what I’m hearing is...” And she supports people by listening and identifying what are the current needs, what do people need now and what can happen later, and by checking in and following-up. Sometimes people will ask her to follow-up with something, and it’s faster. They get more information about what they need right now; Identifying what they need now” (Community Service provider, Urban/Rural, Southeastern Ontario).

FLCN are experts in community supports, extending the services of system partner teams

Often, System Partners such as Physicians, Nurses, and Occupational Therapists have a mandate to provide specific, time-limited care and support to Persons Living with Dementia and their Care Partners. System Partners are experts at providing specialized care, from Emergency Room Nursing to Geriatric Services to Behavioural Supports in Long-Term Care facilities. First Link® Care Navigators are experts in understanding the community supports available to Persons Living with Dementia and their Care Partners. Further, they build connections with those community supports in order to understand strengths, such as the provision of supports in districts just outside of urban areas, as well as limitations, such as long waitlists. In some locations, First Link® Care Navigators provide this information to System Partners during weekly and monthly case conferencing meetings. In these cases, First Link® Care Navigators make recommendations about which community services to refer people to and explain why these services would provide the most appropriate supports. This allows System Partners to provide better care to Persons Living with Dementia and their Care Partners based on the most accurate and complete information possible.

“It’s invaluable. The practicality she adds to the team is invaluable: real-world experience some of us don’t have in terms of supports in the community for people with dementia and their caregivers” (Medical Practitioner, Urban, Southern Ontario).

“If there needs to be dementia education or support then we can refer that person and focus on the others. We don’t need to educate people about dementia; changes in the brain. They’re taking care of it. I can focus on if they are hoarding and extend services that way, or if they don’t have a caregiver, or safety issues, or elder abuse. We don’t have to focus on the whole dementia education and connection piece. We know that

they will do it and do it well...If the program wasn't there, I would have more of a weight on my shoulders" (Medical Practitioner, Rural, Eastern Ontario).

"We do direct referrals to the First Link® Care Navigator but the biggest thing is our Memory Clinic. It's now twice per month. We see three patients at each one, so six per month. The First Link® Care Navigator comes to the Memory Clinic every time; she comes with the caregiver and patient. She does an interview with the caregiver at the same time as we do the cognitive testing. Then she meets with the team and the doctor makes a plan...When we're discussing the findings, she is so good at her job and really understands the disease. She has good input even without meeting the patient: "If they're showing this, maybe it's this. This is what I would suggest." She's an expert in that field because she works so closely with cognitive impairment...Over 90% of the time, the person is referred to the Alzheimer Society from the Memory Clinic. The First Link® Care Navigator is the first face they see, and she explains more about how she will help, what she is here to do, and gets the plan going already. This is the biggest connection for them. The First Link® Care Navigator comes to us. She is part of our team for the day" (Medical Practitioner, Urban/Rural, South Central Ontario).

"We are there, from a medical standpoint, to diagnose, offer treatment options and suggestions for lifestyle changes to improve someone's cognition and support through the new diagnosis, and help them connect with community resources. We are not quite as connected as the person from the Alzheimer Society. Adding that aspect to the plan is something we could try to do ourselves but often she is more aware of what is available, the challenges other people face in accessing those services and working around them. For example, she tells us this day program exists, but the waitlist is a year. She has more of the details about the programs like this because through Alzheimer Society they have that knowledge. She has more practical information about what clients are seeing when they go out in community and try to do those things. A lot of experiential things. Another example is she has experience with caregivers who themselves are unsure about day programs, or the patient is. She says, "this is what works. This is what I could suggest. There is someone at the LHIN who can take you for a visit." Accessing supports for people with dementia and their caregivers in the community; we don't know how to get and navigate this. It adds to our clinic" (Medical Practitioner, Urban, Southern Ontario).

"I guess that there have been lots of times we have referred clients to the Alzheimer Society and then they have referred back to us saying this client may need additional services. They look at services outside the Alzheimer Society to help their clients. That is definitely something that has been helpful. Because the First Link® Care Navigator goes out and interviews clients and talks with them, he may find out that the client also needs Meals on Wheels or Transportation. He would refer them back to me and I would sign them up for those services. It's expanding the information I have access to" (Community Service Provider, Rural, Southern Ontario).

FLCN help system partners to prevent crises

The numbers of Medical Professionals in Ontario are not increasing as quickly as the need for healthcare services for adults living with dementia and cognitive impairments. As a result, there are gaps in the system. Crises happen when Persons Living with Dementia and their Care Partners fall through cracks in the system. These crises can look like caregiver burnout, Persons Living with Dementia wandering or suffering malnutrition, or abuse of Persons Living with Dementia. Often, this happens because people are not receiving the best supports to stay in their homes and enjoy a good quality of life. First Link[®] Care Navigators help System Partners to prevent crises through their close relationships with Persons Living with Dementia and their Care Partners. Due to these relationships, Navigators are often the first person a Care Partner calls when they do not know what to do. Navigators notice changes in circumstances or behaviour that other System Partners do not. As one System Partner said, “I know she will pick up something I am missing.” The First Link[®] Care Navigators then take that information back to System Partners in order to ensure that the best supports available are put in place. Each time changes happen in the lives of Persons Living with Dementia and their Care Partners, First Link[®] Care Navigators are there to help them access additional supports.

“We had a client that came to our adult day program. He was the person with the disease and the spouse was the caregiver. The spouse had a traumatic head injury from a fall and ended up in hospital. The Navigator called. Now, we have man at home alone with dementia. The family can support him on weekends only. He is alone at home. What can we do? Working with the First Link[®] Care Navigator, we were able to get him into an adult day program 5 days per week and get adult respite. He had increasing behaviours because of the change in routine and we were able to get additional supports for him. We worked together as a team to put things in place for that situation. The First Link[®] Care Navigator notified me of that situation. I might not even have been aware otherwise. I don’t know if he would have had to work with the doctor, or gotten more deeply into crisis, before someone was able to provide supports.” (Community Service Provider, rural, south)

“Prevention. In those earlier stages of cognitive change, it’s a huge part of our spiel. And the First Link[®] Care Navigator is talking with patients about what they can do now to keep their memory working in normal stages. Social activity – that’s a huge part of what the Navigator does. Exercise also, diet, and brain-stimulating activity; things in our regular life that we want to keep doing such as meals, grocery shopping, banking. Doing those things actually helps prevent you from getting worse. When we talk about what to do, it’s to preserve brain health. They will progress quicker [without this], have further decline, will not know how to cope, their quality of life will go down, there will probably be more crisis situations they are not prepared for like they can’t live at home, alone, or with the caregiver” (Medical Professional, Urban/Rural, South Central Ontario).

“If my patients are needing assistance but have behaviours, and for whatever reason are refusing or are scared to have shower assistance, then we can’t help them with personal shower assistance. The First Link[®] Care Navigator will come in and slowly integrate; identify strategies or interventions to get person’s hygiene taken care of done and to make sure shower is done. Or she will educate the caregiver, trying to give shower

strategies so the person will be more compliant or techniques on how to get them to listen without refusing the care. It's one of many things. She also helps with transitions to a Nursing Home. Showering and helping with getting a bed in a Nursing Home and helping with the transition. Physically, she will be there. If the person needs to be there by 10:00am admission, she will go to the home in the morning, help the person get settled in, stay with the client and wife or husband to do paper work, and stay until they are comfortable" (Medical Practitioner, Urban, Northeastern Ontario).

FLCN help system partners to access more information in order to provide more targeted supports

First Link® Care Navigators build strong relationships with Persons Living with Dementia and their Care Partners. Through these relationships, they learn detailed information about people's strengths, challenges, questions and concerns. By sharing this information, they can increase System Partners' knowledge and ability to provide the most effective supports. Prior to the addition of the First Link® Care Navigators, often System Partners did not have access to this kind of information and opportunities to connect people with supports were missed. When this happens, it contributes to increased care partner burnout and crises for Persons Living with Dementia.

"I remember one story. There was a turnover in pharmacy staff. A patient was seen in the Memory Clinic, and there were suggestions made that medications affecting cognition hopefully needed to be eliminated or tapered off. The Pharmacist left. And the patient should have been referred for help but was stuck in limbo. It was the First Link® Care Navigator who brought this to the table, to me, so that we could do the medications change" (Medical Practitioner, Urban, Southern Ontario).

"The First Link® Care Navigator and I will do a home visit together. If the Memory Clinic feels it needs a more functional assessment from an Occupational Therapist, I will go in and do that and further assess at home. She will come with me and speak with the caregiver at the same time as the assessment. Or participate and throw in tips and strategies. The advantage is what people are able to say when they are not in front of one another. For me doing an assessment on the patient, if the caregiver is watching, they don't perform as well, or they perform better because of tips from the caregiver, or they are nervous. It's hard for the caregiver to watch or see. Sometimes they don't know how much the person is struggling in the kitchen. On the other side, the caregiver can open up more when the spouse with dementia is not sitting right there. They can express their concerns and the things they want to happen. It works well when we are in the same home visit" (Medical Practitioner, Urban/Rural, South Central Ontario).

"The First Link® Care Navigator makes us more aware; helps out with us having knowledge of the clients before they are in our programs. It makes us able to provide better, more targeted care; knowing what the clients require; their needs and behaviours. So, we are prepared" (Community Service Provider, Urban/Rural, Southeastern Ontario).

“I guess that there have been lots of times we have referred clients to the Alzheimer Society and then they have referred back to us saying this client may need additional services. They look at services outside the Alzheimer Society to help their clients. That is something that has been helpful. Because the First Link® Care Navigator goes out and interviews clients and talks with them, he may find out that the client also needs Meals on Wheels or Transportation. He would refer them back to me and I would sign them up for those services. It’s expanding the information I have access to” (Community Service provider, Rural, Southern Ontario).

FLCN are colleagues and team members of System Partners

Some System Partners, especially in rural areas, are isolated in their roles and know that they would be able to provide better care if they had teams with whom to share expertise and develop care plans. First Link® Care Navigators, in several areas in Ontario, provide the much-needed team colleague for some System Partners. First Link® Care Navigators have been called, “an additional team member” by a few System Partners and it has been identified that they increase capacity by participating in case conferences, Memory Clinics, and in-home assessments. This increases the ability of System Partners to problem-solve around complex care situations, learn more about relevant community services, and reduce System Partner stress while increasing their capacity to provide excellence of care. As a result, all System Partners interviewed as part of this evaluation stated that they are very satisfied with the work and contributions of the First Link® Care Navigators.

“Because I am the only one in my organization that does this role, my support system is with FLCN. I don’t feel isolated myself. I feel they are a part of my team. I can work with them and problem-solve with them” (Community Service Provider, Urban/Rural, Southwestern Ontario).

“The process is more streamlined. We have feedback we didn’t have before. The Care Coordinator actually gets a report from the First Link® Care Navigator. The first one says that the patient or family has been contacted and gives the date of the visit. We get the next report after the first visit” (Medical Practitioner, Urban, Northeastern Ontario).

“Satisfied? Tremendously. Really, because it’s given me the opportunity to meet people early. Where I feel that I can offer them something meaningful so that they can support each other. I use peer mentors in my programs. People that mentor their peers. I said to the Navigator six months in, “this is so awesome. I am meeting people I know I never would have met before.” Our Counsellors have said, like, “if I only had met this couple sooner, they would have been perfect for Early Stage. Now we are catching them...Within months of the Navigator starting her role, I knew this was what we had been looking for. I felt excitement that this is what we needed...real excitement that this is the piece that was missing” (Community Service Provider, Urban/Rural, Southeastern Ontario).

Research Question 2: Program Implementation Processes

The second research question asks: to what extent has First Link® Care Navigation been implemented successfully? System Partners provided information that can be grouped into three key themes: (1) First Link® Care Navigators are a single point of contact for System Partners and the community; (2) First Link® Care Navigators increase the capacity of the First Link® Program to help people navigate and access community supports; (3) First Link® Care Navigators are effectively referring Persons Living with Dementia and their Care Partners to the Alzheimer Society and other community supports; (4) the First Link® Care Navigator role augments First Link® through more consistent follow-up and stronger relationships with Persons Living with Dementia and their Care Partners; (5) some System Partners are not aware of the specific role of the First Link® Care Navigators; and (6) System Partners consistently refer newly-diagnosed Persons Living with Dementia and their Care Partners directly to the First Link® Care Navigator or to the Alzheimer Society. The section below provides more a detailed analysis of these themes.

FLCN are a single point of contact for System Partners and the community

With the introduction of the First Link® Care Navigator role, Persons Living with Dementia, Care Partners, and System Partners have one person to connect with who is mandated with being the first point of contact for people newly diagnosed with dementia. As well, this role is tasked with helping people navigate community services over time. For System Partners, knowing the one person to make referrals to increases their confidence that there will be follow-up on those referrals by an expert in both dementia and community supports. One System Partner explained: “Before the First Link® Care Navigator was in place, I didn’t even know about the First Link® Program. We didn’t have that connection with the program until the Navigating position came in place.” Another System Partner stated: “I work with the FLCN in a consultative role. I only work in Long-Term Care Settings. And when we need to connect people with community supports or transition supports, I go to the First Link® Care Navigator.” For Persons Living with Dementia and their Care Partners, it is less intimidating to contact the Alzheimer Society if they know who to speak with and feel confident that the Navigator will be able to help. This feedback is evidence that the First Link® Care Navigator role is being implemented as expected.

“I think it’s providing the one person who can help them access programs and resources and that’s important. I hear way too often that people don’t know who they were talking to or they talked to this person and then don’t know where they were from. When it’s the specific disease, Alzheimer’s, it’s nice to know that the First Link® Care Navigator is the person they can connect with all the time and can guide them where to go for help” (Community Service Provider, Urban/Rural, Southeastern Ontario).

“We have that one point of contact, which is much easier. It’s quicker access, quicker response time. When we are making referrals, we know the one point of contact. We know where to go. There was a point in time I had a business card for every person at the Alzheimer Society on my desk and didn’t know who to choose. If it’s not her, she redirects me and it has made the process a lot easier” (Community Service Provider, Rural, Southern Ontario).

“It has been easier to build a relationship with one person and have this understanding between the two of us. It has been really positive. He is a go-to person. I can count on him to get the job done. I don’t have to wonder who the intakes are going to. We can always follow-up with each other” (Community Service Provider, Rural, Southern Ontario).

FLCN increase the capacity of the First Link® Program to help people navigate and access community supports

The First Link® Care Navigator role has served to increase the capacity of the First Link® program by designating one person to become an expert on community supports and services. This person then uses this knowledge to support Persons Living with Dementia and their Care Partners throughout their journey, beginning with diagnosis. System Partners report difficulty identifying and keeping track of available community supports, wait lists, changes in locally available services, and the criteria to qualify for particular programs. It is much more difficult for Care Partners who are new to the world of supports for Persons Living with Dementia and who are coping with trying to understand the diagnosis and what it means for their loved one and their future. The First Link® Care Navigators allow the First Link® Program to effectively help Persons Living with Dementia and their Care Partners to navigate and access the right community supports at the right time.

“A difference to First Link®? I am going to say by ensuring that the right service is put in place at the right time...And there is one person who is looking and knows what will be the best path for that person; counselling, respite care, educating staff in the home, connecting with the care providers. It’s ease of access; to connect with the appropriate supports and with supports when needed” (Medical Practitioner, Rural, Eastern Ontario).

“I would say it’s built right into the name of the role. Somebody to help with navigation. People really struggle with that, even when they are otherwise reasonably healthy, with the Healthcare System. With caregivers and people with dementia, they are more vulnerable. Someone to help navigate with supports and appointments helps people to feel more reassured and on the correct path. At our clinic, for example, one of her roles is to write a summary of everything that was discussed at the appointment, dates and times of the next appointment booked, and if they need to go for bloodwork or diagnostic imaging. She will follow up with that too. She is making sure people are not getting lost in the system. It’s needed and impactful” (Medical Practitioner, Urban, Southern Ontario).

FLCN are effectively referring PLWD and their CP to the Alzheimer Society and other community supports

The First Link® Care Navigator role is being implemented successfully across Ontario. The evidence of success includes increased System Partner confidence in the First Link® program and in the Alzheimer Society more generally. Because of the First Link® Care Navigator role, more Persons Living with Dementia and their Care Partners are getting connected with the services and supports they need to stay in their homes longer and with an improved quality of

life. System Partners, seeing this, are making more referrals – including referrals of people living in complex care situations. Referrals are also increasing because System Partners see the ways in which the First Link® Care Navigator role helps to prevent crises in the lives of Persons Living with Dementia and their Care Partners.

“It has increased our referrals and our ability to support people sooner. For the Alzheimer Society in particular, we get a lot of phone calls asking us for information and the admin staff are wonderful, but they often don’t have time to pull apart the issues to tease out what might be going on. Someone may ask for something but the First Link® Care Navigator may hear something in their voice or tone. It’s different than the admin staff. The First Link® Care Navigator may pick something up in the request for info. She’s a clinical person. She can then address this sooner. Hopefully, it may limit a crisis sooner. And she helps our Family Support Counsellors with caseloads and visiting clients. The First Link® Care Navigator helps them too because she can speak with people when she assigns them to one of our counsellors. What she is giving them is a lot of information and she can give the Counsellors clear instructions and information about what the people with dementia and their Care Partners are looking for. She’s giving the counsellor a wonderful picture, so they already know what’s going on and it’s really helpful to them” (Community Service provider, Urban/Rural, Southeastern Ontario).

“There is a huge gap in the community in terms of people with dementia and co-morbidities, responsive behaviours, issues that are impacting the whole household. Community settings can be challenging. The First Link® Care Navigator plays a helpful role by filling the gap. Behaviour Supports Ontario is just providing supports in Long-Term Care. The First Link® Care Navigator fills a gap in the community setting. Among my teammates too; some of the more complicated cases tend to get referred and the First Link® Care Navigator, because she is a great resource, is navigating people through systems in the community and supports they may not be aware of and making the linkages for them. It could be that the person with dementia may also have a psychiatric diagnosis or their care partner does, or health issues, or they are struggling with financial issues. Many need to connect with other resources. Or they might need enhanced services from the LHIN or in-home nursing or a PSW. The First Link® Care Navigator can fill an advocacy role and advocate for these services” (Community Service Provider, Urban, Northern Ontario).

The FLCN role augments First Link® through more consistent follow-up and stronger relationships with PLWD and their CP

Through the First Link® Care Navigators’ mandate to maintain long-term and consistent relationships with Persons Living with Dementia and their Care Partners, they are able to prevent crisis from happening. This is because they learn about potential crises sooner, such as situations in which Care Partners are struggling to cope or Persons Living with Dementia are starting to become verbal or physical with their Care Partners. They are then able to put supports in place such as teaching Care Partners strategies to manage or minimize those behaviours or connecting Care Partners with community-based supports that reduce their isolation and increase their resilience.

“First Link® was always there and then they introduced the Navigator Role. With clients I have worked with, those clients are getting more consistent follow-up because there is someone designated to do that. Before, it’s not that it wasn’t happening. But it was now-and-then follow-up. Now it’s monthly. There is more consistent support for those clients. Also, there is somebody designated to assist with finding those additional supports. It’s building that therapeutic relationship with them and the trust factor. If someone walks into your home that you don’t know, you think, “I don’t know you and why are you telling me all those things?” This is a relationship and they trust her. When she says, “you could benefit from this or that,” they trust her. It does help when a suggestion is made that it comes from a trusted person. They are better supported. I think that also a great part of this role is preventing crises. Because she is involved so regularly. We are seeing needs and addressing them before people end up in a crisis situation. It has shifted to prevention rather than crisis management” (Community Service Provider, Rural, Southern Ontario).

“I have at least 20 new people that have come through the early stage program in just two of my groups. My most recent group had six referrals and five were from the Navigator” (Community Service Provider, Urban/Rural, Southeastern Ontario).

Some System Partners are not aware of the specific role of the FLCN

Six out of fifteen System Partners identified that it is difficult to know which staff person at the Alzheimer Society is the First Link® Care Navigator. This was not reported as a weakness but rather as a strength of the Alzheimer Society and First Link® Program. For example, one System Partner said: “I am so blessed with the team that’s at the Alzheimer Society here. They all do a great job. Whether I am out with the First Link® Care Navigator or one of the other Social Workers, they all provide the same information. It’s hard to see how things have changed. They always provided the same level of support.” While another System Partner explained, “there is no difference between my interactions with the First Link® Care Navigator and other staff.”

When asked for feedback about the impacts of the addition of the First Link® Care Navigator role, four System Partners identified that they would like more information about the specific mandate of the First Link® Care Navigator and how it is different from other staff at the Alzheimer Society. One System Partner said that maybe they would interact with the Navigator more effectively if they understood the role better. This could be a recommendation to the First Link® Program: to ensure that partners understand the role of the First Link® Care Navigator and the ways in which the Navigators can enhance supports for Persons Living with Dementia and their Care Partners in different communities across Ontario.

