



STROKE RECOVERY ASSOCIATION
OF BRITISH COLUMBIA

**COMMUNITY STROKE RECOVERY
NAVIGATOR PROGRAM
PILOT PROJECT**

FINAL REPORT

September 2014

1 CONTENTS

2	Executive Summary	3
3	Introduction	5
3.1	Background	5
3.2	Gaps in Transition - Literature Review.....	7
3.3	Program Development & Implementation	8
3.3.1	Program Development.....	8
3.3.2	Description of Program Implementation	8
3.3.3	Referral Criteria	10
3.3.4	Description of Services.....	10
3.4	Program Goals and Objectives	10
3.5	Evaluation Development	11
3.5.1	Data Collection	11
4	Findings	13
4.1	Services to intended population.....	13
4.1.1	Referrals and their sources.....	13
4.1.2	Enrollment and Completion	14
4.1.3	Initial Contact Response Time	14
4.1.4	CSRN Eligibility Criteria.....	14
4.1.5	Participant Demographics.....	14
4.1.6	Difficulties Post-Stroke	17
4.1.7	Community Services.....	17
4.1.8	Key Points: Did Services Reach Intended Audience?.....	18
4.2	CSRN Service Provision & Utilization	19
4.2.1	Service Utilization.....	19
4.2.2	CSRN Coordinator Time Allocation by Activity	21
4.2.3	CASE VIGNETTE.....	23
4.2.4	Key Points: CSRN Service Utilization and Provision.....	24
4.3	Cost of Services	24
4.3.1	Key Points: Cost of Services	25
4.4	Project Deliverables Performance	26

4.4.1	Project Issues	31
4.5	Client Satisfaction.....	32
4.5.1	Key Points: Client Satisfaction	34
5	Recommendations	35
6	Appendices	37
	Appendix A: Community Stroke Recovery Navigator Program Coordinator Service Activities	37
	Appendix B: Referral Form	38
	Appendix C: Intake Questionnaire.....	39
	Appendix D: Client Activity Log – Sample	45
	Appendix E: Service-Action Plan - Sample	46
	Appendix F: Caregiver Questionnaire.....	48
7	References	49

2 EXECUTIVE SUMMARY

Community re-integration is the least well-developed and funded aspect of stroke recovery. Providers and health care users frequently report that once a stroke survivor is discharge from hospital, the “umbilical cord” of support is cut. Stroke survivors and caregivers end up back home with no plan, no resources and no ongoing treatment for recovery.

Stroke survivors and caregivers find themselves at the kitchen table with a packet of information, feeling overwhelmed and wondering, “Now what?”

The Community Stroke Recovery Navigator (CSRN) Pilot Program successfully brought together Island Health, local hospitals, community organizations and the Stroke Recovery Association BC to support stroke survivors and family caregivers through the transition from hospital to living in the community.

The CSRN program is a step in the right direction in supporting stroke survivors and caregivers to address the long term recovery and reintegration needs of stroke survivors as they transition from hospital to living back at home in the community. The program laid the foundation by:

1. Linking stroke survivors and caregivers with community resources using a brokerage case management model with co-created goals and service plans.
2. Helping clients/caregivers enter and navigate community services and enable them to continue on their journey to recovery.
3. Monitoring the implementation of co-created client goals and service plans.
4. Creating a community directory for stroke survivors, families, caregivers and health professionals.
5. Building partnerships and linkages amongst community service organizations and providers.
6. Delivering stroke recovery education to stroke survivors and caregivers living in the community.

The CSRN program received 102 referrals from hospitals, physicians and the community from Duncan to Campbell River on Vancouver Island between July 2013 and July 2014.

Key Findings

- Enrollment rate into the program was 80% and completion rate was 100%.
- 54% of referrals were community and self-referrals. The remaining 46% of referrals were through hospital and physicians.
- The average initial contact response time was 30 days.
- Participants using the CSRN program varied both in their demographic characteristics and needs, showing that navigation support is a promising strategy to ensure that clients can access the right type of resources, information and support at the right time in their recovery.
- All 82 participants received an assessment and information and referral services. 75% of participants received written service-action plans and 61% attended education sessions. Almost 15% of participants utilized case management services. On average clients used 3.51 of services offered.

“...the health care system didn’t fully understand what recovery meant for us once we got home... most health providers don’t understand that ‘recovery’ really begins once you leave the hospital”.

~ Stroke survivor, SRABC “Bridging the Gap” Project Final Report

- Just over half of participants are satisfied with their current level of assistance, suggesting a large gap in appropriate community-based services and resources to support ongoing long term recovery.
- Stroke survivors return home faced with many difficulties; many of which aren't supported or are severely limited through home and community services such as: ongoing physiotherapy to improve mobility and hand/arm function, speech therapy to assist with language and communication, cognitive rehabilitation to address memory issues and activities of daily living such as transportation, household management and preparing meals.

Recommendations

- CSRN program findings are promising and show a need for long term support for stroke survivors and caregivers that accounts for the individual's specific needs, based on a case management and community development model. Evidence for the effectiveness of community-based programs designed to meet the long-term recovery and community reintegration needs of individuals with stroke is lacking.
- We need the opportunity to build on the seminal work of the CSRN program by conducting properly researched and resourced evaluations on the impact of navigation services post-stroke including:
 - Population health using Health Outcomes and Patient Self-efficacy and Knowledge
 - Experience of Care using client satisfaction indicators and timeliness of service delivery
 - Per Capita Cost using utilization indicators such as Hospital re-admissions rate; Physician or clinic visits and Early Supported Discharge rates
- SRABC needs to find a way of continuing and building upon the groundbreaking work of this pilot project by seeking funds to deliver further navigation and stroke recovery education to the defined target audience.
- The CSRN program findings and recommendations align with SRABC's current Strategic Plan and with the work currently being done by SRABC's Professional Advisory Committee, which is examining the question of how SRABC can best develop programs and services to better support the needs of a wider range of stroke survivors and caregivers.
- The recommendations of this report are being amalgamated with goals for Primary Care Engagement and core principles from the Triple Aim Approach to create a strategy for Program and Service Delivery.
- There is a strong willingness and support with Island Health, Vancouver Island University and community health and social services to partner with SRABC to continue researching and delivering navigation and stroke recovery education programs. Currently, a working partnership with Nanaimo Brain Injury Society and March of Dimes Canada is creating a sustainability plan for continuing to offer key components of the CSRN program in Nanaimo, Parksville and Duncan.

“A lot of time, money and resources can be spent on saving people after a stroke but often very little is focused on bringing them back to life in the community. This work has been left to small under-funded and under-resourced stroke recovery, head injury, and brain injury support groups, which rely heavily on donated funds and volunteer power.”

~ Tim Readman, Executive Director, SRABC

3 INTRODUCTION

3.1 BACKGROUND

The BC Stroke Strategy Service Delivery Framework clearly identifies living back in the community as the desired end point of stroke treatment. It states that “successful reintegration is central to the stroke survivor’s health and social well-being, and strongly contributes to reduction in risk of recurrent stroke”.

Recent BC Stroke Strategy-funded prototype research projects, including the GF Strong Rehabilitation Centre’s ‘Connecting the Dots...A Provincial Stroke Education Toolbox’ project, Fraser Health Authority STart Program in Abbotsford and the SRABC/UBC joint research project “A model for community stroke recovery programs” - an evaluation of the North Shore Stroke Recovery Centre - all show a need for more services to bridge the gap from hospital to home including:

- On-going stroke recovery education.
- Expanding communication pathways between hospital staff, service providers and physicians to strengthen referrals to community resources and linkage programs for stroke survivors and caregivers.
- Provision of follow up with stroke survivors and family caregivers post-discharge to assist in linking them to community resources and in their navigation of health care services.

As part of BC Stroke Services continued collaboration with health authorities and non-profit organizations on improving stroke care, the Provincial Health Services Authority (PHSA) provided SRABC with funding to support the provision of a pilot Community Stroke Recovery Navigator (CSRN) for stroke survivors and family caregivers living on Vancouver Island in March 2013.

The goal of the project was to pilot an approach to delivering the CSRN service to stroke survivors and caregivers from Duncan to Campbell River on Vancouver Island (see map insert next page).

The project included:

- Development and implementation of the CSRN Pilot Program
- Monitoring and managing the program throughout the pilot phase
- Planning and conducting a formative evaluation of the program
- Outlining a framework for sustainability
- Final report outlining the evaluation findings

System navigation, education and case management for stroke survivors and caregivers is limited within Island Health (formerly Vancouver Island Health Authority), which provides health care to more than 765,000 people on Vancouver Island, the islands of the Georgia Strait, and in the mainland communities north of Powell River and south of Rivers Inlet.

Nanaimo General Regional Hospital (NGRH) provides a 3 month follow up post-discharge from its Intensive Outreach Rehabilitation Program and the North Island Stroke Clinic also provides follow up for stroke survivors and family caregivers.

However, such follow up is limited to immediate post-discharge issues. There is some capacity for Home and Community Care to provide case management services for stroke survivors with a higher level of needs; however, it doesn't address long term stroke recovery, self-management or education and is typically restricted to personal care and respite for caregivers. Stroke survivors with mild and moderate symptoms and their family caregivers, however, are typically not eligible for case management services and are often not linked to community and educational resources.

Using a brokerage model¹, the CSRN focused on supporting stroke survivors and caregivers to address the long term recovery and reintegration needs of stroke survivors as they transitioned from hospital to living back at home in the community. Where possible the model incorporated, the best practice standards for community reintegration, as listed in Canadian Best Practices, Section 6.5

Patients and families should be provided with information, support and access to services throughout transitions to the community following a stroke to optimize the return to life roles and activities [Evidence Level B].²

The CSRN Pilot Program brought together Island Health, local hospitals, community organizations and the Stroke Recovery Association BC to create linkages within targeted communities for stroke survivors and family caregivers. The Community Stroke Recovery Navigator coordination role, together with communication and partnering between participating



¹ A case management approach focusing on assessing needs, referring to services, and coordinating and monitoring on-going treatment. The case manager serves as coordinator of services, which are provided by a variety of agencies and professionals.

² Canadian Stroke Best Practices. Community Reintegration. 4th Edition. October 29, 2013. Retrieved from <http://www.strokebestpractices.ca/index.php/transitions/community-reintegration-following-stroke/>

agencies, were designed to pilot an approach to supporting stroke survivors and family caregivers through the transition from hospital/rehabilitation to living in the community.

3.2 GAPS IN TRANSITION - LITERATURE REVIEW

In the past decade, stroke care primarily focused on timely access to acute health care and the inter-professional stroke team. While decreasing the negative outcome of stroke is critical to public health and the families impacted by it, little research is available on “life after stroke”, when stroke survivors and caregivers are discharged from hospital. Cloutier-Fisher (2005) state the importance of having a variety of appropriate home care and community-based services for stroke survivors and their families to promote positive on-going rehabilitation outcomes, enhance quality of life and decrease isolation.

The transition from specialized medically based stroke services (i.e., inpatient rehabilitation) to the community where the survivor lives, works, and socializes marks the true beginning of life after stroke for both the care recipient and caregiver. However, the transition process for stroke survivors and their caregivers back into their respective communities is informal with no established and proven pathways. There appears to be a lack of continuity of care from hospital to home leaving family caregivers and stroke survivors with very little formal support or preparation for long term recovery (Newell et al, 2009; Camergon and Gignac, 2007; Mayo et al, 2007).

