

# NEW ZEALAND SPINAL CORD IMPAIRMENT ACTION PLAN (2014-2019)

## FINAL EVALUATION REPORT

26 MARCH 2020

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## BACKGROUND

*The Action Plan aims to improve the health and wellbeing of people with SCI, promote independence and community participation, and support their family/whānau or significant others who may be assisting with supports and care.*

### NEW ZEALAND SPINAL CORD INJURY ACTION PLAN (2014-2019)

The New Zealand Spinal Cord Action Plan (NZSCIAP) was developed by the Accident Compensation Corporation (ACC) and the Ministry of Health (MOH) in collaboration with a wide range of stakeholders across the health system - including consumer groups, professional bodies, expert clinicians, district health boards (DHBs) and researchers.

The NZSCIAP was implemented 2014-2019 in response to the following identified needs:

- To improve coordination and reduce fragmentation of medical interventions and lifelong supports for people with SCI
- To improve consistency in approaches to supporting people to optimise the health, wellbeing and life expectancy for people with SCI
- Increased life expectancy of people with SCI contributes to progressive complexity for people and their lifelong self-management
- To better tailor services and supports to peoples individual physical and social needs
- To improve the quality of services that support family/whānau of people with SCI

A national governance group comprising service managers, senior clinical leaders and community representatives across SCI services has provided national direction for SCI services - monitoring quality and promoting innovation. The NZSCIAP governance group has met twice per year from 2014-2019.

The NZSCIAP is based around eight objectives, established in response to a situation analysis paper (2013), a UMR literature review (2012) and two UMR research reports (2013).

|                    |   |
|--------------------|---|
| <b>Objective 1</b> | Improve acute clinical outcomes for adults requiring acute SCI care                                 |
| <b>Objective 2</b> | Improve outcomes for children and adolescents   |
| <b>Objective 3</b> | Improve information sharing   |
| <b>Objective 4</b> | Provide nationally consistent SCI rehabilitation services and extend community-based rehabilitation |
| <b>Objective 5</b> | Review and align MOH and ACC processes for access to equipment, housing modifications and transport |
| <b>Objective 6</b> | Develop peer support services   |
| <b>Objective 7</b> | Build health and disability workforce capability  |
| <b>Objective 8</b> | Support improvements for carers taking a cross-agency approach                                      |

# EVALUATION OBJECTIVES & METHODS

## EVALUATION OBJECTIVES

It is of interest to the cross-agency and sector partners to gain an understanding of NZSCIAP effectiveness by evaluating:

- How the NZSCIAP has been implemented.
- The extent to which objectives have been met.

Addendum 1 overviews the questions related to each objective agreed to within the commissioning of this evaluation.

- There was a focus on the SCI-related service delivery experiences of people who had acquired an SCI during the implementation of the NZSCIAP (2014-2019).
- Qualitative data was not collected around Objectives 1, 3 and 7 - however we have collated information about progress from a range of sources (e.g., audit reports and NZSCIAP Governance Group minutes).

In preparing this report, we have also been asked to comment specifically on how the processes surrounding the implementation of the NZSCIAP may have contributed to improved delivery of SCI services within NZ.

## EVALUATION METHODS

We used a mixed-method design to gather data from a range of sources and stakeholders. This method, with a focus on qualitative data collection, was chosen because we were interested in hearing the perspectives of a range of stakeholders about what is working, what is not working and what could be improved along the continuum of care.

The NZSCIAP governance group was encouraged to give feedback at all stages of the evaluation. A draft version of this report was circulated to the governance group, and evaluation findings and recommendations were discussed via an online meeting on 25 March 2020.

## TYPES OF DATA COLLECTED

Three main types of data were collected:



**151 ONLINE SURVEYS**



**17 INTERVIEWS**



**ORGANISATIONAL DATA**

- **Online surveys:** completed by adults with SCI, their family/whānau, carers, and health-care professionals (HCPs) across the care continuum.
- **Interviews:** conducted with both adults with SCI and children/adolescents with SCI (and their nominated family/whānau member).
- **Organisational process and outcome data:** requested from funders, service providers, and from the NZSCIR

## PARTICIPANTS

As overviewed in Appendix 2:

- Seven groups of participants were recruited who had received or provided SCI health or rehabilitation services during the NZSCIAP implementation period 2014-2019
- A total of 151 surveys were completed, and 17 interviews conducted: 13 with adults with SCI and 4 with children/adolescents with SCI and their nominated parent.

***“There have been improvements with the service changes implemented through the NZSCIAP; however, there is still significant room for improvement in all areas of delivery - from inpatient to community follow up, to GP management and community care, education, and accessibility [for] people of varying socioeconomic statuses, cultures, location, and funding streams.”***

*[HCP working in specialist unit]*

# HOW HAS THE NZSCIAP IMPROVED DELIVERY OF SCI SERVICES IN NZ?

## WHAT WORKED WELL?

### Collective Action

Positive outcomes resulting from the NZSCIAP demonstrate the value of having a forum guiding collective action, establishing shared goals and facilitating collaborations between funder, service provider personnel and organisations.

Specific processes that facilitated these positive outcomes included:

- Collectively agreed NZSCIAP objectives at a governance level.
- National perspectives being consistently gathered - rather than individual service/funder perspectives.
- Regular (bi-yearly) forums for communication have contributed to successful collaboration.

### Guiding Framework

The NZSCIAP document has provided an explicit framework to guide action - providing impetus for change nationally and at locality or organisational levels.

Priority action areas, identified within the NZSCIAP document, have provided support for successful research funding applications and service development projects.

### Successful Implementation

Since 2014, there has been successful implementation of the following work programmes:

- *Destination Policy* - increasing direct admissions to the supra-regional specialist spinal centre and reducing the time from admission to decompression.
- *Specialist Paediatric and Adolescent Rehabilitation Service (SPARS)* - ensuring that children/adolescents with SCI can undertake rehabilitation in an age-appropriate specialist service.
- *NZ SCI Registry (NZSCIR)* - routine collection of data across NZ spinal services and funding streams to be used for quality improvement and research purposes.
- *Attendant care pilot project* - development and testing of a process allowing use of a client's existing carers for specific duties when a client is admitted to a public hospital, outside of a specialist SCI service.

