

SOUTHEASTERN ONTARIO
REGIONAL STROKE SUPPORT GROUPS

JUNE 2016 EVALUATION

SUBMITTED TO SOUTH EAST LHIN



CANADA

STROKE NETWORK
of Southeastern Ontario



JUNE 2016 EVALUATION SOUTHEASTERN ONTARIO REGIONAL STROKE SUPPORT GROUPS

Background

In January of 2014, LHIN base funding was secured for the regional Stroke Survivor and Caregiver Support Groups:

- Community & Primary Health Care (CPHC) in Perth/Smiths Falls and Brockville (for LL&G Counties)
- Community Care for South Hastings (CCSH) (for H&PE Counties)
- VON Canada – Kingston, Frontenac, Lennox & Addington (for Kingston region)

Subsequent to the April 2015 Evaluation Report:

- Annual Evaluation Reports will be submitted to the LHIN to coincide with CSS reporting schedules (i.e. June)
- The facilitator for the Perth & Brockville groups attended The Aphasia Institute in Toronto for training in Supportive Conversation in the fall of 2015 supported by the Stroke Network of Southeastern Ontario
- The collaborative regional model which includes the three facilitators as well as representation from the Stroke Network of SEO continues to support the sharing of best practices and strategies through regular teleconferences. Facilitators also participate in the quarterly meetings of the Community Reintegration Leadership Team (CRLT), a committee of the Regional Stroke Network
- The 2015 Community Consultation process facilitated by the Stroke Network of Southeastern Ontario included representation from all support groups as well as all three Support Group Facilitators.
- Shell-Lee Wert (Executive Director, Community Care for South Hastings) and Patti Lennox (Manager, Caregiver Support and Community Programs, CPHC) continue to participate in the Regional Stroke Steering Committee as representatives of the CSS sector.
- In Kingston, a peer-led Social-Recreational Group continues to grow with support from Queen's OT students. This group is intended to further support community reintegration for members of the support groups who are at a stage in their recovery that supports a more independent experience.
- Four Stroke Specific Community Exercise Programs were launched in 2015 serving the Perth, Brockville, Belleville and Kingston areas. Belleville and Kingston are coordinated through VON and Brockville and Perth through CPHC. The Exercise Providers have been linked with the facilitators of the support groups to promote the programs.
- Peer Visiting Volunteer Programs are in place in Kingston (SMOL & community) and Perth (PSFDH). Discussions have been initiated with KGH and Brockville General to expand the peer visiting program to both of these locations. Additional peer visiting volunteers have been trained in Perth and Brockville.



- The Belleville Stroke Support Group Facilitator and Community Care for South Hastings (CCSH) partnered with Quinte District Rehab (QDR) to offer two sessions of an Aphasia Conversation Group in the Belleville area (a 6-week session in May/June of 2015 and a 6-week session in October/November 2015). Each 6-week session was comprised of two communication groups divided by level of communication impairment. All sessions were facilitated by a QDR Speech-Language Pathologist (SLP) in collaboration with the Belleville Stroke Support Group Facilitator. Sessions were well-attended (total of 27 participants – 23 stroke survivors and 4 caregivers) and the evaluation results were very positive.
- Three Living with Stroke[®] (LWS) programs were delivered in this reporting period. Of these, one was an integrated group which included both Acquired Brain Injury (ABI) clients and stroke survivors and their caregivers. This group was co-facilitated by the ABI System Navigator and the Kingston Support Group Facilitator. The Belleville LWS was a LWS & Aphasia program. This was the first LWS program adapted for participants with aphasia that has been offered in the southeast and was co-facilitated by a Speech-Language Pathologist from Quinte District Rehab and the Belleville Support Group Facilitator. Brockville held its initial LWS session as well within this reporting period.
- A pilot outreach initiative in collaboration with regional Ontario Telemedicine Network (OTN) nurses was started in Belleville in 2015. The current initiative provides an opportunity for stroke survivors/caregivers living in rural/remote areas of Quinte to participate in an existing facilitated support group using the OTN. To date, one couple has been integrated into the Belleville Couples Support Group. The project has received positive feedback from both the couple participating from the remote location as well as those participants on-site in Belleville including the Support Group Facilitator. Investigations are now underway to expand this initiative to include an additional location and participants.

