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# **Joint ACC and Health Spinal Cord Impairment Initiative & Implementation Plan**

## **Situation Analysis Paper 24<sup>th</sup> February 2013**

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## Disclaimer

This situation analysis report is a summary of findings from various data, interviews, focus group meetings and literature review findings. The writers have tried to make every effort to ensure the information reported is accurate.

The report has been reviewed and amended based on requests from the Steering Group to the project.

However, due to the high number of participants and broad scope of the project, there may be some minor inaccuracies that will be corrected in the next version of the report.

There were many common themes and a lot of congruence in what was reported, so it can be concluded that this is the reality for people with SCI and SCI services in New Zealand. Where stakeholder statements or themes are supported by evidence, this is noted.

This report has been prepared for the express purpose of developing a SCI implementation plan in New Zealand. It was not a clinical audit; therefore no formal evaluation of the quality of clinical practice has been made.

# Executive Summary

## Introduction

The Ministry of Health and ACC are leading a joint national spinal cord impairment initiative and implementation plan to:

- improve the outcomes and promote increased independence and participation of people with spinal cord impairment.
- develop an implementation plan that outlines an integrated and sustainable approach to support people with spinal cord impairment meeting their goals.
- provide a sound platform to implement new or update existing service models and technologies as appropriate and affordable.

This report describes the current status of supports and services available to people with spinal cord impairment in New Zealand. It presents an in-depth review of current systems, services and supports for people with spinal cord impairment. The review has included:

- consumer research undertaken by UMR Research to understand people's experience,
- an evidential review undertaken by the University of South Australia to understand international practice; and
- collection and analysis of data and information from sector stakeholders, ACC and Ministry to understand current service provision and demand for services.

The review process identified a number of opportunities for improving spinal cord services that could result in significant gains for children, youth and adults with spinal cord impairment.

Readers of this report are encouraged to read the UMR Research Report(UMR Research, 2013) and Evidential Review Reports prepared by the University of South Australia (Univeristy of South Australia, 2012; University of South Australia, 2012a, 2012b).

This is the first of two reports (in addition to the evidence papers) that will form the basis for the joint national spinal cord impairment initiative and implementation plan. The second report will present options and recommendations.

## Spinal Cord Impairment in New Zealand

The ACC and Health systems manage small numbers of high cost and high complexity clients with spinal cord impairment who will have varying levels of loss of control of their limbs, loss of feeling, loss of bladder and bowel control and may also have difficulty breathing or coughing.

People with spinal cord impairment require life-long support including specialised acute and rehabilitation services to maximise their independence and reduce reliance on support services. They are at high risk of major secondary complications (for example, skin breakdown and infections) in the acute phase and are likely to experience many on-going chronic health problems and age prematurely.

The long-term social and financial costs and high life expectancy (survival following diagnosis and longevity) are considered substantial. Where possible ensuring best practice is vital if outcomes are to be maximised and costs minimised. Other countries including Australia have recently developed and are implementing rehabilitation models and action plans specifically targeted to people with spinal cord impairment.

## Incidence

The incidence of spinal cord impairment is difficult to ascertain given differences in definitions, diagnosis and classifications. There is no systematic approach to recording spinal cord impairment and there is no national registry. Where data is collected, it does not capture acute services and is voluntarily provided to the Australasian Rehabilitation Outcomes Centre (AROC) register.

Approximately 130-180 people are diagnosed with spinal cord impairment in New Zealand each year. It is more difficult to ascertain incidence of non-injury cause than injury cause. An estimate of spinal cord impairment as 30 per million per annum in New Zealand is consistent with international estimates for people receiving spinal rehabilitation services. Presently, there are around 1,500 people with spinal cord impairment resulting from an injury that are managed by ACC and less than 1,000 people with a medical or congenital diagnosis of spinal cord impairment who may be receiving supports from Disability Support Services. Although numbers are low, people with SCI are high users of health and associated support services.

Māori and Pacific people are over represented compared with Europeans. Children experience a very low incidence of spinal cord impairment.

Part of the cohort of people with spinal cord impairment is older due to increased life expectancy and also being older when having spinal cord impairment. Ageing with spinal cord impairment is an important consideration, especially with an increasing prevalence of older people including many that will have dual health and injury-related needs.

New Zealand has expertise in the acute management and rehabilitation of people with spinal cord impairment. There are two specialist rehabilitation services which have associated acute care services, all of which are delivered under a multidisciplinary model. There are various outreach services and some specialist home and community support services. New Zealand researchers have been active contributors to a body of evidence which has advanced the care and support services available to people with spinal cord impairment.

Across the continuum of services from acute, rehabilitation and services to support living in the community there appears to be a range of opportunities that could improve services to clients with spinal cord impairment which are outlined below.

## Acute services

There are no consistent destination or transfer policies or clear pathways for acute treatment in New Zealand. Current acute services mean people may be managed locally or transferred to higher level services which may or may not have multidisciplinary expertise in spinal cord impairment.

A consensus viewpoint of the New Zealand Spine Society of the New Zealand Orthopaedic Association has recently been developed which supports two adult specialist acute spinal cord impairment services units in New Zealand.

In general, public hospitals are not well equipped to treat people with spinal cord impairment which can result in avoidable secondary issues occurring and delays in early rehabilitation. Secondary complications lead to longer overall lengths of stays than if care was provided in specialised acute spinal services at an earlier stage.

There is an opportunity for destination and clinical pathways to be developed for both adults and children.

## Rehabilitation services

Rehabilitation is offered by two spinal rehabilitation units and a specialist children's rehabilitation service. There are similarities and differences between the rehabilitation services offered by the adult units. Both ACC and health funded people can access inpatient rehabilitation services; however access is generally better for ACC clients.

Achieving more consistency between regional services may offer the potential to more efficiently manage capacity and capability between the two adult services and meet future demand for spinal cord impairment services.

