



A cunning plan to facilitate funding of peer support services for people with newly acquired SCI in NZ

Synthesising evidence, developing theory & evaluating effectiveness

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PEER SUPPORT

What is peer support?

Support provided by individuals who through their lived experiences of SCI can **offer emotional support and an empathetic understanding** to help others through similar experiences.

Someone who has “gone through a comparable experience with that of another individual and, because of this shared experience, is positioned to act as a positive role model and provide believable hope.”



PEER SUPPORT

What is peer support?

Type and frequency of support provided will vary, depending on the needs of the person being supported, and the purpose and funding model of the peer support.

Increasingly **used across a range of health conditions**, supporting people with traumatic brain injury, acquired brain injury, mental health conditions, burns and chronic pain.

WHO endorses use of non-health professionals such as peers to assist in the delivery of a comprehensive range of health-care and rehabilitation services.

The 'cost' of SCI

The average costs incurred by ACC for supporting injured people with SCI are estimated to be **\$6.2million/lifetime** excluding acute health care costs and wage compensation.

Between August 2016 and 2017, the New Zealand Spinal Cord Injury register (NZSCIR) recorded **161 people with newly acquired SCI**, with 67% of these being due to a traumatic event



Rehabilitation for people with SCI in NZ

New Zealand has two spinal units that provide rehabilitation for people with a SCI

- **Burwood Spinal Unit (BSU) in Christchurch**
- **Auckland Spinal Rehabilitation Unit (ASRU).**

Rehabilitation after SCI can be lengthy

- median length of stay from injury to discharge of **71 days**.

During this time patients are very often **isolated from their communities**

- contributes to feelings of displacement for people with newly acquired SCI during their inpatient rehabilitation.

The **transition from the hospital to a community setting in NZ is hard** for people with SCI.

There is often a delay in return to work and other community participation as people adapt to their situation and injury.

Current peer support in NZ

Provided by charitable consumer-based organisations

No government or ACC funding currently available.

- risk that the peer support service is not sustainable in the current model, given the reliance on charitable giving.

Spinal Support NZ have had volunteer peer supporters working in the Auckland Spinal Rehabilitation Unit for more than 20 years

- since 2018 have employed two peer and family support staff to work within the inpatient unit.

Connecting People (Burwood Spinal Unit) began in 2009 with one paid peer support coordinator. They now have five staff providing peer support.

Since January 2018 - **nationally consistent service**

The gap

Not currently being provided at levels which optimise health outcomes

Current resourcing allows for an average between **1.45 – 1.75 hours per week of face to face peer support.**

- This level of input is consistent with what is provided internationally in intervention studies.

However, **not able to meet demand** with their current levels of resourcing.

On discharge - **0.5 hours** of peer support is currently provided per week to people with newly acquired SCI

- This level of contact does not allow adequate support to help people to adjust to life with a SCI, and to learn to adapt and thrive in home and community settings.

The cunning plan!



1. Sustainable funding model required
2. The amount of peer support provided during the transition home and post discharge period needs to increase