S.U.P.P.O.R.T.

Stroke Understood: a Peer Program Optimizing Recovery Together

SERVICES PROVIDED

- Planning, delivery, and evaluation of 8 support groups (Perth/Smiths Falls Stroke Survivors & Caregivers Support Group, Brockville Stroke Survivors & Caregivers Support Group, Belleville Stroke Survivors Group, Belleville Couples Group, Belleville Caregivers Group, Kingston Caregivers Group, Kingston Couples Group and Kingston Stroke Survivors Group)
- Identification of educational needs of stroke survivors and caregivers with subsequent provision of educational information to the groups verbally, written, and/or via guest speakers.
- Therapeutic group discussions with respect to psychosocial concerns and issues which may be prompted by 'stimulus' questions brought forward by the facilitators
- Management of referrals for potential group participants (which may include home visits)
- Data gathering through the administration of evaluation tools for LHIN Evaluation Reports
- Outreach to and networking with community based partners, healthcare professionals, and health/wellness fair presentations



- Transportation arrangements for stroke survivors and/or caregivers if required
- Referral to community resources, as required, (with consent)
- Monitoring of individual participants as required through phone calls and email.
- System navigation including the identification of appropriate community resources, how to access local supports and services and initiation of referrals
- Case management when social and community resources are either non-existent or limited and the participant requires assistance, information and/or advocacy to meet their needs
- Maintaining administrative records for groups including attendance and case notes
- Responding to general/public requests for information about stroke and community resources and liaising with media
- Participating in regional facilitator teleconferences to support sharing of successes and challenges and to support regional consistency
- Attending regional CRLT meetings on a quarterly basis

METHOD OF DATA COLLECTION

All three regions have been surveying caregivers and survivors on an ongoing basis. The survey load on participants can become quite burdensome particularly for those respondents who have completed an evaluation component more than once. In an effort to reduce load and to increase the validity of survey results, focus of the evaluation continues to be on the perceived recovery scores for stroke survivors, caregiver burden evaluation, and the caregiver and survivor satisfaction tool. To enhance validity of the perceived recovery and caregiver burden scores, a minimum of 6 months is required between the pre and post scores.

As with the April 2015 Evaluation Report, the Stroke Services Evaluation Tool was administered to stroke survivors and caregivers to evaluate their satisfaction with the support groups as well as how they perceived the impact of the support groups on various health and lifestyle domains.

This evaluation again included three additional questions intended to provide a better understanding of how stroke survivors and caregivers are supported when navigating the health and social support systems. The questions are as follows:

1. Are you satisfied with the individual information and/or the referral information that you have received from the group facilitator? Y/N
2. Are you satisfied with the assistance you have received from organizations/individuals other than the stroke group facilitator? Y/N
3. If yes, and you are comfortable saying so, please state the name(s)/organization(s) that provided you with the information/assistance:

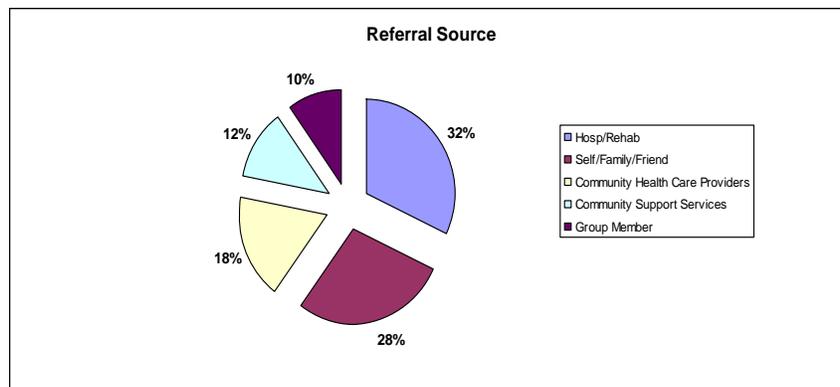
Note that quotes included in this report are derived from responses to the Stroke Services Evaluation Tool. All quotes are italicized.

