COMMUNITY REINTEGRATION FOLLOWING STROKE:
SUPPORTING THE JOURNEY
“We were sitting looking through Christmas pictures of the kids and saying how cute they were and then suddenly she was quiet and didn’t show me any pictures - she didn’t have any movement or sound or conversation, just bang like that – it’s a major game changer.” ~ Caregiver
Background

- 2007 consultation (*Building Capacity to Enhance Community Reintegration of People with Stroke*)
- Validation of results
- Q Sort methodology
- Participants – stroke survivors, caregivers & health care providers (including PSWs)
2007 Consultation

- System Navigation
- Support in the home
- Support for recovery and active engagement
- Support to work through the emotions
- Access to Rehabilitation
- Mobility in the Community
Recruitment

*Stroke Survivors & Caregivers*
- Support groups
- Partners
- Media

*Health Care Providers*
- Partners (CCAC, rehab providers)
- CSS agencies
Response

- 107 participants
- 13 individual interviews (survivors & caregivers)
- 7 focus groups (survivors, caregivers, couples)
- Urban/rural, male/female, younger/older
- 40 health care providers (electronic format with exception of PSWs)
The Q Sort Process

- Laurentian University
- Ranking process
- 30 Q Statements
- Modified for Southeast
- Inverted pyramid
- Less to more importance
Supporting Questions

- What made your most important areas so important?
- Are/were these areas met when you returned to the community?
- Are there any areas that are important to you that were not captured in this exercise?
- What things/activities/people/organizations have most helped you reintegrate into the community?
- What is the single most important thing you would like to see change to help persons who have experienced a stroke successfully reintegrate into the community?
“When he was in hospital, we were told he would never walk again, never eat solid foods again – this was devastating – we were relatively young – all of a sudden you’re not in the fast lane anymore – what are we going to do now? How are we going to survive?” ~ Caregiver
Overall Mean Age: 69 years (SD = 14.2)
Mean Age – Males: 69 years
Mean Age – Females: 68 years
Overall Median age: 69 (Range 25-91)
Participants – Stroke Survivors

Stroke Survivor by Year of Stroke

<table>
<thead>
<tr>
<th>Year of Stroke</th>
<th>Number of Survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td>1985-1989</td>
<td>1</td>
</tr>
<tr>
<td>1990-1994</td>
<td>1</td>
</tr>
<tr>
<td>1995-1999</td>
<td>4</td>
</tr>
<tr>
<td>2000-2004</td>
<td>5</td>
</tr>
<tr>
<td>2005-2009</td>
<td>3</td>
</tr>
<tr>
<td>2010-2015</td>
<td>28</td>
</tr>
</tbody>
</table>
Participants – Stroke Survivors

Stroke Survivors - Rural vs Urban
N = 42

Urban – Belleville, Brockville, Kingston
Participants – Caregivers

Stroke Caregivers

N=23

Overall Mean Age 67 years (SD = 14.5 )
Mean Age – Males 74 years
Mean Age – Females 65 years
Median age 66 (Range = 16 – 88)
Participants – Caregivers

CAREGIVERS - URBAN VERSUS RURAL
n=24

Urban 58%
Rural 42%

Urban – Belleville, Brockville, Kingston
Participants – Health Care Providers

Health Care Provider - By Role
N = 40
Participants – Health Care Providers

Stroke Provider - By Professional Designation
N = 40
Participants – Health Care Providers

PROVIDER BY COUNTY

Kingston
Lanark
All Southeast
Hastings
LLG
Leeds/Grenville
Leeds/Lanark
KFLA
Glengarry
Prince Edward

0
2
4
6
8
10
12
## Q Sort – Stroke Survivors n=30/43

<table>
<thead>
<tr>
<th>ITEM</th>
<th>RANKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>A sense of control</td>
<td>4</td>
</tr>
<tr>
<td>Having clear information</td>
<td>2</td>
</tr>
<tr>
<td>Receiving the practical assistance to remain at home (meal preparation, snow removal)</td>
<td>2</td>
</tr>
<tr>
<td>Recognition of successes and hopes for my future</td>
<td>-2</td>
</tr>
<tr>
<td>Help for me to explain the effects of my stroke to others</td>
<td>-2</td>
</tr>
<tr>
<td>Having a provider assist me by telephone</td>
<td>-2</td>
</tr>
<tr>
<td>Having adequate support for my family including time away (respite)</td>
<td>-3</td>
</tr>
<tr>
<td>Having a provider who checks-in with them</td>
<td>-3</td>
</tr>
<tr>
<td>Having family members involved in my care and my life</td>
<td>-3</td>
</tr>
</tbody>
</table>
## Q Sort – Caregivers (n=17/24)