Overview of the proposed national peer support service

Inpatient rehabilitation peer support

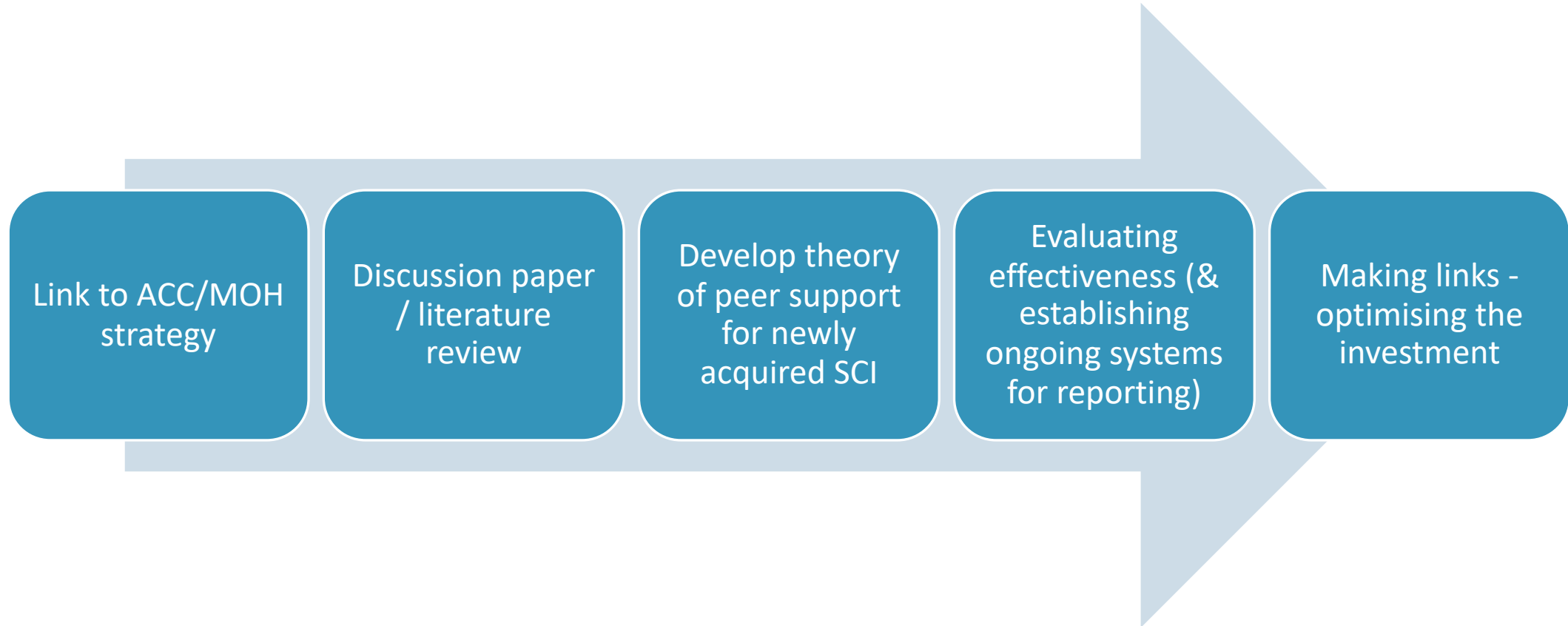
- Provided during the persons stay at either Burwood Spinal Unit (BSU) in Christchurch and the Auckland Spinal Rehabilitation Unit (ASRU)
- In-person 1:1 support
- Family / whanau support
- Group peer-support events

Post-discharge peer support

- Provided for first 6 months of a person's transition to home/community
- 1:1 support via phone or video-conferencing
- Family / whanau support

NB: in practice, peer support is provided across the lifespan of a person with SCI - but this programme of research focuses on inpatient & first 6 months following discharge

The cunning plan – linear form!



Link to funding bodies strategies....

MAKING THE MOST OF THE OPPORTUNITIES....

A solid teal horizontal bar at the bottom of the slide.

NZ Spinal Cord Action Plan (2014-9)

Commitment to implement a nationally consistent framework for providing sustainable peer support services.

- Develop and embed a nationally consistent peer support programme within existing health and disability services,
- Build capacity to provide national peer support coverage,
- Provide training for a peer support programme
- Identify sustainable multi-year funding sources that support continuity of services



Links to ACC strategy

ACC is committed to creating a unique partnership with every New Zealander, **improving their quality of life by minimising the impact of injury.**

A key outcome of ACC is to **rehabilitate injured people in New Zealand more effectively**

- peer support has been shown to support people with newly acquired SCI in a more responsive and effective manner.

ACC aims to ensure that effective rehabilitation is provided in a manner that is both **affordable and sustainable,**

- emphasising more consistent, streamlined and simplified services which support people to live a good life following injury.

ACC is committed to providing **right services at the right time,** and being responsive to the specific needs of each customer.

- The provision of peer support early within a person's rehabilitation has been consistently reported as contributing to rehabilitative support being provided in a more responsive and targeted manner.

Links to ACC strategy

Rapid return to independence after injury > overall health and well-being of customers is significantly improved, & social and economic impacts of their injuries on their whanau, communities and New Zealand are greatly reduced.

- Peer support provides people with newly acquired SCI **skills and strategies that contribute to a successful return to independence.**

Improve customers' outcomes and experiences including **commitment to attending to the priorities of consumers regarding the outcomes that are prioritised, and in the way that services are provided.**

- Peer support has consistently been reported as a positive influence on individual's rehabilitation experiences.



