Perspectives on Engaging Community Service Groups in the KT Process



Helping people with spinal cord injury and their families adjust, adapt and thrive

On both sides of the KT fence. And on it.





Minimizing disability. Maximizing quality of life.

Start PhD in Neuroscience, UBC: neuroprotection

Managing Director **ICORD**

Co-Leader Disability Health Research Network Managing Director **SCI Solutions** Network/RHI

Director, Translation Executive Director Research Program, RHI

SCI BC

1992 2002 2008 2010 2008 2010



Overview

- Part 1: A bit of background on SCI BC
- Part 2: What you need to know before engaging community partners in KT
 - what's the quid quo pro? (understanding motivations)
 - barriers to effective engagement (realities of nonprofits)

Part 3: Keys to successful engagement

- timing
- relevance
- •lexicon
- value

Part 4: Examples, Good and Bad



What the heck does SCI BC* do?

* Acronym warning!

SCI = spinal cord injury

SCI BC = Spinal Cord Injury Organization of BC



Spinal Cord Injury BC

Services

Help people with SCI and their families adjust, adapt and thrive as they deal with a new injury or struggle with the ongoing challenges of living and aging with a physical disability

PEER SERVICES

Members helping members through shared & community experiences

Peer events, group and individual connections, webinars & other education sessions

Peer Coordinators (paid/volunteer), Peer Support Specialists, Peer Mentors (volunteer), Peer participants, Staff

COMMUNICATIONS

Content delivery, information sharing & community building

Websites, Spin Magazine, social media, video content, partnerships, collaboration platforms

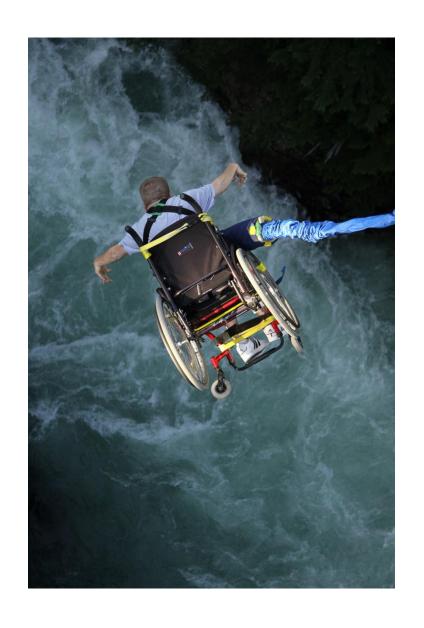
Management/staff, Working Groups led by Executive Office

INFO SERVICES

Resource Centre providing answers & information resources

InfoLine, SCI Information
Database, Swap 'N Shop,
Website, Online Resources,
AccessibleHousingBC,
AccessibleEmploymentBC

Information Services
Agents, Information &
Resource Specialist,
Communications Specialist



"SCI BC is the 'go to' place for information and support from people who really know what you're going through and how to help you get back into real living."



Where does SCI BC deliver its services?



Serving BC



Total Staff: 30

Total FTE: 20.6

Staff with SCI/Disability: 17

- Resource Centres in
 - GF Strong Rehab Centre
 - Prince George
 - Victoria



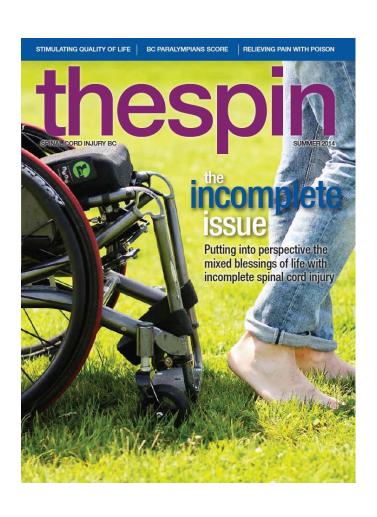
SCI BC Peer Support Program





- 12 Peer Coordinators throughout BC
- Specialized support services at GF Strong Rehab Centre
- Peer support and social events within BC SCI Resource Centres
- Peer Matching
- Group Sessions (from coffee groups to outdoor adventure)
- Monthly webinars and other Education sessions
- Peer Support Specialist fee for service
- Sharing the Peer experience via The Spin, online, etc

BC SCI Resource Centre (Information Services)



- InfoLine
- Physical Resource Centres
- BC SCI Information Database
- Accessible Housing BC
- Accessible Employment BC
- Employment Headstart
- Swap N Shop
- CSIL Manuals
- Spin Magazine



SCI BC Partnerships Overview

Why does SCI BC value partnership? Why do we engage in partnerships?