### Positive Engagement

The opportunity for more positive engagement between funders, service providers at service delivery level.

- Improved communication, consistency and collaboration between supra-spinal services - improvements in clarity around inpatient protocols, including preparation for discharge processes.
- More positive engagement between funders and community providers – seeking solutions that work for people with SCI in community contexts.
- Peer support service providers - development of consistent approaches to peer support between NZ Spinal Trust and Spinal Support NZ

## IMPLICATIONS

- A national forum for ongoing communication, collaboration and shared planning contributes to positive health outcomes for people with SCI.
- Multiple stakeholder involvement in identifying and finding solutions facilitates service provider engagement in resultant change-processes.
- To enact the recommendations emerging from this evaluation ongoing collective action across multiple organisations will be required.

- Nationally agreed goals and actions provide strong impetus for change and support research and quality improvement initiatives.

- Having specific actions based around measurable outcomes are more likely to result in successful service improvement implementation.
- Providing clear pathways for ensuring engagement with service delivery staff will more likely result in changes being embedded.
- Having staged, prioritised actions will ensure that work programs are coordinated.

- Positive engagement can facilitate the setting of agreed goals around implementation at a service level.
- Multiple objectives allow for diverse actions across systems, but in a unified manner.
- There is potential to further develop these communication links ensuring smooth pathways for people with SCI (e.g. between hospital to community).

# HOW HAS THE NZSCIAP IMPROVED DELIVERY OF SCI SERVICES IN NZ?

## FUTURE STRATEGIC DIRECTIONS

### Equitable access to services

Inequity of access to SCI services is a key issue identified across all objectives and from all stakeholders.

- A strong reliance on self-advocacy following discharge from supra-regional services, and the ‘hit and miss’ presence of a navigator to support the persons/whānau journey through the systems over time (i.e. over the years) appears to be contributing to inequity of outcome. Establishing mechanisms to improve access to and navigation through services for those most at risk of poor health outcomes (i.e., those on MOH funding, Māori and those with dual-diagnoses) is recommended.
- It is recommended that consideration be given to developing resources and/or tools to empower the person with SCI (and their family/whānau) to more effectively advocate for themselves. The focus should be on facilitating communication (i.e., targeted to the specific needs of the person and provided at the right time) and increased transparency of information related to processes of care (i.e. at what point modifications are at, when assessments are due, who to contact for what issues) for the person with SCI.
- SCI service delivery organisations should consider service design adaptations they could make to ensure more equitable outcomes for individual people with SCI.

### Participatory service design

Ongoing progress with improving the delivery of SCI services within NZ may be optimised by forming participatory design ‘work-groups’ to focus on improving specific outcomes across the health and rehabilitation continuum. Service design improvements that contribute to meaningful changes in health outcomes are more likely to be made if an intersectoral, transdisciplinary approach is taken. The stakeholders that need to be included in these participatory design approaches include Māori, HCPs working in both acute and community settings, and people with SCI representing a range of different impairments, funding models and demographic features.

It is also recommended that any national leadership group be reviewed to ensure more representation and consultation with community-based HCPs, people with the lived experience of SCI and Māori.

### Innovative service delivery

Innovative outreach service delivery options need to be explored to ensure that all people with SCI (including children/adolescents) receive timely and responsive reviews of their health and rehabilitation needs once they are discharged from specialist spinal services and then over the coming years. Current processes and pathways for providing ongoing specialist support are not responsive to the range of current needs.

For children/adolescents with SCI these options need to be focused on next steps and future planning, rather than predominantly impairment/deficit identification. These could take the form of interdisciplinary meetings, via video-conference, where the range of funders, HCPs and other service providers meet with the child/adolescent and/or their whānau to establish action points for the coming months/years.

## FUTURE WORK PROGRAMME SUGGESTIONS

### Flexible pathways

- Improve acute pathway access and flexibility for people with existing and new co-morbidities and associated trauma. Develop systems to ensure that pathways and protocols remain responsive to the complexity of people’s health and experience. Include the perspective of the person with SCI in any review of cases where the existing pathways/protocols may not have optimised outcomes, thereby ensuring that their perspectives can contribute to new knowledge.

### Pain management

- Improve pain services across the continuum (i.e., including within supra-regional units) so that they better meet the needs of people with SCI, and so they are provided in a timely manner. Aim for each person leaving the spinal unit to have a pain management plan in place, and develop closer collaborations and training of health and rehabilitation professionals across the continuum.

### Housing modification processes

- Evaluate processes (and transparency of processes) for housing modifications around reducing the need for temporary accommodation and increasing the speed of work completion – to reduce both secondary complications and participation restrictions for the person with SCI. It is recommended that specific time targets be considered.

### Transitioning from child to adult services

- Implement a process for transitioning to adult services for children with SCI – including integration into appropriate rehabilitation service providers (not primarily medical specialist review).

### Peer support

- Implement peer support services to children with newly acquired SCI in NZ (and including their family/whānau). Ensure that formalised regular support is offered to all people with SCI regardless of the level of impairment (i.e., complete and incomplete) and their family/ whānau.

## Objective 1: Improve acute clinical outcomes for adults requiring acute SCI care

### WHAT WORKED WELL?

The destination policy has facilitated early access to specialist SCI centres. This aligns with international best-practice as early access has been shown to contribute positively to reduced secondary complications and improved neurological status.

**Direct admissions to the supra-regional specialist spinal centre** increased

 **30% to 70%**

**Time from admission to decompression** reduced significantly for patients admitted directly to the supra-regional centre

 **15 to 8 hours**

**Time from injury to admission for rehabilitation in a specialist spinal unit** decreased significantly post-implementation.

 **13 to 10 days**

*“Early collaboration/intervention and admission to the spinal units at the time of injury appears to have made a positive impact on the long-term outcomes for clients.”*

(Community-based health care provider)

### OTHER FINDINGS

#### LEVELS OF FUNCTION

- There was no significant difference in change in neurological status (measured with American Spinal Injuries Association [ASIA] Impairment Scale [AIS]) between pre- and post-implementation - although the post-implementation group had a higher percentage of people with AIS A (complete injury) and D (motor incomplete) on admission.