But what outcomes?

How can we 'show' effectiveness?

How might this be measured?

Will the funder want something different measured?

Discussion paper

PRESENT THEM WITH THE EVIDENCE... (LINKED TO THEIR STRATEGY)

Discussion paper aims

To **provide an argument** supporting the routine provision of peer support to people with newly acquired traumatic spinal cord injuries (SCI) while they undergo inpatient rehabilitation, and during their first 6-months in the community following discharge

To provide a **tool for discussion** with Accident Compensation Corporation (ACC) that allows consideration of their support for such a proposal and the development of a business case.

Why does peer support work?

Peer support is effective at

- helping people with SCI to **better transition** from inpatient rehabilitation to their home and community
- improving **health outcomes** following a SCI
- improving the **process of rehabilitation** for people with newly acquired SCI

Some limitations within the available evidence – but taken together the evidence supports the value and utility of peer support for people with a newly acquired SCI.

Improving the transition to home

Transitioning from inpatient rehabilitation to living at home in the community can be complex and difficult.

Inpatient rehabilitation systems do not prepare people with SCI to adjust and cope in real-world contexts - unprepared physically and psychologically.

Social support (particularly peer support from others who have a SCI) seems to play an important role in **helping people to adjust to life with a SCI, and learning to adapt and thrive in home and community settings**

Peer support has been shown to a **credible and trustworthy source of information** and help with transition home

Improving health outcomes

Positive effect on **perceived self-efficacy and self-competence** - more able to manage their self-care needs and to integrate back into their communities.

Facilitates **adjustment and adaptation** to new circumstances.

Contributes to improved involvement in important life roles and activities - associations between peer support and **higher quality of life and social participation**

Promotes **life satisfaction** - can assist people to visualise a positive future.

Decreased trend in **secondary health conditions and hospital admissions** after discharge from rehabilitation

- May be related to improved self-confidence in managing SCI issues

Improved experience of rehabilitation process

Positive influence on an individual's rehabilitation experience in most qualitative studies - **high level of perceived effectiveness** suggests that peer support is an important tool in health systems provision

Peers can serve as a **buffer against the constraints of rehabilitation** and the limits that health professionals sometimes place on them - individualised and empowering.

Rich sources of information, providing a sense of understanding, assistance with problem-solving, accessing information and goal setting

Addresses unmet emotional needs during SCI rehabilitation and helps with **encouragement and motivation** to participate in rehabilitation.

A shared understanding with those in similar situations could **reduce feelings of anxiety, and offer motivation and hope** for the future.

The experiences of the **family/whanau** of a person with newly acquired SCI are also improved when peer support is provided.

Possible economic savings

Successful transition to home-based care support systems > **less requirement for paid support** in the short to medium term.

Improved self-management skills > **fewer demands for ACC funded programmes, interventions, or equipment.**

Decrease in secondary health complications, especially if the peer support provided is targeted to education around specific high-risk areas (e.g. skin care or improving physical activity).

Other benefits of a funded peer support service that closely align with ACC's strategic directions:

- *The promotion of a rapid return to independence after injury, thereby contributing to improved overall health and well-being of customers, and reducing the social and economic impacts of their injuries on their whanau and community.*
- *Improving customers' outcomes and experiences, by providing a service that people with SCI prioritise, and by ensuring that the right services are provided at the right time.*
- *The delivery of a consistent, streamlined and simplified peer support service that is known to support people to live a good life following injury, in a timely and effective manner.*

