

Pathways for People with Stroke to Live Fully in the Community



**Final Report
September 25, 2008**

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ACKNOWLEDGEMENTS

We are deeply grateful to the people with stroke and their family members who chose to share their experiences in the sincere hope that it would have a positive impact for those affected by stroke, people living with stroke now, and those who will be affected in the future. Your insights are a critical foundation to this process.

The participation of providers who do offer or could offer services and supports for people affected by stroke was also critical to the process. The strong level of commitment and desire to support positive change was evident. There is tremendous gratitude for the work you do every day to improve the lives of people affected by stroke. While change is clearly needed as people move into the community there is much to build on.

We sincerely hope that the experience of participating in the process – local and regional forums - has created the momentum to act collectively toward local, regional and system improvements.

We would like to acknowledge Champlain and Southeastern Ontario Stroke Regions for allowing us to build on their community engagement work and their generous sharing of their experiences. This has enhanced our process greatly.

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EXECUTIVE SUMMARY

There are approximately 20,000 strokes each year in Ontario and close to 115,000 people are living with stroke. In 2005-06 the incidence of stroke in the Erie St. Clair Local Health Integration Network (LHIN) region was 1,279 and the incidence of stroke in the South West LHIN was 1,565.

A goal of the Southwestern Ontario Stroke Strategy is to build capacity across the Erie St. Clair and South West LHINs to support people with stroke to live more fully in their communities. Modeling on successful projects in the Champlain and Southeastern Ontario Stroke regions, a community engagement process was initiated. The purpose was to obtain a more detailed understanding of the barriers to inclusion and participation that people with stroke and their families experience, and identify possibilities for action. Six community engagement sessions were held with the intent to learn from the experience of people affected by stroke and community providers and develop a shared vision for the changes required.

In the sessions people with stroke, their family members and providers identified what was needed to enable successful community reintegration. Common themes developed which have been described as pathways. While each pathway requires specific actions to ensure change, they are interrelated and an integrated strategy is required to ensure an impact on people's lives. The four pathways are:

Proactive Support and Follow-up to Transition to the Community

This pathway involves the transition from hospital into the community and is critical to enabling the community reintegration process. Proactive support will ensure people have access to timely services and supports that will facilitate their transition to living fully in the community.

The key elements to this pathway include:

- active involvement of families in planning for the transition home
- "just in time education" for individuals and families affected by stroke
- comprehensive and consistent care coordination
- comprehensive, accessible and up-to date resource listing of services and supports
- knowledge of stroke and community services and supports amongst health care providers

Enabling the Person to Live at Home

This pathway refers to the elements required to support the care of the stroke survivor at home. The pathway requires that certain elements are in place – personal care, respite and education for family caregivers as well as home-making support.

The key elements to this pathway include:

- access to personal care
- awareness, training and capacity building of family members
- formal and informal opportunities for respite
- enhanced support during the transition phase when the person with stroke first comes home
- income support for family caregivers

Access to Rehabilitation Services

Rehabilitation services in the community are fundamental to the stroke experience. People want to progress to their maximum potential and recognize that rehabilitation is a critical first step in the recovery process.

The key elements to this pathway include:

- enhanced access to rehabilitation services in the community
- increased intensity and duration of therapies
- specialized stroke expertise of professionals
- integrated approach between hospital and community rehabilitation services
- access to reassessment
- access to social work
- access to vocational rehabilitation
- education for families

A Community Environment that Supports Active Engagement and Continued Recovery

This pathway ensures that people can be active in their community. A return to the community is the initial part of the recovery process. People seek opportunities to engage in activities that will support their continued recovery, enable them to regain their independence and interact with other people affected by stroke as well as the broader community. It requires accessible spaces, societal acceptance and understanding of the capacities and deficits associated with stroke or disability as well as transportation options.

The key elements to this pathway include:

- opportunities to continue the recovery process - community groups such as exercise groups, pool programs and aphasia / conversation groups
- opportunities to socialize, provide mutual support and volunteer
- processes to support the transition into community activities
- welcoming and accessible community spaces that support engagement
- orientation towards building on the assets and skills of people with stroke
- understanding of stroke amongst providers and volunteers working in the community
- accessible low cost transportation options and an affordable approach to regaining a drivers license
- access to appropriate assistive devices
- societal acceptance of people with disabilities
- affordable, accessible housing as well as supportive housing

There is significant existing capacity within the region – many organizations are offering services and working toward changes that will benefit people with stroke and their families. The stage has been set to advance more change if the passion of key stakeholders including people with stroke and their families is supported. Given the scope of actions outlined in the report it is the intent of the Southwestern Ontario Stroke Strategy to share the report with organizations where the mandate and goals are aligned as some of the actions are beyond the influence of the stroke strategy.

The next steps will include:

- Identify priorities for action that are within the Southwestern Ontario Stroke Strategy to influence and determine the associated actions.
- Determine how the work to be advanced aligns with existing initiatives including the current stroke strategy structure.
- Be responsive to the partner organizations / agencies that may wish to move forward on actions outlined in the report.
- Identify how people with stroke and their family members can be engaged in the process - working on specific initiatives and advocating for the changes needed.
- Develop a process to monitor and evaluate progress and share with key stakeholders the changes that are being made and their impact on people with stroke and their families.

INTRODUCTION

There are approximately 20,000 strokes each year in Ontario¹ and close to 115,000 people are living with stroke². In 2005-06 the incidence of stroke in the Erie St. Clair Local Health Integration Network (LHIN) region was 1,279 and the incidence of stroke in the South West LHIN was 1,565. Out of every 100 people who have a stroke, 15 will die, 10 will recover completely, 25 will recover with a minor impairment or disability, 40 will be left with a moderate to severe impairment and 10 will be so severely disabled they will require long-term care³. Stroke is therefore the number one cause of long-term adult neurological disability⁴ and 1 in 5 people living in a long-term care home have a diagnosis of stroke.

The Stroke Strategy team seeks to build capacity across the Erie St. Clair and South West Local Health Integration Network (LHIN) regions to support people with stroke to live more fully in their communities.

We know that people with stroke and their families experience a number of barriers to inclusion and participation in their communities following stroke. There are a variety of services and supports in place across the regions to assist people who have experienced a stroke. However, persons with stroke, their families/support people and care providers often indicate that changes are needed.

For this reason, the Southwestern Ontario Stroke Strategy team decided to embark on a process to:

- work with partners to develop a shared vision of the changes required to support people to reintegrate into their community;
- identify and assess opportunities to create positive changes;
- define priorities for change;
- create a platform to stimulate change;
- identify possible actions; and
- define next steps for advancing action.

A shared vision will help to guide efforts to effectively support people with stroke as they re-integrate into the community.

OVERVIEW OF THE REPORT

This document provides an overview of the process undertaken and the results. It outlines:

- the rationale for the design and the steps in the process;

¹ Ontario Stroke System (OSS) Stroke Evaluations Advisory Committee (July 2007). Ontario Stroke Evaluations Report 2006: Technical Report – A Supplement to “Integrated Stroke Care in Ontario” Ontario Stroke Evaluation Report 2006.

² Heart and Stroke Foundation of Ontario. www.heartandstroke.ca

³ Kirshner, H. et al (2005). Long-Term therapy to prevent stroke. *Journal of the American Board of Family Practice (JABFP)*. 18(6), 528-540.

⁴ Canadian Stroke Network. Canadian Stroke Network Fact – Sheet. www.canadianstrokenetwork.ca/media/downloads/fact.sheet.e.pdf
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- the principles which emerged and are intended to guide any interventions or changes to services/supports;
- the services and supports that are required – the pathways;
- existing capacities that are currently known – more may be identified as discussion evolves;
- possible opportunities for action; and
- recommended next steps.

Quotes from people with stroke and family members provide a context for understanding the challenges faced and the supports required.

To augment some of these perspectives and to provide further support for action excerpts from relevant research/evidence related to each pathway are included.

OVERVIEW OF THE PROCESS

The process was modelled after a similar process undertaken by the Southeast Regional Stroke Centre which was based on the learning from a community planning process conducted through the Champlain Regional Stroke Centre. The intent of all processes was to learn from and leverage the experience of people directly affected by stroke with the experiences of providers working in the field.

There are many different organizations and individuals who have information about the experience of people with stroke, ideas about what could be changed to improve community reintegration and influence to make it happen. To stimulate real change it is imperative to hear a range of perspectives about what changes are required the priorities, the opportunities to build on and most importantly the possibilities for action.

While this report is critical to support further action, the process itself and the experience of participating was intended to energize people and mobilize them toward action.

DISTRICT FORUMS

District forums were held in six districts across the Erie St. Clair and South West LHIN regions in April 2008 including:

- Owen Sound to cover Grey and Bruce Counties
- London to cover Middlesex, Oxford and Elgin Counties
- Stratford to cover Huron and Perth Counties
- Sarnia to cover Lambton County
- Chatham to cover Kent County
- Windsor to cover Essex County

A range of individuals and organizations were invited to participate including people with stroke, their family members and providers working in community health centres, family health teams, community support service agencies, community care access centre, acute care and rehabilitation discharge planning services, rehabilitation services, specialized brain injury services and recreation services. The intent was to include people and organizations representative of the diversity of the region:

- people living in rural, small town and urban areas;
- people across the age spectrum;
- people living on a range of incomes;
- people experiencing a variety of effects following stroke (i.e. aphasia, hemiplegia etc.);
- Anglophones, Francophones and Allophones and representatives from the Aboriginal population.

Over one hundred and eighty people participated in the six forums – a significant number of them were people with stroke or their family members.

FORUM DESIGN

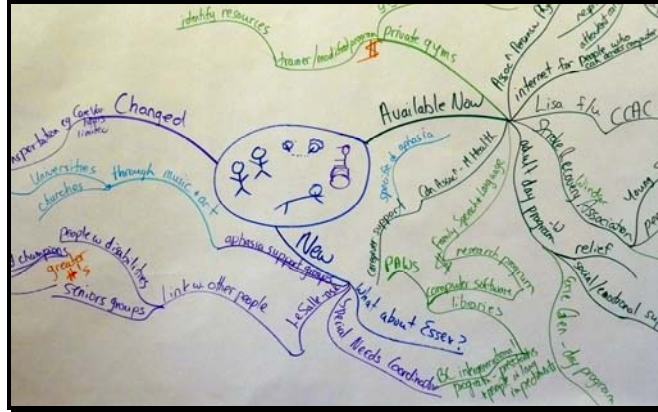
Similar to the process utilized in the Southeastern Ontario Stroke Region the forums were designed to:

- identify the changes in services and supports needed to enhance reintegration of people affected by stroke into the community;
- identify possible actions that could be taken;
- identify assets and opportunities to build on; and
- stimulate energy for action.