#### IMPLEMENTATION OF POLICY

Many of the issues identified by participants in the UMR evaluation (2013) seem to have been addressed by the implementation of the destination policy.

- The UMR Report (2013) stated that many felt that hospitals were not well set up to deal with SCI patients. It was noted in some cases that staff lacked the knowledge to look after SCI patients properly. In general, it is felt that progress has been made in this area over 2014-2019 as a result of the NZSCIAP. HCP's survey respondents were also generally very positive about positive changes that have occurred due to the destination policy implementation.

#### UNCLEAR PATHWAYS

- People with non-traumatic SCI injuries do not appear to have a clear pathway into specialist SCI services.
- People with ASIA D levels of impairment (especially those with a high level of walking function) may not get linked into necessary services, and their impairments or psychological needs may not be addressed as fully as those with ASIA A or B scores.

### RECOMMENDATIONS

#### FOCUS ON REDUCING TIME TO SURGERY

It is recommended that providers continue to explore how to optimise time to surgery particularly for cases when adherence to the policy does not ensure optimal pathways for the individual. While the destination policy has improved early access to specialist SCI services, it is based on regional catchment area rather than being focused on specifically reducing the time between injury and surgery. This means that the process has not always worked well for individuals – all are not accessing the specialist service that can most quickly provide surgical interventions.

#### FLEXIBILITY OF PATHWAY PROCESSES

Greater clarity is required around decision making about where a person should best undergo rehabilitation if they move off the 'destination policy pathway' and receive surgical intervention at a service outside of their home address catchment area (e.g. when the ICU at one of the supra-regional specialist centre is full). Currently in this situation decision-making around movement through services appears to be ad hoc, not always taking into consideration the wishes/needs of people with SCI and their family/whānau

#### FOCUS ON BETTER MEETING THE NEEDS OF THOSE WITH UNCERTAIN OR DUAL DIAGNOSES

Although the destination policy is working well, it is only designed for people with traumatic SCI. However, acute clinical outcomes are impacted by uncertain/unclear diagnosis, emerging neurological clinical picture, and/or dual diagnosis (e.g., pre-existing mental health conditions, TBI, orthopaedic injuries). It is recommended that work now focus on ensuring that people with non-traumatic SCI, associated health conditions and/or injuries have their needs met.

## Objective 2: Improve outcomes for children & adolescents

### WHAT WORKED WELL?

Successful implementation of the Specialist Paediatric and Adolescent Rehabilitation Service (SPARS), ensuring that children/adolescents with an acute SCI can undertake rehabilitation in age-appropriate specialist services. This has led to significant progress being made optimising clinical outcomes for children/adolescents.

**83%** of health care professionals agreed that the implementation of the pathway for children/adolescents with SCI has supported the achievement of optimal health and wellbeing outcomes.

Interviews with children & adolescents and their family/whānau suggest a high level of satisfaction with the services provided within Starship Hospital and the Wilson Centre.

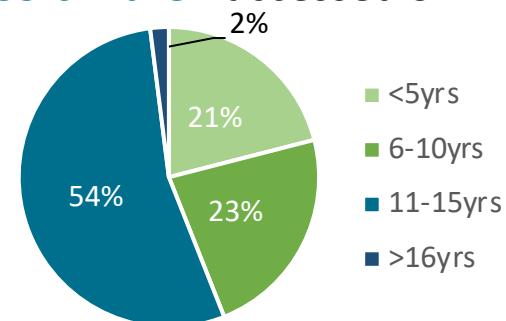
**92%** of health care professionals feel that children and adolescents with SCI are supported to prepare for and to participate in meaningful activities of their choice once discharged from the unit.

Both health care professionals working with children and family members agreed that family carers received adequate levels of advice and information to meet their ongoing rehabilitation and support needs on discharge.

Between 1.1.14 to 31.12.18, **39 children** accessed SPARS



Average length of stay = **67 days**



### OTHER FINDINGS

Children with traumatic SCI and who live in the North Island appear to have a more seamless transition into SPARS. Ensuring that pathways for children/adolescents with non-traumatic and incomplete SCI are consistently implemented, regardless of home location and type of injury, is required. Currently those children who enter SPARS via Starship (rather than directly via the Wilson Centre) are more likely to receive optimal care.

Health care providers and parents reported clear inequities between service provision between MOH and ACC funded clients, with MOH clients receiving less and more fragmented services across the continuum of care. A key difference between MOH and ACC funded clients is the degree of coordination of services that is required by family members, particularly once community-based services are required.

Parents reported that it was difficult to navigate the multitude of specialists, with limited communication and coordination occurring between a wide range of specialists. Access to a consistent case manager was felt to dramatically improve access and coordination of services for ACC clients. On discharge from the Wilson Centre, families were given information for the initial post-discharge period, but not how to negotiate and navigate services and address needs over the longer term.

*“Parts of the pathway have improved. Children with SCI are getting to paediatric services now. For non-ACC clients the level of services that they can access on discharge is still very different to ACC.”*

(Health care provider)

### RECOMMENDATIONS

Further evaluation of reassessment and outreach services is required. Innovative outreach service delivery options should be explored to ensure that children/adolescents receive timely and responsive reviews of their health and rehabilitation needs once they are discharged from the Wilson Centre and then over the coming years. Community-based HCP's should be involved in the development of systems and processes. These options should give greater attention to next steps and future planning, rather than predominantly impairment/deficit identification. Parents who were interviewed wanted reassessments in the years following their child's SCI to develop functional and participatory goals and milestones to work towards, rather than mainly ensuring that the child's medical status is being maintained.

Equipment assessment and provision systems need to be reviewed, especially for those on MOH funding, as they are currently not responsive to the rapidly changing needs of a growing child. Timely provision of housing (and particularly bathroom) modifications for children ensures that personal care supports are not required beyond what is age-appropriate.

Further work is required to clarify and implement the transition from paediatric to adult services.