<table>
<thead>
<tr>
<th>ITEM</th>
<th>RANKING</th>
</tr>
</thead>
<tbody>
<tr>
<td>Having adequate support including time away (respite)</td>
<td>3</td>
</tr>
<tr>
<td>Adequate financial resources</td>
<td>2</td>
</tr>
<tr>
<td>Having a provider who understands and respects our personal choices and beliefs</td>
<td>-3</td>
</tr>
<tr>
<td>Having a provider who &quot;checks-in&quot; with us</td>
<td>-4</td>
</tr>
<tr>
<td>ITEM</td>
<td>RANKING</td>
</tr>
<tr>
<td>-----------------------------------------------------------</td>
<td>---------</td>
</tr>
<tr>
<td>Involvement in decision making about my life</td>
<td>4</td>
</tr>
<tr>
<td>A sense of control</td>
<td>3</td>
</tr>
<tr>
<td>Doing what I love to do</td>
<td>3</td>
</tr>
<tr>
<td>Having a provider who sees what I can do for myself and involves me in my care</td>
<td>2</td>
</tr>
<tr>
<td>Having consistent providers who are skilled in what they do</td>
<td>-2</td>
</tr>
<tr>
<td>Having a provider who can assist me with a return to work, school, leisure and volunteer interests</td>
<td>-2</td>
</tr>
<tr>
<td>Having a provider assist me by telephone</td>
<td>-2</td>
</tr>
<tr>
<td>Getting help to adapt to my “new life”</td>
<td>-2</td>
</tr>
<tr>
<td>Having a provider who communicates well with others</td>
<td>-3</td>
</tr>
</tbody>
</table>
SUCCESSFUL COMMUNITY REINTEGATION THROUGH:

Person-Centred Stroke Care & Rehabilitation Services

**Person-Centred**
- independence and sense of control
- collaborative goal-setting
- optimizing client and family involvement
- education supports for client/family in stroke and care provision
- individualized, coordinated care

**Skilled Stroke Care**
- continuity of care from inpatient to outpatient to community
- interprofessional coordination of care
- consistent providers skilled in stroke care
- enhanced rehab services
- services close to home
- access to specialist follow up care

Individual Well-Being & Meaningful Engagement

**Individual Well-Being**
- accessible, facilitated support groups
- peer support
- social work/mental health services
- recognition of emotional/psychosocial needs as an integral part of stroke care across the continuum
- flexible, responsive respite service

**Meaningful Engagement**
- accessible leisure & recreational services
- re-establish life roles/interests

Community Co-Navigation

- ongoing reassessment of needs
- person to person conversation ("just talk to me")
- linkage to supports & services and assistance to complete relevant applications
- advocacy
- user-friendly resources in various modalities

STROKE SURVIVOR AND CAREGIVER

Supported Mobility in the Community

- affordable, accessible, flexible transportation services
- loss of driving privileges
- accessibility in the community

Access to Supports & Services

**Supports to Live in the Community**
- equipment & home modifications
- responsive community
- home maintenance

**Adequate Financial Resources**
- financial application services
- access to financial supports for services, equipment and home modifications

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- Skilled Stroke Care
  - continuity of care from inpatient to outpatient to community
  - interprofessional coordination of care
  - consistent providers skilled in stroke care
  - enhanced rehab services
  - access to specialist follow up care

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  - accessible, facilitated support groups
  - peer support
  - social work/mental health services
  - flexible, responsive respite service

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  - ongoing reassessment of needs
  - person to person conversation
  - linkage to supports & services
  - advocacy
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  - affordable, accessible, flexible transportation services
  - loss of driving privileges
  - accessibility in the community

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  - equipment & home modifications
  - responsive community
  - home maintenance
  - financial application services
  - access to financial supports for services, equipment and home modifications
## Comparative Chart

