New Zealand Spinal Trust
Te Taratihi Manaaki Tuanui

SPINAL SUPPORT nz
Enabling positive lives
Manaaki te ora pai

PEER SUPPORT PROVIDED TO PEOPLE WITH NEWLY ACQUIRED SCI IN NZ

A TRANSLATIONAL RESEARCH PROJECT

DRAFT SUMMARY REPORT

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BURWOOD ACADEMY
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BACKGROUND INFORMATION

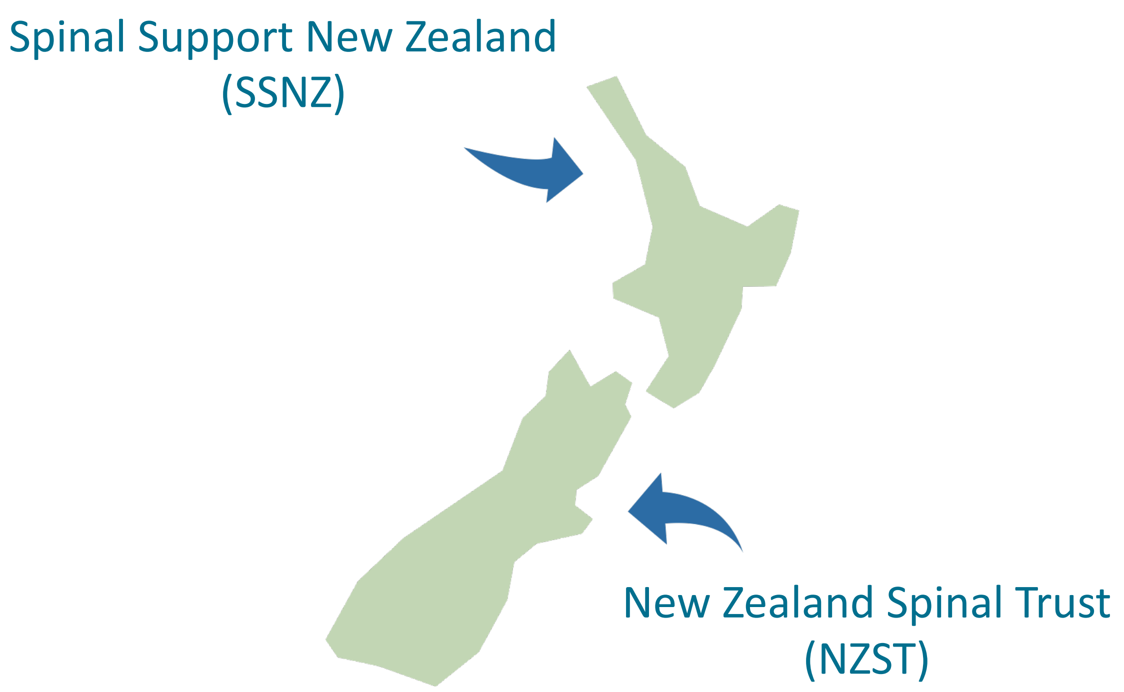
The provision of peer support for people with SCI was endorsed by the New Zealand Spinal Cord Impairment Action Plan (2014-2019) which recommended the implementation of a nationally consistent framework for providing sustainable peer support services. Specifically, the plan identified the need to (a) develop and embed a nationally consistent peer support programme within existing health and disability services, (b) build capacity to provide national peer support coverage, (c) provide training for a peer support programme, and (d) identify sustainable multi-year funding sources that support continuity of services.

Over the past three years, BAIL has worked with the NZST and SSNZ to undertake a programme of research supporting the implementation of NZSCIAP objectives related to peer support provision. The key objective was to 'develop a nationally consistent framework for providing sustainable peer support services' with the following three outcomes:

- People with SCI, their family and whānau receive consistent and practical peer support services through a national peer support programme.
- Sustainable funding is available for SCI peer support agencies.
- Benefits of peer support for people with SCI, their families and whānau are maximised through a targeted approach.

This research is one part of this overall work and has been conducted with the support of a Lotteries Grant, May 2019 – June 2020.

NEW ZEALAND PEER SUPPORT PROVIDER ORGANISATIONS



KEY AIMS OF THIS RESEARCH

Research – what works for who and how?

- How well are people's needs being met?
- What is going well? What could be improved?
- Are there specific things that could be focused on to make sure that peer support is provided in ways that best meets the needs of people with newly acquired SCI?

