Victorian Order of Nurses Canada

SMILE Program Evaluation Report

FINAL: July 2015

Prepared By:

BOC
BALANCE OF CARE
Research & Evaluation Group

SHS CONSULTING
POLICY • RESEARCH • COMMUNITY DEVELOPMENT

ACKNOWLEDGEMENTS

The completion of the ***VON SMILE Evaluation Report*** is a result of the insight, experiences and stories shared by a diverse range of individuals.

We would like to thank the Evaluation Steering Committee for their input and direction during the preparation of this report:

- Lori Cooper, VON Canada
- Judy Stewart, VON Canada
- Carole Dove, VON Canada
- Janice Pietrantonio, VON Canada
- Katie Carignan-Jackson, VON Canada
- Sherri Huckstep, VON Canada
- Michael O'Hara, VON Canada
- Michelle Jones, SMILE
- Darryl Tooley, SE LHIN
- Benedict Menachery, SE LHIN
- Joanne Billing, SE CCAC
- Dr. John Puxty, St. Mary's of the Lake Providence Care
- Marsha Stephen, Belleville and Quinte West Community Health Centre

We would like to also thank the various stakeholders including VON Staff and Care Coordinators, CCAC Staff and Care Coordinators, service providers, both traditional and non-traditional, and other experts including long-term care and the Alzheimer's Society for donating their time to speak with members of the consulting team either through a focus group, interview or survey.

We would like to acknowledge and thank the SMILE clients and caregivers who participated in this study either by completing a survey or telephone interview and providing invaluable insight into their experience with SMILE and for sharing their personal stories with us.

Together, the experiences from this broad range of stakeholders have contributed towards the development of a thoughtful evaluation of the VON Canada SMILE program.

Thank-you.

EXECUTIVE SUMMARY

OVERVIEW

HOW SMILE BEGAN

In 2007, the Province of Ontario announced its *Aging at Home Strategy*; it aimed to "enable people to continue leading healthy and independent lives in their own homes."

Under the provincial Strategy, each of Ontario's 14 Local Health Integration Networks (LHINs) were directed to lead the development of a regional program that would "achieve an integrated system of community-based services within its funding allocation." The intent was to grow traditional supports, and catalyze new and innovative service delivery approaches.

The South East LHIN (SE LHIN) subsequently initiated a collaborative planning process that actively engaged service providers and seniors. These stakeholders co-designed the Seniors Managing Independent Living Easily (SMILE) program as "a new regional long-term functional support program" for seniors aging at home. SMILE thus constituted a key component of the South East LHIN's local *Aging at Home Plan*, which linked to the LHIN's *Integrated Health Services Plan* and *Annual Service Plan*, and built on other ongoing initiatives in the home and community care (H&CC) sector.

SMILE was designed to enhance the quality of life, independence and functional capacity of seniors living in their own homes, and to support the informal caregivers who provide the majority of the everyday care required by seniors who cannot manage on their own. In doing so, SMILE also aimed to moderate demand for costly, and sometimes avoidable, hospital and residential long-term care (LTC).

In response to changing provincial policy priorities, particularly its ER/ALC strategy, meant to reduce wait times for hospital emergency departments and numbers of hospital beds occupied by people who no longer require hospital care, SMILE has evolved to serve higher needs seniors. Since 2014, following a prioritization exercise, SMILE now targets seniors at more imminent risk of hospitalization or referral to residential LTC.

This evolution poses new challenges for SMILE as it strives to meet changing needs in new and innovative ways. It also offers new opportunities to demonstrate how SMILE's "client-centred" approach can be scaled-up to provide more equitable access to appropriate community-based care for growing numbers of seniors and caregivers in the SE LHIN, and spread to meet similar challenges in other regions of the province.

Key goals of this evaluation, therefore, were to assess SMILE's performance to date, including its capacity to respond to new population needs in a dynamic policy environment; and to identify "lessons learned" to guide SMILE's continuing evolution, and hopefully, policy and practice in home and community care more broadly.

HOW SMILE WORKS

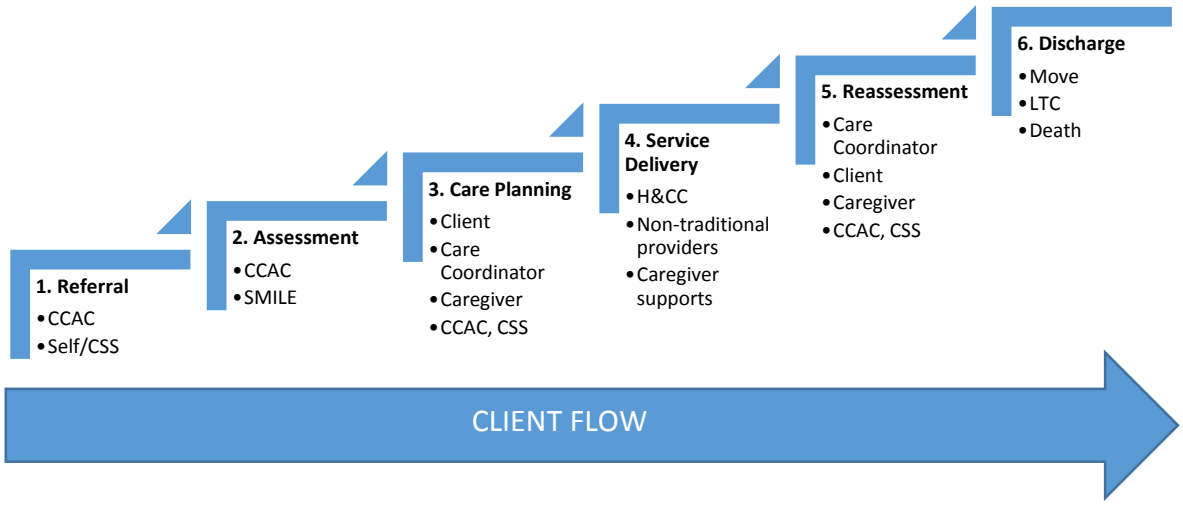
As noted, SMILE's main purpose is to enable growing numbers of seniors and their caregivers to remain in their homes as independently as possible for as long as possible, thus enhancing their wellbeing, independence and quality of life, and moderating demand for costly hospitalization and residential LTC.

To do this, SMILE builds on a foundation of "client-centred" care. In contrast to "provider-centred" models which offer clients what providers deem necessary, "client-centred" models begin by asking what is most important to clients and caregivers, and how their needs can best be met using resources available at the local level. As such, "client-centred" models also push beyond conventional "service by service" delivery approaches, where clients and caregivers with multiple ongoing needs may have to navigate multiple services from multiple providers, each with their own access points, eligibility requirements and service offerings, to more integrated approaches which "wrap" services and supports around clients and caregivers.

The SMILE program operates out of the VON offices in Trenton, Ontario; staff include a total of 32 client care coordinators, team assistants, a verification team, and administrative staff, as well as a team of volunteers. There are two types of SMILE Care Coordinators: Area Care Coordinators assigned to specific geographic service areas within the South East LHIN region; and Office-Based Care Coordinators who oversee the region as a whole.

As summarized in the chart below, SMILE clients normally move through a series of steps designed to identify needs and preferences, build care plans, review these plans, and then adapt plans as necessary. These steps are expanded on within the full Evaluation Report.

SMILE Program Steps



SMILE TODAY

As we will see in the evaluation findings, SMILE is a valued contributor to the SE LHIN, working in partnership with the SE CCAC, CSSAs, hospitals, primary health care providers (e.g., community health centres and family health teams) and other service organizations (e.g., the Alzheimer Society) to serve a growing population of seniors and their caregivers.

SMILE is distinguished by its reach. In contrast to other providers (with the exception of the SE CCAC) which tend to be based in a particular locality, SMILE covers the entire SE LHIN, including both urban and rural areas, thus contributing to more equitable access to community-based services and supports across the region as a whole.

SMILE also has an extended scope. By helping clients and caregivers to access formal H&CC providers, as well as non-traditional providers such as neighbours, and supporting informal caregivers, SMILE is able to lever local capacity to expand the "basket of services;" this is of particular importance in underserviced rural areas.

Most importantly, SMILE exemplifies a model of "client-centred" care which policy-makers increasingly see as the key to health system transformation in Ontario and beyond. Not only does SMILE address a first main objective of *Patients First: Ontario's 2015 Action Plan for Health Care* by connecting seniors and caregivers to "better coordinated and integrated care in the community, closer to home," it also addresses a second objective by providing education, information and transparency that clients and caregivers need to make the right decisions about their own care, and thus maintain their independence.

Moreover, SMILE anticipates and addresses many of the 16 recommendations to improve patient- and family-centred care contained in the recent report of Ontario's Expert panel on Home and Community Care (Donner, 2015); these recommendations similarly emphasize the importance of mechanisms to clarify what services are available, and to coordinate and integrate services around client needs in a predictable, transparent manner.

SMILE currently serves more than 2,000 clients with an annual budget of $6.4 million.

EVAULATION

A FRAMEWORK

The evaluation was designed to conduct a fair and comprehensive assessment of the SMILE Program; in doing so, it aimed to contribute to the evidence base around what works best for which clients, in which contexts.

The primary objectives of the evaluation were to:

- Determine the impact of the SMILE Program for clients, caregivers and the system as a whole

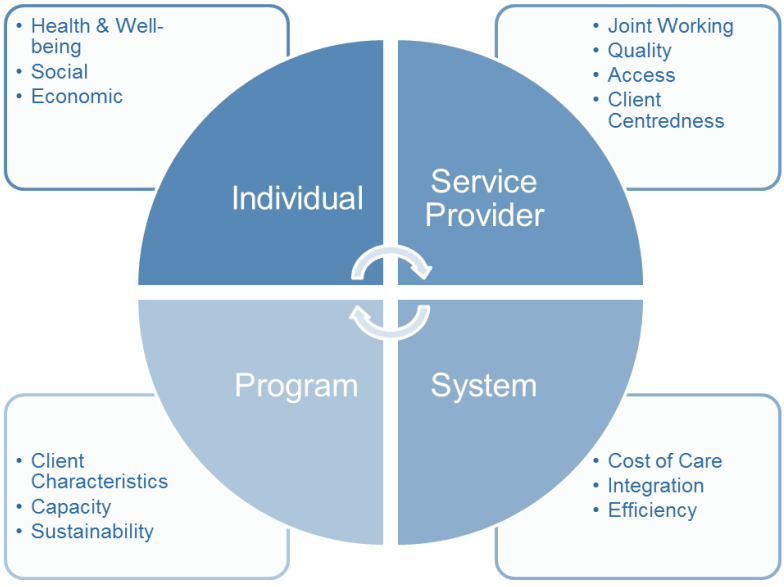
- Determine the benefits of the model for the client population
- Evaluate the impact on client trajectory
- Evaluate the financial outcomes of the program
- Determine the impact of the 'funding follows client' model on client well being

Another key interest for the evaluation is to inform further program development opportunities.

The evaluation of SMILE was informed by a previous evaluation of the program conducted in 2010 by Hollander Analytical, and by growing international literature on the evaluation of community-based programs and supports for older persons and their caregivers. For example the study team considered findings from the National Evaluation of Partnerships for Older People Projects (POPP) in the UK as well as the Health Quality Ontario's "attributes framework" for a "high performing health system" (2012) and the objectives of the Ontario's 2015 Action Plan for Health Care. Based on this research, **key evaluation indicators include quality, costs, impact and transferability.**

The SMILE evaluation framework also used a multi-dimensional approach, designed to make the best use of available qualitative and quantitative data sources to examine process and outcomes at a number of different levels of impact (individual, program, service provider, system).

SMILE Evaluation Framework



To do this, the evaluation design was organized into two major components:

- A Balance of Care component which included a policy scan; Expert Panel and simulation; and a review of client case notes
- A Stakeholder Engagement component which included surveys of clients, caregivers, and providers; focus groups with VON staff, Care Coordinators; service providers; telephone interviews with clients and caregivers; and key informant interviews.

To further validate preliminary findings, and assist in the framing of recommendations for SMILE's future, the study team conducted a half-day "Think Tank" of senior organization leaders, policy planners, and experts in Trenton, Ontario, on March 31, 2015.

KEY FINDINGS

Quality

Overall clients are caregivers are very happy with SMILE

- Overall, clients and caregivers are very satisfied with the SMILE program
- SMILE staff are highly engaged and collaborative

SMILE helps people stay at home

- Clients and caregivers feel that SMILE helps seniors remain at home; many clients strongly believe they couldn't remain at home without SMILE's support
- SMILE enables seniors to remain at home by working with service providers to create a "circle of care" around the unit of care

> *"Without the help SMILE provides for me, I would have had to give up the home I love. Thank you from my heart, SMILE" - Client*

SMILE is uniquely meeting needs of seniors at home

- The respite / relief offered to caregivers by SMILE is highly valued; it can allow caregivers to spend more quality time with their senior loved one and improve their ability to care

> *SMILE Case Managers are completely responsive when you call them with a concern or something that is not working. They couldn't be more accommodating" - Caregiver*

- The flexibility and responsiveness of SMILE in meeting clients' current and evolving needs, and in seeking creative solutions to any issues that may arise, are highly valued by clients and caregivers

- SMILE addresses broader social determinants of health by meeting the health and social needs of vulnerable and frail seniors, who are often isolated and may earn a low-income; the socialization element of SMILE is seen as highly valuable by many stakeholder groups
- Some clients' needs may be too high for self-management and require a more supported self-management approach

SMILE is valuable partner in building capacity within the local health system

- There is an opportunity to formalize collaboration with CCAC, to revive collaborative forums that previously existed to engage CSS agencies and SMILE, and to create opportunities for individual service providers to collaborate and access training

> *"It's good to know help is just a phone call away" - Client*

- SMILE has helped build capacity in the South East LHIN's senior-serving sector to meet the needs of an aging population with a growing number of seniors with complex needs
- SMILE has raised awareness of available CSS supports in the South East LHIN
- SMILE leverages community resources to meet the everyday needs of seniors and their caregivers, which helps to build local and system capacity while overcoming gaps in access in underserviced – often rural – areas
- Through building connections with a range of service providers and caregivers, SMILE is helping build a more integrated health system in the SE LHIN

Costs

SMILE helps create affordable access to services

- SMILE creates affordable access to support services for seniors earning a low-income
- SMILE's ability to leverage non-traditional providers may increase cost-effectiveness
- Creating access to Lifeline, transportation to medical appointments and knowing where to go for help when it is needed may slow clients' functional decline and prevent clients from calling an ambulance and using hospital unnecessarily
- Through iCART, SMILE will help ensure clients who may be high users of the health system and may be 'falling through the cracks' are able to access needed supports

> *"Without SMILE, I would be in a long-term care facility. Thanks to the help I receive, I am able to be in my apartment on my own" - Client*

There is an opportunity for greater efficiency through updated business systems

- There is a need to improve business systems in order to realize administrative efficiencies, including within the payments and verification process

Impact

SMILE has a positive impact on client and caregiver wellbeing

- SMILE positively impacts clients' sense of wellbeing, including their overall health, social connectedness, psychological wellbeing, and comfort and safety at home
- SMILE clients are able to regain a sense of independence and control; this can translate into an improved sense of purpose and life satisfaction, which serve to benefit one's overall health and wellbeing

> *"It has elevated every aspect of my life. Provided me with a renewed interest in engaging with the world" - Client*

SMILE facilitates greater access to services

- SMILE creates access to a diverse range of services and supports for seniors and their caregivers in the South East LHIN
- SMILE makes connections between service providers of various types and assists seniors and caregivers with service navigation, even if they are not eligible for the program
- In conjunction with other services and supports, SMILE is able to address the needs of seniors who may become high cost utilizers of the health system
- SMILE is likely helping to divert clients from costly hospital and institutional care

Transferability and Sustainability

Demand for SMILE is growing

- The need for SMILE is underscored by current wait lists, the aging population and gaps in services within some areas
- Due to resource constraints and external pressures to focus on higher need clients, SMILE's focus has shifted to include clients with more complex needs; stakeholders express concern regarding sustainability of this approach

SMILE may benefit other communities/regions

- The SMILE model could be replicated in similar areas, including, but not limited to, those of a similar rural character
- SMILE has evolved over time and adapted to lessons learned; systems and processes have been, and continue to be, built and refined to support efficient and effective operations going forward

> *"I only know about my smiling lady. I could not survive without her. She takes very good care of me" - Client*

- SMILE is seen as a good complement to CSS, CCAC and informal supports; while can also be a model for clients and caregivers who utilize SMILE and non-traditional approaches only

MOVING FORWARD

The recommendations moving forward for SMILE build on the evaluation findings and also locate SMILE's client-centred approach strategically within the current policy environment.

CLIENT AND CAREGIVER

1. ***Position SMILE as a proven and scalable model of "client-centred" care***
   SMILE offers a proven model which can be scaled up and spread to new clients and new communities across urban and rural areas of Ontario.
2. ***Communicate how SMILE supports the broader "unit of care"***
   SMILE's value added accrues to caregivers and their broader communities; investments in SMILE thus generate dividends well beyond the individual client which need to be taken into account when assessing outcomes and "value for money."
3. ***Clarify the value of "supported" self-management***
   Smile expands care options, and thus choice, by making connections to established providers and levering a wider range of local resources. Smile then continue to monitor care and address issues, which vulnerable persons might find difficult to do.
4. ***Advocate for "client-centred" funding***
   Current funding models tend to be based on historical funding patterns and provider market share. In contrast, "client-centred" funding models are based on the client's needs.

PROGRAM

1. ***Enrich and broaden the conversation***
   Enriching and broadening the conversations of SMILE through a mix of short surveys, one-minute evaluations, focus groups and town-hall meetings will help to strengthen client voice, and raise SMILE's visibility and tangibly.
2. ***Strengthen the evidence base***
   Policy will be informed by experts and evidence, including "hard outcomes" such as health care utilization and costs.
3. ***Use technology to improve performances and outcomes***
   Technology is one of the tools that will help modernize service delivery.
4. ***Elaborate a modular accountability framework***
   SMILE's success in supporting clients and caregivers reflects its flexibility and capacity to adapt to changing needs and trends. This can create questions, however, among clients, caregivers and stakeholders on expectations surrounding these relationships.

PROVIDER

1. ***Engage SMILE Care Coordinators within inter-organization care teams***
   Inter-organization care teams are aimed at building on current successes and value of SMILE Care Coordinators, and working collaboratively to identify strategies to bridge care gaps and better serve client needs.
2. ***Position SMILE to lead the emergence of community hubs***
   Community hubs are increasingly seen in Ontario and internationally as a promising means of building community capacity.

SYSTEM

1. ***Engage with Health Links***
   SMILE needs to be "at the table" as Health Links gain traction. Through Health Links, as well as through continuing engagement with the SE LHIN and other system partners, SMILE can increase its visibility
2. ***Maximize the potential of the VON infrastructure***
   SMILE could draw more heavily on staff at VON's provincial and national offices to build the evidence base which the Province sees as an essential resource for system change.

Further details and strategies for implementation are described in the full Evaluation Report.

CONTENTS

1.0 SMILE FUNDAMENTALS

1.1 SMILE AS THE SOUTH EAST LHIN'S *AGING AT HOME* PLAN

In 2007, Ontario announced its *Aging at Home Strategy*; it aimed to "enable people to continue leading healthy and independent lives in their own homes."

Under the Strategy, each of Ontario's 14 Local Health Integration Networks (LHINs) were each directed to lead the development of a regional program that would "achieve an integrated system of community-based services within its funding allocation." The intent was to grow traditional supports, and catalyze new and innovative service delivery approaches.

In response, the South East LHIN (SE LHIN) actively engaged service providers and seniors in a collaborative planning process; they co-designed the Seniors Managing Independent Living Easily (SMILE) program as "a new regional long-term functional support program" for seniors aging at home. SMILE thus constituted a key component of the South East LHIN's local *Aging at Home Plan*, which linked to the LHIN's *Integrated Health Services Plan* and *Annual Service Plan*, and built on other ongoing initiatives in the home and community care (H&CC) sector.

SMILE was designed to enhance the quality of life, independence and functional capacity of seniors living in their own homes, and in doing so, to support the informal caregivers who provide the bulk of the everyday care required by seniors who cannot manage on their own.

SMILE's value proposition was summarized by the SE LHIN as follows[1]:

> At its introduction in the spring of 2008, the SMILE program will be unique in the province of Ontario in its focus on assisting the frail elderly to live at home by defining and assigning individualized budgets for services that are matched to needs, and supporting options in modalities of service delivery, that include the use of existing (e.g., community support service agency) and non-traditional service providers. By empowering seniors to make decisions over aspects of their day-to-day care that can crucially affect their independence and quality of life, the program protects their dignity.

SMILE's "client-centred" approach was highlighted[2]:

> The plan sets out an innovative care delivery model that respects and supports the intent of the province's Aging at Home Strategy, while being regional in scope. The model is 100% innovative in that it offers a brand-new way of looking at, and organizing the provision of services considered essential to maintaining independence at home, such as: meals; housekeeping; shopping; laundry; running errands; transportation to

[1] *South East Local Health Integration Network (2008). Aging at Home Plan: A Plan to Help Seniors Stay at Home.*
[2] Ibid.

and from medical appointments; and seasonal chores. It represents a radical shift in current thinking from a traditional supply driven market of health service provision, where pre-designed structures each supply a pre-determined set of services, to one driven by needs, where the individual needs of clients/patients drive the supply of services. From that respect, the model also mirrors the Ontario health care system's patient-centered philosophy.

Since its inception, SMILE has continued to strengthen this "client-centred" approach which policy-makers now see as a key to health system transformation in Ontario. By focusing on what clients need, SMILE anticipates and addresses key objectives of *Patients First: Ontario's 2015 Action Plan for Health Care*[3]. These include connecting seniors and caregivers to "better coordinated and integrated care in the community, closer to home;" and providing education, information and transparency that clients and caregivers need to make the right decisions about their own care.

SMILE similarly anticipates and addresses many of the 16 recommendations contained in the recent report of Ontario's Expert Panel on Home and Community Care[4]; these recommendations similarly emphasize the importance of client and family-centred care, along with mechanisms to clarify what services are available, ensure equity, and coordinate and integrate services around client needs in a predictable, transparent manner.

SMILE has also demonstrated its capacity to adapt to new policy priorities and different needs. Key among these is the provincial ER/ALC strategy which aims to reduce wait times for hospital emergency departments and numbers of hospital beds occupied by people who no longer require hospital care; SMILE now supports increasing numbers of seniors with higher needs at more imminent risk of hospitalization or referral to residential LTC.

In such a dynamic environment, SMILE, along with other H&CC providers, faces new challenges as they try to support new needs in innovative ways.

But this environment also offers SMILE new opportunities to demonstrate how its "client-centred" approach, now the focal point of provincial policy, can be adapted and scaled-up to ensure more equitable access to appropriate community-based care for growing numbers of seniors and caregivers with higher as well as lower needs, living in urban and rural areas of the SE LHIN, and other parts of the province.

SMILE currently serves more than 2,000 clients with an annual budget of $6.4 million.

---

[3] *Government of Ontario (2015). Patients First: Action Plan for Health Care.* http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf

[4] *Expert Group on Home & Community Care. (2015). Bringing Care Home.* http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

1.2 EVOLUTION OF SMILE

SMILE emerged with a preventative-maintenance focus. A review of material from the early stages of the program, and interviews with stakeholders involved with SMILE since its inception, clarify that SMILE was designed to meet "the long-term care needs of seniors who are elderly and at risk of progressive frailty, premature dependency and institutionalization, but well enough to live at home." In its early days, stakeholders held, as a stretch goal, that SMILE could help improve seniors' functional health status over time. In the first 18 months of operation, SMILE staff worked to refine admission criteria, which were revised four times, but continued to focus on admitting seniors earlier rather than later.

That said, a possible shift in focus toward higher needs clients was always seen as a possibility. For example, approximately 60 participants in a full-day planning session in November 2007 agreed that, in times of restricted resources, "the most vulnerable seniors should be given priority access to services."

Such a time was not long in coming. In 2009, the Ministry of Health and Long-Term Care (MoHLTC) directed all LHINs to reduce ER/ALC wait times as a priority[5]. Operationally, this meant shifting resources toward seniors at more imminent risk of hospitalization or residential LTC, and those requiring more resource-intensive post-hospital care.

In 2009/2010 SMILE began to focus more on individuals who were "very frail" and "most at risk" of institutionalization. Of course, given constrained resources, this meant that fewer lower needs clients could be served by SMILE. A prioritization exercise conducted in 2013-2014 concluded that to make room for higher needs seniors already on the waitlist, some lower needs clients would have to be discharged.

According to the management response to a 2011 evaluation of SMILE[6], stakeholders found this shift in focus to be challenging; however, both the Victorian Order of Nurses (VON, SMILE's "parent" organization) and the South East LHIN still believed that the program would continue to impact positively on the lives of clients and caregivers, and on the system[7].

Confirming this new focus, in 2014 the South East LHIN described SMILE as[8]:

> …a long-term functional support program for frail and elderly seniors most at risk of premature institutionalization to receive help with activities that are essential to daily living, allowing them to remain in their homes. Because dignity is a matter of choice,

---

[5] Ontario Ministry of Health and Long-Term Care. Ontario Wait Times. Accessed on-line at http://www.health.gov.on.ca/en/pro/programs/waittimes/edrs/strategy.aspx

[6] Miller, Jo Ann and Margaret MacAdam. (2011). Evaluation of the Seniors Managing Independent Living Easily (SMILE) Program. Hollander Analytical Services Ltd.