Research across Canada demonstrates stroke survivors and their families often have difficulty transitioning back into the community. The research shows that the majority of stroke survivors and caregivers felt the hospital discharge process was inadequate and sent them home unprepared (Smith, Forster & Young, 2009). It has been noted that admission to hospital is highly formalized and closely documented whereas very little of this structure and process exists for discharge. This can result in stroke survivors re-entering the community with no support systems in place, which often leads to increased caregivers stress and burden and a decrease in stroke survivor independence (Newell et al, 2009; Cameron and Gignac, 2007; Mayo et al, 2008).

Stroke survivors, family caregivers and clinicians in Canada have indicated that a major gap exists between discharging patients and successfully supporting both stroke survivors and caregivers in the community (Canadian Stroke Strategy, 2010). Merry-Lambert and Nichol (2008) show how the current public system has several barriers to community reintegration including:

- Inpatient rehabilitation focuses on discharge planning.
- Limited community rehabilitation services and restrictions on scope of services
- Variable access to services.
- Inadequate follow-up to respond to the evolving needs of the client.
- Inadequate documentation of client goals, interventions and outcomes to support need for enhanced community services.

Approximately 80% of people who survive a stroke return home to their community, and at least 50% require some kind of help from other people at home (Opara and Jaracz, 2010). Additionally, stroke survivors often have significant or subtle cognition, memory or

communicative challenges. When looking at interventions to ensure a successful return to home and community, a stroke survivor's level of family support and the availability of support for the family must also be taken into account. Physical recovery is still often used as the main criteria for discharge while communication ability and cognitive and emotional functioning are often forgotten. Since social and learning skills are dependent on cognition and receptive and expressive language, this can be disastrous for stroke survivors and their loved ones.

One in eight caregivers assist loved ones recovering from stroke with case management functions such as health care system navigation (Opara and Jaracz, 2010). In many cases, caregivers take on the role of locating the specific service or organization that offers a particular program, determine eligibility which involves understanding how the health care system works, and provide a strong case showing why their loved one is eligible for services (Egan, Anderson and McTaggart, 2010). Very few families learned about stroke specific services at hospital discharge, from their family physician or from other health care providers. Bhogal et al (2003) found that failure to access adequate support in the community could potentially negate the best efforts and results of stroke rehabilitation and ongoing recovery. In other words, a lot of time, money and resources can be spent on saving people after a stroke but often very little is focused on bringing them back to life in the community. This work has been left to small under-funded and under-resourced stroke recovery, head injury, and brain injury support groups, which rely heavily on donated funds and volunteer power.

Based on the literature review and information provided by local stakeholders, the CSRN was designed to address some of the transitional gaps that stroke survivors and caregivers face when returning to live in the community. The CSRN Pilot Program primarily focused on:

1. Linking stroke survivors and caregivers with community resources using a brokerage case management model with co-created goals and service plans.
2. Providing educational sessions on long-term stroke recovery and system navigation.

3.3 PROGRAM DEVELOPMENT & IMPLEMENTATION

The pilot was delivered from March 2013 through July 31, 2014. There were two phases to the pilot program – development of the program and implementation of the program.

3.3.1 Program Development

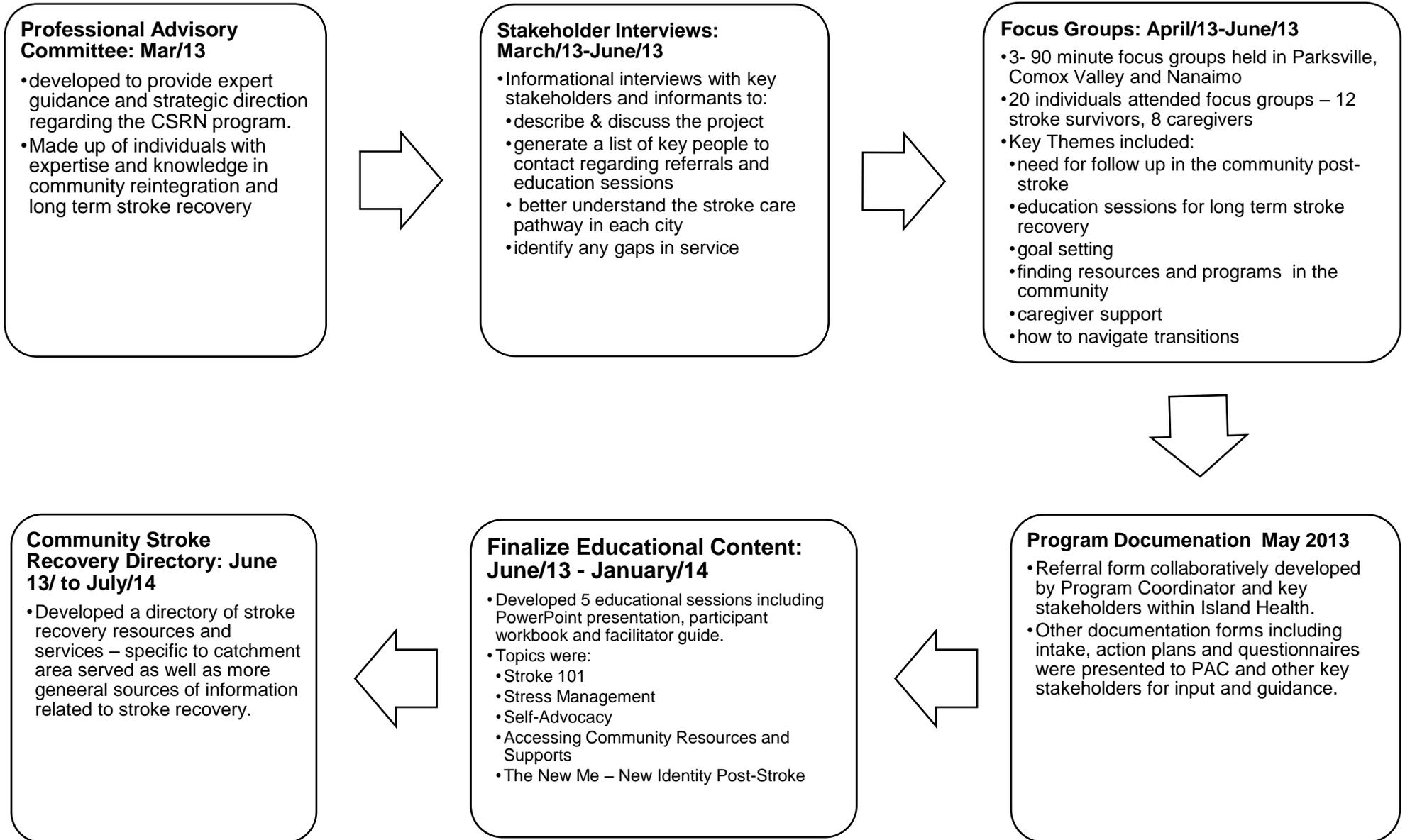
Development of the program occurred from March 1, 2013 to June 30, 2013. Table 1 shows the key activities during program development.

Information on program deliverables from key activities is found under Program Development Deliverables in the Findings section of the report.

3.3.2 Description of Program Implementation

Referrals and client intake began July 1, 2013 and continued until July 31, 2014. The pilot's catchment area included the main north to south corridor from Duncan to Campbell River (excluding the Gulf Islands and Port Alberni). The Program Coordinator worked remotely from a home office in Comox.

Table 1: Program Development Timelines and Activities



3.3.3 Referral Criteria

The referral criteria included:

- A confirmed diagnosis of stroke, ischemic or hemorrhagic.
- Living in the community prior to having a stroke.
- Have a caregiver available and interested.
- Be a resident in the pilot communities.

A simple Referral Form made referrals quick and easy. Stroke survivor consent was required on the form. Referrals were faxed, emailed or telephone in directly to the Program Coordinator and clients were contacted within 6 weeks of referral into the program.

3.3.4 Description of Services

System navigation support is a strategy to ensure that patients or clients can access the “right person, right treatment, right time in the right setting” (Cameron and Gignac, 2007). Interventions to increase stroke survivors and caregivers’ knowledge about community services and how to access them can increase their sense of competence and reduce depression (Reinhard, Given, Nirvana and Bemis, 2008).

For stroke survivors and family caregivers transitioning from hospital to home, “More case management programs may be useful to help ease this transition, promote safe and effective hospital discharges, and support caregivers in their ongoing, post-hospital care” (Reinhard, Given, Nirvana and Bemis, 2008; p.1-353).

The CSRN was based on a brokerage case management model as described in the literature (Egan, Anderson & McTaggart, 2010; 2010; Lutz & Young 2010; Cameron & Gignac, 2007; Bhogal et al, 2003) and included the following services

1. Client assessment and service-action plan.
2. Follow up phone support/availability.
3. Liaison with community services.
4. Client and caregiver education on self-management.
5. Collaboration and linkages with other community and health care providers.

Details of service activities performed by the CSRN Program Coordinator are listed in Appendix A.

3.4 PROGRAM GOALS AND OBJECTIVES

The **goal of the program** was to pilot an approach to provide a post-hospital, community-based stroke recovery navigation service, to support stroke survivor re-integration into community life.

The **specific project objectives** are as follows:

1. Link stroke survivors and caregivers with community resources using a brokerage case management model with co-created goals and service plans.
2. Help clients/caregivers enter and navigate community services and enable them to continue on their journey to recovery.
3. Monitor the implementation of co-created client goals and service plans.

4. Create and distribute a stroke recovery directory for stroke survivors, families, caregivers and health professionals.
5. Build partnerships and linkages amongst community service organizations and providers.
6. Deliver stroke recovery education to stroke survivors and caregivers living in the community.

3.5 EVALUATION DEVELOPMENT

Given the early stage of development and the innovative nature of the Community Stroke Navigator Program, we applied a formative evaluation approach. Typically, formative evaluations are completed on a program before assessing the impact of a program. This evaluation sought to:

- Examine quantity of services utilized.
- Conduct a basic program cost analysis.
- Gather information/data on participant demographics.
- Assess the quality of service provided by participants' personal reaction to the CSRN services.
- Gather information on successes and problems with project delivery.
- Provide recommendations for sustainability including modification, continuation, or expansion of the CSRN's activities.

Evaluation questions included:

1. Did the CSRN program reach its intended audience?
2. What services were delivered to clients?
3. What is the average cost per participant?
4. Were the goals and objectives of the project achieved?
5. Were clients satisfied with services?

3.5.1 Data Collection

Data collection focused on gathering information on participants, overall participant satisfaction, program costs, service utilization and program deliverables. Table 2 provides a summary of the tools and procedures used with the evaluation questions. Appendices B through E include the following:

- Referral form (Appendix B)
- Intake questionnaire (Appendix C)
- Client contact /activity log (Appendix D)
- Service-care plan (Appendix E)
- Caregiver profile (Appendix F)

Table 2: CSRN Program Evaluation Plan

Evaluation Questions	Tools	Procedures
Did the CSRN program reach its intended population?	<ul style="list-style-type: none"> • Referral Form • Intake Questionnaire • Client Contact Form 	<ul style="list-style-type: none"> • Review of data collected on participants
What services were offered to clients?	<ul style="list-style-type: none"> • Client Contact Form • Service-Action plans • Case Management Activities 	<ul style="list-style-type: none"> • Focus Group with stroke survivors and family caregivers • Review of Client Contact Form • Review of Service-Action Plans • Recording of Program Coordinator's case management activities
What is the average cost per participant	<ul style="list-style-type: none"> • Program Budget Tracking 	<ul style="list-style-type: none"> • Review of Program Costs and Service Utilization
Were the goals and objectives of the project achieved	<ul style="list-style-type: none"> • Program Deliverables 	<ul style="list-style-type: none"> • Review of timelines, deliverables, successes and challenges of program delivery
Service satisfaction	<ul style="list-style-type: none"> • Client satisfaction survey 	<ul style="list-style-type: none"> • Review of surveys

4 FINDINGS

Findings of the CSRN Program are broken into sections according to evaluation questions.