System Partners consistently refer newly diagnosed PLWD and their CP directly to the FLCN or to the Alzheimer Society

All System Partners interviewed for this evaluation make referrals to the Alzheimer Society. System Partners who are familiar with the role of the First Link® Care Navigators make referrals directly to this person. The number of referrals ranges from 3-6 per month to 4-6 per week, depending on the specific role of the System Partner and the number of Persons Living with

Dementia and cognitive impairments they interact with on a weekly or monthly basis. One System Partner said, “every time a person has dementia, I refer to First Link®.” Another explained, “if I meet with a family and the Alzheimer Society is not already involved, I make the referral.” A third stated, “we rarely don’t refer to the First Link® Care Navigator. She’s part of the Memory Clinic. She’s there with us.”

“When I make a referral to the First Link® Care Navigator, you can expect the client to hear from her. I know they will...We refer to them constantly. There are two Geriatric Clinics per month and their packages are there” (Medical Practitioner, Rural, Eastern Ontario).

In cases in which new referrals are not made directly to the First Link® Care Navigator, the person in this role becomes the first point of contact for Persons Living with Dementia and their Care Partners who are interacting with the Alzheimer Society for the first time. One System Partner said that while they didn’t know about the specific role of the Navigator, for them an additional team member meant more capacity in the First Link® team and they were making more referrals as a result. People are reaching the First Link® Care Navigators and benefitting from their expertise and knowledge of, and connections with, the community. It would make the referral process more streamlined if all new referrals were made directly to the First Link® Care Navigators. One System Partner said that she thinks this will come with time, as more System Partners understand the specific role of the Navigators and the expertise they bring to the table.

“A young gentleman, in his early 60s, had been assessed out of area because was living out of area. During the assessment in the Memory Clinic, they thought that he probably had dementia. Due to the specific circumstances, they couldn’t make a definitive diagnosis. The man had to move to this area and his family asked if they would have to keep transporting him back and forth to the Memory Clinic out-of-area. They contacted the Alzheimer Society. The Alzheimer Society connected with his family physician and said, “here are the resources in this area.” They suggested that they would be able to support him to connect with resources in this area. They were able to get him connected with my team through the family physician’s referral. This guy probably has had several strokes. We will be able to connect him with a local stroke team instead of him travelling for stroke follow-up. And the family will be connected with supports to help this young man” (Medical Practitioner, Rural, Southern Ontario).

“If the First Link® Care Navigator is already involved, I tend to let them take the lead and we support from behind the scenes. I have gone out with the First Link® Care Navigator when she was new to her role to meet with clients because she wasn’t aware of our services and I could go with her to see what she had to offer. We learned from one another. Going forward, when she went out as the First Link® Care Navigator she could speak about services that are offered in area not specific to the Alzheimer Society. The one client we first went out to, she did excellent. He didn’t want anything to do with anyone coming to the home. She was able to get consent to go, and then able to talk with him and let him see benefits of me coming along. We talked about what each of us could offer. He wasn’t interested at that time. Since then, she has talked with him monthly and he is starting to say, “maybe I could use that help and those services now.”

*The relationship is building she is able to give him some additional supports”
(Community Service Provider, Rural, Southern Ontario).*

Research Question 3: Program Context

The third research question asks: how has First Link[®] Care Navigation impacted the overall First Link[®] Program and Care System over time (throughout 2018-2020)? In response to this question, the interviews with System Partners yielded information that can be grouped into three key themes: (1) First Link[®] Care Navigators bring many service providers together to support people with dementia and their Care Partners and stay throughout; (2) First Link[®] Care Navigators help to prevent hospitalization and early entry into Long-Term Care; and (3) First Link[®] Care Navigators make links to essential psycho-social supports, reducing doctor and Emergency Room visits. The section below provides more a detailed analysis of these themes.

FLCN bring many service providers together to support PLWD and their CP and stay throughout

The Healthcare System sometimes operates in silos, with different specialists and service providers engaging with PLWD around specific concerns. When service providers are not connected with one another, it falls on the PLWD and their CPs to navigate a complex system with sometimes conflicting advice and expert opinions on what is their best course of action. First Link[®] Care Navigators take the pressure off of Persons Living with Dementia and their Care Partners in two ways. First, they ensure that information flows between service providers so that each knows more about what the others recommend or prescribe. Second, they support Persons Living with Dementia and their Care Partners to navigate the recommendations from service providers based on deep knowledge of available community supports and detailed knowledge of the strengths and everyday struggles of the family.

“The community connections of the First Link[®] Care Navigator, the level of expertise that person has, it probably has fostered a more collaborative approach in the community and cemented the importance of that approach” (Community Service Provider, Urban, Northern Ontario).

“I think it’s involving more community partners. I have been nursing for three decades and never used to see a referral from a doctor saying refer to the Alzheimer Society. They are finally realizing that this is an actual treatment or service that should be presented as a referral” (Medical Practitioner, Urban, Northeastern Ontario).

“The Navigator is the frontline professional that starts and stays. They could be there years and years. Some of the purchased professionals, OT, PT, personal shower assistance, are contracted over a limited timeframe. Once the referral is made to the Navigator, the family doesn’t discharge. They are the frontline long-term professional on the team. They provide consistent support for family. They have the office where people can drop by if they can’t talk in the home. Groups are held different places. There is a lot of linking and connecting. The support is always there” (Medical Practitioner, Urban, Northeastern Ontario).

FLCN help to prevent hospitalization and early entry into long-term care

In the Healthcare System, one of the clear gaps is the relative absence of supports for the Care Partners of Persons Living with Dementia. The First Link® Care Navigator role addresses this gap by providing specific supports to Care Partners, helping them to understand dementia, teaching strategies to cope with behaviour and cognition changes in their loved one, and making links to community supports and services. Through these actions, the First Link® Care Navigator augments Health System care. This augmented care serves to prevent hospitalization and early entry into Long-Term Care by allowing Care Partners to provide better care for longer to Persons Living with Dementia, keeping families together and people in their homes longer.

“With the Navigator role, I feel that they are able to, when new people are diagnosed, be helped through the system earlier than in the past. Early onset diagnosis rather than mid to later. This is nice. We are connecting with people when they are not in crisis mode. It’s more proactive than reactive. When referrals are coming sooner, the GP’s office is sending referrals to First Link®. It’s helping significantly with caregiver stress and burnout because the services are being offered early instead of when things are too late”
(Community Service Provider, Urban/Rural, Southeastern Ontario).

“If people are not connected with mental health, other supports and counselling by the First Link® Care Navigator? That’s the big question. There is the potential for increased health care visits, a potential for more caregiver burnout. It’s, you know, there is a potential for crises and people not managing their care-giving role; not managing or caregiver burnout. For people with dementia, this could impact the direct care that is required and the relationship in terms of it could lead to neglectful care, and a lack of a meaningful care situation. [Or] a caregiver is just not going to do it any longer. They are unable to sustain the caregiving role. That is a crisis because our system really doesn’t accommodate for the circumstances where a caregiver can’t continue. It can lead to a person being brought into Emerg. I have seen that. Because they can’t, they are unable to continue as a caregiver...It’s often the person with dementia who is the person being brought in [to Emerg] because the caregiver is unable to manage and support that person...It’s a huge system issue also. Often, the person needs to live somewhere else. And that’s a long-term issue within our whole healthcare system; the availability of Long-Term-Care beds, the timely placement of individuals. That’s also a problem because where do you go?” (Medical Practitioner, Urban, Central Ontario).

“The First Link® Care Navigator is a critical piece. A lot of times, even if we’re not talking about the person with dementia, it’s the caregiver. Caregiver burnout is high. We don’t want a crisis because if the caregiver goes down, what happens to the person with the disease? It’s case by case. But in the example, I gave earlier, the caregiver can no longer be in that role and you have a person with dementia who can’t be alone. They go to respite care or use other resources. Now, you’re using other, more costly, resources”
(Community Service Provider, Rural, Southern Ontario).

“I just think having them around decreases the chance of early Long-Term Care and crisis. The saddest situation is when someone is crying signing paperwork because they are living with someone they are not able to care for anymore...We try but we have so

many and our visits are only every three months... Their response time in the home really helps, starting with education. All the Nursing Homes reject patients with responsive behaviours who haven't been diagnosed early. They will take them if you can prove: "if you do this, this will work." The Navigator makes this possible through their work; knowing how to de-escalate and the behaviour goes away. Often, at first, they are rejected from Nursing Homes. Then, we have to have the Alzheimer Society go in with behavioural supports and get them to have a Care Plan. That takes time to build strategies, show they work, and reapply to Long-Term Care three months later. The risk of this is that then we get in this crisis situation again... the person has so many behaviours that are atypical, like wandering, and then has to go in a secure unit. There are only a small amount of those. If we can find out why they are wandering, sometimes because of a UTI or chest infection, and they just need good infection meds, then installing bells and getting them to not wander, and then we show that it works. Then the Nursing Home accepts them. Delays mean more stress on the caregiver, more chance someone will be in crisis. Who suffers is the patient and family" (Medical Professional, Urban, Northeastern Ontario).

FLCN make links to essential psycho-social supports, reducing doctor and emergency room visits

In addition, First Link® Care Navigators specifically connect Care Partners with psycho-social supports that address the impacts on care partner mental health when they are in situations of providing 24/7 care to Persons Living with Dementia. These psycho-social supports help to reduce the shame and stigma of living in a household with a person with dementia, supporting Care Partners to reach out to other caregivers in order to reduce isolation. This happens through direct psycho-social supports such as caregiver support groups and mental health counselling services. It also happens through Adult Day Programs, in-home respite supports, and personal support services. The First Link® Care Navigator stays with Care Partners along the way, anticipating future needs and helping people with dementia to get onto waitlists for services it is anticipated they will need in the future. This also reduces care partner stress because they know that when the time comes that they can no longer provide in-home care there will be options for their loved one.

"It's important to connect earlier in the disease because what I've seen over the years in my nursing career is that people need repeated conversations about connecting with resources, whether those resources are the Alzheimer Society, Home and Community Care, or any sort of community support. When people hear that repeated messaging they eventually will connect...It's really hearing repeat messaging and making sure there is awareness, whether it's the person themselves or their family. Often people don't connect initially. It make take several service providers making those recommendations...[Or] people realizing, "I do need that support." The Alzheimer Society provides that psycho-social piece. Often, within the Healthcare system, it's not there" (Medical Practitioner, Urban, Central Ontario).

"What we're seeing is, for example, someone who is experiencing further decline in their cognition and their abilities, and a Care Partners who would, and they have told us this, "perhaps they would be moving to Long-Term Care sooner. But we know we have a

support system here, so we are not accessing those crisis supports as early as we would have.” Sometimes what people tell us is that, “if I didn’t call you I would have been in the emergency department or doctor’s office today. Because I have been introduced to the Alzheimer Society, I know that’s where I can go first” (Community Service Provider, Urban/Rural, Southeastern Ontario).

“The social piece is probably more important than anything. With all due respect to medications and other things. For medicine in general, and nursing in particular, if people are supported the journey is much easier; smoother. It decreases anxiety and phone calls and concerns coming back to the doctor once people realize there is a different way of managing and responding in problem areas. Information is vital for a smoother journey...It’s efficiency or efficient use of the primary care provider’s time when social issues are attended to in that comprehensive way” (Medical Practitioner, Rural, Central Ontario).

Research Question 4: Program Improvements

The fourth research question was: what would improve First Link[®] Care Navigation? There were a very small number of recommendations for program improvements which arose from the Interviews with System Partners. This is likely related to the high rates of satisfaction with the First Link[®] Care Navigator role on the part of Persons Living with Dementia and their Care Partners, as well as System Partners themselves.

1. Add the FLCN to the LHIN electronic documents-sharing system.

Two System Partners recommended that the First Link[®] Care Navigator be added to the electronic documents sharing system in place through the LHINs so that referrals would be easier and more less time-consuming.

2. Hire more FLCN to meet the high demand for their services.

Two System Partners recommended that additional First Link[®] Care Navigators be added to the team due to the high demand for the supports this role provides. A Community Service Provider who works with people living in both urban and rural areas in the southeast said: “Our Navigator is really busy. And so, my own personal concern is, I really think that we could have two Navigators. I truly think that if she had a partner, there would be enough work for both of them. Because the need is so big, there could be a need for two.” While a Medical Professional working with people living in rural areas in Southern Ontario said:

“I am truly amazed at how much work they do with so few people [staff]. It seems rather magical that they are able to connect with so many people. Their staff is not very big and they serve a huge population. If anything, I would be an advocate for more of them. They do an amazing job.”

3. Ensure that information about the FLCN and the Alzheimer Society programs is available online to allow access for more Care Partners.

Three System Partners made recommendations that related to challenges related to the wider Alzheimer Society rather than the First Link[®] Care Navigator specifically. One recommended that the name of the Alzheimer Society be changed because, “there is a stigma associated with Alzheimer’s and people don’t want to be associated with it.” The second recommendation to the Alzheimer Society is that there be more information available online because: “it can be difficult for caregivers to take the person out at night when they have worked all day, and on the weekends they want to rest.”

4. Ensure that PSWs are trained in dementia care so that they can provide the best respite care in the home when FLCN see a need for respite care.

Finally, a Medical Professional working with people living in rural areas in Southern Ontario identified the lack of Personal Support Workers trained specifically to work with people with dementia and cognitive impairments. She pointed out that this is a gap in healthcare in the province, and said:

“I truly wish there was a program. I’m not sure whether it would be volunteer. I wish they had some ability to manage a group of support people; people who would go in and provide respite. Well-educated. One of the challenges in the community is that our respite caregivers are usually PSWs from a contracted agency who don’t necessarily have expertise in dementia care. I don’t think there has been enough resources provided to people doing respite care to provide the best respite care possible in the home. They can sit there for four hours but they don’t know what to do in those four hours to make them productive. And the Alzheimer Society is one of the best organizations to actually be able to spearhead this.”

Challenges and Data Limitations

One limitation of the data is that while the research team made attempts to contact Physicians as part of this evaluation, none were available to participate. Instead, Nurses in a number of different community and clinical care settings, as well as other Medical Professionals, along with community service providers, participated in the System Partner Interviews.

In some sites across the province, respondents reported that the Alzheimer Society staff team provides seamless service to Persons Living with Dementia and their Care Partners. As a result, the System Partners interviewed were unable to differentiate service provided by the First Link[®] Care Navigator as compared to other members of the staff team. This was the case particularly for System Partners whose interaction with the Alzheimer Society is as a referring agency. However, all System Partners reported positive interactions, whether they usually connect with the First Link[®] Care Navigator or a staff in another position at the Alzheimer Society. In this case, positive interactions are defined as: (i) confidence that the Persons Living with Dementia and their Care Partner(s) will receive immediate and ongoing support from the Alzheimer Society; and (ii) confidence that the Alzheimer Society staff have in-depth knowledge of the community supports available to Persons Living with Dementia and their Care Partner(s) and will connect Persons Living with Dementia and their Care Partner(s) with the appropriate supports at the appropriate time.

This evaluation encountered several logistical constraints that limited the number of surveys completed by PLWD and CP. The logistical difficulties included: (1) only French-speaking clients in some societies (the request for a French survey came later into the data collection period, giving societies less time to have this survey completed); (2) being new to the program, (for some Societies it was not appropriate to carry out a survey since people were not yet familiar with the program); (3) data collection period challenging for some Societies (e.g., big fundraisers around Christmas time); and (4) difficulties in getting ahold of clients (some Societies do not see clients regularly face-to-face or only have contact with them by phone).

Report on Surveys

This report summarizes three different surveys conducted with Persons Living with Dementia, Care Partners, and First Link® Care Navigators.

Methodology

Persons Living with Dementia (PLWD) Survey

Each ASiO volunteered one evaluation coordinator (responsible for overseeing the survey process) and one survey volunteer (responsible for providing any survey taking support to PLWD clients) to assist with this survey. Both individuals attended a 2-hour training seminar on survey methods provided by CCBR. The evaluation coordinator from each ASiO then provided a de-identified list of all PLWD clients from their ASiO. Using this list, CCBR randomly selected PLWD clients within each ASiO and stratified the intended sample size using proportionate allocation. The evaluation coordinator at each ASiO then matched the CCBR randomly selected list with identifying information on the selected clients to confirm each client's functional ability to take the survey. If any PLWD client needed to be replaced, CCBR re-sampled from the de-identified list using a random-systematic sampling strategy. Once the list had been finalized, the evaluation coordinator then contacted the PLWD clients to notify them of their selection for the survey and to request their participation. All PLWD clients were given the option of either completing the survey online or on paper. All PLWD clients were also given the option of completing the survey unassisted, with the assistance of their Care Partners, or with the assistance of an ASiO survey volunteer. Any survey respondents who refused to complete the survey were substituted using the original de-identified survey respondent list using the same method of random-systematic sampling. The survey opened November 25, 2018 and closed at 6:00 pm on March 1, 2019. All received paper surveys were entered as digital surveys by CCBR staff.

The PLWD survey yielded 72 surveys and a response rate of 29%. Due to uneven response rates across ASiOs, the final survey data was not proportionately allocated according to ASiO PLWD client list size. Due to logistical constraints, 21 ASiOs were included in the final survey sample. Given the population size of 367 PLWD clients served by the included 21 ASiOs (and a 95% Confidence Level), this survey has an estimated 10% margin of error for any generalizations across the 21 ASiOs.

Care Partners (CP) Survey

The evaluation coordinator from each ASiO provided CCBR with a de-identified list of all CP clients from their ASiO. Using this list, CCBR randomly selected CP clients within each ASiO and stratified the intended sample size using proportionate allocation. The evaluation coordinator at each ASiO then matched the CCBR randomly selected list with identifying information on each client. The evaluation coordinator then contacted the selected CP clients to notify them of their selection for the survey and to request their participation. All CP clients were given the option of either completing the survey online or on paper. Any survey respondents who refused to complete the survey were substituted using the original de-identified survey respondent list through random-systematic sampling. The survey opened November 2018 and closed at 6:00pm on March 1, 2019. All received paper surveys were entered as digital surveys by CCBR staff.

The CP survey yielded 141 surveys and a response rate of 41%. Due to logistical constraints, 24 ASiOs were included in the final survey sample. Given the population size of 1752 CP clients served by the 24 ASiOs included in the survey (and a 95% Confidence Level), this survey has an estimated 8% margin of error for any generalizations across the 24 ASiOs. Due to uneven response rates across ASiOs, the final survey data was not proportionately allocated according to ASiO size.

First Link® Care Navigators (FLCN) Survey

The on-line survey for First Link® Care Navigators was opened in March 2019. All FLCNs who had been in their role for at least 3 months were requested to complete the survey. All 39 FLCNs who matched this criterion were approached to complete the online survey and, due to logistical constraints, 37 of these FLCNs were able to complete the online survey (95% response rate).

Demographics

Demographics of Persons Living with Dementia (PLWD)

A total of 72 Persons Living with Dementia responded to the survey. Of the 72 respondents, 31 (44.3%) completed the survey independently, 20 (28.6%) with the help of their Care Partner, and 19 (27.1%) with the help of a volunteer.

Of the total number of respondents, 30 (41.7%) identify as men while 42 (58.3%) identify as women. While the age range of respondents is between 56 to 90 years, with an average age of 76 years (SD=8.28). Of the 72 respondents, 22.7% report a total household income of less than \$25,000 per year, 63.7% report an income between \$25,000 to \$74,999, while 13.6% reported an income above \$75,000.

Sixty-five (90.3%) respondents speak English only at home. Seven speak one or more additional languages (e.g. French, German, Indonesian, and Cantonese, Mandarin, and Vietnamese), while one speaks only Swedish. Survey respondents identify with 29 different “ethnic origins.” The largest groups are 16 participants who identify as “Canadian” and 10 who identify as “English.”

Respondents are connected with 19 different Alzheimer Society locations; 46.2% were connected with within one month of diagnosis, 11.5% within more than one month, 17.3% within between 3- six months and 13.5% within one year. Of 72 respondents, 25 (36.2%) were first connected to the Alzheimer Society through information from their doctor, nine (13%) found the Alzheimer Society on their own and 16 (23.2%) heard about the Alzheimer Society from someone else.

Thirty-three (45.8%) of respondents report that they are “able to function independently” while 39 (54.2%) “require mild to moderate assistance and support.” In addition, 65.33% reported that they have dementia while the most common reported co-morbidities are Arthritis/Osteoarthritis (40%), Depression (40%), High Blood Pressure, and Stroke (37.33%).

Demographics of Care Partners (CP)

A total number of 141 Care Partners responded to the survey. Of respondents, 78 (55.3%) are family members, while 60 (42.6%) are spouses and one (0.7%) is a friend. Care partners range in age from 37 years to 90 years of age. The average age of CP respondents is 64 years (SD=11.77). In addition, 108 (76.6%) are women, while 32 (22.7%) are men. One person preferred not to identify their gender. Of the 141 survey respondents, 14.2% report a total household income of less than \$25,000, 56.6% report between \$25,000 to \$74,999, while 29.2% report a household income above \$75,000.