[7] VON Canada Ontario (2011). SMILE Program Evaluation Response: A Management Response Report to the SMILE Program Evaluation completed in April 2011 by Hollander Analytical Services Ltd.

[8] Accessed at: *http://www.southeastlhin.on.ca/goalsandachievements/Achievements/SMILE.aspx*

SMILE offers these seniors option in managing their care, selecting services and deciding who comes into their home and when.

As of fall 2014, we understand that SMILE staff now communicate to the public that the program aims to support very frail seniors with multiple chronic illnesses who are at immediate risk of referral to residential LTC. In October 2014 the program initiated a waiting list as demand continued to grow.

Currently, the South East LHIN envisions SMILE as serving seniors and caregivers at two key points along the care trajectory: those already eligible for community support services, and those eligible for community support services and CCAC support; approximately 70% of SMILE clients are now served collaboratively by SMILE and the SE CCAC.

SMILE is now also a part of iCART, a local initiative aimed at identifying seniors who present at hospital emergency departments, but potentially could be supported in the community.

Such collaborative efforts, particularly around seniors with multiple chronic needs, is seen by stakeholders and policy-makers to be of crucial value not only for maintaining clients and caregivers in their own homes, but for moderating demand for costly hospital and institutional care. SMILE also views collaboration as an essential ingredient of its "client-centred" approach to care which moves beyond what single providers can provide, to wrap services from multiple around clients and caregivers in an integrated way.

As we shall see, clients and caregivers laud SMILE's ability to help them connect with a range of community-based resources needed to continue to live at home and in dignity.

1.3 BRIEF OVERVIEW OF SMILE

1.3.1 PURPOSE OF SMILE

The purpose of SMILE, as articulated in 2014, is as follows: SMILE enables the growing number of frail elderly people in the South East LHIN region to remain in their homes safer and longer[9].

1.3.2 SMILE'S GOALS

In order to realize this purpose, VON has established the following program goals for SMILE:

- To ensure that **seniors** who are at risk of progressive frailty, premature dependency and institutionalization, **and their informal caregivers**, receive services that **best meet their needs no matter where they live** in the region;
- To **address long term care and acute care pressures** by reducing the risk of premature dependence and institutionalization in the senior population;

[9] VON Canada – SMILE Program (2014). OACCAC Conference Poster.

- To provide **individualized support** for instrumental activities of daily living (IADLs) that meet the specific needs of seniors and enable a comparison to the IADL requirements of comparable seniors in other settings (through the use of a **standard assessment**); and,
- To **improve the quality of life** of the senior population.

1.3.3 SMILE ELIGIBILITY

Consistent with the mandate of Ontario's Health Links, which focus on individuals who are among the highest (and most costly) health care users, SMILE now increasingly targets older persons (and caregivers) with multiple chronic needs "at risk" of hospitalization or institutional care, or requiring post-hospital care.

To be eligible for the SMILE program, individuals must normally meet the following criteria:

- The individual must be unable to independently manage 4 or more instrumental activities of daily living (IADL's); i.e., shopping, laundry, housekeeping, outdoor chores, transportation, and meal preparation.
- The individual would also:
    - Be over 75 years of age, or living with a chronic disease related to advanced aging; i.e. stroke, Parkinson's, arthritis, coronary artery disease
    - Live alone, or with a caregiver unable to consistently assist with IADL's
    - Be at risk of hospitalization, admission to Long Term Care, or giving up their home within the next year without additional support.
- The individual would typically experience one of the following:
    - Significant cognitive impairment
    - Significant functional impairment that causes problems with mobility
    - Deterioration of health status as demonstrated by hospitalization, visits to the ER and/or unscheduled physician visits in the last 90 days.

1.3.4 SMILE PROGRAM STRUCTURE AND PROCESS

Headquartered at VON's Trenton offices, SMILE program has 32 staff members including client care coordinators, team assistants, a verification team, and administrative staff as well as volunteers.

There are two types of SMILE Care Coordinators: Area Care Coordinators and Office-Based Care Coordinators. Each Area Care Coordinator is assigned to a geographic service area within the South East LHIN.

As summarized in the chart below, SMILE clients typically move through a planned series of steps designed to identify needs and preferences, build comprehensive care plans, review these plans, and then adapt plans as necessary.

- In the first step, seniors are referred to the SMILE program. While in its early days, SMILE received most of its referrals from the community through community support service agencies (CSSAs) or via self-referral, a growing proportion of mostly higher needs referrals now comes from the South East Community Care Access Centre (SE CCAC). SMILE continues to accept some community and self-referrals; however, the program no longer relies on "multiple access portals" through which senior-serving organizations in the community could refer seniors directly to SMILE.

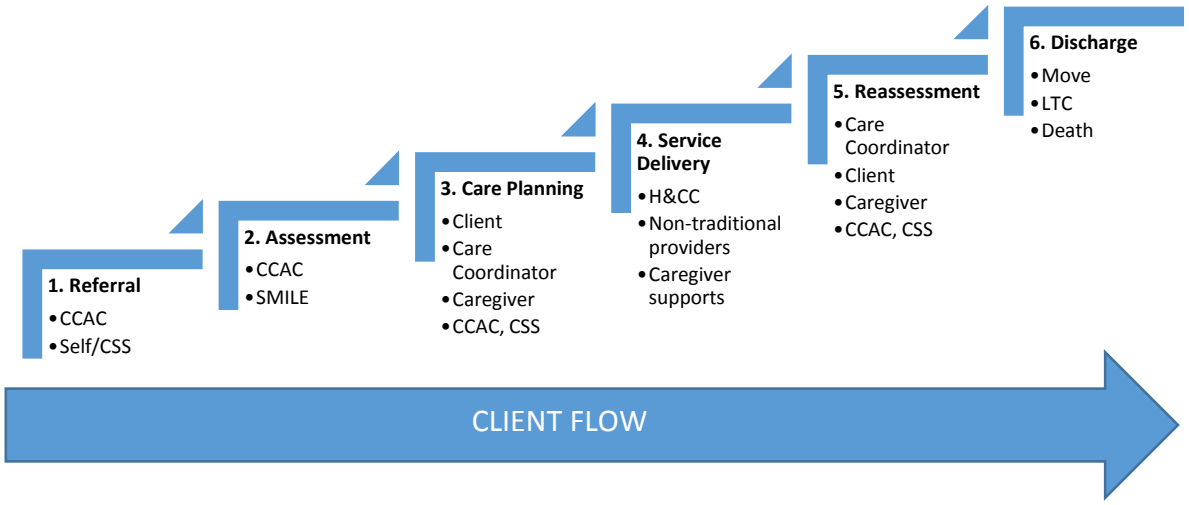
- In the second step, a needs assessment is conducted by a SMILE Care Coordinator (using the interRAI Resident Assessment Instrument – Community Health Assessment (RAI-CHA)) when a current CCAC assessment (using the Resident Assessment Instrument – Home Care (RAI-HC)) is not available.

- In the third step a SMILE Care Coordinator works with the senior and caregiver (as appropriate) to co-create an individualized care plan aimed at maintaining functional ability and independence at the highest level possible. Care Coordinators employ a detailed "Determination of Eligibility" form which guides conversations around how seniors and caregivers see their needs, which needs are unmet, and how needs can best be met and by whom. Care Coordinators use nominal budgets (averaging about $3600/client/year) to help clients plan and access the most appropriate combinations of services and supports available at the local level including formal H&CC services (e.g., household management and transportation); supports from non-traditional providers (e.g., assistance from a neighbour); and supports for informal caregivers (e.g., respite). Care plans specify services selected, service providers, and start dates; they also indicate how SMILE budgets will "flow," whether to the senior and caregiver, who will then pay service providers, or directly to providers.

- In the fourth and fifth steps, care plans and services are regularly monitored by the Care Coordinator and adjusted as necessary. Monitoring includes a scheduled three-month check-in and an in-home re-assessment using the RAI-CHA instrument every 6 months. While in many cases, needs will increase as seniors age, in some cases, seniors and caregivers will experience improvements in functional status or develop new coping strategies which require fewer external resources. Clients and caregivers can also call SMILE any time using a 1-888 number if they have any inquiries, issues, questions or concerns.

- In the sixth step, clients may be discharged from SMILE. However, since SMILE is intended to provide long-term functional support, clients are not normally discharged unless they relocate out of the service area, are admitted to LTC, elect to discontinue service, or pass away.

SMILE PROGRAM STEPS



Flexibility and adaptability are hallmarks of SMILE's client-centred approach. Not only can Care Coordinators continuously adjust services to meet changing needs and preferences, they do so knowing what services are available at the local level; this "on the ground" knowledge is crucial since as recent reports have emphasized (e.g., Donner, 2015), H&CC resources vary extensively from community to community. Solutions that work for one senior and caregiver in one community at a particular point in time, may not work in other communities or as needs change.

Here, SMILE Care Coordinators have the unique ability to lever "non-traditional" providers such as neighbours, a major advantage particularly where established providers are not present, or have only limited capacity. This enhances access in communities where access may otherwise be difficult to achieve, and it empowers clients and caregivers to select providers which work best for them.

Reflecting this, SMILE has no "set" menu of services; core services may include tailored combinations of:

- Household management (cleaning, laundry)
- Meals
- Errands
- Transportation for Medical Issues
- Outdoor chores (grass cutting, snow removal, eaves trough cleaning, and outdoor window cleaning)
- Budgeting, bill payments and completing forms
- Security monitoring

In addition, clients and caregivers may also access other community-based programs and services, when available, including:

- Day programs
- Caregiver respite services, including support and education
- Client intervention and assistance
- Foot care
- Meals on Wheels and congregate dining
- Home help/homemaking
- Respite services
- Social and recreational programs
- Transportation

SMILE Care Coordinators aim to build independence and enable choice. They provide ongoing education, counselling and problem-solving to seniors and caregivers, and assist them to select and manage their own services to the extent possible.

As such, SMILE may be characterized as a "supported self-management" model. In contrast to classic "self-management" models, where individuals may receive funding and then have to navigate and manage services and providers on their own, the SMILE model provides continuing support from experienced front-line professionals throughout the entire care process.

Such support is particularly valuable where seniors have multiple ongoing needs requiring services and supports from multiple providers each with their own access points, eligibility requirements, service offerings, and user fees. It is also essential where informal caregivers may not have the personal resources and capacity needed to navigate and manage services on their own, or where caregivers may themselves require care recalling that many informal caregivers of seniors (e.g., spouses) are also seniors[10].

Moreover, while "self-management" models may assume that seniors and caregivers can choose among providers, this assumption may not hold true in underserviced areas where formal services are "thin on the ground;" there may simply be little to choose from.

This underlines another key strength of the SMILE program. In addition to accessing established providers where they are available, SMILE also offers access to non-traditional providers such as friends or neighbours thus levering new capacity and building more sustainable support networks. (Note that immediate family or live-in caregivers are not eligible to be compensated through SMILE).

Further, SMILE can tailor solutions which use available resources effectively. If, for instance, a

[10] Williams AP, Peckham, A, Watkins J, Warrick N, Tam T, Rudoler D, Spalding K. Caring for Caregivers: Facing Up To Tough Challenges. Healthcare Quarterly Vol. 17 No. 3, 2014: 20-23.

client requires transportation, they may choose a taxi service, community based transportation service or mobility transit option, or a drive from a neighbour or friend. Similarly, if meals are identified as a need, they might access a Meals-on-Wheels program if one is available, a local restaurant, or a neighbour who can prepare, or help prepare familiar dishes.

Clients are also have scope to direct how an hour's service is spent. For example, one shopping trip might be to the grocery store, and another to the pharmacy. Or, a homemaker may spend more time on laundry, if necessary, versus vacuuming, depending on needs.

SMILE Care Coordinators do not duplicate or replace existing services. However, if a financial hardship is demonstrated by the senior or caregiver, SMILE will consider funding specific services. For example, if a senior cannot afford proper nutritious meals because they are using much of their income to pay for transportation, SMILE might consider assuming the cost of transportation.

SMILE eligibility is, in part, determined by whether a senior has a dedicated caregiver who can reasonably provide needed care. However, if the caregiver appears at risk of burnout, the Care Coordinator can choose to perform an assessment of caregiver stress and strain in order to recommend, if necessary, that SMILE assume responsibility for funding some services currently performed by the over-taxed caregiver.

Moreover, SMILE does not leave the seniors and caregiver to manage on their own; Care Coordinators takes deliberate measures to ensure ongoing quality and safety.

As noted, SMILE Care Coordinators regularly monitor all care provided by all providers to SMILE clients, and clients have access to a 1-888 to seek assistance or report concerns at any time.

SMILE also performs an environmental risk assessment (ERA) to identify risk factors that all providers (including non-traditional providers) should be aware of; the ERA is also an integral element of CCAC client assessments. Risks may include client or family members who smoke; presence of a pet; lack of water or electricity in the home; presence of a firearm in the home; and clients who are hoarders or have mental health challenges. It is VON policy to do a new ERA annually or when any new risk is identified.

Pure Self-Management

- Client identifies individual needs
- Client chooses how they would prefer needs to be met
- Client selects service providers based on who they know or what agencies could serve them
- Client schedules and manages service providers

Supported Self-Management

- Client and caregiver(s), as applicable, collaborate with Care Coordinator to identify needs
- Care Coordinator assists with service navigation and coordination of service providers to meet senior's individual needs

Intensive Case Management

- Care Coordinator determines needs using standard assessment tool
- Care Coordinator identifies locally available services
- Care Coordinator recommends service provider to senior and coordinates delivery

.

Moreover, to ensure robust management and accountability, multiple checks are built into the care process. For example,

- SMILE has a payments and verification team that checks invoices against the client's care plan and processes payments
- If a client care plan changes, changes have to be signed-off by a Care Coordinator
- If a client budget exceeds $7,800, SMILE's management team must review and approve

Finally, it is worth re-emphasizing that SMILE reaches seniors and caregivers across the entire SE LHIN. In doing so, SMILE enhances access and equity across the region, ensuring that seniors and caregivers, no matter where they live, can access the high quality, appropriate, community-based supports and services they need to remain at home.

2.0 SMILE EVALUATION FRAMEWORK

2.1 PURPOSE

The evaluation aimed **to design and conduct a fair and extensive evaluation of the SMILE Program** as a guide to its continuing evolution.

Primary objectives were to:

- Determine the impact of the SMILE Program at key points in the local health care system
- Determine the benefits of the model for the client population
- Evaluate the impact on client trajectory
- Evaluate the financial outcomes of the program
- Determine the impact of the 'funding follows client' model on client well being

2.2 EVALUATION DESIGN

The evaluation of SMILE was informed by the results of a previous evaluation conducted in 2010 by Hollander Analytical (see Section 3.2), and by growing international literature on the evaluation of community-based programs and supports for older persons and their caregivers.

For example, we considered the National Evaluation of Partnerships for Older People Projects (POPP) in the UK conducted by the PSSRU (Personal Social Services Research Unit, also the originator of the Balance of Care approach). Under POPP, a range of community-based, local "ground-up" projects were funded across the UK with the aim of promoting the health, wellbeing and independence of older persons, while preventing or delaying the need for higher intensity or institutional care. The Evaluation found that these projects resulted in improved quality of life for participants and cost savings, as well as better local working relationships[11].

We judged the validated, multi-dimensional evaluation approach used by the National Evaluation to be applicable to SMILE; the dimensions used strongly align with Health Quality Ontario's "attributes framework" for a "high performing health system" (2012) and with the objectives of Ontario's 2015 Action Plan for Health Care. These include:

- Quality
    - Access to services: extent to which access to health and social care is improved for older persons and informal caregivers; extent to which older persons are more able to remain at home

[11] For details see National Evaluation of Partnerships for Older People Projects: Executive Summary (2009), available on-line at http://www.pssru.ac.uk/pdf/rs053.pdf).

  - Care coordination/integration: extent to which practice enhances joint working between providers/sectors; extent to which practice enhances patient flow out of hospitals and reduces unnecessary or early referrals to residential long-term care
  - Patient/family centredness: extent to which cared-for persons and caregivers are encouraged to participate in their care decisions; extent to which practice improves/enhances patient autonomy and improves satisfaction

- Costs
  - Cost-effectiveness: extent to which the practice reduce the incremental costs of care; requires capital investment or added funding; reduces hospitalizations/emergency visits

- Impact
  - Health impact: extent to which practice improves the health and functional status of participants; addresses the broader determinants of health; reduces social isolation

- Transferability
  - Transferability/sustainability: presence of mechanisms to sustain the practice; extent to which it is applicable to more than one jurisdiction/region; addresses the needs of older persons with chronic health and social needs; addresses the needs of older persons likely to become high cost utilizers.

This approach was validated and finalized in consultation with VON Canada.

As shown in the Figure below, the SMILE evaluation framework used a multi-dimensional approach, designed to make the best use of available qualitative and quantitative data sources, and to examine process and outcomes at a key levels including:

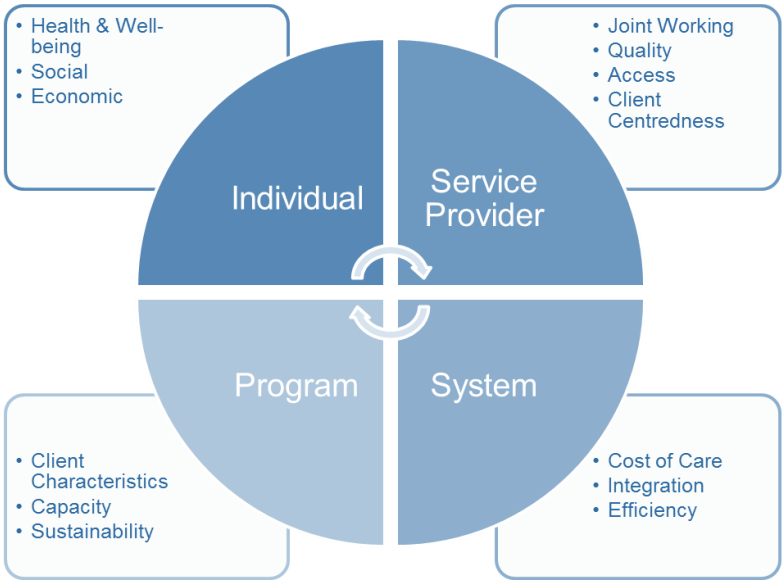
- The individual level - the evaluation framework considered the impact on the health and wellbeing of SMILE's clients, both older persons and caregivers, including their perspectives on SMILE's ability to help them access community-based services required to allow them to continue to live at home

- The program level – the evaluation focused on SMILE's capacity to connect clients to needed community-based services and supports, including conventional and non-traditional providers, to provide client-centred care, enhance care coordination, and encourage participation in care decisions

- The service provider level – the evaluation examined the extent to which SMILE contributed to joint working and coordination between different services and providers, in the process, improving the overall quality, accessibility and client-centredness of care

- The system level - the evaluation asked about SMILE's ability to enhance cost-effectiveness and sustainability, by providing the most appropriate, community-based care, and moderating demand for costly hospital and institutional care.

SMILE Evaluation Framework



The evaluation included two major components:

- A Balance of Care component which included a policy scan; analysis of client assessment data; an Expert Panel and simulation; and a review of client case notes
- A Stakeholder Engagement component which included mailed surveys of clients, caregivers, and providers; focus groups; and, a series of key informant interviews.

Findings from these two components were cross-checked and integrated using "**triangulation**." According to the Encyclopedia or Social Science Research Methods (2003), "triangulation refers to the use of more than one approach to the investigation of a research question in order to enhance confidence in the ensuing findings." The underlying logic is that if multiple data points all tell the same story, uncertainty around interpretation is greatly reduced, and findings can be considered robust.

To further validate and elaborate preliminary findings, and assist in the framing of recommendations for SMILE's future, we conducted a half-day "Think Tank" of senior organization leaders, policy planners, and experts in Trenton, Ontario, on March 31, 2015. After reviewing key findings, we asked participants to comment on key design dimensions of the SMILE program going forward, including targeting (who should be prioritized as SMILE clients); basket of services (what services should be included/excluded); service delivery (how program performance could be improved); and value added (where should SMILE aim to achieve gains for individuals, communities, and the health care system).

Details of each of these components follow.

2.3 BALANCE OF CARE COMPONENT

The Balance of Care (*BoC)* is a policy planning tool adapted from the UK and used by our team in 12 of Ontario's 14 LHINs (as well as in First Nations communities) to assist local providers, planners, policy-makers and other stakeholders in creating local solutions for local needs.

Consistent with current focus of Ontario's Health Links on high intensity, high cost users, *BoC* projects often begin by focusing on individuals "at risk" of loss of independence, typically home care long-stay clients, those waiting for residential long-term care (LTC), and those occupying hospital alternate level of care (ALC) beds. *BoC* projects ask what can be done at the local level to support people in their own homes and communities to avoid or delay hospital or residential LTC and facilitate timely discharge when hospital care is required[12]. However, they also ask what could be done on a preventive/maintenance basis to avoid or delay individuals becoming "at risk."

The *BoC* emphasizes that although planners, providers and policy-makers may have little control over changing population needs, they have considerable choice in how to deploy available resources to meet needs. While conventional projections of the care needs of an aging population often assume that a greater number of older persons will require a proportionately greater number of hospital and residential LTC "beds," the *BoC* looks more broadly to the need for long-term care "places," including combinations of community-based services and supports that can be used to maintain persons with long-term needs and their informal caregivers. Such "places" may be in adult day programs, supportive housing and assisted living, as well as in the family home[13]. They may also be generated through programs like SMILE.

BoC projects emphasize that needs and service approaches will have a large local component. For example, older persons living in rural areas often face the "double jeopardy" of fewer formal services and fewer informal caregivers, in turn increasing the likelihood of hospitalization or admission to residential LTC even at relatively low levels of need[14]. To work in rural areas, solutions will have to be adapted to low population density and long distances; for example, instead of using conventional case conferences where participants gather at the same physical location, web-enabled "virtual" rounds and case conferences can facilitate inter-

---

[12] Williams, AP., Challis, D., Deber, R., Watkins, J., Kuluski, K., Lum, J., Daub, S. (2009). Balancing institutional and community-based care: Why some older persons can age successfully at home while others require residential long-term care. *Healthcare Quarterly*. 12(2). 95-105.

[13] Williams, AP., Peckham, A., Rudoler, D., Tam, T., Watkins, J., (2014). Erie St. Clair (ESC) Balance of Care Project: Windsor-Essex Final Report. Submitted to: Erie St. Clari Local Health Integration Network.

[14] Kuluski, K., Williams, AP., Berta, W., Laporte, A. (2012). Home care or long-term care? Setting the balance of care in urban and rural northwestern Ontario, Canada. *Health and Social Care in the Community*. 20(4). 438-448.

disciplinary, inter-organization teams over long distances. Alternatively, as in the case of the SMILE program, available local resources, including "non-traditional providers" can "fill gaps" by providing non-medical supports that are nevertheless essential for daily living, such as household management, respite, outdoor chores, and transportation which can help older persons and their caregivers continue to live in their own homes.

Thus, *BoC Projects* aim to ground discussion in local realities. The most current assessment data are used to look at actual needs. Steering Committees and Expert Panels are convened to bring together the most experienced front-line providers and senior leaders from across the continuum of care (e.g., hospitals, LTC, supportive housing, community supports, primary care) to interpret findings and formulate care strategies. Projects often "deep dive" into particular challenges; for example, previous projects in the North East and North West LHINs have looked specifically at the potential of supportive housing to maintain older people in the community and "divert" them from LTC wait-lists [15] [16].

Subject to data availability, the BoC component of the SMILE evaluation aimed to:

- Present needs profiles of SMILE clients and home care clients (including those waiting for LTC)
- Gain insight from experienced front-line providers representing organizations across the care continuum about current needs and local capacity and approaches to meet needs in community settings
- Assess the extent to which SMILE aims and outcomes align with key policy priorities in Ontario.

2.4 BALANCE OF CARE DATA AND METHODS

The BoC component also utilized multiple data sources and methods.

2.4.1 POLICY SCAN

We conducted a targeted high level scan of the policy context for the SMILE program to assess the extent to which SMILE aligns with key policy priorities and directions in the province. Among the documents considered:

- The "Walker" Report: *Caring for Our Aging Population and Addressing Alternate Level of Care* (2011)

[15] Williams, AP., Watkins, J., Kuluski, K. (2010). The North West Balance of Care Project II: Final Report. Submitted to North West Community Care Access Centre.

[16] SHS Consulting and Balance of Care Research Group (2009). North East Local Health Integration Network Aging at Home Strategy. Seniors' Residential/housing Options – Capacity Assessment and Projections. Final Report. Submitted to North East Local Health Integration Network.

- The "Sinha" Report: *Living Longer, Living Well: Highlights and Key Recommendations* (2013)
- *Ontario's Action Plan for Seniors* (2013)
- *Ontario's Patients First: Action Plan for Health Care* (2015)
- Expert Group on Home and Community Care Report*: Bringing Care Home* (2015).

2.4.2 CLIENT ASSESSMENT DATA

We analyzed client assessment data for different groups of SMILE and CCAC clients including:

- CCAC long-stay clients *only* (N = 4784 as of November 2014)
- CCAC LTC wait-listed clients *only* (N = 561 as of November 2014)
- SMILE clients assessed using the RAI-CHA (N = 3439 as of January 2015)
- SMILE clients assessed using the RAI-HC (N = 446 as of March 2015)[17]

We used four multiple-item measures to stratify SMILE clients and, for the purposes of comparison, CCAC long-stay and LTC wait-listed clients, into 36 relatively homogenous needs-based sub-groups. These measures were:

- Cognitive performance: including short term memory, cognitive skills for decision-making, expressive communication and eating self-performance (coded into 2 categories: intact, not intact).
- Level of difficulty with ADLs (activities of daily living): including eating, personal hygiene, locomotion, and toilet use (coded into 3 categories: no difficulty, some difficulty, great difficulty).
- Level of difficulty with IADLs (instrumental activities of daily living): including meal preparation, housekeeping, phone use, and medication management (coded into 3 categories: no difficulty, some difficulty, great difficulty).
- Presence of an informal/family caregiver in the home (coded into 2 categories: present, not present).