4.1 SERVICES TO INTENDED POPULATION

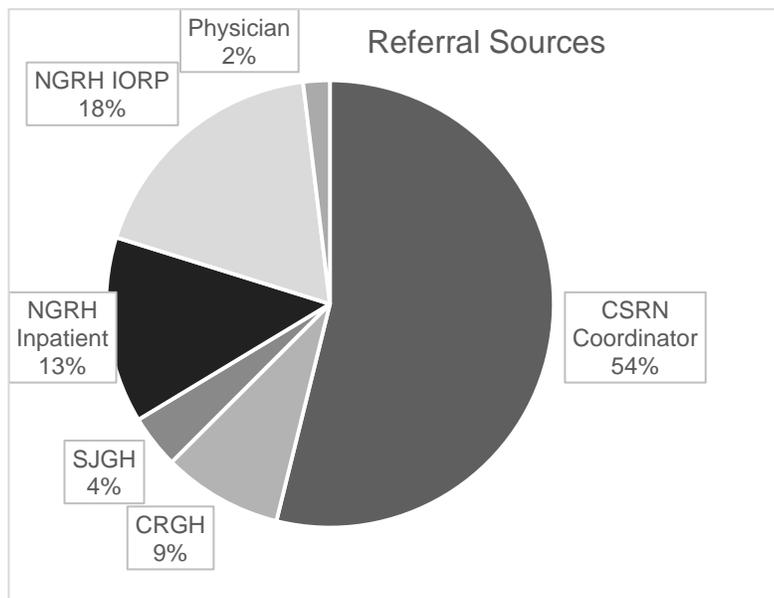
To answer the first evaluation question, a review of number of referrals, source of referrals and enrollment rate helped to show how participants heard of the program, how long it took for initial contact and who enrolled and completed the project. Additionally, a summary of participant characteristics helped to determine who the CSRN program serviced.

4.1.1 Referrals and their sources

There were 102 referrals into the CSRN program between June 2013 and July 2014. During the development phase of the project, we projected receiving 60% of referrals through hospitals and physicians with the remaining 40% through community avenues including education sessions, press releases and the CSRN Coordinator.

Figure 1 shows the source of referrals; 54% of referrals came through the CSRN Coordinator³. The remaining 46% of referrals were through hospital and physicians. Nanaimo General Regional Hospital (NGRH) provided the greatest percentage of referrals (31%); followed by Campbell River General Hospital (CRGH) at 9% and St. Joseph's General Hospital (SJGH) with 4%, respectively. Physicians provided 2% of referrals to the project.

Figure 1: Source of Referrals



³ This included recruitment through media releases, education sessions, SRABC Branches and word of mouth.

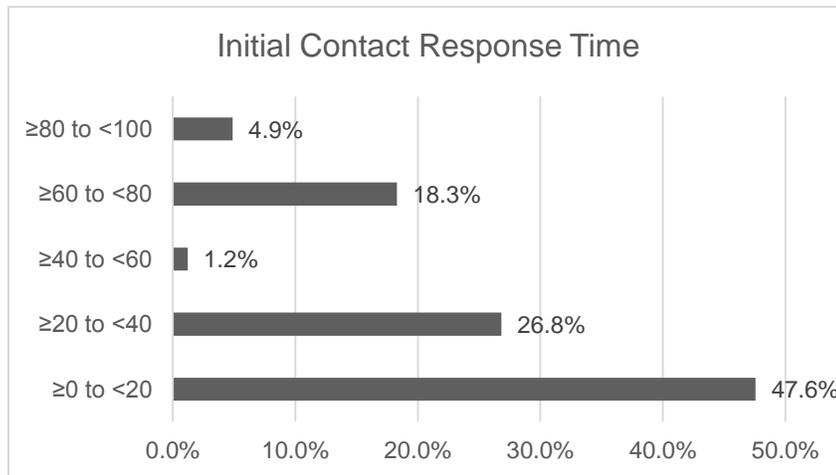
4.1.2 Enrollment and Completion

There was an 80% enrollment rate and a 100% completion rate. In other words, of the 102 referrals received, 82 participants enrolled in the CSRN and 82 assessments were completed. The criterion for completion rate was based on one assessment completed with the participant.

4.1.3 Initial Contact Response Time

The average initial contact response time was 30 days. Almost 75% of all participants were initially contacted within 6 weeks. Figure 2 shows initial contact response time by number of days. One of the objectives stated in the referral process was that participants would be contacted within two to 6 weeks.

Figure 2: Initial Contact Response Time



4.1.4 CSRN Eligibility Criteria

89% of all participants met the eligibility criteria. 11% of participants did not have a caregiver available; however, assessments were still completed with those participants. In other words, all participants who wanted to take part in the CSRN were serviced.

4.1.5 Participant Demographics

The demographic section of the intake questionnaire was directed at collecting information about the stroke survivor and is summarized in Table 3. Some key points:

- The average age of participants in CSRN was 70.4 years old.
- Although 58% of participants were over 70 years old; 22% were under the age of 60 years old.
- The majority of participants were female (56.7%).
- The majority of participants had their stroke less than year ago (56.7%).
- Almost 90% of participants were admitted to hospital.
- Over a third (34.3%) of participants were unsure what type of stroke they had; 38.8% had an ischemic stroke while 26.9% had a hemorrhagic stroke.
- Almost 27% of participants had a previous stroke.
- Over 28% of participants were living by themselves in the community.
- Almost 20% of participants were living in a supported environment such as Assisted Living.

Table 3: Summary of Participant Demographics

Age	n=67	%
Under 60 yrs	15	22.4%
61 to 70 yrs	13	19.4%
71 years to 80 yrs	21	31.3%
Over 80 yrs	18	26.9%
Gender	n=67	%
Male	29	43.3%
Female	38	56.7%
Date of Stroke	n=67	%
< 1 year	38	56.7%
1-2 years	22	32.8%
> 2 years	7	10.5%
Admitted to hospital	n=67	%
Yes	60	89.6%
No	7	10.4%
Type of Stroke	n=67	%
Ischemic	26	38.8%
Hemmoraghic	18	26.9%
Not known	23	34.3%
Previous Stroke	n=67	%
Yes	18	26.9%
No	49	73.1%
Housing Type	n=67	%
House	37	55.2%
Apartment	11	16.4%
Mobile Home	6	9.0%
Assisted Living	13	19.4%
Living Arrangements	n=67	%
Spouse	44	65.7%
Children	1	1.5%
Other family	3	4.5%
Alone	19	28.4%
City	n=67	%
Comox Valley	17	25.4%
Campbell River	4	6.0%
Parksville/Qualicum	13	19.4%
Nanaimo	23	34.3%
Duncan	10	14.9%

A summary of caregiver demographics is found in Table 4. Some key points:

- Almost 25% of caregivers were over 80 years and almost 30% were under 60 years.
- While the majority of caregivers were spouses (61%); over 25% were adult children.
- Close to 30% of caregivers were not living with the stroke survivor.
- Almost 30% of caregivers indicated they were providing over 100 hours of care per week. Care was defined as any form of assistance for recipient, i.e., care management/coordination, personal care, activities of daily living, emotional support, etc.
- While the majority of caregivers were retired or not working (73%); 27% were working full time or part time.

Table 4: Caregiving Demographics

Age	n=41	%
<50 yrs	7	17.1%
51 to 59 yrs	5	12.2%
60 to 69 yrs	6	14.6%
70 to 79 yrs	13	31.7%
80 yrs +	10	24.4%
Type of Caregiver	n=41	%
Spouse	25	61.0%
Adult Child	11	26.8%
Other relative	5	12.2%
Living with Care Recipient	n=41	%
Yes	29	70.7%
No	12	29.3%
Length Caregiving	n=41	%
Less than a yr	23	56.1%
1 to 2 yrs	13	31.7%
Over 2 yrs	5	12.2%
Caregiving Hours per week	n=41	%
10 hrs or less	9	22.0%
11 to 50 hrs	15	36.6%
51 to 99 hrs	5	12.2%
100 + hrs	12	29.3%
Employment Status	n=41	%
Full Time	9	22.0%
Part time	2	4.9%
Not employed	5	12.2%
Retired	25	61.0%

4.1.6 Difficulties Post-Stroke

During the assessment, stroke survivors were asked to answer “yes” or “no” to “What areas are you having difficulty with?” Figure 3 shows which areas participants had difficulty with post-stroke. Responses show that participants have difficulty in many different areas post-stroke. By far the most prevalent difficult is fatigue (94.9%) followed by mobility (66.7%). Arm and hand function and memory were also frequently reported (61.5). Activities required to remain independent such as household duties and preparing meals were a challenge for several participants.

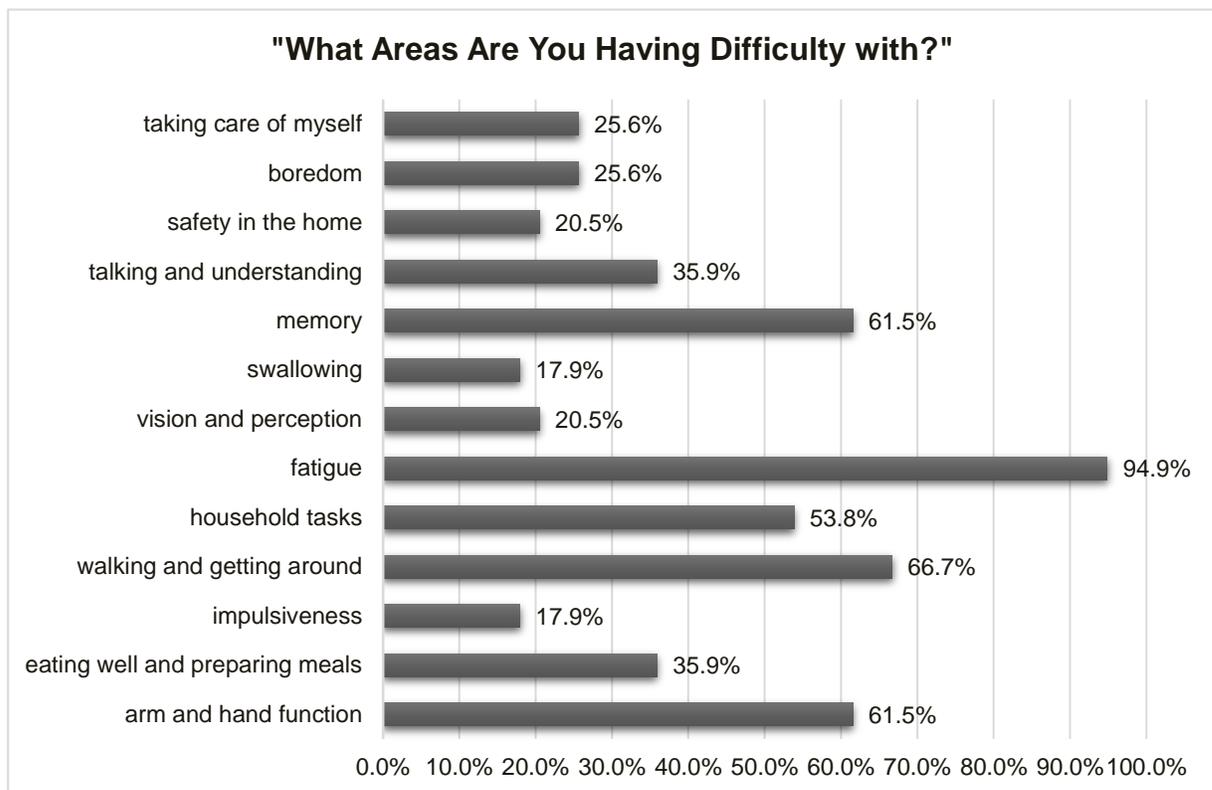


Figure 3: Areas Participants Had Difficulty with Post-Stroke

4.1.7 Community Services

Participants were asked about which community services they were receiving, either through the public or private sector. Figure 4 shows community services received at the time of the assessment. Just over half (53%) of participants were satisfied with the help they were receiving. Services being received were physiotherapy (28%) and speech therapy (23%), which were through private sources or stroke recovery branches. A little over 16% of participants were accessing outpatient rehabilitation services.