Build organisational capacity

- Development of systems to facilitate consistent gathering and collation of data so can demonstrate consistency and have a clearer idea of what peer support is provided. This will support applications for sustainable funding
- Staff training > research assistant role, and other incidental learnings regarding ongoing evaluation approaches
- Collaborative knowledge translation and planning workshop > integrate research findings and recommendations with existing organisational knowledge and expertise

EVALUATION OBJECTIVES & METHODS

EVALUATION RESEARCH OBJECTIVES

This evaluation research aimed to:

- explore how effectively the New Zealand Spinal Trust (NZST) and Spinal Support New Zealand (SSNZ) deliver peer support to people with newly acquired SCI
- better understand what aspects of peer support works for people with newly acquired SCI
- develop a deeper 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

We used a partnership research approach in which peer support organisational staff have worked alongside the BAIL research team to undertake this evaluation. This study has therefore also developed structures and processes for an ongoing programme of evaluation within NZST and SSNZ. This data will be used for ongoing monitoring and service development, ensuring NZ-wide consistency peer support provision. Skills developed by the peer support organisations will allow them to undertake continuing service development based on systematic evaluative approaches in the future.

TYPES OF DATA COLLECTED

Four main types of data were collected:

11 ONLINE SURVEYS

3 CASE STUDIES

10 INTERVIEWS AT TWO TIME-POINTS

ORGANISATIONAL DATA

- **Online surveys:** completed by adults with SCI close to their discharge from the spinal unit
- **Case studies:** data recorded by the peer support provider (also working as a research assistant) regarding how peer support was provided to individuals and the specific nature of that support.
- **Interviews:** conducted with adults with SCI (5 participants from each spinal unit) at two time points - on discharge and 6-months following discharge
- **Organisational process and outcome data:** de-identified prospective demographic data and service provision process data collected by NZST and SSNZ

KEY RESEARCH QUESTIONS

To what extent does peer support meet people's needs?

How does it work?

How should it best be provided?

What is being offered, and to who?

HOW DOES PEER SUPPORT IMPROVED HEALTH OUTCOMES?

WHAT WORKS WELL?

POSITIVE OUTCOMES

- Peer support provides people with a newly acquired SCI with a sense of belonging – ensuring that they do not feel alone and unsupported
- Peer support helps people with a new SCI to face the future realistically and optimistically – providing hope and optimism about the future, while also supporting them to realistically face challenges
- Peer support helps people with a new SCI to acquire tips and tricks that allow them to function well with a SCI. Peer supporters also help people to integrate information provided by the health professionals in ways that are relevant for them
- By providing coaching and examples of living, peer support contributes to people learning to adapt and respond to a range of challenges
- Peer support empowers people with newly acquired SCI – enabling them to 'take back their power' so that they can more effectively advocate for themselves
- Peer support ensures that people with newly acquired SCI can know what is possible – that they have a right to expect certain things (validation) and that things are possible (inspiration)

IMPLICATIONS

- People with newly acquired SCI highly value peer support and the vital role that peer support plays in SCI rehabilitation.
- Provision of peer support is a key part of interdisciplinary rehabilitation service provision, particularly in the first 6 months of a newly acquired SCI.
- Peer support prepares people to live well with an SCI, and particularly for the challenges they will face as they continue to adjust to living with an SCI after their discharge.

I asked [John] 'How do you get into your car?'. Because I want to get back to driving. So, he showed me how he got into his car. And I was like 'wow', then then you know, seeing his car had been modified to suit his needs. I was like, "I want to do something like that and get a car and hopefully be more confident in myself to get out instead of feeling stuck in my own thoughts and what ifs.

HOW COULD PEER SUPPORT SERVICES BE IMPROVED IN NZ?

PRIORITISED CHALLENGES FROM COLLABORATIVE WORKSHOP

ADMISSION TO DISCHARGE

- The informal nature of peer support interactions may not be structured enough. Key information may be missed for some people and contribute to them not feeling as well prepared for living in the community as they might have been.
- Language differences provide a barrier for some peer support interactions. Interpreter support is required at times but is not readily available.
- Currently peer supporters are not routinely involved with the provision of health information within the spinal units. More structured education sessions led by peer supporters may contribute to increased integration of health information into knowledge that is relevant for the person with a new SCI.
- Families are reporting that they would like to receive support from peers (e.g., other family members of a person with an SCI who can share their experiences.
- Some groups of people (e.g. families and people who can walk) are frequently stating that they are not offered the levels of peer support they want.