Each of the 36 sub-groups were then assigned a fictitious surname. For example, the first, relatively low needs sub-group, containing individuals who were cognitively intact, experienced no difficulty performing ADL or IADL tasks, and had a caregiver living with them, was named "Appleton." Similarly, the 36th sub-group, named "J. Johns," contained individuals who were not cognitively intact, could not perform ADL and IADL tasks independently, and did not have a caregiver living with them.

We then developed "vignettes," written to simulate case notes, for typical individuals in each of eight sub-groups representing key combinations of needs. Vignettes were created for eight heavily populated sub-groups representing seniors at different levels of need, with and without a caregiver present in the home:

[17] Includes SMILE clients who had a RAI-HC as of March 2015 (point in time).

- Copper and Davis – intact cognitively; low levels of difficulty with ADLs; moderate levels of difficulty with IADLs; with and without a caregiver living in the home respectively
- Quinn and Rogers – intact cognitively; high levels of difficulty with ADLs; high levels of difficulty with IADLs; with and without a caregiver living in the home respectively
- Won and Xavier – not intact cognitively; low levels of difficulty with ADLs; moderate levels of difficulty with IADLs; with and without a caregiver living in the home respectively
- I. Innis and J. Johns -- not intact cognitively; high levels of difficulty with ADLs; high levels of difficulty with IADLs; with and without a caregiver living in the home respectively.

2.4.3 EXPERT PANEL AND SIMULATION

On November 12, 2014, we convened a full-day Expert Panel of 11 experienced front-line case managers from across the health and social care continuum in the SE LHIN; this included representatives from aboriginal health, social services, hospitals, community support services, CCAC, seniors' homes, community mental health, primary care, and VoN.

Panel members "simulated" the work that an inter-disciplinary, inter-organizational team would do to construct care packages required to maintain typical individuals (and caregivers), in each of the eight needs sub-groups, safely and appropriately at home, regardless of cost.

The Expert Panel was attended by five evaluation team members who facilitated discussion, and recorded detailed field notes which were subsequently cross-checked and analyzed to identify key themes.

2.4.4 CLIENT CASE NOTES AND BUDGETS

In January, 2015 we received and analyzed actual case notes written by SMILE Care Coordinators for 138 current SMILE clients. Clients were randomly selected by SMILE staff who removed all personal identifiers before transmitting them to the evaluation team on an encrypted data key.

These case notes recorded the characteristics and needs of clients and (if present) caregivers, including diagnoses, caregiver status (e.g., coping, at the point of burnout) and services offered. They also described interactions with clients (including caregivers), as well as with other service providers such as the SE CCAC. As such, they provide "rich" qualitative insight into the process of identifying care needs, establishing priorities, and constructing care plans.

Two evaluation team members reviewed case notes independently and met to verify emerging themes which were subsequently verified and elaborated using computer assisted data analysis software (NVivo).

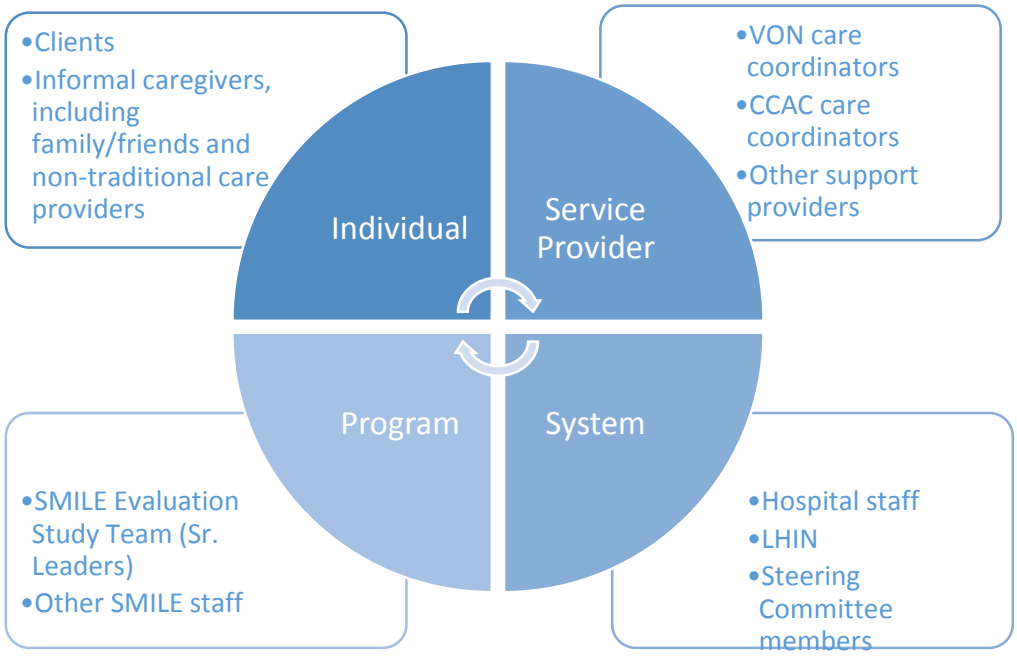
We then used the case notes to create four "client journeys" representing SMILE clients; these journeys offer first-hand perspectives on the experiences of clients, caregivers, and SMILE Care Coordinators.

In March, 2015, we received and analyzed de-identified individual-level budget estimates for all SMILE clients from April 1, 2014 to March 31, 2015. In addition to computing an overall average budget allocation per client, we looked for information that would help to explain variation at the individual level both in terms of budget allocation, and services provided.

2.5 STAKEHOLDER ENGAGEMENT COMPONENT

In the second evaluation component, stakeholders were identified for each of the four levels of impact.

Stakeholder Engagement Framework



2.5.1 ENGAGEMENT METHODS

Based on the evaluation framework, the consulting team developed a detailed engagement strategy, which listed the stakeholders, activities and timelines for the consultation process. This information is summarized in the table below.

Table 1: Consultation Activities

Activity	Level of Impact	Stakeholders	Format	Timing
Context Interviews	• Program • Service Provider • System	• VON leadership • CCAC leadership • LHIN system planners	• In-person and phone-based Interviews, and focus groups	• Summer 2014
Round One Focus Groups	• Program • Service Provider	• VON SMILE CCC's and office staff • CCAC care coordinators	• In-person group interviews / focus groups	• Fall 2014
Round One Interviews	• Program • Service Provider	• VON Canada Finance • Geriatrician	• In-person interviews	• Fall 2014
Surveys	• Individual • Service Provider	• Clients • Caregivers • Traditional service providers (ie. CSS agencies) • Non-traditional service providers and brokered workers	• Mail-in and online surveys	• Winter 2014/2015
Round Two Consultations	• Individual • Service Provider	• Clients • Caregivers	• Phone-based interviews	• Winter 2015
Phone-based Consultations	• Individual • System	• Clients • Caregivers • CCAC and hospital discharge planners	• Phone-based interviews	• Spring 2015

2.5.2 EXPECTED OUTCOMES

The main objective in meeting with a broad range of stakeholders was to understand and evaluate the impact of the SMILE program on clients, service providers, program staff, and the health system in general. Expected consultation outcomes were identified for each stakeholder category and are summarized below.

Individual Level (surveys, interviews, focus groups):

Clients

- impact of SMILE on clients
- social impact of SMILE program
- insight to enable comparative analysis

Caregivers

- impact of SMILE on caregivers
- impact of SMILE on caregivers' loved ones
- social impact of SMILE program
- insight to enable comparative analysis

Program Level (meetings, interviews, ongoing dialogue):

SMILE Study Team

- overview of SMILE program, partners and evolution
- data and data sources
- input into consultation approach
- capacity of SMILE
- key issues, trends and opportunities
- feedback on all project deliverables

VON Staff

- administration / backoffice operation of SMILE
- capacity of SMILE and level of resources

Provider Level (focus groups, interviews):

SMILE Office CCs

- impact of SMILE on clients and caregivers
- joint working / care coordination within SMILE
- key issues, trends and opportunities
- identifying SMILE client profile

SMILE Area CCs

- impact of SMILE on clients and caregivers
- impact of SMILE on other care providers
- key issues, trends, and opportunities
- identifying SMILE client profile

CCAC CCs

- impact of SMILE on clients and caregivers
- understanding joint working / care coordination within SMILE
- key issues, trends and opportunities
- SMILE client profile

CSS Provider

- impact of SMILE on client
- provider level impacts among professional agencies

Non-Traditional Individual Provider

- impact of SMILE on non-traditional care providers

System Level (meetings, Expert Panel, Think Tank):

Steering Committee	LHIN	Hospital Staff	Individuals who Participated in Smile Planning
•assist in interpretation of study findings •review draft report •assist in knowledge transfer •improve understanding for members of individual level impacts of SMILE	•strategic perspective on value of SMILE •understand capacity and potential for SMILE •impact or potential impact of changing system dynamics on future of SMILE within SE LHIN	•sense of system-level impacts of SMILE	•the evolution of SMILE •key issues, trends and opportunities

Participation by stakeholders in the various engagement activities is summarized in Section 3.5.1. A copy of all surveys is provided in Appendix A.

2.5.1 ANALYSIS OF STAKEHOLDER ENGAGEMENT RESULTS

During each of the in-person and telephone-based consultation activities described above, a member of the consulting team facilitated while another took detailed notes. These notes were grouped first by level of impact, second by stakeholder group and third by emergent theme. The emergent themes were determined through a detailed review of each set of consultation notes.

The four surveys each used a combination of multiple choice, Likert scale and open-ended questions. Responses to the multiple choice and Likert scale questions were coded and response frequencies were tabulated by question. The open-ended survey questions were also assigned codes, based on categories or themes that emerged through a review of responses. For the purposes of inputting data, the categories were quite narrow and detailed. Ultimately, some codes or categories could be combined to present an analysis of findings according to broader themes, such as service quality, but the spreadsheet data is much more detailed. The spreadsheet was generally organized by stakeholder and method.

Results of all stakeholder engagement activities are summarized in Section 3.5 of this report.

2.5.2 MOST SIGNIFICANT BENEFIT

As part of the evaluation, the consulting team explored with the various stakeholder groups (SMILE and CCAC CCC's, Service Providers (including traditional and non-traditional) and clients and caregivers) what they think is the **most significant benefit of SMILE**. At times, the phrasing was altered slightly to ask about the "most valuable part of SMILE" (surveys) or the "best part of SMILE" (client and caregiver telephone interviews). During Round One of the consultation process, SMILE Office-Based and Area Care Coordinators and CCAC Care Coordinators were first asked about the "most significant benefit" of SMILE for their clients, and then, as a follow-up

question, they were asked to identify, using a scale of 1 to 5, the extent to which SMILE itself is responsible for that benefit, versus it being possible that the benefit could have been realized without SMILE support. We did not ask the latter "attribution" question of Service Providers, clients or caregivers. An overview of the results of this consultation methodology is included in Section 3.5. The detailed comparative analysis of the SMILE and CCAC Care Coordinators' responses is included in Appendix B.

2.6 THINK TANK

On March 31, 2015, we conducted a half-day "Think Tank" in Trenton, Ontario, to validate and elaborate evaluation findings.

The Think Tank was attended by 10 senior leaders from SMILE, the SE LHIN, the SE CCAC, a local Health Link, other CSS providers. It was facilitated by four members of the evaluation team who presented findings from each of the evaluation components and asked participants to consider how program performance and impact could be improved along four key design dimensions:

- Targeting (Who): As demand increases, who should SMILE prioritize? Older persons and caregivers at immediate risk, or future risk of illness or loss of independence? Older persons and caregivers in underserviced areas? Other needs (e.g., mental health)?
- Basket of services (What): As needs become more complex, should SMILE aim to provide/coordinate a broader range of supports? IADL only? ADL? Primary health care?
- Service delivery (How): How can SMILE improve program delivery? What about the use of interdisciplinary/cross-organization/cross-sectoral teams? What about technology? What about alternative funding mechanisms (including "bundled" capitated payment adjusted to assessed client needs and volume and pooled across clients)? Service delivery (How)
- Value Added (Why): Where should SMILE aim to generate valued added? Maintain individual older persons in the community? Support older persons and caregivers? Build social capital? Sustain health care systems?

We also asked Think Tank participants to consider key elements of the business case for SMILE. We posed the following questions:

- How well is SMILE aligned with key policy priorities: access, equity, client-centred care, education and information to support client decision-making, care coordination, care "closer to home"? How could it be better aligned?
- Is SMILE scalable? Can it be adapted to other regions?
- How can SMILE best lever formal, informal and non-traditional assets to ensure sustainability? What additional investments will be required? Should new funding models be considered?
- Are there risks? How should they be managed?
- How can partner/stakeholder engagement be strengthened?

The evaluation team recorded detailed field notes, and subsequently cross-checked them when writing up the results.

3.0 FINDINGS

3.1 POLICY SCAN

Our high level scan of Ontario's policy context identified two major themes of particular relevance to SMILE:

- The first concerns the need to move beyond fragmented non-systems of episodic hospital-based care, to an integrated continuum of community-based services and supports including prevention and maintenance. Such a continuum is seen to be crucial for responding to the growing numbers of seniors and caregivers who have multiple, chronic health and social needs, and as a means of moderating demand for more costly, and sometimes inappropriate hospital and institutional care.
- A second key theme is that to do this effectively, you also need to move beyond the logic of "provider-driven" care, where clients receive what providers can give them, to "client-centred" care where services are tailored to meet the changing needs of seniors and their informal caregivers.

Ontario's 4 year, $1.1 billion Aging at Home (AAH) initiative, announced in 2007, reflected these themes [18]. AAH aimed to enhance H&CC capacity not only to "enable people to continue leading healthy and independent lives in their own homes," but also to prevent or delay illness and disability, and thus moderate demand for more costly institutional care. To do this AAH aimed to improve access to non-medical, but essential supports for instrumental activities of daily living (IADLs) such as meals, transportation, shopping, friendly visiting, snow shoveling, adult day programs, caregiver relief/support.

As discussed earlier, SMILE emerged as an innovative response to AAH in the SE LHIN, one of Ontario's most rural and fastest-aging regions[19] [20]. According to the 2013 Canadian Community Health Survey (CCHS), the SE LHIN remains characterized by higher-than-average rates of chronic conditions such as arthritis, diabetes, high blood pressure and chronic obstructive pulmonary disease (COPD) for those 65 years of age and older[21]. From its inception, SMILE was committed not only to building a continuum of community-based care, including non-medical supports for everyday living, but doing it around the needs of seniors and caregivers.

---

[18] Ministry of Health and Long-Term Care (2010) http://news.ontario.ca/mohltc/en/2010/8/aging-at-home-strategy.html

[19] South East LHIN (2008). *Aging at Home Plan: A Plan to Help Seniors Stay at Home.*

[20] South East LHIN. Integrated Health Services Plan 2013-2016.

[21] Statistics Canada, CCHS, 2013. CANSIM Table 105-0501

As it turned out, preventive/maintenance focus was overtaken, in 2009-10, by the provincial ER/ALC strategy, with 50% of AAH funding re-directed toward post-hospital care; in 2010-11, 25% of LHIN AAH funding was retained by the province for its ALC initiatives, with the remaining 75% targeting ALC problems at the LHIN level. ALC rates continue to pose challenges across Ontario; in the SE LHIN they have tended to be higher than the provincial average.

Walker's insightful analysis (2011) of Ontario's persistent ALC problem concluded that while often seen as a hospital problem, ALC rates are a reflection of an under-resourced community sector; a lack of appropriate community-based care can lead older persons to "default" to more costly and inappropriate hospital and institutional care[22] and then make it difficult for them to return home. According to Walker, "current models of care" rely too heavily on acute care hospital resources and reproduce a culture which emphasizes 'permanent' placement of seniors in LTC. "Once in hospitals older persons can wait excessively long periods of time for discharge even though acute care settings are not appropriate for persons with "restorative, supportive or rehabilitative needs…" Moreover, longer hospital stays can actually accelerate cognitive, physical, and emotional decline and increase the likelihood of hospital-related infections, falls and other adverse events. As Walker observed, "**Seniors want to live in their homes for as long as possible and receive dependable and reliable community supports to meet their social, physical, emotional, nutritional, health professional and caregiver needs.**"[23] To do this, Walker advocated for a "fundamental system redesign" which would "improve access to the right care" through more robust community resources.

Such a redesign was also advocated by Dr. Samir Sinha's extensive review of demand- and supply-side issues associated with Ontario's aging population[24]. He observed that current episodic care systems are not well equipped to address the needs of growing numbers of older persons with multiple chronic health and social needs, a minority of whom who are among the most intensive users of costly medical care. He argued for policies and investments aimed at establishing a continuum of care for older persons which would allow them to live in their own homes for as long as possible and avoid unnecessary use of costly hospital and institutional care. This continuum would include:

- Wellness and prevention programs to improve functional capacity, independence and the ability of older adults to stay home longer
- Improved access to primary care, H&CC services, and home-based care options
- Senior friendly hospital care, when care is required, with timely discharge to home and community care

---

[22] Walker, D. (2011). Caring for Out Aging Population and Addressing Alternate Level of Care. http://www.homecareontario.ca/documanager/files/news/report--walker_2011--ontario.pdf

[23] Ibid.

[24] Sinha, S. (2012). Living Longer Living Well. http://www.health.gov.on.ca/en/common/ministry/publications/reports/seniors_strategy/docs/seniors_strategy.pdf

- Enhanced LTC environments, including improved capacity to support short-stay and restorative options and discharge back to the community.

Ontario's recently announced *Patients First: Action Plan for Health Care* (2015) acknowledges that in spite of gains made since the publication of the first provincial Action Plan in 2012, "there's still more work to do;" that work must begin by putting "**people and patients first.**"

The Plan sets out four main objectives[25] including:

- Access: Improve access – providing faster access to the right care.
- Connect: Connect services – delivering better coordinated and integrated care in the community, closer to home.
- Inform: Support people and patients – providing the education, information and transparency they need to make the right decisions about their health.
- Protect: Protect our universal public health care system – making decisions based on value and quality, to sustain the system for generations to come.

The theme of "more to do" is likewise a key focus of the recent report of Ontario's Expert Group of Home and Community Care titled *Bringing Care Home (2015)* "[26] led by Gail Donner. The report emphasizes that H&CC plays a crucial role in the lives of older persons and their caregivers, and in the broader health system; however, there is "no coordinated system strategy" with the result that "everyone – clients and families, providers and funders – is frustrated with a system that fails to meet the needs of clients and families".

Although the Expert Group acknowledges that it was not able to identify a single solution, "no one thinks the status quo is an option"[27]. It also identifies a series of principles to guide future development of the sector. These by-now familiar principles include:

- Client and family-centred care; focus on what the family wants, not what the providers with to provide. "The residents of Ontario told us that they want the family to be the 'client' and the planning and delivery of care to be truly client and family-centered. Although policy makers and providers have long supported the principle of family-centered care, home and community care continues to look more like it is focused on what the providers want, rather than on the needs and preferences of clients and families."
- Support for family caregivers. "Our health system could not sustain the current levels of care in the community without the continued contribution of family caregivers. If we expect family caregivers to continue to support and care for their loved one, we need to support them."

---

[25] Government of Ontario (2015). Patients First: Action Plan for Health Care. http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf

[26] Expert Group on Home & Community Care. (2015). Bringing Care Home. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

[27] Ibid.

- A "basket of services." "Stakeholders expressed a strong need for a clearly defined publicly-funded "basket of services" that recognizes that non-clinical supports such as homemaking, meal preparation, supportive housing, transportation and respite are often essential to supporting an individual at home. They also wanted this information to be easily accessible."
- Structural change in home and community care. "Many told us that families have to deal with too many different agencies and that the current structure is cumbersome, has too much overlap, is not efficient and is not delivering the services that families need."

The provincial response to the Donner report is of considerable interest. In its May, 2015, announcement, the province indicated that will begin a series of changes designed to provide better coordinated and integrated home and community care; to assist clients and caregivers understand what to expect and how to access care; to ensure more integrated home and community care after leaving the hospital; and to access more services that support patients and caregivers[28].

Among the likely changes are new funding mechanism which would "bundle" funding for different clinical services into "integrated funding models;" these are likely to be offered first to hospital systems like St. Joseph's in Hamilton.

Of more direct relevance to the H&CC sector, and to SMILE, are subsequent suggestions by the Minister of Health and Long-Term Care that the province will soon move to establish pilot projects to give patients or caregivers money to spend on home health services; "self-directed care" is already working well for parents of autistic children and could be similarly used to support seniors and their caregivers[29]. He noted that the province will also look toward the development of a "statement of values" for home and community care; and clarification around which H&CC services people can expect no matter where they live.

In sum, progress toward a continuum of client-centred, community-based care remains a key aim of policy-makers and planners in Ontario; however, progress has been slow, impacting negatively on seniors and caregivers and on the health care system as a whole. This in turn is adding to political momentum to make changes to H&CC, both "top-down" changes which could include new funding mechanisms for hospitals, but also more "bottom-up" changes which could see experimentation with "self-managed" funding models as a means of achieving more client-centred care.

As discussed in more detail below, SMILE appears well positioned to contribute to such change. SMILE is continuously strengthening its working relationships with other providers across the care continuum including local hospitals through iCART; it is levering new community-based resources to improve access to needed care across urban and rural areas of the SE LHIN; and it

[28] http://news.ontario.ca/mohltc/en/2015/03/ontario-endorses-expert-report-on-home-and-community-care.html
[29] http://www.theglobeandmail.com/news/national/ontario-health-minister-expected-to-address-scathing-report-on-home-care/article24415170/

continues to build its experience and expertise with "supported self-management," an approach particularly applicable to seniors and caregivers who need help to continue to live in the community.

3.2 PREVIOUS EVALUATION OF SMILE

In this volatile and challenging policy environment, SMILE "hits the ground running."

In 2013, using the Health Innovation Portal Evaluation Framework, the Health Council of Canada recognized SMILE as an Emerging (Commendable) Practice. In 2015, Donner's Expert Group singled-out SMILE as an example of an integrated and/or population-based service delivery model in Ontario[30].

A previous, and very comprehensive program evaluation of SMILE, conducted in 2010 by Hollander Analytical Services,[31] determined that SMILE had already met or surpassed key goals. It found that:

- SMILE was designed the way clients wanted it to be
- Other stakeholders lauded SMILE's client-centred care approach and flexibility to access a broad array of services
- Individuals in both rural and urban areas reported that they were able to self-refer to the program, to self-manage their services if they wished, and to choose services from non-traditional as well as traditional service providers.

This evaluation also documented positive outcomes for clients, caregivers and the health care system. For clients, major findings were that:

- Over 95% of SMILE clients said they preferred to live at home, and most said that because of SMILE it was very easy to do so
- SMILE clients experienced no measurable deterioration in functional status over a six month time period covered by the evaluation; no significant changes were observed on any of the IADL, cognitive functioning and mood variables as well as most variables related to ADLs and psychological well-being
- SMILE clients experienced improvements in walking without assistive devices and in participation in daily exercise
- Although based on a small sample size, SMILE clients were less likely to report hospital and/or ER visits
- SMILE clients perceived improvements in health related quality of life for physical health

---

[30] Expert Group on Home & Community Care. (2015). Bringing Care Home. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

[31] Miller, Jo Ann and Margaret MacAdam. (2011). Evaluation of the Seniors Managing Independent Living Easily (SMILE) Program. Hollander Analytical Services Ltd.

- SMILE clients expressed confidence that they could control and manage their own health

For caregivers, the evaluation found that:

- The majority of caregivers (about 85%) preferred that cared-for older persons continued to live at home
- There were high and sustained levels of caregiver satisfaction (over 80% at all points)

With respect to health care utilization and costs, the evaluation concluded that:

- The most frequently used services were light housekeeping, transportation for medically related issues, laundry and shopping
- In addition to paid formal services provided, caregivers contributed 30 to 41 hours of unpaid care per week, thus substantially subsidizing total care costs.

While all of these findings reflect positively on SMILE, we think this last finding is particularly noteworthy. Even as policy-makers and planners have increasingly emphasized the principle of "client-centred" care, they have been slower to recognize that for community-dwelling seniors with ongoing needs, the "client" and "caregiver" often constitute an integral "unit of care." Donner makes this precise point in her 2015 report, observing that if informal caregivers withdraw, formal care systems will bear a growing and likely unsustainable burden.

Here, SMILE is well ahead of the curve, since caregivers are actively involved in building care packages, and they receive ongoing counselling and support, and where appropriate, direct services such as respite, to sustain them in their role.

3.3 BALANCE OF CARE (BOC)

3.3.1 SE LHIN REGIONAL CONTEXT

The Balance of Care Component of the evaluation aimed to bring together the best available data and the most knowledgeable experts to think about changing needs, and approaches to meeting needs, in the SE LHIN.

Demand side. The SE LHIN has the largest proportion of seniors in the province; it is also the largest rural health region in Southern Ontario[32].