Issues with the current evidence base

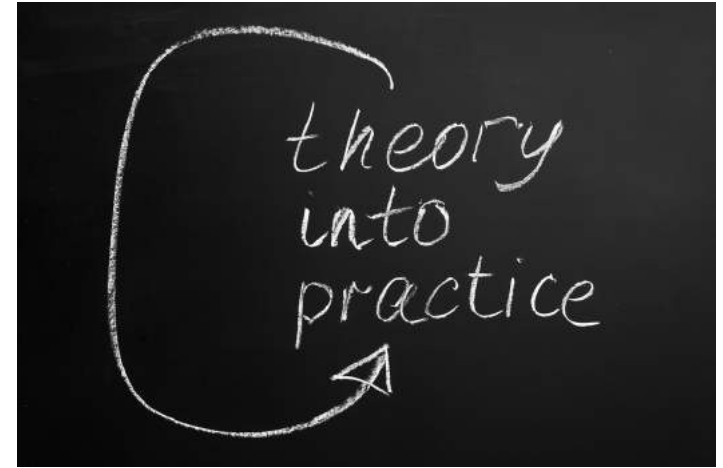
Only a small number of studies demonstrate evidence of effectiveness using robustly designed randomised controlled studies. There are a number of factors contributing to this:

- **differences in the way peer support has been delivered**, and the amount of support given
- **ethically problematic** to withhold peer support from control group
- The **effects often only seen over the longer term** > difficult to capture short-term effects using existing outcome measure.

Specific outcome-focussed peer-led interventions have tended to demonstrate change

The **description and characterisation of peer support interventions are often not described adequately** within the literature > comparisons between peer support intervention studies difficult.

Measuring the effects can be problematic with existing objective measures of health outcomes > currently, there are no standardised outcome measures to evaluate peer support.



Developing theory

WHY AND HOW DOES PEER SUPPORT WORK IN NZ?

HOW IS PEER SUPPORT PROVIDED?

WHAT OUTCOMES SHOULD WE BE MEASURING?

Peer support actively promotes the experience and practice of **belonging, autonomy and competence**, while also supporting the development of **optimism and adaptive coping**.



Belonging

Early stage: “I am not alone”

Later stage: there is a group of people I can share experiences with and draw support from
Later still: I can still fully participate in the wider world

Autonomy

Early stage: I can question my care (e.g., equipment provision)
Later stage: I feel in control of my life

Competence

Early stage: I can do things for myself (e.g., daily functioning)
Later stage: I can function in the community
Later still: I can set goals and achieve them; I have a focus and purpose

Optimism

Early stage: Life is worth living
Later stage: I can have a future focus; I am excited about the future

Adaptive coping

Early stage: I am able to cope with change
Later stage: I can change the strategies I use so that I can respond to different challenges appropriately

