DISCUSSION PAPER

To Accident Compensation Corporation

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Peer Support for people with Spinal Cord Injury in New Zealand

1 Purpose

A. 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 from the Burwood Spinal Unit (BSU) in Christchurch, and the Auckland Spinal Rehabilitation Unit (ASRU).
B. 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.

2 Alignment to ACC Strategic Direction

The provision of peer support to people with newly acquired SCI closely aligns with ACC's strategic direction

- 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[1] and 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.[2] 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.
- ACC recognises that when rehabilitation services promote a rapid return to independence after injury, the overall health and well-being of customers is significantly improved, and the social and economic impacts of their injuries on their whanau, communities and New Zealand are greatly reduced.[1,2] Peer support provides people with newly acquired SCI skills and strategies that contribute to a successful return to independence.

- A key strategic direction of ACC is to improve customers' outcomes and experiences.[1] This includes a 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.
- As a co-collaborator (with the New Zealand Ministry of Health) on the New Zealand Spinal Cord Impairment Action Plan 2014-2019[3], ACC has indicated a commitment to implement a nationally consistent framework for providing sustainable peer support services. This commitment was to 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, and identify sustainable multi-year funding sources that support continuity of services.

3 Recommendations

1. An ACC funded national peer support service be delivered to people with new traumatically-acquired SCI.

2. Peer support to be funded for the duration of a person's inpatient stay, and for the first 6-months following their discharge from either the Auckland or Burwood Spinal Units.

3. Connecting People (part of the NZ Spinal Trust) and The Association for Spinal Concerns (TASC) provide peer support services within NZ, given their proven track record of providing peer support services to date.

4 Background

SCI in New Zealand

SCI refers to neurological damage that has occurred to cervical, thoracic, lumbar or sacral areas of the spinal cord. A SCI can result in a range of impairments including loss of strength, loss of sensation, and changes to bladder, bowel and sexual function.

The average costs incurred by ACC for supporting injured people with SCI are estimated to be $6.2million/lifetime[4] excluding acute health care costs and wage compensation.

The annual incidence of both traumatic and non-traumatic SCI in NZ is estimated at 30/million.[5] 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.[6] Those with traumatic injuries were mostly men (78%) with a median age of 50 years. The most common causes of traumatic SCI in NZ were as a result of falls (36%), sports injuries (28%) and transport-related accidents (23%).[6]

Following initial discharge, people with SCI are reported to have more than double the number of hospital visits and three times longer hospitalisation duration per person per year as compared with the general population.[7]

Rehabilitation for people with SCI in NZ

New Zealand has two spinal units that provide rehabilitation for people with a SCI - the Burwood Spinal Unit (BSU) in Christchurch and the Auckland Spinal Rehabilitation Unit (ASRU).

The goal of SCI rehabilitation is to assist the person with SCI to maximise their function and independence, and to help them develop skills for reintegration into the community and to valued life roles. SCI rehabilitation is provided by multidisciplinary teams including rehabilitation medicine specialists, nurses, physiotherapists, occupational therapists, social workers, dieticians, speech and language therapists, and psychologists.

Rehabilitation after SCI can be lengthy, with a median length of stay from injury to discharge of 71 days.[6] During this time patients are very often isolated from their communities (given the location of the two spinal units in Auckland and Christchurch) contributing to feelings of dislocation for people with newly acquired SCI during their inpatient rehabilitation.

After discharge from the spinal unit, rehabilitation of people with traumatic SCI continues to be provided in the community via ACC providers, with regular lifelong follow up provided by the spinal units through outreach services. A reassessment undertaken by the multidisciplinary rehabilitation team from the spinal unit is normally provided to people 6 to 12 months after their discharge from hospital.

The transition from the hospital to a community setting in NZ is hard for people with SCI.[8-10] There is often a delay in return to work[11,12] and other community participation as people adapt to their situation and injury.

Current peer support services within NZ

New Zealand currently has two peer support services provided by charitable consumer-based organisations: TASC, at the Auckland Spinal Rehabilitation Unit, and Connecting People (part of the New Zealand Spinal Trust), at the Burwood Spinal Unit. There is no government or ACC funding currently available.

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

TASC have had volunteer peer supporters working in the Auckland Spinal Rehabilitation Unit for more than 20 years but since 2018 have employed two peer and family support staff to work within the inpatient unit. Connecting People began in 2009 with one paid peer support coordinator. They now have five staff providing peer support.

TASC and Connecting People have developed a nationally consistent service based on a theoretical model developed through research.[13] This was implemented nationally in January 2018.