[32] [32] South East LHIN (2008). *Aging at Home Plan: A Plan to Help Seniors Stay at Home.*
[32] South East LHIN. Integrated Health Services Plan 2013-2016.
[32] Statistics Canada, CCHS, 2013. CANSIM Table 105-0501

Like other predominately rural areas of Canada, the population of the SE LHIN is aging, not only because people are living longer (albeit more often with chronic health and social needs), but also because of population outflow as younger adults leave to pursue education and jobs in urban centres.

Health needs in the SE LHIN tend to be more marked than in other areas of the province (Statistics Canada, 2013). For example, the 2013 Canadian Community Health Survey (CCHS) found that 25.7% of the SE LHIN residents (age 12+) were diagnosed with arthritis, 9.2% with diabetes, and 23.1% with high blood pressure[33]. These percentages were significantly higher than the provincial averages of 17.7% for arthritis, 6.7% for diabetes, and 18.5% for high blood pressure ($p<0.05$). For seniors (age 65+) in SE LHIN, the prevalence rates of these chronic conditions were also higher than the rest of the province, but not statistically significant ($p>0.05$).

Supply side: Particularly in rural areas, seniors with such needs may face the double jeopardy of limited access to formal community-based services and limited access to informal caregivers – family, friends and neighbors who provide most of the everyday care required by older persons. In combination, these factors can reduce the likelihood of being able to remain at home[34] [35] [36] [37].

The SE LHIN is also characterized by hospital "flow" problems and a greater reliance on residential LTC. According to the provincial data, in March 2015, 14.1% of hospital in-patient beds in Ontario were deemed to be ALC; in the SE LHIN, the corresponding estimate was 19%[38]. Moreover, as the name "alternate level of care" would suggest, ALC rates appear to be associated with a lack of discharge options: in March 2015, about 40% of individuals occupying ALC beds across the province were classified as waiting for residential LTC beds; in the SE LHIN the number was 66%. Between April 2013 and April 2015, the number of ALC patients across Ontario waiting for home care with CCAC services rose from 500 to 633, an increase of about 25%.

---

[33] Statistics Canada, CCHS, 2013. CANSIM Table 105-0501

[34] Kuluski, K., Williams, AP., Berta, W., Laporte, A. (2012). Home care or long-term care? Setting the balance of care in urban and rural northwestern Ontario, Canada. *Health and Social Care in the Community*. 20(4). 438-448.

[35] Kuluski, K., Williams, AP., Laporte, A., Berta, W. (2012). The role of community-based care capacity in shaping risk of long-term care facility placement. *Healthcare Policy.* 8(1). 92-105.

[36] Organization for Economic Co-operation and Development (2011). Help wanted? Providing and paying for long-term care. Chapter 3. The impact of Caring on Family carers. Retrieved from: http://www.oecd.org/els/health-systems/47884865.pdf

[37] Hollander, Guiping and Chappell (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42-49.

[38] Cancer Care Ontario. *Access to Care. Alternate Level of Care (*ALC) Accessed on line, July 2015, at http://www.oha.com/CurrentIssues/Issues/Documents/ALC%20Report%20-%20April%202015.pdf

Figure 1 Percentage of Inpatient Beds Occupied by ALC Patients (March 2015)

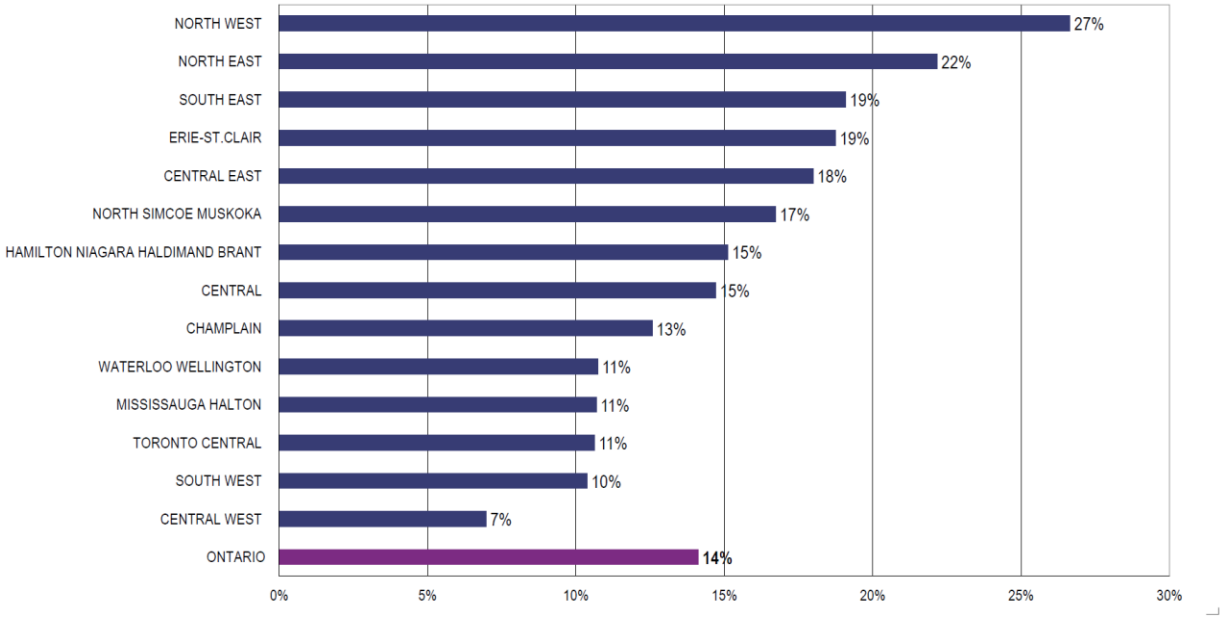
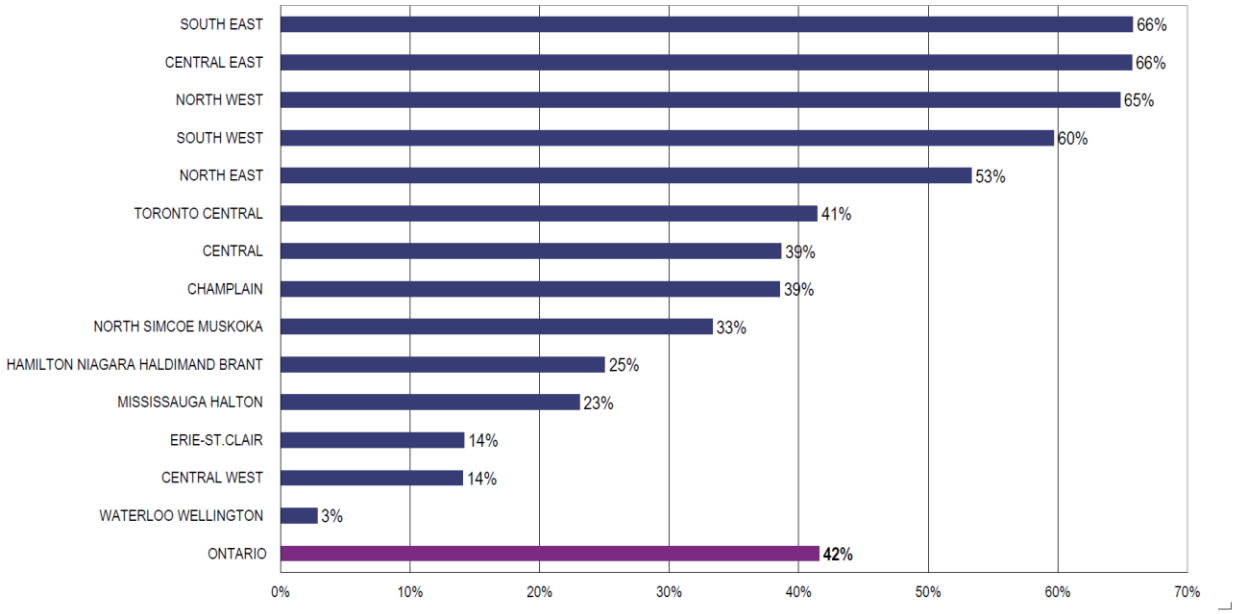


Figure 2 Percentage of ALC Patients Waiting for Long Term Care (March 2015)



CCACs across the province are now responding to similar challenges by redeploying greater proportions of their resources to clients requiring post-hospital care and those at the point of admission to residential LTC; mostly anecdotal reports suggest that, as a result, community-based providers such as SMILE are also experiencing an upward shift in the needs of their clients. We look for evidence of such shifts in our analysis of client assessment data below.

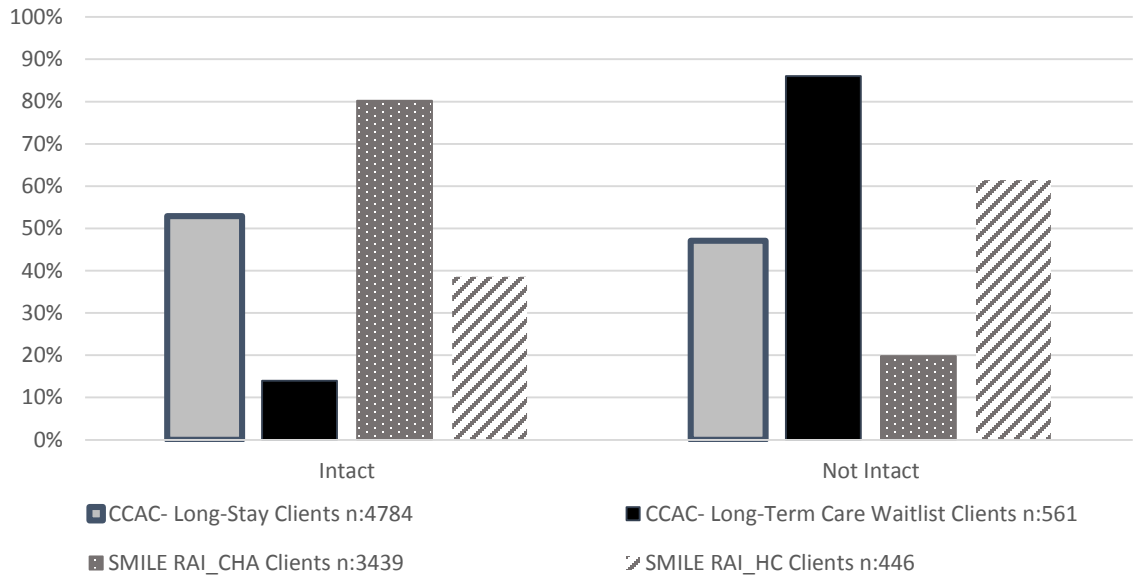
3.3.2 ANALYSIS OF RAI-CHA AND RAI-HC CLIENT ASSESSMENT DATA

As described earlier, we used the most current RAI-CHA and RAI-HC client assessment data available (November 2014 and January 2015) to stratify SMILE clients, CCAC long-stay and CCAC LTC wait-listed clients, into relatively homogeneous needs sub-groups based on:

- Cognitive performance
- ADL difficulty
- IADL difficulty
- Presence of an informal/family caregiver in the home.

Cognitive Performance. The Cognitive Performance Scale identifies individuals who have short-term memory problems, make decisions that are poor or unsafe, and require cues and/or supervisions on a continuous basis. Individuals categorized as "intact" have scale scores which indicate that they do not experience such challenges; individuals categorized as "not intact" experience these challenges to some degree ranging up to severe cognitive impairment.

Figure 3 Cognitive Performance Scale



The data in Figure 3 show that:

- About half (52.9%) of CCAC long-stay clients were assessed as cognitively intact; however, most (over 86%) CCAC LTC wait-listed clients experienced some level of cognitive difficulty
- By comparison, a large majority (80.2%) of SMILE RAI-CHA clients were cognitively intact; however, almost two thirds (61.4%) of SMILE RAI-HC clients (those referred from CCAC) experienced cognitive impairment.

Thus, SMILE clients referred from CCAC appeared more likely than CCAC long-stay clients to experience cognitive challenges.

ADL Difficulty. The data in Figure 4 show levels of difficulty with ADLs experienced by SMILE and CCAC clients where:

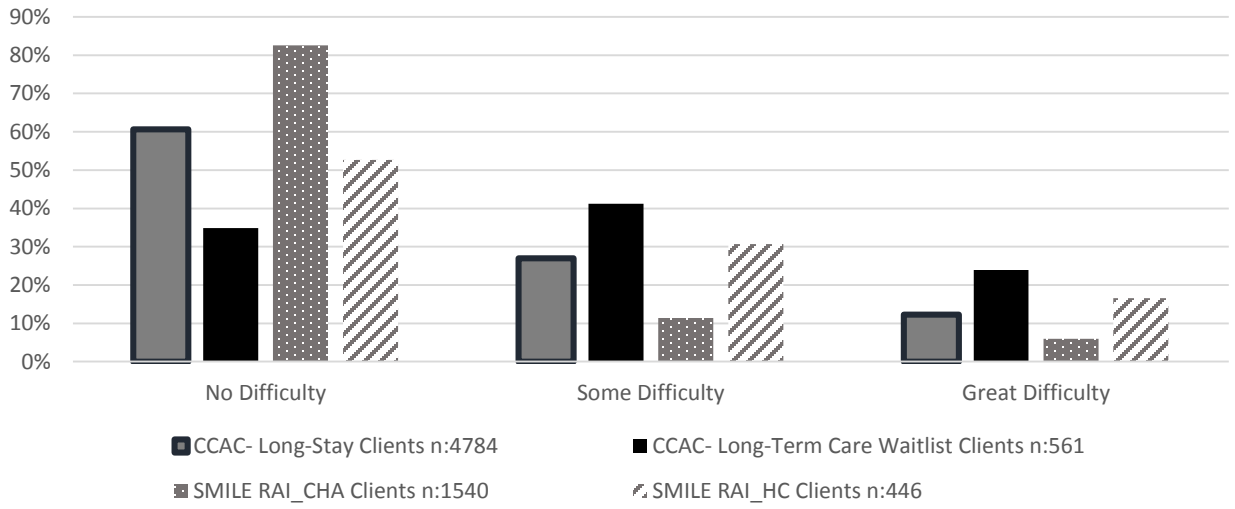
- "No difficulty" indicates that individuals can perform tasks such as eating, personal hygiene, locomotion, and toilet use independently
- "Some difficulty," that they require some help (e.g., a meal set up)
- "Great difficulty," that they are fully reliant on others (e.g., placing food in the mouth).

Figure 4 reveals that:

- About two thirds (60.6%) of CCAC long-stay clients experienced no difficulty with ADLs; about a quarter (27%) experienced some difficulty; and 12.3% experienced great difficulty. As might be expected, CCAC LTC wait-listed clients experienced higher levels of difficulty with ADLs: 41.2% experienced some difficulty, and about a quarter (23.9%) experienced great difficulty with ADLs
- By comparison, only a small percentage of SMILE RAI-CHA clients experienced great difficulty with IADLs (6%). However, SMILE RAI-HC clients (those referred from CCAC) appeared more likely than CCAC long-stay clients to experience great difficulty with IADLs (16.6%).

These data suggest, therefore, that SMILE RAI-HC clients were more likely to experience some difficulty with ADLs than CCAC long-stay clients, and they were only somewhat less likely than CCAC LTC wait-listed clients to experience great difficulty with ADLs.

Figure 4 Activities of Daily Living Difficulty Scale



*SMILE RAI_CHA missing cases: 1899

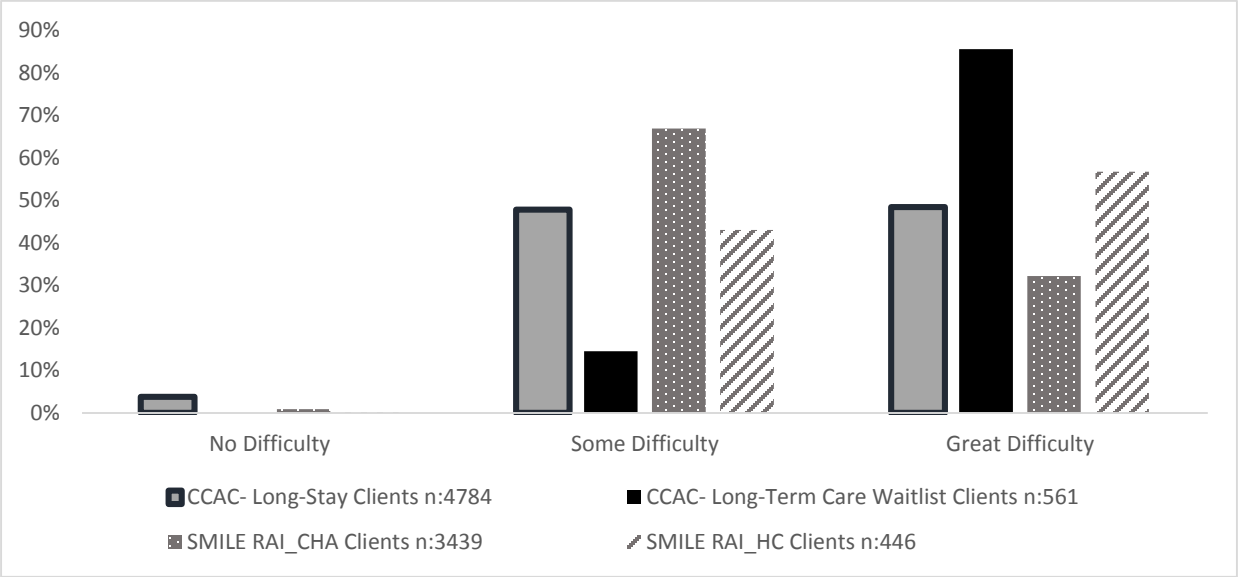
IADL Difficulty. Figure 5 reveals that most CCAC and SMILE clients experienced moderate to high levels of difficulty with IADLs.

- Few CCAC clients experienced "no difficulty" with IADLs; in fact, about half (48.4%) of CCAC long-stay clients and 85.5% of CCAC LTC wait-listed clients experienced great difficulty, meaning they could not perform IADL tasks without extensive assistance
- About a third of SMILE RAI-CHA clients (32.2%) experienced great difficulty with IADLs. This compares to more than half (56.7%) of SMILE RAI-HC clients who experienced great difficulty with IADLs, a higher proportion than for CCAC long-stay clients (48.4%).

These data suggest two key findings:

- First, IADLs are a key driver of referral to LTC
- SMILE RAI-HC clients (those referred from CCAC) experienced needs comparable to, or greater than, CCAC long-stay clients.

Figure 5 Instrumental Activities of Daily Living



Live-In Caregiver. Family, friends and neighbors provide most of the instrumental care required to maintain the well-being and independence of community-dwelling older persons[39] [40].

Figure 6 shows that:

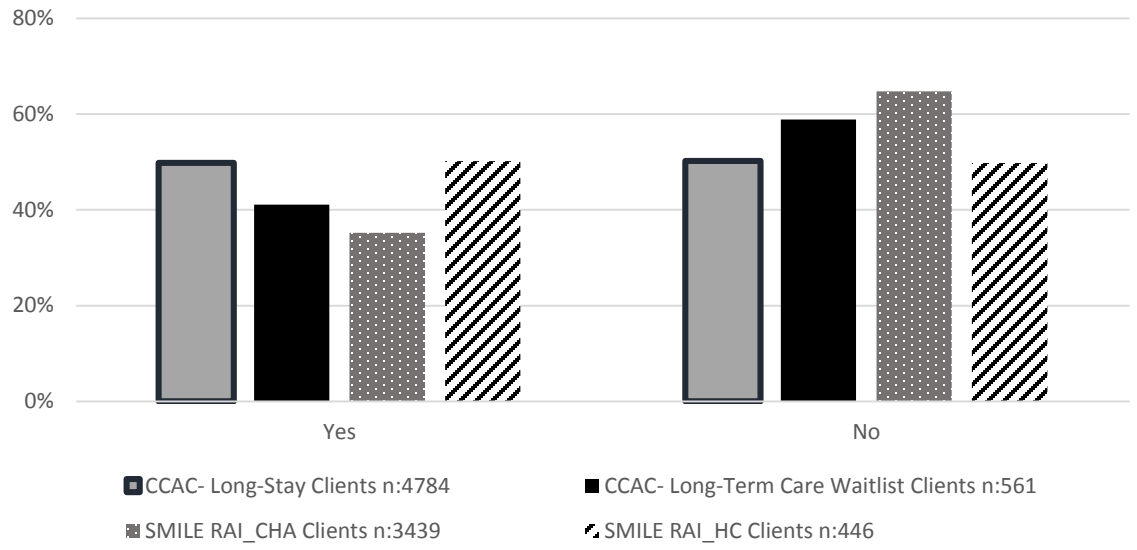
- Just under half of CCAC and SMILE clients overall had caregivers living with them
- However, SMILE RAI-HC clients were less likely than CCAC long-stay clients to have a caregiver living with them.

As noted earlier, particularly in rural areas, where there may be limited access to formal community-based services, the presence/absence of a caregiver can strongly influence whether seniors can remain in their own homes. While seniors may receive care from family, friends and neighbours living outside the home, these caregivers may be less likely than those living in the home, to be able to provide ongoing personal care, and 24/7 monitoring, a key consideration for seniors living with cognitive limitations.

[39] Organization for Economic Co-operation and Development (2011). Help wanted? Providing and paying for long-term care. Chapter 3. The impact of Caring on Family carers. Retrieved from: http://www.oecd.org/els/health-systems/47884865.pdf

[40] Hollander, Guiping and Chappell (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2), 42-49.

Figure 6 Presence of a Live-In Caregiver



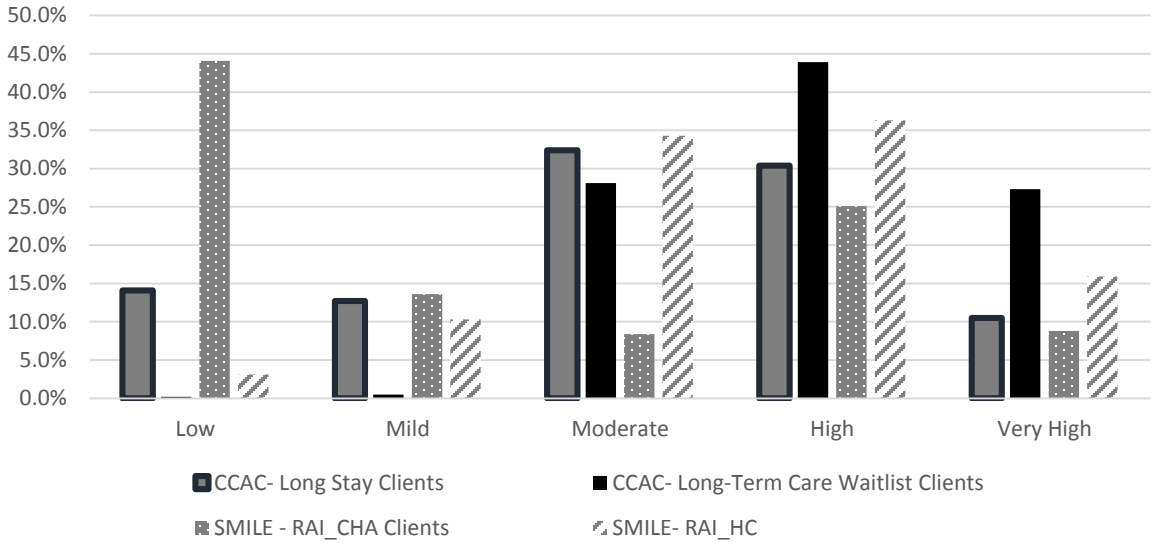
MAPLe Scores. MAPLe (Method of Assigning Priority levels) is a screening algorithm generated from RAI-HC and RAI-CHA assessments; its aggregate scores provide a summary indication of client need. MAPLe scores are widely used by CCACs across Ontario to determine eligibility for home care services and referral to LTC. Higher MAPLe scores suggest higher levels of need and, therefore, a greater likelihood of referral to long-term care.

As shown in Figure 7, we re-coded MAPLe scores for CCAC long-stay, CCAC LTC wait list clients, and SMILE clients into 5 categories: low, mild, moderate, high and very high.

Figure 7 reveals that:

- Almost all (99.3) CCAC LTC wait-list clients had moderate to very high MAPLe scores; almost three quarters (71.2%) had high or very high scores. Close to three quarters (73.3%) of CCAC long-stay clients had moderate to high MAPLe scores; conversely, only a quarter (26.8%) had low or mild scores
- In comparison, more than half of SMILE RAI-CHA clients (57.7%) had low or mild MAPLe scores; nevertheless, a third (33.9%) had scores that placed them in the high or very high needs categories. Moreover, more than half (52.2%) of SMILE RAI-HC clients had high or very high MAPLe scores.

Figure 7 MAPLe Scores



In sum, the data in Figure 7 show that:

- Most home care clients waiting for admission to LTC have high or very high MAPLe scores
- More than half of SMILE RAI-HC clients experienced similarly high levels of assessed need; in fact, they were more likely that CCAC long-stay clients to have high or very high MAPLe scores.

Distribution of Selected BoC Sub-groups for CCAC and SMILE Clients. In addition to looking separately at measures of ADL difficulty, IADL difficulty, cognition, and presence of a live-in caregiver, we combined these four measures to stratify CCAC and SMILE clients into 36 relatively homogeneous needs sub-groups. We then compared distributions across eight of the most heavily populated sub-groups.