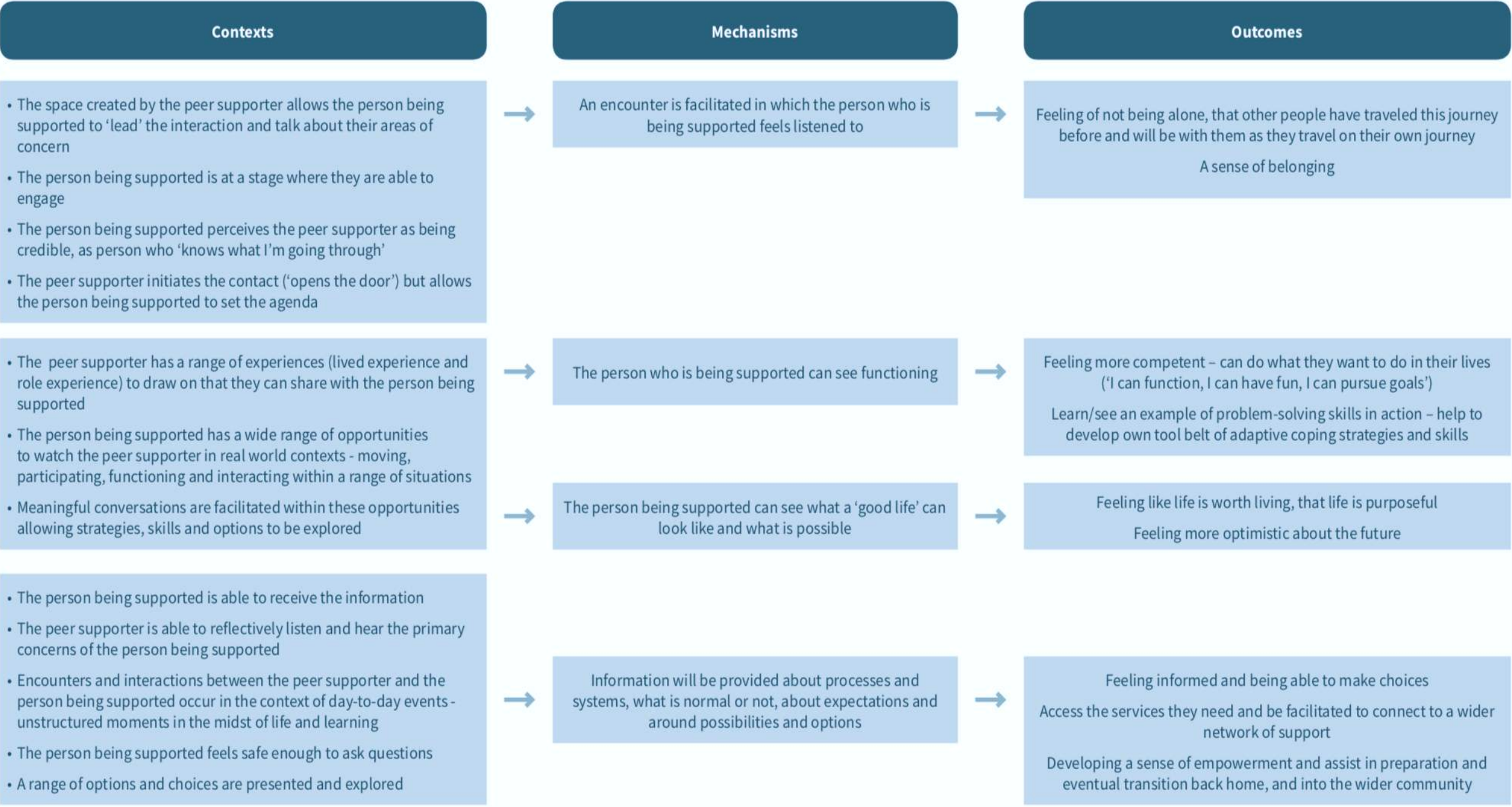


Figure 2. Theoretical model for peer support provided to people undergoing inpatient rehabilitation following SCI

INTRODUCTION

Peer support positively influences the rehabilitation experience of individual with spinal cord impairment (SCI).^{1,2} However, the specific mechanisms of peer support are not well understood.² Within New Zealand, peer support services are provided by two charitable consumer-based organisations based at the Auckland Spinal Rehabilitation Unit, and the Burwood Spinal Unit. The aim of this study was to develop a theoretical model which could be used to guide the development and evaluation of a nationally consistent peer support service, outlining in which situations, how, and why peer support facilitates improved health outcomes for people with newly acquired SCI.



RESULTS

The developed theoretical model aligns to Self Determination Theory⁴ which has been used as the basis for previous SCI peer support research.⁵ The addition of concepts related to optimism and adaptive coping extends this understanding. Of particular note, this theoretical model explicates how contextual factors (e.g. how and where peer support is offered) may impact on outcomes. The context in which peer support is provided and the manner in which it is offered, may be as important as what is provided and by whom - with the relational and physical spaces in which peer support occurs impacting on the degree to which key mechanisms are facilitated.

METHODS

We used realist evaluation methods³ to develop explanatory theory about how peer support tasks and activities are received, interpreted and acted upon by people with newly acquired SCI to produce an outcome or pattern of outcomes. We reviewed published SCI peer support literature and service provider documentation, and used realist logic to analyse data collected from focus groups and interviews with 10 peer support provider staff. A model was conceptualised and then refined in response to feedback gathered from further focus groups with peer supporters. Key context-mechanism-outcome (CMO) configurations³ were used to develop a theoretical model overviewing how peer support works.

CONCLUSION

Understanding how interventions might exert their effect is essential for service development, evaluation and implementation. This model will inform the ongoing development and evaluation of peer support services for people with newly acquired SCI. It is anticipated that this theoretical model could be applied in other contexts, either internationally or with different health conditions.