Building on concepts and tools for collaborative research and social action, the design was intended to support all participants to actively contribute to the process. The facilitation techniques used allowed a wide cross-section of stakeholders to learn together and engage in shared analysis – a critical step to moving toward action. The techniques supported participants to focus on the issues of primary interest to that group and their visual nature allowed people to easily track the outcomes of the dialogue.

In the morning participants focused on determining desired changes to improve the experience of people with stroke as they reintegrate into the community. A free-listing technique was used to generate significant information about desired changes. Working in small groups, participants identified three to four key changes and documented them on cards. The larger group then re-convened and participants categorized the desired changes into themes. The resulting discussion focused on developing a shared understanding of the changes needed and why they were important.

Although all changes identified are being brought together in this report, participants in each forum were given an opportunity to indicate which themes were of primary interest to them. The top two or three areas of change were used as the focus for discussion in the afternoon session. Depending on the priority changes identified different facilitation techniques were used to explore that topic. Many of the sessions focused on identifying what opportunities existed to build on in that district, what actions could be taken and who would need to be involved.



REGIONAL FORUM

The intent of the regional forum was to:

- validate the emerging principles to guide action and the areas for change which would enable community reintegration;
- confirm and identify known capacities or initiatives which could be built on to achieve desired changes;
- review the possible actions identified to date and modify them as needed; and
- determine how to advance action.

A *Preliminary Report* documenting the results of the district forums was developed and distributed in advance of the regional forum.

A cross section of participants including providers and people with stroke and their family members were invited to participate in the forum. Forty people participated – the majority of whom had participated in one of the district forums.

In the morning an overview of the emerging principles and areas for change was presented. People with stroke and family members were then asked to indicate how well these reflected their experience and understanding of what needed to change. Subsequently, providers were given an opportunity to clarify what they had heard and offer their own reflections.

Participants were then given an opportunity to review large murals which outlined the existing capacities and possible actions needed. Additions and changes were made by participants.

In the afternoon discussions were held about possible leadership for advancing action. The intent was to clarify how possible actions related to existing initiatives and what organizations or groups could lead change in specific areas. Given the size of the Southwestern stroke region and the coverage of two LHIN regions further work is required to define actions.



WHAT WE HEARD

While there were some differences unique to each district within the Erie St. Clair and South West LHIN regions, the common experience of people with stroke and their families across the Southwestern Ontario Stroke region was evident.

Four pathways have emerged as the critical to support effective community reintegration. Different elements of these pathways have been established in different districts. The services or supports that are in place differ somewhat and in many cases are offered by different providers reflecting the history of how services evolve to respond to identified needs. Gaps in services and supports and the processes to access them do exist.

Overall, the emerging principles and pathways were seen to be an accurate reflection of what had previously surfaced in the district forums. People affected by stroke and their families indicated that their experiences and desires for change were accurately captured. Some changes were made and are reflected in this report to strengthen the emphasis on particular needs.

EMERGING PRINCIPLES

A set of principles emerged to guide service delivery approaches that support active community re-engagement of people with stroke.⁵

- Provide client/family centred services - acknowledge the differences amongst people with stroke and their families
- Support ongoing learning for the person with stroke and their family
- Foster stroke expertise amongst service providers and volunteers
- Recognize the desire for independence and to make a meaningful contribution

⁵ Some of these principles were first identified through the initiative in the Southeastern Ontario Stroke Region. Pathways for People with Stroke to Live Fully in the Community September 25, 2008

- Recognize the tremendous emotional impact that a stroke can have on an individual and family
- Identify the commonalities between people with stroke and people with other physical disabilities
- Assume an equitable approach to the provision of services and supports
- Recognize the many costs associated with stroke (private rehabilitation, transportation, community services, recreation, adapted equipment, home renovation, loss of income) and strive to overcome finance as a barrier to accessing services and supports
- Recognize the valuable role peers can assume for people with stroke and for family
- Build on existing and create new partnerships and relationships amongst the myriad of community services and supports
- Create opportunities for people with stroke and their families to connect with providers to work toward change

EMERGING PATHWAYS

Four key pathways which enable community reintegration have been identified. Each pathway requires focus to ensure change occurs where required; yet, they are all interrelated and need to be considered together for their overall impact on people's lives.

Proactive Support and Follow-up to Transition to the Community is critical to enabling the community reintegration process. Without active support, many people do not access the services and supports that will facilitate their transition to living fully in the community.

Enabling the Person to Live at Home requires that certain elements are in place – accessible housing and appropriate equipment, personal care, respite and education for family caregivers assuming part of that role as well as home-making support.

Access to Rehabilitation Services in the community is fundamental to the stroke experience. People want to progress to their maximum potential – recognizing that rehabilitation is a critical first step in the recovery process.

A Community Environment that Supports Active Engagement and Continued Recovery ensures that people can be active in their community. A return to the community is the initial part of the recovery process. Rehabilitation is only the beginning, recovery is a longer process. Therefore, people seek opportunities to engage in activities that will support their continued recovery, enable them to regain their independence and interact with other people affected by stroke as well as the broader community. It requires accessible spaces, societal acceptance and understanding of the capacities and deficits associated with stroke or disability as well as transportation options.

Figure 1 depicts the pathways as an integrated model for people with stroke to live fully in the community.

Pathways for People with Stroke to Live Fully in the Community

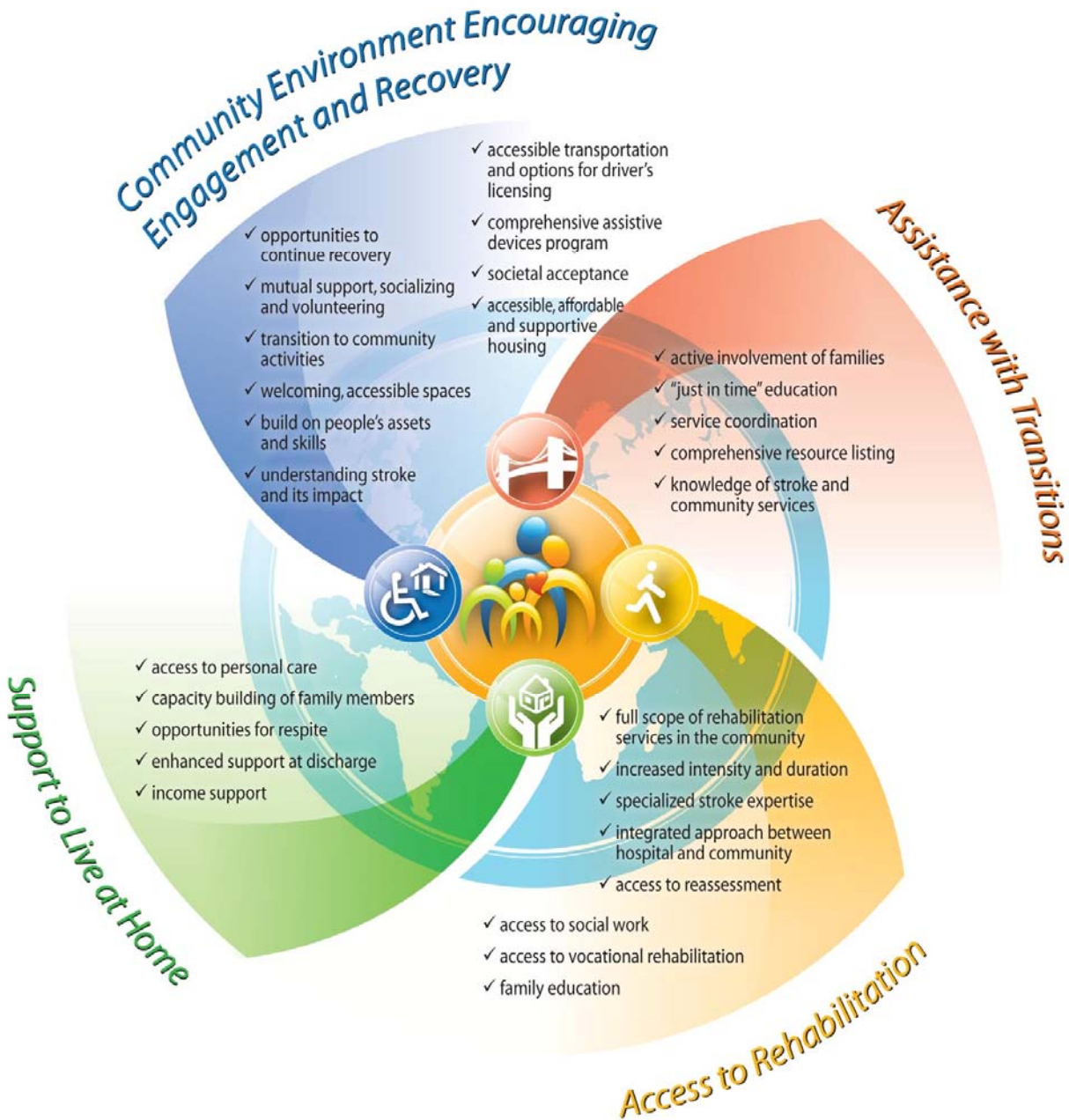


Figure 1: Pathways for People with Stroke to Live Fully in the Community

WHAT IS NEEDED?

Active involvement of families in the planning for the transition home: The planning for transitioning back to the community needs to start in the acute setting and continue through rehabilitation. Families want and need to be actively involved in planning and preparing for re-entry into the community. Family members want to know many things including:

- what type of recovery can be expected;
- what complications may occur;
- what the risk of future strokes is;
- what type of care is needed;
- what and how much rehabilitation they will have access to;
- when the person will come home;
- what needs to change at home to enable that;
- how they can support the ongoing recovery of the person with stroke; and
- what services and supports are available to enable that recovery.