Within NZ, peer support actively promotes the experience and practice of belonging, autonomy and competence, while also supporting the development of optimism and adaptive coping. The theoretical model, developed through research, aligns with and extends the use of Self Determination Theory[14] as the theoretical basis for effective peer support. This theory has also been identified as the basis for peer support across three Canadian provinces.[15]

What is peer support?

Peer support can be defined as 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.[18,19] A peer is defined as being 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."[18 p.132]

Peer support can also be referred to as peer mentoring, peer coaching or peer counselling.

- Peer counsellor – provides knowledge, guidance, tools
- Peer educator – delivers formal education or training
- Peer support – informal and unstructured
- Peer facilitator – facilitates group interactions
- Peer case manager – assists or coordinates[19]

A peer supporter is thought to act as a role model, supporter and advisor,[20] and to offer emotional, informational, esteem and tangible support.[21]

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

Topics that may be addressed during peer support interactions may include: community integration, medical supplies, equipment and assistive technology options, partnering with health professionals for quality care, empowerment, managing stress, building a support network, participation in recreational activities; travel logistics; managing health and secondary health conditions with a SCI; self-care and daily living tasks; sports and leisure time physical activity; accessible housing; community resources; attitudinal barriers; family and relationships; employment and vocational issues.[16,20,22,23]

Peer support is increasingly used across a range of health conditions, supporting people with traumatic brain injury,[24] acquired brain injury,[25-27] mental health conditions,[28-30] burns[31] and chronic pain.[32]

The World Health Organisation endorse the utilisation of non-health professionals such as peers to assist in the delivery of a comprehensive range of health-care and rehabilitation services.[33 p.113]

How peer support is effective at improving health outcomes after SCI

Peer support is effective at (a) helping people with SCI to better transition from inpatient rehabilitation to their home and community, (b) improving health outcomes following a SCI, and (c) in improving the process of rehabilitation for people with newly acquired SCI. While there are some limitations within the available evidence supporting the effectiveness of peer support, taken together the evidence supports the value and utility of peer support for people with a newly acquired SCI.

Peer support assists with improving the transition to home

Transitioning from inpatient rehabilitation to living at home in the community can be complex and difficult.[8] Inpatient rehabilitation systems do not appear to adequately prepare people with SCI to adjust and cope in real-world contexts, leaving them unprepared both physically and psychologically.

After returning home, individuals with SCI often experience isolation, depression and low levels of physical and psychosocial functioning[34] with low self-efficacy being associated with poor adjustment post discharge.[35]

Traditional rehabilitation approaches frequently do not support people with SCI to improve their social participation in valued activities and life roles.[36-37]

- Social support, and 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[38]
- Peer support has been shown to a credible and trustworthy source of information[39] and help with transition home[8]

Peer support is effective at improving health outcomes

Peer support has a positive effect on perceived self-efficacy and self-competence, helping people with newly acquired SCI to feel more able to manage their self-care needs and to integrate back into their communities.[40-41] Increased self-efficacy can also have a positive effect on symptoms of depression and anxiety.[42]

Peer support facilitates a person with newly acquired SCI to adjust and adapt more easily to their new circumstances.[16,39,43]

Peer support contributes to improved involvement in important life roles and activities, with associations between peer support and higher quality of life and social participation demonstrated.[21,39,43,44] Peer support promotes life satisfaction and can assist people to visualise a positive future.[39,43,45]

A decreased trend in secondary health conditions and hospital admissions after discharge from rehabilitation has been demonstrated following the provision of peer support.[40,41] This may be related to improved self-confidence in managing SCI issues.[40,46]

An emerging body of literature has shown the effectiveness of SCI peer support when such programs target specific behaviours such as wheelchair training skills[47] and strength-training exercise.[48]

Peer support improves customers experiences of the process of rehabilitation

Peer support has been reported as having a positive influence on an individual's rehabilitation experience in most qualitative studies exploring the perspectives of those living with SCI.[23, 49-51]

The experiences of the family/whanau of a person with newly acquired SCI are also improved when peer support is provided.[52,53]

Peers can serve as a buffer against the constraints of rehabilitation and the limits that health professionals sometimes place on them.[54] The way that peer support services are provided are individualised and empowering.[13,20,21,52]

SCI peers are rich sources of information, providing a sense of understanding, assistance with problem-solving, accessing information and goal setting.[16,51] Peer support can be a valuable resource for people with newly acquired SCI as they can help with both practical and functional tasks. Peer supporters can give credibility to the practical advice, and information that health care professionals cannot.[16,40,52]

Peer support addresses unmet emotional needs during SCI rehabilitation[16] and helps with encouragement and motivation to participate in rehabilitation.[39] A shared understanding with those in similar situations could reduce feelings of anxiety, and offer motivation and hope for the future.[50,55]

A high level of perceived effectiveness suggests that peer support is an important tool in health systems provision for people with SCI.[52,56]

5 Funding peer support services for people with SCI in NZ

Peer support can be provided cost-effectively and sustainably.