Most respondents (125 or 88.7%) speak English only at home; 10 speak one additional language (e.g., Dutch, French, German, Italian, Macedonian, Malayalam, Polish, Russian, or Spanish) at home, while three speak only a language other than English. Further, respondents identify with 40 different “ethnic origins.” The largest groups are 32 (22.7%) who identify as “Canadian,” 16 (11.3%) who identify as “Caucasian,” and 15 (10.6%) who identify as “English.”

The 141 Care Partners who responded to the survey are connected with 24 different Alzheimer Society locations. Forty-three (35.2%) report that it took less than one month from the time of diagnosis until they were connected to the Alzheimer Society, 12.3% report that it took more than one month, 19.7% reported that it took between 3-6 months, 14.8% report that it took 1 year, while 13.9% report that it took more than one year. Further 35 report that their doctor first connected them with the Alzheimer Society, 40 found the Alzheimer Society on their own, while 24 heard about the Alzheimer Society from someone else.

Demographics of First Link® Care Navigators (FLCN)

Of the 37 FLCN survey respondents, 14 are from South Western Ontario, seven are from South Central Ontario, seven are from Northern Ontario, five are from Central Ontario, while four are from Eastern Ontario. Of respondents, 28 reported that they work with both urban and rural clients, five said that they work with urban clients only, while four work with clients from rural areas only. Eighteen (50%) of the FLCN have a Social Work background, six (16.7%) a Nursing background, while 12 (33.3%) have a background in other areas including:

- ✓ Gerontology
- ✓ Activation Gerontology
- ✓ Recreation
- ✓ Therapeutic Recreation
- ✓ Developmental Services
- ✓ Psychology

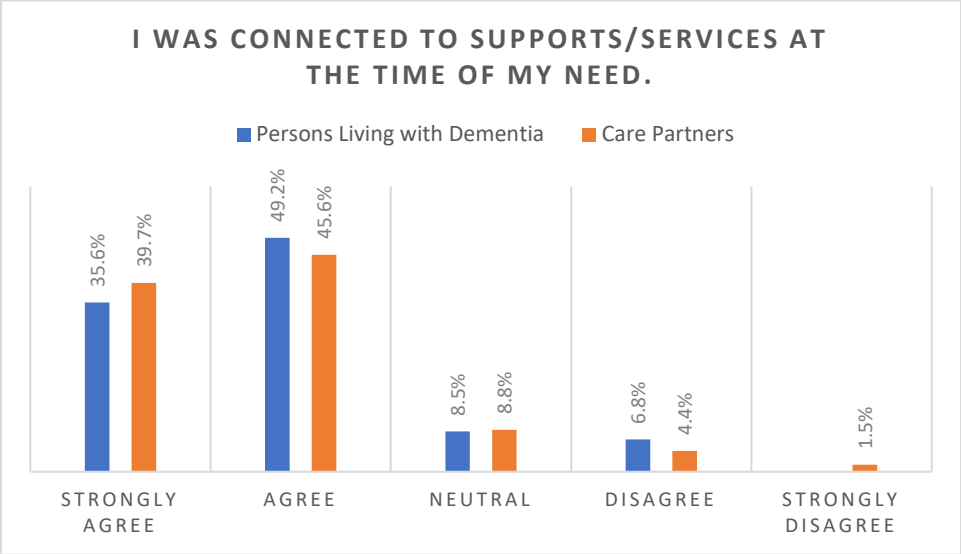
First Link® Care Navigators who responded to this survey worked at many different organizations in a wide variety of positions prior to their work as the First Link® Care Navigator. About 50% were employed at the Alzheimer Society prior to becoming First Link® Care Navigators; seven within the First Link® program. Thirteen worked for Community Services with other agencies; five worked in Long-Term Care facilities, hospitals or Health Clinics; while for two this is their first job following graduation.

Findings by Research Question

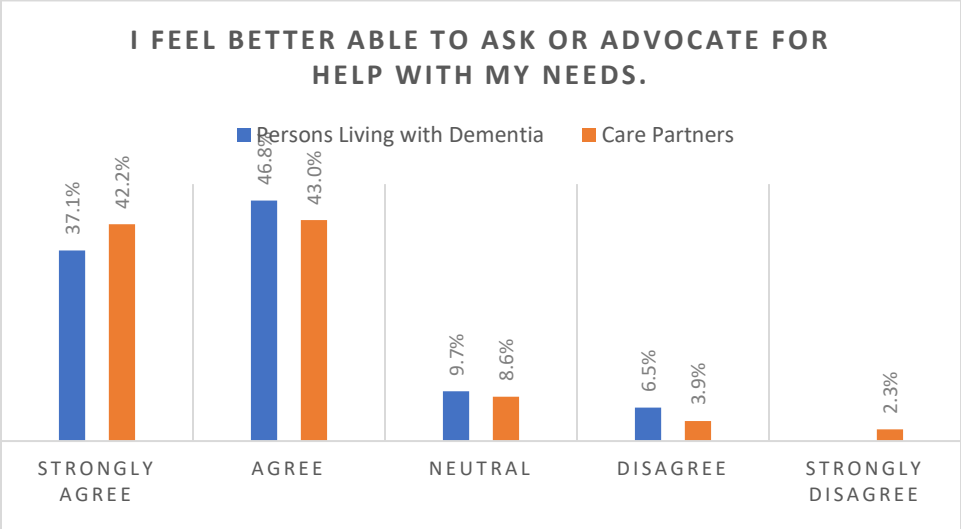
Research Question 1: Program Outcomes

Impacts on PLWD and CP

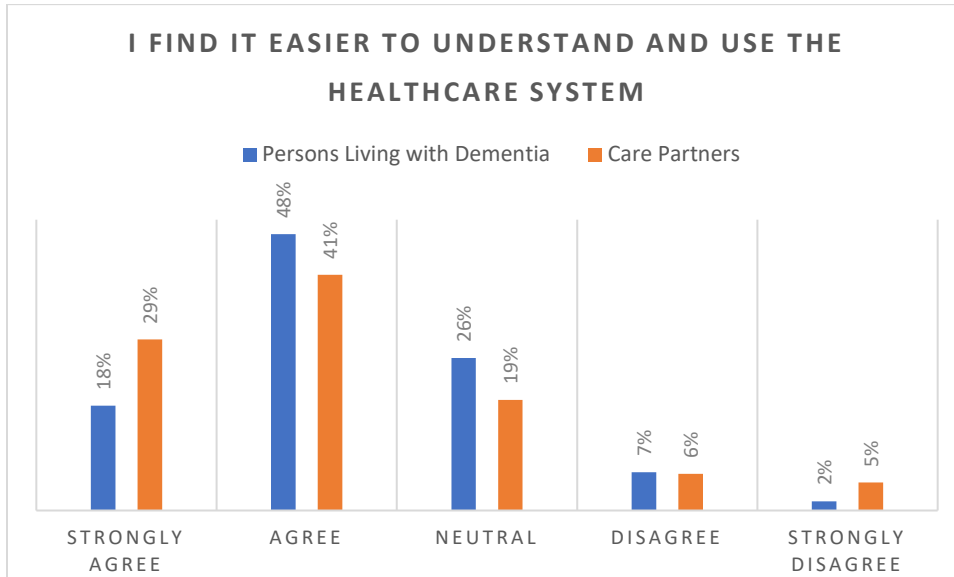
Overall, 84.8% of Persons Living with Dementia and 85.3% of Care Partners agree or strongly agree that they were connected to supports/services at the time of their need.



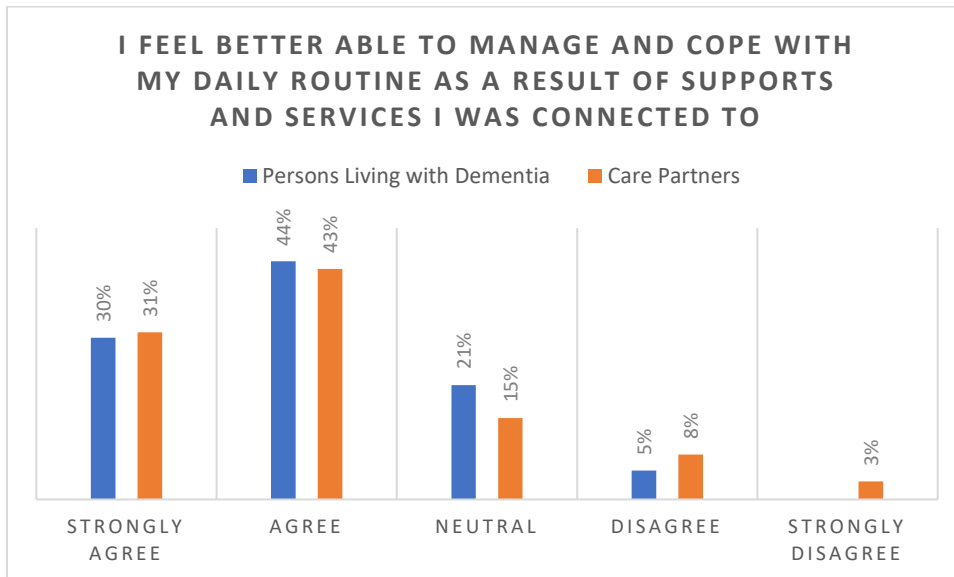
Of respondents, 83.9% of Persons Living with Dementia and 85.2% of Care Partners agree or strongly agree that they feel better able to ask or advocate for help with their needs.



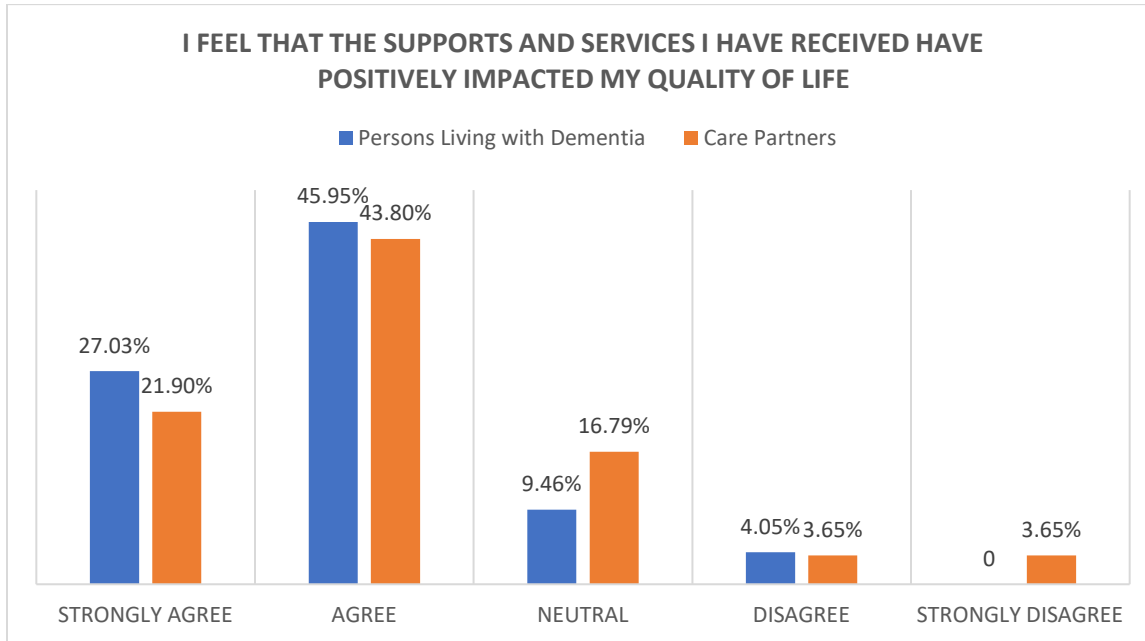
Further, 66% of Persons Living with Dementia and 70% of Care Partners find it easier to understand and use the Healthcare System.



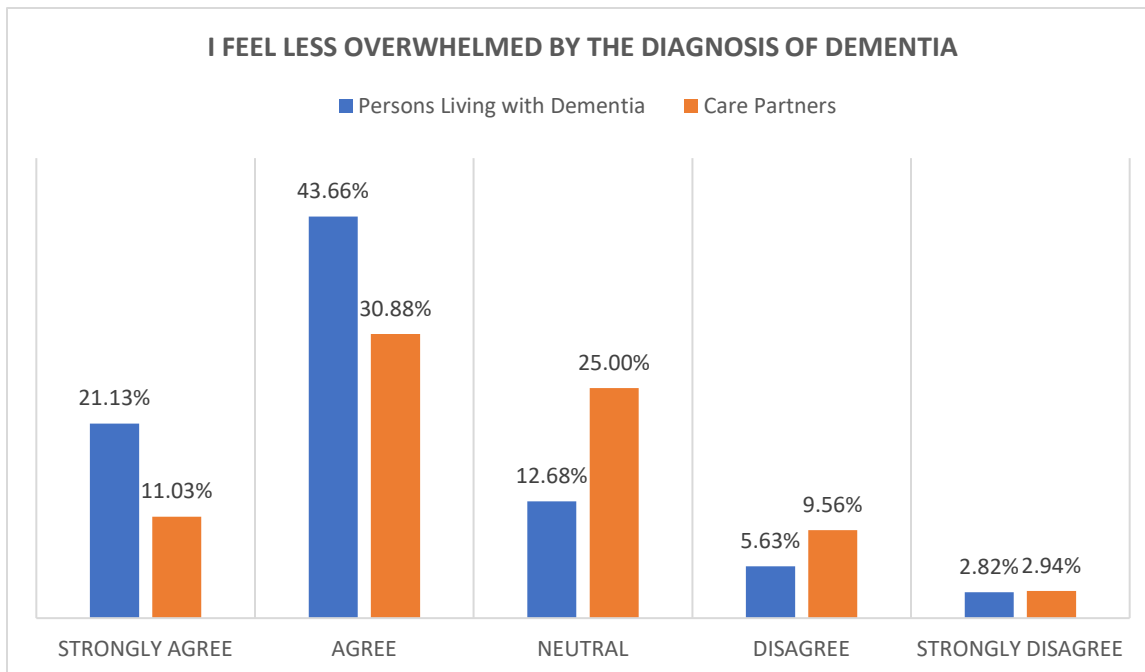
While 74% of Persons Living with Dementia and 74% of Care Partners feel better able to manage and cope with their daily routine as a result of supports and services they were connected to.



In addition, 72.98% of Persons Living with Dementia and 65.7% of Care Partners feel that the supports and services they have received have positively impacted their quality of life.

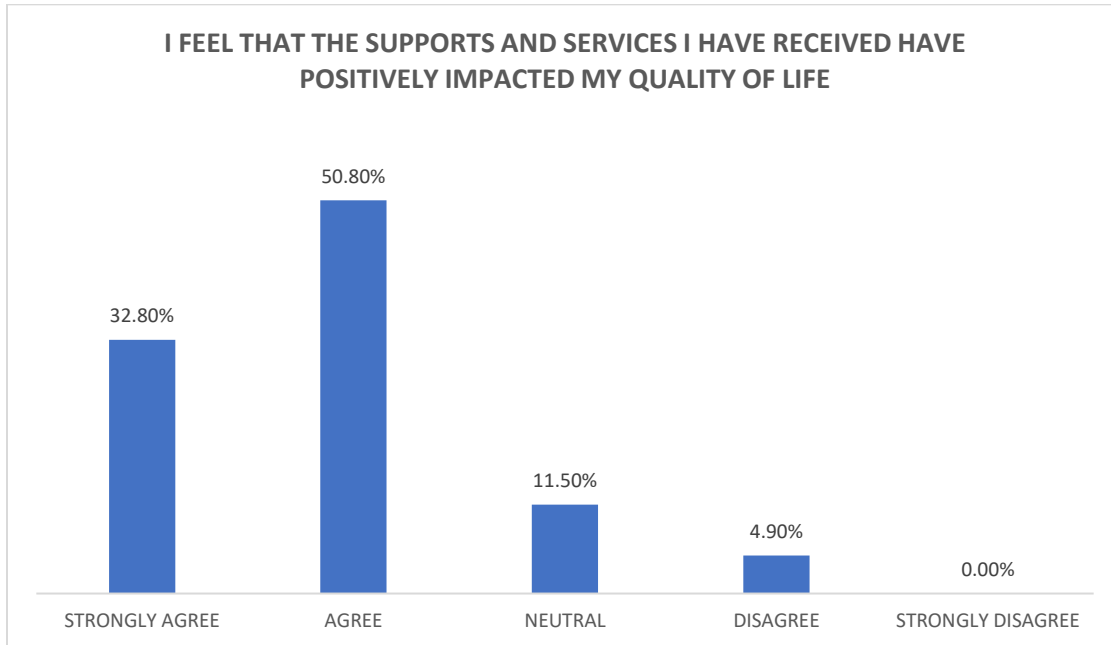


Also, 64.79% of Persons Living with Dementia and 41.91% of Care Partners feel less overwhelmed by the diagnosis of dementia.

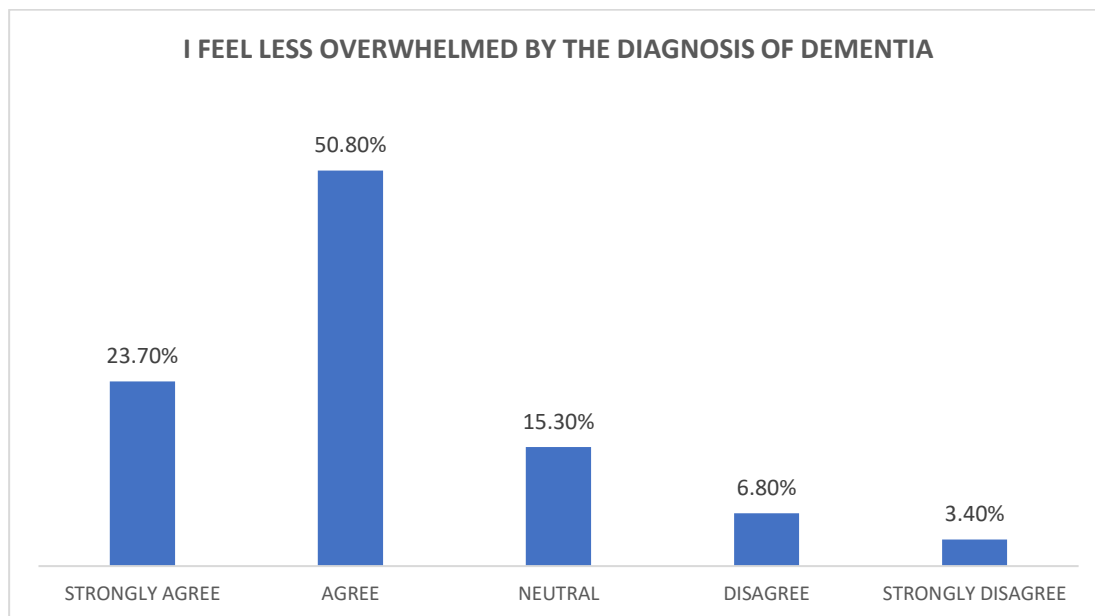


Impacts on PLWD Only

In the last 90 days, for Persons Living with Dementia, the number of visits to a Doctor or Nurse Practitioner about their health ranged from 0-25 with a median of 2 and an average of 3.22 (SD=4.58). Of Persons Living with Dementia who responded, 83.6% agree or strongly agree that the supports and services received from the Alzheimer Society have positively impacted their quality of life.

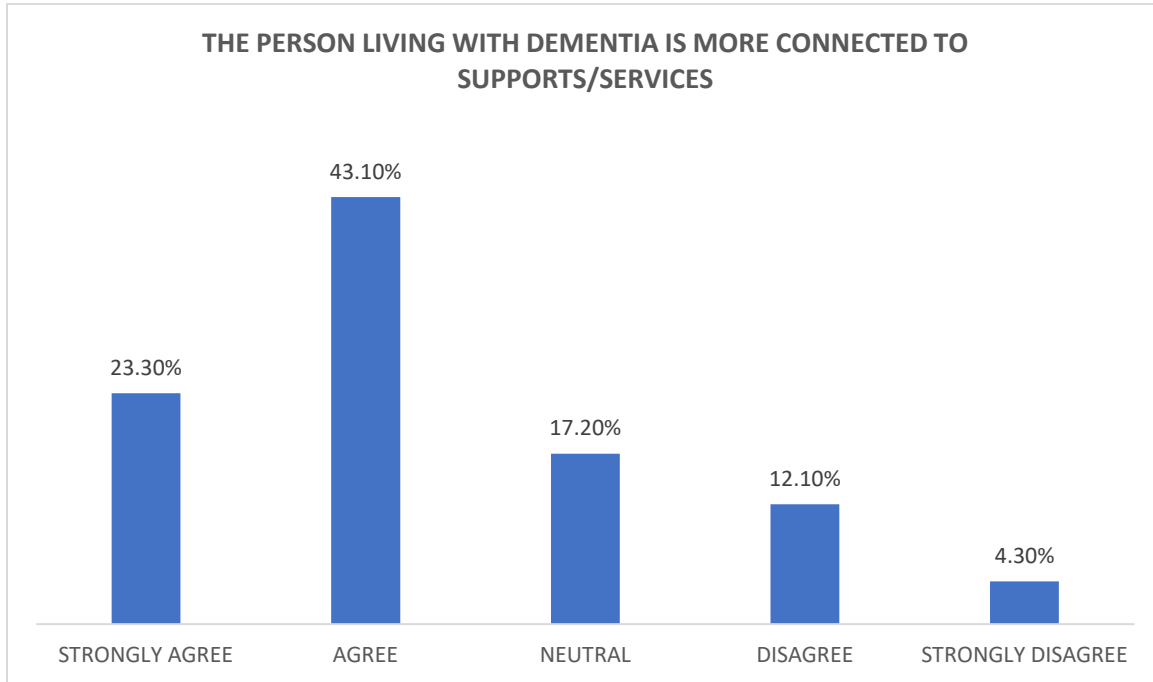


Further, 74.5% of Persons Living with Dementia who responded agree or strongly agree that the supports and services from the Alzheimer Society have led to feeling less overwhelmed by the diagnosis.