SERVICES PROVIDED

- 8 facilitated stroke groups
- 3 Heart and Stroke Foundation Living with Stroke™ series (one offered as LWS & Aphasia in Belleville, other 2 in Kingston & Brockville)
- 2 Peer Visiting Programs (Kingston & Perth)
- 1 Social/Recreational Group (Kingston)
- 1 Outreach Initiative (Belleville)
- 1 Supported Communication Group (Belleville)

REFERRAL SOURCES

Fig. 1 Source of New Referrals



Source: Stroke Services Evaluation Tool

A total of 50 new referrals have been received subsequent to the last report. Self-referrals (survivor or family member) as well as hospital and rehab settings continue to be significant referral sources.

STROKE SUPPORT GROUP MEMBERSHIP

- 78 survivors and 45 caregivers are attending support groups

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH - CAREGIVER BURDEN

Caregiver Support Groups

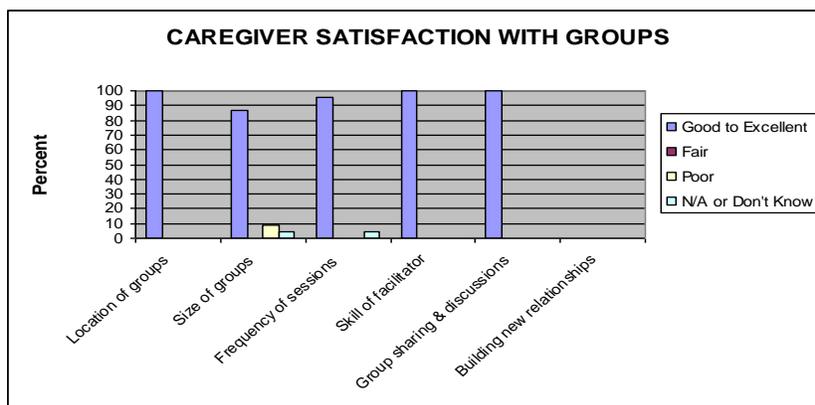
As stated in previous Evaluation Reports, the needs of the caregivers are recognized and addressed by the facilitators and through the support of their peers. Groups include:

- Education re stroke to enhance understanding of the current health status of their loved one as well as tips to support illness prevention & health promotion to reduce the risk of another stroke or other disease (e.g., cardiac and diabetes)
- Information on identifying stressors and implementation of coping strategies

- Referral/facilitating connections to community supports and, when identified as a need, to additional counselling
- Peer support and providing the opportunity to engage with others who are on a similar life journey/facing common issues and concerns

DEMONSTRATED SATISFACTION - CAREGIVERS AND SURVIVORS

Fig.2 Caregiver Satisfaction Evaluation Tool Results

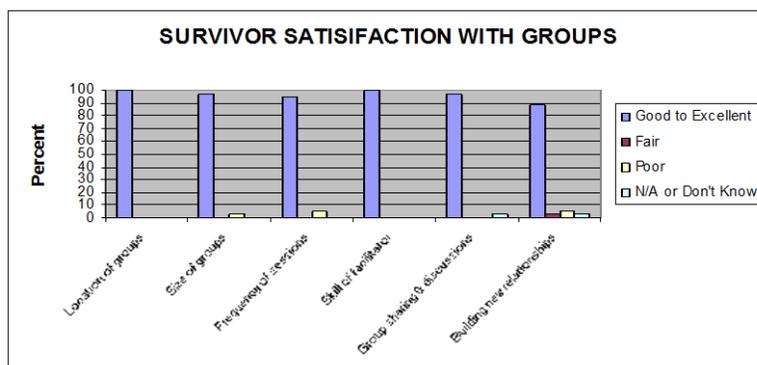


SOURCE: STROKE SERVICES EVALUATION TOOL

“The group is always useful and a good social gathering of like minds.” ~ Caregiver