REFERENCES

1. Sweet SN, Noreau L, Leblond J, & Martin Ginn KA. (2015) Peer support need fulfillment among adults with spinal cord injury: relationships with participation, life satisfaction and individual characteristics. *Disability and Rehabilitation*, 38(6):558-65.
2. Divanoglou A, & Georgiou M. (2016) Perceived effectiveness and mechanisms of community peer-based programmes for Spinal Cord Injuries— a systematic review of qualitative findings. *Spinal Cord*, 55(1):229-34.
3. Pawson R & Tilley N. (1997) *Realistic Evaluation*. London: SAGE.
4. Ryan RM & Deci EL. (2000) Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1):68-78.
5. Sweet, SN, Michalovec, E, Lattimer-Chew, AG, Fortin, M, Noreau, L, Zehner, W, & Martin Ginn, KA. (2018) Spinal cord injury peer mentorship: Applying self-determination theory to explain quality of life and participation. *Archives of Physical Medicine and Rehabilitation*, 99(3):468-476.e12.

Paper for publication

|Developing theory explaining peer support health outcome improvement for people with spinal
cord impairment: a realist approach

Martin, R.A., Nunnerley J., Zahra S, Bourke, J., Dunn, J., Snell, D. & SCI advisory team

Applying for funding (a few times)





Lottery Grants Board
Te Puna Tahua
.....
LOTTO FUNDS FOR YOUR COMMUNITY

Evaluation of NZ-wide peer support services

& STRENGTHEN NATIONALLY CONSISTENT SERVICE

& SERVICE IMPROVEMENT

& DEVELOP ONGOING PROGRAMME OF AUDIT AND EVALUATION

Study aims

- ❖ To explore **how effectively** peer support is delivered to people with newly acquired SCI in NZ
- ❖ To better understand **what aspects of peer support works** for people with newly acquired SCI
- ❖ To develop a **deeper theoretical understanding** of relationships between the context in which peer support is delivered, how it is intended to work (i.e., mechanisms of effect) and outcomes that people with newly acquired SCI perceive have occurred in response to receiving peer support

Associated aims

- ❖ **Improve the peer support service they provide** - to develop more sustainable services, and to provide evidence that could be used when applying for ongoing service provision funding from other sources, e.g. ACC
- ❖ Develop the structure for an **ongoing programme of evaluation** that can be used for monitoring and service development going forward

Part A: To what extent does it work?

- ❖ **Online questionnaire survey**
- ❖ Completed at **two time points**
 1. Around time of discharge from spinal unit
 2. 6-month following discharge from spinal unit
- ❖ Collection of quantitative data using the **Reintegration to Normal Living Index (RNLI)**
- ❖ Collection of qualitative data by asking to what extent the proposed peer support theory developed in earlier phases of this research applies to them (i.e., **Likert Scale to rate to what extent the proposed mechanisms apply**).

Part B: How does it work?

- ❖ **Focus group and/or interviews** with 20 people with a newly acquired SCI
- ❖ Completed at **two time points**
 1. Around time of discharge from spinal unit
 2. 6-month following discharge from spinal unit