## Objective 3: Improved information sharing

### WHAT WORKED WELL?

#### NZ Spinal Cord Injury Registry (NZSCIR)

in partnership with the Rick Hansen Institute was launched on 1 August 2016.

Data has been collected for all people entering either supra-regional spinal service, providing a baseline and enabling measurement of the incidence and prevalence of SCI. This takes the form of a minimal data set (MDS) and for those consenting for a full data set.

NZSCIR is recognised as a reliable/valuable data source, with over 50 requests for data or information. Requests have been made from clinicians, researchers and providers within NZ and overseas. The majority have been for basic data, and they have been redirected to the 2016/17 NZSCIR annual report.

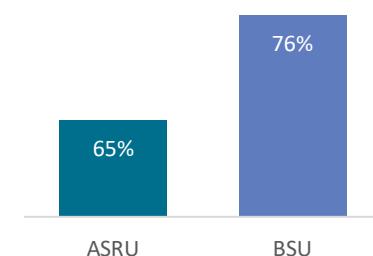
NZSCIR has developed a memorandum of understanding with the Order of St John (St John Ambulance) to share data to improve the accuracy of both the St John Ambulance database and that of the NZSCIR in respect of diagnosis, injury time, location etc.

#### NZSCIR participants August 2016 – December 2018

**70%** of participants (on average) contribute to the full data set collection.

**326** participants with full data set

**154** participants with minimal data set



Consent for full data set is higher in BSU than ASRU

### OTHER FINDINGS

It is not possible to determine the funding sources of participants in the NZSCIR from minimal data set (NZSCIR only collects funding data as part of the full data set). This may have implications for using the data to look at equity of outcomes over time.

The implementation of the NZSCIR is ongoing, and there are still a number of tasks which are behind schedule or are yet to be commenced. Insufficient resourcing of registry coordinators is the main contributing factor to delays in completing implementation. E.g. collection of community follow-up data has been delayed resulting in initial participants missing the 18-month community follow ups.

There have been 10 formal data access requests requiring use of the Data Access Protocol. The NZSCIR staff have noted significant challenges and requirements to implement the NZSCIR, including meeting legislative and regulatory requirements that protect security and privacy of information, development and refinement of policies and procedures. This means that, to date, a number of data requests have not been fulfilled.

### DEVELOPMENT OF E-SHARED PLANS

- Limited progress has been made in relation to this task. However, throughout all data sources and across all objective there is a strong message about the need to improve systems and process for sharing information both between providers and with the person with SCI (and/or their family/whānau)
- Communication is a key area of concern. Between providers, there is fragmentation, reduced timeliness of service provision, and duplication. People with SCI and/or their family indicated that there is a lack of transparency and lack of control over the processes of funding and care.

### RECOMMENDATIONS

- Further work is needed for the NZSCIR to be independent in producing data analysis and yearly reports. The NZSCIR staff feel there would be benefits in NZSCIR having independence in these areas while still meeting security and legislative requirements of the RHI.
- Regular reassessment of data collection priorities (data point review) is required to ensure data collected remains relevant and meaningful to the NZ SCI population while still being comparable to international data sets
- Promote the use of registry data for quality improvement, sharing this with clinicians, consumers and funders.
- Further work to streamline a process for researchers and clinicians accessing data in a timely way (especially data from most recent years cohort.)
- Consideration of sustainable funding for NZSCIR. Consideration should also be given to reviewing current staffing structure and roles to optimise the efficiency of the NZSCIR.
- Optimise use of the NZSCIR to share information between services, but prioritise the transparency of this information for the person with SCI.

## Objective 4: Providing nationally consistent SCI rehabilitation services & extend community-based rehabilitation

### WHAT WORKED WELL?

Community provider survey respondents noted an increase in engagement between funders and community providers as a result of the work programmes undertaken as part of the NZSCIAP implementation – seeking solutions that work for people with SCI in community contexts.

Data from ASRU and BSU suggest that there are ongoing changes being made to the way that reassessment and outreach services are being provided to maintain sustainability from a service provider's perspective. Actions are being taken to implement IT systems that reliably track people for follow-ups and reassessments.

The NZSCIR community follow up questions survey (to be administered at 18 months, 5 years and 10 years+) will provide useful data in the future to explore people's secondary complications and health conditions, health care utilisation, pain management and return to work outcomes more fully.

People were generally very positive about the services they received in the spinal units, both in surveys and interviews. Generally adults with SCI report that the immediate post-discharge community services have been delivered in an effective and timely manner, and in a way that optimises their health and wellbeing outcomes.

*“In my experience the issue centres around how well anyone with an SCI or their support can advocate for themselves. There is no transparency around the decision-making process.”*

(Adult with SCI)

### OTHER FINDINGS

Actions to reduce the impact of funding differences on equity of outcome is urgently required. A key area of inequity relates to the absence of navigation support provided to MOH-funded clients to access services and supports that they are entitled to, but do not know are available to them.

Specific, timely, accessible and personally meaningful provision of information for people with SCI remains an issue. Currently, information is not routinely provided in a variety of forms so as to improve recall and accessibility. Information is often provided generically, without establishing the understanding of the person with SCI, resulting in poor knowledge acquisition.

Changes are being made to the way that reassessment and outreach services are being provided to maintain sustainability from a service provider's perspective. However, little consideration appears to have been given to how people with SCI would like service delivered to them – in terms of timeliness and modes of delivery. Innovative outreach service delivery options need to be explored to ensure that adults with SCI receive timely and responsive reviews of their health and rehabilitation needs once they are discharged from supra-regional spinal services and then over the coming years.

Overall, the current systems are viewed as 'not seeing me as a person and not as invested in the outcome as I am'. This is consistent with findings of the UMR Report (2013). Interview data suggests that the 'expert' opinion of HCPs is often prioritised over people's own experiences of 'what will work for me, in my situation.'

To what extent do adults with SCI agree that they received the following support and/or services?