“Very supportive and encouraging.” ~ Caregiver

Fig. 3 Survivor Satisfaction Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Love this group it always makes me feel great after I have attended.” ~ Survivor

“Our care group is very good and a comfort to be involved in.” ~ Caregiver



Figures 2 and 3 indicate a continued high level of satisfaction with groups for both stroke survivors and caregivers. The excellent ratings are consistent with previous reports and clearly demonstrate a very high confidence in the skills of the facilitators. The facilitator continues to play a key role:

- Liaising with health and social services partners to enhance referrals.
- Conducting intake assessments to ensure an effective transition into the appropriate group and to gain an understanding of the needs of each individual participant.
- Coordinating the groups including responding to education and information needs by arranging speakers with the relevant expertise.
- Ensuring that all voices are heard in the group setting and that there is a therapeutic balance between an acknowledgement of this significant life event and the fostering of hope.
- Providing system navigation support to make certain that survivors and caregivers are linked to community resources and managing referrals where appropriate.

As noted earlier, three additional questions have been included in the SSE tool. Respondents indicated 95% agreement when asked if they were satisfied with the individual information and/or the referral information that they received from the group facilitator. In response to the question, “Are you satisfied with the assistance you have received from organizations/individuals other than the stroke group facilitator?” 85% indicated that they were satisfied. When respondents were also asked to provide the name(s) or organization(s) that had provided the information, the following were cited (categories inserted for report purposes):

Support Group Facilitators

- [Facilitator] is very knowledgeable and helpful.
- [Facilitator] is very good X 2
- Was referred (by group facilitator) to an excellent physiotherapist.
- Without [facilitator] I wouldn't have gotten the connection or # for [local] Rehab , Mothers Assistance, CCAC, Pathways to Independence

Health System

- VON X 5
- RCBIS X 3
- CCAC X 3
- CCSH X 2
- Physiotherapy X 2, Speech X 1
- SMOL X 2
- Stroke Prevention Clinic X 2 [and stroke prevention nurse] in Belleville Hospital
- Physician X 2
- Day Hospital
- PSW



Support Group Members

- We learned a lot from each other and were a great support to each other
- Another group member
- Get lots of info from other stroke survivors

Additional Comments

"I find the CCAC often not helpful or they don't know where to find you help." ~ Caregiver

"Lack of coordination and info sharing between hospitals, and community service organizations." ~ Caregiver

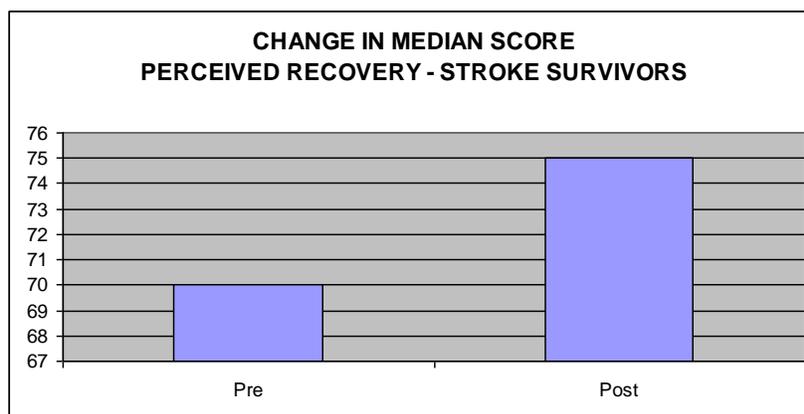
"I have been happy with the medical profession in general." ~ Survivor

"I found the group very helpful and the group leader outstanding in the sense she always had time for you and made you feel very welcome and was great at getting info regarding LTC homes." ~ Caregiver

These survey responses continue to highlight a rather fragmented and random navigation system (consistent with results from the April 2015 survey) as well as confirming the benefit of having the facilitators fulfill a knowledgeable and consistent access point for system navigation that is responsive to the needs of each individual.