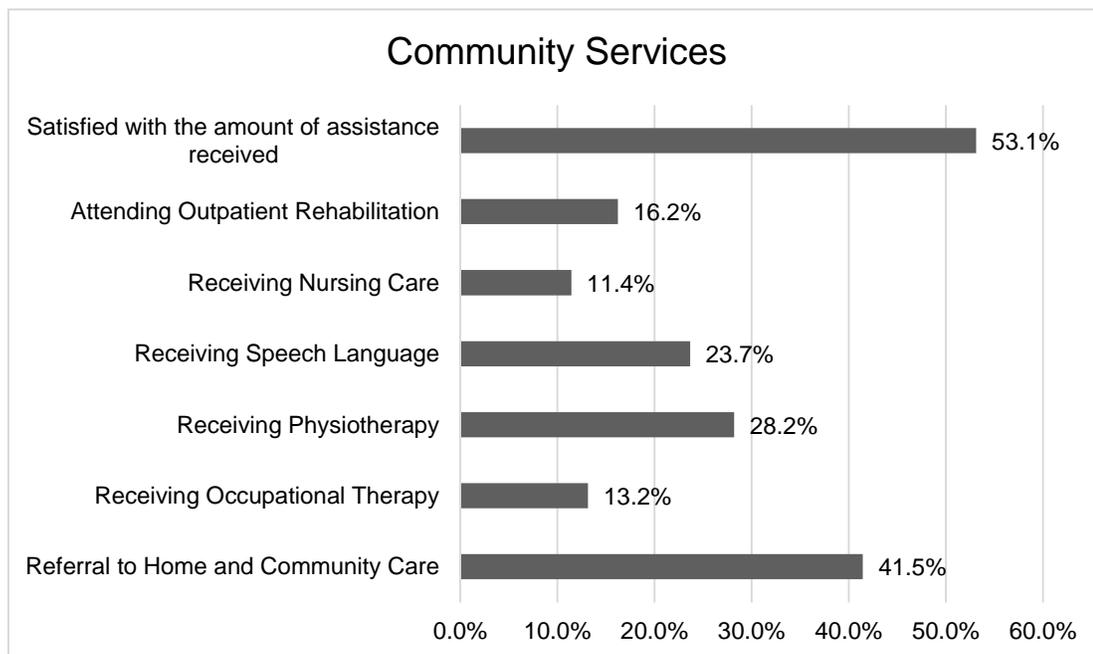


Figure 4: Community Services Accessed

4.1.8 Key Points: Did Services Reach Intended Audience?

Referral and Sources

- Primary care engagement through physicians proved very difficult. A poster and referral form was faxed to over 100 physicians in the project catchment area.
- Although appreciative of all the connections we made during the project, staff from NGRH made the most of the referral program.
- With no hospital in Parksville/Qualicum area, there was difficulty establishing a key contact for referrals. A connection with the Integrated Health Centre was made; however, it was difficult to establish a line of referrals with the “right person”.
- Press releases and offering education sessions were a very successful avenue in reaching participants from the community.
- Referrals from hospitals and physicians into the program appeared very low. There were no direct referrals from stroke survivors who presented at emergency but not admitted or for those who were admitted to hospital but who did not go into rehabilitation. It would be helpful to have access to the following statistics going forward:
 - Overall # of strokes in the catchment area each month.
 - # of stroke patients presenting to emergency but not admitted to hospital in the catchment area each month.
 - # of stroke patients admitted to hospitals in the catchment area each month.
 - # admitted to inpatient rehabilitation in the catchment area each month.
 - # admitted to the various stroke clinics (North Island) and the Intensive Outreach Rehabilitation Program in the catchment areas each month.

- # of stroke patients transferred to a different hospital than where they presented?

Participant Demographics: Stroke Survivors and Caregivers

- It is impossible to know if the project is truly serving the intended audience without feedback from clients who declined to take part. However, review of the data suggests the project reached a portion of intended users. Other key points:
 - Timeliness: The majority of participants were contacted within 6 weeks of their referral
 - Inclusiveness: The range of participant age was 48 years to 89 years with a wide variety of post-stroke needs, suggesting a sense of inclusiveness.
 - Eligibility: Almost 90% of participants met the eligibility criteria. The exception was having a caregiver present for the assessment.
- An emerging question from this project, “How do community based services reach or provide follow up with stroke survivors and caregivers post-hospital discharge”? In particular,
 - Stroke survivors who present at Emergency but are not admitted
 - Stroke survivors who are admitted to hospital but not eligible for rehabilitation
 - Stroke survivors who present at regular physician appointment post-discharge
- 11% of participants had no caregivers present for the assessment due to working schedules; long distance or the stroke survivor simply did not have a caregiver to assist them. Additionally, a quarter of stroke survivors had aging caregivers over 80 years old, with their own physical and emotional challenges. This particular group may require more “up front time” post-discharge as well as follow up in the community.
- Generally speaking, caregivers were eager to be present during the assessment to have their own questions answered as well to provide support for their loved one. A gap in knowledge regarding caregiving and stroke is the exact type of help caregivers are providing to their loved ones.
- Stroke survivors return home faced with many difficulties; many of which aren’t supported or are severely limited through home and community services such as ongoing physiotherapy to improve mobility and hand/arm function, speech therapy to assist with language and communication, cognitive rehabilitation to address memory issues and activities of daily living such as transportation, household management and preparing meals.
- Just over half of participants are satisfied with the assistance they are receiving, suggesting a large gap in appropriate community-based services and resources to support ongoing long term recovery.

4.2 CSRN SERVICE PROVISION & UTILIZATION

Data collected on the Case Management Activities form and Contact/Activity Log were summarized to present the following information:

- Service Utilization.
- Time spent by CSRN Coordinator.
- Case Vignette – Mr. & Mrs. Smith.

4.2.1 Service Utilization

Figure 5 shows the types of services offered and utilized by CSRN participants. On average clients used 3.51 services. All 82 participants received an assessment and information and referral services. 75% of participants received written service-action plans and 61% attended education sessions. Almost 15% of participants utilized case management services.

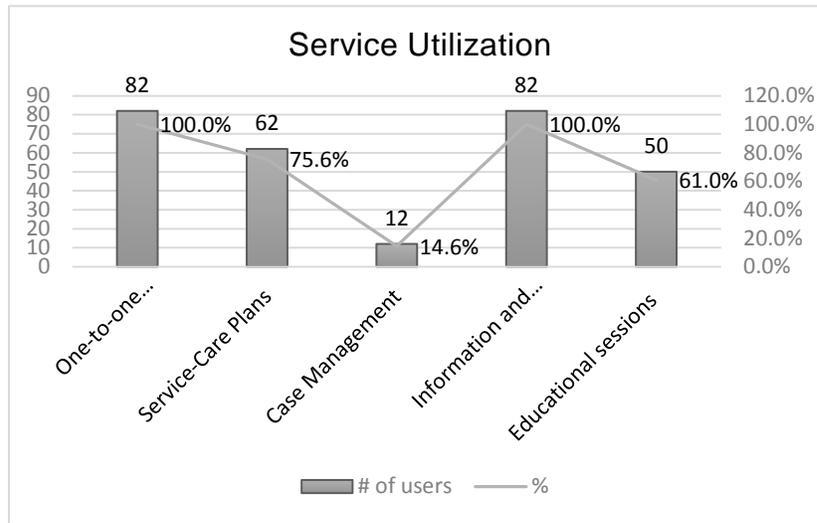


Figure 5: CSRN Service Utilization, # of users and %

Table 5 shows a breakdown of Case Management activities and Information and Referral activities.

Table 5: Breakdown of Case Management and Information and Referral Services

Specific Service	N ⁴	Time (Hrs)	% of Time
CM ⁵ - Caregiver Support	32	8	6.3%
CM - Housing	3	6	4.8%
CM - System Navigation	8	6	4.8%
CM - Transportation	9	2	1.6%
CM - Vocational Support	8	6	4.8%
I&R ⁶ - Cognitive rehabilitation	16	3	2.4%
I&R - Finding community resources	58	10	7.9%
I&R - Decision making	34	7	5.6%
I&R - Emotional support	52	15	11.9%
I&R - Fatigue	29	6	4.8%
I&R - Financial matters	18	8	6.3%
I&R - Future care planning	32	6	4.8%
I&R - Goal setting	38	7	5.6%
I&R - Ongoing physiotherapy	22	8	6.3%
I&R - Ongoing speech therapy	14	8	6.3%
I&R - Peer support opportunities	30	6	4.8%
I&R - Secondary prevention	60	9	7.1%

⁴ N = number of times service was provided

⁵ CM = case management service

⁶ I&R = information and referral service

I&R - Self-Advocacy	12	5	4.0%
Total	475	126	100.0%

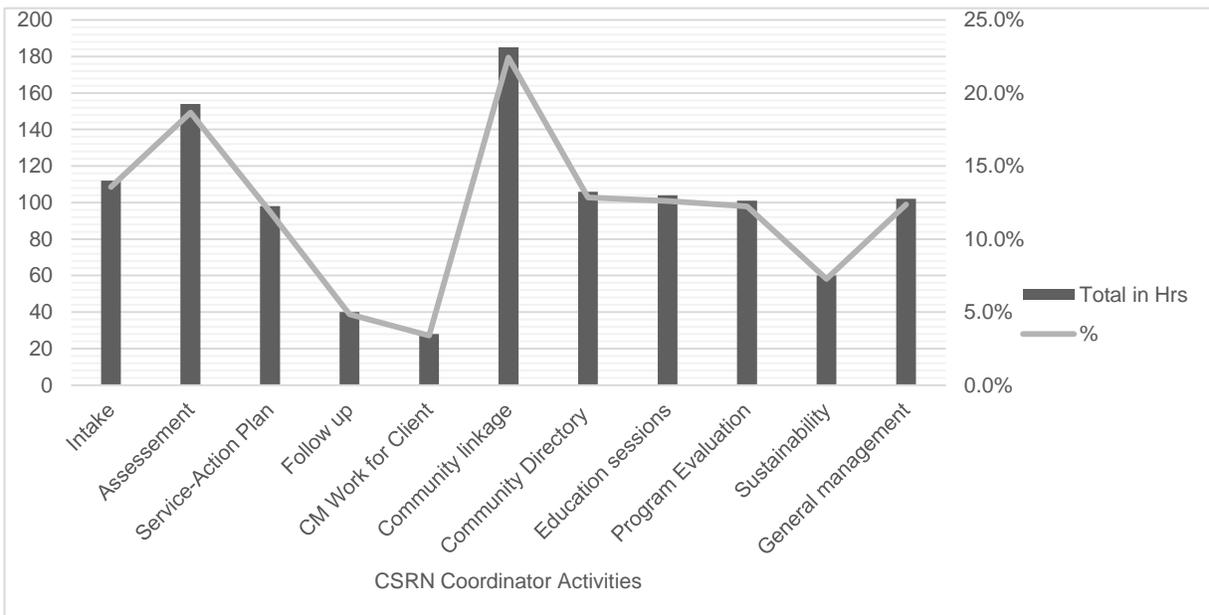
Highlights and additional details from Table 5 include:

- Caregiver support (6.3%) was provided where possible and often a 15 minute call was all that was required.
- Emotional support (11.9%) was provided through information on coping with emotions post-stroke, supporting both the caregiver and recipient and referrals to private counselling as well as local caregiving and peer support groups.
- Finding community resources (7.9%) was varied and depended on the needs of participants. Typically, participants were looking for specific resources in their community, connections, what questions to ask, etc.
- Secondary prevention (7.1%) was important an important concern for many participants.