<table>
<thead>
<tr>
<th></th>
<th>What made areas important?</th>
<th>Were important areas met?</th>
<th>What most helped with integration?</th>
<th>Single most important change.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Person-Centered Stroke Care &amp; Rehabilitation Services</strong></td>
<td>Stroke Survivors Caregivers Health Care Providers</td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors Caregivers Health Care Providers</td>
</tr>
<tr>
<td><strong>Individual Well-Being &amp; Meaningful Engagement</strong></td>
<td>Stroke Survivors Caregivers</td>
<td>Caregivers</td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors Caregivers Health Care Providers</td>
</tr>
<tr>
<td><strong>Community Co-Navigation</strong></td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors Caregivers Health Care Providers</td>
</tr>
<tr>
<td><strong>Supported Mobility in the Community</strong></td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors</td>
<td>Stroke Survivors</td>
<td>Stroke Survivors</td>
</tr>
<tr>
<td><strong>Access to Supports &amp; Services</strong></td>
<td>Stroke Survivors Caregivers</td>
<td>Stroke Survivors</td>
<td>Stroke Survivors</td>
<td>Stroke Survivors</td>
</tr>
</tbody>
</table>
“Involvement in decision making was important. I was going through a life changing event. I felt I had dictated to life up to that point and want to continue to be driving force in where my life is going.” ~ Survivor

“Being involved in care and life of loved one. We are life partners or soul mates. Of course I need to be there first and foremost. I am his and he is mine.” ~ Caregiver
Person-Centred Stroke Care & Rehabilitation Services

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- independence and sense of control
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- individualized, coordinated care

**Skilled Stroke Care**
- continuity of care from inpatient to outpatient to community
- interprofessional coordination of care
- consistent providers skilled in stroke care
- enhanced rehab services
- services close to home
- access to specialist follow up care
Individual Well-Being & Meaningful Engagement

“Respite is very important as I do most everything so get at the end of myself sometimes. Even when we go away on a holiday, it’s not really a holiday, it’s just me in a different place.” ~ Caregiver

“I remember my grandfather crying a lot after he had a stroke but not understanding why. Now I understand.” ~ Survivor
Individual Well-Being & Meaningful Engagement

**Individual Well-Being**
- accessible, facilitated support groups
- peer support
- social work/mental health services
- recognition of emotional/psychosocial needs as an integral part of stroke care across the continuum
- flexible, responsive respite service

**Meaningful Engagement**
- accessible leisure & recreational services
- re-establish life roles/interests
Community Co-Navigation

“Would be nice to have one central person to go to. One central person, if he or she is keen on what they are doing, they can be most useful. Someone to coordinate things and know what’s available ...you find out by yourself but it takes a little while.” ~ Survivor

“Important where you start the process – not good if you start without information, with not knowing where to turn – you are not talked to as an adult – you get behind, you feel like you’re behind the 8 ball – you end up waiting a long time without knowing things.” ~ Caregiver
Community Co-Navigation

- ongoing reassessment of needs
- person to person conversation (“just talk to me”)
- linkage to supports & services and assistance to complete relevant applications
- advocacy
- user-friendly resources in various modalities
“You feel like a burden to others when asking for transportation. Friends say okay but after 7 or 8 times....or my husband has to take time off work. One of the biggest gifts I got was when a friend offered to take me out to breakfast. I had been a prisoner in my own home.” ~ Survivor

“For a very brief time a worker was able to drive [stroke survivor] on local errands like to get groceries and for [stroke survivor] this was the most wonderful thing. They had to stop because of liability. So now, she may be invited to lunch but can’t go because has no way to get there.” ~ Caregiver
Supported Mobility in the Community

- affordable, accessible, flexible transportation services
- loss of driving privileges
- accessibility in the community
Access to Supports & Services

“Need adequate financial resources. You suddenly can’t go to work, have decreased money and the bills are coming in and your credit is gone. You can’t find out who you should talk to. You have to learn to survive on that little bit of money.” ~ Survivor

“Practical help is important – this is new to me, I have never been involved with someone who had a stroke before.” ~ Caregiver
Access to Supports & Services

Supports to Live in the Community
- equipment & home modifications
- responsive community
- home maintenance

Adequate Financial Resources
- financial application services
- access to financial supports for services, equipment and home modifications
Limitations

- Younger stroke survivors
- Individuals living with aphasia
- Focus groups/support groups
- LTC as community
Finalizing Report/Recommendations

- Q Sort data analysis (Laurentian)
- Discussion analysis (Stroke Network)
- Review by Community Reintegration Leadership Team
- Review by Regional Stroke Steering Committee
- Refining recommendations
Contact

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Questions