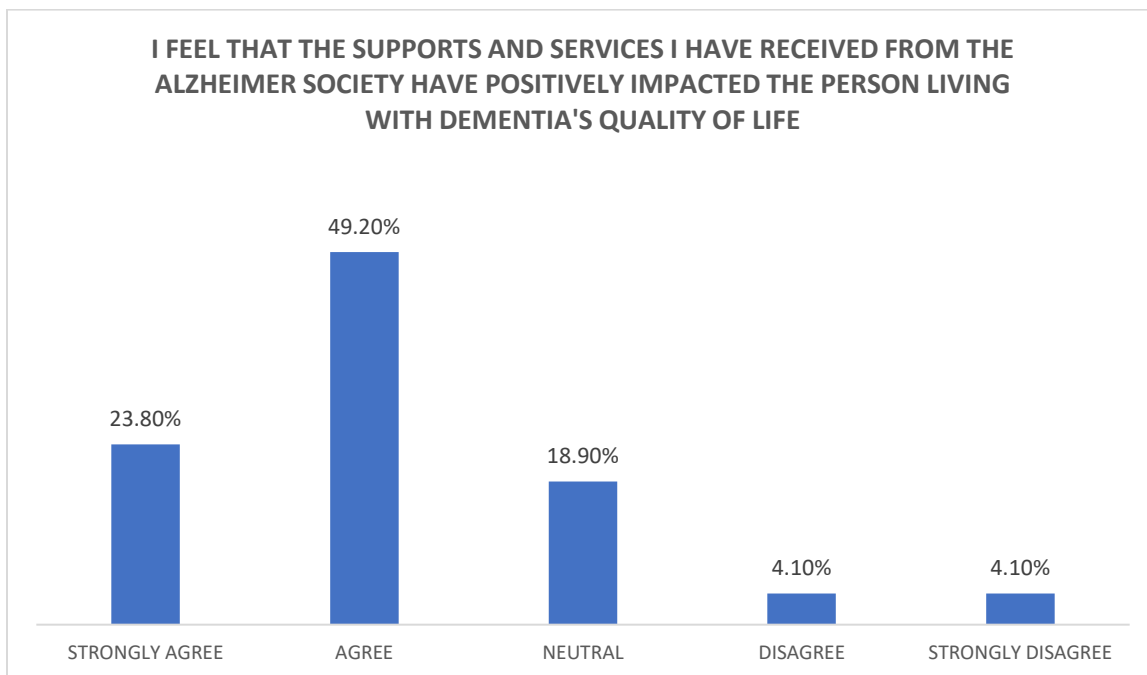


Impacts on PLWD as Reported by CP

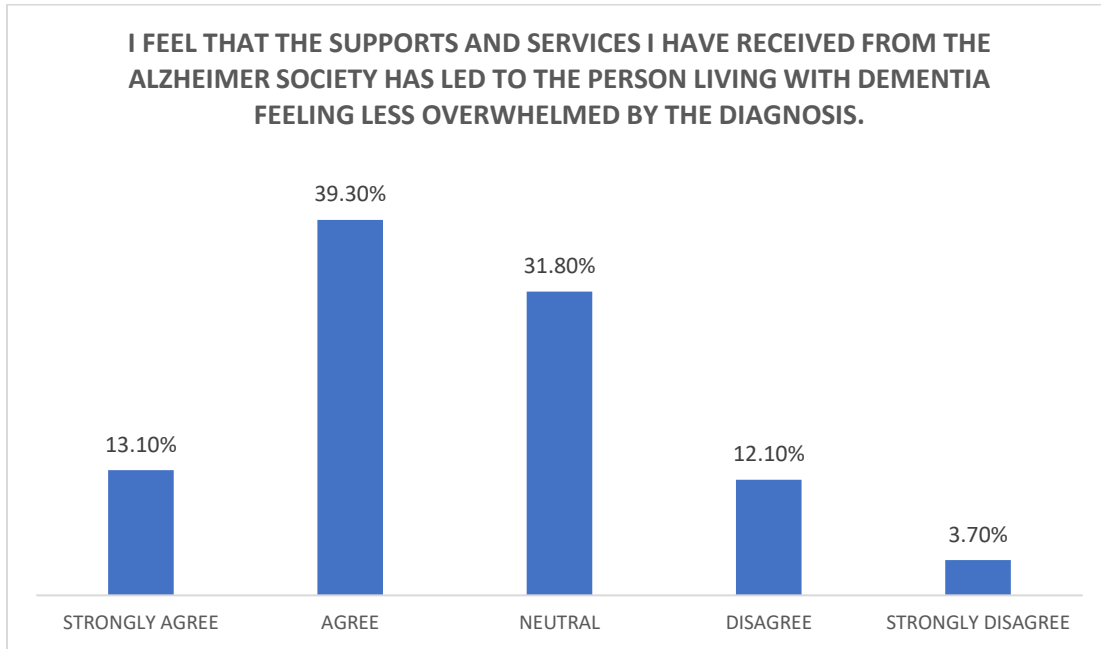
Also, 66.4% of Care Partners agree or strongly agree that the person living with dementia is more connected to supports/services.



Of Care Partners who responded, 73% agree or strongly agree that the supports and services received from the Alzheimer Society have positively impacted the quality of life of the person living with dementia.

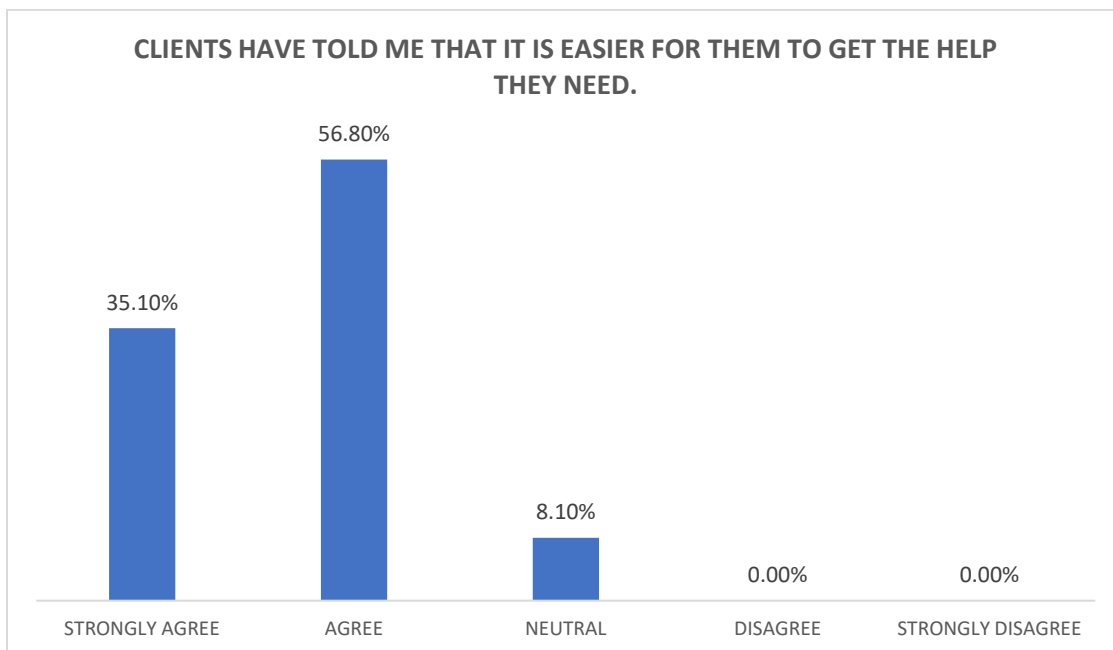


Further, 52.4% of Care Partners who responded agree or strongly agree that the supports and services from the Alzheimer Society have led to the person living with dementia feeling less overwhelmed by the diagnosis.

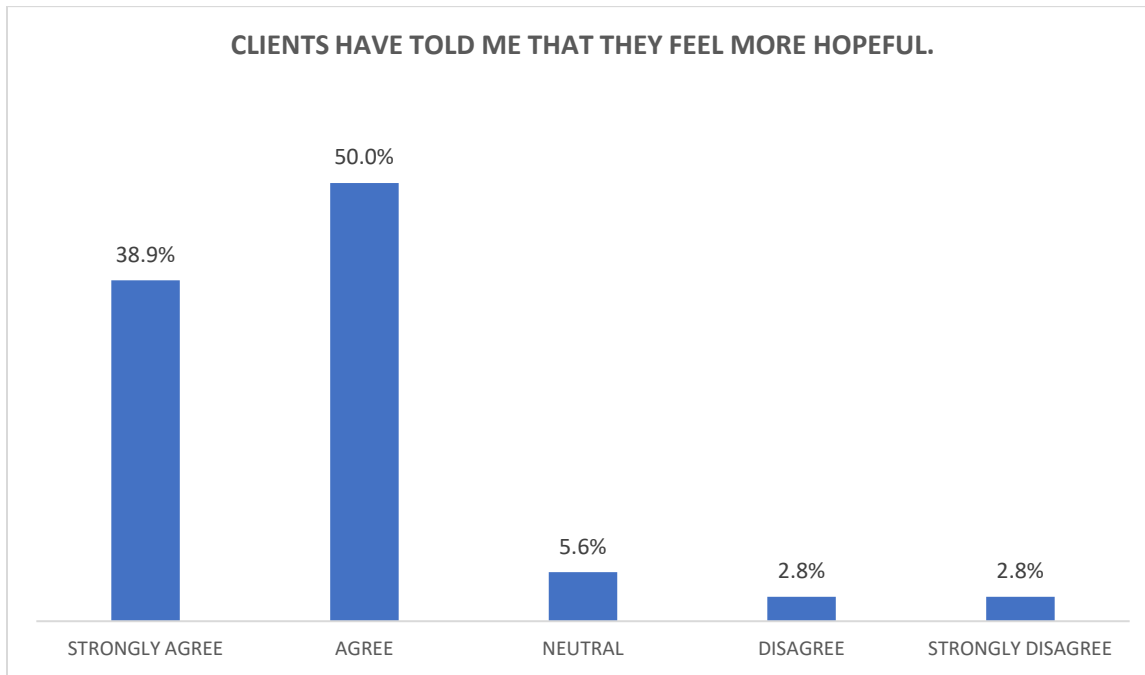


Impacts on PLWD as Reported by FLCN

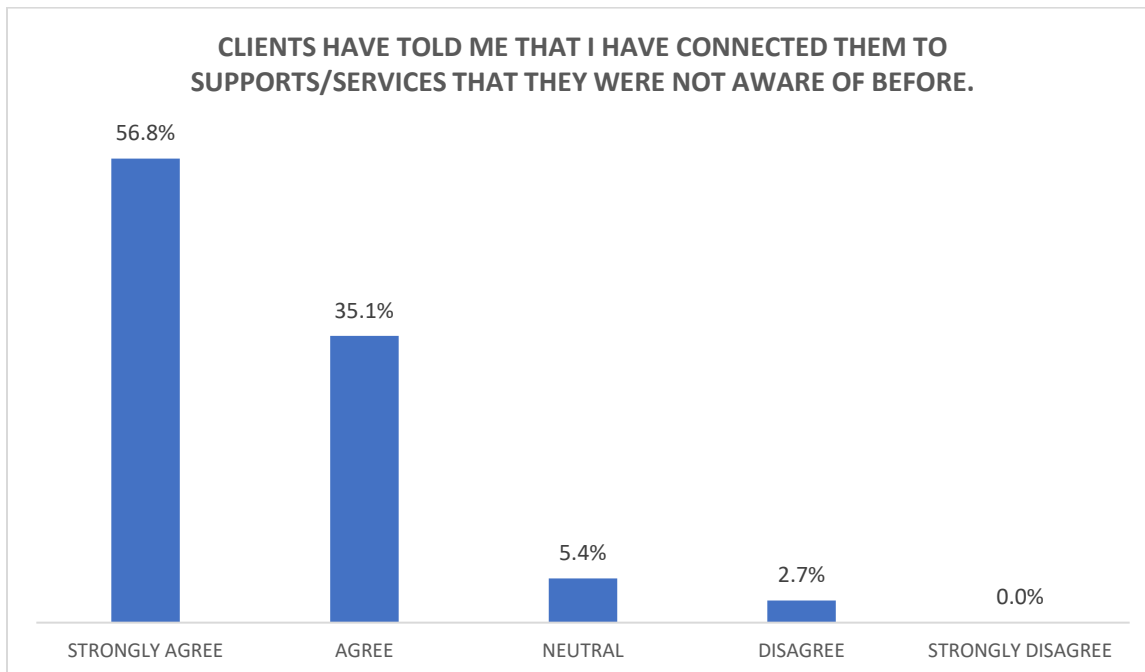
Overall, 91.9% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia have told them it is easier for them to get the help they need.



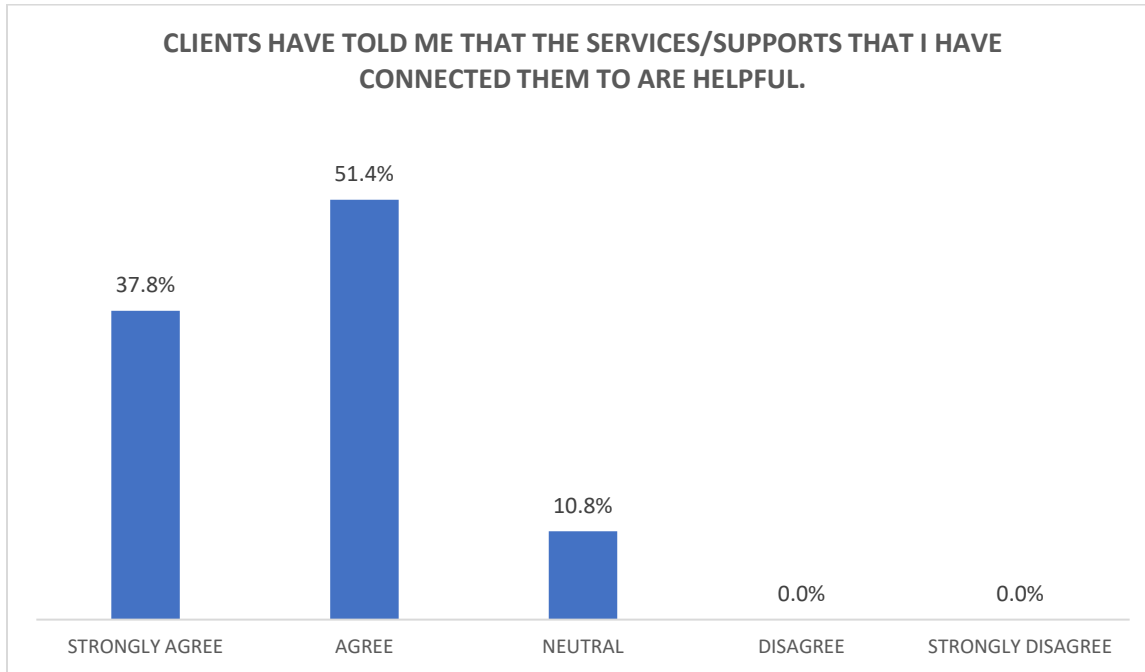
While 88.9% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia have expressed that they feel more hopeful.



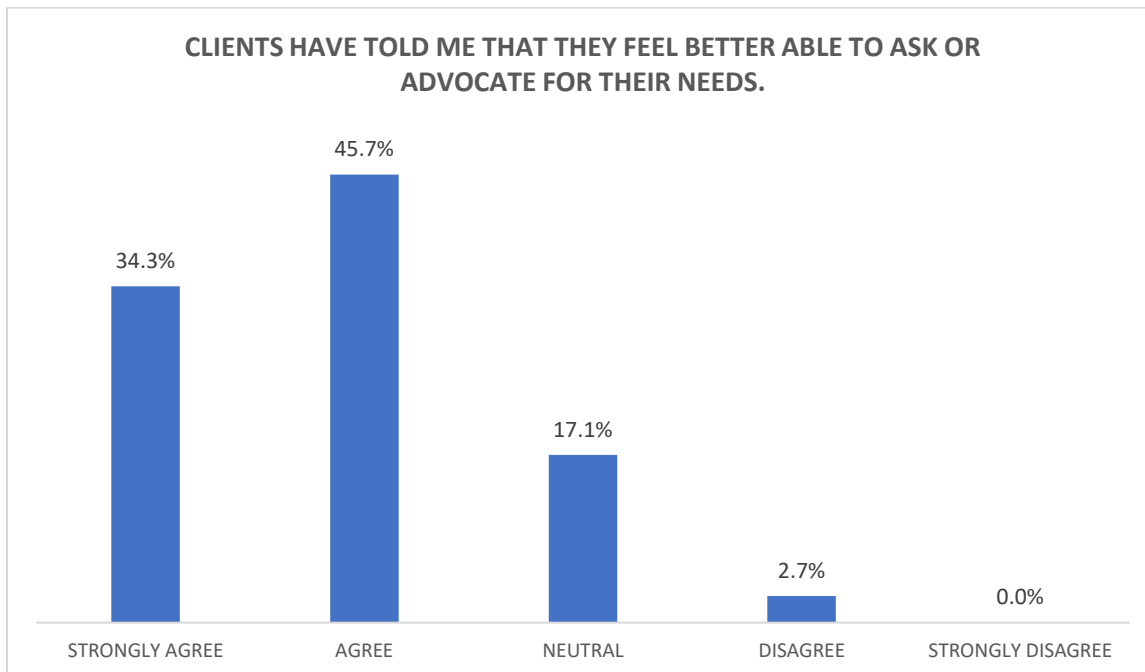
Further, 91.9% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia said that they have connected to supports/services they were not aware of before.



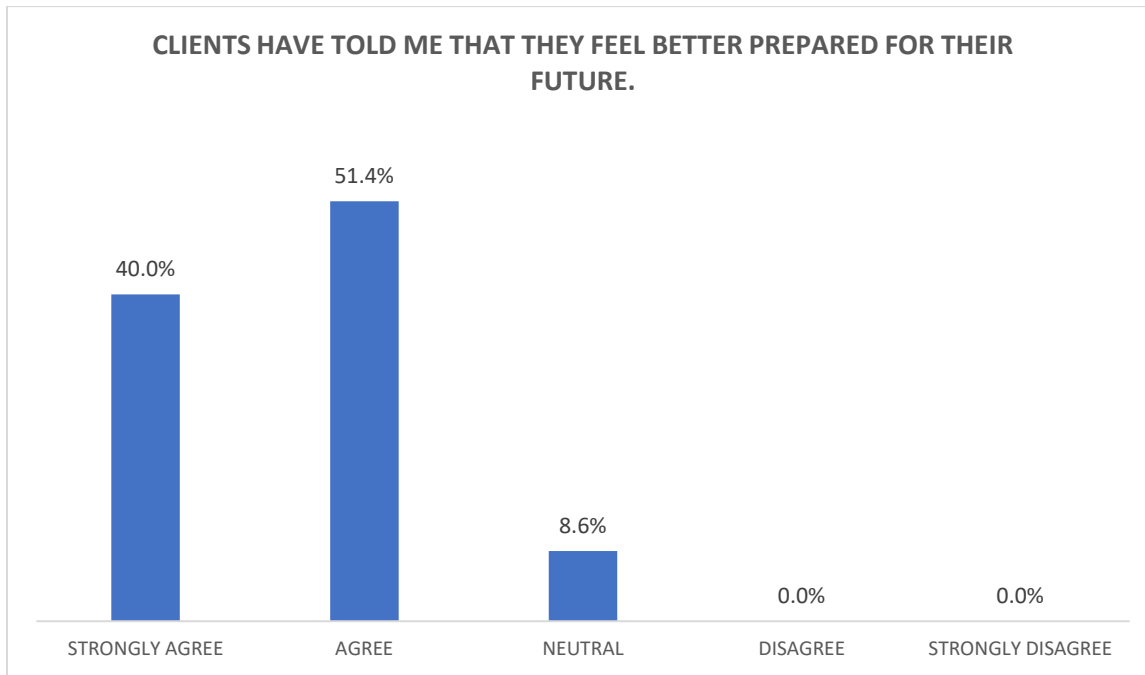
Also, 89.2% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia have expressed that the services/supports they have been connected to are helpful.