The majority of differences in rehabilitation are in the community. For example, physical therapy, housing modifications, transportation options, vocational rehabilitation services, continence supplies and access to services to assist with mental wellbeing. The current rehabilitation model lacks an active community-based rehabilitation component. The lack of community-based rehabilitation is a factor in preventing early discharge which is costly because clients tend to have long lengths of stay in spinal rehabilitation units.

Another barrier to discharge relates to the slow access to ACC and DSS services and supports (e.g. specialised equipment and housing modifications) which can result in longer lengths of stay and a slower transition to living in the community.

Rehabilitation for children and transition from youth to adult services has no clear pathway. The lack of rehabilitation physicians in New Zealand is an acknowledged problem that contributes to this. However there are two paediatricians who offer specialist rehabilitation at the children's rehabilitation service in Auckland.

There is an opportunity to improve rehabilitation services, and transition planning, especially for children and health funded people.

## Living in the Community

Having spinal cord impairment affects a person's whole life – their basic needs, social and personal roles, personal and mental wellbeing, participation, medical needs and activities.

Links with family and whānau, community friends and significant others are vital for wellbeing and quality of life. Under the current system, there is a lack of formal peer support available that can facilitate people with spinal cord impairment to receive practical advice on how to live independently and navigate through service options. Some support is provided by the New Zealand Spinal Trust and TASC but is not funded by government agencies.

Carers (unpaid and paid) are a vital link in supporting quality of life, or not. People with spinal cord impairment often experience significant barriers to access and participation in a range of aspects of living in the community. Transport is a major barrier to community access, including employment.

Health and community support services frequently do not have enough spinal cord impairment specific knowledge and can miss opportunities to prevent secondary complications.

## Review, reassessment

Although there is evidence on the benefits of health reviews, there is little evidence on the frequency of reviews and monitoring/health surveillance.

The review type and frequency are important to maintaining optimal wellness and should be individualised as risk factors and personal circumstances can vary by person.

The absence of a national data base of people with spinal cord impairment poses difficulties with follow-up. This contributes to variable practice in on-going monitoring and prevention of health issues arising for people with SCI that impact on quality of life and are costly to address (e.g. pressure areas, musculoskeletal issues, bladder/bowel issues etc.).

## Other factors

This report has also identified a number of other factors that impact on quality of life for people with SCI. There may be opportunities to improve services and supports that relate to:

- pain management as this has been identified as a significant daily issue for many
- living with and managing changes in sexual function and intimacy
- increasing the focus on mental wellbeing as this is a very important aspect of quality of life that currently receives little focus
- how partners and families and whānau could have improved access counselling or psychological assistance.
- **Formal opportunities for peer and family support**

## Service Planning

Additional areas for service planning have been identified. These include workforce, highly specialised procedures, long term ventilation and research.



Of particular relevance are the challenges in developing and maintaining a skilled workforce attributed to the high level of complexity and low volume of people requiring specialised support. There is an opportunity to improve current training programmes for support workers to better prepare support workers to competently work with a person with spinal cord impairment.

## Conclusion

The situation analysis report demonstrates strengths in acute and inpatient service provision where these services are provided in specialist settings with multidisciplinary teams skilled in spinal cord impairment.

People receiving services under ACC have greater access to community rehabilitation and environmental supports that enable them to participate in the community and maximise their independence.

The report has identified a number of opportunities for improving spinal cord services that could result in gains in service efficiencies and outcomes for people with spinal cord impairment, their family and whānau within existing policy, financial and system constraints.

## SECTION 1: Introduction

This report describes the current status of supports and services available to people with spinal cord impairment (SCI). It brings together information gathered from multiple inputs and summarises key themes that will inform options for the development of the joint national spinal cord impairment initiative and implementation plan.

This is the first of two reports (in addition to the evidence papers) that will form the basis for the joint national SCI initiative and implementation plan. It is divided into seven sections:

- Introduction
- Methodology
- Spinal cord impairment in New Zealand
- Acute pathways and inpatient rehabilitation
- Living in the community
- Issues for service planning
- Applied research.

Each substantive section has a summary at the beginning. The second report will present options and recommendations.

### 1 What is Spinal Cord Impairment?

SCI results from a compromise of the spinal cord as a result of traumatic insult, vascular disruption or a disease process that may be immediate or insidious in onset. The consequence is a loss or reduction in voluntary motor function, sensory deprivation and disruption of autonomic function related to the level and severity of the cord damage (Krischblum, 2009).

### 2 Problem definition

The ACC and Health systems manage small numbers of high cost and high complexity clients with spinal cord impairment who will have varying levels of loss of control of their limbs, loss of feeling, loss of bladder and bowel control and may also have difficulty breathing or coughing.

There are approximately 130-180 people diagnosed with spinal cord impairment in New Zealand each year. Presently, there are around 1,500 people with spinal cord impairment resulting from an injury that are managed by ACC and less than 1,000 people with a medical or congenital diagnosis of spinal cord impairment who may be receiving supports from Disability Support Services. Although numbers are low, people with SCI are high users of health and associated support services.

People with SCI require life-long support including specialised acute and rehabilitation services to maximise their independence and reduce reliance on support services. They are at high risk of major secondary complications (for example, skin breakdown and infections) in the acute phase and are likely to experience many on-going chronic health problems and age prematurely.

The average costs for ACC clients with SCI over their lifetime are significant. The average cost of injury rehabilitation and support (excluding weekly compensation) is \$6.2 m for per person. The average is higher for people under the age of 20 at the time of their injury at \$13.2m and lower for those aged 60 and over at the time of their injury at \$0.9m. Note the acute care costs for injury are not included in these averages.

ACC costs for rehabilitation and support for people with SCI is made up of attendant care (59%), inpatient rehabilitation (6%), housing modifications and equipment (14%) and other social rehabilitation (21%).