Figure 8 shows that, for CCAC clients:

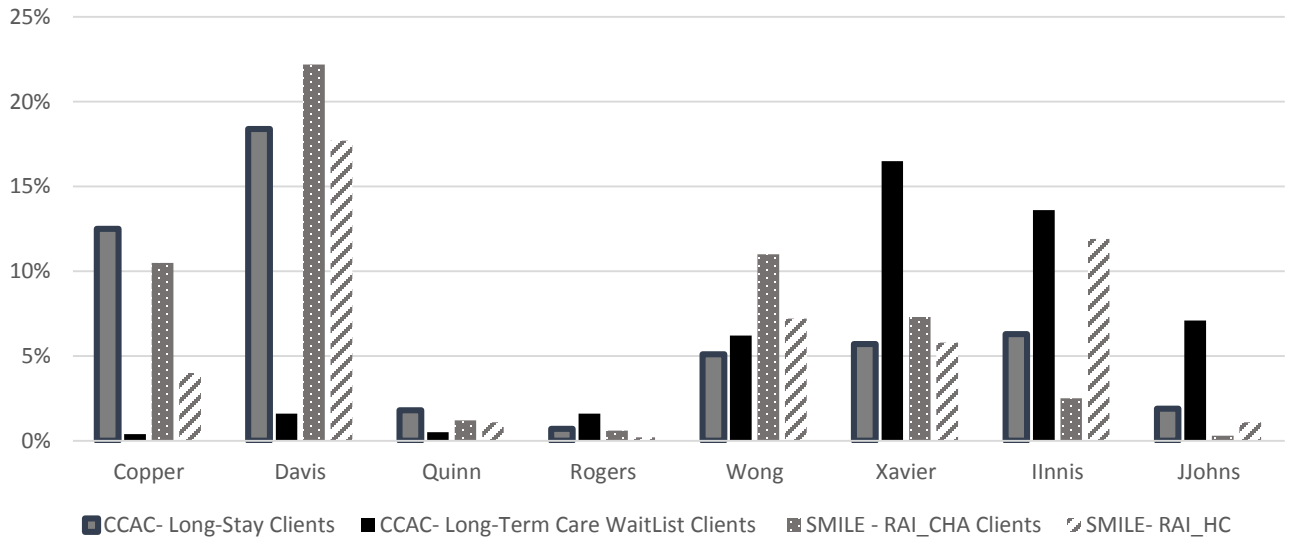
- About a third (30.9%) of CCAC long-stay clients fall into Copper and Davis, the two lowest needs sub-groups shown in the Figure; less than a tenth (8.2%) fall into I. Innis and J. Johns, the highest needs sub-groups
- CCAC LTC wait-listed clients are more likely than CCAC long-stay clients to fall into higher needs sub-groups: about a fifth (20.7%) are categorized as I Innis or J Johns; more than 4 in ten (42.9%) are captured in Wong, Xavier, I. Innis and J. Johns

Comparing CCAC and SMILE clients, the data show that:

- Similar percentages of CCAC long-stay and SMILE RAI-CHA clients (33.4% and 34.5% respectively) are found in the two lowest needs sub-groups, Copper and Davis; fewer SMILE RAI-HC clients (21.7%) have such low needs

- At the other end of the needs spectrum, about a fifth (20.7%) of CCAC LTC wait-list clients are found in the two highest needs sub-groups, I Innis and J Johns; recall that individuals in these two sub-groups have great difficulty with ADLs and IADLs and they also have cognitive difficulties (although I Innis has a live-in caregiver and J Johns does not) making them strong candidates for LTC. In comparison, over one in ten (13%) SMILE RAI-HC clients are also found in these very high needs sub-groups
- Also of note, similar percentages of CCAC LTC wait-listed clients and SMILE RAI-HC clients are found in the I Innis sub-group (13.6% versus 11.9% respectively). Moreover, CCAC long-stay clients are actually less likely than SMILE RAI-HC clients to be in the top two needs sub-groups combined (8.2% vs. 13.0%)

Figure 8 Distribution of Selected Vignettes



In sum, the distributions of CCAC and SMILE clients across needs sub-groups suggests that:

- SMILE RAI-HC clients referred from CCAC (a growing proportion of all SMILE clients) have assessed needs that are comparable to, or higher than, CCAC long-stay clients
- Almost a third of SMILE RAI-HC clients have needs which locate them at the high end of the needs spectrum (Wong to J Johns). Moreover, SMILE RAI-HC clients are more likely to occupy the two highest needs sub-groups (I Innis and J Johns) than CCAC long-stay clients; people in these sub-groups are likely candidates for referral to LTC.

3.3.3 EXPERT PANEL

Our Expert Panel included experienced providers from across the care continuum in the SE LHIN: Aboriginal health, social services, hospitals, CSS agencies, the SE CCAC, seniors' homes, community mental health, primary care, and SMILE.

Recall that evaluation team members presented Panellists with eight vignettes corresponding to the eight BoC sub-groups introduced in the analysis above; vignettes were written to emulate notes used by case managers when making care decisions. For example, the vignette for Copper, at a relatively low level of need, stated:

> "*Copper is cognitively intact and functionally independent in all activities of daily living (ADLs) with the exception of bathing (limited assistance is required). Copper has no difficulty using the phone, some difficulty with transportation, managing medications and preparing meals; great difficulty with housekeeping. Copper has a live-in caregiver (a spouse) who provides advice/emotional support and assistance with instrumental activities of daily living (IADLs).*"

Expert Panel members were also offered additional information gleaned from the assessment data:

- **Cognition**- Intact (short-term memory recall is good for most people in this group, makes consistent/reasonable/safe decisions and can express ideas without difficulty).
- **ADL**- No help required with most ADLs (locomotion inside the home, eating, toilet use and personal hygiene), client requires limited assistance when bathing (still highly involved in activity but requires some assistance/guided maneuvering).
- **IADL**- No difficulty managing medications and using the phone, some difficulty with meal preparation and transportation (needs some help, is very slow/fatigues), and great difficulty with housekeeping (little or no involvement in the activity is possible).
- **Caregiver (in home?)-** No. Has an adult/child caregiver living outside of the home who provides advice/emotional support and assistance with IADLs.

Panellists were then asked to construct "ideal" care packages for typical individuals in this and other sub-groups. They began by considering what would be required to maintain Copper (and caregiver) safely and appropriately at home; costs were not to be considered. Table 2 presents details of the care package constructed for Copper.

Table 2. Expert Panel Care Package for Copper

Service	Frequency (per week)
Congregate Dining	3 days
Meal Preparation	5 meals
Transportation	3 round trips
Adult Day Program	2 days
Physician	Evaluation and re-evaluation to adjust care plans
Mild Exercise Program (SMART)	2 times

Although still at the low end of the needs spectrum, Expert Panel members emphasized that Copper's care plan should be established as early as possible and then adjusted as needs changed. Here, the ideas was to begin by doing initial benchmarking assessments, flagging risk factors, and establishing predictable care pathways.

Panelists observed that at this level care plans should aim to help seniors and caregivers anticipate and adapt to life changes; they should encourage independence, not dependence, with services and supports aligned as much as possible to complement, rather than substitute for, current resources and abilities. In the case of Copper, who experiences few cognitive or ADL difficulties but has problems with IADLs, and has a caregiver living with them, services should be planned to get Copper out of the house, to maintain social engagement and provide some meals.

Panelists emphasized that where a caregiver is present, their needs and capacity should also be part of the equation. While caregivers might not qualify as home care "clients" per se, care packages should be designed to support them as an integral part of the "unit of care." In the case of Copper, caregivers would benefit from "time out" to do chores and tend to their own needs when the senior was at the day program; support for meals would also make their efforts more manageable and get them used to the idea of people coming into the home to assist them.

Panelists noted that Copper would have been an ideal client for SMILE as it was originally designed. They observed that SMILE's initial focus had been on early intervention to maintain individuals at the highest functional state possible, for as long as possible, and thus avoid or delay institutional care. However, SMILE and other CSS agencies were taking on fewer clients at Copper's level of need. Nevertheless, early admissions were still highly desirable since they had greater potential to anticipate and manage changing needs, and to avoid crisis for the client and caregiver potentially leading to more rapid decline and loss of independence.

Expert Panel members identified additional challenges in making "ideal" packages work in the real world. For example, they observed that even at a relatively low level of assessed need, an appropriate care package would require connecting with multiple providers (e.g., day program, transportation, CCAC, primary care physician) each with their own entry points, assessments, eligibility criteria.

Moreover, even when connections to needed services were made (assuming that needed services were available, which was often not the case outside of urban areas), challenges could still occur. For example, Copper would not likely be eligible for CCAC personal support, and even if they were, home care Personal Support Workers (PSWs) might not do homemaking. Although CSS agencies could arrange for homemaking, this would involve sending in another worker. Fees added other complications; while CCAC and physician services were free of charge, CSS homemaking, day programs and transportation would often involve some cost to

the client which could deter access particularly for those with limited incomes.

As the session progressed, Panellists considered vignettes for each of the eight sub-groups identified earlier in the analysis, with succeeding vignettes representing clients with higher levels of need. Discussion reiterated many similar: intervention should begin as early as possible; independence rather than dependence should be the main aim; support for everyday IADLs such as meals, transportation and homemaking was crucial; caregiver needs should always be considered as an integral part of care planning; and increasingly more complex care plans made a coordinating mechanism all the more important.

Additional considerations arose when Panellists came to "Wong," the first of the sub-groups to experience cognitive limitations. At this point, clients became less able to direct their own care, and thus more dependent on caregivers (whether living in the home or elsewhere). This, in turn, meant explicitly considering what caregivers (including many who would be seniors themselves) would need to continue in their crucial supportive role.

At the high end of the needs spectrum, the vignette for "I. Innis" described an individual living with cognitive challenges, who required extensive assistance with ADLs and IADLs, but had a caregiver living with them.

> *"I. Innis is not cognitively intact and requires assistance with all ADLs (extensive assistance required when eating; maximal assistance required with locomotion in the home and personal hygiene activities; totally dependent on others when toileting and bathing). I. Innis also experiences great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation). I. Innis has a live-in caregiver. This caregiver provides advice/emotional support and assistance with ADLs, IADLs."*

Panellists received additional details about I. Innis:

- **Cognition**- Not Intact (short term memory problem, never/rarely makes decisions, ability to make self-understood is limited to making concrete requests).
- **ADL**- Extensive assistance required when eating (full performance of part of these activities performed by others); totally dependent on others to complete all other ADLs (locomotion in the home, toilet use, bathing and personal hygiene) - full performance of activities performed by others.
- **IADL**- Great difficulty with all IADLs (housekeeping, meal preparation, managing medications, phone use and transportation) - little or no involvement in activity is possible.
- **Caregiver (in home?)**- Yes. Caregiver is a spouse or adult child who provides advice/emotional support and assistance with IADLs and ADLs.

Like previous vignettes, this one stimulated considerable discussion around what would be needed to maintain I. Innis and their caregiver at home; it also led Panelists to ask whether

home would be a viable care setting for individuals with such high needs. Expert Panelists ultimately agreed that a viable community-based care plan could be put in place, and that in fact (confirming what we saw in the SMILE-HC assessment data), they already supported many clients that looked like I Innis.

However, Expert Panelists also recognized that such plans were complex and required extensive management; without an informal caregiver present to provide ongoing surveillance and support on a 24/7 basis, care in the home would likely still not be safe or viable. In addition to providing a range of emotional, personal and instrumental supports, caregivers would typically need to assume a pivotal role in the day-to-day management of providers and services, even with professional case managers in the mix. Thus, direct caregiver supports in the form of education and counselling, in-home help, day programs and respite were seen as vital.

Table 3 Expert Panel Care Package for I. Innis.

Service	Frequency (per week)
Transportation	2 round trips
Friendly Visiting	1 visit
Caregiver Support- Counselling, Training, Education	2 times/month
Caregiver Support – Paid Staff	8 visits + 6 x 48 hour blocks/year
CCAC Physiotherapy	6 visits (over 13 weeks)
CCAC Occupational Therapy	2 visits (over 13 weeks)
CSS Personal Support	14 hours
Long Term Care Home Respite	3 months/year
Homemaking Services	3 times
Case Management	

Panelists further observed that such a plan would probably still not work if it were the entry point to formal care; particularly for individuals living with dementia and their caregivers, the degree of change it represented, and the presence of many new and unfamiliar people in the home would likely lead to resistance. If the process of introducing services were started early enough, it was entirely possible that individuals with I. Innis' needs could safely and appropriately continue to live at home rather in residential LTC; if attempted too late, it was unlikely that such a package could succeed leaving hospitalization or referral to LTC as the likely outcomes.

Extending this logic, Expert Panelists did not construct a care package for J. Johns, the final sub-group; while individuals in this sub-group had needs which were essentially similar to those of I. Innis, they did not have a caregiver living with them.

A number of important "take-away" messages emerged from the Expert Panel discussion:

- First, "client-centred care" should be, and for many H&CC agencies already is, the driving principle for care planning and delivery. This principle ensures that care is wrapped around the needs of seniors and older persons, to maintain wellbeing, functional capacity and quality of life, at the highest levels possible, for as long as possible, in community settings. This is good for people, most of whom would prefer to stay in their own homes and communities, and good for the system, since it moderates demand for already stretched residential LTC. According to one Panelist, it is important that service providers "don't ask what matters, but what matters to you [the client]."

- Second, providing "client-centred care" has a substantial local component since different communities vary considerably in terms of access to service; community supports available in urban areas are less available in rural areas. Instead of thinking of a "set" menu of services, care packages should combine available resources, including non-traditional providers, to meet needs. For example, if a senior requires assistance with meals, such assistance might be achieved through meals-on-wheels, congregate dining, or homemaking, where available; or informal caregivers could be offered respite from CSS agencies or via neighbours to allow time for shopping and meal preparation; or, a neighbour might prepare familiar foods and keep the refrigerator well stocked. In addition to planning community care as a "downward substitution" for residential LTC, plans thus almost always involve some degree of "horizontal substitution" where available supports and services are combined to meet needs.

- Third, as needs and care packages become more complex, involving combinations of providers and services, more intensive care management is required. Although some higher needs seniors and caregivers might be able to self-manage, most require some level of ongoing support from professional case managers who can help identify needs, build care plans using local resources, and assist in managing and monitoring services on an ongoing basis. This is particularly for seniors living with dementia and their caregivers the challenges, and for those living in underserviced areas, who can face formidable challenges accessing and coordinating care. Some Panelists observed that even with their experience, they did not always know what was available locally. Panelists pointed to the importance of integrating mechanisms such as inter-organizational, inter-disciplinary teams not only to improve client care, but to develop a shared understanding of how all the pieces of the system could fit together, and how individual providers could do their part to strengthen the "circle of care."

- Fourth, in the face of growing and more complex needs, the community sector faces increasingly tough challenges. For example, although Panelists unanimously agreed that "before-the-fact" prevention and maintenance is optimal, more resources were now being directed to "after-the-fact" post-hospital care. As a result SMILE and other providers were now taking on clients requiring more resource-intensive care, with growing wait lists. Panelists cited the work done by local Alzheimer Societies through

First Link programs as a best practice, since it begin as soon as older persons are diagnosed with dementia, and provides caregivers with education and support so they know what to expect, and how to get the supports they require, as needs progress.

3.4 ANALYSIS OF CLIENT CASE NOTES AND BUDGETS

SMILE staff pulled case notes for 138 randomly selected SMILE; these case notes record the characteristics and needs of SMILE clients and caregivers, and document care decisions. As such, they provide rich insight into the "client journey" through SMILE.

We began our analysis by focusing on essentials:

- "Who" clients are
- "What" they received
- "How" care packages were put in place and managed
- "Why" clients and caregivers engaged in the process and what value-added they perceived as a result.

3.4.1 WHO: CLIENT CHARACTERISTICS

Confirming the fact that SMILE supports seniors with increasingly higher levels of need, the case notes show that SMILE clients often experience complex combinations of ongoing health and social needs. In addition to requiring a range of personal and instrumental supports, SMILE clients also experienced loss of family members, situations where abuse was a concern, and degrees of emotional distress and social isolation. Moreover, of those SMILE clients with identified caregivers, most of whom were daughters or spouses, the majority were considered to be at risk of burnout.

Seniors experienced a range of medical conditions including:

- Congestive heart failure
- Alzheimer disease and other dementias (ADOD)
- Arthritis
- Emphysema
- Incontinence.

Seniors and caregivers also had a range of instrumental needs including:

- Banking
- Grocery shopping
- Meal preparation
- Laundry
- Transportation
- Outdoor chores (e.g., snow removal).

MAPLe scores were not always recorded at the point of admission, particularly during the early

years of the program; however, available scores suggest that needs steadily increased as the program became more established.

The data in the Table below suggest:

- Increasing numbers of admissions over time; since cases were selected randomly, you would expect sample numbers to increase proportionately.
- Increasing MAPLe scores. Although available for only a small number of clients, this reflects SMILE's ability to adapt to clients with higher needs
- Small numbers of referrals to LTC even as client numbers and needs increase; this finding adds weight to qualitative accounts in the case notes which suggest a large measure of success in crafting care plans which allow even high needs people to avoid residential LTC.

Table 4 Year of SMILE Admissions, Average MAPLe Scores, and Referrals to LTC by Year

Year of Admission	Number of Client Case Notes Sampled	Average MAPLe Score at time of Admission (if recorded)	Number of SMILE Clients Referred to LTC
2008	7		0
2009	21		0 (1 withdrawn)
2010	22		3 (1 withdrawn)
2011	13	2	0
2012	27	2.3	2
2013	30	3.4	3 (2 prior to SMILE admission)
2014	18	3.3	2 (1 prior to SMILE admission)

With respect to LTC referrals, we note that:

- Some referrals (2 in 2013 and an additional 2 in 2014) had been made prior to admission to SMILE – these clients arrived at the point of requiring LTC
- Two clients who had made applications to LTC subsequently withdrew their applications given SMILE's ongoing support.

3.4.2 WHAT: SERVICES

The case notes show that SMILE provided access to a range of IADL supports such as household management (cleaning, shopping, meal preparation), outdoor services (grass cutting, snow removal, bringing in wood), foot care, transportation, meal preparation, assistance with shopping, and Lifeline. SMILE does not provide ADL services like bathing or personal care.

The case notes also clarify that SMILE accessed services through a mix of established community-based providers (e.g., CCAC and CSS) and non-traditional providers (e.g., neighbours and friends) reflecting both client preferences and resources available at the local level.

In addition, SMILE Care Coordinators actively engaged with caregivers to ensure their participation in care planning and delivery, and to ensure that they were supported and remained involved.

3.4.3 HOW: MECHANISMS

The case notes confirm that SMILE Care Coordinators act as the connecting point between clients, caregivers, and other service providers, including established providers such as CCAC and non-traditional providers such as neighbours.

The notes also elaborate the process described earlier. When a client is admitted from the community, Care Coordinators will conduct an assessment using the RAI-CHA instrument; in the case of clients referred from CCAC, they will typically access and review an existing RAI-HC assessment (although often in hard copy). They then determine eligibility and schedule an initial home visit.

Subsequently, the Care Coordinator, client and caregiver (where appropriate) will discuss needs and preferences and develop a care plan. Services can be either coordinated by the client (who may know neighbors/friends who can perform needed tasks) or by SMILE who would generally begin by offering a choice of available service providers. About two weeks after finalizing the care plan, the Care Coordinator reviews progress with the client and caregiver, and makes any needed adjustments. Care plans are then updated quarterly or in response to changing needs. Regular service provider audits are conducted along with regular visits to review overall progress.

The case notes show that clients do make choices between two main reimbursement methods:

- Client reimbursement, where the clients pays the provider directly, provides receipts, and is then repaid by SMILE
- Direct provider reimbursement, where service providers invoice SMILE directly and the client signs paperwork to verify a particular service was delivered.

3.4.4 WHY: SMILE'S VALUE ADDED

Rather than becoming the end point of the care plan, the case notes show that nominal client budgets (averaging about $300/client/month) become the platform for an ongoing process of problem identification and problem-solving which empowers seniors and caregivers to control care decisions to the extent they are able, and does not simply leave them to manage on their own.

SMILE Care Coordinator's comments show that they look ahead, identify available service options, and help build support networks of conventional providers, non-traditional providers, family, friends and neighbours.

SMILE does this both in urban areas where conventional services providers are more accessible, but in rural areas, where they are less likely to be present. In underserviced areas SMILE Care Coordinators add value by accessing "non-traditional" providers such as neighbors to perform everyday but essential IADL tasks such as meal preparation, household management and transportation. As a result caregivers and seniors are more confident in their ability to stay in their own home, and less likely to consider referral to LTC.

Although SMILE clients often have needs comparable to CCAC LTC wait-listed clients, only 12 of 138 represented in the case notes initiated applications to LTC; four subsequently turned down a bed offer; and only one was actually discharged to LTC.

The case notes include numerous supportive quotes from clients:

- [SMILE] "allowed me to live here, I couldn`t live independently without it"
- "I couldn't live without them. XXXXX is really nice"
- "Don't know what to do if I didn't have XXXXX's help"
- "I don't know what we would do without her"

Case notes also record positive feedback from caregivers:

- "Happy with the services and we are managing well with them"; "I am much more rested now than before"
- "I can leave and know that XXXXX is safe and she looks forward to spending time with XXXXX."
- "Spouse getting burned out, spouse has 10% vision and must get more support if he will not be able to cope and she will need LTC placement".
- "I just can't put him in one of those places- he isn't ready and I am not ready, thanks to the help from SMILE and CCAC I can manage him at home longer especially since I am getting some sleep now."
- **"The SMILE program is amazing, I can't advocate enough, I don't know where Mom would be without them. The SMILE program is the reason Mom is not in LTC at this time."**

The case notes also suggest a range of system-level benefits beginning with inter-organizational collaboration. For example, they document extensive collaboration between SMILE and CCAC coordinators, ranging from comparing notes on client assessments, to jointly planning care pathways. For example, in a case where a CCAC client had been referred to SMILE, and where CCAC was subsequently planning to reduce service hours, the CCAC case manager contacted the SMILE Care Coordinator to ensure that care needs would continue to be met (i.e. meal prep, laundry).

Of course, the case notes also point to some challenges. For instance, case notes mention concerns around the reliability, service quality and accountability of non-traditional providers, as well as Care Coordinator's efforts to resolve these challenges. Like established providers, non-traditional providers may sometimes fail to provide agreed-up services in a timely fashion, or in a way that is acceptable to the client.

Case notes also record a number of concerns regarding possible abuse of clients by family members, and potential (but not actual) problems such as theft; they also document potentially unsafe working environments caused by hording, mould, or other hazards.

The fact that such concerns arise is not surprising; in fact, it would be noteworthy if no concerns were documented. What seems to be key here, is that the Care Coordinators are using their professional eyes to closely monitor seniors, caregivers and providers; SMILE clients are not left on their own to deal with inevitable problems regardless of whether care is provided through established or non-traditional sources. Clients and providers are regularly monitored by SMILE Case Coordinators and SMILE clients also have access to a region-wide telephone line to voice any problems or concerns.

We reviewed and synthesized client case notes to create four typical "client journeys" each illustrating how SMILE addresses a different aspect of need.

- The first client journey involves Jane, an older person with dementia who cannot be left on her own for more than a short period of time, and whose future is uncertain because her informal caregiver and formal service providers cannot guarantee needed coverage.

- Jane needs extensive assistance with all of her ADLs and IADLs, which is very time consuming and demanding. Jane's spouse, who lives with her, is her primary caregiver, but he works full-time, including weekends, and says that he is at the point of burnout.

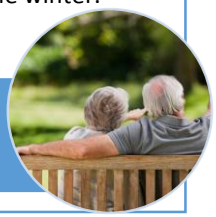
- To sustain Jane and her husband, the SMILE CCC established a care plan which adds housekeeping, help with outdoor chores, foot care, and monthly respite, to the home care services already provided through CCAC, including six hours of personal care a day, two days a week, and three visits a week to an Adult Day Program.

- Case notes show that Jane's husband, who was previously thinking about placing Jane in LTC, now thinks this new package has been "working out well … and they are pleased;" Jane's husband also benefits from "much needed breaks" and is willing to continue to have Jane at home.

- The SMILE CCC continued to monitor the situation and to adjust the care plan in response to changing external circumstances. For example, when informed of a planned reduction in CCAC service hours, the CCC was able to contact the CCAC case manager and negotiate a continuation of existing hours. Given an extremely cold and snowy winter, the SMILE CCC was also able to promise that the $500 a year budget cap for outdoor chores could be lifted "if necessary" to support Jane and her husband through the winter.

- Jane and her husband are still at home.

Client Jouney #1: Bridging System Gaps



- Rachel is 85 years old with arthritis and chronic back pain. She recently had a stroke, which further limits her functional abilities. Her spouse is her primary caregiver but he also has "significant medical issues that makes the stress of caregiving hazardous to his own health." Their daughter works full time and "tries to help but her time is limited." According to the case notes, Rachel and her spouse are "struggling."

- After an initial home visit, Rachel was admitted to the SMILE program. She reported having a recent fall, which resulted in an ER visit; she now wears a brace, which further limits her functional abilities. To meet Rachel's individual needs, and ensure that her husband can continue as caregiver, the SMILE CCC negotiated a care package which includes housekeeping, meal preparation, foot care and Lifeline, as well as PSW assistance once a week. In addition, the SMILE CCC advised Rachel's husband to connect with the caregiver support groups offered by the local Alzheimer Society because friendships are "important for [his] health."

- At the three month reassessment, Rachel's husband reported that SMILE was essential for the couple's continued independence; he "doesn't know what [he] would do without [the housekeeping services]" because he is "so tired at the end of the day [that he] just can't get anything done around the apartment". His "number one priority is to care for [Rachel]" and without SMILE's support, the house "would be in despair". The meals were also of "great help as [he] is often too tired at the end of the day to make a meal for the both of them and then tackle the clean-up."