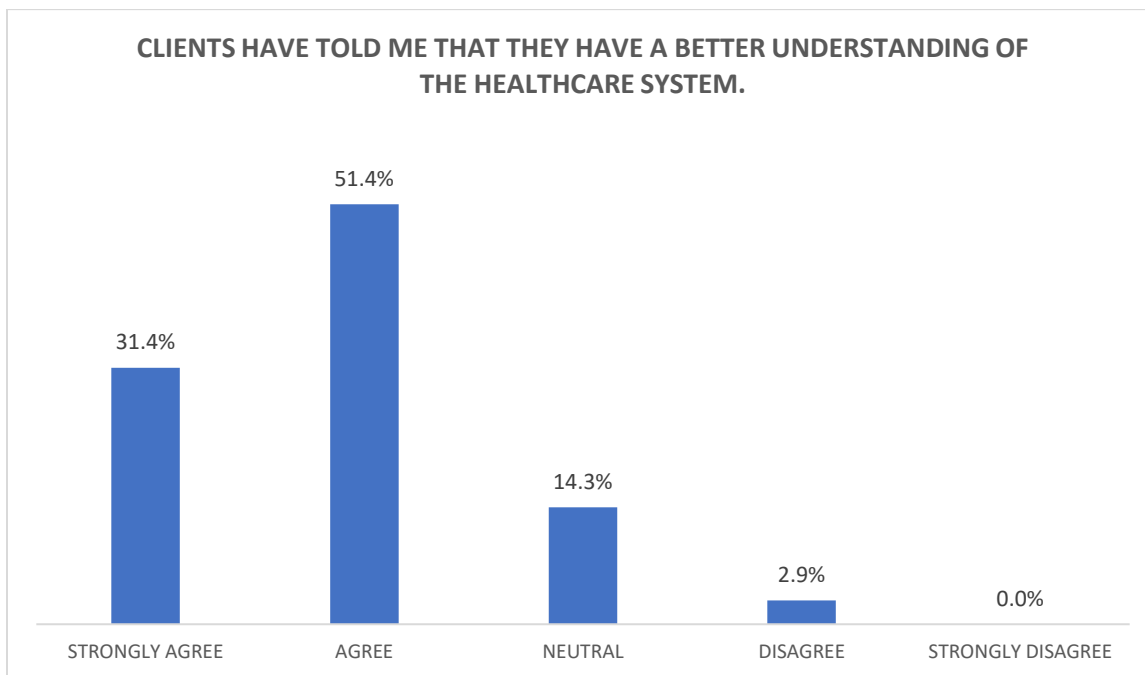
As well, 80% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia have said they feel better able to ask or advocate for their needs.



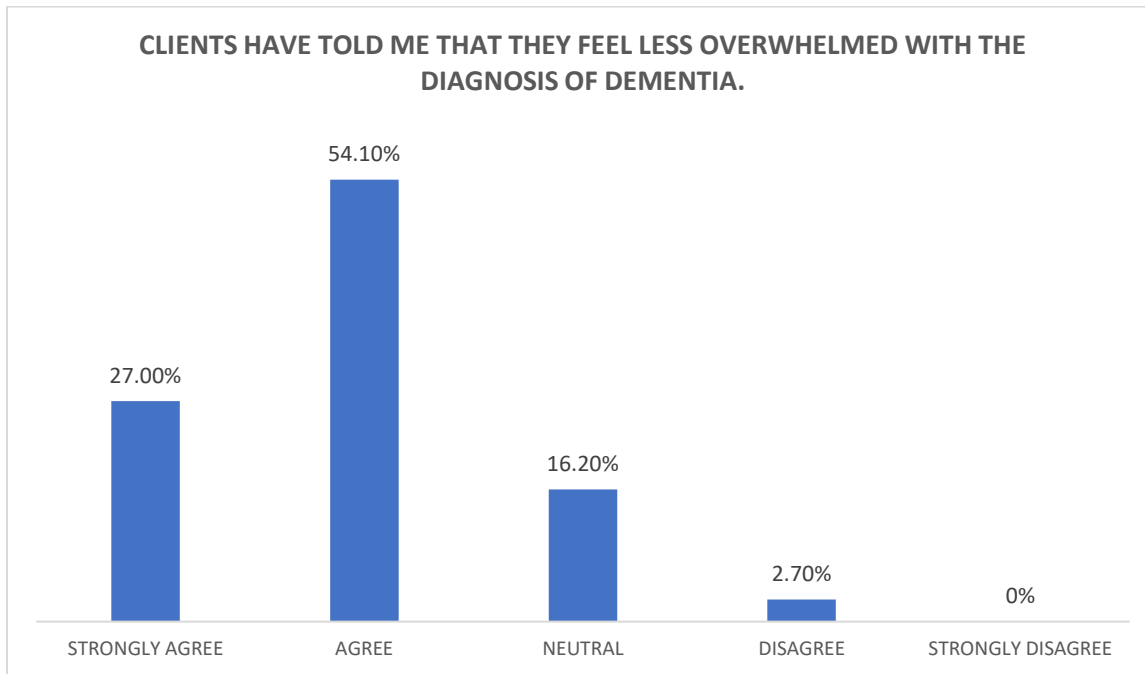
In addition, 91.4% of First Link[®] Care Navigators who responded agree or strongly agree that Persons Living with Dementia indicated that they feel better prepared for their future.



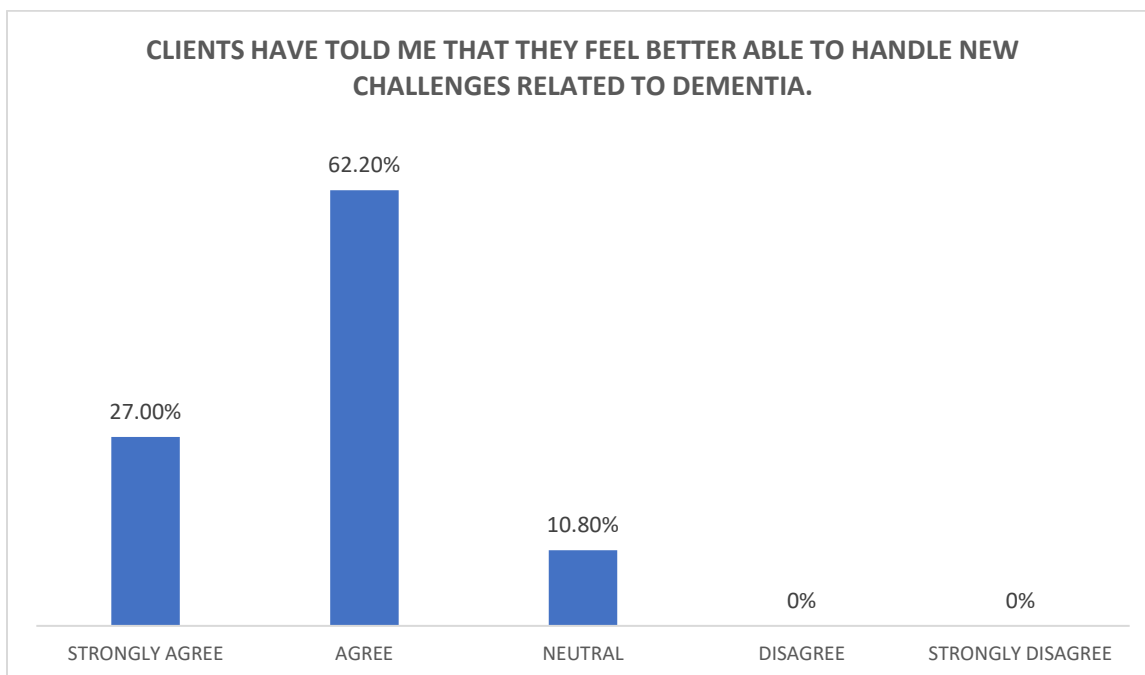
As well, 82.8% of First Link[®] Care Navigators who responded agree or strongly agree that Persons Living with Dementia report a better understanding of the Healthcare System.



In addition, 81.1% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia have reported that they feel less overwhelmed with the diagnosis of dementia.

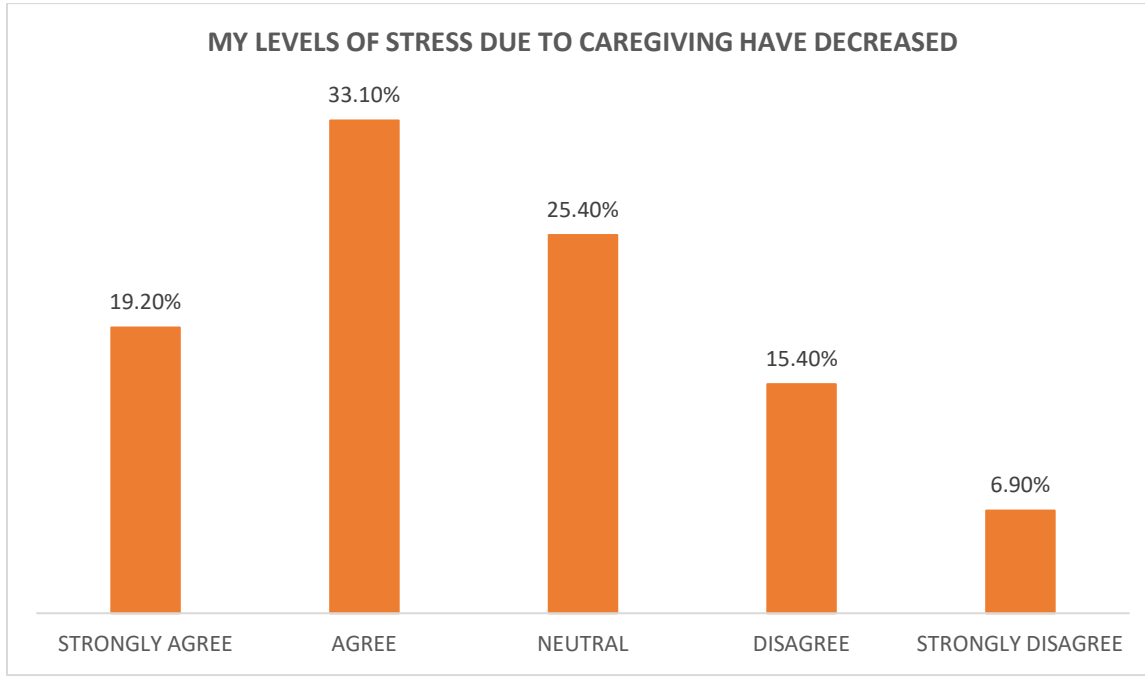


Finally, 89.2% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia have said they feel better able to handle new challenges related to dementia.

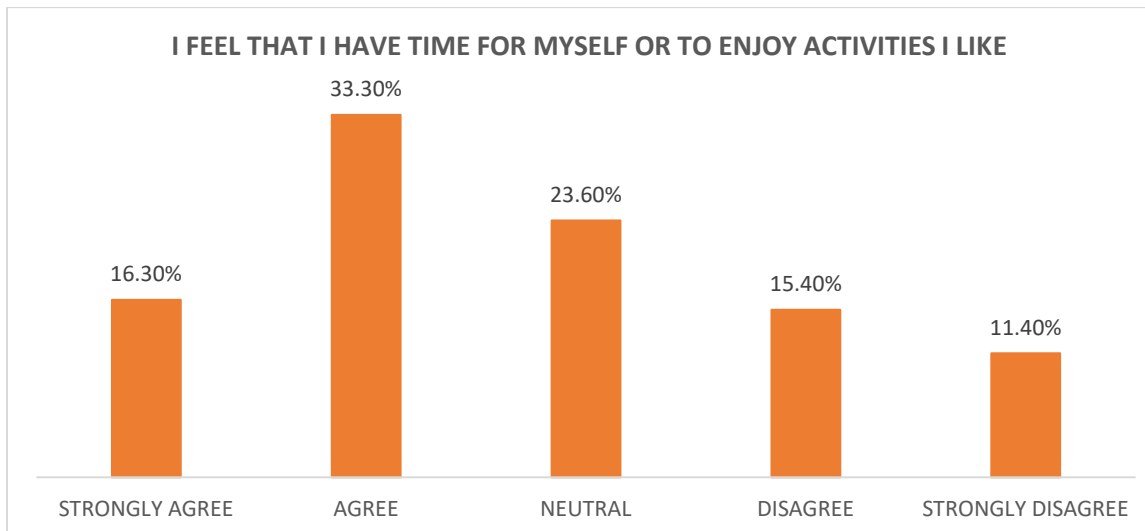


Impacts on CP Only

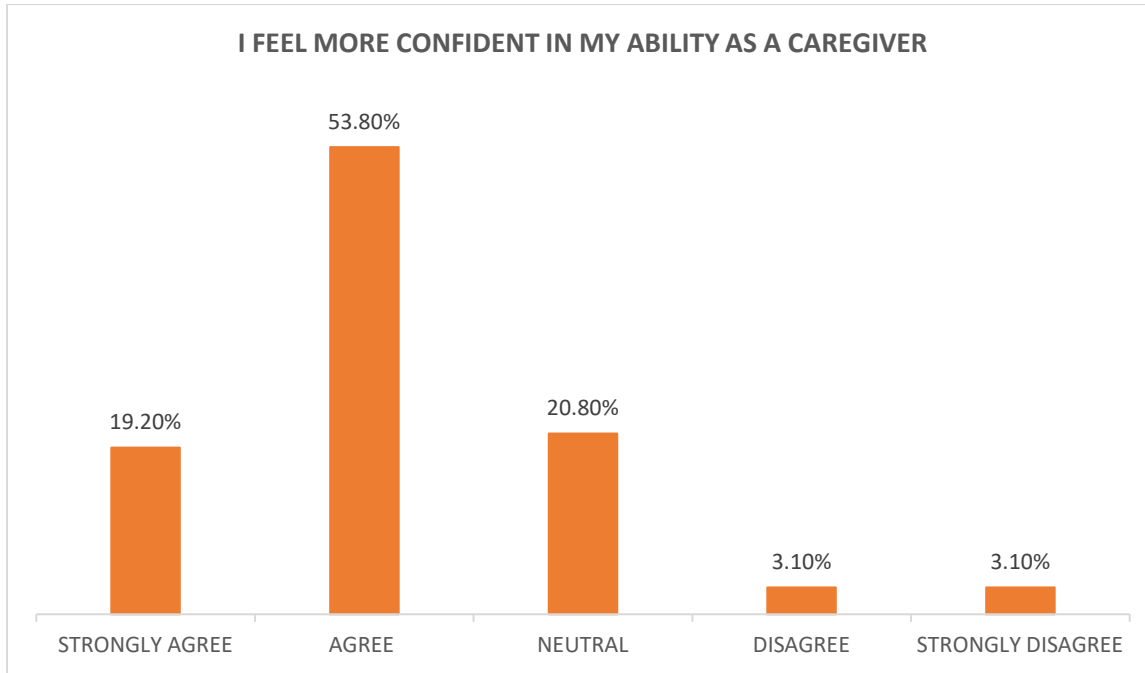
Overall, 52.3% of Care Partners who responded agree or strongly agree that their levels of stress due to caregiving have decreased.



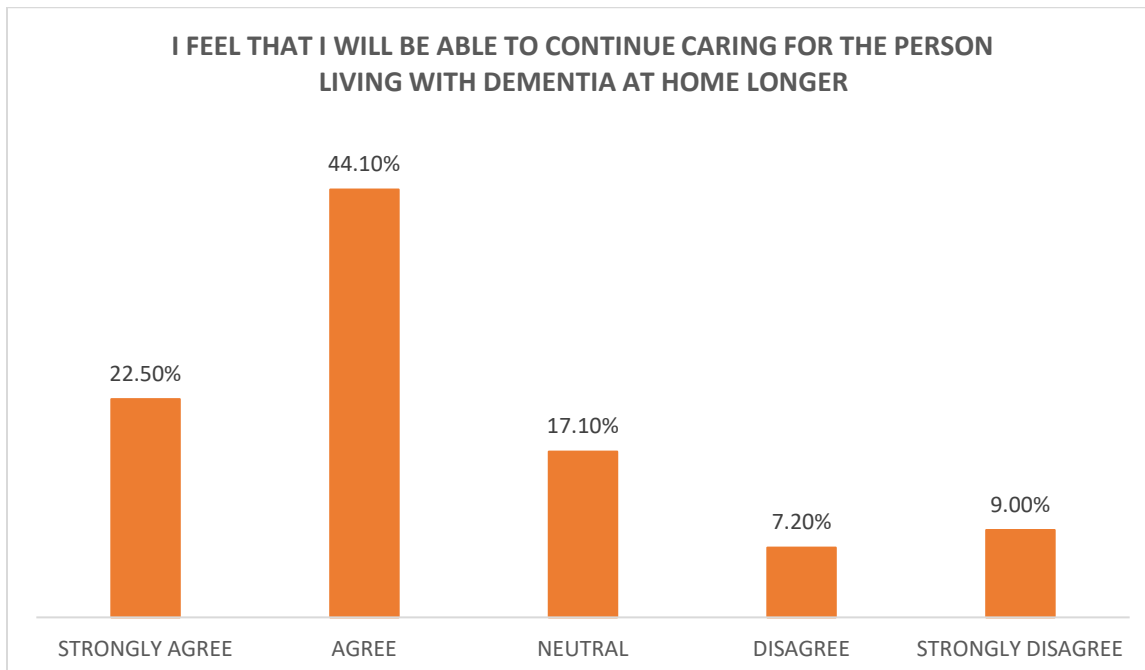
While 49.6% of Care Partners agree or strongly agree that they have time for themselves to enjoy activities they like.



Further, 73% of Care Partners agree or strongly agree that they feel more confident in their ability as a caregiver.

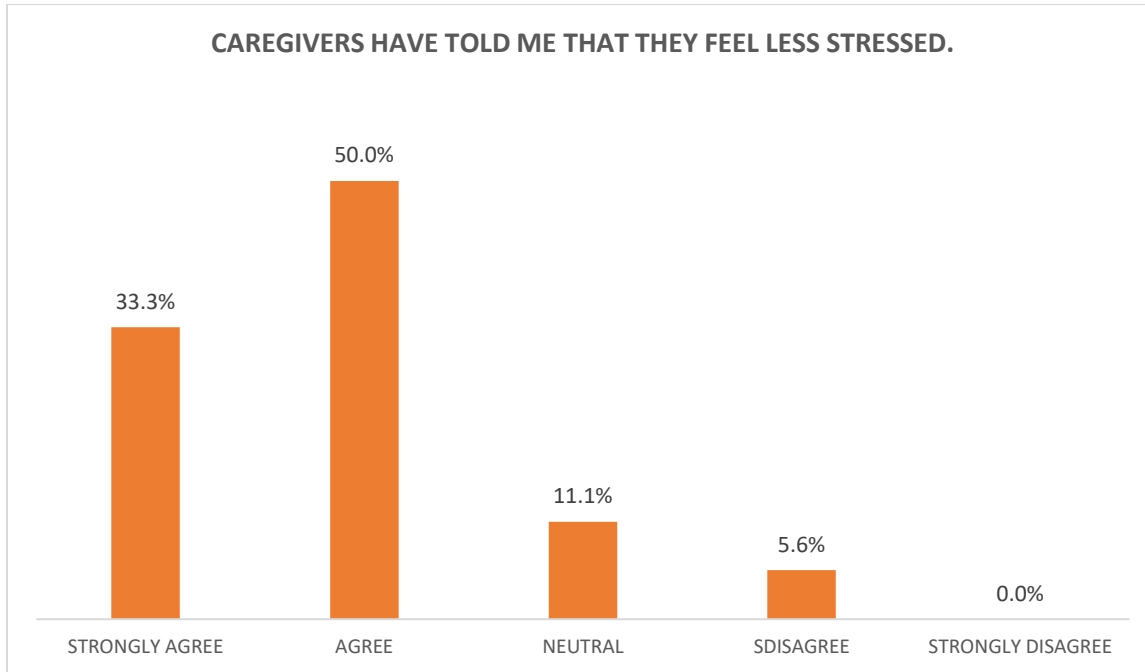


Care Partners report that the number of visits to a doctor or nurse practitioner in the last 90 days ranged from 0 to 15 times with a median of 1 and a mean of 1.61 (SD=2.13) for their own health. Overall, 66.6% agree or strongly agree that they will be able to continue caring for the person living with dementia at home longer.