4.2.2 CSRN Coordinator Time Allocation by Activity

Figure 6 and Table 6 shows the CSRN Coordinator's Time Allocation by Activity. Review of hours show the Coordinator spending 57% of time in direct service activities⁷. On average, participants received 5.25 hours of services.

Figure 6: CSRN Coordinator Time Allocation by Activity



⁷ Direct service activities included: Intake and assessment; service-care planning: case management; follow up on phone with participants and education sessions

Table 6: CSRN Coordinator's Time Allocation by Activity

Activity	Total in Hrs	%
Intake	112	13.6%
Assessement	154	18.7%
Service-Action Plan	98	11.9%
Follow up	40	4.8%
CM Work for Client	28	3.4%
Community linkage	185	22.4%
Community Directory	106	12.8%
Education sessions	104	12.6%
Program Evaluation	101	12.2%
Sustainability	60	7.3%
General program management	102	12.4%

4.2.3 CASE VIGNETTE

Mr. Smith is a 58-year-old male, married and living in his home. He suffered a hemorrhagic stroke 14 months ago and spent 2 weeks in hospital followed by 6 weeks in inpatient rehabilitation. He has difficulty with speech, short-term memory, complains of fatigue and is in a wheelchair, which he self-propels. Mr. Smith considers himself very fortunate in his recovery. He does, however, feels frustrated by his inability to work, being in a wheelchair, and his lack of energy and his feelings of poor self-worth. Prior to his stroke, Mr. Smith worked as an electrical engineer, enjoyed hiking and fishing and volunteered in the community. Mrs. Smith feels fortunate that her husband is as capable as he is although she feels she does all the household activities. She assists her husband with bathing and takes on the role of case manager. She feels her health has declined slightly since caregiving and is grateful for her strong support system in the community.



She assists her husband with bathing and takes on the role of case manager. She feels her health has declined slightly since caregiving and is grateful for her strong support system in the community.

CSRN Assessment: Priorities emerging from the assessment:

- Goal-setting: Mr. Smith didn't feel as though he was progressing with his ability to walk up the stairs. .
- On-going therapeutic programming: Mr. Smith wanted to work on getting out of the wheelchair and being able to walk more than 20 metres and up and down the stairs. Mr. Smith wanted to improve his speech.
- Peer support: Mr. Smith felt, at times, reluctant to go out into the community with his current disabilities. He was seeking support from others in the same situation.
- Volunteer opportunities: Mr. Smith wanted to feel useful again and identify what he could do in his community.
- Caregiver Support: Mrs. Smith spoke of keeping balance in her life and being able to identify the signs of burnout.

Service-Action Plan⁸

- Goal-setting: Goal-setting strategies were discussed for Mr. Smith to set realistic goals as well as simple ways to track progress going up and down the stairs. Identified motivators and barriers. Discussion on ways to reduce barriers.
- Information and Referral including provision of:
 - Referrals to a neuro-physiotherapist and speech language pathologist were made (private).
 - Strategies on cost effective ways to utilize private therapies to complement other affordable options.
 - A list of community resources for specific rehabilitation based exercise programming
 - A list of online resources and tools for speech and community based activities
 - Referral to local stroke recovery support group where volunteer based speech activities are available
- Peer Support: Referral to local stroke recovery support group for peer support. Mr. Smith also signed up for the 4 part education sessions on long-term stroke recovery.
- Volunteer Opportunities: Identified volunteer options that were realistic with Mr. Smith's current functional abilities.
- Caregiver Support: Referral to monthly local caregiver support group. Information on caregiver burnout as well as self-assessment tools provided.

Benefits

- Mr. Smith accessed the local stroke recovery branch and received weekly speech therapy and peer support. He felt as though talking to other stroke survivors would help motivate him to set goals and get out of the house.
- Private neuro-physiotherapy was accessed to set up a monthly plan to improve Mr. Smith's ability to go up and down stairs.
- Mr. Smith felt volunteering once a month sorting pictures for a local nonprofit was a realistic commitment. He would travel to and from to the nonprofit using taxi saver coupons.
- Mrs. Smith was going to try the monthly caregiving support session to see if she would benefit attending.

⁸ Appendix E provides a sample service action plan

4.2.4 Key Points: CSRN Service Utilization and Provision

- The range of services provided to participants by the CSRN program corresponds to a brokerage model. Services utilized and provided were consistent from client to client in terms of focus and type of support and information being provided.
- Given the type of case management model utilized, the type of service utilization seems reasonable and expected with the majority of time being spent doing assessments, information and referral and service-care plans.
- Additionally, case management activities on behalf of clients is low due to the time intensity involved in coordination, advocacy and counseling involved. The focus of a brokerage model is to support clients in their own self-advocacy, self-management and long term stroke recovery.
- Given the program is in its first year of operation, the amount of time provided with service provision seems reasonable.
- Table 5 shows there is a great deal of variance in what type of information, referrals and support stroke survivors and caregivers need. This reflects the very nature of how every stroke is different and supports the notion that participants should “receive the right type of service, information and support at the right time”.
- Community linkage activities (indirect client service) was a much larger than anticipated part of the CSRN Navigator role. Liaising regularly with key individuals within the stroke care and recovery pathway was critical to increase awareness of the program, to help coordinate referrals and services and to discuss how such organizations could partner and collaborate effectively in supporting clients in long term stroke recovery.
- There was some trial and error in finding the most suitable form of group stroke recovery education. The 4 part Community Stroke Recovery Education sessions appeared to meet the needs primarily of stroke survivors.
- A gap identified was a family caregiver education series with a formal structure and educational components.

4.3 COST OF SERVICES

The CSRN pilot project was managed and implemented by a Program Coordinator at approximately 19 hours per week for 52 weeks. The Program Coordinator education background included a Master’s Degree in Gerontology and over 5 years’ experience in case management and 15 years’ experience working with stroke survivors and family caregivers.

The Program Coordinator processed 102 referrals and met with 82 clients for an in-home assessment. Additionally, the Program Coordinator coordinated and implemented a total of 20 group education sessions.

Table 7 shows a very rudimentary breakdown of direct service costs to clients. Only direct service costs were included in the Program Coordinator time and excluded the development work prior to implementation, program evaluation and sustainability work done by the Program Coordinator. We adjusted intake hours to reflect 82 clients rather than 102 referrals.

The average cost per participant for navigation services was \$369 and \$160 for group education sessions (4 part series).

Table 7: Breakdown of Costs, Direct Service to Clients

Direct Service Costs	Navigator Program N=82	Education Sessions N=50
Project Supplies	\$ 650.00	\$ 613.00
Travel Costs	\$ 6,122.40	\$ 1,530.60
Program Coordinator Time	\$ 23,520.00	\$ 5,880.00
Total Direct Service Costs	\$ 30,292.40	\$ 8,023.60
Average Cost per Participant	\$ 369.42	\$ 160.47

4.3.1 Key Points: Cost of Services

- The case load of 102 intakes and 82 clients for a part-time Coordinator is manageable. The CSRN Coordinator felt there was room to service additional clients. There simply were not the referrals from hospital and physicians as anticipated in the first half of the project.
- The average cost per participant seems reasonable. A service utilization analysis conducted by Integrated Health Service Plan for the Central West Local Health Integration Network in 2009 showed an average client cost of \$308.50 for intake and case management services through their Community Support Services. As the CSRN Program is seminal, there is no comparison to draw from. This was the only comparable source of information located through a Google search.
- Group education sessions appear to be a very cost effective means to provide support, information and education for stroke survivors and caregivers. A more formal evaluation on their effectiveness is warranted.
- Further service utilization analysis is warranted to give a more accurate cost per participant for navigation services.

4.4 PROJECT DELIVERABLES PERFORMANCE

The goal of this section of the report is to determine if the project met the deliverables outlined in the initial proposal. In Table 8, we review activities in the development of the program and objectives with a detailed explanation of how the deliverable was met.

Table 8: Goals, Objectives and Activities – Review of Deliverables

Deliverable	Explanation
<p>Link stroke survivors and caregivers with community resources using a brokerage case management model with co-created goals and service plans Help clients/caregivers enter and navigate community services and enable them to continue on their journey to recovery Monitor the implementation of co-created client goals and service plans</p>	<ul style="list-style-type: none"> • Processed 102 referrals • Completed 82 intake assessments • Assisted 82 clients navigate community services and provide information on stroke recovery • Completed 62 service action plans with clients • Provided 65 follow up phone calls with clients • For complete details - see Findings Section; 4.
<p>Develop Professional Advisory Committee</p>	<ul style="list-style-type: none"> • PAC developed in February 2013 • 8 members including individuals with the following qualifications: <ul style="list-style-type: none"> ○ Physiatrist ○ Speech Language Pathology ○ Occupational Therapist ○ Physiotherapist • 8 PAC meeting were held with documented minutes

Deliverable	Explanation
<p>Conduct information interviews with key stakeholders and informants</p>	<ul style="list-style-type: none"> • 19 informational interviews conducted with key stakeholders including <ul style="list-style-type: none"> ○ Intensive Outreach Rehabilitation Program (IORP) Team at Nanaimo General Regional Hospital ○ Rehabilitation Team at St. Joseph's Hospital, including physiotherapist and occupational therapist ○ Stroke Nurse, North Island Stroke Clinic and at Nanaimo General Hospital, ○ Home and Community Care Managers Nanaimo, Comox, and Campbell River, ○ Private practitioners, including neuro-physiotherapist, speech language therapist ○ CEO of St. Joseph's Hospital ○ ABI community providers in Nanaimo, Comox and Campbell River ○ Social workers (Acute and IORP) ○ Three pharmacists in Parksville, Comox and Campbell River ○ Patient educator, Integrated ○ Stroke Lead at St. Joseph's Hospital ○ VIHA Stroke Coordinator • Information from interviews applied to: <ul style="list-style-type: none"> ○ Development of referral form ○ Categories for Community Stroke Directory • Contact sheet of key individuals to contact regarding program status and collaboration • General themes from the interviews focused on understanding community navigation, how to design an easy to use referral form and how to create awareness of the program in communities as well as internal distribution within VIHA. One of the identified gaps in service was simply a lack of resources in the community for stroke survivors and caregivers post-hospital discharge.