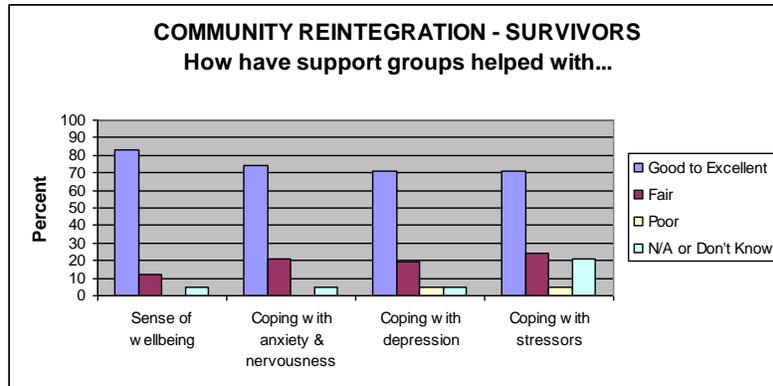
PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – STROKE SURVIVORS

Survivor Perceived Recovery Score



The Perceived Recovery Score asks stroke survivors to provide an overall perception of their recovery using a scale of 0 to 100 with 0 indicating no recovery and 100 indicating full recovery. Twelve stroke survivors were surveyed; pre score data obtained from 2015 collection. Results indicated an increase in the median score as compared to last reporting period.

Fig. 4 Survivor Well-Being Evaluation Tool Results



Source: Stroke Services Evaluation Tool

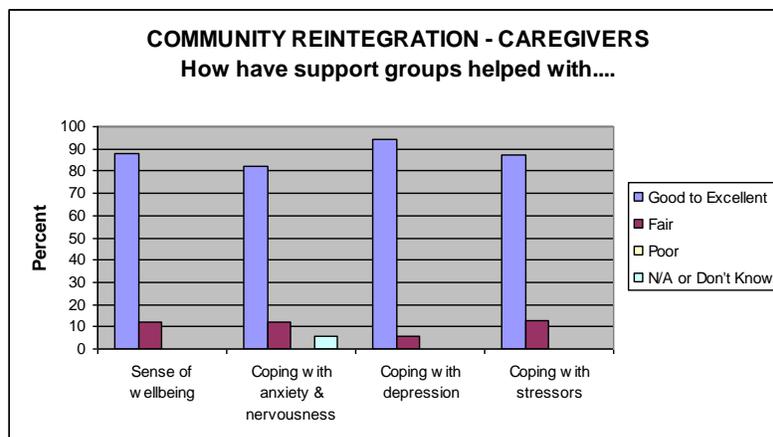
“It has helped me a great deal. It has helped with my recovery.” ~ Survivor

“Cared for my husband who is suffering from Alzheimer's disease, at home until my first stroke in Feb. 2013. He is now a resident of a long term care facility and is in the later stages of the disease. My stress level is pretty high!!” ~ Survivor

- The majority of stroke survivors saw the group as “good to excellent” in contributing to a sense of well-being as well as helping them cope with anxiety/nervousness, depression and stressors.
- Having an opportunity to share feelings, experiences and successes in a ‘safe’ venue supports emotional well-being and personal capacity to cope.
- Peers are often significant sources of support and experiential advice; they are also walking that recovery journey.