“Just in time education” for individuals and families affected by stroke: While many family members indicated that they did receive some education in the hospitals they frequently experienced it as overwhelming. While it is recognized that health care professionals often try to provide the information they think people will need in the community, if that information is not immediately relevant people have a hard time absorbing it. Education needs to be incorporated with a follow-up function.

Comprehensive and consistent service coordination: The service coordination and follow-up function needs to extend beyond medical care to incorporate:

- assessment of the needs of the individual with stroke and the family members involved in providing care;
- monitoring of the mental health of the person with stroke and their family members (including children) and supporting or making arrangements to access informal or formal interventions as needed;
- ability to arrange for assessments and re-assessments as well as rehabilitation services;
- support to arrange for appropriate housing and associated financial support – new accessible housing, supportive housing, renovations of existing housing, adaptive equipment;
- clear information about financial support and assistance to access financial support for people with insurance, pensions or benefits who are trying to activate them, for people without those benefits– there are many obvious as well as hidden costs associated with having a stroke such as medications, lab tests and equipment purchases;

...what people said

“There are services out there but if you don’t know about them you can’t access them.”

“Where do I go for help? Who do I call? I have no idea what is out there.”

“Stroke survivors and caregivers need to be masterminds in navigating the system after hospital and this can be a very painful process.”

“I was never asked if I needed help when I got home.”

“We are concerned that after 4 weeks in the hospital we had no follow-up at home at all.”

“I am amazed at what supports do exist and how little we knew about them despite our tremendous efforts to find supports.”

- up-to-date information about the services available and how to access them as well as support to transition into programs that will enable continued recovery;
- support for the whole family to ensure that services are in place including respite and support in the home where needed;
- ensuring that systems are in place to monitor medications and do appropriate testing for secondary prevention;
- ensuring adequate and appropriate communication between health care professionals; and
- advocacy for families seeking access to the services and supports they require.

Families are seeking a trusted relationship with a professional able to guide them through planning for their transition back to the community and to provide consistent service coordination, follow-up and follow-through once they re-enter the community. The intent is to establish a client/family centred service with service coordinators who have the time to be proactive and focus on the unique circumstances of the situation in both the short and long term as circumstances change. The level of support required differs depending on the severity of the stroke however people with stroke and their families indicate that they all require some level of support – including those with mild physical, perceptible, cognitive or communicative deficits.

Comprehensive, accessible and up-to-date resource listing of services and supports: A comprehensive, accessible, current resource listing with information about how to access services is required to support this function. This listing could also be accessed on-line for people who are computer savvy.

Knowledge of stroke and community appropriate service and/supports amongst health care providers: The service provider(s) responsible for supporting transition and follow-up require a real understanding of stroke and the kinds of services and supports that will benefit individuals and their families immediately and as they continue to recover and circumstances change.

WHAT IS AVAILABLE?

Different organizations have assumed a role in providing support and follow-up for individuals and their families to transition into the community post stroke. Sometimes the role falls clearly into the mandate of the provider and in others cases the role has emerged in response to identified needs and gaps.

Community Care Access Centres (CCAC) have a mandate for assisting people to navigate through the health care and community service environment. While some people in the forums indicated that they did get the services and support they needed with the

assistance of a case manager there was indication that more could be done to fulfill that function to its maximum potential. Changes identified include:

...what people said

“The caregiver becomes the therapist. The caregiver/therapist needs to be involved in the hospital before discharge”

“Listen to what I am saying to you and give me the education I need. Give me the education when I need it and can hear it.”

“Information overload. Give me some today and a little more tomorrow. Break it down.”

“The education in the hospital does not always stick because it doesn’t necessarily make sense until you get home.”

“We still think of stroke as an elder person’s disease but I am young. How do I talk to my kids about it? How do I/we support them? I needed advice or help to deal with the kids. It was up to us to come up with ideas.”

“Getting CPP was an extremely difficult stressful process. We had to appeal three times before we got it.”

- ensure case managers have an understanding of stroke and the services that are of benefit to individuals and families to enable recovery and coping with unique circumstances;
- establish a proactive approach to providing case management support for people who are not or who are no longer receiving services that are offered or coordinated through CCAC;
- and monitor the mental health of the person with stroke and their family caregivers and refer them to appropriate services/supports as needed.

Erie St. Clair LHIN Region

- The Erie St. Clair CCAC office serving Chatham Kent has dedicated funding for case managers and rehabilitation professionals working with people who have acquired brain injuries. As well, the case managers on the acquired brain injury teams have had specialized training in stroke.

South West LHIN Region

- The South West CCAC is increasingly locating staff within community health centre, family health team and community support service locations to facilitate access to clients and enhance linkages between services.

Regional and District Stroke Centres are responsible for coordinating stroke services across the continuum from prevention to community reintegration within a particular geographic area. Some have assumed a mandate for following up with clients upon discharge from either acute or rehabilitation services.

Erie St. Clair LHIN Region

- The Windsor Essex District Stroke Centre has utilized its enhanced funding to provide a nurse in Windsor and in Leamington to provide follow-up support to people with stroke discharged from acute or rehabilitation services.
- The Sarnia-Lambton District Stroke Centre provides follow-up phone calls to stroke survivors who are discharged from acute care and do not receive inpatient or outpatient rehabilitation.

South West LHIN Region

- The Grey Bruce Rehabilitation Unit does a 6 week follow-up post discharge. The patient meets with specific therapists for reassessment and recommendations.
- London Health Sciences Centre-University Hospital is currently piloting follow-up phone calls to stroke survivors discharged home from acute care who do not require inpatient rehabilitation.
- Specialized Community Stroke Rehabilitation Teams have recently been funded through the Aging at Home Strategy. It is anticipated that these teams would be able to assume a follow-up function in each district across the South West LHIN region.

...what people said

"I want to be able to turn to someone who knows about stroke."

"One person to triage my questions would be good."

"People don't think to ask things. We don't know what we don't know."

"Many people do not qualify for CCAC so they do not get case management support. If you don't need CCAC services after 6 months you get taken off of the caseload. This is not right. People need follow-up."

"Both my mother and father-in-law have had strokes. I work in the system but I have had a hard time myself."

Secondary Stroke Prevention Clinics located in Regional and District Stroke Centres fulfill a partial role in assisting people to identify services and supports that they require – both to prevent them from having another stroke and to support their recovery process.

Community health centres and existing/emerging family health teams are expected to assume a case coordination function for their clients with chronic/complex conditions. Social workers, nurses and nurse practitioners assume this role.

Acquired Brain Injury Services are increasingly serving people with stroke. Originally designed to serve people with traumatic brain injury the services have evolved to include the stroke population.

Erie St. Clair LHIN Region

- The Brain Injury Association of Chatham Kent has a community reintegration coordinator responsible for fulfilling this case coordination function.

Southwest LHIN Region

- St. Joseph's Health Care - Parkwood Hospital has an Acquired Brain Injury Outreach Team to do follow-up with people with acquired brain injury including some people with stroke.

Stroke Recovery Associations provide opportunities for people affected by stroke to exchange information about services and supports. Each association works differently, has different sources of funding, and different staffing – volunteer and paid. The capacity of the associations to provide a formal peer support program within hospitals and in the community is largely dependent on their resource base and whether or not they have staff responsible for coordinating activities and recruiting and training volunteers as well as the relationship that has been defined with providers. Some of the associations are linked to the March of Dimes and Stroke Recovery Canada.

Erie St. Clair LHIN Region

- Stroke Recovery Associations are established in Sarnia and in Windsor.
- A new association is evolving in the Leamington area.
- While not a formal association a support group for younger stroke survivors exists in Windsor and is supported by the Windsor Essex District Stroke Centre.
- There is a "Friends of Stroke" group in Chatham.

Southwest LHIN Region

- Stroke Recovery Association exists in London and in Owen Sound an association is pending.
- A network of people with stroke and their families is emerging in the West Lorne area.
- A group for younger stroke survivors and their families also exists in Oxford.

Community Support Services agencies frequently fulfill a mandate to provide information and referral to people affected by stroke. Community support service agencies exist across the Erie St. Clair and South West LHIN regions.

Home and Community Care Programs exist in many aboriginal communities. Each program operates differently according to the needs of the community. Some of these programs may provide a nurse case manager to represent First Nation people and can facilitate the integration

of clients with stroke into the community. For example, on Walpole Island, the nurse case manager can attend rounds in hospital, knows the resources offered in the community, and often is aware of family dynamics, housing conditions, transportation issues and other barriers. Together with the parts of the health care continuum the nurse case manager can help to facilitate community reintegration. Not all Home and Community Programs have the same services. The services available are available for band members living in the community. Another resource in all First Nation communities is **Health Centres**. These centres focus on health promotion and prevention and provide services to band members who live in and outside of the community.

The South West LHIN is working with partners to design an enhanced **system navigation service** to make it easier for people to get information about and access the services they require.

A **stroke website** is under development which will include information about services and supports for stroke survivors, families and health care professionals living in Huron and Perth Counties and will be accessed through the Healthline.ca (www.thehealthline.ca).

WHAT CAN BE DONE?

- a. Define the service coordination and follow-up model for people with stroke in each district to clarify the roles and responsibilities of the key partners engaged – district stroke centre, community care access centre, family health teams/ community health centres, community support service agencies and specialized services like acquired brain injury. Determine the distinction between follow-up support and case management of services, define unique roles and establish a clear triage process as needed. Link the work to existing LHIN initiatives designed to enhance system navigation to ensure that the work is aligned and will address the needs of people affected by stroke.
- b. Establish a process to ensure that every person and their family affected by stroke receive the transition and follow-up support needed to access appropriate services and supports. At a minimum people require an assessment to determine if additional supports are needed including supports to continue the recovery process.
- c. Establish guidelines to support staff involved to ask the right questions to assess needs specific to stroke and determine appropriate referrals – for the full scope of community services.
- d. Clarify the role of Stroke Consumer Groups (e.g. Stroke Recovery Associations, Friends of Stroke etc.) in supporting people affected by stroke to access the services and supports they might benefit from – including peer support.
- e. Define the core competencies of people responsible for service coordination and follow-up. This need has also been identified in the Southeastern Ontario Stroke Region and could be done in partnership.

...what people said

“People need just in time guidance. Workers need stroke knowledge and awareness of the services available.”

“Why can't there be a case worker that follows up on you?”