Deliverable	Explanation
Deliver stroke survivor and caregiver focus groups	<ul style="list-style-type: none"> • 3- 90 minute focus groups held in Parksville, Comox Valley and Nanaimo • 20 individuals attended focus groups – 12 stroke survivors, 8 caregivers • Findings from the focus group assisted in developing the educational content as well as broad categories of the Community Directory. • Identified areas of need <ul style="list-style-type: none"> ○ Stroke & Recovery Education ○ Social Interaction & Recreation ○ Mobility & Fitness ○ Thinking & Memory ○ Caregiver Support ○ Finding Other Resources in the Healthcare System/Community ○ Stress Management ○ Self-Advocacy
Program Documentation	<ul style="list-style-type: none"> • Referral form collaboratively developed by Program Coordinator and key stakeholders within Island Health. • Creation of the following tools and resources <ul style="list-style-type: none"> ○ Referral form ○ Referral database ○ Client consent form ○ Case management tools including service-action plans and case management activity tracking

Deliverable	Explanation
<p>Finalize Educational Content Deliver stroke recovery education to stroke survivors and caregivers living in the community</p>	<ul style="list-style-type: none"> • Delivered 20 educational sessions in total • Attended 3 Chronic Pain Self-Management Sessions to become better acquainted with the model and which components would be helpful in implementing the Community Stroke Recovery Navigator education sessions. • Comprehensive review of stroke recovery educational materials and resources in the following areas: <ul style="list-style-type: none"> ○ Exercise and mobility ○ Communication and Language ○ Social Support ○ Problem solving ○ Goal setting ○ Self-advocacy ○ Visual and perception ○ Executive Functioning ○ Leisure and recreation self-assessments • Developed 4 educational sessions series including PowerPoint presentation, participant workbook and facilitator guide. Topics are: <ul style="list-style-type: none"> ○ Stress Management ○ Self-Advocacy ○ Accessing Community Resources and Supports ○ The New Me – Re-identify Post-Stroke • Developed 2 caregivers support sessions on: <ul style="list-style-type: none"> ○ Spousal caregiving ○ Caregiver Burnout • Coordinated 2 stroke presentations using local speakers on: <ul style="list-style-type: none"> ○ Neuro-rehabilitation ○ Medication Management

Deliverable	Explanation
<p>Build partnerships and linkages amongst community service organizations and providers</p> <p>Create awareness materials and educate referrals</p> <p>Create a sustainability framework</p>	<ul style="list-style-type: none"> • PowerPoint presentation developed for educating referral sources and community partners • Rack card and poster developed for marketing and increasing awareness • Held 25 community linkage sessions (by phone or in person) with professionals in the community. • Held 4 awareness presentations to VIHA staff including outpatient and inpatient rehabilitation team at Nanaimo General Regional Hospital, Home and Community Care teams in Campbell River and the Comox Valley, St. Joseph Hospital Rehabilitation Team. • A quarterly newsletter was sent out to all established contacts with an update on number of referrals, resources and review of the Navigator Program. • Sent 122 emails and faxes to physicians and community contacts with a copy of referral form and poster. • Creation of a collaborative group of professionals and volunteers for a Stroke Roundtable in Nanaimo • Created community partnerships with Integrated Health Network, Comox Valley Brain Injury Society, St. Joseph's Hospital and Nanaimo Brain Injury Society in delivery stroke recovery education sessions • Co-developed a funding application with Vancouver Island University and Family Caregivers Network Society to research and test peer navigator model, based on the framework being utilized SRABC. The application was not successful. • Currently developed a working partnership with Nanaimo Brain Injury Society and March of Dimes Canada in creating a sustainability plan for key components of CSRN in Nanaimo, Parksville and Duncan.
<p>Create and distribute a stroke recovery directory for stroke survivors, families, caregivers and health professionals</p>	<ul style="list-style-type: none"> • Developed a list of educational/information sources (videos, fact sheets, books, tools, etc.) under the 7 Steps to Stroke Recovery • Held a 90 minute support session to all Vancouver Island Branch Coordinators to introduce the information sheet and directory of resources

4.4.1 Project Issues

The major project issues that arose in planning and implementation are outlined below.

- **Getting Buy-In from Key Stakeholders:** Although the project was eventually well received by key hospital staff, there was an uphill challenge to simply “get in the right room with the right people”.
 - Identifying stroke leads at hospital was challenging and took enormous time and in-person meetings to establish credibility. This led to very slow and few referrals in the first half of the project.
 - Parksville doesn’t have a hospital and the Integrated Health Centre had just opened during the CSRN project. We had a difficult time finding the right person to connect with to establish direct referrals.
 - St. Joseph’s Hospital is an affiliate of Island Health and at the time of the project, there wasn’t a strong stroke lead. It took over 10 months to find the right person to connect with and to establish a strong connection. Unfortunately, there were few referrals as a result.
 - We didn’t realize that there isn’t just one person to connect with in hospitals. We came realize that in order to get referrals, we needed to speak to and educate many different staff members in various roles within the hospitals.
 - Additionally, SRABC doesn’t have the evidence-based research to back up the effects of community-based programs such as navigation services. In fact, this type of research doesn’t exist in BC and only to a limited degree in Canada. Therefore, gaining credibility and trust with key stakeholders in health care through qualitative measures was slower and took more of the Program Coordinator’s time.
- **Primary Care Engagement:** We faxed over 100 physicians in the catchment area; however, we later learned the best route to physicians is through the Division of Family Practices. This resulted in very few referrals from physicians.
- **Education Health Professionals on Stroke Recovery Terms:** Many meetings with key stakeholders solely focused on what “Navigation” and “Community Re-integration” meant in long term stroke recovery.
 - While this presented an opportunity to bridge the gap in knowledge, it also contributed to slow referrals at the start of the project.
 - We only had time to provide a handful of education sessions on what long term stroke recovery means.
- **Stroke Recovery Education:** It took some trial and error to find the right formula for education sessions. We originally coordinated monthly education sessions in each community. However, we found attendance low and challenges finding space.
 - The 4-part education series solved this project issue right away and led to high attendance and referrals into the program.
- **Turnover in Island Health Stroke Coordinator:** the initial Island Health Stroke Coordinator retired and there was a gap in time prior to filling this position. As a result, a key connection

with Island Health that could help support and promote the CSRN program was less prominent in the second half of the project.

- **Geographical Limitations:** We initially thought assessments could be done in office or by telephone. We soon realized that for almost all participants, an in home visit was best way to collect information and provide support and resources.
 - This resulted in less timely assessments as the Program Coordinator needed to coordinate at least 2-3 visits in each community on one day.
 - It also contributed to a higher travel cost than initially anticipated.
- **Timing of the Project:** Originally, the project implementation was slated to begin in April 2013. However, the funding was delayed for a few months. Therefore, implementation began in July. Starting the project at this time wasn't ideal
 - It was not only challenging to set up meetings with providers but with stroke survivors and family caregivers as well. This led to less timely assessments and resulted in less awareness at the start of the project.
 - Additionally, the Program Coordinator had booked off holiday time in August for 2 weeks, which contributed to less timely assessments.
- **Sustainability:** We were really confident the joint funding application in May 2014 with Vancouver Island University and Family Caregiver Network Society would be successful. We invested a great deal of time and energy into those relationships and the application during that process.
 - When we received news that the application wasn't successful, we needed to go back to drawing table regarding sustainability.
 - It took additional time to establish a new plan with new partners resulting in a gap in the Navigator program being sustained beyond August 2014. We are confident that the current working partners will result in at least one or two key components of the Navigator program being offered by January 2015.

4.5 CLIENT SATISFACTION

We implemented a “reactive satisfaction” of the CSRN, which measured the participant’s immediate positive or negative response to the services provided. Based on previous satisfaction surveys, responses tend to be very positive. Therefore, we wanted to keep the evaluation short and easy to complete and focus on content of the assessment, timely service and providing adequate assistance. We therefore opted to ask the following questions in Table 9 at the end of the assessment.

Table 9: CSRN Client Satisfaction Questions

Navigator Satisfaction questions	Strongly Agree	Agree	Unsure	Disagree	Strongly Disagree	Not Applicable
My referral was responded to in a prompt and courteous manner	<input type="checkbox"/>					
The Program Coordinator was knowledgeable and helpful	<input type="checkbox"/>					
The Navigator Program increased my awareness of resources available for stroke survivors and caregivers.	<input type="checkbox"/>					
I would recommend the Navigator Program to other stroke survivors and caregivers	<input type="checkbox"/>					
How could the Navigator Program be strengthened?						

Of the 82 assessments, 63 participants chose to answer the satisfaction survey. The feedback is summarized in Table 10.

Table 10: CSRN Client Satisfaction Survey Responses in Percentage

Navigator Satisfaction questions	Strongly Agree (N=63)	Agree (N=63)	Unsure (N=63)	Disagree (N=63)
My referral and assessment were responded to promptly	63.5%	31.7%	0.0%	4.8%
The Program Coordinator was knowledgeable and helpful	90.5%	9.5%	0.0%	0.0%
The Navigator Program increased my awareness of resources available for stroke survivors and caregivers	87.3%	9.5%	3.2%	0.0%
I would recommend the Navigator Program to other stroke survivors and caregivers	93.7%	6.3%	0.0%	0.0%

Below are some qualitative responses to the question, “How could the Navigator Program be strengthened?”

“I would have liked to have seen someone in the hospital before I left, to give me an idea of what to expect or even to just prepare me a little bit for when reality hit that I no longer had the safety of the rehab team.”

“Caregivers need practical guidance and information on what to expect when caring for someone with a stroke. I was never shown how to properly assist my husband during his transfers from the bed to the bathroom. Having someone make sure I had the right skills before leaving hospital or within the first 2 days of being home would be very helpful.”

“The very fact that you are sitting in my living room doing a follow up visit is amazing. Since leaving hospital, I’ve felt very disconnected from my recovery. Knowing that a service like this exists gives me hope for other stroke survivors.”

“We had to wait a little too long to be assessed and I felt as though we sort of figured things out by the time we had a visit. The information was still helpful but I would have liked to have had it sooner. Getting in to see stroke survivors and family caregivers within the first month, I think, would be most helpful.”

“The Service-Action plan was really helpful in giving us something to start on. I could probably use some support when I’m feeling a little down. Another visit from a volunteer or from you again to check in to see how I’m doing down the road would be a nice boost for me.”

“Even though we are doing well with recovering from the stroke and we are pretty much back to “normal living”, it’s really important to have people like you available to be our cheerleaders and remind us how well we are doing. The program has something for everyone to take away, even if it is validating what they are currently doing.

“I think the program is very strong already. Having a professional with knowledge to bounce ideas around and to bring a fresh perspective is so helpful during recovery. I’m a different person now and so things that worked before, don’t necessarily work now. Having guidance and assistance in these areas are really important for stroke survivors.”

4.5.1 Key Points: Client Satisfaction

- The CSRN Pilot program was very well received by participants.
- 90% of participants strongly agreed the Program Coordinator was perceived to be knowledgeable and helpful.
- 87% of participants strongly agreed the program increased their awareness of resources in the community.
- The timeliness of assessments could be improved. Although most individuals were seen within 6 weeks, there was general feedback that an in-home visit within the first month would be more beneficial.
- Feedback on how to strengthen the program is extremely beneficial and will be applied to future projects on navigation services and stroke recovery education.