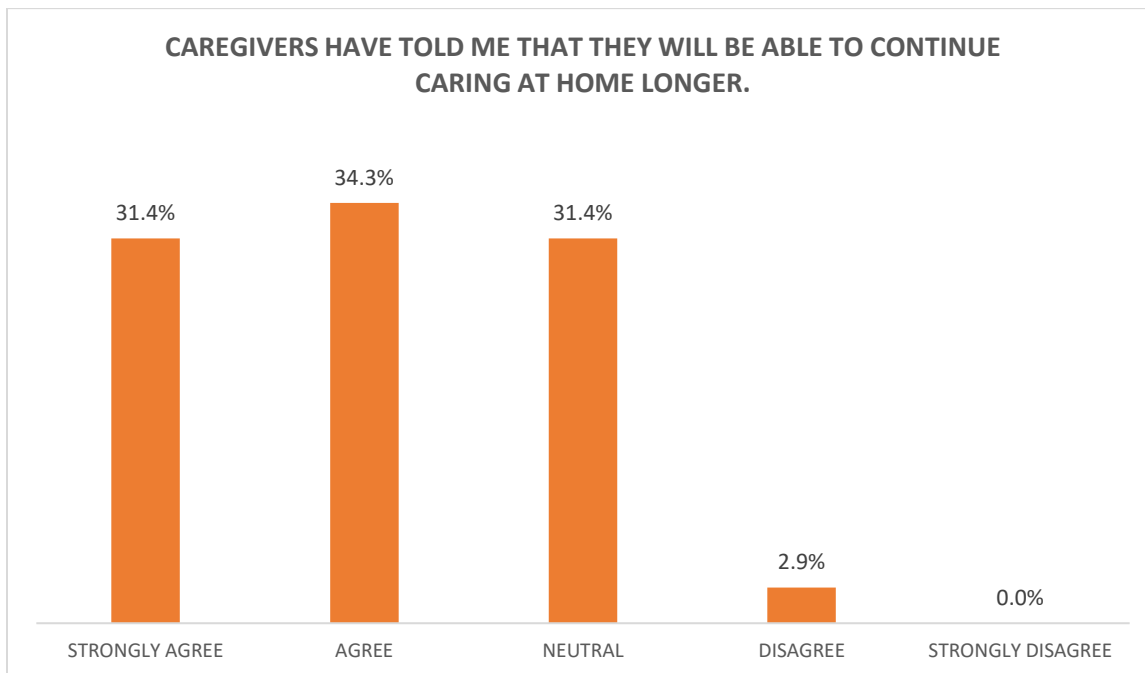


Impacts on CP as Reported by FLCN

Of respondents, 83.3% of First Link® Care Navigators agree or strongly agree that Care Partners report feeling less stressed.



As well, First Link® Care Navigators who responded agree or strongly agree that 65.7% of Care Partners report they will be able to continue caring at home longer.



PLWD and CP Perspectives on Program Impact (based on Qualitative Data)

The information presented below was provided in response to the open-ended questions at the end of each survey. Both Persons Living with Dementia and their Care Partners were asked to provide comments about the First Link[®] Care Navigation program. The main six themes emerged:

1. First Link[®] Care Navigators and the Alzheimer Society ensure that Persons Living with Dementia and their Care Partners have social connections and experience a sense of community.

“I am very independent, and I am depressed so don't join as many things as I should. Not having support from family, I am grateful for your services.” (Person Living with Dementia)

“I found the Ropes program in Goderich to be very helpful. It makes you realize you are not alone. The staff was excellent. Thank you.” (Person Living with Dementia)

“I think the FLCN is a terrific person. The only person who calls to see how I am doing. The FLCN connected me to many services I did not know about.” (Care Partner)

2. First Link[®] Care Navigators contribute to clients feeling less overwhelmed, less stressed, and better able to cope.

“It is very helpful to hear what is available and to have someone to talk to, so I don't feel so overwhelmed and alone by the diagnosis of Lewy Body Dementia.” (Person Living with Dementia)

“I feel that I better understand dementia. And my wife and I feel more equipped to live with memory issues and know more about the help that is available.” (Person Living with Dementia)

“Your services have given all of the family some peace of mind and relieved some of stress knowing that there are services available that will give us all a break. It's good knowing that as she progresses, there are programs ready to assist us.” (Care Partner)

3. There is not enough help with only First Link[®] Care Navigators.

“I wish that we could have had more time given to us for support to care for Dad at home. We had to put him in a nursing home. Families would like to keep their loved ones at home till possible. Link [FLCN] should ask the government for more personal support workers to help caregivers so they could keep loved ones home. We hear that it is better for the elderly to be kept in their own environment, but this is impossible for we don't have help.” (Care Partner)

4. First Link[®] Care Navigators are helpful in providing realistic advice to clients, so they can make informed decisions.

“It is particularly helpful when the Care Navigator has had direct experience working within the supportive housing or community support services sectors and can advise on how these systems “really” work vs. what is on a website or what one is told by the first contact at a given agency.” (Care Partner)

“I recommend that the Alzheimer Society Service be contacted first. We could have saved a lot of frustration, stress and grief if the doctor would have referred us to the Alzheimer Society Service first.” (Care Partner)

5. The importance of an early referral to the Alzheimer Society and the ongoing support by First Link[®] Care Navigators cannot be overstated.

“I was connected extremely late to the Alzheimer’s Society. Once I was connected, the one on one support was helpful to feel heard. The meditation class they connected me with was a life saver. I use it still every day. Sometimes more than once a day. If I had been connected earlier, it would have been helpful to join things organized with my Mom, but it was a little late by that point for me to do. I think the doctors need further education. The test for dementia and Alzheimer’s is so simple that is done at the doctor’s office; it does not capture what a caregiver sees. I asked for help for years at the doctor level and was continually told that she was fine. Very frustrating. I asked for help many times even once I was connected with the GAIN Clinic and the Central East LHIN, specifically saying, “I know I look fine but I’m not fine. I need help.” But I guess I always looked fine, so I didn’t get the necessary help from the Healthcare System. Funny, I forgot how horrible the journey had been until I’m remembering it right now. In conclusion, Alzheimer Society helped me because I was connected, free of charge, to a meditation class that has let me deal with pressures of life. And the one on one sessions that Victoria did for me made me feel respected and heard. Thank you for that.” (Care Partner)

6. There is not enough information available to the community about the First Link[®] Care Navigation program.

“Website difficult to navigate. Hard to locate key Care Navigators. Only got a Care Navigator via your social worker who conducted our First Steps workshop. Alzheimer Society should invest heavily in making website much more user-friendly (especially considering your clientele and potential donors).” (Care Partner)

FLCN Perspectives on Program Impact (based on Qualitative Data)

The information presented below was provided in response to the open-ended questions at the end of the survey. FLCN were asked about their perspectives on how the First Link[®] Care Navigation program impacted clients’ quality of life and on their role in this process.

The main four themes emerged:

1. Clients experience an improved quality of life due to the program.

“It is improving quality of life, especially for those that are isolated or that have family far away. Clients are able to remain in their home longer, are able to get the support they require sooner, are being educated about the supports available sooner which alleviates stress down the road for caregivers as well as those living with a diagnosis. Home visits are appreciated for those that struggle to leave their home.” (First Link® Care Navigator)

“Clients are getting more intentional follow up than before and clients are accessing more services and programs within Alzheimer Society and community organizations, essentially helping them live well and at home longer.” (First Link® Care Navigator)

2. Persons Living with Dementia and their Care Partners are more hopeful and better able to navigate the healthcare system.

“I believe First Link® is drastically improving supports, teaches clients how to navigate a complicated health care system and is getting people into education and support groups etc. faster. People often say, “I can't believe I got to speak with someone today.” They leave feeling hopeful and more ready to take on the heavy responsibilities they are facing.” (First Link® Care Navigator)

“Clarifies what the client wants and how to go about making it happen. First Link® Care Navigators help clients break down issues into solvable problems and reduce feelings of hopelessness and helplessness.” (First Link® Care Navigators)

3. First Link® Care Navigators are contributing to decreased hospitalization and crisis.

“Clients are connected to Alzheimer Society more quickly; able to access services more quickly. This is decreasing hospital stays, crisis, care partner burnout, and Long-Term Care transitions.” (First Link® Care Navigator)

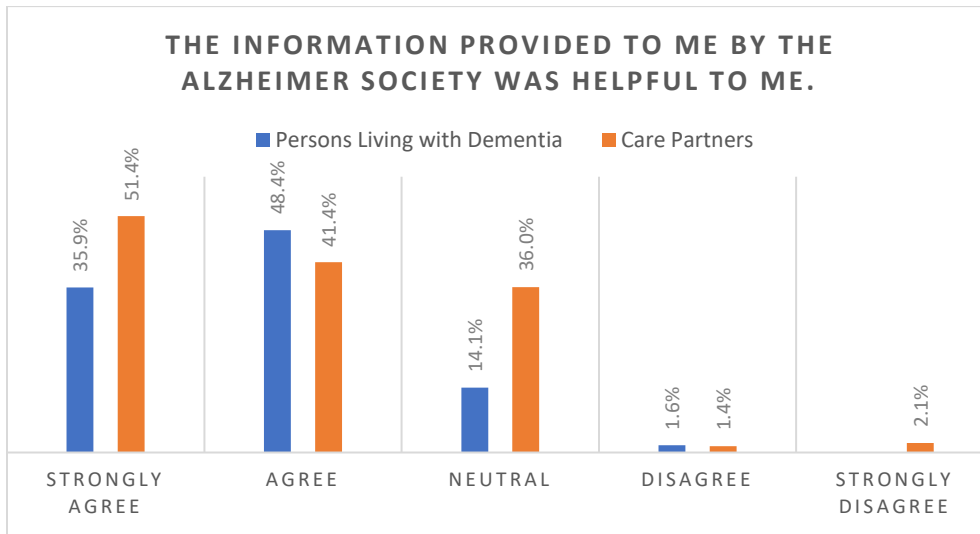
4. First Link® Care Navigators lead by example and strengthen the ability of Persons Living with Dementia and their Care Partners to navigate the Healthcare System.

“By providing knowledge of what's out there, including Alzheimer Society services, we are empowering our clients to help them cope with the disease. Also, showing by example empowers our clients to continue to advocate on their own behalf.” (First Link® Care Navigators)

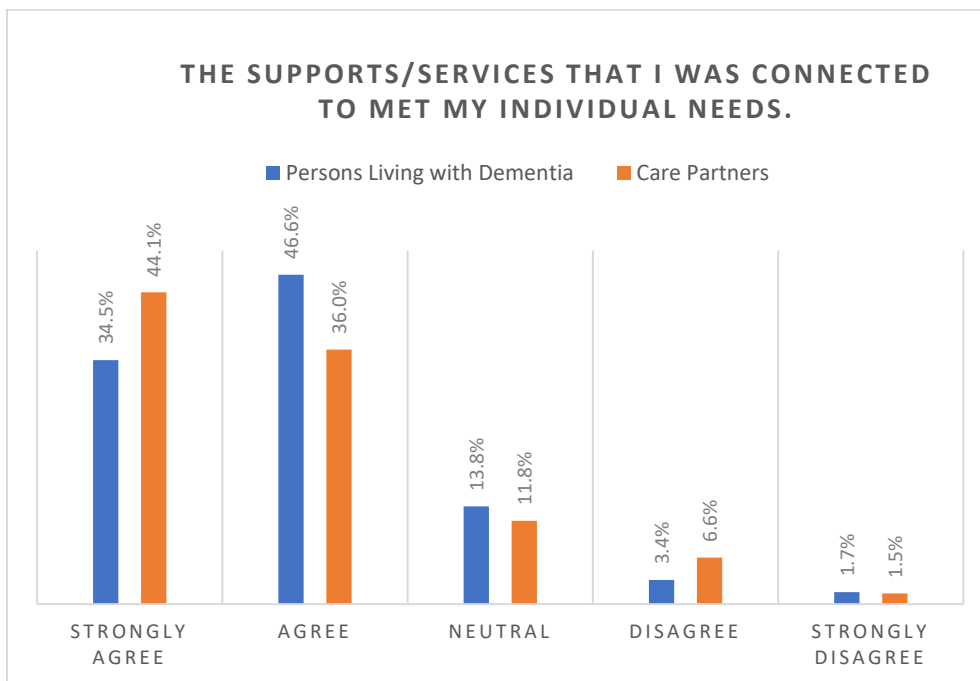
Research Question 2: Program Implementation Processes

Program Implementation as Experienced by PLWD and CP

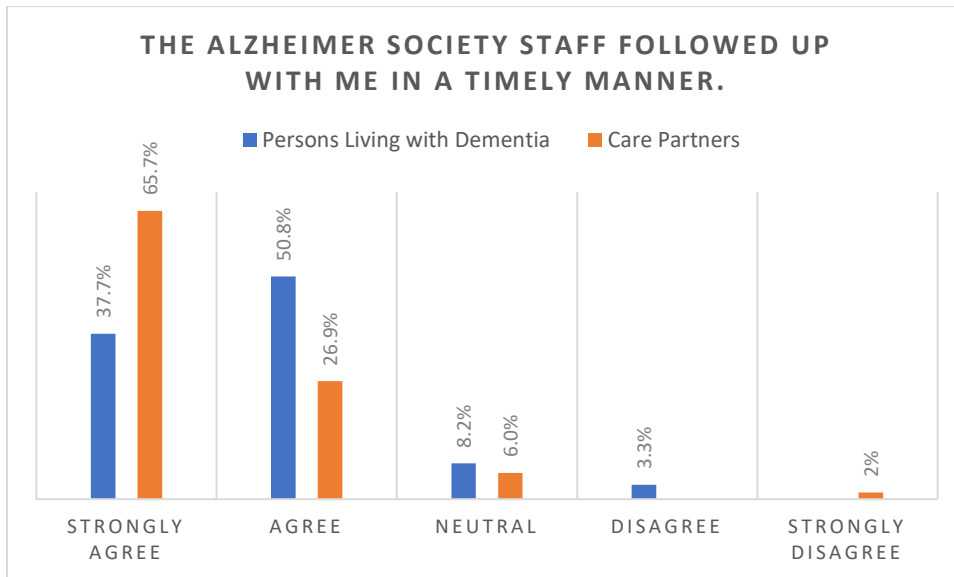
Of respondents, 84.3% of Persons Living with Dementia and 92.8% of Care Partners agree or strongly agree that report that the information provided by the Alzheimer Society was helpful to them.



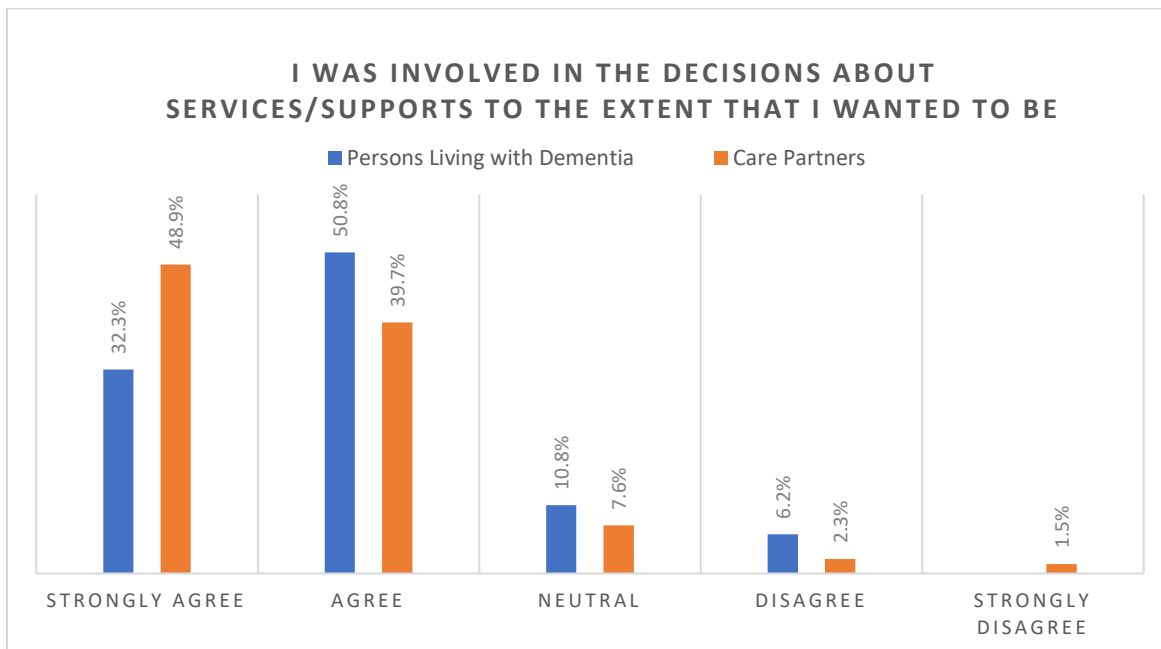
The First Link® Care Navigators are connecting Persons Living with Dementia and their Care Partners to supports/services that meet their individual needs, attested to by the fact that 81.1% of Persons Living with Dementia and 80.1% of Care Partners agree or strongly agree with this.



Of respondents, 88.5% of Persons Living with Dementia and 92.6% of Care Partners agree or strongly agree that the Alzheimer Society staff followed-up with them in a timely manner.

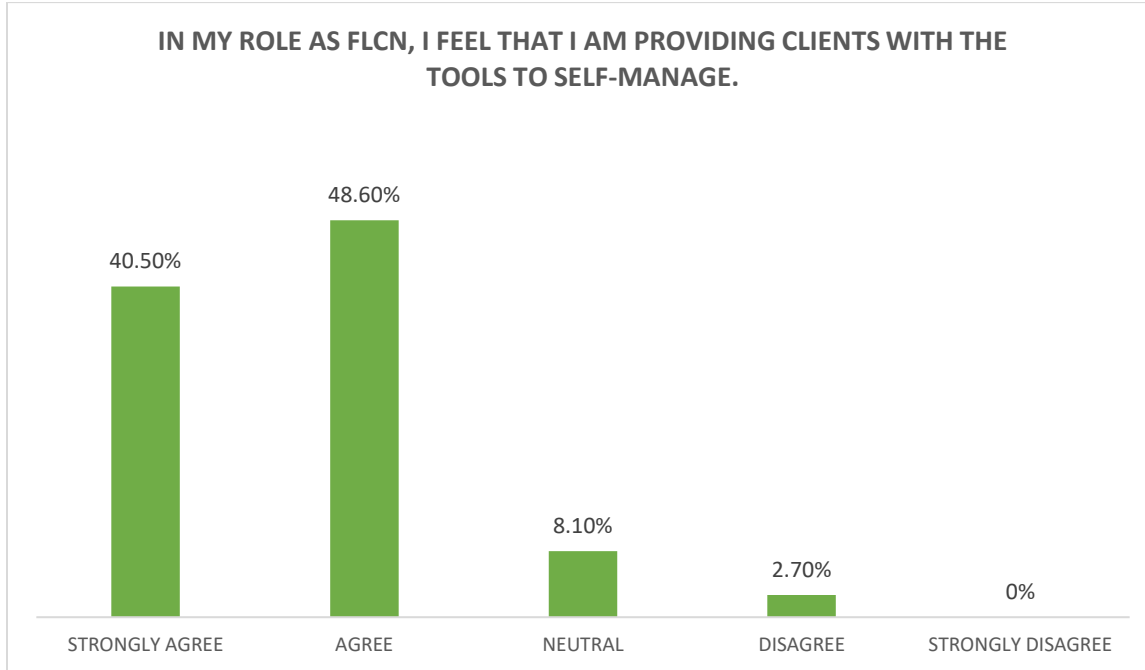


In addition, 83% of Persons Living with Dementia and 88.6% of Care Partners agree or strongly agree that they were involved in the decisions about supports/services to the extent that they wanted to be.