- We are on a mission to help people with SCI and their families adjust, adapt and thrive as they deal with a new injury or struggle with the ongoing challenges of living and aging with a physical disability.
- We can't do this alone we NEED partnerships.

What type of partnerships are we talking about today?

- Formal partnerships
- Collaborations
- Excluding sponsorship-type relationships and government



Key Partnerships

What sectors are we partnering with?

- Other disability-focused community service providers
- The private sector
- Health authorities
- Research institutions





Beyond, Every Day.









Research & Academic Institutions

ICORD (UBC & Vancouver Coastal Health Research Institute)

- Resource Centre and Fitness Centre in Blusson Spinal Cord Centre
- Scholarships and Bursaries
- Research projects (as co-applicant and/or a community partner)
- Knowledge Translation, including Café Scientifiques, which we help promote, host and webcast
- Research participation

McMaster (SCI Action Canada, Kathleen Martin-Ginis)

- Research projects (as co-applicant and/or a community partner)
- Knowledge Translation

University of Northern BC

• Research projects (as a community partner) relating to community accessibility and inclusion



Inspiring Innovation and Discovery

Health Authorities

Vancouver Coastal Health

- Office space provided to us at GF Strong's main entry (becoming a resource centre)
- Allow us to provide services within their facilities
- Collaborate on hosting education sessions, such as our annual SCI Forum
- Collaborative development of education and service initiatives
- Health authority staff help with recruitment for and participation in our Peer events
- Referral to our programs





What you need to know before engaging community partners in KT

What's the quid quo pro?
(Understanding motivations)

Barriers to effective engagement (The realities faced by nonprofits)



Before engaging community partners: What's the quid quo pro? Understanding motivations

Q: What might motivate a nonprofit to participate in KT activities/research?

Tips: Don't forget, nonprofits are businesses. They don't have to do things for free. There has to be something in it for them.

- Better outcomes for their members/clients
- Evidence to support enhancing quality of services
- Revenue
- Future funding (evidence for funding applications)

Before engaging community partners: Understanding motivations 2

Q: What are some turnoffs to participation?

- Assumptions that the nonprofit will want to do it because its going to be of great interest to them
- Researchers often think their results and projects are far more interesting & relevant to the community than they actually are
- Arrogance and ignorance
- Commitment to participate too great with insufficient reward
- Degree of participation offered too trivial (no ability to help shape the project)

Before engaging community partners: Know the barriers to effective engagement Realities faced by nonprofits

Q: What do think some of the barriers are?

- •Typically under resourced people, infrastructure, time
- May lack specific expertise required
 - Not just a matter of providing money for a new role
- Lack of alignment with mission
- Competing priorities
- Lack of trust need to build relationships



Part 3: Keys to successful engagement

- □timing
- □ relevance
- □ lexicon
- □value



Keys to Successful Engagement: **Timing**

Q: When is the best time to engage?

- At the project planning stage preferably before grants are submitted
- SCI BC gets a lot of requests to "help out" with projects.
 We only engage when we are included early in the development process and/or it has direct benefits for our members and our organization.



Keys to Successful Engagement: Relevance

Q: What might make a project relevant to a nonprofit?

- Alignment with the organization's vision and mission
- Enhance operational capacity (eg, increased knowledge, expertise, competence
- Enhanced outcomes through services provided

Q: How can relevancy be determined/ensured?

- Take the time to understand what the organization does
- Ask about priorities
- Ask before the plan is fully developed!