Current peer support service resourcing levels:

- Due to resourcing constraints within the charitable consumer-based organisations, peer support services are not currently being provided at levels which optimise health outcomes for people with newly acquired SCI.
- Current resourcing allows for an average between 1.45 – 1.75 hours per week of face to face peer support to be provided in the two NZ inpatient rehabilitation units. This level of input is consistent with what is provided internationally in intervention studies.[40,41] However, while levels of input are adapted to suit the stage of rehabilitation and the different needs of people with newly acquired SCI, in general TASC and CP have found that they are not able to meet demand with their current levels of resourcing.
- Current resourcing means that on discharge an average of 0.5 hours of peer support is currently provided per week to people with newly acquired SCI once they transition back to their homes and local communities. 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. Other peer support services outlined in published literature, especially those tailored to preventing secondary health complications, provide higher levels of post discharge intervention than those currently able to be provided in NZ under current levels of resourcing.[40,59]

Proposed peer support service resourcing levels:

It is proposed the amount of peer support needs to increase from current levels, especially that provided in the 6-months following their discharge, to ensure that health outcomes are optimised in people with newly acquired SCI and that people more effectively transition to home from inpatient rehabilitation.

The effective provision of peer support within an inpatient rehabilitation setting also involves attending multidisciplinary and family planning and discharge meetings, supporting family/whanau, and coordinating group peer-support events (e.g. community-based activities).

Possible economic savings resulting from SCI peer support:

- Successful transition to home-based care support systems for ACC clients with SCI, requiring less requirement for paid support in the short to medium term.
- Improved self-management skills of people with newly acquired SCI, contributing to fewer demands for ACC funded programmes, interventions, or equipment.
- Reduction in hospital readmissions with SCI secondary health complications.
- 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.

6 Issues

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

- There are differences in the way peer support has been delivered, and the amount of support that has been given, across the studies
- It is ethically problematic to withhold peer support from the control group, making between-group comparison studies difficult.
- The effects of peer support are often only seen over the longer term, and it can be difficult to capture short-term effects using existing outcome measures. For example, current self-efficacy scales which are presented as a total score, may not be responsive to changes within specific domains of self-efficacy (e.g., managing self-care tasks or feeling competent accessing the community)
- Specific outcome-focussed peer-led interventions have tended to demonstrate change (e.g. the effectiveness of peer support on wheelchair skills or physical activity), but the effects of peer support are more difficult to show when measuring more general or distal outcomes.

A small number of cohort studies has examined the association between peer support and health outcomes retrospectively. However, it can be difficult to account for all confounding variables in these studies. There are many qualitative studies and a qualitative metasynthesis that support the perceived effectiveness of peer support based on the experiences of people with SCI and their families. The description and characterisation of peer support interventions are often not described adequately within the literature. This makes comparisons between peer support intervention studies difficult.

Measuring the effects of peer support can be problematic with existing objective measures of health outcomes. There is a need to develop appropriate and psychometrically sound measures that can detect peer support effects on people with newly acquired SCI. Currently, there are no standardised outcome measures to evaluate peer support. This is an area of research activity internationally.[57]

Currently, the primary outcome areas that are measured in quantitative studies include:

- Self-efficacy, e.g., Modified General Self-efficacy Scale[40] or Moorong Self-Efficacy Scale[58]
- Satisfaction with life, e.g., Satisfaction with Life Questionnaire[17]
- Participation in valued roles and activities, e.g., Patient-Perceived Participation in Daily Activities Questionnaire[17]
- Satisfaction with the provision of healthcare services and/or rehabilitation, e.g., Health Care Climate Questionnaire[58]
- Rates of secondary health complications – it should be noted that these have been measured when peer support has tailored to address a specific issue (e.g. skin care) rather than the provision of peer support more generally

7 Proposal for ACC funded national peer support service

It is proposed that ACC consider funding a national peer support service since support provided by peers has been shown to improve health outcomes, improve the transition from inpatient rehabilitation to home and community settings, and improve the process of rehabilitation for people with newly acquired SCI. We propose that:

1. A funded national peer support service be delivered to people with new traumatically-acquired SCI, ensuring long-term sustainability.
    a. Peer support optimises outcomes following SCI, particularly those outcomes focused on social participation and the ability of people with newly-acquired SCI to resume important activities and life roles.
    b. High levels of perceived effectiveness necessitate the higher integration of community peer-based programmes in health-care systems, and the provision of adequate long-term funding.[54,56]

2. Peer support be funded for the duration of a person's inpatient stay, and for the first 6-months following their discharge from either the Auckland or Burwood Spinal Units.
    a. Peer support delivered during this period will ensure that rehabilitation is provided in an individualised, timely and effective manner - with the 'right support' being given at the 'right time'.
    b. The provision of peer-support during this period will encourage the person with newly acquired SCI to more effectively self-manage their recovery. A focus on enabled recovery, with people with long-term impairments needing to take a more active role in accessing the support they require, also aligns with ACC's strategic direction.