Rehabilitation needs well coordinated



Smooth transition to community services



Support to prevent secondary complications



Access to specialist pain management services



Timely access to health and rehabilitative support



Access to reassessment



Support to manage pain



Access to psychological support

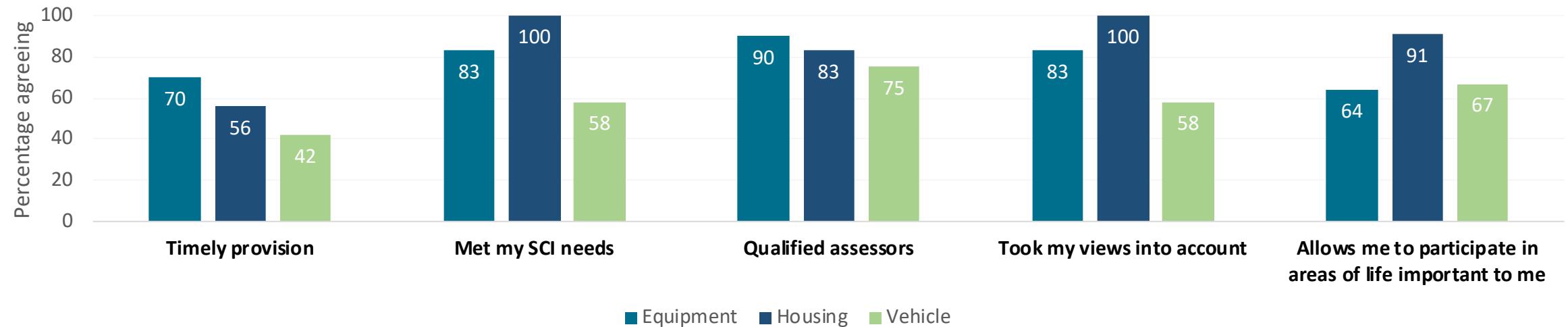
### RECOMMENDATIONS

People with SCI feel that current processes and pathways are not transparent to them – hence, they do not feel that their needs are consistently met. It is suggested that options for improving service navigation for the person with SCI. Such navigational support has the potential to improve appropriateness, accessibility and timing of support thereby improving equitable outcomes, and is likely to significantly reduce stress and distress for the person with SCI and their family/whānau.

Review of pain services across the continuum (i.e., including within supra-regional units) so that they better meet the needs of people with SCI, and so they are provided in a timely manner. Aim for each person leaving the spinal unit to have a pain management plan in place and develop closer collaborations and training of health and rehabilitation professionals across the continuum.

## Objective 5: Review & align MOH and ACC processes for access to equipment, housing modifications and transport

To what extent did adults with SCI agree that their equipment, housing and vehicle needs were met?



All participant groups repeatedly referred to the inequity between those receiving ACC funding and those receiving MOH funding, particularly once living in the community. This inequity was evident in access to equipment, housing and vehicle modifications and was strongly reported in all survey responses across all participant groupings, and in interview data.

### OTHER FINDINGS & RECOMMENDATIONS

A major effort is required to reduce inequality between people receiving ACC and MOH funding across housing, equipment, and vehicle modification processes. Supporting those on MOH funding to access services that are already available should be a short-term focus.

People with non-traumatic and traumatic SCI are provided with similar equipment in most categories related to activities of daily living and basic mobility. However, people with non-traumatic SCI were less likely to receive power wheelchairs, vehicle aids, communication devices, standing frames/chairs or environmental controls. These equipment categories have the potential to significantly impact on the person with SCI's ability to participate in areas of life that are important to them.

More effort needs to be made to always include family in decisions around equipment, housing and vehicles to ensure that the needs of the entire whānau are considered within the decision-making process.

Housing processes (regardless of funder) need to be reviewed to ensure transparency, timeliness of modifications, a reduction in the length of time in temporary accommodation, an increase in project management coordination, and to reduce stress experienced by people with SCI and their whānau. Delay in housing is a key area of future work given the impact of these delays on costs, secondary health conditions and participation restrictions for the person with SCI and their families. The timeliness of bathroom modifications for children/adolescents is especially important, given unnecessary personal care support being offered beyond what is age-appropriate.

Develop a navigation tool for the person with SCI - to facilitate increased transparency in information related to processes for accessing equipment, housing modification and vehicle provision (i.e. at what point modifications are at, who to contact for what issues) for the person with SCI. The tool would be aimed at empowering the person with SCI (and their family/whānau) to more effectively advocate for their needs by identifying who they need to liaise with.

*"After 2 years 3 months, housing modifications are not done yet, vehicle modification done and still waiting on several bits of equipment to be assessed to get back into social things . . . So in the meantime my partner is waiting and becoming more reclusive, more isolated, extremely frustrated and dangerously depressed each week that goes by! There is nothing I can do to make it better so I'm now stuck too."*

(Family Member)

## Objective 6: Develop peer support services

### WHAT WORKED WELL?

1. Significant efforts have been made implementing service improvement measures to develop consistent approaches to peer support service provision across NZ.
2. NZST and SSNZ are collaborating on developing a nationally consistent delivery model that is being implemented at both ASRU and BSU. However, this has not had a focus on support of paediatric and adolescents with SCI.
3. Spinal Support NZ has employed two peer support staff (1 FTE) to ensure consistency across NZ services (i.e. doubled their total staffing levels).
4. A scoping review of peer support literature has been completed and presented to ACC to stimulate ongoing discussion and dialogue
5. Research has been undertaken to develop peer support theory for national use. This process has contributed to a knowledge mobilisation process, ensuring that peer support delivery aligns with best available evidence.
6. A Lotteries funded peer support evaluation is underway and includes organisational capacity building for ongoing service delivery monitoring.

### To what extent do adults with SCI agree that peer support helped them with the following aspects of their rehabilitation?

When peer support was received, people were very positive about it and the benefits of this service.



**Contributed to a more positive inpatient experience**



**Helped me cope and adjust to an SCI**



**Helped transition from hospital to home**



**Answered questions I had about how best to access services and equipment**

### OTHER FINDINGS

Awareness of peer support services is limited. Within the surveys, 26% of adults with SCI and 43% of family members were unaware of the peer support services. It should also be noted that of the 44 adults with SCI who filled out the survey, only 35% of adults and 13% of family members answered survey questions specifically related to peer support. Even in interviews when understanding was more fully explored, many did not report having received peer support.