5 RECOMMENDATIONS

- It is recommended that SRABC find ways of continuing and building upon the groundbreaking work of this pilot project by seeking funds to deliver further navigation and stroke recovery education to the defined target audience.
 - The CSRN program findings and recommendations align with SRABC's current Strategic Plan and with work current being done by SRABC's Professional Advisory Committee, which is examining the question of how SRABC can best develop programs and services to better support the needs of a wider range of stroke survivors and caregivers.
 - The recommendations of this report are being amalgamated with goals for Primary Care Engagement and core principles from the Triple Aim Approach to create a strategy for Program and Service Delivery.
- The BC Stroke Strategy has provided leadership in promoting careful studies of the more acute aspects of stroke care, such as the impact of TIA clinics and Early Supported Discharge. However, evidence for the effectiveness of community-based programs and services designed to meet the long-term recovery and community integration needs of individuals with stroke is lacking.
 - We need the opportunity to build on the seminal work of the CSRN by conducting properly researched and resourced evaluations.
 - Further empirical-based research on the impact of navigation services post-stroke offers opportunities to study:
 - Population health using Health Outcomes and Patient self-efficacy and knowledge
 - Experience of Care using client satisfaction indicators and timeliness of service delivery
 - Per Capita Cost using Utilization indicators such as:
 - Hospital re-admissions rates.
 - Physician or clinic visits.
 - Early Supported Discharge rates.
- A secondary phase to the CSRN pilot is recommended and could include:
 - Test a multi-faceted community navigation program for post-stroke survivors and family caregivers that includes self-navigation, lay navigation, and paid case management services.
 - The navigation program would be customized through a screening tool to address the client's varying level of health, emotional and social support needs from a low level of need to high level of need.
 - Develop a Lay Navigation Volunteer Management and Training Program to provide one-to-one volunteer navigation support through local citizens and volunteer agencies. A starting point would be to identify select SRABC Branches that have the capacity to participate in the delivery of navigation services.
 - Develop a Hospital Visitation program to provide timely access to psychosocial information and peer support for stroke survivors and caregivers as they transition from hospital to home. Services would include informational and education sessions for caregivers in acute and rehab units as well as peer visits stroke survivors

- Continue to expand and maintain a current- up- to-date network of resources for people affected by stroke in BC. The paid Coordinator would work with a trained volunteer to update the database.
- Continue to build on existing partnerships and improve inter-agency cooperation, collaboration and dialogue to create partnerships and relationships between individuals, family, friends, community resources and groups, health services, and self-help organizations.
 - Draft a community engagement plan to develop a “shared care model” including:
 - Identifying “champions” within Island Health to support and promote a Navigator Program
 - Engagement of physicians and other primary care service providers through Family Practice Divisions
 - Health Authorities
 - Interagency collaboration
 - Stroke Recovery Branches
 - At the time of this report, SRABC is moving forward in collaboration with Nanaimo Brain Injury Society and March of Dimes to pilot a joint Hospital Visitation program and Family Caregiver Education series. The target audience is expanding to include acquired brain injury and stroke survivors.
 - There is a strong willingness and support from community organizations and Island Health to partner with us and a strong desire to expand and continue offering Navigation services on Vancouver Island.

6 APPENDICES

APPENDIX A: COMMUNITY STROKE RECOVERY NAVIGATOR PROGRAM COORDINATOR SERVICE ACTIVITIES

Client Assessment and Service-Care Plan

- Management of referrals for CSRN participants including coordination of assessments.
- Completion of intake assessments using the project questionnaires.
- Writing and typing of a service-care plan.

Information and Referral

- Research service and resource options for clients with other providers
- Referral to community resources, as required and with consent.
- Provision of written and verbal information related to stroke recovery and caregiving. Sources included books, social media, websites, videos, research and general articles, etc.
- Develop a directory of stroke recovery resources, programs and services.

Community Linkage

- Outreach to and networking with community based partners.

Case management

- Provided case management services when social resources were not available or limited non-existent or limited and the participant required assistance, support, information and/or advocacy to meet their needs.
- System navigation including the identification of appropriate community resources, how to access their system, and initiating a referral.

Monitoring and Follow-Up

- Follow up by telephone with clients to determine client's satisfaction with service-care plan.

Stroke Recovery Education

- Develop content, coordinate and delivery community-based stroke recovery education.

Program Management

- Monthly reports
- Monthly meetings with PAC
- Regular meetings with staff and Executive Director
- Filing and database management
- General program planning activities

APPENDIX B: REFERRAL FORM

Community Stroke Recovery Navigation Program

REFERRAL FORM

REFERRAL GUIDELINES

1. To refer a stroke survivor, please complete this form and return it by FAX at **1-866-737-0273** or by e-mail to vancouverislandsrabc@gmail.com.
2. Please note that **ONLY** individuals who have suffered a stroke and have a caregiver/friend who can help them AND were living in the community prior to their stroke are eligible for the program.
3. The Community Stroke Recovery Navigation Program will help direct the person who had a stroke and their caregivers to the right services in their community as well as answer questions about living with stroke post-hospital discharge.
4. The Intake Process: (i) Coordinator evaluates referral to ensure eligibility required), (ii) the person is contacted within 14 days of referral; (iii) s/he will be evaluated on the telephone for the most pressing needs and given the following options: small group education sessions, one-to-one assessment (in home, in Coordinator's office or over the telephone); (iv) follow up assessment will take place 3 months after the initial assessment.

NEW REFERRAL INFORMATION

Name: _____ Phone: _____

Next of Kin & relationship:

Phone (if different than above): _____

REFERRAL MADE BY:

Self

VIHA program: HCC IP Rehab Acute care OP Rehab

VIHA Site: NRGH SJGH CRH Other _____

Community Agency (_____)

Other: _____

CLIENT CONSENT

Client consents for referral to the Community Stroke Recovery Navigator Program

Client Signature: _____ Date: _____

APPENDIX C: INTAKE QUESTIONNAIRE

GENERAL INFORMATION

Name: _____ Today's Date: _____

Gender: Male Female Your Age: _____

What city do you live in? _____

Date of Stroke (MM/YY): _____

Were you admitted to hospital? Yes No

Did you go to inpatient rehabilitation Yes No

Type of stroke Ischaemic (clot) Hemorrhagic (bleed) Not Known

Have you had a previous stroke? Yes No

If Yes, date of previous stroke (Year only): _____

MY LIVING ARRANGEMENTS

I live in a:

- | | |
|--------------------------------------|---|
| <input type="checkbox"/> house | <input type="checkbox"/> retirement home |
| <input type="checkbox"/> apartment | <input type="checkbox"/> no fixed address |
| <input type="checkbox"/> mobile home | <input type="checkbox"/> other: _____ |

I live with:

- | | |
|---|--|
| <input type="checkbox"/> spouse/partner | <input type="checkbox"/> alone |
| <input type="checkbox"/> children | <input type="checkbox"/> private caregiver |
| <input type="checkbox"/> other family members | <input type="checkbox"/> Other: _____ |

Please check 'yes' or 'no' or N/A (not applicable) to each of the following questions:

What areas are you having difficulty with? Please check all that apply.):

- | | |
|--|--|
| <input type="checkbox"/> difficulty with arm and hand function | <input type="checkbox"/> talking and understanding |
| <input type="checkbox"/> eating well and preparing meals | <input type="checkbox"/> safety in the home |
| <input type="checkbox"/> impulsiveness | <input type="checkbox"/> boredom |
| <input type="checkbox"/> difficulty walking and getting around | <input type="checkbox"/> taking care of myself |
| <input type="checkbox"/> household tasks | <input type="checkbox"/> other: _____ |
| <input type="checkbox"/> fatigue | |
| <input type="checkbox"/> difficulty with vision and perception | |
| <input type="checkbox"/> difficulty swallowing | |
| <input type="checkbox"/> difficulty with memory | |

MY COMMUNITY SERVICES

	YES	NO	N/A
I have been referred to Home and Community Care (VIHA)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am receiving			
• Occupational Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Physiotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Speech Language	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Social Work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Dietician	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Nursing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• I am attending outpatient rehab	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	YES	NO	N/A
I am receiving the following community support services:			
• Meals	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Home Maintenance	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Housekeeping	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
• Other	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

I am satisfied with the amount of assistance that I receive. YES NO N/A

- I would like to learn more on:
- adjusting to life after stroke
 - ways to improve my quality of life
 - how to support and care for my loved one
 - managing emotional changes
 - managing my finances
 - learn about community resources
 - learn how to reduce risk of another stroke
 - other: _____

HEALTH MANAGEMENT

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I am taking all of the medicines that my doctor(s) has prescribed.	0	1	2	--
I understand <u>why</u> I am taking all my prescription medications	0	1	2	--
I understand <u>how</u> to take all my prescription medications.	0	1	2	--
All my questions about the medicines I am taking have been	0	1	2	--

answered.

I have told my doctor about all the other drugs, vitamins, or supplements that I am taking.	0	1	2	--
I am sleeping well	0	1	2	--
I am eating well	0	1	2	--
My ability to chew and swallow is the same as before my stroke	0	1	2	--
	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
My thinking is the same as before my stroke.	0	1	2	--
My emotions are similar to before my stroke.	0	1	2	--
I feel that I can deal with life events as they happen.	0	1	2	--

DAILY ROUTINES

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I am comfortable preparing my own meals.	0	1	2	--
I am able to look after my personal needs - dressing, bathing/showering, nail care (hands and feet).	0	1	2	--
I am able to toilet myself - getting to the bathroom on my own, using the toilet.	0	1	2	--
I know about continence products (e.g. Depends	0	1	2	--
I am comfortable caring for my children.	0	1	2	--
I am able to manage my daily tasks at home (e.g. washing dishes, doing laundry, vacuuming, dusting, yard work, snow removal).	0	1	2	--

WORK

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I have returned to my previous work.	0	1	2	--
I feel able to return to work.	0	1	2	--
I have a plan to return to work.	0	1	2	--
I feel able to participate in retraining for a new job or other education	0	1	2	--
I feel able to participate in volunteer activities.	0	1	2	--
I am able to concentrate well and participate in all activities at work.	0	1	2	--
I have enough energy for work.	0	1	2	--

MY SOCIAL NETWORK

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I am comfortable rejoining the groups and activities that I was involved in prior to my stroke.	0	1	2	--
I go out of the house about as often as I did before my stroke.	0	1	2	--
I have someone who give me emotional support.	0	1	2	--
I am able to do the things I want to do.	0	1	2	--

MY HOME

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I am able to get around my home easily.	0	1	2	--
I am using special equipment to move around our home (e.g. walker, raised toilet seat, grab bars).	0	1	2	--
My home has been adapted to help me with my mobility (e.g. wheelchair ramps, stair rails).	0	1	2	--
I am always steady on my feet.	0	1	2	--
I receive help in and around my home from people who do not get paid to help me - friends, relatives, volunteers, family.	0	1	2	--

MY COMMUNICATION

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I feel able to communicate my needs and desires.	0	1	2	--
I always understand what people are saying.	0	1	2	--
I am satisfied with the way I communicate.	0	1	2	--
I feel comfortable communicating in groups.	0	1	2	--
I have aids to help me communicate - pictures, communication board, etc	0	1	2	--

MY COMMUNITY MOBILITY

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I have returned to driving.	0	1	2	--
I am comfortable driving in my local area/short distances.	0	1	2	--
I am comfortable driving long distances.	0	1	2	--
I am comfortable driving at night.	0	1	2	--
I would like to start driving again, etc	0	1	2	--
I know where to go for a driving assessment so I can start to drive again.	0	1	2	--
I am comfortable using transportation services (e.g. public transit, accessible transit, volunteer drivers).	0	1	2	--
I am able to get to those places I need to - grocery shopping, rehabilitation, doctor's appointments, work	0	1	2	--

MY FINANCES

	Does not describe my situation	Partially describes my situation	Fully describes my situation	N/A
I am comfortable managing my finances - banking, paying bills.	0	1	2	--
I have enough money for my needs.	0	1	2	--
I am receiving disability insurance/pension).	0	1	2	--
I know how to get financial assistance - disability, pensions, disability tax credit, etc.	0	1	2	--

Is there anything else you would like to ask us? Is there anything else you would like us to know?