3. 'Connecting People' (part of the NZ Spinal Trust) and The Association for Spinal Concerns (TASC) provide peer support services within NZ, given their proven track record of providing peer support services to date.
    a. Consistent funding at a national level will further support the delivery and evaluation of a sustainable peer support service, and the training of peer supporters, across sites.
    b. Connecting People and TASC are already embedded within their respective spinal units. They are respected providers of peer support and have established roles within the multidisciplinary rehabilitation teams.
    c. Working with Connecting People and TASC will allow a unique partnership opportunity to develop. ACC strategic intentions will in part be met by creating opportunities for greater collaboration around client outcomes. The development of a national peer support service will allow ACC to create a unique partnership with people with SCI both as providers and as consumers.[59]

4. Careful consideration will need to be given to the selection or development of outcome measures that would best capture change in health outcomes, along with key performance indicators of the NZ peer support service. In addition, a robust evaluation of the service should be implemented to assess and report on the effectiveness of the programme on short- and long-term health outcomes for people with traumatically acquired SCI within NZ. For this, a prospective longitudinal study design is recommended.

8 Next steps

- If the recommendations as per point 3 in the paper are agreed to in principle, then ACC commit to supporting the creation and submission of a business case.
- ACC commit to assist NZST and TASC in formulating a business case for consideration and potential approval.

9 References

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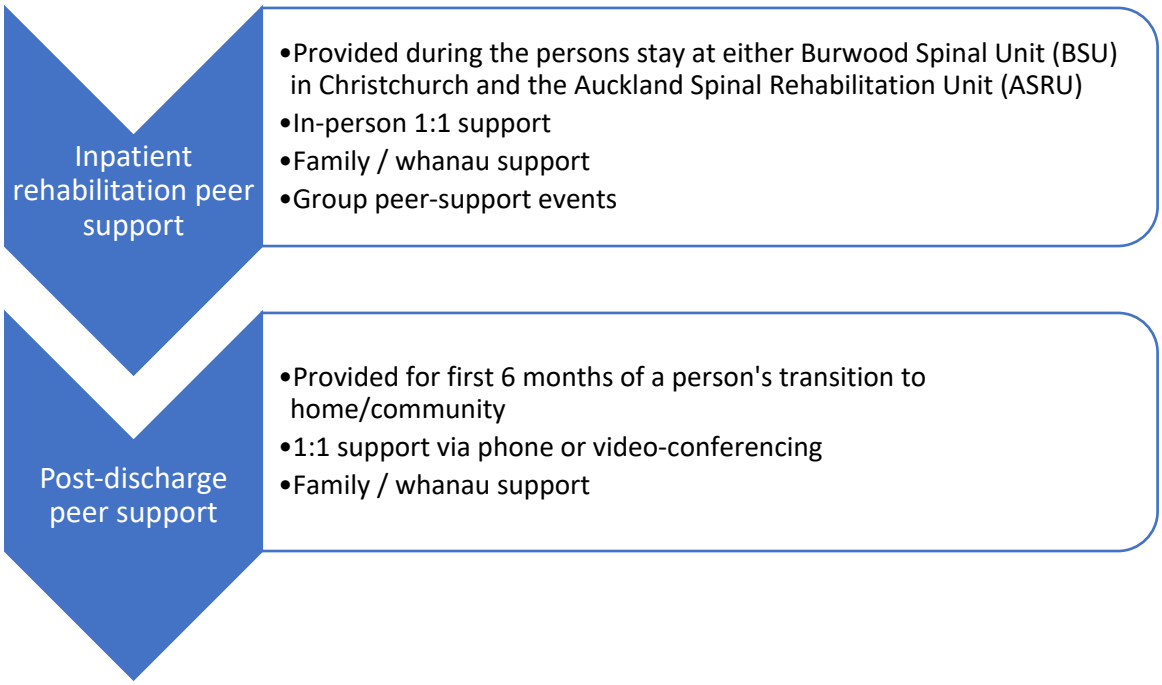
10 Appendix: Overview of the proposed national peer support service



Due to resourcing constraints within the charitable consumer-based organisations, peer support services are not currently being provided at levels which optimise health outcomes for people with newly acquired SCI.

It is proposed the amount of peer support provided during the transition home and post discharge period needs to increase from current levels to ensure that people more effectively transition to home from inpatient rehabilitation.