A lack of peer support for people with higher levels of walking ability, or those with an incomplete injury was more frequently alluded to both within the interviews and the surveys with adults with SCI.

**I: So your mum was saying it would have been nice, as a parent, to have had other people to chat to, would that be the same for you as well?**

**P: Yeah, I think like just to see like how well they're recovering, and it just might give me like a bit of like inspiration to like just keep going and I didn't get any of that.**

[Child PLEx]

### RECOMMENDATIONS

Ensure that formalised regular support is offered to all people with SCI regardless of the level of impairment (i.e., complete and incomplete) and their family/ whānau. This includes implementing peer support services to children with newly acquired SCI in NZ (and including their family/whānau).

Ensure that peer support services are sustainable - for people funded by both ACC and MOH - by securing funding for a consistent NZ-wide peer support service for people (adults and children) from time of injury until they feel well supported in the community. Expert opinion currently indicates that this should be until 6-months post-discharge; however, further research is required to determine this.

Continue to develop consistent implementation and evaluation processes between units, while also ensuring that data of interest to future funders is collected.

For NZST and SSNZ to consider whether they may be able to offer a more formalised navigational support role (e.g. to those with MOH funding). This could potentially be established within Enabling Good Lives systems and processes.

## Objective 7: Build health and disability workforce capability

### WHAT WORKED WELL?

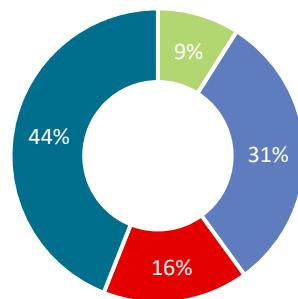
Revision and review of Community Support Services, Core Health and Disability Support Assessment, Planning, and Coordination unit standards resulted in the registration of the new subfield - Health, Disability, and Aged Support - and several new domains.

- Only 20% of carer respondents had no qualifications indicating that changes to the NZQA may be translating to improved training of SCI carers.
- It is anticipated that the NZQA Level 4 framework with three sub-specialities (SCI, TBI and chronic conditions) may improve carer education on SCI.

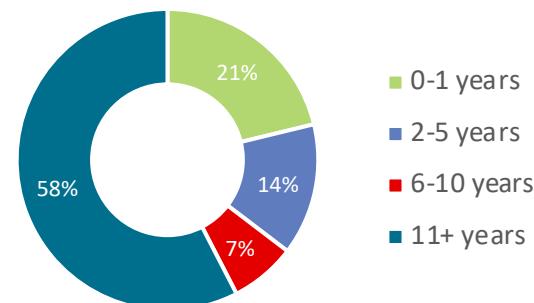
Improved collaboration and engagement between funders and community-based providers has been experienced by some community HCPs

*The engagement of our funder with us as suppliers to come up with positive solutions to any challenges [has worked well]. DHBs are now also engaging with community suppliers and becoming aware that we are longstanding champions for this group of the [SCI] population*  
[Community HCP]

Years of SCI experience – health care professionals working in specialist units



Years of SCI experience – health care professionals working in the community



- 0-1 years
- 2-5 years
- 6-10 years
- 11+ years

*Although some spinal unit therapists are good at communicating with community therapists, many aren't, and it is really unhelpful for clients when they get two different lots of advice, i.e. at follow-up clinics. The unit therapists are clinical experts in SCI but those of us in community have specialised skills too and we need to work together and respect each other's viewpoints. I would love the opportunity every couple of years to network with the teams (e.g. Skype) and for us each to ask questions and make sure we're on the same page with all our advice.*  
[Community HCP]

### OTHER FINDINGS

It is possible that more experienced SCI community-based HCPs are working with ACC funded clients (within larger provider organisations) enhancing inequities of service provision between funding streams.

Many people with SCI reported that Emergency Department staff are not well-trained in providing SCI-related acute care.

GPs are a key resource for people with SCI in the community, especially for those with MOH funding. However, they often have limited knowledge of SCI specific issues. While people with SCI talked about the need to find a GP who was familiar with SCI, they also did not expect them to have all the answers. What they appeared to value more was a trusting relationship, and a willingness to work together to find out answers to questions and problems.

### RECOMMENDATIONS

There is general agreement that more training of HCPs across the continuum is required; however, HCPs working in different settings have opposing perspectives on who is most in need of training. There is, therefore, a need for collaborative training approaches that recognise each other's skillsets and where different perspectives can be shared and learnt from.

- There needs to be increased opportunities for cross-pollination of skills and expertise, especially between inpatient and community providers such as the Combined National Spinal Study Days.
- Consideration should be given to community-based providers sharing information and carers skills with unit-based HCPs.
- Consideration should be given to Telehealth options for joint assessment and planning between HCPs.

*Sometimes [it] feels like the [spinal unit] runs as an expert model, which is essential as this is where expertise must be for patients with SCI - but [it] feels like those expertise aren't shared or celebrated in community settings.*  
[Community HCP]

## Objective 8: Support improvements for carers taking a cross-agency approach

### WHAT WORKED WELL?

#### ATTENDANT CARE PILOT

A recommendation of the UMR Report (2013) was to allow caregivers to stay in hospital with their clients with SCI. This was addressed by the NZSCIAP. ACC initiated a pilot project with the Auckland-region DHBs and relevant ACC Home and Community Support Service to develop and test a process that allows use of a client's existing attendant carers for limited and specific duties when a client is admitted to a public hospital, outside of a specialist SCI service. An evaluation of this pilot is currently being finalised.

Paid carers generally feel that they have an appropriate level of knowledge and experience, and they feel that they have been adequately trained for their role. The majority of adults with SCI also felt that their carers have an appropriate level of knowledge who are reliable.

**91%**

of the carer respondents felt that they had an appropriate level of knowledge to provide support to a person with SCI.

**76%**

of carer respondents agreed that they have access to adequate equipment and resources to care for their client in a way that maintains safety.

**68%**

of carer respondents felt that their employer provided adequate training for them to be a support worker.