Client Jouney #2: Enhancing Caregiver Resilience

- Bill is 72 years old; he lives in a rural area where there are few formal providers.

- An initial home visit conducted by the SMILE CCC with Bill and his daughter revealed that Bill has mobility problems due to osteoporosis, requires a walker and has had a series of falls. Bill recalled an incident where he was trying to raise up from his rolling computer chair but lost his balance and fell. He also recalled another incident where he fell with his walker while he was outside and a "neighbor helped him up and took him to the ER".

- With Bill and his daughter, the CCC constructed a care plan including Lifeline to contact emergency help if required, as well as housekeeping and help with outdoor chores. However, because there were no formal service providers in Bill's area capable of providing needed supports, the CCC asked Bill if he knew anyone that would be interested in doing so. Bill subsequently reported that a neighbor had agreed to provide housekeeping and help with outdoor chores; budget and method of reimbursement were then finalized.

- A follow-up home visit three months later, the CCC noted that even though Bill's daughter had passed away, Bill was doing well, with needed care continuing to be provided by a neighbour. Bill is "happy with the housekeeping and wears the Lifeline button when [at] home". Bill says that he has had the "[service provider] so long now that [he] is very comfortable and can talk to her as a friend." Because of the home supports, Bill is now able to attend the Legion almost daily and had met new friends that "help [him] on a regular basis." For example, one friend "calls him every second day … to check up on him." He stated that he now has a "good group of friends and [he is] always out visiting people. [He] try to walk as much as [he] can." Without this support network, Bill believes "he would not be able to stay in his own home."

Client Jouney #3: Building Support Networks

- John has been diagnosed with congestive heart failure, bladder incontinence and vision loss. John lives alone with few outside contacts. His spouse passed away and his son lives nearby, but offers limited assistance.
- John's son learned about SMILE from a neighbour and made the initial contact. An assessment revealed that in addition declining health and physical well-being, John is exhibiting signs of depression.
- The SMILE CCC developed a care plan aimed at meeting his immediate physical needs; it included housekeeping, meals preparation and transportation for medical appointments. During a follow-up visit, housekeeping was increased from bi-weekly to weekly, in part to ensure that John has more regular contact with other people.
- John has since reported that he "really enjoys the worker's company" because he is lonely. Moreover, encouraged by ongoing support from SMILE, John now takes a bus to church weekly and occasionally stops for lunch with friends before returning home, which helps with his depression. John is "very happy with services in place" which he says have "allowed me to live here, I couldn't live independently without [them]."

Client Jouney #4: Overcoming Socal Isolation

In sum, the client case notes add rich qualitative insight into how SMILE works and how it adds value for seniors, caregivers and the system. In particular, these notes elaborate that:

- Since its inception, SMILE has progressively "ramped up" and adapted it "client-centred" model to support individuals at higher levels of need, including seniors at the point of admission to LTC, and caregivers at the point of burnout; not only can the SMILE model support clients with lower levels of need, as originally planned, it also does well at high levels of need
- Even at lower levels of need, care packages are often complex, requiring connections to multiple services and providers, as well as ongoing management and monitoring. Here, SMILE Care Coordinators play a crucial role by working in partnership with seniors and caregivers to identify and prioritize their needs and preferences, and to tailor solutions which maximize choice and independence. This role becomes all the more crucial as needs progress
- Even at higher levels of need, supports for IADLs remain a crucial components of care packages; transportation to medical appointments, housekeeping, meals and opportunities for social engagement, are seen by seniors, caregivers, and Care Coordinators to promote wellbeing and independence, slow decline, and avoid or delay the need for residential LTC
- SMILE levers local community resources by engaging established providers as well as non-traditional providers; the latter offer new potential for ensuring more equitable access in under-serviced areas

- SMILE provides ongoing support and monitoring. Potentially vulnerable seniors and caregivers are not left on their own to identify problems or raise concerns; SMILE is there to ensure high quality, appropriate care.

3.5 STAKEHOLDER ENGAGEMENT

Results from the various consultation activities provide the unique perspectives, experiences and stories of a wide range of stakeholders affected by the SMILE program. We engaged stakeholders through a variety of methods and were able to identify a number of key themes, or messages, about SMILE. Below we highlight these key themes and message

3.5.1 WHO WE HEARD FROM

Below, we summarize participation in the consultations and surveys. Overall, we heard from approximately 350 stakeholders including 227 clients and 56 caregivers.

Table 5: Consultation Participants by Activity

	Surveys	Focus Groups	Interviews	Total	Turnout Rate
SMILE Area Care Coordinators	N/A	6	N/A	6	75%
SMILE Office Care Coordinators	N/A	4	N/A	4	80%
SMILE Office Staff	N/A	4	N/A	4	67%
CCAC Care Coordinators	N/A	2	N/A	2	67%
Finance	N/A	N/A	1	1	100%
Geriatrics	N/A	N/A	1	1	100%
CSS Agencies	12	4	0	16	27%
Individual Service Providers, including Brokered Workers	30	4	2	36	24%
Clients	209	N/A	18	227	40%
Caregivers	51	N/A	5	56	39%

Participant Breakdown

The following section provides an overview of the general breakdown (relationship with SMILE, services received, geography) of who we heard from through the various consultation activities.

Through the surveys, we asked clients how long they had received funding through SMILE. The table below summarizes their responses (n=209, r=187)

Table 6: Response to Client Survey Question 4

How long have you received funding from SMILE?				
Code	Value	Frequency	Percent	In all, 44% of SMILE clients surveyed had been clients for two years (24 months) or more, while 33% had been clients for more than one year but less than two, and 12% were new clients of less than one year.
1	<12	26	12%	
2	12>24	69	33%	
3	>24	92	44%	

We also asked caregivers to identify how long their senior loved one had been receiving funding through SMILE. The table below summarizes their responses (n=52, r=46).

Table 7: Response to Caregiver Survey Question 4

How long has your senior loved one received funding from SMILE?				
Code	Value	Frequency	Percent	The vast majority of caregivers surveyed have loved ones who have received services for one year or more, with only 23% being clients of less than one year and 33% each being clients for between one year and two, or two years or more.
1	<12	12	24%	
2	12>24	17	33%	
3	>24	17	33%	

Through the interviews, we asked clients about the types of services SMILE funds for them (n=18, r=18). While one respondent declined to answer this question, the other 17 listed the following care packages[41]

- Taxi, laundry, vacuuming and grocery pick-up
- Housekeeping, transportation, lawn care, foot care and Lifeline
- Transportation to appointments, meals and "the button" (Lifeline)
- Snow ploughing and yard work, transportation to doctor's appointments
- Housework, meals, transportation to doctor's appointments, and yard work and snow ploughing
- Snow ploughing and grass cutting, housekeeping and transportation
- "Part of" their transportation and winter snow removal
- House cleaning, foot care, snow removal and summer chores, and meals
- Outings and/or homemaking, and meals
- House cleaning, laundry, foot care and "emergency wrist band" (Lifeline)

[41] While we have paraphrased when necessary, we have tried to preserve clients' own words

- Washing and “general clean-up”
- Housekeeping, laundry, foot care and meals
- Housework
- Housekeeping and laundry
- Washing, dishes and laundry, winter and summer outdoor chores
- House cleaning and snow ploughing / outdoor work
- Shopping assistance, cleaning, transportation and outdoor help (winter and summer)

Caregivers summarized the services being provided through SMILE as follows:

- Monthly nail care, weekly home support and snow and yard work
- House cleaning, grocery pick-up and, if requested, medication pick-up
- Whatever is required on a particular day for house cleaning (ie. vacuuming, change / wash bedding, bathroom, dusting etc.)

In addition to the list of services accessed through SMILE, caregivers confirmed that at least one other agency is involved in delivering services, sometimes in addition to informal care provided by family and friends. Therefore, all of the caregivers’ loved ones receiving SMILE receive additional formal and/or informal support. This is consistent with what we have learned about services access by SMILE clients overall.

Individual service providers themselves identified the following services that they are providing:

- Foot Care
- Homemaking
- Transportation
- Day Program
- Housekeeping/Housework
- Meals (prep, cooking)
- Respite
- Shopping
- Mow lawn/outdoor chores

Community Support Agencies identified the following services that they are providing:

- Foot Care
- Homemaking/organizing
- Transportation
- Household management
- Day program
- Laundry
- Meals (prep,cooking)
- Respite

- Shopping
- Mow/plow/outdoor chores
- Socialization/Social Interaction/Companionship
- Errands
- Case Management

Most service providers and agencies provide services in both rural and urban areas, while about a quarter serve urban areas only and a quarter service rural areas only. The majority of both individual providers and agencies feel their area is underserviced. Most serve two or more clients and most have been providing services to SMILE clients for more than two years.

3.5.2 WHAT WE HEARD: SUMMARY

From the engagement process, a variety of themes, or key messages emerged about SMILE. These are listed below, by level of impact: Individual, Program, Service Provider and System.

Individual

Generally speaking, clients and caregivers love SMILE

- Through both the interviews and surveys, feedback was largely positive
- The financial assistance of services offered by SMILE is particularly important for some clients and/or caregivers
- Caregivers, and often their families (particularly in cases where an adult child is a primary caregiver), benefit from, and appreciate, the respite / relief offered by SMILE
- Stakeholders emphasize that there is a positive social impact of SMILE and that it helps to reduce social isolation among clients
- Clients and caregivers believe SMILE has helped, or is responsible, for clients being able to remain at home
- The relationships between clients and providers can be the most valuable part of SMILE for clients

Clients responding to the survey strongly agree that SMILE has a positive impact on their well-being

- 87% of clients agreed or strongly agreed that their quality of life has improved as a result of SMILE
- 86% agreed or strongly agreed that they feel more confident knowing where to go for help when they need it
- 74% agreed or strongly agreed that they have the support they need for everyday tasks
- 76% agreed or strongly agreed that their ability to stay as healthy as possible has improved

- 60% agreed or strongly agreed that their ability to maintain relationships with their friends and family has improved
- 73% agreed or strongly agreed that they feel more in control of their own life
- 72% agreed or strongly agreed that they feel less worried or stressed about the future

Caregivers responding to the survey strong agree that SMILE has a positive impact on their well-being

- 83% of respondents agreed or strongly agreed that their quality of life has improved as a result of SMILE
- 85% agreed or strongly agreed that they feel more confident about knowing where to go for help when they need it
- 81% agreed or strongly agreed that their ability to run errands, do chores or deal with other personal commitments has improved
- 63% agreed or strongly agreed that their ability to maintain relationships with friends and family has improved
- 65% agreed or strongly agreed that they feel more in control of their own life
- 65% agreed or strongly agreed that they feel less worried and stressed about the future

Clients and caregivers offered some ideas for how to make SMILE better

- Improvements to communication, organization / coordination and training for service providers were recommended
- Clients and caregivers both perceive a need for more funding, for clients (especially in cases where funding / time had been cut or was otherwise seen as inadequate to meet the needs of clients and/or their spouses) and/or for the program itself, and some suggested that access should be expanded, within the SE LHIN and/or in other areas
- Opportunity for having a report to clarify services, time and budgets (which could be updated regularly versus just at assessment/reassessment phase)

Some clients need more support with management and administration

- Some clients and caregivers felt that the administrative responsibility for clients (i.e. to complete paperwork to be reimbursed by SMILE, sign providers' paperwork and/or complete background checks on non-traditional providers) was challenging. In addition, some may not be aware of the option for direct billing which may help alleviate this burden.
- Self-management is not the preferred option for all SMILE clients; some need or want more support with choosing their providers, in particular, and would like to choose from a list of 'proven' providers
- Some clients may benefit from more frequent check-ins, while others would prefer less frequent check-ins / reviews / assessments

Clients and caregivers appreciate SMILE's flexibility and responsiveness

- Clients and caregivers appreciate SMILE's willingness to help with various and/or changing needs
- Clients and caregivers appreciate providers' flexibility in helping with whatever the client needs at the time
- Clients see SMILE as being helpful to their health and wellbeing in the long-term

Consistent, scheduled service is important to clients

- Clients look forward to their visits with workers and SMILE CCCs
- Unexpected changes in the way services are delivered can be stressful for clients
- Clients seem to prefer receiving service from as few providers as possible, which also enables relationship building; this can be the most valuable part of SMILE for clients
- It can be confusing for clients and caregivers to deal with multiple providers

Clients and caregivers believe SMILE has an impact on system

- Through the surveys, 62% of clientsagreed or strongly agreed that they are less likely to use the hospital emergency department or call 911
- 94% of caregiver (survey respondents) agreed or strongly agreed that their loved one is more able to continue to live safely at home as a result of SMILE
- 67% of caregiver respondents agreed or strongly agreed that their loved one was less likely to experience a crisis as a result of SMILE

Program

SMILE Staff are highly engaged

- SMILE staff, including CCCs, team assistants and office staff are highly engaged and collaborative; they believe strongly in the SMILE philosophy around client choice
- Staff engagement is seen as an asset to the program
- Through the survey, 92% of client respondents agreed or strongly agreed that they feel comfortable with the people who come into their house

Opportunities for improved business systems

- There is a need to improve business systems and expedite the payments process
- There seems to be an opportunity to reduce the amount of manual labour involved in administering the SMILE program through wider use of technology
- Better business systems would likely also support more proactive management of financial risks for the program
- CCCs would like 'benchmarks' to be able to compare client budgets

Most clients use non-traditional providers

- Based on feedback, less than 20% of payments are made to CSS agencies
- It seems that costs can often determine whether a client chooses a CSS provider or non-traditional provider

Despite a robust administrative backbone, SMILE is fairly efficient:

- SMILE's administration-to-program spending ratio is 17%, which seems to be consistent with other community support services offered by VON
- Volunteer support is a vital component to the SMILE program
- Stakeholders feel that client needs – and being efficient in meeting those needs – are important, and this is well-supported by SMILE's unique program

Demand for SMILE is increasing

- The volume of referrals has steadily increased
- CCCs believe there is an immediate need to be able to take on new clients

Service Provider

Overall, service providers believe SMILE has made a positive impact

- The services and funding offered by SMILE are seen by service provider stakeholders as beneficial and needed
- CCAC Care Coordinators felt that a key impact of SMILE is reducing caregiver stress and strain

SMILE is seen as complementary to CCAC

- SMILE's flexibility and ability to be creative in the care planning process were cited by CCAC as key strengths
- CCAC and SMILE generally have a positive working relationship, although there may be an opportunity to formalize collaboration and information sharing
- There may be a need for SMILE to confirm/clarify eligibility criteria for CCAC

Opportunity for improved payment process

- There is general agreement among service providers that SMILE's payment process is slow and needs improvement

There is a desire to improve communication between SMILE and service providers

- Stakeholders expressed a desire for improved communication between SMILE and service providers (i.e. ongoing dialogue, input on assessment/reassessment, overall care planning, partnership building)

- SMILE used to meet regularly with CSS agency partners, but this seems to have stopped, there is interest in reviving these forums
- Service providers think SMILE should consider their input as part of the care planning process
- Some individual support providers feel that they regularly contribute time and money beyond what they are compensated for (i.e. travel expenses)
- While some providers expressed challenges with SMILE, they also acknowledged that SMILE helps seniors remain at home

CSS agencies believe they should get the first referral

- CSS agencies suggested that given SMILE and other CSS agencies are all LHIN-funded, SMILE should give CSS agencies the first referral rather than going straight to a non-traditional provider (may be opportunity to address this concern through enhanced communications)

SMILE has helped raise awareness about the CSS sector

- Seniors and caregivers are more aware of available CSS services as a result of SMILE

There are concerns about SMILE's eligibility criteria and assessment process

- Some stakeholders believe all assessments should be done by SMILE in person, rather than over the phone even if assessment by other agency has already been done
- Many service providers believe that SMILE should focus more on supporting lower income clients and should consider looking at income as part of the eligibility criteria

System

SMILE's fit in local health system

- SMILE is seen as a good complement to existing CSS and/or CCAC services
- SMILE is also considered as part of the hospital discharge planning process and is now part of iCART, which will identify seniors in the emergency department and connect them to CCAC, SMILE and/or CSS services

Some uncertainty of program sustainability given low turnover

- Some stakeholders expressed uncertainty as to whether the current model, which seems to be increasingly targeting seniors with high / complex needs, will be financially sustainable, particularly given that there are few occasions to discharge clients and take on new ones, within a limited budget

Concerns around best 'management option'

- Given that SMILE is seeing more high need / complex clients, there are questions about whether self-management is appropriate
- One stakeholder identified that research has questioned the effectiveness of full case management, and they think that SMILE's approach to supported self-management may be most appropriate for the client base

SMILE clients have complex health and social needs

- Social vulnerability (income, isolation etc.) is a key factor driving clients' needs
- Rural dwellers may be more likely to be socially vulnerable and in need of support

The impact of SMILE on clients and caregivers is generally positive

- Stakeholders believe clients and caregivers are grateful for SMILE; think it is important
- SMILE performs tasks that would otherwise put pressure on informal caregivers

3.6 THINK TANK

At the March, 2015, Think Tank, participants reviewed evaluation findings to date, considered four key design dimensions of SMILE, and discussed what would be needed to build a business case to scale up, spread and sustain SMILE; highlights are presented below.

While previous stages of the evaluation focused on SMILE's current clients and operations, the Think Tank concentrated more on what SMILE should aim to do on a go-forward basis.

3.6.1 DESIGN DIMENSIONS

Who SMILE serves. Participants clarified that while "who" has often been defined in the mainstream of the health care system in terms of an individual service to an individual patient, the focus in the community has to be much broader, encompassing not only a range of supports and services required to meet the often complex, and continuing, health and social needs of seniors, but the needs and capacity of informal caregivers and their social networks as well.

This acknowledges that while formal providers like CCAC and CSS agencies deliver many essential services to older persons living in the community, informal and often unpaid caregivers such as family, friends and neighbors still do most of the "heavy lifting" on a day-to-day basis. In the community, the "unit of care" extends well beyond the individual[42].

In this connection, participants suggested that SMILE's "client-centred" model, now focused on

[42] Expert Group on Home & Community Care. (2015). Bringing Care Home. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

seniors, was also directly applicable to the care of other vulnerable populations such as persons with mental health needs. SMILE is strongly aligned with the province's renewed policy emphasis on "patient-centered" care, and on better coordinated, integrated care "closer to home"[43].

With respect to targeting, Think Tank participants debated whether or not SMILE would be able to maintain its original "before-the-fact" preventive/maintenance focus as system pressures mount to serve those already waiting for residential LTC, and those requiring post-hospital care. They noted that as CCAC increasingly redirects its resources "upstream" to move people out of hospital faster and serve people with more intensive support needs, those with less marked, but ongoing needs, will accordingly fall to other CSS agencies; in turn, these community providers will also have to concentrate their resources on fewer, but higher needs clients. Given an aging population, the rise of complex chronic needs, and the fact that greater numbers of higher needs people will require care in community settings, it is likely that needs "thresholds" for SMILE and other CSS will continue to rise.

Participants observed that such trends have already resulted in growing wait lists for SMILE, in turn, posing tough questions around how always limited program resources are best used. They indicated that although the "sweet spot" for SMILE is to catch people early and keep them late, SMILE is now also successfully supporting higher needs individuals with more extensive support needs.

Participants asked whether SMILE should aim for "depth," trying to provide everything that individual clients need to keep them at home, or "breadth," providing a little to everyone? Should SMILE and other H&CC providers consider "means" as well as needs, including the ability to purchase care privately (e.g., in a commercial retirement home)? What expectations should caregivers have, and what should be expected of them in return?

What SMILE provides. Think Tank participants acknowledged the importance of the IADL supports accessed by SMILE clients and caregivers, including those at higher levels of need. They noted, for example, how the recent snowy winter had demonstrated the critical role of such basics as snow removal, without which many seniors and caregivers would not have been able to get out of their homes to buy groceries, do banking, attend medical appointments, or see other people. Even though such basics are not "health care" per se, an inability to access them could quickly result in decline and illness, as well as hospitalization and placement in LTC.

They also emphasized the importance of SMILE's role in making connections with needed services and providers within and beyond the community sector. In doing this, SMILE minimizes the number of providers entering the home, improves coordination, enhances consistency of

[43] Government of Ontario (2015). Patients First: Action Plan for Health Care. http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf

provider, and offers clients greater autonomy and choice, reflected in glowing endorsements from SMILE clients and caregivers. It was noted that "connecting services" and delivering better coordinated and integrated "patient centred care" are also key policy goals in Ontario[44].

While some participants observed that this connecting role might appear to duplicate CCAC's service navigation mandate, important distinctions should be made.

First, this role is not limited to SMILE's clients; SMILE Care Coordinators provide information and advice to people who may not be clients of any agency, but who do want to know what to do when the time comes. This prevents people from "falling through the cracks" or waiting to the point of crisis when solutions become more difficult, with hospitalization and LTC too often appearing as "default" options.

Second, SMILE's role extends beyond established providers. Particularly in "underserviced areas" where needed formal services may not be readily accessible, SMILE connects clients with non-traditional providers such as neighbors and friends as well as other community resources such as churches and the Legion, and it regularly monitors such care.

Third, as demonstrated by the deepening collaboration with CCAC as more home care clients are referred to SMILE, and as CCAC and SMILE case managers work more closely together to serve shared clients, what SMILE does complements and extends, rather than substitutes for, CCAC system navigation. As CCAC increasingly focuses on individuals requiring post-hospital care, and those waiting for residential LTC, there is all the more work to be done with clients and caregivers who are "at risk" of institutionalization even if they are not yet there. Even so, SMILE clients increasingly look like CCAC clients waiting for LTC; SMILE thus appears to play a complementary role in reducing pressures for residential beds.

How services are provided. In their discussion of "how" SMILE makes these connections, Think Tank participants once again emphasized the pivotal role of SMILE Care Coordinators.

As discussed above, Care Coordinators use nominal budgets, averaging about $300/client/month, to engage seniors and caregivers in a dynamic process of problem identification and problem-solving leading to the co-creation of care plans. While meeting immediate needs, the process also aims to look to the future to consider how resources can be brought together to anticipate and serve client and caregiver needs over the longer term.

A key part of this process is identifying what resources actually are available at the local level, since these vary extensively within and between urban and rural areas; solutions that might work in one area, or for one client, may simply not work elsewhere.

[44] Government of Ontario (2015). Patients First: Action Plan for Health Care. http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf

Left to themselves, clients and caregivers often do not know how to access existing services, since access points, eligibility, and user fees vary extensively. As BoC Expert Panel participants acknowledged earlier, professional case managers can themselves face challenges when building care packages. Here, the partnership of Care Coordinator, senior and caregiver is essential, since together they are more likely to know what combinations are likely to make the best use of local resources including established providers, non-traditional providers and other community organizations such as churches and the Legion.

The role of CCCs in helping to distinguish between what people "want" and what they actually "need" was also commented. While the former might include services and supports which are nice for everyone to have (e.g., homemaking), CCCs work with clients and caregivers to determine what they can reasonably do for themselves, and what additional supports are required to maintain them in their own homes. While, for example, most clients or their caregivers can manage their own laundry, some frail older couples might not be able to lift wet clothing out of the washer.

Why – SMILE's added value. Think Tank participants concurred that SMILE makes important contributions at different levels.

At the level of the client and caregiver, SMILE:

- Provides "client-centred" care which promotes choice and independence, and enhances the ability to continue to live in the community
- Addresses immediate needs and avoids future crisis which might result in an unwanted and avoidable hospitalization or referral to LTC
- Supports often stressed and burdened informal caregivers who provide the bulk of the care required to maintain older persons safely and appropriately at home
- Connects clients and caregivers to a range of established and non-traditional providers and other community resources thus levering community capacity and strengthening social networks particularly in underserviced areas
- Provides ongoing monitoring and support to make adjustments as needed, and to deal with any problems or issues which clients might not be able to deal with on their own.

At the system level, SMILE:

- Promotes equity of access, since there is a single program which covers urban as well as under-serviced rural areas across the region
- Builds partnerships and collaboration with other providers such as CCAC and CSS agencies
- Encourages more effective and appropriate use of resources, by establishing viable community-based care options
- Builds new capacity and promotes local economic development, by engaging community resources such as non-traditional providers.

Moreover, SMILE's client-centred model is readily scalable:

- Because it serves persons with multiple health and social needs, SMILE could be extended to serve other vulnerable populations in the community such as persons with mental health challenges and their caregivers, who, along with persons living with dementia, now account for the bulk of hospital ALC beds across the province
- Because it builds connections with and between service providers, the SMILE model could easily be extended to other key system players such as Community Health Centers (CHCs), thus making the important link to primary health care.

SMILE could also be used as the platform to build "community hubs." Because it already connects clients to providers, and providers to other providers, SMILE could work to build hubs which initially "co-locate" services and providers in a single location, and then work to promote collaboration and integration. It was observed that hubs have been mandated by the Premier of Ontario as a way of bringing together diverse community resources, particularly in underserviced areas, and for vulnerable populations. Here, existing VON adult day programs might be used to bring different providers together at a single location, thus promoting inter-organizational collaboration, shared programming and service integration.

Think Tank participants emphasized that SMILE also offers considerable "value added" as a "rural model," effectively building a system around client and caregiver needs where a system doesn't currently exist by leveraging formal, informal and non-traditional assets.