“I had no idea these things were available. This may help us take the next step.”

“A phone call follow-up would be nice.”

“We need to be linked to someone in an advisory capacity with suggestions on where to go next.”

Information, transition and follow-up is really interrelated with recovery.”

- f. Develop a centralized information database, which is maintained so it continues to be current. Leverage existing information technology infrastructure. Consider including the 20 most frequently asked questions from people with stroke.
- g. Increase the cultural awareness and education of staff working with First Nation people in regards to history, colonization and residential schools and build relationships with these communities. More cultural awareness of the First Nation people and improved communication and partnership between native and non-native health care professionals will improve care and community reintegration for these people.

ENABLING THE PERSON TO LIVE AT HOME

WHAT IS NEEDED?

Access to personal care: Once the person is at home they often require personal care. The person with physical deficits may require support to bathe, assistance to get dressed and support to prepare and eat meals. Someone with cognitive deficits may require monitoring to ensure that they remain safe while someone with aphasia requires communication supports. Many people indicated a need for increased access to personal care.

Awareness, training and capacity building of family members: Family members who assume a caregiving role seek to understand the condition of the person with stroke and how they can best support them and where possible facilitate their recovery. They seek education and training to enable them to build their capacity to assume the caregiving role.

Formal and informal opportunities for respite care: Family members – whether they are employed outside of the home or not – frequently assume a significant caregiving role. To stay healthy they require respite for personal time to rejuvenate and to engage in the activities of daily living - shopping, banking, medical appointments and recreation/social activities. Without respite, people with stroke who require significant care are

at risk of a transfer into a long-term care home as family caregivers become overburdened with the responsibility resulting in a deterioration of their own health. In some circumstances family members have difficulty acknowledging and accepting that support is needed. They are cautious that others will not provide the loving care required. A proactive approach to follow-up by a trusted individual can serve to overcome the barrier to requesting support.

Enhanced support during the transition phase when the person with stroke first comes home: During the transition from acute care or rehabilitation to home families can sometimes benefit from enhanced support. They are often overextended and not ready for the new reality

...what people said

“All of a sudden you expect my wife to be a psychologist, speech therapist, physiotherapist, occupational therapist. We need education. We don’t have the training. You do!!”

“The education is important. Even now my wife doesn’t understand and she complains that I am always sleeping.”

“When they first come home from the hospital it is quite overwhelming.”

“It took me 2 ½ years to admit that I needed some help. That is very difficult.”

“I get respite care. It is nice because I know that he is safe when I leave. It is also the same people/team so they know him and know what he can and cannot do.”

“The government needs to re-evaluate the number of hours CCAC can provide.”

“People’s needs are met in the hospital and might be met if they access CCAC but there is a gap if they fall out of needing CCAC for health services.”

of having the person with stroke return home and the expectations of them for caregiving. A range of supports - personal care, home-making and respite are needed as the family adjusts.

Income support: Family members who assume a caregiving function frequently give up employment to assume this function. The need to change tax laws to provide better credit to family members and cover employment leaves would alleviate significant financial hardship.

WHAT IS AVAILABLE?

Community Support Service agencies and Community Care Access Centres provide a wide range of services that can enable people to live in their home and community. Many of the services can be accessed directly through self referral.

Community Support Service agencies offer:

- Respite care
- Personal care
- Attendant care
- Friendly visiting
- Adult day programs
- Home making assistance
- Home maintenance
- Security checks
- Meal programs (Meals on Wheels, congregate dining)
- Wellness programs

...what people said

“My husband has to be cared for 24 hours. You always have to be on your guard. He gets into trouble. He is like a child. When he is quiet he is getting into trouble. My husband now comes to the clubhouse. It is a safe space and it is respite for me.”

“Respite should not just be in the home but a place where the stroke survivor can go.”

“We never did anything together before the stroke but now we are together all of the time.”

Community support service agencies have evolved differently in different communities in response to local needs. More recently with enhanced government funding, agencies are working toward providing a similar basket of services across the province for both seniors and adults with physical disabilities.

Community Care Access Centres offer:

- Respite care
- Personal care
- Home making assistance
- Nursing
- Therapies (occupational therapy, physiotherapy, speech and language therapy, nutrition, social work)
- Medical supplies and equipment
- Information and referral
- Case management

WHAT CAN BE DONE?

- a. Ensure staff responsible for planning and follow-up of clients support family members to plan for re-entry to the community and establish regular contact and regular intervention to monitor what families need at different points in time e.g. personal care, respite. A trusted established relationship with a professional will help to identify when support is needed and to enable people to accept the support.

- b. Establish a process to link families with Community Support Service agencies in the acute/rehab setting to facilitate access to services.
- c. Consider implementing a transition to home program modelled after other Ontario cities which provides enhanced personal care and home-making support to individuals and families during the initial period as the person transitions to home.
- d. Partner with the LHINs and other organizations to review respite care options and work toward ensuring that sufficient options are available across the region to support people in caregiving roles.
- e. Where possible, establish creative approaches to providing low or no cost respite which serve to support the socialization and recovery of the person with stroke e.g. enhanced Friendly Visitor Program, stroke recovery transition programs.

ACCESS TO REHABILITATION SERVICES

WHAT IS NEEDED?

Enhanced access to rehabilitation services in the community: People with stroke identified a need for enhanced access to publicly funded, community-based in home and out-patient rehabilitation services particularly speech and language pathology, physiotherapy, occupational therapy and recreation therapy. People want to know they are getting the services they need to maximize their recovery. Currently, distance to travel for rehabilitation is a barrier to access for many clients. Clients who are forced to travel very long distances at considerable cost and difficulty in terms of personal stamina may not be able to do so.

Increased intensity and duration of therapies: People would like to enhance the intensity and duration of therapy they receive. As people gain their endurance they continue to make progress and need therapy to do so. While interdisciplinary day rehabilitation programs can serve a critical need they are not available in most communities. Community rehabilitation services are available through agencies contracted with the CCACs but they are limited and in most cases are not offered by therapists with stroke expertise. There was some indication that the therapist's role is focused exclusively on assessment and the identification of exercises to be carried out by personal care workers.

...what people said

"We have been waiting weeks for out-patient therapy services."

"CCAC needs therapy staff with specific stroke expertise."

"The length of time people get rehab needs to be individualized."

"All the therapists ever did was reassessment."

"Vocational training needs to be part of rehabilitation."

"I need support to deal with his personality changes."

"Patients/caregivers need to know that the first three months is when changes occur the most and after that things slow down. Every professional needs to reinforce this (this being recovery time is optimal)."

Specialized stroke expertise of professionals: People with stroke and their family members are seeking rehabilitation from therapists who have developed an expertise in stroke. They want to know they are getting access to the best possible therapy to reach their full potential.

Integrated approach between hospital and community rehabilitation services: People with stroke would like in-patient or day program rehabilitation services to be aligned with community

rehabilitation services to ensure that assessments and goal planning are appropriately communicated and transferred between practitioners. Integration may also support a timely transition to avoid a loss of function or progress of the person with stroke.

Access to reassessment: People are seeking monitoring and reassessment of their condition. Over time many people continue to recover function and some people could benefit from therapy to continue the progress. Others lose function and require some therapy to regain it. A case coordinator could potentially have a role to support this function.

Access to social work: Individuals and families (including the children) often require support to cope with the changes that have happened in their lives. Non family emotional support can be critical to enabling people to adjust to their new circumstances. Peers can also assume a valuable role. There is a need to monitor, identify and manage depression of the person with stroke and possibly their family members.

Access to vocational rehabilitation: Increasingly young people who were or are planning to be in the workforce experience a stroke. It is imperative that they have access to vocational rehabilitation to regain skills or develop new skills to enable them to re-enter the workforce and earn an income. Currently, access to vocational rehabilitation appears to be limited.

Education for families: Families seek opportunities to learn from professionals about the stroke. They want to understand the potential for recovery and how they can be actively involved in supporting that recovery.

WHAT IS AVAILABLE?

Community Care Access Centres offer a range of in home therapies – occupational therapy, physiotherapy, speech and language therapy, social work and nutrition. In most areas the staff offering the service do not specialize in stroke care.

Erie St. Clair LHIN Region

- The Erie St. Clair CCAC – Chatham-Kent office offers an acquired brain injury team who provides rehabilitation service for people with acquired brain injuries. The program has dedicated funding and case managers who have had stroke education.

Hospitals provide a range of ambulatory/day hospital services. A survey of Stroke Rehabilitation Publicly Funded Ambulatory/Day Hospital Services offered within Southwestern Ontario (Erie St Clair and South West LHINs) was conducted in February 2007. The following conclusions were reached in relationship to the thirty-six Community, Small Rural, Acute Tertiary and Freestanding Rehabilitation hospitals:

Ambulatory/Outpatient Services:

- 89% (32/36) reported providing single services on an outpatient basis for stroke survivors. It is important to note that this reflects the presence of services, and is not indicative of either the therapeutic intensity or clinical expertise with which the services are delivered.⁶

⁶ **Clinical expertise:** the proficiency and judgment that individual clinicians acquire through clinical experience and clinical practice. Increased expertise is reflected in many ways, but especially in more effective and efficient diagnosis and in the more thoughtful identification and compassionate use of individual patients' predicaments, rights, and preferences in making clinical decisions about their care.
BMJ 1996 312:71-72

- 54% (15/28) of those reporting numbers of stroke survivors served by single service outpatient programs see 0-5 stroke survivors per year; and 86% (24/28) reported seeing less than 25 stroke patients annually. This volume would be insufficient to build clinical expertise in stroke care.
- 65% (22/34) of those responding reduced outpatient services when staffing shortages arise to cover higher priority acute services. This has significant impact on the actual availability of services.
- 51% (18/35) of responding facilities reported experiencing cuts to ambulatory/ outpatient services within the past 5 years.
- The majority, 89% (32/36), reported physiotherapy as a service offered for stroke on an outpatient basis
- Access to occupational therapy services and speech language services was significantly more limited, being offered at only 44% (16/36) and 42% (15/36) of facilities respectively
- Access is seriously limited for social work services (19%)
- It is evident that access to interdisciplinary team care for ambulatory stroke rehabilitation services is not widely available in Southwestern Ontario

Day Hospital Services:

- There are 5 Day Hospitals in Southwestern Ontario – Hanover, London, Petrolia, Sarnia, Stratford
- All offer physiotherapy
- 3 of the 5 offer occupational therapy, speech language pathology and social work
- 4 of 5 provided recreation therapy services
- 3 facilities reported cuts to Day Hospital services within the last 5 years

...what people said

"I gotta still do therapy because I am still getting better."