DISCHARGE TO 6-MONTHS

- Improved peer support follow-up is required once a person is discharged from the spinal unit.
- Once they are discharged, people with a new SCI need to feel an ongoing sense of care that aligns with the care they received as an inpatient
- People with a new SCI report that the real learning begins when they get home. However, peer support at this time is limited and/or hard to access and navigate.
- There are currently limited resources available to provide post-discharge peer support. The majority of paid peer support resources (charitably funded) are currently directed to peer support provided to people while they inpatients.

FUTURE WORK SUGGESTIONS

How might we make sure interactions are purposeful so that people (and families) get all the information and support they need?

- Have a structured and scheduled approach to sharing information – possibly develop a 'curriculum' based on the 'Back on Track' information book; also consider development of FAQ sheets
- Timetable peer support interaction times
- Explicitly consider how to provide peer support to people with a new SCI who are walking
- Ensure that peer support is focusing on the needs and wants of people with a new SCI – take time to get to know their specific needs
- Explicitly consider how to provide peer support to family/whānau of people with a new SCI

How might we improve follow-up so people don't feel abandoned after discharge?

- Provide monthly informal online catchups
- Provide structured community online meetings
- Designated follow-up people (volunteers providing peer support in the community) organised prior to discharge
- Continue to develop a network of supported regional volunteers
- Have a follow-up plan that is co-designed between the person with new SCI and the peer support providers
- Have a specific monthly phone-in time

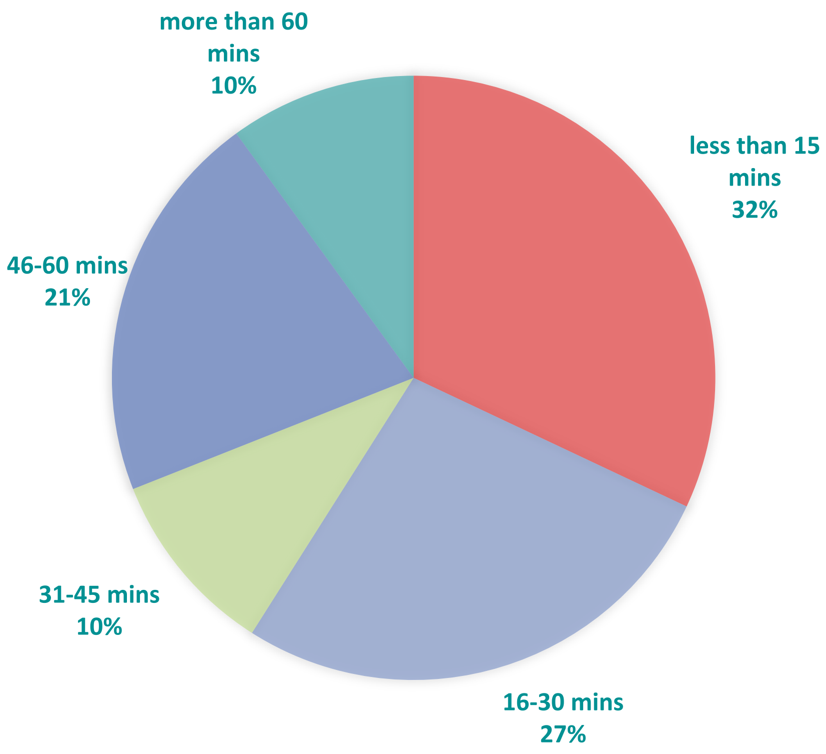
WHAT PEER SUPPORT IS BEING OFFERED?

DATA COLLECTED 1 FEBRUARY 2020 – 20 MARCH 2020 (COVID-19 DISRUPTED)

317 INTERACTIONS **223** HOURS IN TOTAL

“I mean I quite like chatting with them and getting information from them, ‘cos I’m obviously new to this new life. And especially in the beginning of my rehab, it’s a bit too much. I don’t know what happens to my body, I don’t know whether I walking or not. So I’m getting lots of information from them - and then sharing kind of emotional things with them. In the very beginning there were lots of emotions going on with my brain and then chatting with them and seeing, and they shared their experience with me which is great. They made me realise that I can do things if I want to.”