Nevertheless, Think Tank participants recognized that there are challenges in making the case for scaling up and spreading SMILE in a climate of "no new money." For example, although participants strongly endorsed the concept of early "before-the-fact" preventive care, they also agreed that "proving" this concept is always challenging because of the difficulties inherent in demonstrating "near misses," clients who would have otherwise ended up in hospitals or residential LTC, and caregivers who would otherwise have burned out, if not for timely access to needed community supports.

In SMILE's case, these challenges are complicated by factors including:

- Ongoing shifts in eligibility. To respond to changing needs, SMILE has progressively shifted its focus from lower needs clients, to those with higher needs. On the one hand, this means that resource allocation patterns, and anticipated outcomes are also shifting, making evaluation difficult. On the other hand, SMILE continues to demonstrate that its flexible, client-centred approach is adaptable to a wide range of needs
- Shared client assessments. Because SMILE conducts RAI-CHA assessments for a diminishing proportion of clients accessing the program directly from the community, and receives hard copies of RAI-HC assessments conducted by CCAC for a growing proportion of clients referred from CCAC, there are challenges tracking clients over time, and determining their care destination after they leave SMILE. Electronic client records, even for shared CCAC/SMILE clients, are not normally shared between the two

collaborating organizations; however, going forward it should be possible to design protocol to address this issue

- Lack of systematic utilization and costing data. SMILE's individualized care packages connect clients and caregivers to a wide range of community-based services and supports including those from CCAC, other CSS agencies and non-traditional providers. While once again demonstrating a flexible, client-centred approach, and levering available resources, this means that overall utilization patterns and total care costs per client are difficult to document.

Nevertheless, in spite of such qualifications which apply equally to many providers across the health care system, Think Tank participants strongly endorsed SMILE's client-centred approach which they viewed as an essential step forward in the evolution of an accessible, comprehensive and accountable home and community care system in Ontario. In addition to better meeting the needs of seniors and caregivers, SMILE encourages the most effective use of community resources even where conventional services and providers are lacking thus promoting more equitable, and predictable access.

4.0 SUMMARY AND RECOMMENDATIONS

In this final section we summarize the evaluation findings which speak to what SMILE has already achieved, and, in view of the positive results being achieved, offer recommendations to scale-up, spread and sustain SMILE going forward.

4.1 WHAT WE DID

To ensure that the SMILE evaluation met high standards, we adapted the validated multi-dimensional approach used for the National Evaluation of Partnerships for Older People Projects (POPP) in the UK; the evaluation assessed different community-based approaches to promote the health, well-being and independence of older persons and prevent or delay the need for higher intensity or institutional care[45]. Dimensions measured by the evaluation, which we judged to be particularly applicable to SMILE, include:

- Quality
    - Access to services: extent to which access to health and social care is improved for older persons and informal caregivers; extent to which older persons are more able to remain at home

[45] http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Olderpeople/PartnershipsforOlderPeopleProjects/index.htm

    - Care coordination/integration: extent to which practice enhances joint working between providers/sectors; extent to which practice enhances patient flow out of hospitals and reduces unnecessary or early referrals to residential long-term care
    - Patient/family centredness: extent to which cared-for persons and caregivers are encouraged to participate in their care decisions; extent to which practice improves/enhances patient autonomy and improves satisfaction
- Costs
    - Cost-effectiveness: extent to which the practice reduce the incremental costs of care; requires capital investment or added funding; reduces hospitalizations/emergency visits
- Impact
    - Health impact: extent to which practice improves the health and functional status of participants; addressed the broader determinants of health; reduces social isolation
- Transferability
    - Transferability/sustainability: presence of mechanisms to sustain the practice; extent to which it is applicable to more than one jurisdiction/region; addresses the needs of older persons with chronic health and social needs; addresses the needs of older persons likely to become high cost utilizers.

We noted that these dimensions are also strongly aligned with the main principles of Ontario's 2015 Action Plan for Healthcare, *Patients First*[46]. These principles are:

- Access: improve access – providing faster access to the right care
- Connect: delivering better coordinated and integrated care in the community, closer to home
- Inform: support people and patients – providing the education, information and transparency they need to make the right decisions about their health
- Protect: protect our universal public health care system – making decisions based on value and quality, to sustain the system for generations to come.

We then used a mix of qualitative and quantitative data and methods (in two major evaluation components), and triangulated the results, to assess SMILE's performance at the individual level (client and caregiver level), and also at organizational (program/provider) and system levels:

- Client and caregivers
- Program
- Providers
- System

[46] Government of Ontario (2015). Patients First: Action Plan for Health Care. http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/docs/rep_patientsfirst.pdf

Since we began the evaluation, other developments have occurred which also impact on our conclusions and recommendations. These include the release, in March 2015, of the report by Ontario's Expert Group on Home and Community Care titled "Bringing Care Home ("the Donner Report")[47]; and the announcement by the Ontario government in May 2015, of its "Roadmap to Strengthen Home and Community Care."[48]

4.2 WHAT WE FOUND

We believe that the findings of our extensive, multi-methods evaluation, build a strong case in support of SMILE's performance to date. They also point to new opportunities for continuously improving SMILE's performance, and for spreading and scaling-up SMILE's client-centred approach to serve new populations across urban and rural areas of the province.

In saying this, we acknowledge that this case is not air-tight in the sense of providing definitive "smoking gun" evidence that SMILE saves money for the system or that it directly reduces demand for hospital beds or residential LTC. We note, however, that such evidence is exceedingly rare outside of the often narrow confines of randomized controlled clinical trials which would not be applicable to SMILE, the complex needs of its clients, or the dynamic environment in which it takes place.

Nevertheless, we do argue that the case for SMILE is systematic and plausible, and that it meets accepted international standards for evaluation of community-based programs and services including the use of quantitative and qualitative data to measure key performance dimensions.

Moreover, our findings are consistent with, and build upon, the results of a previous, and very comprehensive evaluation, which also found evidence that SMILE produces value-added for clients, caregivers, and the health care system as a whole.

Perhaps most importantly, SMILE anticipates and directly addresses key policy priorities in Ontario, including those re-emphasized in Ontario's 2015 "Roadmap" to strengthen home and community care. SMILE clearly puts clients and caregivers first; clients and caregiver are overwhelmingly satisfied with their experience with SMILE and believe that it allows them to stay in their own homes longer; and SMILE builds much needed capacity, not only by connecting seniors and caregivers to established community providers when they are available, but by levering non-traditional community resources, and supporting informal caregivers who provide most of the care required by older persons on a daily basis. Moreover, SMILE does this across the entire region, in urban and rural areas, ensuring greater equity of access and consistency no matter where people live.

[47] http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf
[48] http://www.health.gov.on.ca/en/public/programs/ccac/roadmap.pdf

In this section, we begin by briefly reviewing key evaluation findings for caregivers and clients, the program, providers and system, and then present overall conclusions.

4.2.1 CLIENT AND CAREGIVERS

Overall, clients and caregivers are very satisfied with the SMILE program. Clients and caregivers report feeling comfortable with the support staff coming into their home and, for many, they look forward to visits and develop positive relationships with their support provider. This support and the flexibility of the SMILE model allow clients to access the support they need as they need it while also providing respite/relief to caregivers thereby supporting the broader "unit of care" and facilitating more quality time between loved one and caregiver. Importantly, for low income seniors, SMILE creates affordable access to support services that otherwise would not be available.

The evaluation also found that SMILE positively impacts clients' sense of well-being, including their overall health, social connectedness, psychological wellbeing, and comfort and safety at home. The supported self-management model further helps to enhance clients' sense of independence and control.

As part of the stakeholder consultation, the evaluation found that clients and caregivers strongly agree that SMILE helps seniors remain at home. Many clients reported that they don't believe they could remain at home without the support of SMILE.

The evaluation also found that the demand for SMILE has been increasing and wait times are growing. Stakeholders emphasized the need to increase SMILE services (i.e. funding/hours to existing clients and taking on new clients, and to expand SMILE into other areas).

4.2.2 PROGRAM LEVEL

The SMILE philosophy is built on client choice setting it apart from conventional CSS programs and facilitating client-centred approach. SMILE staff are highly engaged and dedicated to this approach. SMILE addresses broader social determinants of health by meeting the health and social needs of vulnerable and frail seniors, who are often isolated and may earn a low-income; the socialization element of SMILE is seen as highly valuable by many stakeholder groups.

The evaluation found that there are opportunities to improve current business systems in order to realize administrative efficiencies in particular with the payments and verification processes. The evaluation also pointed to the desire for more up to date information on client budgets by Care Coordinators. Similarly stakeholders identified the opportunity to ensure an update to date list of providers (both traditional and non-traditional).

While stakeholders tend to agree that non-traditional providers may increase cost-effectiveness and contribute to client choice there may be opportunities to create a better understanding of the framework for these partnerships.

In addition, the evaluation found that the SMILE model could indeed be replicated in similar underserviced areas, including, but not limited to, those of a similar rural nature. SMILE has evolved over time and adapted to lessons learned; systems and processes have been, and continue to be, built and refined to support efficient and effective operations going forward. These systems and processes would be transferable.

4.2.3 PROVIDERS

Overall the evaluation found that SMILE Care Coordinators have a good working relationship with its service delivery partners. SMILE has raised awareness of available CSS supports in the South East LHIN and works with service providers to create a "circle of care" around the unit of care enabling seniors to remain at home.

SMILE is seen as a good complement to CSS, CCAC and informal supports; while can also be a model for clients and caregivers who utilize SMILE and non-traditional approaches only. SMILE has helped build capacity in the South East LHIN's senior-serving sector to meet the needs of an aging population with a growing number of seniors with complex needs.

The evaluation results pointed to opportunities to enhance existing relationships with its partners including to formalize collaboration with CCAC, to revive collaborative forums that previously existed to engage CSS agencies and SMILE, and to create opportunities for individual service providers to collaborate and access training.

4.2.4 SYSTEM

Overall, the evaluation found that SMILE addresses the everyday but essential needs of seniors with chronic health and social needs, and can help, in particular, to meet the needs of socially vulnerable seniors, who may be isolated and earn a low income. Moreover, SMILE leverages community resources to meet the everyday needs of seniors and their caregivers, which helps to build local and system capacity while overcoming gaps in access in underserviced – often rural – areas. Through building connections with a range of service providers and caregivers, SMILE is helping build a more integrated health system in the SE LHIN

In addition, the evaluation found that creating access to Lifeline, transportation to medical appointments and knowing where to go for help when it is needed may slow clients' functional decline and prevent clients from calling an ambulance and using hospital unnecessarily. Through iCART, SMILE will help ensure clients who may be high users of the health system and may be 'falling through the cracks' are able to access needed supports to prevent avoidable hospitalization and age safely and independently at home. While it may not be reasonable to expect SMILE alone to reduce visits to hospital, since SMILE assists with IADL needs and could

not be expected to reduce existing health care needs, SMILE may help prevent crises or new health needs brought on by falls due to clutter in the home, unsanitary living conditions, improper nutrition, inability to access medical appointments etc.

In sum, we conclude that:

- SMILE offers a proven, "client-centred" care model strongly aligned with Ontario's policy agenda; by equipping Care Coordinators to work with seniors and caregivers to identify needs and preferences, build individualized solutions using local resources, and monitor and adjust care plans, SMILE enhances independence and choice, and works to keep seniors and caregivers, including growing numbers at high levels of need, safely and appropriately in their own homes. In doing so, it also expands the "unit of care" to include informal caregivers who do most of the heavy lifting in the community, and without whom care plans, particularly for seniors with cognitive challenges, would often not be viable

- Although initially aimed at seniors and caregivers at future risk of loss of independence, SMILE has demonstrated its ability to support individuals at higher levels of need comparable to CCAC long-stay clients, as well as those waiting for LTC. It has also shown its capacity to do this in underserviced rural areas, by making connections with established providers, when available, and leveraging new capacity through non-traditional providers. While the evaluation was not able to find "smoking gun" evidence that SMILE has directly reduced LTC admissions and ALC rates – noting that such evidence is extremely rare across the health care system as a whole – seniors, caregivers, Care Coordinators and other stakeholders strongly believe that SMILE does help seniors stay at home longer, in large part by reducing uncertainty, providing ongoing support and monitoring to adjust to changing needs, and strengthening the informal care base

- In addition to connecting seniors and caregivers to services, SMILE also works to connect providers with other providers, thus contributing to system integration "from the ground up;" the iCART initiative is an excellent example of how this is now happening across sectors. In doing so, SMILE contributes to joint working within and beyond H&CC, an essential ingredient of solutions to improve "flow" across the health care system as a whole, and ensure that people get the most appropriate care, in the most appropriate and cost-effective location

On questions of costs – does SMILE achieve cost-savings? Is SMILE cost-effective? The evaluation does not provide definitive answers. A number of factors, including SMILE's continuously shifting focus (from prevention/maintenance to substitution for LTC and hospital ER visits), along with challenges tracking the full costs of all community-based services provided

to SMILE clients, make definitive answers elusive. Nevertheless, the weight of evidence points in the right direction; by equipping seniors and caregivers, including those at increasingly higher levels of need, to remain independent and in their own homes, SMILE promotes "downward substitution" from hospital and institutional care, to community-based care, and in doing so, avoids situations where hospitalization and institutionalization become the costly "default" options

4.3 WHAT WE RECOMMEND

4.3.1 SPREADING, SCALING-UP, SUSTAINING SMILE

Our recommendations for SMILE build on these findings; as noted, they also locate SMILE's client-centred approach strategically within a dynamic policy environment which now includes Donner's recent report on home and community care and the province's 2015 "Roadmap to Strengthen Home and Community Care."

The Roadmap identifies a series of goals to guide policy and practice in home and community care. Roadmap goals are:

- Put Clients and Caregivers First. The planning and delivery of home and community care is client and caregiver-centred. Everyone who has needs that can be reasonably met in the home or community will receive support to do so.
- Improve Client and Caregiver Experience. Clients and caregivers understand the support they can expect and they experience a timely, responsive system. Service delivery information is publicly available and easily accessible.
- Drive Greater Quality, Consistency and Transparency. Clients receive consistent, high quality care throughout the province. Care is informed by experts and evidence. Home and community care programs use standardized tools and supports to strengthen the quality of services and programs delivered.
- Plan for and Expand Capacity. Investments focus on increasing capacity and improving performance in the home and community care system.
- Modernize Delivery. Updated funding models, consistent assessment approaches, flexible contracting, workforce stabilization and improved technology are used throughout the sector[49].

The Roadmap also hints at more far-reaching changes to come. For example, Minister Hoskins' statement refers specifically to the "success of St. Joseph's Health System's Integrated Comprehensive Care Demonstration Project [in Hamilton] where integrating funding across multiple providers and care settings improved the patient experience, reduced time spent in

[49] Expert Group on Home & Community Care. (2015). Bringing Care Home. http://health.gov.on.ca/en/public/programs/ccac/docs/hcc_report.pdf

hospital and decreased the number of emergency room visits"[50]. This seems to anticipate the long-expected emergence of new "vertically integrated" provider organizations with responsibility for a whole client care trajectory as well as new funding mechanisms (such as "bundled funding") which would give needs-adjusted per capita payments to organizations providing a comprehensive range of services to an identified population.

In such a volatile environment, we think it is crucial not only to "do good" for seniors and caregivers, but to be seen to be doing good. Our recommendations thus aim not only at continuously improving SMILE's performance and quality, but to position it strategically by strengthening relationships with stakeholders within and beyond the home and community care sector, communicating clear messages about the value of SMILE's "client-centred" approach, and building political capital to sustain, scale-up and spread SMILE to other vulnerable populations, and to other parts of the province.

4.3.2 CLIENT AND CAREGIVER (CLIENT CARE) RECOMMENDATIONS

Consistent with the 2015 Roadmap's renewed emphasis on putting "clients and caregivers first," our first set of recommendations focuses on the people that SMILE serves.

Recommendation 1.1: Position SMILE as a proven and scalable model of "client-centred" care. SMILE's defining commitment is to its clients. As policy-makers and planners increasingly understand and emphasize "client-centred care," SMILE offers a proven model which can be scaled up and spread to new clients and new communities across urban and rural areas of Ontario.

SMILE can begin by making its model more visible to clients and caregivers at different levels of need in the SE LHIN; in doing so, it can strengthen its working relations with other stakeholders.

For example, regular public information and education events can be organized in collaboration with the SE LHIN, SE CCAC and other stakeholders including the Alzheimer Society (especially following the recent announcement of a new provincial Alzheimer initiative), Community Health Centres, public health units, and community mental health agencies. Events could be located in easy-to-access public spaces such as malls, community halls, churches, adult day programs, buildings where seniors live, and LTC facilities. Events would aim to:

- Better equip the majority of older persons and caregivers who may never become SMILE clients to anticipate and adapt to changing life circumstances and needs, and modify their lifestyles and home environments to support healthy aging

[50] Ministry of Health and Long-term Care (2015). Patients first: A roadmap to strengthen home and community care. http://news.ontario.ca/mohltc/en/2015/05/patients-first.html

- Ensure that people who may need SMILE and other community supports in the future, don't "slip through the cracks," that they begin to understand their options and know how to connect with community-based providers when they need them
- Identify people who can immediately benefit from SMILE and other community-based programs and begin intake to ensure that hospitalization or residential LTC do not become "default" options
- Raise SMILE's profile in the community and strengthen its linkages with partners across the care continuum to "plan for and expand capacity" in the sector, one of the key goals of the 2015 Roadmap.

Meeting Centres for Dementia in the Netherlands (previously called Alzheimer Cafes) provide an example of what can be done proactively and at low cost to support clients and caregivers, and make SMILE more visible. Meeting Centres:

- Take place in a wide variety of settings including LTC facilities (which also familiarize people with these settings and eases possible transitions)
- Offer a range of therapeutic, recreational and social activities and support services in collaboration with partners
- Support informal caregivers through information, discussion groups, counselling, one-on-one support for specific issues, and the creation of social network for caregivers
- Provide additional consultations on a regular or as-needed basis.[51]

Recommendation 1.2: Communicate how SMILE supports a broader "unit of care." As the report of Ontario's Expert Group on Home and Community Care observed, "the health care system needs to think more broadly beyond the individual receiving care." This idea also figures prominently in the first goal of the 2015 Roadmap, which (albeit not in the title) shifts toward the more encompassing and appropriate idea of "clients and caregivers."

Of course, this is not news for SMILE, which always looks to the characteristics and needs of seniors and caregivers together. However, across the system, funding mechanisms, eligibility criteria and performance measures continue to lag, with caregivers often still not recognized as home care "clients" and performance targets still defined predominately in terms of services provided to individual "patients."

Here the approach used by SMILE Care Coordinators to co-create individualized community support packages offers a "best practice" since it involves:

- Jointly assessing the needs and capacity of clients and caregivers
- Empowering clients and caregivers to make choices to the extent possible

[51] Mak, S., Jani, H., Bednarik, R. Alzheimer Café. Retrieved from: http://interlinks.euro.centre.org/node/42

- Connecting clients and caregivers with an expanded range of community resources which support both sets of needs.

This also means redefining outcomes. Instead of focusing only on the individual "patient" or "client," SMILE's value added accrues to caregivers and their broader communities; investments in SMILE thus generate dividends well beyond the individual "patient" which need to be taken into account when assessing outcomes and "value for money."

Because it works in rural areas where formal service infrastructure is underdeveloped, and because it can access non-traditional providers and service organizations, SMILE is also in a unique position to build local capacity in places where it is very difficult to build; thus, the SMILE model can be expanded to improve access and equity across Ontario.

Recommendation 1.3. Clarify the value of "supported" self-management. The "backgrounder" to the 2015 Roadmap notes that over the next two years, Ontario will "pilot different approaches" to give Ontarians more choice over "who provides services in their home and when these services are delivered;" this will likely include models of "self-managed care" [52].

Here SMILE has broken important ground by showing not only when self-directed care can work to improve client and caregiver choice and independence, but when it works less well.

For example, SMILE's experience demonstrates that as needs become more complex, it is progressively more challenging to access and manage multiple services and providers; even professional case managers can find this tough work. Such challenges are further magnified when seniors experience cognitive limitations, or when caregivers (many of whom are themselves seniors) also require care. This does not mean removing client choice and independence; rather, it means providing sufficient support so that clients and caregivers have real choices. Clients and caregivers consistently lauded SMILE Care Coordinators for their essential support in establishing, implementing and monitoring care plans around their needs and preferences.

Moreover, in underserviced areas, the idea of "client choice" may ring hollow if there are few services to choose from. Here SMILE expands care options, and thus choice, by making connections to established providers, and levering a wider range of local resources including non-traditional providers. SMILE then continues to monitor care and address problems, which vulnerable persons might find difficult to do on their own.

In addition to strongly aligning with Roadmap goals, the SMILE model thus also embeds key operational principles of proven self-management models internationally. For example, Personal Health Budgets (PHBs) in England:

---

[52] Ministry of Health and Long-term Care (2015). Patients first: A roadmap to strengthen home and community care. http://news.ontario.ca/mohltc/en/2015/05/patients-first.html

- Provide funding to clients to support identified health and well-being needs
- Are planned and agreed upon by clients and local care coordinators who also provide education and support to help clients understand choices, limitations and obligations.

Personal Cash Budgets in the Netherlands embed similar principles. These budgets:

- May be accessed by caregivers experiencing a financial burden related to caregiving
- Are set at approximately 75% of the cost of institutional care
- Encourage recipients to hire a family member or friend to provide needed care
- Are associated with enhanced feelings of independence among recipients and reduced likelihood of institutionalization.

Recommendation 1.4. Advocate for "client-centred" funding. Current funding models tend to be based on historical funding patterns and provider market share. While offering the advantage of predictability, such models are only loosely connected to client needs. In fact, they may penalize providers that take on higher needs, higher cost clients; incent them to "shift costs" through referrals to other providers; and mitigate against collaboration since providers are paid only for the services they provide.

In contrast, "client-centred" funding models are based on the client's needs. For example, Japan's long-term care insurance system uses standardized assessments, emphasizing IADL needs, to sort seniors requiring ongoing support into seven discrete categories; those in higher needs categories accordingly receive larger care budgets[53].

The well documented PACE On Loc Lifeways integrated care program for high needs seniors in San Francisco, California, uses an even simpler funding mechanism; when it accepts clients eligible for nursing home care, On Loc receives 95% of the cost of a nursing home bed to maintain them in the community. Since On Loc still pays the full cost of any hospital or residential care required, it has a strong incentive to make the best possible use of community-based prevention and maintenance[54].

As noted above, Dutch Personal Cash Budgets also incorporate this straight-forward approach by setting budgets at 75% of the cost of institutional care.

SMILE is well positioned to lead implementation of client-centred models. SMILE Care Coordinators now have years of experience using client budgets to build flexible community care packages around clients and caregivers.

---

[53] Campbell, JC. Japan's Long-Term Care Insurance Program as a Model for Middle-Income Nations. In Universal Coverage for Inclusive and Sustainable Development: Lessons from Japan. Naoki Igami, Editor. World Bank Study, 2014.

[54] Further information may be accessed at http://www.onlok.org/

Given that growing numbers of SMILE clients have assessed needs comparable to those of CCAC clients waiting for LTC, a good first step may be for SMILE to negotiate for a comparable level of funding for this group; currently the cost of a LTC bed in Ontario is about $160/day/bed with the province paying just over $100. This, of course, does not include the massive capital costs of building beds.

Even heavily discounted (say to the Dutch 75%), such funding would allow SMILE to ramp-up its service infrastructure to serve higher needs clients without having to push out those with lower needs until they also reach the point of crisis. As is now the case in Ontario's LTC facilities, funding could then be adjusted annually, based on the previous year's average level of need.

In return, SMILE would take on financial and clinical responsibility for all community-based services required to maintain LTC eligible seniors and their caregivers in the community. SMILE would then have a major incentive to find innovative ways to support higher needs seniors and caregivers, thus mitigating pressure on LTC and hospital beds. It would also promote greater transparency and accountability, since expenditures and outcomes would be clear.

With more experience, funding rates could then be adjusted for clients at different levels of need, including those now referred to SMILE by iCART.

Because SMILE's reach extends across the SE LHIN region, SMILE offers strong potential to introduce client-centred funding across urban and rural communities simultaneously, improving access and equity[55]. This addresses a key goal of Ontario's 2015 Roadmap: "everyone who has needs that can be reasonably met in the home or community will receive support to do so" … "across the province."

4.3.3 PROGRAM (OPERATIONAL) RECOMMENDATIONS

Our second set of recommendations looks to changes to strengthen SMILE's operational performance.

Recommendation 2.1. Enrich and broaden the conversation. The evaluation findings show that clients and caregivers overwhelmingly appreciate and support SMILE; they believe that SMILE plays an essential role in helping them stay in the community. Clients and caregivers also had many valuable suggestions for strengthening SMILE.

We suggest enriching and broadening this conversation through a mix of short surveys, one-minute evaluations, focus groups and town-hall meetings; in addition to strengthening client voice, this raises SMILE's visibility and tangibly demonstrates SMILE's "client-centredness." The 2015 Roadmap puts patients first; Health Quality Ontario considers "patient experience" as an essential performance metric.

[55] Kuluski, K., Williams, AP., Laporte, A., Berta, W. (2012). The role of community-based care capacity in shaping risk of long-term care facility placement. *Healthcare Policy.* 8(1). 92-105.

We think that similar approaches could be used to strengthen engagement with other stakeholders and "take the pulse" of the communities that SMILE serves. How do others see SMILE? Are there emerging issues which SMILE should have on its radar? Are there "lessons learned" to improve performance and quality?