"Stroke survivors have expressed to me that they want more therapy. We live in a rural community and they may qualify for out-patient services in London but they do not have the transportation."

"If therapy can be provided in big centres why can't it be provided in more rural/local settings?"

Regional and District Stroke Centres have

evolved new services to meet the rehabilitation needs of people affected by stroke since the inception of the Stroke Strategy.

Erie St. Clair LHIN Region

- The Windsor Essex Enhanced District Stroke Centre provides stroke rehabilitation follow-up. A stroke nurse provides follow-up for stroke survivors discharged from inpatient rehabilitation. The hospital also has physiatry services that provide follow-up and work closely with the stroke nurse.

South West LHIN Region

- Funding has been approved from the Aging at Home Strategy for three Specialized Community Stroke Rehabilitation Teams. The teams will include the following complement of therapy services – speech and language pathology, physiotherapy, occupational therapy, social work, nursing and recreation therapy. The teams are in the planning phase. The need for follow-up will be provided by these teams for each district within the South West LHIN. These teams will also need to determine what steps can be taken to address the gap in vocational rehabilitation. Teams will be established in: Stratford for Huron and Perth Counties; Owen Sound for Grey and Bruce Counties; and London for Middlesex, Oxford and Elgin Counties.

The University of Western Ontario – School of Communication Sciences and Disorders in London, Ontario offers Community Aphasia Groups. These groups are therapeutic in nature with a speech and language pathologist involved. Three groups are offered annually for an 8-10 week session.

WHAT CAN BE DONE?

- a. Establish the new Specialized Community Stroke Rehabilitation service to enhance access to rehabilitation services in the South West LHIN region. Ensure the service is integrated with existing therapy services.
- b. Assess what is in place in the Erie St. Clair LHIN region and determine how services could be augmented. Explore the feasibility of establishing a similar service to the South West LHIN region if appropriate.
- c. Advocate for enhanced publicly funded rehabilitation services in the community including social work services.
- d. Determine what role therapy assistants (communication, occupational and physical) could assume in supporting rehabilitation in the home.
- e. Consider what role peers could have to complement the new Specialized Community Stroke Rehabilitation service. The Assertive Community Treatment Teams that support people with mental health issues living in the community include peers as part of the team complement.
- f. Explore the uptake of the West GTA Stroke Network's Community Best Practice Guideline (2005) by CCACs which are intended to facilitate case management decision making related to service planning for rehabilitation (number of visits and length of stay to achieve goals).
- g. Develop a strategy to support people to access appropriate vocational therapy: determine what services are needed and for how many people; clarify what services are available and the roles of respective partners – employers, insurance companies, educational institutions, government, non profit agencies; determine what changes are needed to enhance access to appropriate services and supports; and advocate for any changes needed.

A COMMUNITY ENVIRONMENT THAT SUPPORTS ACTIVE ENGAGEMENT AND CONTINUED RECOVERY

WHAT IS NEEDED?

Opportunities to continue the recovery process: Many people want opportunities to be physically active as they work to regain or maintain their function. Through walking, swimming, water aerobics, strength training and a wide range of other activities people continue to build capacity. Some activities may need to be modified to serve people with

...what people said

"People require motivating information. They need to know why it is important to exercise. They also need support from others to motivate them to go on."

"There needs to be a community aphasia group."

"We need a transition program to help take the next step into the community."

"We need a transition program away from the hospital to connect back to the hospital. but also to look forward."

physical deficits. Some people have hired personal trainers to support them to continue their recovery. Others indicate interest in doing so but can not afford it. No or low cost options or access to subsidies must be considered to ensure access given the financial impact of the stroke on individuals/families and the associated costs of transportation. As well, people who experience aphasia seek opportunities to engage with other people with aphasia to practice speaking.

Opportunities to socialize, provide mutual support and volunteer: At least in the short-term, many but not all people seek the company of others who share the stroke experience and understand the resulting changes that can happen in speech, cognition and physical capacity. The opportunities to engage with peers can start in the hospital and continue into the community.

Through socialization with peers, people with stroke develop increased confidence, understand their capacities and accept their current deficits which can enable them to renew or establish other relationships in the broader community. It can also be a vehicle to regain confidence to return to work. If opportunities are not available to connect with others, the person with stroke can become increasingly isolated and over time it can become even more difficult to engage with others.

Opportunities for mutual support amongst caregivers are beneficial. People can relate to a shared experience and help each other problem solve and adjust to their new circumstance.

Most people want to contribute to society in some way. Some people with stroke have indicated that they seek volunteer opportunities and ways to give back - to support other people with stroke or the broader population.

Processes to support transition into community activities: People who are vulnerable and have experienced a loss of self esteem due to stroke and/or who may not have a strong history of participating in community activities often require some initial assistance to establish the first linkages. Active support through a volunteer leisure buddy, a recreation therapist or another trusted community worker could facilitate the transition. Holding appointments in facilities where there are opportunities to engage in activities with other people with stroke or physical disabilities may also facilitate engagement. Understanding the barriers to integration and providing the appropriate supports is an investment in the long term independence of people with stroke which in turn provides greater freedom for family members who have assumed a caregiving role.

Welcoming spaces that support engagement: People with stroke have different perspectives about where they want to participate in activities. Some want to have activities exclusive to people with stroke or people with disabilities given their experiences and fear of not being accepted in the broader population. Other people want to be integrated into the broader community immediately e.g. attending activities within a recreation complex. Others expected integration to happen over time as their own confidence builds. Some were uncomfortable being associated with brain injury services and the label and potential stigma they fear. Other people who have had direct experience of the services were more comfortable. Respect and understanding for the different perspectives and how they impact integration is needed. If the intent is to support people to integrate fully into the community, providers need to be conscious of how the locations and the names of services enable that. The viability of services and the required critical mass to enable a service to be sustained is also a critical consideration in planning.

Accessible spaces: If communities were designed to be more accessible people could continue their recovery process more easily. Key spaces that should be accessible include community centres, restaurants, clubs and malls. Too often spaces, which have been designated accessible, do not meet the standards of real accessibility. Reference was made to washrooms, ramps, doorways, sidewalks and parking.

Orientation toward building on assets and skills of people with stroke:

Too often the dialogue seems to focus on a person's deficits after having a stroke and what is not possible. Shifting the collective orientation toward capacities and what is possible generates hope and encourages a continual focus on recovery. This is important both for the people seeking to return to employment and for people who are retired and are seeking to re-engage in community activities.

...what people said

"Friendly visitors are good but we need to match people's interest."

"After rehab you are not done you are just beginning your life again."

"There needs to be other interests. All of your activities can not centre around stroke"

"The activities I like are much more mainstream. I do not want to rely on other people."

"Why aren't people joining our Stroke Recovery Association?"

Understanding of stroke amongst providers and volunteers working in the community:

People with stroke and their family members are seeking support for their ongoing recovery from people who understand the stroke experience, the deficits that may result and the potential for recovery. As the person with stroke recovers their needs change and the role of the family caregivers can shift. The transition to more independence is sometimes difficult to make for both the person with stroke and their caregiver. Community-based providers and volunteers can assume a valuable role in educating people about the stroke recovery process.

Accessible, low cost transportation options: In the cities and larger towns such as London, Windsor and Sarnia - public transit does exist. In rural communities it does not. Transportation is provided by community support service agencies either through volunteer drivers driving their own vehicles or in some cases through paid drivers driving accessible vans. Transport is available at a relatively low cost on a per mileage basis but rural distances still make the final costs prohibitive. As a result people limit their activities and socialization becomes a reduced priority relative to grocery shopping or medical appointments. Ultimately this has a negative impact on people's health – particularly their mental health.

Where public transit does exist a review of policies and practices is needed to ensure that: people receive support to get in and out of the person's home and the vehicle – recognizing the potential liability issues; and people with cognitive deficits could also utilize the service.

...what people said

"You don't have any life after stroke. There is no spontaneity."

"To me accessibility is a major major factor."

"We need a coordinated transportation system that serves Windsor and the outer areas that is cost effective"

"Returning to driving costs too much – the assessment."

"Some of the facilities for wheelchair accessibility are awful! Facilities such as doctors offices, hospitals... It is the patient and caregivers that suffer. Lack of accessibility limits where you can go"

"People have crossed the road away from me when they see me coming. I have been there since 1969."

The desire for enhanced spontaneity

is frequently identified. People with stroke feel limited in their ability to be active without planning it far in advance.

An affordable approach to regaining a driver's license: The current cost exceeds \$500 for testing one's ability to drive plus lessons if they are deemed necessary. The total cost of regaining the license often exceeds \$2000 yet financial support is not available for people who cannot afford the associated costs. A new approach is required. People living in rural areas are particularly challenged when they can not drive. The cost of car adaptations is a further barrier to returning to driving.

Access to a comprehensive assistive devices program: Changes are required to enhance access to assistive devices through the Assistive Devices Program (ADP) funded by the provincial government including: increased access to ADP authorizers to complete assessments; reduced cost of the assessment which is not covered by OHIP; reduction in the cost share percentage for people who can not afford the 25% currently required; increased access to specialized wheelchair/positioning clinics and adult augmentative communication clinics (people are often required to travel outside of their district/region for these services); coverage for equipment required solely for outside mobility e.g. to the grocery store or recreational activity; coverage for equipment required to engage in recreational activities; and coverage for equipment to facilitate some activities of daily living and instrumental activities of daily living (e.g. raised toilet seats, transfer poles, and kitchen aids) as well as specialized telephones to support communication.

Societal acceptance of people with disabilities: People with stroke and their family members have struggled with the reaction of friends and neighbours to their stroke. They feel a basic lack of understanding and acceptance from adults in their social networks. Not surprisingly the experience with younger generations who have direct experience with integrated classrooms is more positive. The need to continue to educate adults about stroke and other disabilities and to create opportunities for integration to facilitate understanding is apparent.