**76%**

of adults with SCI felt that that their carers have an appropriate level of knowledge to meet their SCI-related support needs.

**84%**

of carers feel that their role as a support worker for a person with SCI is sustainable, with 68% feeling that their workload is appropriate.

**88%**

of adults with SCI felt that they have reliable carers. 86% also feel that they are well supported by their care agency.

*NB: Carer survey respondents (n = 29) were all employed via a care agency with more than half working as carers for more than six years (0-1 years 19%; 2-5 years 36%; 6-10 years 36% and more than 11 years 30%). Twenty two percent of the respondents were also family members of the adult with SCI they provided care to.*

### OTHER FINDINGS

56% of carers feel well supported by their employer in their role as a support worker, and 65% of adults with SCI felt that their carers are well supported by their employers.

60% of carers felt that their emotional and mental health needs were met, and 72% agreed that their cultural needs are appropriately addressed by their employer.

Only 35% of adults with SCI agreed or strongly agreed that they had received adequate training and support on how to manage their carers

Family members of adults with SCI are not confident that their family member would be well cared for if they were sick or wished to take a holiday – regardless of whether their support is primarily provided by a care agency or not.

### RECOMMENDATIONS

It is recommended that people with SCI are provided training on how to manage carers, not just how to direct care.

- Evaluate the effectiveness of current carer training within the spinal units - does the system of carers coming to the spinal unit for a short period prior to discharge best meet the needs of the carer and person with SCI?
- Consideration should be given to alternative training options. For example, would community-based training by unit staff in community settings improve the transition home, and optimise unit-HCP understanding of contextual factors within the home that could impact on functioning?

Further investigation is required to better understand why family members do not feel confident to take some time off and implement appropriate processes to mitigate this.

## LIMITATIONS IN DATA COLLECTION

### OVERALL RECRUITMENT

Overall recruitment numbers were lower than anticipated. The perspectives of the following groups are therefore limited within this evaluation:

- Community-based HCPs (particularly those providing MOH services)
- Paediatric HCPs working within education services
- Privately employed carers
- Family/whanau of people with SCI

### INTERVIEWS

- There was limited recruitment of participants living rurally.
- We also had lower recruitment than we wanted of participants that are MOH funded.

### SURVEYS

- Lower recruitment rates than expected were evident for adults with SCI and their families.
- There were no responses from community HCPs working only with MOH funded clients, despite targeted recruitment.

### ORGANISATIONAL DATA

- Obtaining organisational data was more difficult than we anticipated. Data was not routinely being collected in alignment with NZSCIAP objectives.
- NZSCIR was the best source of data, however data provided for this evaluation is indicative data only (i.e., it has been taken from dashboards and not cleaned and ready for use in research).

## GLOSSARY

|                |   |               |  |
|----------------|---|---------------|--|
| <b>ACC</b>     | Accident Compensation Corporation           | <b>NZSCIR</b> | New Zealand Spinal Cord Registry                         |
| <b>ADHB</b>    | Auckland District Health Board              | <b>NZST</b>   | New Zealand Spinal Trust                                 |
| <b>AIS</b>     | ASIA Impairment Scale                       | <b>OT</b>     | Occupational Therapist                                   |
| <b>ASIA</b>    | American Spinal Injuries Association        | <b>PLEx</b>   | Person with Lived Experience                             |
| <b>ASRU</b>    | Auckland Spinal Rehabilitation Unit         | <b>PT</b>     | Physiotherapist  |
| <b>BSU</b>     | Burwood Spinal Unit                         | <b>RHI</b>    | Rick Hansen Institute                                    |
| <b>CDHB</b>    | Canterbury District Health Board            | <b>SPARS</b>  | Special Paediatric and Adolescent Rehabilitation Service |
| <b>CMDHB</b>   | Counties Manukau District Health Board      | <b>SSNZ</b>   | Spinal Support New Zealand                               |
| <b>DHB</b>     | District Health Board                       | <b>SSH</b>    | Starship Hospital  |
| <b>HCP</b>     | Health Care Professional                    | <b>SCI</b>    | Spinal Cord Injury/Impairment                            |
| <b>MOH</b>     | Ministry of Health                          | <b>TSCI</b>   | Traumatic Spinal Cord Injury/Impairment                  |
| <b>NTSCI</b>   | Non-Traumatic Spinal Cord Injury/Impairment | <b>WC</b>     | Wilson Centre  |
| <b>NZSCIAP</b> | New Zealand Spinal Cord Action Plan         |               |  |

## ACKNOWLEDGMENTS

The authors would like to thank the following for their contribution to this evaluation:

- NZSCI Action Plan Governance Group
- Advisors with the lived experience of SCI and health care professional advisors who have offered their expertise to the development of this evaluation and its recommendations: Ian Beattie, Ian Simpson, Amy Glassford, Sabine Krasniqi, Debra Edmonds, Kathy Dwyer, Nicola Billing, David Tielman, Kathryn Edward
- Emma Bailey (ACC) for project management support
- Christine Howard-Brown (previously ACC) for support in establishing the scope of this evaluation
- Health care professionals and managers working in service provider organisations, who have supported recruitment and organisational data provision
- NZSCIR coordinators who have supported with recruitment and data acquisition
- Participants who generously gave their time to take part in the surveys and interviews

## DISCLAIMER

- The report authors have taken great care to ensure the information supplied within the project timeframe is accurate. However, neither the Burwood Academy of Independent Living (BAIL) nor the contributors involved can accept responsibility for any errors, or omissions. All responsibility for action based on any information in this report rests with the reader.
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# Appendix 1