Recommendation 2.2. Strengthen the evidence base. As described, our evaluation used multiple methods and data sources to examine SMILE; these sources provide rich insight into not only the "who" and "what" of SMILE's clients and services, but the "how" and "why" of how SMILE works and how it generates value added. As the POPP evaluation framework demonstrates, "mixed" methods are recognized internationally as not just legitimate, but essential components of evaluation and policy-making."

However, as the Roadmap points out, policy will also be informed by "experts and evidence" including, one can assume, emphasis on "hard" outcomes such as health care utilization and costs.

To build SMILE's evidence base, we recommend:

- Establishing a "balanced scorecard" of performance measures along different dimensions including client/caregiver experience, joint working with other providers, and health care utilization and costs
- Ensuring that SMILE has access to up-to-date electronic assessments for all of its clients and their caregivers including those referred from other providers or programs such as CCAC and iCART
- Establishing methods for linking assessments to SMILE care plans in electronic format which show details of services accessed from formal providers (including CCAC and CSS) and non-traditional providers
- Tracking the costs of SMILE care packages at the level of the individual client and caregiver, including costs incurred by SMILE and other publicly funded providers, to facilitate comparative cost analysis between SMILE and alternatives such as LTC and hospital beds
- Tracking, to the extent possible, what actually happens to SMILE clients, whether they are able to stay at home and for how long, and how often they are admitted to hospital.

Recommendation 2.3. Use technology to improve performance and outcomes. According to Ontario's Roadmap, technology is one of the tools that will help modernize delivery. Some technologies – such as telehealth -- are already widely used in Ontario. Newer technologies include wearable sensors to detect movement in bed-ridden persons. IBM and Apple have just announced a plan to provide iPads to older persons in Japan which will come loaded with senior friendly apps and large buttons (including a "help" button) designed to make it easier to coordinate medical reminders, shopping, doctor appointments, household maintenance,

household cleaning and transportation[56]; similar technologies are now being tested by Community Health Centres in Ontario.

Such "smart" technologies do not replace, but can extend the range and capacity of SMILE staff and make it easier for them to track their decisions, especially as needs become more complex. We offer two examples:

- The first is the Neighbourhood Model (Buurtzorg) originated in the Netherlands. Developed through frustration with fragmented community care services, this model equips "block nurses" with encrypted smart phones which they use to conduct assessments, track and coordinate services, and communicate with clients and caregivers
- The second is the extensively evaluated PACE (Program of All Inclusive Care for the Elderly) model in the US, which has been adapted to rural areas. Technologies used to bridge distance gaps and enhance care include: consumer and caregiver access to websites that support access to information around care options; use of remote health monitoring devices; use of electronic health records and care pathways linked to support coordination of care across different providers; use of electronic communication to reduce isolation; and telehealth systems to provide access to specialist and integrated interdisciplinary care[57].

We are also aware of Ontario initiatives that successfully use technologies to improve care access and quality in community settings. For example:

- The Children's Treatment Network (CTN) of Simcoe York is an extensively evaluated model of care for children with ongoing complex needs and their caregivers. It uses technology to support a shared client record (including assessment data and a single plan of care) which is then available to all team members and families. Technology is also used to facilitate virtual team meetings to review changing client needs and adjust care plans as required[58].

Recommendation 2.4. Elaborate a modular accountability framework. SMILE's success in supporting clients and caregivers reflects its flexibility and capacity to adapt not only to the changing needs of clients and caregivers, but to highly variable formal and non-traditional assets present at the local level, in urban and rural areas. Of course, these same characteristics pose questions around what clients, caregivers and other stakeholders can expect from SMILE, and what SMILE should expect in return.

---

[56] Kessler, S. (2015). Apple and IBM announce plans for an elder-support service in Japan. Retrieved from: http://www.fastcompany.com/3045749/tech-forecast/apple-and-ibm-announce-plans-for-an-elder-support-service-in-japan

[57] Helpful information on rural "models that work" in the US including their use of technology, can be found at http://199.237.254.34/quality/models.html

[58] More details can be found at http://www.ctn-simcoeyork.ca/

Consistent with the 2015 Roadmap's emphasis on "quality, consistency and transparency," we recommend elaborating a modular accountability framework. For example, the module for clients and caregivers could include:

- A client and caregiver "bill of rights" with easy-to-understand statements of roles and responsibilities, including the expectation that clients and caregivers will continue to do as much as possible for themselves
- Choice of care management and reimbursement models, including self-management, supported self-management, or case management
- Choice of care providers, including non-traditional providers (excluding family members)
- A list of goals and outcomes to be included and assessed in individualized "service agreements."

For established providers, such frameworks could include:

- A statement of expectations including participation in care conferences, information sharing, and compliance with privacy and confidentiality requirements.

For non-traditional providers, accountability frameworks could include:

- Template agreements identifying services to be provided, fees and payment methods, and any requirements around references or police checks
- A statement that although SMILE will not act as employer, it will monitor services and provide support to resolve disputes.

4.3.4 PROVIDER (OPERATIONAL) RECOMMENDATIONS

Interdisciplinary, inter-organization collaboration, or joint working, is widely seen as the foundation of more integrated, coordinated care. Our third set of recommendations aims to strengthen joint working with partners and other stakeholders.

Recommendation 3.1. Engage SMILE Care Coordinators within inter-organization care teams. SMILE Care Coordinators were consistently identified by clients and caregivers as the key to SMILE's success; they worked to integrate care from different sources around peoples' needs. The thrust of this recommendation is to take this important function and ramp it up, by working to establish inter-organization care teams including SMILE Care Coordinators.

The Expert Panel we conducted as part of the SMILE evaluation points to the potential for such collaborative approaches. Panelists, all of whom were experienced and dedicated professionals, observed that they were not always fully aware of what other providers did even for shared clients; through the process of considering different client "vignettes" and building ideal care packages, they identified collaborative strategies for bridging care gaps which better served client needs and made the best use of available resources.

As noted in the example above, "virtual rounds" are already being used in Ontario to encourage joint working and innovative approaches to client care. Such "rounds" can be conducted electronically using web-based conferencing packages, an important consideration for rural

areas where distances are long. To minimize issues around confidentiality and data sharing, they can use composite "vignettes" synthesized from client records, or, as in hospitals, actual client records. The focus of such rounds could be limited to H&CC, or it could be widened to include primary care, acute care, mental health and rehabilitation.

Recommendation 3.2. Position SMILE to lead the emergence of community hubs.
Community hubs are increasingly seen in Ontario and internationally as a promising means of building community capacity. Although hubs come in many different shapes and sizes, the logic is that by gathering together (or co-locating) different providers at a single location, you can improve access, build familiarity and trust, and promote joint working.

We noted earlier, that in her 2014 mandate letters to the Ministers of Health and Long-Term Care, Education, Housing, and Municipal Affairs, the Premier of Ontario directs the development of a policy on community hubs to "reflect the perspective of health and wellness" and to promote collaboration on "shared responsibilities" within government. She recently appointed a Special Advisor on Community Hubs who has now begun consultations[59].

There are excellent examples of high performing hubs in the province including:

- Langs in Cambridge Ontario, which brings together over 20 community partners offering services to a large rural area
- Unison Health and Community Services in Toronto, which offers a range of community-based primary care and community support to diverse communities in the Bathurst Finch area.

Here, SMILE has the considerable advantage of access to VON's extensive network of resources including day programs which could potentially become sites for community hubs. In addition to bringing together formal providers, hubs can also provide meeting space for informal caregivers and non-traditional providers.

Given that SMILE and VON already have strong relationships with Community Health Centres in the SE LHIN, and that CHCs are also strong advocates for community-based client-centred care, a SMILE/CHC hub which improves services for both groups of clients, would seem to be a great place to start.

4.3.5 SYSTEM (STRATEGIC) RECOMMENDATIONS

Our final recommendations look to actions at the system level; these anticipate changes-to-come as the Province considers wide-ranging structural reforms in home and community care and beyond.

[59] Lum, J., Ying, A. (2014). Community hubs: Right care, right place, right time. Retrieved from: http://www.crncc.ca/knowledge/factsheets/pdf/InFocus-CommunityHubs.pdf

Recommendation 4.1. Engage with Health Links. SMILE needs to be "at the table" as Health Links gain traction; not only are Health Links designed to promote "bottom-up" change, they are contiguous with hospital catchment areas which could prove crucial if vertically integrated hospital organizations emerge in Ontario. Through Health Links, as well as through continuing engagement with the SE LHIN and other system partners, SMILE can increase its visibility.

In this connection, the iCART initiative offers an illustrative example of how crucial linkages and joint working can be established across sectors to relieve persistent system challenges and improve outcomes for people. While iCART now involves only two hospitals, a successful roll-out would likely see it spread to more hospitals and Health Links in the SE. SMILE (and its parent, the VON) is one of a few community-based organizations that covers the entire SE LHIN (and much of the province); it is thus ideally situated not only to be a key player in all Health Links, but to bring valuable intelligence to local decision–making tables about what works best, under what conditions in different parts of the region.

Recommendation 4.2. Maximize the potential of the VON infrastructure. Our final recommendation recognizes that SMILE is one of a few community-based programs with direct access to provincial and national infrastructures. Such infrastructures offer considerable scope to generate transferable lessons learned around what works best for whom under what conditions; such intelligence is essential to the design and implementation of local programs as well as broader system change. While employing a full-scale research staff is likely not an option for SMILE, is could draw more heavily on staff at VON's provincial and national offices to build the evidence base which the provincial Roadmap sees as an essential resource for system change.

APPENDIX A: CONSULTATION SURVEYS

1. Client Survey
2. Caregiver Survey
3. Community Support Service Agency Survey
4. Individual (non-traditional) Service Provider Survey

VON SMILE Program

Client Survey

Please help us improve SMILE

SHS Consulting and the Balance of Care Research and Evaluation Group, University of Toronto, have been asked by VON Canada to find out how well the SMILE program works for **clients** like you and how it could be improved to better meet your needs.

Your views matter

To do this, we are asking you to complete and return a short survey which asks about your experience with SMILE – what you think is most valuable, what you think is least valuable, and what you think should be changed. We also ask about a number of possible benefits that you may experience as a result of SMILE.

Your response is completely voluntary; your identity will not be shared

Whether or not you choose to respond to the survey is completely up to you.

If you do choose to respond, your identity will not be revealed in any report or publication.

If you do not choose to respond, nothing will change in the services SMILE provides to you – in fact, SMILE will not know who answered and who didn't.

We need to hear from you

To ensure that we have a full and fair picture of what SMILE does best, and how it could do better, please take a few minutes to complete the short survey below and return it in the self-addressed stamped envelope. Using the contact information, you may also request a personal interview by phone. Or you may choose to complete the survey online at: https://www.surveymonkey.com/r/smileclient

For further information or to request a personal interview

For questions about this survey, or to request a personal interview, please contact Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109

If you have questions about the SMILE program, please contact Katie Carignan-Jackson, Administrative Assistant for the SMILE program at katie.carignan-jackson@von.ca or 1-888-866-6647 ext. 5334

Questions about SMILE

1. What do you find most valuable about SMILE?

2. What do you find least valuable about SMILE?

3. How could SMILE be improved?

Questions about You

4. How long have you received funding from SMILE? Please check the appropriate box.

- ☐ Less than 12 months
- ☐ 12 to 24 months
- ☐ More than 24 months

5. How strongly do you agree or disagree with each of the following statements about SMILE (Please check the appropriate box for each statement).

Statement	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
a. My quality of life has improved					
b. I feel more confident about knowing where to go for help when I need it					
c. I have the support I need for everyday tasks such as meal preparation and housekeeping					
d. My ability to stay as healthy as possible has improved					
e. My ability to maintain relationships with friends and family has improved					
f. I feel more in control of my own life					
g. I feel less worried and stressed about the future					
h. I feel as though I am in a safe environment					
i. I feel comfortable with the people who come into my house					
j. I am more able to afford the care I need					
k. I am less likely to use the hospital emergency department or call 911					

6. If you were giving SMILE a report card, what grade would you give it? Please check the appropriate box.

- ☐ A Excellent
- ☐ B Very Good
- ☐ C Good
- ☐ D Poor
- ☐ F Fail

7. Do you have any other comments or ideas about SMILE you would like to share?

Your views are important!

Please complete and return your survey using the enclosed self-addressed, stamped envelope by January 9, 2015.

Alternatively, you can complete this survey on-line at
https://www.surveymonkey.com/r/smileclient

Or, you can request a personal interview by contacting Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

THANK YOU!

BOC
BALANCE OF CARE
Research & Evaluation Group

SHS CONSULTING

VON SMILE Program

Caregiver Survey

Please help us improve SMILE

SHS Consulting and the Balance of Care Research and Evaluation Group, University of Toronto, have been asked by VON Canada to find out how well the SMILE program works for **caregivers** like you and how it could be improved to better meet your needs and the needs of the people you care for.

Your views matter

To do this, we are asking you to complete and return a short survey about your experiences with SMILE – what you think is most valuable, what is least valuable, and how you think SMILE could be improved. We also ask about the benefits you may experience from SMILE.

Your response is completely voluntary; your identity will not be shared

Whether or not you choose to respond to the survey is completely up to you.

If you do choose to respond, your identity will not be revealed in any report or publication.

If you do not choose to respond, nothing will change in the services SMILE provides to you or loved ones – in fact, SMILE will not know who answered and who didn't.

We need to hear from you

To ensure that we have a full and fair picture of what SMILE does best, and how it could do better, please take a few minutes to complete the short survey below and return it in the self-addressed stamped envelope. Using the contact information, you may also request a personal interview by phone. Or, you can complete the survey online at: https://www.surveymonkey.com/r/smilecaregiver

For further information or to request a personal interview

If you have any questions about this survey, or if you wish to request a personal interview, please contact Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

If you have questions about the SMILE program, please contact Katie Carignan-Jackson, Administrative Assistant for the SMILE program at katie.carignan-jackson@von.ca or 1-888-866-6647 ext. 5334.

Questions about SMILE

1. Thinking about you and the person you care for, what do you find most valuable about SMILE?

2. What do you find least valuable about SMILE?

3. How could SMILE be improved?

Questions about You

4. How long have has your senior loved one received funding from SMILE? Please check the appropriate box.

- ☐ Less than 12 months
- ☐ 12 to 24 months
- ☐ More than 24 months

5. How strongly do you agree or disagree with each of the following statements about SMILE (Please check the appropriate box for each statement).

Statement	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
a. My quality of life has improved					
b. The quality of life of the person I care for has improved					
c. I feel more confident about knowing where to go for help when I need it					
d. My ability to run errands, do chores or deal with other personal commitments has improved					
e. My ability to focus on my own health needs has improved (i.e. attending your own medical appointments)					
f. My ability to maintain relationships with friends and family has improved					
g. I feel more in control of my own life					
h. I feel less worried and stressed about the future					
i. The person I care for is in a safe environment					
j. The person I care for is more able to continue to live safely at home					

Statement	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
k. The person I care for is less likely to experience crisis					
l. The person I care for is more likely to receive the care they need					
m. I feel less financial strain					
n. I am less likely to use the hospital emergency department or call 911					
o. I am able to spend more quality time with the person I care for					

5. If you were giving SMILE a report card, what grade would you give it? (Please check the appropriate box).

- ☐ A Excellent
- ☐ B Very Good
- ☐ C Good
- ☐ D Poor
- ☐ F Fail

Your views are important!

Please complete and return your survey using the enclosed self-addressed, stamped envelope by January 9, 2015.

Alternatively, you can complete this survey on-line at
https://www.surveymonkey.com/r/smilecaregiver

Or, you can request a personal interview by contacting Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

THANK YOU!

BOC BALANCE OF CARE Research & Evaluation Group

SHS CONSULTING

VON SMILE Program

Service Provider Survey

Please help us improve SMILE

SHS Consulting and the Balance of Care Research and Evaluation Group, University of Toronto, have been asked by VON Canada to evaluate the impact of the SMILE program on clients, informal caregivers, home & community care providers, and the health system as a whole in the South East LHIN.

Your views matter

As part of this process, we are asking you, and other home & community care providers, to complete and return a short survey which asks about your experiences with SMILE.

Your response is completely voluntary; your identity will not be shared

Whether or not you choose to respond to the survey is completely up to you.

If you do choose to respond, your identity will not be revealed in any report or publication.

If you do not choose to respond, nothing about your relationship with VON Canada as a SMILE service provider will change – in fact, SMILE will not know who answered and who didn't.

We need to hear from you

To ensure that we have a full and fair picture of what SMILE does best, and how it could do better, please take a few minutes to complete the short survey and return it in the self-addressed stamped envelope. Using the contact information below, you may also request a personal interview by phone. Or, you can complete the survey online at: https://www.surveymonkey.com/r/smilecssprovider

For further information or to request a personal interview

For questions about this survey, or to request a personal interview, please contact Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

If you have questions about the evaluation of the SMILE program, please contact Katie Carignan-Jackson, Administrative Assistant for the SMILE program at katie.carignan-jackson@von.ca or 1-888-866-6647 ext. 5334.

Part 1: Questions about your organization

1. How long has your organization worked with SMILE?

2. During a typical week, how many SMILE clients does your organization normally serve?

3. What kinds of services does your organization typically provide to SMILE clients (e.g., homemaking, meals, transportation)?

4. Which of the following best characterizes the community in which your SMILE clients live?

- ☐ Rural
- ☐ Urban
- ☐ Rural/urban mix

5. In this community, how would you describe the balance between what people need and available home and community care (e.g., over serviced, under serviced, wrong mix of services)?

Part 2: Questions about SMILE

6. What do you find most valuable about SMILE?

7. What do you find least valuable about SMILE?

8. How could SMILE be improved?

9. Please describe how SMILE encourages (or could encourage) greater coordination between service providers.

10. If you were giving SMILE a report card, what grade would you give it? (Please check the appropriate box).

- ☐ A Excellent
- ☐ B Very Good
- ☐ C Good
- ☐ D Poor
- ☐ F Fail

11. Do you have any additional comments you would like to share about the SMILE program?

Your views are important!

Please complete and return your survey using the enclosed self-addressed, stamped envelope by January 9, 2015.

Alternatively, you can complete this survey on-line at
https://www.surveymonkey.com/r/smilecssprovider

Or, you can request a personal interview by contacting Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

THANK YOU!

BOC
BALANCE OF CARE
Research & Evaluation Group

SHS CONSULTING

VON SMILE Program

Service Provider Survey (Individual)

Please help us improve SMILE

SHS Consulting and the Balance of Care Research and Evaluation Group, University of Toronto, have been asked by VON Canada to evaluate the impact of the SMILE program on clients, informal caregivers, home & community care providers, and the health system as a whole in the South East LHIN.

Your views matter

As part of this process, we are asking you to complete and return a short survey which asks about your experiences with SMILE.

Your response is completely voluntary; your identity will not be shared

Whether or not you choose to respond to the survey is completely up to you.

If you do choose to respond, your identity will not be revealed in any report or publication.

If you do not choose to respond, nothing about your relationship with VON Canada as a SMILE service provider will change – in fact, SMILE will not know who answered and who didn't.

We need to hear from you

To ensure that we have a full and fair picture of what SMILE does best, and how it could do better, please take a few minutes to complete the short survey and return it in the self-addressed stamped envelope. Using the contact information below, you may also request a personal interview by phone. Or, you can complete the survey online at: https://www.surveymonkey.com/r/smilecareprovider

For further information or to request a personal interview

For questions about this survey, or to request a personal interview, please contact Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

If you have questions about the evaluation of the SMILE program, please contact Katie Carignan-Jackson, Administrative Assistant for the SMILE program at katie.carignan-jackson@von.ca or 1-888-866-6647 ext. 5334.

Part 1: Questions about You

1. How long have you/your business been working with SMILE?

2. During a typical week, how many SMILE clients do you normally serve?

3. What kinds of services do you typically provide to SMILE clients (e.g., homemaking, shopping, meal preparation, transportation)?

4. Which of the following best characterizes the community in which your clients live?

- ☐ Rural
- ☐ Urban
- ☐ Rural/urban mix

5. In this community, how would you describe the balance between what people need and available home and community care services (e.g., over serviced, under serviced, wrong mix of services)?

Part 2: Questions about SMILE

6. What do you find most valuable about SMILE?

7. What do you find least valuable about SMILE?

8. How could SMILE be improved?

9. Please describe how SMILE currently benefits, or could benefit, local communities and small businesses like yours.

10. If you were giving SMILE a report card, what grade would you give it? (Please check the appropriate box).

- ☐ A Excellent
- ☐ B Very Good
- ☐ C Good
- ☐ D Poor
- ☐ F Fail

11. Do you have any additional comments you would like to share about the SMILE program?

Your views are important!

Please complete and return your survey using the enclosed self-addressed, stamped envelope by January 9, 2015.

Alternatively, you can complete this survey on-line at
https://www.surveymonkey.com/r/smilecareprovider

Or, you can request a personal interview by contacting Jodi Ball from SHS Consulting at jball@shs-inc.ca or (905) 763-7555 ext. 109.

THANK YOU!

BOC
BALANCE OF CARE
Research & Evaluation Group

SHS CONSULTING

APPENDIX B: MOST SIGNIFICANT CHANGE STORIES

CARE COORDINATORS

Question: What do you think is the most significant benefit experienced by your clients as a result of SMILE?

Follow-up: On a scale of 1 – 5, to what extent is SMILE responsible for this benefit with 1 meaning it would have happened without SMILE and 5 meaning it couldn't have happened without SMILE?

RESPONSES: VON Care Coordinators

Participant	Story	Rating
Area Care Coordinator	To remain independent in their own home as long as possible.	5
Area Care Coordinator	Allows client to maintain a level of independence that is great enough to allow them to remain living in their home and out of LTC.	4.5
Area Care Coordinator	The ability to remain in their own home as independent as possible for as long as possible	4
Area Care Coordinator	The ability to maintain independently living in their home	4
Area Care Coordinator	The fact that they are able to remain in their own home for longer than they might have without the help of SMILE	3
Area Care Coordinator	Supports elderly seniors to identify what they feel are their needs to help them remain in the location of their choice longer	5
Area Care Coordinator	The services SMILE provides enable seniors to maintain their independence and control in their lives/situations to remain in their own environment.	4.5[60]
Office/Area Care Coordinator (shared)	Keeping them in their own homes for as long as possible and delaying admission to LTC and preventing ER visits and hospital admissions.	3
Office Coordinator	The ability to maintain independence within their chosen home for a longer period of time	4
Office Coordinator	Keeping their highest level of independence or returning to their highest level of independence.	5

[60] Actual response was "In most cases would be 4 to 5" so averaged at 4.5 for purposes of analyses / reporting.

Office Coordinator[61]	Feeling greater sense of wellbeing through services coming into home and assisting with those things they cannot perform for themselves.	5
Office Coordinator	Individualized care – recognition that client has individual needs and therefore no two clients or care plans are alike - clients have choice and flexibility – clients are partners in care coordination.	4

RESPONSES: CCAC

Position	Story	Rating
CCAC Care Coordinator	Delay admission to LTC; prevent caregiver burnout; promotes general safety; fills a gap in care plans between CCAC & SMILE	5
CCAC Care Coordinator	Allows people to remain in own homes; meet IADL needs – cleaning, shopping, appointments; with CCAC providing personal care, SMILE often supports the unmet needs CCAC cannot assist with	5

ANALYSIS BY EMERGING THEME

Question: What do you think is the most significant benefit experienced by your clients as a result of SMILE?

BENEFITS: Individual Level - Clients

Concept	Number of Mentions	Average Rating (Scale of 1-5)[62]
Independence – maintain	7	4.4
Independence – regain	1	5
Remain in own home / home of choice	10	4.2
Choice – of service / support	2	
Control – maintain	1	
Flexibility – in service / support	1	
Individual needs – help identify	1	
Assist with tasks client cannot perform / help meet unmet IADL needs	2	
Wellbeing – sense of	1	

[61] Identified only as "Client Care Coordinator" but mixed in with Office Coordinator stories, so assume Office Coordinator.

[62] Note – we only analyzed the rating assigned for the most common responses for benefits by theme.

BENEFITS: Individual Level - Caregiver

Concept	Number of Mentions
Prevent burnout	1

BENEFITS: Service Provider Level - CCAC

Concept	Number of Mentions
Complement CCAC Services / meet needs CCAC cannot	2[63]

BENEFITS: System Level

Concept	Number of Mentions	Average Rating (Scale of 1-5)
Remain home "as long as possible"	6	4
LTC – delay	2	
LTC – prevent	1	
Prevent Emergency Department Visits	1	
Prevent Hospitalization	1	

TYPICAL STORIES

Typical "Most Significant Benefit" Story: VON Care Coordinators (Office & Area)

According to VON Care Coordinators, the most significant benefit their clients experience as a result of the SMILE program is that they are able to: (a) live independently (b) in their own home for (c) as long as possible. On a scale of 1-5, with 5 indicating that this benefit couldn't have been experienced without SMILE, VON Care Coordinators assigned average ratings of a) 4.2, b) 4.4 and c) 4, respectively, indicating that, while it wouldn't be impossible for the benefit to be experienced without SMILE, they felt strongly that it wouldn't have been experienced without SMILE (1 indicated that clients would have experienced the benefit without SMILE).

Typical "Most Significant Benefit" Story: CCAC Care Coordinators

According to CCAC Care Coordinators, the most significant benefit their clients experience as a result of the SMILE program is that SMILE meets needs that CCAC cannot meet. On a scale of 1-5, with 5 indicating that this benefit couldn't have been experienced without SMILE, CCAC Care Coordinators assigned the maximum rating of 5, indicating that they feel this benefit couldn't have been experienced without SMILE.

[63] Each of two CCAC Coordinators mentioned this