Affordable, accessible housing and supportive housing: In order for people with stroke to live in the community they require accessible housing. Depending on the financial position of the family they may be able to afford the renovations or to purchase at the market rate. Others require affordable housing. As well, individuals with stroke who live alone may benefit from living in a supportive housing arrangement – combination of accessible housing, personal care and opportunities to socialize. There was some indication that there is a shortage of supportive housing available in the region.

WHAT IS AVAILABLE?

Community Support Service agencies offer day programs to serve frail elderly people who require an opportunity to socialize and to provide family caregiver respite. Other programs appropriate to people with stroke and their families have also been established.

South West LHIN region

- The Midwestern Adult Day Services offers the SAYS (Stroke and You Surviving) Program in Clinton. It is an informal weekly gathering to share information and learn from each other. Stroke survivors lead the group with support from a facilitator. Volunteer drivers provide transportation.
- The Dorchester VON is in the planning stages of developing a caregiver support group.

- The Oxford VON is developing a new volunteer based program tentatively called “Life after Stroke Program” which will be designed to support stroke survivors transitioning from hospital to the community after stroke. Some components to the program will include assessment of the stroke survivors ongoing needs and assistance to identify and access other community services and programs as well as support the stroke survivor living in the community through friendly visits or follow-up phone calls for social support or community re-integration (i.e. leisure activities, grocery shopping etc.).

Recreational organizations in communities across the LHIN regions have numerous facilities where activities are and can be held to meet the needs of people with stroke such as municipal recreation facilities, YM/YWCA’s, activity centres operated by community support service, churches, community health centres and privately owned facilities. Some of these facilities already have programs in place that may be appropriate to encourage people with stroke to engage in. Others could be adapted.

Hospital rehabilitation services dedicate recreational therapists to support people to engage actively in community activities. Their expertise could be utilized to develop/modify options that are appropriate to the stroke population.

Erie St. Clair LHIN Region

- The Chatham-Kent Health Alliance, together with the Chatham-Kent Brain Injury Association, Erie St. Clair CCAC, Southwestern Ontario Stroke Strategy and other community partners are developing a transition program to support people with stroke to integrate into the community. Currently, the “Friends of Stroke” group supported by the recreation therapist from the hospital meet at the New Beginnings Clubhouse on a monthly basis. Supports are also in place for family caregivers.

Acquired Brain Injury Services are evolving to offer programs and services for people with stroke and their families.

Erie St. Clair LHIN Region

- The Brain Injury Association of Chatham-Kent and their partners recently received an Ontario Trillium Foundation Grant to evaluate the effectiveness of the New Beginnings Clubhouse programming on the quality of life of stroke survivors and their caregivers in the municipality of Chatham-Kent. The same organization is an active partner in establishing a transition program for people with stroke.

Stroke Recovery Associations provide opportunities for people affected by stroke to support each other, to socialize and to participate in activities of interest. Each association or network has different capacity depending on their resources.

Erie St. Clair LHIN Region

- Stroke Recovery Associations are established in Sarnia and in Windsor.
- A new association is evolving in the Leamington area.
- While not a formal association a support group for younger stroke survivors exists in Windsor and is supported by the Windsor Essex District Stroke Centre.
- “Friends of Stroke” group exists in Chatham.

Southwest LHIN Region

- Stroke Recovery Association exists in London and in Owen Sound an association is pending.
- A network of people with stroke and their families is emerging in the West Lorne area.
- A group for younger stroke survivors and their families also exists in Oxford County through the Oxford VON.
- There is a stroke survivor group run out of the Midwestern Adult Day Services in Clinton

The Heart and Stroke Foundation is currently offering training sessions for people who will offer the revised Living with Stroke Program - a program which offers both education and support amongst peers. Most districts in Southwestern Ontario have sent representatives to receive the training and have committed to running the program in their district.

Friendship Centres provide services to native people however operate without medical professionals. The centres provide services such as social supports, aboriginal healing and wellness. They do not provide direct care. There are Friendship Centres located in London, Owen Sound and Windsor. Each Friendship Centre which are located outside of the First Nation communities and **Home and Community Programs and Health Centres** located in aboriginal communities operate differently based on the needs of the communities they serve.

The Southwestern Ontario Stroke Strategy has different resources and training opportunities that can be of benefit to providers in the field:

- Motivational Interviewing workshops for health care professionals to enable them to work with patients/clients in a way that supports them;
- educational resources related to supporting recovery; and
- training of a Master Trainer for the Patient Self Management Program (Stanford Model) which will be piloted in the region in the coming year.

Training programs have been established to enhance support for people with physical disabilities to engage in the community.

South West LHIN Region

- St. Joseph's Health Care – Parkwood Hospital in London, Ontario offers the Third Age Outreach which includes programs such as the “Lean on Me” volunteer training program for volunteers working with people with disabilities and an “Accessible Seniors Aquatic Program” created as a supported recreational exercise class for seniors who have mobility concerns and need to exercise in a safe, closely supervised environment. The

...what people said

“We pay a personal trainer twice per week at the YMCA. It is the only hour that I am free to do water aerobics. He needs someone with him to use the machines.”

“Could the CCAC homemaker go to the Y with him to work the machines?”

“This is something new to me that she is willing to go into a group on her own. I am always with her.”

“When stroke survivors are together the camaraderie is unbelievable. Your regular friends go away. You need someone to be your friends.”

“People need options. It is not so much the programs as the people that are important. For example, friendly visiting with other stroke survivors.”

“Closet strokes. If you haven't gone out because your friends no longer talk to you, you tend not to go out and become a closet stroke. A lot of family and friends can not deal with it.”

Third Age Outreach also provides “Golf Clinics for People with Physical Challenges” enabling people to golf using modifications and / or specialized equipment.

- St. Joseph’s Health Centre – Parkwood Hospital in London, Ontario offers the Parkwood Fitness Centre which provides adapted, supervised fitness facilities for people with a disability which is limiting their participation in community activities with the goal to provide members with the skills to access an active and healthy lifestyle within the community.
- The Grey Bruce District Stroke Centre, Play in Grey Bruce, Grey Bruce Health Services Rehabilitation Unit and the Canadian Paraplegic Association received funding from the Ministry of Health Promotion through Communities in Action to develop and implement “Fit for All” - a training program for recreation providers and personal fitness trainers to adapt their services for people with physical disabilities.

The Association of Persons with Physical Disabilities in Windsor was identified as having a range of programs that may be appropriate to people with stroke – respite, vocational rehabilitation, supportive housing, attendant care and recreation. Similar associations may exist in other communities.

The Ontario provincial government has established an accessibility agenda which is resulting in some positive changes:

- The Ontarians with Disabilities Act mandated the formation of Municipal Accessibility Advisory Committees (MAAC) responsible for guiding initiatives to enhance accessibility in each municipality with a population of over 10,000. Positive changes are evident when new buildings such as recreation facilities are developed. Municipal recreation departments and transportation services are evolving with a stronger focus to serve people with disabilities.
- The new accessibility guidelines released in January 2008 is expected to enhance access further as businesses and public institutions implement the changes to enhance accessibility.
- The Ministry of Health and Long-term Care has recently allocated \$40 million through the Aging at Home Strategy for the Assistive Devices Program. Decisions are pending about how those funds will be used. The Ontario Stroke System is working toward influencing those decisions to ensure the needs of people with stroke are considered.

Transportation initiatives have been established to enhance accessibility.

Erie St. Clair LHIN region

- Five new vans have been provided to community support service agencies to transport people to appointments and activities.
- A pilot project is being conducted in Chatham Kent to expand accessible public transport.

South West LHIN Region

- Eight new vans have been allocated to community support service agencies.
- Closing the Gap Healthcare Group, the Grey Bruce District Stroke Centre, the Alzheimer’s Society Grey Bruce and Blue Water Driving Academy Ltd. Have collaborated to introduce a proven program for objectively assessing medically at risk-

...what people said

“People need to get more involved with Accessibility Advisory Committees.”

“There is very little knowledge about places that are accessible. There are not a lot of accessible washrooms. We need to make people aware of where they can go.”

“Education is needed to the general public – to show some compassion.”

drivers within Grey and Bruce Counties. Driver Risk Management Assessments created by DriveABLE Assessment Centres Inc. will now be available in Owen Sound. Similar services are available in Windsor Essex and in London.

Known **housing and equipment initiatives** related to enhancing accessibility include:

- Canada Mortgage and Housing Corporation (CMHC) offers assistance through a program entitled the Residential Rehabilitation Assistance Program (known as RRAP). Through local CMHC offices or municipalities people can access forgivable loans to undertake necessary repairs to people who own their own homes and who live on a low income or to renovate their home to make it accessible.
- Service clubs sometimes offer financial support to people in unique circumstances.
- The Ministry of Health and Long-term Care in partnership with the LHINs has identified supportive housing as an area for enhanced funding.
- The March of Dimes operates a home and vehicle modification program as well as an assistive devices program and a recycled equipment program.

WHAT CAN BE DONE?

a. Identify existing community-based opportunities for people to participate in physical activities with the assistance of exercise specialists who can develop adapted programming. Where necessary, establish new opportunities building on existing public and non profit facilities and services. Build on the work and research carried out on similar initiatives:

- Next Steps Program in Mississauga – a partnership between the Credit Valley Hospital and the City of Mississauga Recreation Department. This program is funded as an adult day program.
- City of Ottawa Stroke Program developed in collaboration with the Champlain Regional Stroke Centre and other community-based partners
- Brockville YMCA program developed in response to the needs identified through the Southeastern Ontario Stroke region consultation
- Fitness and Mobility Exercise Program (FAME) – an exercise program developed and tested for stroke and implemented in a community setting. The Canadian Centre for Activity and Aging in London recently did a FAME pilot “Implementation of a Community Based Exercise Program for Stroke Survivors”.
- “Getting on with the Rest of Your Life After Stroke” national pilot study (combination of leisure education and exercise - pool or land). London was one of the pilot sites for the study which took place at the Boys and Girls Club and included the pool component.
- “Moving on after Stroke” program developed by

... what people said

“I find that I am still making improvements. I just got my arm moving.”

“Support groups like Friends of Stroke just don’t work for me. I will volunteer as a speaker to speak to other stroke survivors though. There are opportunities for stroke survivors to be champions for others.”

“Coming back as a stroke survivor is about getting back to what I did before the stroke. It did not include the clubhouse. Maybe if I had a follow-up appointment at the clubhouse it might have been a good introduction.”