The long-term social and financial costs and high life expectancy (survival following diagnosis and longevity) are considered substantial. Where possible ensuring best practice is vital if outcomes are to be maximised and costs minimised. Other countries including Australia have recently developed and are implementing rehabilitation models and action plans specifically targeted to people with SCI.

### **3 Why do we need a Spinal Cord Impairment Initiative?**

A spinal cord injury rehabilitation services report drafted in May 1995 by the Ministry of Health, Tertiary Review Committee (Ministry of Health, 1995) identified a number of issues associated with the delivery of services that remain valid today, for example, determining quality measures of effective rehabilitation.

A review of the continuum of spinal services for traumatically injured adults and children in New Zealand completed by the Commission on Accreditation of Rehabilitation Facilities (CARF)(CARF International, n.d.) International for ACC in 2010 identified a number of opportunities for improvement including developing a strategic vision for spinal cord services in New Zealand, driving consistency of care and improving communication and use of outcome measures. CARF noted the potential for New Zealand to be a world leader in developing a service delivery system that provides excellent benefits to people with SCI which are consistent, effective and efficient.

The model used in New Zealand for assessment, treatment and rehabilitation for people with spinal cord impairment is not well described nor clearly defined or consistent.

### **4 Objectives**

The Ministry of Health and ACC are leading the development of a joint national spinal cord impairment initiative and implementation plan to:

- improve the outcomes and promote increased independence and participation of people with SCI.
- develop an implementation plan that outlines an integrated and sustainable approach to support people with SCI meeting their goals.
- provide a sound platform to implement new or update existing service models and technologies as appropriate and affordable.

The initiative and implementation plan will describe the continuum of support for people with SCI and family / whānau. This is for all ages and includes:

- pre-hospital care /retrieval
- acute care and management
- sub-acute care/rehabilitation and management
- community reintegration and on-going care and support
- transitions within the continuum.

The joint national initiative and implementation plan for SCI will aim to:

- provide a client centric focus, including family and whānau where appropriate
- improve consistency, quality and outcomes for people with SCI to the maximum extent possible<sup>1</sup>
- provide evidence based, agreed approaches to service development and delivery
- enable benchmarking for future service monitoring and evaluation
- reduce inequalities for people with SCIs to the maximum extent possible
- foster strong clinical leadership
- guide the purchase of high quality services that represent value for money
- estimate and plan for future needs across a five year period (or longer if it is needed to inform capital and other planning processes).

## 5 Methodology

Inputs to this report include:

- an evidential review completed by the University of South Australia (Univeristy of South Australia, 2012; University of South Australia, 2012a, 2012b)
- a consumer perspectives research report (UMR Research, 2013)
- a cultural perspectives research report (Accident Compensation Corporation, 2012a)
- an analysis of ACC and Hospital Discharge Data for SCI (Accident Compensation Corporation, 2012c)
- AROC reporting (Australian Health Services Research Institute, 2010-2012)
- a survey of nursing and allied health staff (Ministry of Health & Accident Compensation Corporation, 2012b)
- findings from reference group meetings and various focus group meetings undertaken within the scope of the project (Ministry of Health & Accident Compensation Corporation, 2012a)

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<sup>1</sup> given the different legislative and funding arrangements

- various reports undertaken prior to the project being initiated (CARF International, n.d.; Ministry of Health, 1995)
- policy and strategy documents as referenced in the strategy section of this document
- service schedules and specifications for services and supports

Key themes have been taken from these inputs to create a summary of the current status of SCI services and supports available in New Zealand and how these relate to available evidence. For in-depth information, readers are encouraged to read the full reports that have been key inputs contributing to this report.

This report will be reviewed by the reference group to the project to assist in forming recommendations and options as part of the strategy development process.

For further information on the project scope and approach, please refer to the project initiation document (Ministry of Health & Accident Compensation Corporation, 2012a).

## SECTION 2: New Zealand context

### 1 Spinal Cord Impairment in New Zealand

#### Overview:

- The incidence of SCI is difficult to ascertain given differences in definitions, diagnosis and classifications. It is more difficult to ascertain incidence of non-injury cause than injury cause.
- An estimate of SCI as 30 per million (132) per annum in New Zealand is consistent with international estimates for people receiving spinal rehabilitation services.
- Māori and Pacific people are over represented compared with Europeans.
- There are very small numbers of children (single numbers per year) and between 100 and 170<sup>2</sup> adults per year.
- The average age of a person with traumatic SCI is 34 years at time of injury.
- 70 % of people with SCI are male.
- 50% of people with SCI are likely to have an incomplete or complete paraplegia.
- Approximately 45% of injured people live in the Waikato, Bay of Plenty and Auckland areas.
- Mortality rates are low.
- The split between injury and non-injury cause is reported as 55:45 % by Spinal Rehabilitation Units and AROC data and has changed over time to include more non-injury causes. If international classification codes (ICD) are used, non-injury cases would be double that of injury cases.

#### Opportunity for improvement:

- Current data collection methods require refinement if accurate rates of incidence of SCI are to be determined.

### 2 Incidence

Estimates of incidence of SCI vary nationally and internationally due to differences in definitions, diagnosis and classifications (Accident Compensation Corporation, 2012c). The New Zealand National Minimum Data Set is not specific enough to identify SCI through diagnostic codes and does not have linking functional information. For example, a person with an infection causing SCI may not be captured in the dataset as having a SCI. In New Zealand, determining incidence is further compounded by the lack of a national data base specific to SCI.

Best estimates of SCI based on admissions to New Zealand's two specialist spinal rehabilitation units is 30 per million (Derrett S, 2012). This was noted by Derrett to be the same mean calculated from a worldwide review of incidence completed in 2006. Data from the Derrett longitudinal study found the incidence to be 29 per million for European, 46 per million for Maori, 70 per million for Pacific and 16

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<sup>2</sup> The number is higher based on hospital admission ICD codes. This may include some non-permanent SCI or differences in definitions.