Keys to Successful Engagement: Lexicon: Speaking the right language

Different stakeholders have very different lexicons

- Language can be a barrier. Take the time to learn the language of the stakeholder with which you are engaging
- Avoid buzzwords and acronyms
- You don't need to dumb things down just use the right language
- Eg., took a half day to agree on common language relating to different peer support roles (peer mentor, peer volunteer, peer expert, peer match, peer coordinator, etc). This was crucial for development of protocols

Keys to Successful Engagement: Value Proposition

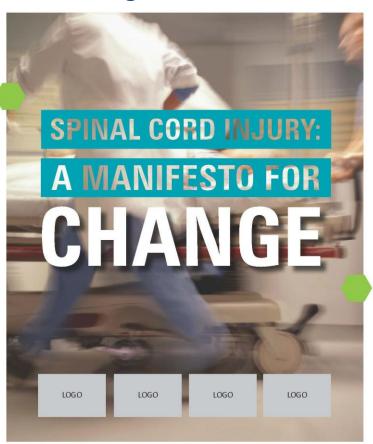
Q: What are some key elements that should be considered when putting forward the value proposition for engagement?

- If you can't articulate it, you might not want to bother!
- Enhance outcomes/impact and further mission
- Enhance operational sustainability in short- and long-term
- Tangible benefits to members/clients/participants



Keys to Successful Engagement: A bad example!

□timing □ □ relevance □ lexicon □ value



- Sounds pretty awesome, right?! Who wouldn't want to support this?
- SCI BC, that's who. Why?
- Our proposed role? Simply to help send the document out
- Absolutely no involvement in the development of the document or project
- KT/advocacy piece to improve health service for 3 conditions that are not all top priorities
- Our role in the change it describes diminishes SCI BC's services and is completely insulting
- Instead of supporting it, I'm going one step further than ignoring it.

Spinal Cord Injury BC

#Backfire

Keys to Successful Engagement: A good example

□timing □relevance □lexicon □value

What is Autonomic Dysreflexia?

Autonomic Dysreflexia (AD) is a potentially life threatening complication of spinal cord injury at T6 or above. It is caused by various painful or irritating stimuli below the level of the Spinal Cord Injury. This in turn triggers blood pressure which may rise dangerously. The most typical cause of AD is a distended bladder. Other causes could be overfull bowel, constipation or impaction, pressure sore, sunburn, in-grown toenail, skin irritant such as rivet on jeans, infection, tight clothing, or fracture. Symptoms may include elevated blood pressure (from what your baseline is), headache, sweating, flushed face, anxiety, bradycardia (slow pulse rate). Treatments is to removed the BP will start returning to your baseline.



CoastalHealth
G. F. Strong Rehab Centre

SCI-BC Infoline 1-800-689-2477

- This wallet card was developed in partnership with researchers, clinicians and SCI BC
- Early engagement: We helped ensure the language is appropriate for our members
- Clinicians ensured the validity of the information and that the language is appropriate for physicians
- We helped with the design and delivery
- The card is carried by people with SCI it could help them save their lives

Keys to Successful Engagement Another good example

□timing □relevance □lexicon □value



and inclusion in society," says Martin Ginis, "Canadians with disabilities consistently identify three areas where they feel the most restrictions, and where they'd most like to participate – in the workforce, in sports and recreation, and

Martin Ginis' project Enhancing Community Participation in Canadians with Physical Disabilities: Development,

Implementation and Evaluation of a Partnered Strategy has been awarded \$2,643,997 and was one of only

fourteen chosen by SSHRC in the Canada-wide Partnership Grants competition. McMaster co-applicants Catherine

Connelly, Canada Research Chair in Organizational Behaviour and associate professor in the DeGroote School of

kinesiology, will be part of the Sport (both recreational and competitive leisure time physical activities) team.

Business, will lead the Employment (both employment-seeking and retention) team, and Steven Bray, professor of

"Our partnership is poised to generate new knowledge that can be turned into products, tools and services that will

simply being able to move about their communities independently and with dignity.

at heart of \$3.3M from

* \$13.6M for Discovery

. Steacie Prize Award

McMaster-Fraunhofer

BEAM receives \$4M

. Early Researcher Awards

CFI funds 6 research

lecture

projects

research from NSERC

- Research partner engaged SCI BC in project's conceptual development phase
- A lot of time was spent ensuring common language was used
- Research partner ensured the priorities of the community and community partner were understood and included
- Project was designed to take advantage of existing services (based upon what SCI BC already does), minimizing impact of participation
- Thoughtful remuneration for involvement



Questions?