“Services tend to be for older stroke survivors. Younger people are missing the radar.”

“It is hard trying to get someone to be active who has never been active.”

- Baycrest in Toronto. The program combines goal setting and fitness.
- Cardiac rehabilitation programs which are offered in many communities across the country.
- b. Establish groups for people with aphasia to communicate together and offer peer support. The Southwestern Ontario Stroke Strategy staff are currently examining different aphasia group models that could be used based on the experiences of other communities and the Aphasia Institute. Programs which use music have been identified as being of particular interest.
 - c. Design a model of engagement and establish a clear transition process and support to link individuals to community based recovery programs. Consider the unique needs/interests of people with stroke, people who want one-on-one contact and those who prefer groups, age and activity interests, the need for personal care, adaptations, mobility support and/or communication support, the cost of participating, and transportation availability and the associated costs.
 - d. When assessing existing and planning new/modified recovery programs consider how they can benefit family caregivers as well e.g. provide respite, create opportunities for the family member to witness/acknowledge the capacity of the person with stroke.
 - e. Identify alternative ways to facilitate contact in rural areas or amongst those who are more housebound – chat lines, phone buddies.
 - f. Assess the capacity of existing stroke consumer groups (e.g. stroke recovery associations, Friends of Stroke etc.) to provide appropriate peer support. Where necessary and desired provide some organizational development support to increase the likelihood that the needs of diverse people can be met.
 - g. Increase the collaboration and networking with Friendship Centres, Home and Community Programs and Health Centres to enhance awareness of the availability of services for First Nation people.
 - h. Build relationships with Municipal Accessibility Advisory Committees to: inform them of the experiences of people with stroke related to accessing affordable accessible housing, accessible public spaces and public transportation; seek representation of people with stroke where possible to ensure their voice is heard; and advocate for consumer input and assessment into the design of accessible spaces.
 - i. Work with LHINs and partner organizations to expand access to affordable transportation in rural areas. Is it possible to access enhanced subsidies to support community support service agencies offering service in rural areas?
 - j. Monitor the developments in Owen Sound to determine if that is an appropriate approach to expanding access to Driver Risk Management Assessments.
 - k. Seek to advise on decisions about how the new Aging at Home Assistive Devices Program funding will be allocated. Advocate for access to specialized wheelchair positioning and augmentative communication services for all residents within Southwestern Ontario.
 - l. Identify what supportive housing options are available within the Erie St. Clair and South West LHIN regions. Support efforts to develop more as appropriate.

CONCLUSION

The stage has been set to advance change to enhance community reintegration of people affected by stroke. There are many people who have a deep passion for being part of the process – including people with stroke and their family members. The key to real change is to harness and support this passion.

It is clear from discussion at the regional forum that the needs identified through the process have affirmed what some people are already working toward. In other cases, action has been stimulated in response to participation in the district forums. Further action is expected when this report is released.

The health and community services system is complex. The system is changing rapidly and roles are being redefined. Now that it is clear what people with stroke and their families need it will be easier for different stakeholders to work together to identify the opportunities for implementing the changes.

The next steps will include:

- Identify priorities for action that are within the Southwestern Ontario Stroke Strategy to influence and determine the associated actions.
- Determine how the work to be advanced aligns with existing initiatives including the current stroke strategy structure.
- Be responsive to the partner organizations / agencies that may wish to move forward on actions outlined in the report.
- Identify how people with stroke and their family members can be engaged in the process - working on specific initiatives and advocating for the changes needed.
- Develop a process to monitor and evaluate progress and share with key stakeholders the changes that are being made and their impact on people with stroke and their families.

It will be critical to ensure the voice of people with stroke and their families is heard throughout the change process to make certain the changes made will address the needs they have identified. They are living the experience.

APPENDIX – SUPPORTING RESEARCH AND EVIDENCE

Excerpts from the known research and evidence that supports the perspectives of people with stroke, their family caregivers and service providers are outlined in relation to each pathway.

Proactive Support and Follow-up to Transition to the Community

1. The “Timing It Right” framework highlights the changing experiences and consequent support needs of family caregivers of stroke survivors across the care continuum. Five difference phases of caregiver support are discussed: event/diagnosis; stabilization; preparation; implementation; and adaptation. Recognition of family caregivers changing support needs across the care continuum will assist health care professionals to provide more timely and appropriate support (Cameron & Gignac, in press).
2. Information from 14 caregivers identified the following as primary barriers to undertaking and maintaining the caregiving role: lack of collaboration with the health care team, the intensity of the caregiving role, the negative impact on the caregiver, and the lack of community support for the caregiving role. Caregivers identified the following factors as facilitative: coordination of care, progress of the patient towards normalcy, mastery of the caregiving role, supportive social environment, and accessible community resources (White et al, 2007).
3. King et al (2001) highlight the importance of maintaining caregiver health and preventing depression and identify variables to target for the reduction of depression.
4. Caregivers experience a profound sense of loss, need to adjust to a new relationship with a spouse, take on new responsibilities, feel the demands of caregiving, and must depend on the support of others while maintaining hope and optimism (Coombs, 2007).
5. Research has shown that the information needs of caregivers are not being met across healthcare settings. O’Connell et al (2003) interviewed caregivers to determine their perspectives on support and education needs at 2 different stages in the recovery of a stroke survivor: the acute hospital and community. A multifaceted approach is needed which involves the development and implementation of a specifically designed educational materials for caregivers; the use of a tool such as a patient-held record to assist in and improve the continuity and communication of care, and the provision of ongoing support from a stroke nurse practitioner who would follow stroke survivors from the acute setting into the community (O’Connell, Baker, & Prosser, 2003).
6. Health care professionals need more knowledge about this transition from the perspective of the caregivers. Caregivers who were new to the role were interviewed prior to the stroke survivor’s discharge and 4 weeks after discharge. Restructuring life for caregiving was associated with 5 dimensions of participants’ lives: daily life, managing multiple roles, relationship with the stroke survivor, future hopes and plans, and time for self (Silva-Smith, 2007).
7. As patients move across the healthcare continuum at a faster pace, the role of the case manager including coordination, collaboration and advocacy has become increasingly crucial in assuring that the care delivered demonstrates efficacy, efficiency and high quality (Carr, 2005).
8. Kim and Soeken (2005) found a 6% decrease in readmission rate for patients who received hospital-based case management interventions.

9. A model of care management resulted in a significantly better profile of health and prevention for stroke/transient ischemic attack patients 3 months post discharge (Allen et al, 2002).
10. A retrospective chart review was completed on 23 patients with stroke using two different models of care delivery: unit-based nursing case management and standard nursing care. Unit-based case management noted improved outcomes in relation to interdisciplinary utilization, timeliness of referrals, patient education, discharge dispositions, home safety assessments, next-site-of-care communications, length of hospital stay, and patient satisfaction (Baker, Miller, Sitterding, & Hajewski, 1998).
11. Better methods of providing information for long-term survivors of stroke, and for addressing their emotional and psychological needs are required. Primary Care should be the first point of contact for information or problems, even if these were non medical (Hare, Rogers, Lester, McManus, & Mant, 2006).
12. Lilley, Lincoln and Francis (2003) investigated stroke survivors' and carers' perceptions of a family support organizer (FSO) services. Interviewees who received FSO reported that the service was valuable in many respects, including helping to claim benefits, as a source of information on stroke, and providing continuity between stroke services. Interviewees who did not receive the service described feelings of isolation and being let down by other stroke services after discharge and reported problems accessing information.
13. Kalra et al (2004) reported that caregivers who received training experienced less burden, anxiety and depression and had a higher quality of life within one year post stroke.
14. The majority of carers stated that they felt "let down" by the hospital discharge process because they found out about community support services only through avenues other than hospital staff such as friends, the internet or other carers. (Ski & O'Connell, 2007).
15. Claiborne (2006) found that care coordination provided by social workers significantly improves stroke patients' medical utilization with significant cost savings.
16. "Patients with chronic health problems need care that is coordinated across time and centred on their needs, values and preferences" (WHO, 2005, pg. 16).

Enabling the Person to Live at Home

1. The top five self-care needs about which information was desired by people dealing with stroke were: preventing falls; maintaining adequate nutrition; staying active; managing stress; and dealing with emotional and mood changes (Pierce, Finn, & Steiner, 2004).
2. Stroke survivors living in the community need more help with domestic chores and personal care. Informal carers require better support, especially spouses and those caring for depressed or anxious stroke survivors (Addington-Hall, Lay, Altmann, & McCarthy, 1998).
3. Clinicians need to incorporate the following carers' concerns into the plans for rehabilitation: making sure that the patient is safe at all times, knowing what his/her future needs will be, knowing what to do in specific situations in which the patient is unable to perform the task independently and dealing with the emotional aspects of the patient (Belciug, 2006).
4. Education is essential for successful transition from hospital to home. Physical and occupational therapists surveyed reported that demonstrating safe transfer techniques was the most frequently chosen information need (Cook, Pierce, Hicks, & Steiner, 2006).

5. Professional support to family caregivers is essential so as to sustain home care and protect the caregiver's health. This is particularly important during the first 12 weeks transitional period after hospital discharge (Sit, Wong, Clinton, Li, & Fong, 2004).
6. One caregiver remarked that she hadn't ever asked for respite because "when you're overwhelmed, just calling to ask for help is too big a mountain to cross" (Cameron, 2003).
7. The same strategies will not work for everyone. More attention is required to support caregivers in identifying what will result in respite for them (Meredith, 2003).