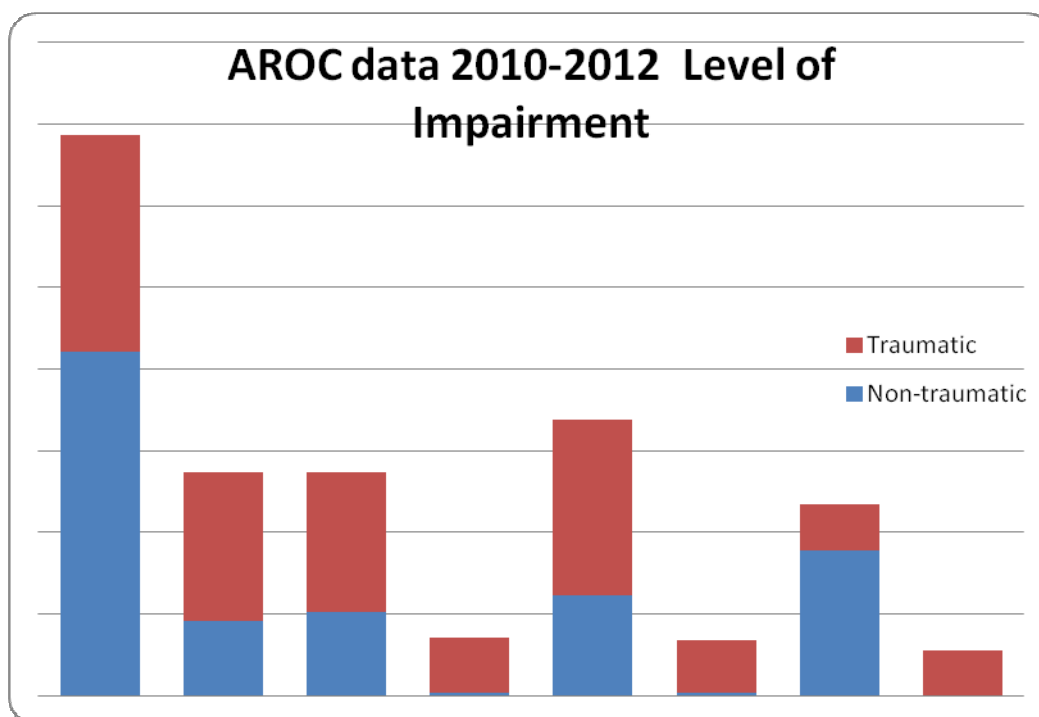
per million for other ethnicities. 77% of people with SCI were male and 80% had a cause attributed to injury. Auckland Spinal Rehabilitation Unit (ASRU) and Burwood Spinal Unit (BSU) report a higher incidence of non-injury related admissions, which is increasing over time, representing a split closer to 55:45 in favour of injury causes.

ACC held data for injury causes of SCI has averaged 100 per year (81-117) since 2005 (Accident Compensation Corporation, 2012c). 75% are male and 80% of clients are managed by the National Serious Injury Service of ACC. The number of SCI cases is fairly evenly distributed over the 15-54 age groups and the mean age at time of injury is 34 years and average age now is 50 years. There are few children and single figures are reported for children aged 0-9 years. This is consistent with opinion from paediatric orthopaedic and neurosurgeons participating in this project that stated the incidence of SCI injury is small compared with congenital and acquired medical conditions causing SCI.

Approximately 12% of serious injury clients with SCI are not transferred to either the ASRU or BSU based on this data.

Approximately 30% of ACC clients were from the Auckland region and 13% from the Canterbury region. There has been a shift northwards in where injuries are occurring over the last five years.

AROC data which includes data from 18 New Zealand district health boards for the years 2010 – 2012 has averaged 168 SCI per year (range 157-179) (Australian Health Services Research Institute, 2010-2012). This data includes traumatic and non-traumatic reported cases of which 46% are non-traumatic causes. Approximately 50% of people have complete or incomplete paraplegia as identified in AROC data for the period 2010-2012. A graph of levels of impairment is shown below:



The mean age of people in this dataset is 49 years; 70% are male and 17% are Maori. Approximately 40 people per year (23%) do not receive services from either the ASRU or BSU based on this data. Co-morbidity rates from AROC data found a co-morbidity rate of 30% for people with non-traumatic SCI and a rate of 21% for people with traumatic SCI.

ACC held data suggests a low mortality rate. Key district health board specialists indicate a rate of 18-40% for people with co-morbidities.

Neural tube defects causing spina bifida estimated from 2001-2008 data has a mean of 32 per year (Ministry for Primary Industries, 2012). This number could reduce by up to 20% if folic acid is taken before and during early pregnancy. The incidence of spina bifida is decreasing in most parts of the world and is estimated as 0.2 – 0.4 per 1000 live births. Not all children with spina bifida will have neurologic impairment as this is dependent on the position and extent of the lesion<sup>3</sup>.

Spinal tumours affecting the spinal cord include those that arise within the spinal cord and others that arise outside of the spinal cord but cause compression of the spinal cord. Internationally, the incidence rate is estimated as being between 0.5-2.5 cases per 100,000 population and are slightly more common in men than women.<sup>4</sup> 85% of metastatic lesions cause spinal cord compression and are usually of the thoracic spine. The severity of spinal cord compromise varies. Mortality correlates with the prognosis of the primary cancer.

Infections involving the spinal cord and transverse myelitis, an inflammation of the spinal cord are reported as being very rare. Permanent SCI can result from these conditions.

People with SCI are ageing. ACC has an ageing portfolio of people with SCI with approximately 20% of people now aged over 60 years of which 16% were aged less than 60 at the time of their injury.

### **3 Strategic and policy framework**

Strategies, policy and funding systems influence the delivery of health and disability support services in New Zealand.