PARTICIPANTS WHO HAVE SEEN IMPROVED HEALTH – CAREGIVERS

Fig. 5 Caregiver Well-Being Evaluation Tool Results



SOURCE: STROKE SERVICES EVALUATION TOOL

“Look forward to these meetings, and I find them very helpful.” ~ Caregiver

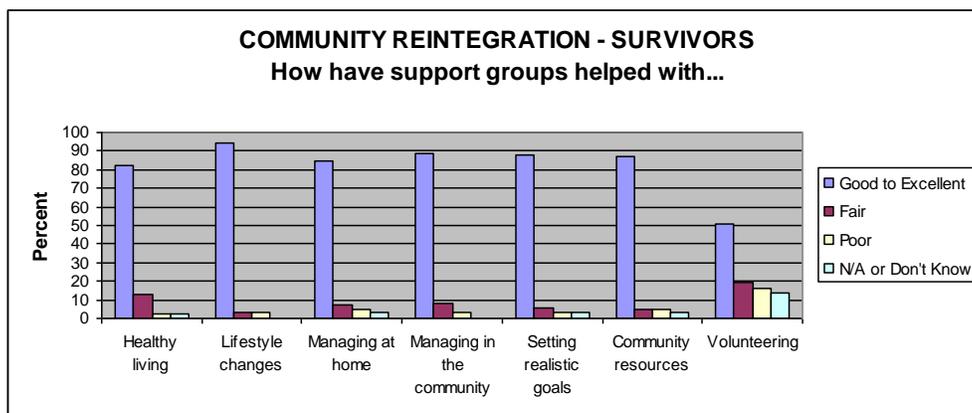
“It is very hard on the partners to remember we've had a stroke and that it has changed us. They get very frustrated with us from time to time and if they understood more about us it may stop some arguments or fights at home. I know myself if my husband yells at me I get worse and I can't even think; let alone answer questions.” ~Survivor

“Many services are offered and are there for the taking. Encouragement for and access to these is generously offered. Personally, I have received and continue to, all the help I have needed.” ~ Caregiver

There is a significant 24/7 burden of care placed on informal caregivers (most typically a spouse). Often, the role of caregiving is new to the individual and the stroke event has impacted on their other life roles as well (e.g., volunteering, career, social & recreational activities). As well, future plans must be altered, financial status re-evaluated, modifications made to the home environment and a myriad of other adjustments. All of this often takes a toll on the caregiver’s own health. Attending a support group provides an opportunity to share challenges and successes and can also lead to new relationships and less social isolation.

PARTICIPANTS ABLE TO TRANSITION BACK TO COMMUNITY SETTING

Fig 6 Survivor Community Re-Integration Evaluation Tool Results



Source: Stroke Services Evaluation Tool

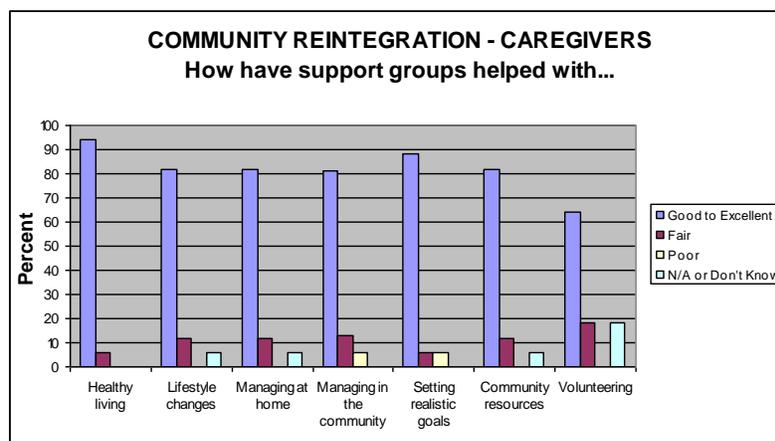
“Am grateful to have this support system since I am living alone and my family is far away!” ~ Survivor