APPENDIX D: CLIENT ACTIVITY LOG – SAMPLE

Client Name: Mrs. Robb

Date	Contact/Activity	Results of Contact/Activity
March 7/14	Mrs. Robb, coordination of assessment	Left message with possible date and time
March 10/14	Mrs. Robb, confirming assessment date	Confirmed assessment date
March 17/14	Home visit to Mrs. Robb	Complete in home visit
March 24/14	Emailed service action plan to daughter, Audrey	Audrey to review plan and email me with any questions
May 15/14	Emailed daughter, Audrey to follow up on service action plan	Audrey felt confident in implementing activities listed with her Mom

APPENDIX E: SERVICE-ACTION PLAN - SAMPLE

CLIENT PRIORITIES & ACTION PLAN

CLIENT NAME: Stroke Recovery

DATE: January 22, 2014

PRIORITIES

1. Monitoring Health & Tracking Medical Appointments
2. Speech Language Pathologist
3. Kitchen Tips
4. Goal Setting

PRIORITY #1: Health monitoring, tracking medical appointments

As health and functional abilities change, it's important to keep track of observations (general and/or specific) as well as important information using:

- i. **Observation Journal:** helpful to jot down one or two sentences specific to any health and memory changes for both care recipient and caregiver. For example, it could pertain to a near fall, increase in energy, walking longer distances, less/more pain, more/less confusion, improved speech, etc. It's good to write down what makes it better, what makes it worse, how long a specific situation lasts and perceived level of pain, discomfort or fatigue.
 - a. It can be as simple as using a notebook to record something like this:

Date and Time	Health Event or Change in Health	Length of event or change What made it worse/better	Other Notes
June 18, 2013 in AM	Stroke walked an extra kilometer	Was fatigued afterwards but felt good during the walk	Want to buy a pedometer

** if writing is an issue, you can record an observation or have a family member write it down for you.

- ii. **Tracking Medical Appointments/Communication with Service Providers:** having someone take notes at medical appointments or when speaking to health providers is very useful. Fill in the worksheet prior to going to the appointment and take notes. Keep all notes in a binder. If speaking to a health provider over the phone, you can use the same form.
 - a. **Attached are forms to track medical appointments**
 - b. **Bring forms to your medical appointment**

PRIORITY #2: SPEECH LANGUAGE PATHOLOGIST

We spoke about Stroke's current activities in improving speech. Also she is on a waitlist for outpatient speech.

We discussed the importance of getting a better idea of the aphasia faced by Stroke and specific resources to assist her in her recovery.

Attending a support group is also helpful, which Stroke is currently doing.

Follow this link to some good resources on Amazon or perhaps at your local library (?)

http://www.amazon.ca/s/ref=nb_sb_noss?url=search-alias%3Daps&field-keywords=speech+therapy+stroke&rh=i%3Aaps%2Ck%3Aspeech+therapy+stroke

It is most helpful to have the speech language pathologist suggest the best resource; however, if wait times are too long the following activity books are very helpful:

- Workbook for Cognitive Skills by Susan Howell Brubaker
- Speech Therapy Aphasia Rehab by Amanda Anderson

Communication tips: <http://www.dal.ca/diff/inteRACT/faq-s/strategies.html>

Software and Apps: <http://www.dal.ca/diff/inteRACT/faq-s/strategies.html>

Brain Retraining: There is a really good site called www.MemoryAid.org that has a variety of very good cognitive training activities. It would be best to identify areas that Helen is motivated to improve and start there. Some of the areas we discussed were short term memory, number literacy, word finding and problem solving. The membership is pretty affordable at \$14.99 per month. What I do, is pay for one month and make a pdf of the applicable activities and keep them on file.

PRIORITY #3: KITCHEN TIPS

Stroke4Carers website has some good basic tips: <http://www.stroke4carers.org/?p=446>

Although I know Stroke is able to use both hands, there was some concern about the side that has less strength. Here is an interesting video to watch: <http://vimeo.com/66672808>

There are many more, I use the search terms in Google – “kitchen tips stroke” and then go to videos.

PRIORITY #4: GOAL SETTING

It is really helpful to start with the Global Assessment Tool for Stroke Recovery followed by some basic goal setting plans. This is really helpful for individuals that are motivated by writing things down. I hope it helps.

Attached Documentation:

- Health Appointment Worksheet
- Observation Journal
- Sample Brain Retraining Activity from MemoryAid.org
- Global Assessment Tool for Stroke Recovery
- Goal Setting plans

APPENDIX F: CAREGIVER QUESTIONNAIRE

Name: _____

Date: _____

Age: _____

What is your relationship to the person you care for?

- | | | |
|--|---|----------------------------------|
| <input type="checkbox"/> Husband/Partner | <input type="checkbox"/> Son/son-in-law | <input type="checkbox"/> Sister |
| <input type="checkbox"/> Wife/Partner | <input type="checkbox"/> Daughter/daughter-in-law | <input type="checkbox"/> Brother |
| <input type="checkbox"/> Other relative: _____ | <input type="checkbox"/> Non-relative: _____ | <input type="checkbox"/> Mother |
| | | <input type="checkbox"/> Father |

Do you and the stroke survivor live in the same home/residence?

- Yes, live together No, live separately

If no: where does the stroke survivor live?

- | | |
|--|---|
| <input type="checkbox"/> Lives with spouse | <input type="checkbox"/> Assisted living |
| <input type="checkbox"/> With other family | <input type="checkbox"/> Independent living |
| <input type="checkbox"/> Lives alone | <input type="checkbox"/> Nursing home |
| | <input type="checkbox"/> Other: _____ |

How long have you been providing care? Months: _____ Years: _____

How many hours per week do you provide assistance, care, supervision or companionship?

Hours per week: _____

Are you currently employed?

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> Full time (35 hours/week or more) | <input type="checkbox"/> Not employed |
| <input type="checkbox"/> Part time (less than 35 hours/week) | <input type="checkbox"/> Retired |
| <input type="checkbox"/> Leave of absence | |

Has your employment status changed as a result of caregiving duties?

- | | |
|---|---|
| <input type="checkbox"/> No change | <input type="checkbox"/> Early retirement |
| <input type="checkbox"/> Changed jobs | <input type="checkbox"/> Began working |
| <input type="checkbox"/> Family/medical leave | <input type="checkbox"/> Quit job |
| <input type="checkbox"/> Leave of absence | <input type="checkbox"/> Laid off |
| <input type="checkbox"/> Increased hours | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Decreased hours | |

7 REFERENCES

- Bakas, T., Farran, C. J., Austin, J. K., Given, B. A., Johnson, E. A., & Williams, L. S. (2009). Stroke caregiver outcomes from the Telephone Assessment and Skill- Building Kit (TASK). *Topics in Stroke Rehabilitation*, 16(2), 105–121. Retrieved from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3021456/>
- Bhugal, S. K., et al. (2003), Community reintegration after stroke, *Top Stroke Rehabil*, 10 (2), 107-29. Retrieved from: <http://thomasland.metapress.com/content/f50lwewe6aj464fk/fulltext.pdf>
- Cameron, J., and Gignac, M., (2007). “Timing It Right”: A conceptual framework for addressing the support needs of family caregivers to stroke survivors from the hospital to the home. *Patient Education and Counseling*, 70(3):305-14.
- Canadian Institute for Health Information (2010). Supporting Informal Caregivers— The Heart of Home Care. Analysis in Brief. August 2010. Retrieved from: http://secure.cihi.ca/cihiweb/products/Caregiver_Distress_AIB_2010_EN.pdf
- Canadian Stroke Strategy. (2010). Canadian Best Practice Recommendations for Stroke Care. Retrieved from: http://www.strokebestpractices.ca/wpcontent/uploads/2011/04/2010BPR_ENG.pdf
- Clarke, P., Marshall, V., Black, S.E. and Colantonio, A. (2002). Well-Being After Stroke in Canadian Seniors Findings From the Canadian Study of Health and Aging. *Stroke*, 33: 1016-1021 doi: 10.1161/ 01.STR.0000013066.24300.F9
- Cloutier-Fisher, D.S. (2005). Different Strokes Need for Help Among Stroke-affected Persons in British Columbia. *Canadian Journal of Public Health*, May-June, pp. 221-225. Retrieved from: http://scholar.google.ca/scholar_url?hl=en&q=http://journal.cpha.ca/index.php/cjph/article/download/602/602&sa=X&scisig=AAGBfm3TIDx7fhX0dntVmlaP08hQ_mi8lw&oi=scholarr&ei=ItnLUKziDoPTiwLNmYCwCQ&ved=0CC4QgAMoADAA
- Deeken, J., Taylor, K., Mangan, P., Yabroff, R., Ingham, J.M. (2003). Care for the Caregivers: A Review of Self-Report Instruments Developed to Measure the Burden, Needs, and Quality of

Life of Informal Caregivers. *Journal of Pain and Symptom Management*, 26 (4): 922-953

Duxbury, L., Higgins, C., Schroeder, B. (2009). Balancing Paid Work and Caregiving Responsibilities: A Closer Look at Family Caregivers in Canada. Retrieved from <http://www.ccc-ccan.ca/media.php?mid=237>

Egan, M., Anderson, S., and McTaggart, J. (2010). Community Navigation for Stroke Survivors and Their Care Partners: Description and Evaluation. *Topics in Stroke Rehabilitation*, 17(3):183-90

Family Caregiver Alliance (2006). Caregiver Assessment: Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. I). San Francisco: Author

Gibson, M.J., Kelly, K.A. and Kaplan, A.K. (2012). Family Caregiving and Transitional Care: A Critical Review. Family Caregiver Alliance, October. Retrieved from: http://caregiver.org/caregiver/jsp/content/pdfs/FamilyCGing_andTransCare_CR_FINAL10.29.2012.pdf

Jørgensen, H.S., Reith, J., Nakayama, H., Kammersgaard, L.P., Raaschou, H.O., Skyhøj Olsen, T. (1999). What Determines Good Recovery in Patients With the Most Severe Strokes? The Copenhagen Stroke Study. *Stroke*, 30: 2008-2012 doi: 10.1161/01.STR.30.10.2008

Lutz, B. and Young, M.E. (2010). Rethinking Intervention Strategies in Stroke Family Caregiving. *Rehabilitation Nursing*, 35:4, July/August. Retrieved from: <http://www.rehabnurse.org/pdf/rnj324.pdf>

Mayo, N., Nadeau, L., Ahmed, S., White, C., Grad, R., Huang, A., Yaffe, M., Wood-Dauphinee, S., (2008). Bridging the gap: the effectiveness of teaming a stroke coordinator with patient's personal physician on the outcome of stroke. *Age and Ageing*, 37: 32–38. doi:10.1093/ageing/afm133

Merry-Lambert, L., & Nichol, L. (2008). Winnipeg Regional Health Authority Home Care Program. "Community Stroke Care Service -A Client-Centered Approach to Community Re-Engagement". Community Presentation on September 18. Retrieved from

<http://www.neostrokestrategy.com/oldportal/uploads/Louise%20Nichol%20and%20Linda%20Merry-Lambert%20-%20Community%20integration%20post-stroke.pdf>

Newell, J.M., Lyons, R., Martin-Misener, R., and Shearer, C.L. (2009). Creating a Supportive Environment for Living with Stroke in Rural Areas: Two Low-Cost Community-Based Interventions. *Topics in Stroke Rehabilitation*, 16(2):147-56.

Opara, J.A. and Jarack, K. (2010). Quality of life of post-stroke patients and their caregivers. *J Med Life*. 15; 3(3): 216–220. PMID: PMC3018998

Reinhard, S., Given, B., Nirvana, H.P., Bemis, A. (2008). Patient Safety and Quality: An Evidence-Based Handbook for Nurses. Hughes RG, editor. Rockville (MD): Agency for Healthcare Research and Quality (US); Chapter 14: Supporting Family Caregivers in Providing Care. Retrieved from <http://www.ncbi.nlm.nih.gov/books/NBK2665/#ch14.r69>

Salter K, Teasell R, Bhogal S, and Foley N. (2008) *Community Reintegration*. Retrieved from EBRSR: Evidence-Based Review of Stroke Rehabilitation: www.ebrsr.com

Smith, J., Forster, A. and Young J. (2009). Cochrane review: information provision for stroke patients and their caregivers. *Clinical Rehab*, 23(3):195-206. doi: 10.1177/0269215508092820.