A central theme within key strategies is improving health and wellbeing, providing equitable access to services, addressing disparities, acknowledging the Treaty of Waitangi and involving consumers. Also relevant are a number of other key documents such as the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) and the Disability Action Plan<sup>5</sup>.

Differences in legislation, systems, policies and available funding can impact on people with SCI. It is important to understand the context as to why New Zealand's dual system creates differences in income and service provision which is summarised in appendix one.

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<sup>3</sup> <http://www.adhb.govt.nz/newborn/Guidelines/Neurology/NeuralTubeDefects.htm>

<sup>4</sup> <http://emedicine.medscape.com/article/779872-overview#a0199>

<sup>5</sup> <http://www.odt.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan-diagram.html>



A current priority for the Government is to improve health outcomes whilst managing a lower economic growth path.

## SECTION 3: Current situation – acute services & inpatient rehabilitation

### 1 Pre-hospital

#### Overview:

- Where relevant destination policies exist, these are used to assist in determining the place of definitive care for people with suspected SCI.
- The Guidelines for a structured approach to the provision of Optimal Trauma Care recommend a person with suspected traumatic SCI to be taken to a district or advanced trauma service.
- The National Helicopter Dispatch Protocols for Ambulance Services (in draft) recommends helicopter transport for suspected paraplegia or quadriplegia where more than one hour can be saved in transport time.
- DHB boundaries and lack of destination policies can impact on which hospital a person with suspected SCI is taken to.
- Paramedics are considered by St John Ambulance and Wellington Free Ambulance to be competent in the management of people presenting acutely with suspected SCI.

#### Opportunities for improvement:

- Regional trauma centres and intensive care units with special resources for the acute management of SCI could be formally identified to inform resource planning and the definition of definitive care in a New Zealand context.
- A paediatric pathway could be fully described.

#### 1.1 Adults

In New Zealand, people acutely presenting with SCI symptoms will usually be managed through the ambulance service or primary healthcare services. People presenting to general practitioners are referred to secondary services, usually an orthopaedic surgeon or other specialist and may or may not use ambulance services. Others may present directly to an emergency department or an after-hours service.

Much of the information to inform the current situation was gathered from the pre-hospital focus group meeting included representatives from St John Ambulance, Wellington Free Ambulance, Life Flight Trust (on behalf of air ambulance operators), the National Ambulance Sector Office (NASO) and Major Trauma Clinical Network. Key points about pre-hospital services in New Zealand:

- road ambulances are required to take the patient to the place of definitive care.
- definitive care for a suspected SCI patient had not been explicit until the recent updated publication of the Guidelines for a structured approach to the provision of Optimal Trauma Care (Royal Australasian College of Surgeons New Zealand Trauma Committee, 2012b) which states patients with SCI with weakness and/or sensory loss should be transferred to a facility with the capacity to deal with the problem, usually a district or advanced trauma service.

- the National Helicopter Dispatch Protocols for Ambulance Services (consultation document in draft) (National Ambulance Sector, 2012) notes paraplegia or quadriplegia to be time sensitive conditions which could justify the use of a helicopter where more than one hour can be saved in the transportation time.
- members of the focus group noted there can be problems in taking a patient to the best definitive care option when DHB boundaries and associated funding effectively determine the destination.
- destination policies which outline where to send patients with certain conditions including SCI are in place for some DHBs. Where these are in place they generally work well. The Major Trauma Network will be working with DHBs and ambulance services to develop destination policies where they are not in place. Ambulance Service members of the focus group considered paramedics are appropriately trained in the early identification and safe management of suspected traumatic SCI.

## 1.2 Paediatrics<sup>6</sup>

The pre-hospital focus group and paediatric experts contributing to this project noted a specific paediatric pathway for SCI is not in place, however the Guidelines for a Structured Approach to the provision of Optimal Trauma Care includes information specific to children which includes transfer to a paediatric intensive care unit.

## 1.3 Evidence

The evidential review (Univeristy of South Australia, 2012; University of South Australia, 2012a, 2012b) found satisfactory evidence to suggest that transportation of patients with acute or suspected traumatic SCI to the definitive hospital can occur within 24 hours of injury and that use of a helicopter shows a mortality benefit compared to ground transport dependent on the geography and travel times to appropriate hospital facilities. Identifying regional trauma centres with special resources for the acute management of SCI is recommended.

The United Kingdom National Spinal Cord Injury Strategy Board (National Health Services, 2011) recommends that people with injuries suggestive of unstable SCI who are within 45 minutes of travelling time of a major trauma centre should bypass other units unless there is other major trauma requiring initial assessment and optimisation at a local trauma unit. They also make provision for direct transfer to a spinal cord injury centre which offers acute and rehabilitation services where the mechanism of injury rules out other major trauma.

Participants to the consumer perspectives research did not specifically comment on pre-hospital services but made comments on acute services which is discussed in the next section.

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<sup>6</sup> For the purposes of this report, paediatrics refers to children and youth that are most appropriately managed through a paediatric service – therefore no age definition is given.

## 2 Acute services

### Overview:

- No formal protocols are consistently in place or used for destination, transport or acute surgical/nonsurgical management of people with SCI.
- Counties Manukau DHB and Canterbury DHB offer spinal services that include acute services and rehabilitation for people with SCI. Both DHBs have acute spinal surgical services with referral/discharge to rehabilitation.]
- Canterbury DHB spinal service includes a portion of acute care at Burwood Hospital. Counties Manukau DHB spinal service includes acute care at Middlemore Hospital.
- There is no formal referral system or on-call spine service for SCI outside of the Burwood Spinal Service located at Canterbury DHB. Middlemore Hospital at Counties Manukau DHB accepts referrals and provides a multidisciplinary acute service and uses an international acute/intensive care SCI clinical protocol
- Current acute services means people may be managed locally or transferred to higher level services which may or may not have SCI expertise available across a multidisciplinary team.
- A consensus viewpoint of the New Zealand Spine Society has recently been developed which is in support of a two adult specialist acute SCI Services/Centres in New Zealand.
- Consumer perspectives research found general hospitals (both for acute and planned events) were not well set up for managing SCI (injury and non-injury) and staff were not sufficiently skilled. The recent nursing and allied health survey supports this position.