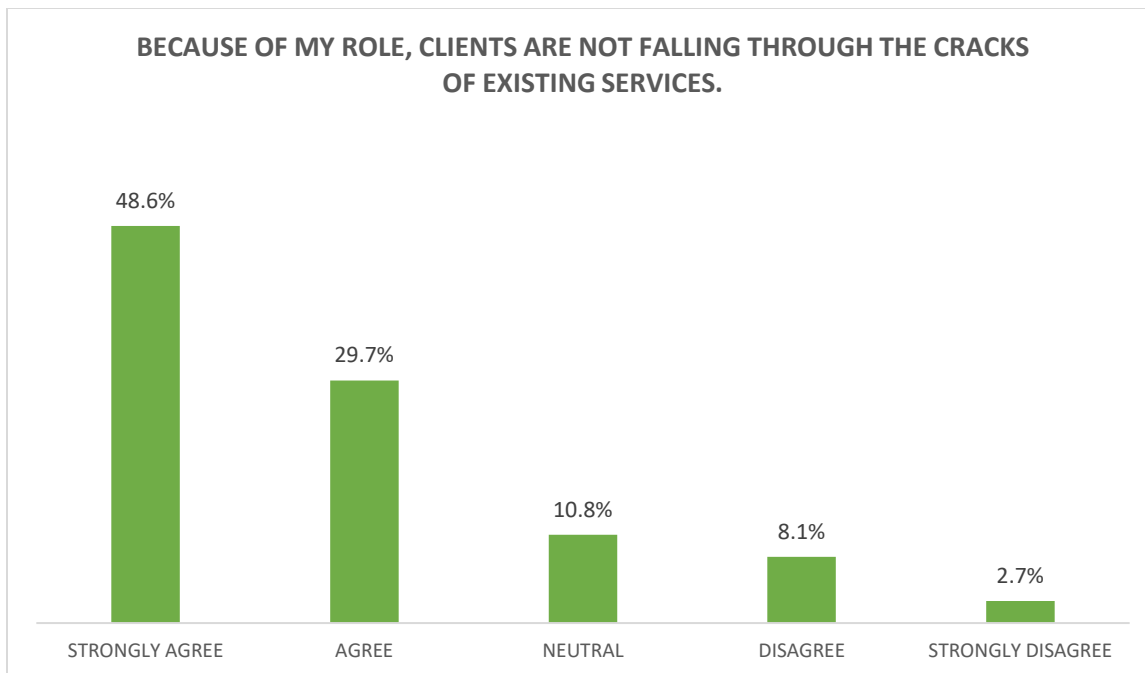


FLCN Self-Evaluation

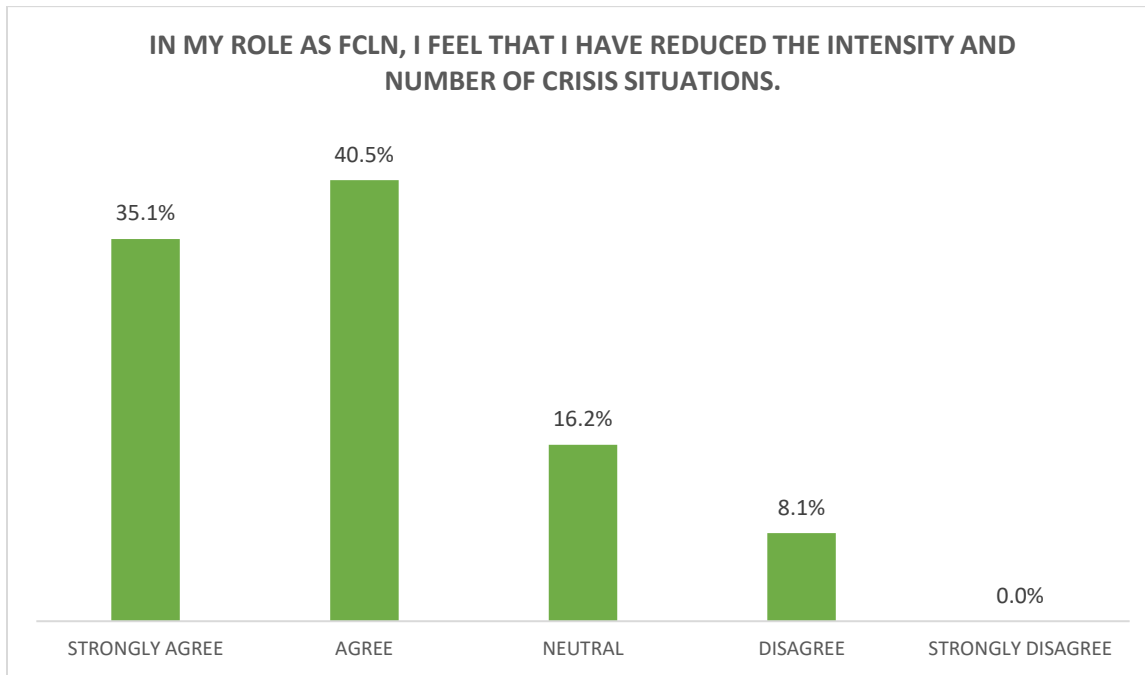
Of respondents, 89.1% of First Link® Care Navigators agree or strongly agree that they are providing clients with the tools to self-manage.



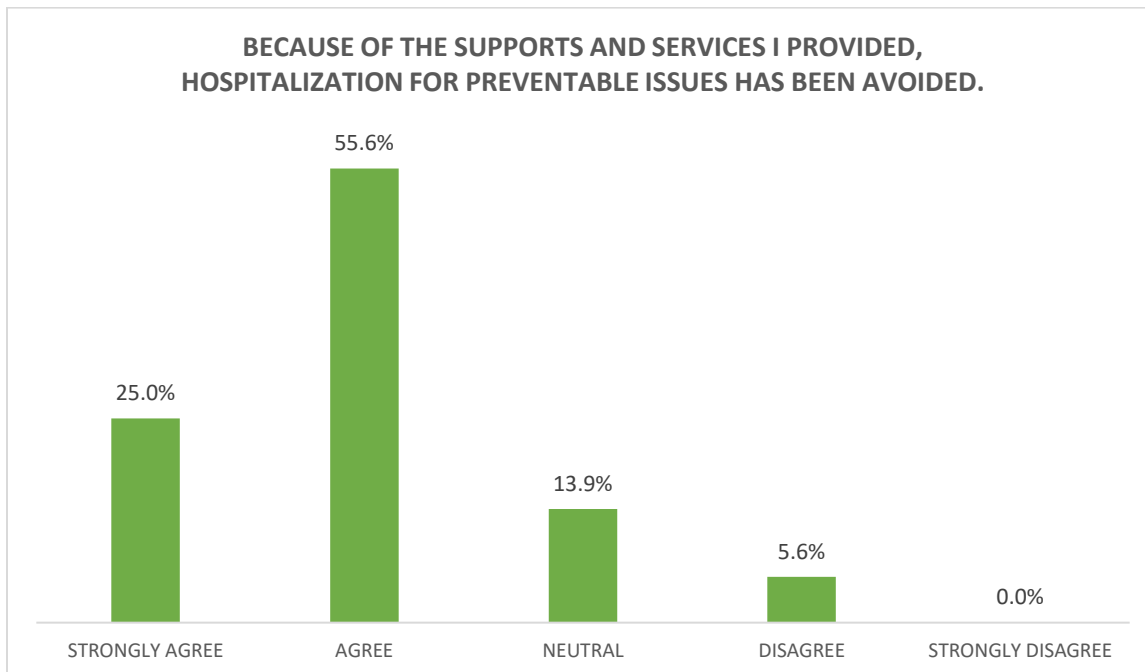
Further, 78.3% of First Link® Care Navigators who responded agree or strongly agree that Persons Living with Dementia are not falling through the cracks of existing services.



Of respondents, 75.6% of First Link® Care Navigators agree or strongly agree that they have reduced the intensity and number of crisis situations.



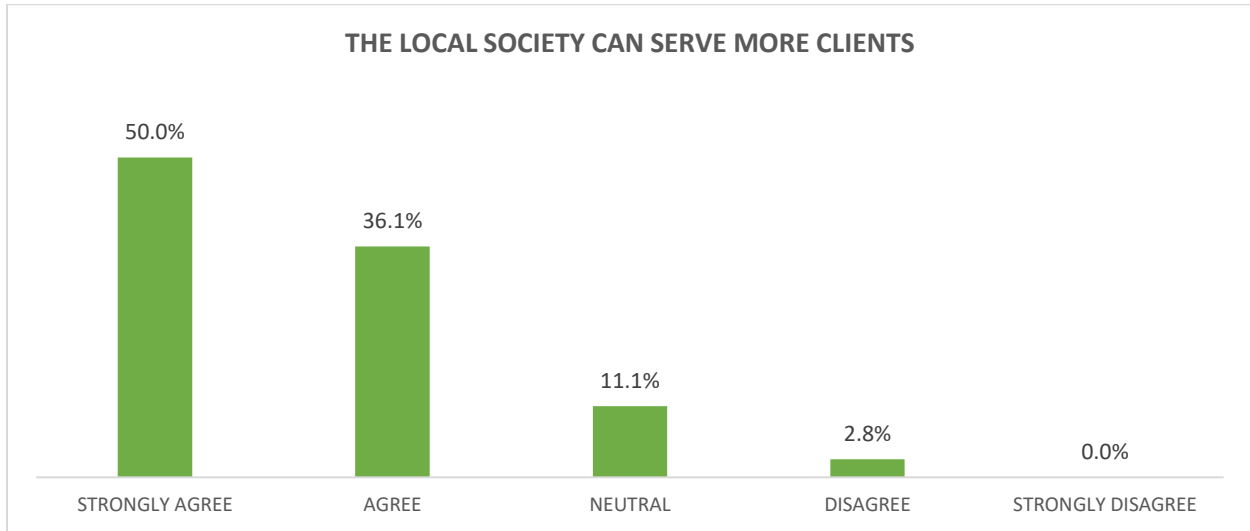
Further, 80.6% of First Link® Care Navigators who responded agree or strongly agree that because of the supports and services they have provided, hospitalization for preventable issues has been avoided.



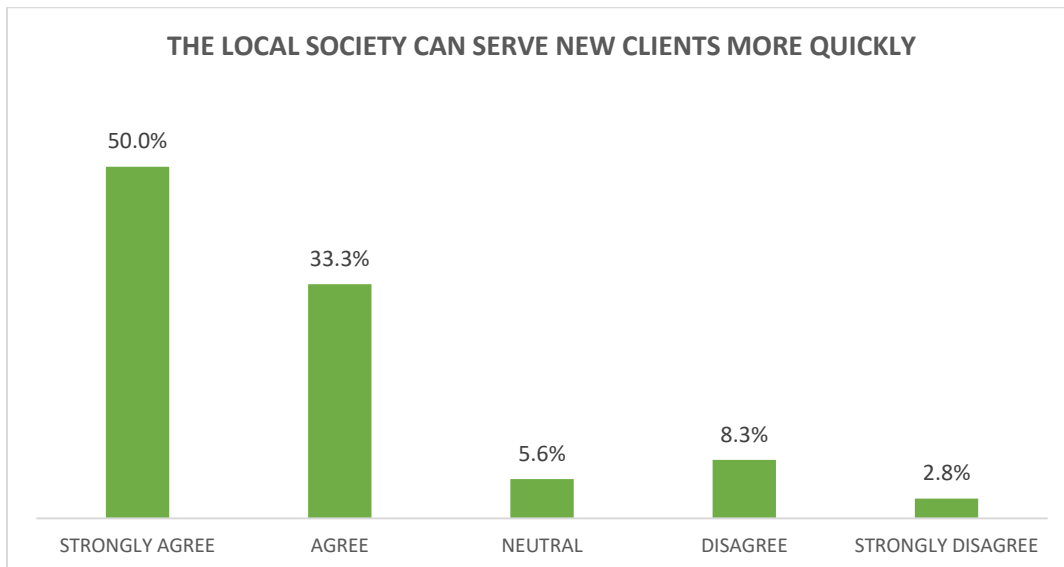
Research Question 3: Program Context

FLCN Self-Evaluation

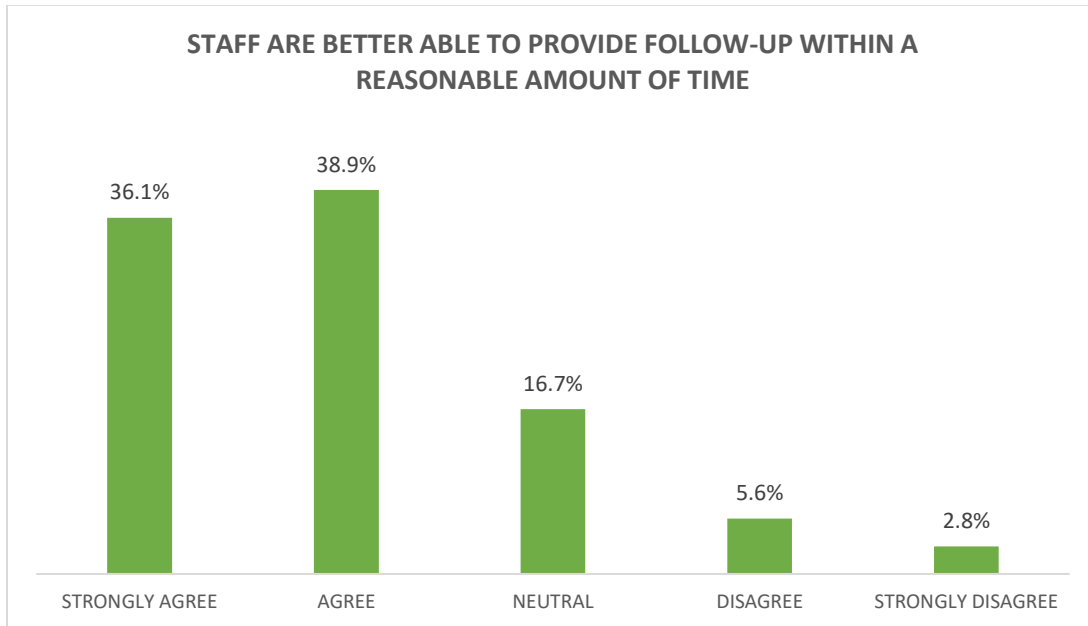
Of respondents, 86.1% of First Link® Care Navigators who responded agree or strongly agree that the local Alzheimer Society can serve more Persons Living with Dementia.



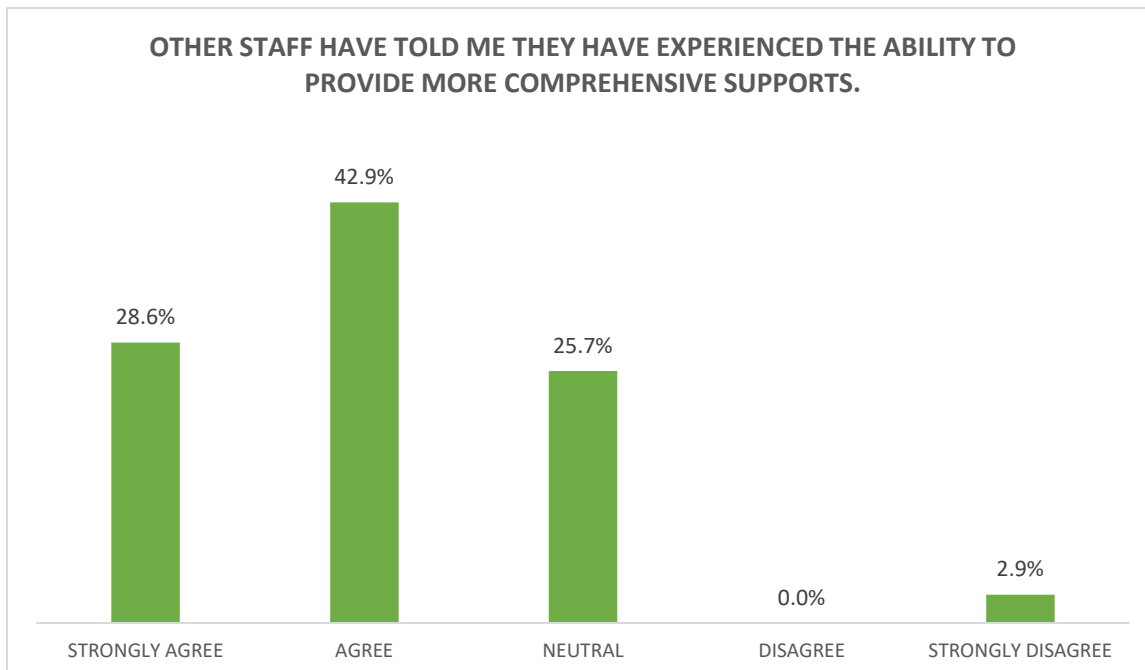
Of respondents, 83.3% of First Link® Care Navigators agree or strongly agree that the local Alzheimer Society can serve new clients more quickly.



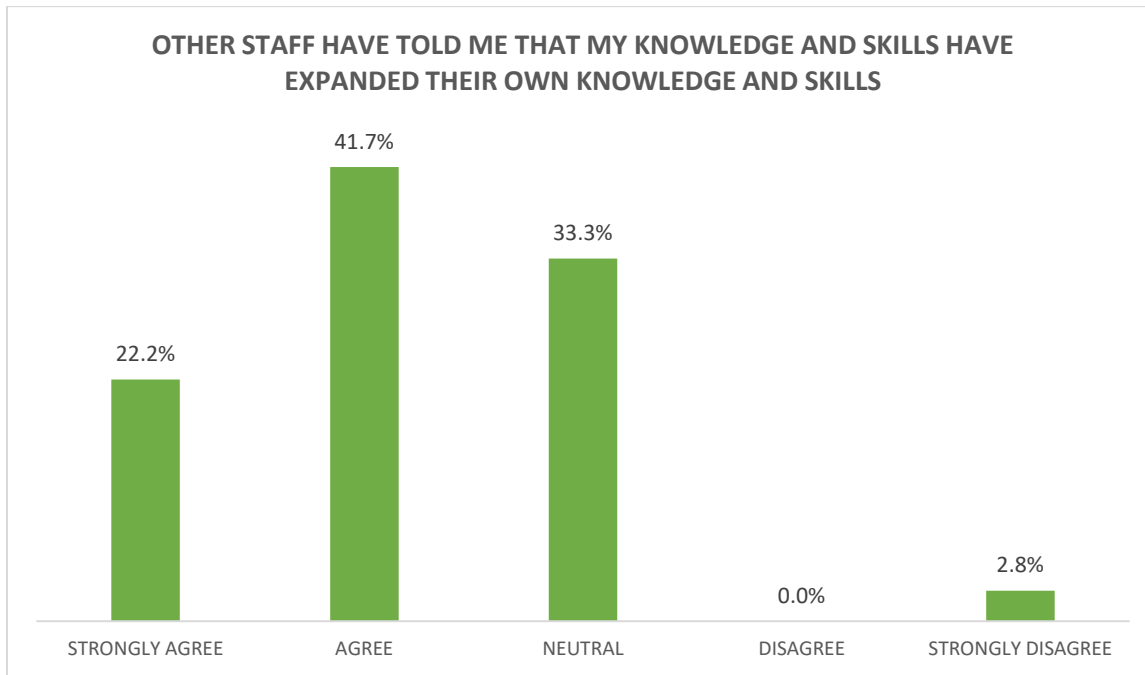
Further, 75% of First Link® Care Navigators who responded agree or strongly agree that staff are better able to provide timely follow-up.



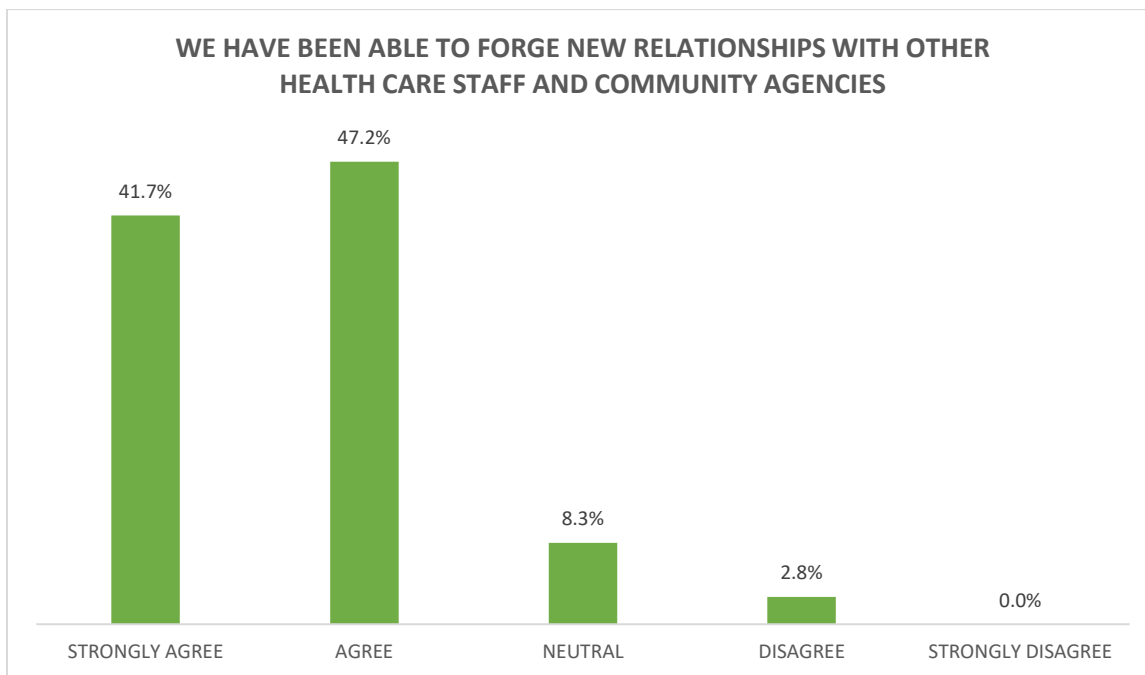
Of respondents, 71.5% of First Link® Care Navigators agree or strongly agree that other staff report that they can provide more comprehensive supports.