INTERACTION LENGTH

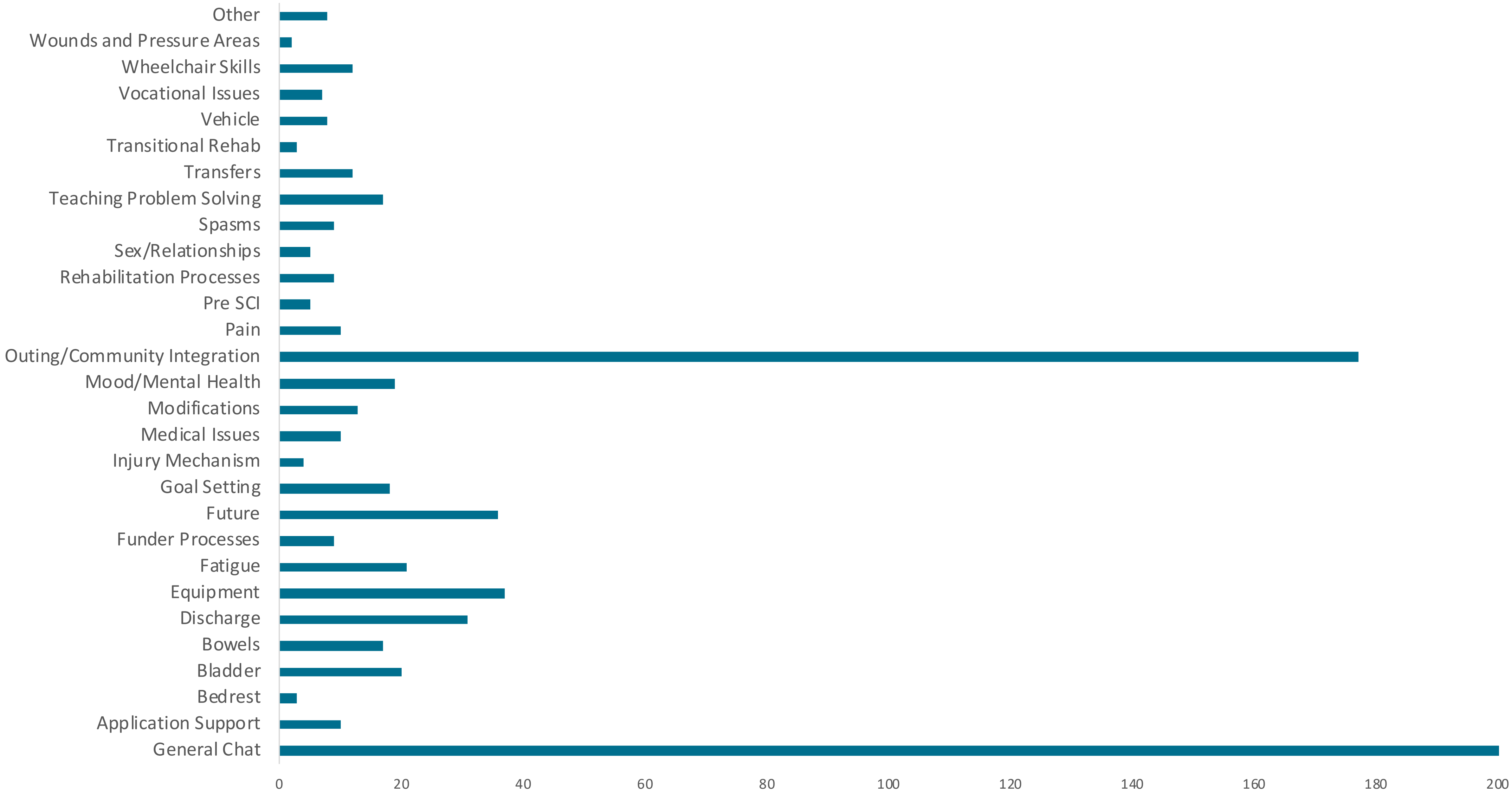


WHAT IS BEING OFFERED?

They speak in layman’s terms. You know what I mean? When they explain stuff to me it just makes more sense. Because everybody else spoke, to me it was like, “Yeah, OK,” but it went in one ear and out the other, but when they spoke to me about the same stuff, you know, then I realised, “OK, now I get it.”

WHAT IS BEING DISCUSSED?

DATA COLLECTED 1 FEBRUARY 2020 – 20 MARCH 2020 (COVID-19 DISRUPTED)



[John] definitely changed my thoughts about my injury. I mean, life after my injury. [John] was majorly inspirational. He pretty much shared straight away what his life was like after his injury. Just his stories of what he is up to and doing. So, I got an idea of what the rest of my life could look like. Seeing someone like [John] living his life – your grief doesn't become so hard because you think, "I can do this".

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DISCLAIMER

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