### Opportunities for improvement:

- Formal protocols, systems and processes could be put in place to ensure the acute management of people with SCI occurs within an acute specialist spinal service. This would provide consistency in services and prevent low volumes of patients being dispersed across multiple hospitals. Maintaining clinical expertise in SCI would therefore be easier.
- Outcomes for people presenting acutely with SCI are likely to improve if specialist acute SCI services are established and are available equitably.
- Spinal rehabilitation units report the high rate of preventable secondary complications associated with acute inpatient services would reduce if patients receive care in SCI specific acute services.
- Paediatrics may benefit from having its own acute pathway for SCI.
- On-call acute SCI roster for paediatrics could be established.
- Clinical pathways/protocols for use in emergency departments to guide SCI care would be beneficial.

### 2.1 Adults

Acute services for people with traumatic and non-traumatic SCI are provided by DHBs. For people with multi-trauma and SCI or isolated SCI they are assessed and transferred based on the Guidelines for a structured approach to the provision of Optimal Trauma Care (Royal Australasian College of Surgeons New Zealand Trauma Committee, 2012a). For those patients with multiple injuries including spinal cord impairment, they will be transferred to the nearest trauma service. They may be transferred from a lower level to a higher level of trauma care based on level of need from their injuries. They will usually be transferred to a trauma service within the DHB region in which their injury or acute event occurred.

To date acute SCI has not been identified as a specialty area requiring its own clearly defined pathway outside of self-promotion by Canterbury DHB and in the ICU at Middlemore Hospital at Counties Manukau DHB. Other than Canterbury DHB, there is no clear referral system for people presenting acutely with SCI. The decision to keep or transfer a patient is determined by the receiving acute hospital. This means that a patient may or may not be transferred to a specialist acute SCI service.

Recently, as part of the SCI initiative and implementation plan project, the New Zealand Spine Society of the Orthopaedic Association developed a consensus viewpoint at their annual Scientific meeting (November 2012), on the management of spinal cord injured patients as shown in the box below.

***With respect to the management of adult spinal cord injured patients***

**Low velocity injuries**

- Initial triage and assessment by either paramedics or attending doctors with rapid referral and transfer directly to a tertiary Spinal Trauma Unit

**High velocity injuries and multi-trauma**

- Immediate transfer to nearest regional trauma hospital
- Early/rapid assessment at trauma hospital with early involvement of local trauma and orthopaedic services and early discussion with tertiary Spinal Trauma Unit
- Transfer of patient to tertiary Spinal Trauma Unit for definitive care as soon as cleared fit for transfer.

***Location of Tertiary Spinal Trauma Units***

**South Island and lower North Island**

- Christchurch Hospital/Burwood Spinal Service

**Upper North Island**

- A single acute spinal trauma Service/Centre based in the Auckland area
- Post-operative early transfer to the Auckland Spinal Rehabilitation Unit for rehabilitation

### 2.1.1 South Island and Lower North Island Current State

Canterbury DHB actively promotes early consultation with the on-call spine surgeon or physician by all DHBs in its Spinal Service catchment area with an aim of early transfer to Christchurch Hospital where a person has a suspected SCI. As Christchurch Hospital has an acute spinal service, patients within their wider catchment area are likely to be referred early, but this is not always the case. Analysis of National Minimum Data Set hospital discharge data for people who received ACC funded primary rehabilitation at Burwood Hospital shows that 87% were transferred to Burwood from Christchurch Hospital<sup>7</sup>. People receiving rehabilitation at BSU were more likely to have had two transfers within their acute period of

<sup>7</sup> Note: This is based on the analysis of NMDS hospital discharge data for 210 people who received ACC funded primary rehabilitation at Burwood Hospital which shows that 87% (182 of 210) were transferred there directly from Christchurch Hospital, and 13% were admitted from another hospital.

care than people transferred to the ASRU, indicating a transfer to Christchurch Hospital occurs prior to admission to the BSU.

Once at Christchurch Hospital, a person is assessed in the emergency department before being transferred to either the intensive care unit (ICU) or the orthopaedic trauma unit. The orthopaedic trauma unit is a five bed unit within the orthopaedic ward. Acute management offered by Canterbury DHB includes specialist multidisciplinary care, imaging, chest assessment, surgical fixation if required and other medical management. There is a very close working relationship between BSU and acute staff who work across Christchurch and Burwood Hospital sites.

People with SCI usually stay a minimum of 24 hours in the unit and may complete their acute care management at BSU as there is a desire to shorten time in acute services in favour of a rehabilitation environment that will provide hope and positivism for a newly diagnosed person with SCI. The length of stay in the orthopaedic trauma unit is determined by clinical need and availability of beds at BSU. Overall, new ACC NSIS clients transferred to BSU whether from Christchurch Hospital or another hospital had an average of 14.6 days in acute services with a further 10 days of acute care delivered at BSU.

### 2.1.2 Upper North Island

There is an acute on-call spine service operating from Middlemore Hospital, Counties Manukau DHB. This is available to the ARSU catchment area. However, there is no formal pathway or expectation for the transfer of patients to Middlemore for people outside of the region. It becomes the responsibility of the referring service to find a service and hospital that will or can accept a patient. In general tertiary hospitals will accept early transfers but there can be difficulties in finding a destination for a patient especially where the on-call orthopaedic surgeon may not be a spine surgeon.