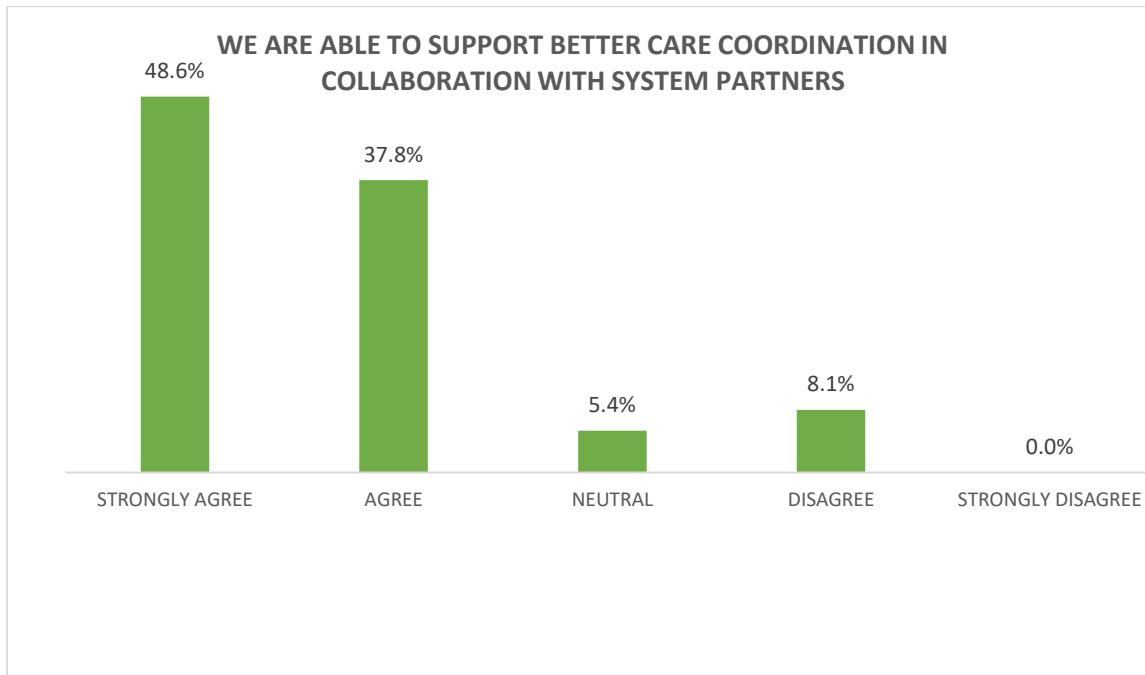
Of respondents, 63.9% of First Link® Care Navigators agree or strongly agree that other staff report that their own knowledge and skills has expanded that of their colleagues.



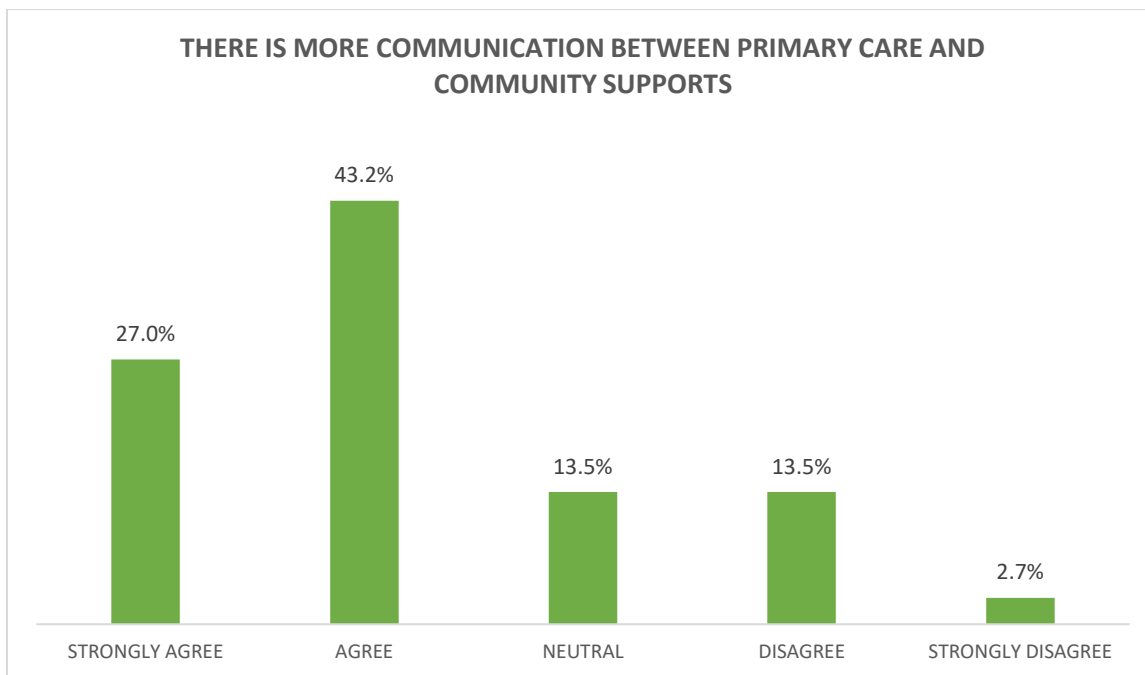
Of respondents, 88.9% of First Link® Care Navigators agree or strongly agree that they have been able to build new relationships with other Healthcare staff and community agencies.



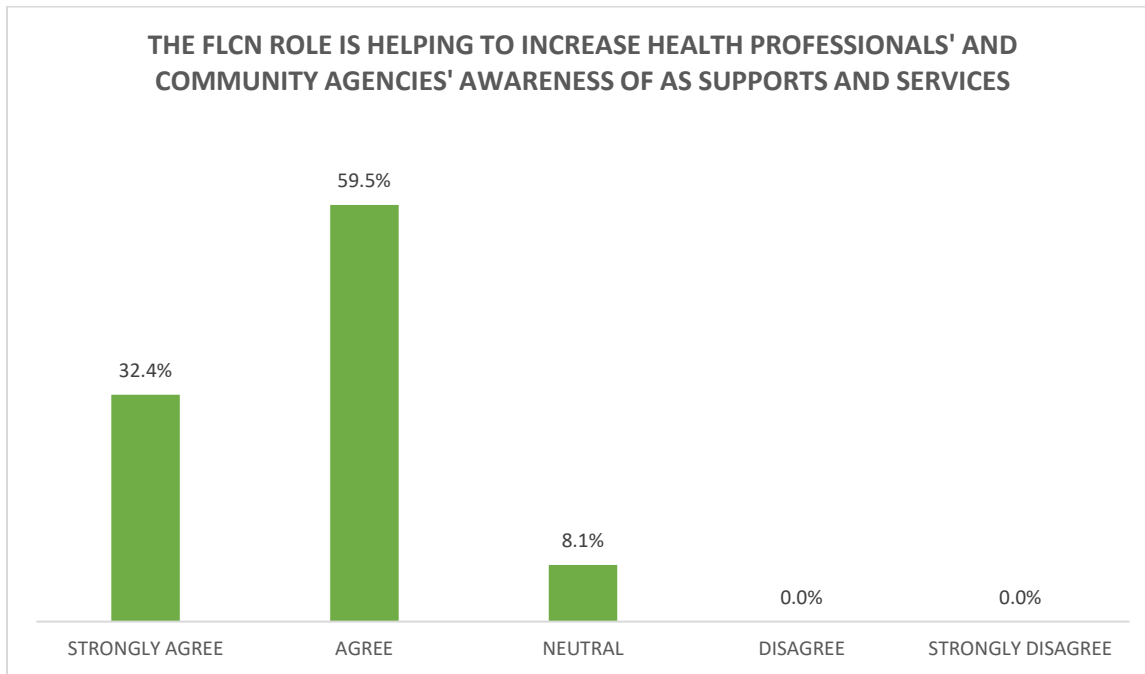
In addition, 86.4% of First Link® Care Navigators who responded agree or strongly agree that they are able to support better care coordination in collaboration with System Partners.



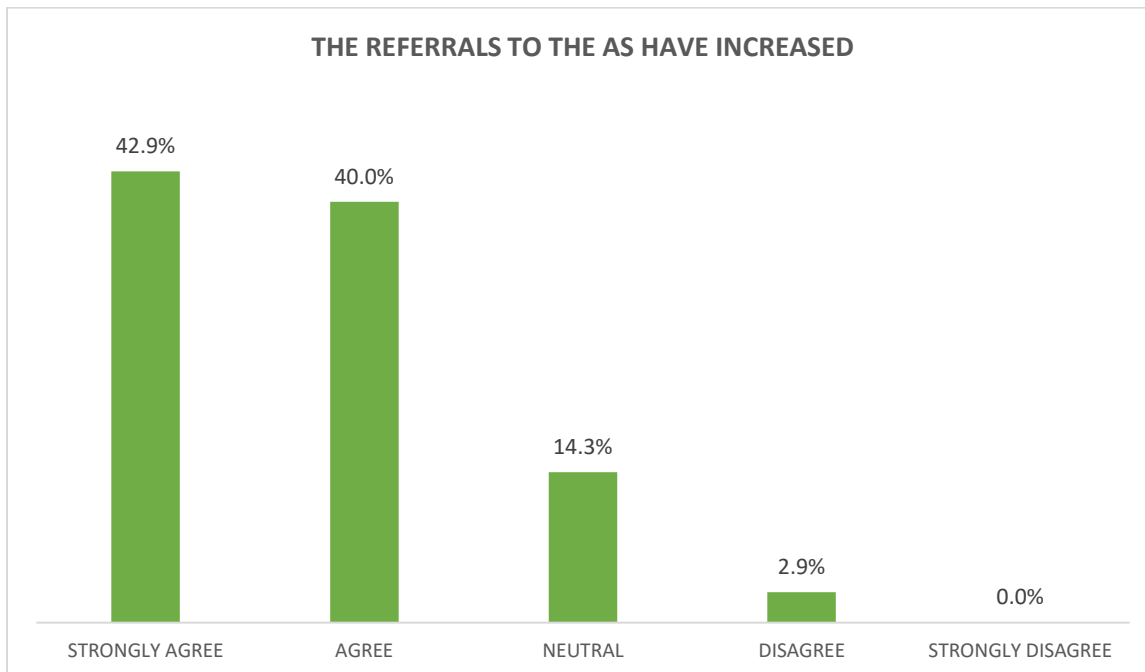
Further, 70.2% of First Link® Care Navigators who responded agree or strongly agree that there is more communication between primary care and community supports.



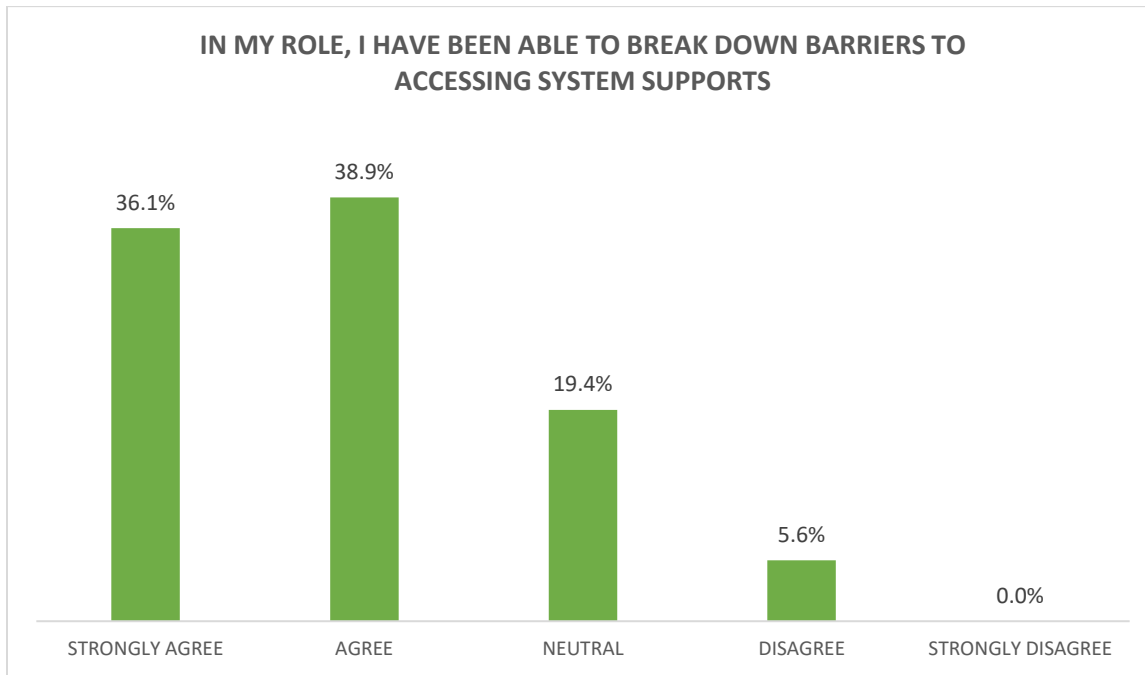
Almost all First Link® Care Navigators who responded (91.9%) agree or strongly agree that their role is helping to increase health professionals' and community agencies' awareness of Alzheimer Society supports and services.



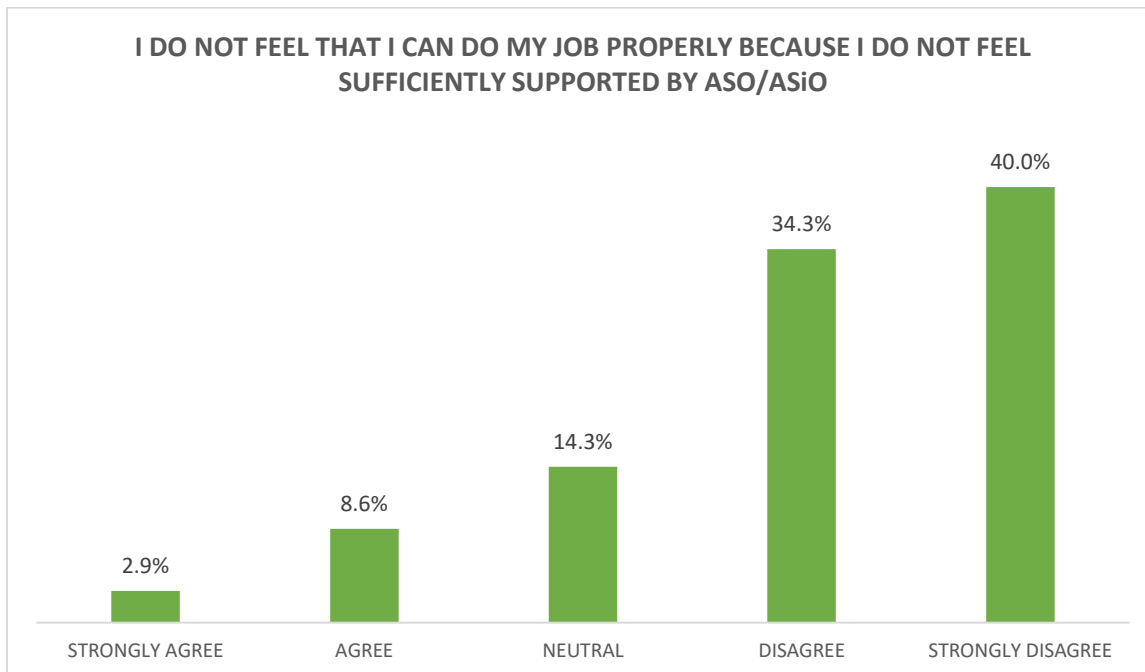
Of respondents, 82.9% of First Link® Care Navigators agree or strongly agree that the referrals to the Alzheimer Society have increased.



In addition, 75% of First Link[®] Care Navigators who responded agree or strongly agree that in their role, they have been able to break down barriers to accessing system supports.



Finally, overall First Link[®] Care Navigators feel supported by the Alzheimer Society. Only 11.5% of respondents do not feel that they can do their job properly because they do not feel sufficiently supported by the Alzheimer Society.



Research Question 4: Program Improvements

Recommendations by CP and FLCN

1. Reduce wait times for clients, decrease caseloads for FLCN, and make more regular follow-ups.

“We have had many new referrals and during busy intake months (ex. January) it is hard to get to intentional follow ups. One more day/week of hours would be great!” (First Link® Care Navigator)

“To increase the number of Navigators at the Society so that all clients could have navigation support.” (First Link® Care Navigator)

2. Invest in a client-friendly website with clear information about the First Link® Care Navigator role.

“Website difficult to navigate. Hard to locate key Care Navigators. Only got a Care Navigator via your social worker who conducted our First Steps workshop. Society should invest heavily in making website much more user-friendly (especially considering your clientele and potential donors).” (Care Partner)

3. More marketing materials about the FLCN role (i.e., brochures, email posters, etc.) to help share information with System Partners and community members.

“Explaining to partners how what we do is different from other coordinators/case managers/care navigators in other health care/community agencies.” (First Link® Care Navigator)

4. More accessible transportation services to reduce transportation barriers for clients.

“Lack of transportation to services is a big barrier to services - so if FLCN could connect with Transportation services that would be amazing (in an ideal world).” (First Link® Care Navigator)

5. More effective and efficient communication and referral processes among System Partners to avoid duplication and reduce wait times.

“We need an easier, quicker way to connect with community agencies, or to access information from other agencies, to avoid duplication and wait time.” (First Link® Care Navigator)

“There is a lack of services and community supports available to clients especially in rural areas. More education about what each System Partner does is needed to avoid duplication of service.” (First Link® Care Navigator)

“We must provide relevant information amongst the client's 'circle of care.' This will allow for continuity of care, reduced [requirement for] storytelling and improved connections. [It will improve] intentional follow up with System Partners and clients.” (First Link® Care Navigator)

6. Enhance interagency collaboration through integration into Memory Clinics, case conferencing, bi-monthly meetings, etc.

“Just more time to continue to build relationships together as the role is still fairly new in some Chapters. Also, the opportunity for FLCN's to have a presence around partner and coordinated care planning tables if not already happening would be beneficial. Continued work to be done with Primary Care and ideas about how to strengthen those relationships with all and not only a select few who refer a lot.” (First Link® Care Navigator)

7. Implement a database system that connects FLCN/Alzheimer Society caseloads with other healthcare providers (or add FLCN/AS to existing online referral systems).

“1. Opportunity for shared education (i.e., Memory Clinic Booster Days). 2. Efficient and confidential electronic information sharing systems (NOT fax machine). 3. For regular referrers who do not have memory clinic, a once a month/bimonthly collaboration meeting with external System Partners.” (First Link® Care Navigators)

8. Reduce wait times for community supports and healthcare services by an increased investment and expended resources.

“The biggest challenge that I as a FLCN face right now is the PSW shortage and the long wait lists for other community supports. There is a very large need for more money to be put into community supports if we are trying to keep people from accessing Long Term Care prematurely.” (First Link® Care Navigator)

“When linking clients to community support services, they are told there is a few months wait in order to initiate. Clients express feeling let down by the Healthcare System.” (First Link® Care Navigator)

9. More recognition and respect of the FLCN role by primary healthcare providers.

“The recognition of our role by primary care providers. We would need a clear written set of regulations or protocol between the two to better help support the client. We are not considered as part of the Circle of Care and face a great deal of resistance from primary care providers.” (First Link® Care Navigator)

“I have never received a doctor referral from the largest town in my area (8,000 people). Doctors refer to CMHA and NWLHIN only. This is a huge gap.” (First Link® Care Navigator)

10. Earlier referrals to the Alzheimer Society to ensure early intervention and crisis prevention.

“I don't know how to demonstrate it, but I'm sure that by gathering a team early, and connecting to community supports early, we are preventing, or at least equipping people to better manage, crises.” (First Link® Care Navigator)

Appendix 1

Steering Committee Members

Mary Burnett, Chief Executive Officer, Alzheimer Society of Brant, Haldimand Norfolk, Hamilton Halton

Mary Ellen Parker, Chief Executive Officer, Alzheimer Society of Chatham-Kent

Michelle Janisse, First Link® Care Navigator, Alzheimer Society of Chatham-Kent

Debbie Deichert, Executive Director, Alzheimer Society of Perth County

Lisa Hughes, First Link® Care Navigator, Alzheimer Society of Peterborough, Kawartha Lakes, Northumberland & Haliburton

Rosemary Fiss, Manager of Education & Support Programs, Alzheimer Society of Windsor & Essex County

Gagan Gill, Public Policy & Programs Analyst, Alzheimer Society Ontario

Christina Stergiou, First Link® Program Director, Alzheimer Society Ontario