Access to Rehabilitation Services

1. Follow-up examinations should be an integral part of post-stroke rehabilitation. Rehabilitation treatment in the community should be strengthened (Greenberg, Treger, & Ring, 2004).
2. The most notable concern held by carers was the waiting time between hospital discharge and initiating therapy in the home. A number of carers felt abandoned during this period and that the stroke survivor had 'gone backwards'. (Ski & O'Connell, 2007)
3. The Stroke Rehabilitation Pilot Project of Southeastern Ontario demonstrated improved functional outcomes at a year post stroke and decreased hospital readmissions in the group that received timely and enhanced intensity of rehabilitation services on transition from inpatient rehabilitation into the community (Regional Stroke Steering Committee of Southeastern Ontario, 2004).
4. The Stroke Rehabilitation Pilot Project of Southwestern Ontario involved a Stroke Rehabilitation Outpatient Service for stroke survivors with severe disability. The key findings included:
 - Improvement was demonstrated in all functional measures at follow-up 6 months post-discharge.
 - The comparison group, on average, declined in function and rated their quality of life significantly less than the pilot group.
 - Caregivers showed improvement in their quality of life.
 - Consumer satisfaction results (% positive) were $\geq 90\%$.
 - Average cost savings to the health care system per client (annual cost of LTC – total cost of OT, PT, SLP treatment provided) of \$41,152 per year each for the 7 clients that avoided institutionalization and \$35,000 each for the 4 clients returned home from LTC placement.
 - The "just-in-time" access to client specific consultation for stroke survivors and education/training related to stroke rehabilitation showed significant improvement in self-ratings by the participants, which were sustained after three months.

(Southwestern Regional Stroke Strategy, 2004)
5. Ongoing rehabilitation (beyond six months post stroke) can further improve activities of daily living (ADL) and fitness. Stroke rehabilitation involves programs to reduce impairments, enhance recovery and adapt to persisting disabilities. The risk of deterioration in ability can be reduced or reversed by further rehabilitation input. Therapy-based rehabilitation services can: reduce poor outcomes (i.e., prevent hospital readmission); promote participation in desired activities; increase ADLs; and reduce external home care supports. Canadian Best Practice Recommendations for Stroke Care include:
 - Stroke survivors should continue to have access to specialized stroke care and rehabilitation after leaving hospital

- Any stroke survivor with reduced activity at six months or later after stroke should be assessed for appropriate targeted rehabilitation
 - People living in the community who have difficulty with ADL should have access, as appropriate, to therapy services to improve, or prevent deterioration in ADL
 - (Canadian Stroke Network and the Heart and Stroke Foundation of Canada, 2006)
6. An emphasis on physical recovery and the management of self-care tasks in rehabilitation appears to be insufficient to facilitate the achievement of clients' goals. Access to rehabilitation services in the clients' home and community environment may help clients and partners remove barriers that limit resumption of past activities, break the "downward cycle that can lead to partner exhaustion and depression" and improve quality of life (Stanton, 2000).
 7. In a systematic review of randomized controlled trials of stroke patients, the effects of therapy-based rehabilitation services targeted towards patients residing in the community was analyzed. Reviewers sought to identify the proportion of patients who had deteriorated or were dependent in personal activities of daily living and performance in personal activities of daily living at the end of follow-up. The main results identified a heterogeneous group of 14 trials including 1617 patients. Therapy-based rehabilitation services reduced the odds of a poor outcome and increased personal activity of daily living scores (Outpatient Service Trialists, 2002).
 8. Comprehensive understanding and involvement of the person, family/caregiver, and environmental system are required for stroke rehabilitation. Without adequate resources and support it is difficult for patients to sustain the gains made during inpatient care or to make further progress in the community. It is essential that the treatment team know the patient (including history, expectations, coping style, resources and emotional support system in order to fully engage him/her in the treatment process. Motivation and hope for improvement is a critical factor for functional improvement (VA/DoD Clinical Practice Guidelines, 2002 & Duncan et al., 2005).
 9. The Report of the Consensus Panel on the Stroke Rehabilitation System "Time is Function" outlines the following standards which should be considered in planning of rehabilitation services:
 - Standard #4: Stroke survivors should have a mechanism to access or re-access the rehabilitation environment, if clinically indicated, regardless of the time that has elapsed since the stroke.
 - Standard #9 Once it is determined that a stroke survivor will benefit from Community rehabilitation and once rehab ready, the stroke survivor will have access to an interprofessional rehabilitation team with expertise in stroke care.
 - Standard #13: All stroke survivors, regardless of where they live, will have equitable access to the same standard of care at the appropriate intensity and duration.
 - Standard #16: Stroke Survivors who are discharged to the community with home-based stroke rehabilitation services will be provided with these services as per available evidence-based guidelines.

(Heart and Stroke Foundation of Ontario, 2007)
 10. This researched showed that patients treated by a community stroke team were more satisfied with the emotional support they received. Their carers were under less strain and were more satisfied with their knowledge of stroke recovery and with the services received (Lincoln et al, 2004).

11. Multidisciplinary rehabilitation is effective improving functional outcomes of stroke patients regardless of starting point of the intervention or initial severity of disability (Miyai, 1998).
12. This study revealed that higher levels of informational social work support services influenced stroke outcomes and were associated with lower total hospital charges (Rizzo, 2006).
13. Return to work in stroke patients should be considered one of the indicators of successful rehabilitation as it influences self-image, well-being and life satisfaction (Treger, Shames, Giaquinto & Ring, 2007).
14. Rehabilitation has been perceived as primarily aimed at restoring bodily functions and a return to everyday activities, rather than at promoting return to work. An individual's capacity and ability to return to work is enhanced by motivation and self-efficacy in combination with external support (Medin, Barajas, & Ekberg, 2006).

A Community Environment that Supports Active Engagement and Continued Recovery

1. Rudman, Hebert & Reid (2006) reported that both stroke survivors and caregivers described stroke survivors as having minimal choice regarding their occupations and as facing seemingly impossible barriers to participation in many desired occupations. Stroke survivors mostly engaged in occupations that were either necessary, such as bathing and eating, or readily available, such as reading or watching television. This situation of occupation by default resulted from the combination of many environmental and personal factors, such as inaccessible community environments, specific impairments, feelings of fear and frustration, and an attitude of resignation.
2. Stroke has a significant impact on quality of life (QOL) of survivors, but some individuals find ways to adapt to their functional disabilities and report high QOL. Common elements of this process consist of reordering priorities to focus on those activities considered most salient to an individual's identity; then drawing on existing resources, including health services and social supports, to maintain a customary activity, even in a modified form, retaining salient aspects of the individual's identity and maintaining a sense of continuity in his or her life (Clarke & Black, 2005).
3. Stroke survivor's participation in daily activities and social roles was assessed after discharge at 6 months and between 2 to 4 years. A significant reduction in participation in daily activities was observed, specifically in the areas of nutrition, fitness, personal care and housing; however participation in social roles was maintained during this period (Desrosiers et al, 2006).
4. A short-term community-based exercise program can improve and retain mobility, functional capacity, and balance and result in a demonstrable impact upon the performance of activities and abilities (Eng et al, 2003).
5. Stroke survivors benefit from participation in recreational therapy interventions through a community reintegration program designed to improve functional status, mood and independence in leisure pursuits (Lewis, 2006).
6. Participation is more than activity performance in context; instead, it relates to "being a part of" the community and having access to participation opportunities and supports (Hammel, Jones, Gossett, & Mogan, 2006).
7. Volunteer Stroke Service Groups include members in an interpersonal network, provide members with the opportunity to develop interpersonal relations, provide members with support, provide opportunities for personal growth and development, supply members with

a purpose, structure and routine, help members establish and confirm their identity, beliefs and values, help members accomplish individual and shared goals, and provide members with the opportunity to influence others and be influenced (Legg, Stott, Ellis, & Sellars, 2007).

8. A systematic review of the literature revealed that improved social support as an intervention improves outcomes and that an active educational-counseling approach has a positive impact on family functioning post stroke (Bhogal, Teasell, Foley, & Speechley, 2003).
9. Compared to a group that did not receive professional support from a stroke association (home visits, telephone contacts and stroke information), primary caregivers of stroke survivors with professional support reported a significant increase in social activities and quality of life (Rombough et al, 2007).
10. Social isolation not only inhibits the experience of connectedness with others but can also promote depression and physical illness for individuals managing transition at one month post stroke. The inability to regain full participation in leisure and community activities appears to be more closely linked to poor psychosocial outcomes such as depression and poor quality of life than do difficulties in performing basic activities of daily living (Rittman et al, 2007).
11. Community-based group-exercise interventions that include agility or stretching/weight shifting exercises were effective in enhancing functional balance, mobility and standing postural reflexes, which reduces the risk of falls in the older age group with chronic stroke. These programs increase regular physical activities for older adults with chronic conditions and could offset secondary complications that often occur after a sedentary lifestyle (Marigold et al, 2005).
12. An 8 week water-based exercise program indicated a 22% improvement in cardiovascular fitness in a small group of people with stroke with relatively high function. It also showed increases in maximal workload, gait speed and paretic lower extremity muscle strength. The researchers concluded that a water based exercise program may be an effective way to promote fitness in people with stroke (Chu et al, 2004).
13. Language impairment and functional communication can be improved by therapy services that are delivered to persons with aphasia in community-based programs. Improvements are seen in individuals with chronic as well as acute aphasia and independent of diagnostic type of aphasia, impairment severity at start of care, or geographic program location (Aftonomos, Appelbaum, & Steele, 1999).
14. Reintegration into community after a person sustains a stroke is related more to one's functional ability than his/her social support (Newsham, 1998).
15. Stroke recovery does not merely refer to the restoration of physiological function to the maximum potential. It also includes the ability to live independently and the psychological adaptation to the stroke, as well as continuing to participate in and contribute to the society (Sit, 2000).
16. Many people who have had a stroke want to get out of their house more often. An intervention package capable of re-enabling people to drive or be driven, to use a pavement scooter safely, to provide information about the alternatives and to encourage best use of public transport is worth developing (Logan, Dyas, & Gladman, 2004).
17. Stroke survivors are making decisions about their driving capabilities without professional advice and/or evaluation. The results also suggest that rehabilitation professionals need to

devote more attention and resources to driving issues when working with stroke survivors and their families (Fisk, Owsley, & Pulley, 1997).

18. Gosman-Hedstrom et al (2002) found that it is not expensive for the community to equip stroke survivors and their caregivers with assistive technology, and economic resources should be available to this vulnerable group of people.
19. Because of the difficulty of mobility, perceived social stigma related to physical and cognitive deficits or depression, many stroke patients become socially isolated. Social isolation is also strongly correlated with post stroke depression. When withdrawn socially, stroke patients are not likely to venture into the neighbourhood for walks, use the public swimming pool or travel to a local gym. Studies have shown that even in stroke survivors with a significant degree of recovery social isolation was still evident. To enhance exercise compliance the issue of social isolation will need to be addressed and resolved (Gordon et al., 2004).

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