Historically orthopaedic care has developed in Auckland with a single hospital (Middlemore), followed by a two hospital system (Middlemore and Auckland City Hospital), and more recently there have been three acute hospitals in the Auckland region to include North Shore Hospital. At the same time Waikato Hospital has become a major trauma centre. Not all of these hospitals provide all of the services for other acute injuries/morbidities that may coexist. Patients with multiple injuries are prioritised on the basis of injuries other than the acute spine trauma. All of these hospitals have developed spinal surgical expertise but do not necessarily have a multidisciplinary approach supported by health professionals with specialist SCI skills.

Middlemore Hospital through self-promotion and its history in providing acute SCI services receives more transfers than other upper North Island tertiary hospitals for the acute management of SCI. Over the last three years, 46% of injury and non-injury patients with SCI in the acute service are from other DHBs.

The CMDHB ICU team has created a SCI management guideline that functions within the New Zealand health care setting and specifically at CMDHB, with consideration of best practice within the scope of the available budget. The team performed an extensive literature review followed by a two week placement of a multi-disciplinary CMDHB team at internationally renowned spinal units in Vancouver, Canada and Seattle, Washington. They discussed SCI management with world experts in the field of

spinal cord injury and reviewed operational practice guidelines from admission to discharge. In addition they interviewed patients in these centres to listen to their experiences. Discussions also occurred with the Clinical Directors of the large, tertiary spinal cord referral centres Princess Alexandra Hospital, Australia, and University Hospital Wales, United Kingdom. SCI guidelines from those centres were provided for review. The CMDHB ICU SCI practice guidelines have provided CMDHB SCI patients with improved acute SCI management, diminished complications and mechanical ventilation management and weaning prior to discharge to the ASRU<sup>8</sup>(Counties Manukau District Health Board, 2012).ACC data shows that in a cohort of 378<sup>8</sup> people acutely presenting with SCI that nine had three transfers before their transfer to a spinal rehabilitation unit and four had four transfers. This data set also found 64% of people were transferred to the ASRU after receiving their acute care at their initial treating hospital and that the average length of stay in acute services was 26.2 days. Data received<sup>9</sup> from Counties Manukau DHB, Auckland DHB and Waikato DHB had acute lengths of stay of 17.4 days, 14 days and 21 days respectively.

## Conclusion

This confirms that people in the upper North Island and some from the region serviced by Christchurch are not routinely being transferred to an acute service that specialises in SCI prior to their transfer for rehabilitation.

## 2.2 Paediatrics

There is no specialist paediatric SCI roster across New Zealand and national coverage of suitably qualified paediatric surgeons does not exist. This means that where a paediatrician requires specialist advice it is ad hoc and that in the absence of protocols for acute management a child may or may not be transferred to Starship Hospital Paediatric Intensive Care Unit (PICU).

Paediatric surgeons working at Starship Hospital felt that there is no uniformity or national consistency in how children presenting acutely with SCI are managed. Outside of Starship Hospital it is unlikely that a child would have access to a paediatric interdisciplinary team with specialist skills in SCI. It was also felt that as the numbers of children are so low (likely to be 0-5 per year), it would be difficult for surgeons to maintain competence.

However, in a survey of paediatric spine surgeons undertaken by a consultant at Starship Hospital found surgeons would rather keep their patients than transfer them to Starship Hospital unless they were requiring ventilation. The respondents to the survey did however, want good access to advice as part of a hub and spoke model.

Although there was strong support for the hub and spoke model, the majority of paediatric experts interviewed for this project recommended that an acute SCI roster specific to paediatrics was required and should be managed out of Starship Hospital and that after a case discussion with the referring

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<sup>8</sup> A five year period from 2006-2010.

<sup>9</sup> Data varied and was for either the last two or three financial years related to acute SCI. Data extracts were based on ICD-10 coding which included injury and non-injury codes.

hospital clinician it would be most likely the child presenting acutely with SCI would be transferred to the Starship Hospital PICU for their acute care irrespective of whether they were ventilated or not.

## 2.3 Evidence

Treatment provided in acute services for both injury and non-injury also varies.

Assessment and treatment is discussed in the evidential review (Univeristy of South Australia, 2012; University of South Australia, 2012b). The evidence supports early decompression and stabilisation of the spine occurring 8-24 hours following acute injury and is associated with improved clinical and neurological outcomes.

Surgeons with spinal expertise on the reference and clinical advisory groups were concerned that not all patients, particularly those with incomplete injuries receive surgical decompression which is considered to give better long term neurological recovery. Having a dedicated unit with availability of a multidisciplinary team of specialists, operating rooms and ICU were considered important factors in providing definitive care and giving a person the best chance of early decompression. It was also noted by these surgeons and the clinical advisory group that the secondary complication rate is high in the acute period resulting in pressure areas, bowel and bladder complications for approximately 25-33% of people. Avoidance of complications is seen as critical as complications go on to compromise long term outcomes and create significant delays in rehabilitation programmes.

The evidential review (Univeristy of South Australia, 2012) includes a recommendation that SCI patients are expeditiously directed to an acute specialised spinal cord injury centre. This then allows for early interdisciplinary care and is associated with faster transfers to rehabilitation and fewer medical secondary complications, greater efficiency in functional gains and reduced overall length of stay and reductions in overall mortality.

The NHS Clinical Advisory Group (National Health Services, 2011) states specialised assessment of people with new spinal cord injury must take place immediately after injury. Where there is significant injury and the person is in a major trauma centre, the consultant must ensure early contact (within four hours) with the specialist SCI centre to discuss the management of the patient. The appropriate location for optimal medical management including the SCI must be agreed taking into account other injuries and pre-existing medical conditions. Early transfer to the acute SCI centre is recommended and has been shown to reduce complications. For people without major trauma, they should be transferred directly to the acute SCI centre. Protocols are required to support the implementation of these recommendations.