## EVALUATION QUESTIONS

| Objective   | Evaluation Questions   |
|---|--|
| <p><b>Objective 2</b><br/>Outcomes for children and adolescents with SCI have improved</p>  | <p>To what extent have children and their whānau received consistent rehabilitation services?<br/>Focus on:</p> <ul style="list-style-type: none"> <li>• Early involvement with Starship/Wilson Centre rehabilitation teams and appropriately timed discharge</li> <li>• Co-ordinated post-acute rehabilitation</li> </ul> <p>To what extent has a transition process for adolescents moving to adult services been addressed?</p> |
| <p><b>Objective 4</b><br/>There are nationally consistent SCI rehabilitation services that extend to community-based rehabilitation</p> | <p>To what extent and how consistently do people with SCI feel that current processes and pathways support ongoing rehabilitation needs?<br/>Focus on:</p> <ul style="list-style-type: none"> <li>• Information</li> <li>• Timeliness and access to services particularly reassessment</li> <li>• Pain and psychological services – particularly access for family</li> </ul>  |
| <p><b>Objective 5</b><br/>Processes have been reviewed and aligned for access to equipment, housing modifications and transport.</p>    | <p>To what extent have people with SCI had timely and appropriate access to equipment and appropriate housing?<br/>Focus on:</p> <ul style="list-style-type: none"> <li>• How has this affected rehabilitation outcomes?</li> <li>• How qualified/experienced are the assessors?</li> <li>• Equity ACC &amp; MOH</li> </ul>  |
| <p><b>Objective 6</b><br/>Peer support services are developed</p>   | <p>To what extent have people with SCI received adequate peer support?</p> <ul style="list-style-type: none"> <li>• Is there consistency nationwide (including for paediatric injuries)?</li> <li>• Is peer support extended to family/whānau?</li> </ul>  |
| <p><b>Objective 8</b><br/>Support improvements for carers taking a cross agency approach</p>  | <p>To what extent have paid and unpaid carers including family and whānau been supported in their role?<br/>Focus on enabling carers to:</p> <ul style="list-style-type: none"> <li>• remain in caring role</li> <li>• maintain mental and physical wellbeing</li> </ul> <p>How has this contributed to the support of people with SCI?</p>  |

## Appendix 2

### OVERVIEW OF EVALUATION DATA COLLECTION METHODS, AND SAMPLE CHARACTERISTICS

| Participant grouping  | Number of participants  | Recruitment methods  | Sample summary   |
|---|---|--|--|
| <b>Adults with SCI - sustained 2014-2019</b>  | Survey: n = 44<br><br>Interviews: n = 13<br><br>Case studies: n = 3       | <ul style="list-style-type: none"> <li>NZSCIR email invitation</li> <li>Online consumer forums (e.g. NZST and SSNZ Facebook groups)</li> </ul>   | <p>Surveys:</p> <ul style="list-style-type: none"> <li>68% male</li> <li>79% NZE; 12% Māori; 6% Samoan; 6% Tongan</li> <li>62% ACC funded</li> </ul> <p>Interviews:</p> <ul style="list-style-type: none"> <li>62% male</li> <li>85% NZE; 15% Māori</li> <li>69% ACC funded</li> </ul> |
| <b>Children &lt;18 years with SCI – sustained 2014-2019; &amp;/or their family/whānau</b>     | Interviews with child/adolescent & parent: n = 4<br><br>Case study: n = 1 | <ul style="list-style-type: none"> <li>Names and contact details provided by Specialist Paediatric and Adolescent Rehabilitation Services (SPARS) rehabilitation specialist</li> </ul>             | <ul style="list-style-type: none"> <li>n = 3 ACC funded</li> <li>Age range: 6 – 15 years</li> <li>1 aged over 15 at time of interview (nearing transition to adult services)</li> </ul>  |
| <b>Family and/or whānau of adults with SCI - sustained SCI 2014-2019</b>                      | Survey: n =10   | <ul style="list-style-type: none"> <li>Recruited via adult with SCI, and online consumer forums (e.g. NZST and SSNZ Facebook groups)</li> </ul>  | <p>Survey:</p> <ul style="list-style-type: none"> <li>75% live with a family member with SCI</li> <li>63% were partners</li> <li>63% provide care</li> </ul>   |
| <b>Paid carers - who have cared for a person with SCI 2014-2019</b>                           | Survey: n = 29  | <ul style="list-style-type: none"> <li>Recruited via adult with SCI, advertisements on online consumer forums (e.g. NZST and SSNZ Facebook groups), and email via Healthcare NZ manager</li> </ul> | <ul style="list-style-type: none"> <li>No privately employed carers</li> <li>56% have worked as a support worker for &gt; 6 years</li> <li>20% related to the person they provide care to</li> </ul>   |
| <b>Health care professionals within spinal units - working with adults with SCI 2014-2019</b> | Survey: n = 37  | <ul style="list-style-type: none"> <li>Emails sent to staff by DHB managers/clinical advisors</li> </ul>   | <ul style="list-style-type: none"> <li>64% of respondents from ARSU</li> <li>Mainly OT, PT and nurse respondents</li> <li>46% have &gt; 11 years' experience</li> </ul>  |

## Appendix 2

### OVERVIEW OF EVALUATION DATA COLLECTION METHODS, AND SAMPLE CHARACTERISTICS cont.

| Participant grouping   | Number of participants | Recruitment methods   | Sample summary  |
|--|------------------------|---|---|
| <b>Community-based health care professionals - working with adults with SCI 2014 - 2019</b>  | Survey: n = 18         | <ul style="list-style-type: none"> <li>Email invitations to ACC contracted provider organisations, and to DHB contact emails held by spinal unit therapists</li> </ul>  | <ul style="list-style-type: none"> <li>21% with 0-1 years of experience</li> <li>57% with &gt;11 years of experience</li> <li>86% provide only ACC-funded services</li> <li>None who provide services to ONLY MOH-funded clients</li> <li>57% were physiotherapists; 21% nurses</li> <li>Good spread across NZ regions</li> </ul> |
| <b>Health care professionals working with children and/or young people with SCI - Starship/Wilson Centre &amp; community-based providers 2014 - 2019</b> | Survey: n = 13         | <ul style="list-style-type: none"> <li>Email invitation sent to Starship Hospital/Wilson Centre staff</li> <li>Emails to ACC-contracted providers</li> <li>Advertisements on online professional support forums (e.g. paediatric special interest group)</li> </ul> | <ul style="list-style-type: none"> <li>n = 6 from Wilson Centre</li> <li>Limited community-based providers (n = 4)</li> <li>Only one community provider working in Ministry of Education setting</li> </ul>   |