“I really enjoy this group through the years. We always have a laugh or share a tear & best of all there is always something to learn.” ~ Survivor

HOSPITAL ADMISSIONS

- During this reporting period, two of the 45 caregivers attending support groups reported an admission to hospital (fall, dehydration)
- Four stroke survivors of the 78 attending the support groups reported hospital admissions during the evaluation period (bypass surgery, chest pain and shortness of breath, kidney failure; dehydration & electrolyte imbalance; increased creatinine blood level; kidney function)

Fig. 7 Caregiver Community Re-Engagement Evaluation Tool Results



Source: Stroke Services Evaluation Tool

“Our facilitator is a very enthusiastic leader.” ~ Caregiver

Caregivers continue to view the support groups as helpful to daily living across many domains and the positive contributions that support groups make to the health status of the caregivers will, in turn, improve the health of the stroke survivors for whom they care.

With respect to the low scores for volunteering, it is evident that the care burden held by the family members of stroke can leave little time for volunteering. Having said that, it is interesting to note that one respondent saw volunteering as an opportunity to publicize the support groups.

EVALUATION SUMMARY

- Sense of well-being supported by participation in the groups rated as good to excellent for the majority of both caregivers and stroke survivors
- Individual abilities to cope with anxiety, nervousness and depression were rated as good to excellent for the majority of both caregivers and stroke survivors
- Consistent positive feedback on the skills of the facilitators and the valuable role they play for successful and therapeutic groups as well as system navigation

RECOMMENDATIONS FOR CONTINUED SUCCESS

The recent community consultation, [What We Heard: Charting A Course For Successful Community Reintegration After Stroke](#) facilitated by the Stroke Network of Southeastern Ontario confirmed the significant benefit of the support group model as voiced by stroke survivors and caregivers who participated in the process. Of the five themes that emerged from the consultation process, support groups were cited as enablers to meeting the identified criteria for four of them:

- *Person-Centred Skilled Stroke Care & Rehabilitation*
- *Individual Well-Being & Meaningful Engagement*
- *Community Co-Navigation*
- *Access to Supports & Services*

It should also be noted that the community support service agencies hosting the support groups also contribute to the fifth theme, *Supported Mobility in the Community* by assisting with transportation to support groups as able.

As well, recent documents such as *Patients First* and the SE LHIN IHSP4 focus on equitable access, system integration and partnerships all of which are reflected in the structure and processes of the facilitated support groups. At the same time, best practice documents such as *Quality Based Procedures for Stroke (Acute and Post Acute)* and the *Canadian Stroke Best Practice Recommendations* specifically speak to support groups as a best practice. In light of these publications and the evaluation findings within this report, the following recommendations are put forward. Consideration for:

- future expanded base funding to support the growth of existing groups while ensuring that group size remains within recommended therapeutic numbers. Given the complexity of stroke and associated multifactorial impacts, the recommendation for the southeast support groups would be 15. Many resources cite smaller numbers. For example, in *Discovery Circles, The National Stroke Association's Guide to Organizing and Facilitating Stroke Support Groups*, it is suggested that 6 to 10 people is the most effective. (National Stroke Association, 1997).
- additional funding to support co-facilitation by a Speech Language Pathologist to sustain the Aphasia Support Group initiated in Belleville and to expand this model to other areas in the southeast given that the evaluation results demonstrate the benefits of this model and the participant numbers demonstrate the need. This model could include an outreach OTN component for rural areas.
- additional funding to support the coordination/facilitation necessary to sustain and expand the OTN outreach initiative piloted in Belleville. This would enable the participation of stroke survivors and caregivers residing in rural/remote areas where distance and/or cost of transportation are significant barriers to support group participation. Requests for this service have already been received from Bancroft, Picton, Napanee, and Sharbot Lake.
- additional funding to arrange and provide a respite component to operate in conjunction with the caregiver support group in each area in order to facilitate participation of caregivers who are unable to leave their loved one home unattended.