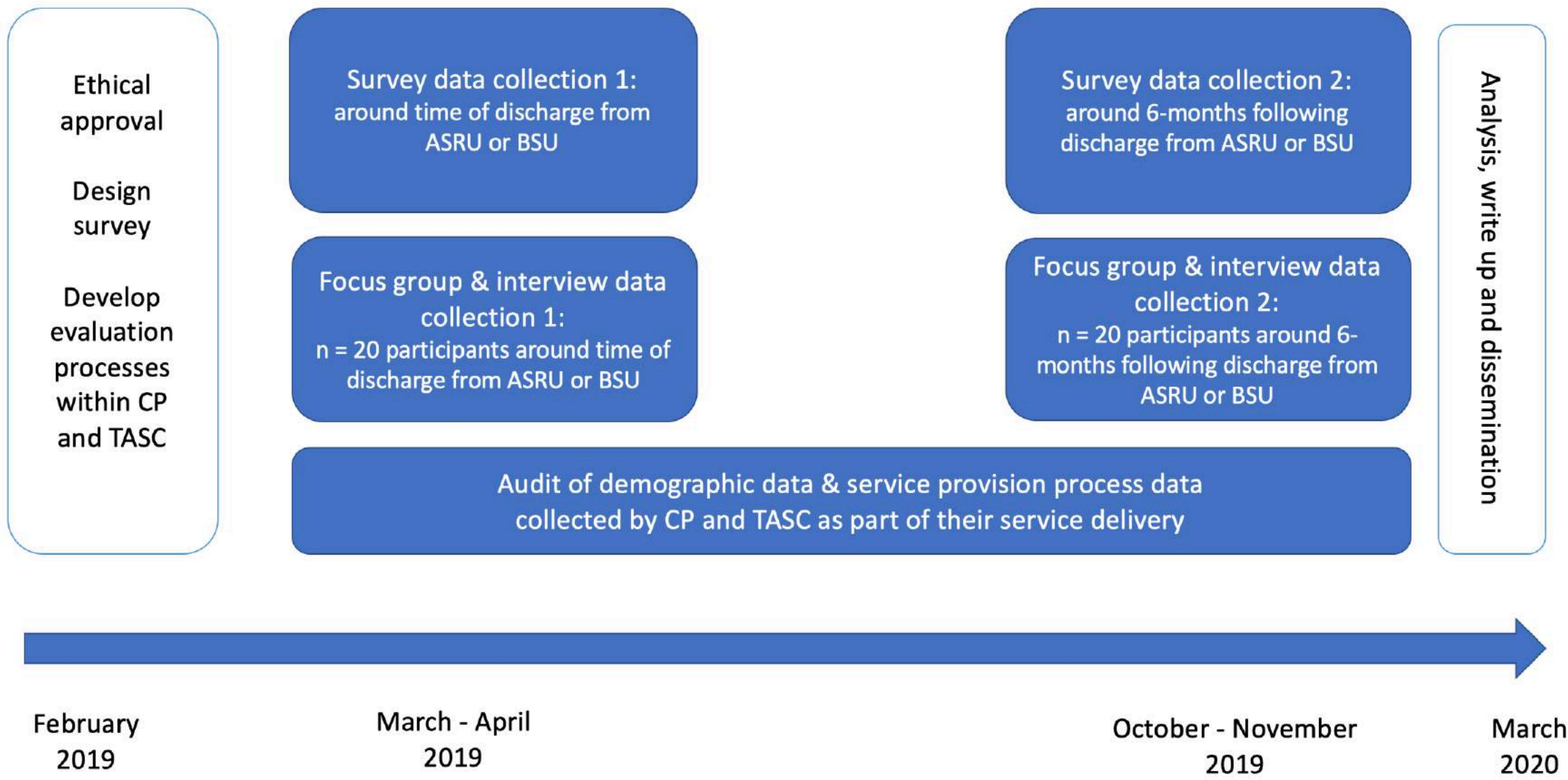
Part C: What is being offered & to whom?

Who is getting peer support?

Analysis of de-identified prospective demographic data and service provision process data collected by peer support service provider organisations

What is being provided to people?

Peer support provision data e.g., amount of peer support given to each person, the topics covered in peer support sessions, and locations in which peer support was provided (i.e. in the unit, at the hospital cafe, in the gym, in the community).



Using the findings

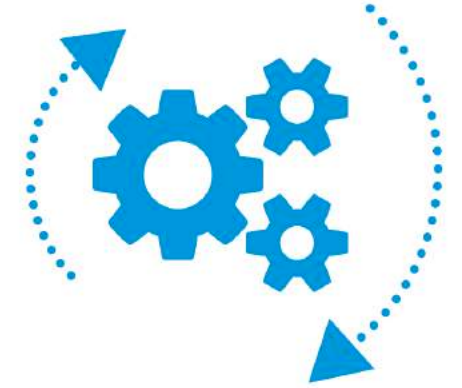
Improve the service offered

- Aligned to person with new SCI priorities
- More targeted
- Increased clarity about aims of peer support & how best to do that...

Nationally consistent audit & evaluation systems - collecting the same data in the same way

Embed evaluation skills within organisations providing peer support

World domination!



Making the most of the 'investment'

Collaborations



❖ **Shane Sweet** – Assistant Professor
Department of Kinesiology & Physical
Education, McGill University

Coordinating a number of studies exploring
peer support for people with SCI in Canada

Delphi study to develop peer support specific
outcome measure – also with Australia?

❖ **Nic Kayes** – Senior Lecturer, School of
Clinical Sciences and Co-Director, Centre for
Person Centred Research

HRC grant to explore peer support provision
to people with TBI in NZ



Questions & discussions