The nursing and allied health survey (Ministry of Health & Accident Compensation Corporation, 2012b) found that nursing staff generally thought there was no guidance or pathway for acute services to meet the specific needs of people with SCI and that there was a lack of experience and knowledge outside of spinal rehabilitation units. There were challenges in keeping a workforce skilled and competent due to high staff turnover and low volumes of people presenting acutely with SCI. This finding is consistent with the Spinal Cord Injury Plan for New South Wales (New South Wales Department of Health, 2010) that references throughput of approximately 50 cases per year is required to maintain specialist



expertise in this area. New Zealand clinicians on the clinical advisory group also support grouping patients in order to maintain expertise. Recent volumes of acute patients provided by Counties Manukau DHB, Auckland DHB and Waikato DHBs average 41 per year at Middlemore, 24 at Auckland and 32 at Waikato (Midland Region). Waikato DHB indicated that many of their SCI patients have multiple injuries that prevent safe transfer but acknowledged that early transfer for rehabilitation input in the post-acute interval is important.

Chief executive officers of DHBs were asked to support a recommendation that arose from the acute focus group of the project, clinical advisory group and New Zealand Spine Society that two acute SCI acute services and related pathways are established in New Zealand as this would result in the following patient benefits:

- improved overall neurologic outcomes
- faster transfers to rehabilitation
- reduced overall length of stay
- reduction in mortality rate

Twelve DHBs responded to this memo<sup>10</sup>. All those DHBs that responded are in support of the recommendation. Waikato DHB who has an accredited Trauma Unit<sup>11</sup> and has a high volume of SCI multi-trauma patients was concerned that people are not unnecessarily transferred which resulted in the following recommendation from them:

An early consultation between the receiving hospital and acute spine service (Auckland or Christchurch) should occur to agree a treatment plan for all cases of acute spinal cord impairment. Each plan will be individually developed to provide the best opportunity for immediate treatment (which may occur at a tertiary hospital) and subsequent rehabilitation. Where patients have multi-trauma and are within an advanced trauma service, they will be treated at that service and transferred from the trauma service as soon as possible so acute rehabilitation can be provided.

There is limited data available on the acute management of non-traumatic SCI (University of South Australia, 2012b). In the two studies reported in the evidential review, decreased complication rates, improvements in functional and mobility outcomes were associated with specialist SCI centres providing acute care. Counties Manukau DHB data found 70% of acute admissions to Middlemore Hospital for SCI are injury related<sup>12</sup>.

NHS Clinical Advisory Group (National Health Services, 2011) includes specific advice for the acute management of children with SCI. It states that occurrence is rare and that due to small numbers it is

<sup>10</sup> Note Auckland, Capital & Coast, Counties Manukau, Hutt Valley, Nelson Marlborough, South Canterbury, West Coast and Waitemata did not respond by the due date just prior to Christmas and are being followed up by DHB Shared Services.

<sup>11</sup> Royal Australasian College of Surgeons (RACS) Level 1 verification

<sup>12</sup> Acute admission data has not been provided by Canterbury DHB.

not appropriate for spinal cord injury centres to manage children as they should be managed at a children's or combined adult/paediatric multi-trauma centre.

The evidential review (University of South Australia, 2012) found that the acute needs of children with major injury are different to those of adults and systems of care need to address this. Guidelines and/or local policies for the management of children with acute SCI are required whereby all children with a suspected acute SCI are taken to a children's major hospital trauma centre. The centre should provide an on-call service to ensure advice and timely transfers occur.

UMR Consumer Perspectives Research (UMR Research, 2013) includes a section on early stage assistance. Participants to the research reported that generally hospitals were not well set up to deal with SCI patients with comments relating to lack of staff training when dealing with SCI patients, lack of clinical knowledge relating to rarer SCI conditions, which participants associated with poorer outcomes, and lack of appropriate support including meaning that family support was even more crucial. This finding provides further support for specialist units.

## **2.4 Emergency and Acute services for people with established SCI**

Reference group members and the community living advisory group raised concerns about the quality and knowledge of staff working with people with SCI in emergency departments and inpatient services when admitted for matters that may be related or unrelated to their SCI. Examples given included staff saying to patients to take care of themselves as they don't know what to do, through to people feeling like they were generally ignored or avoided. The results of this were if people couldn't take care of themselves, e.g. turning, bowel and bladder cares, or their family couldn't come in to do these, then there were frequently secondary, and sometimes complex, issues, such as on-going and long term pressure sores, compacted bowels, falls etc. These concerns were also raised by the interviewees in the UMR consumer perspectives research (UMR Research, 2013).

Three key opportunities for improving this situation and preventing secondary complications were proposed:

- education and fact sheets for emergency and inpatient staff
- wider use of the health passport<sup>13</sup> may be useful. The health passport provides individualised information of their condition and needs.
- use of a national data base where a flag could be sent to the specialist spinal rehabilitation units so they could proactively educate / support emergency or hospital staff based on (a) their knowledge of the individual and / or (b) general SCI treatment and care inputs.

The nursing and allied health survey (Ministry of Health & Accident Compensation Corporation, 2012b) found that there was generally no guidance or a pathway for assisting staff to meet the specific needs of people presenting with SCI and there was a lack of knowledge outside of those units or services specifically set up for SCI (e.g. Christchurch Hospital which has an orthopaedic trauma service). Specific

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<sup>13</sup> <http://www.hdc.org.nz/about-us/disability/health-passport>

skill gaps that would be assisted by having clinical guidelines or protocols included pain management, prevention of pressure areas, bowel and bladder management and management of dysreflexia.

### 3 Rehabilitation services

#### **Overview:**

- People admitted acutely with SCI are not always known to the spinal rehabilitation units prior to referral to them. At ASRU, this more often occurs with referrals from hospitals outside the Auckland area.
- There is no national data base that identifies people as having a SCI. AROC data is being consistently collected for both spinal rehabilitation units.
- ASRU admits people who still require medical care as long as they are medically able to participate in SCI education and rehabilitation. BSU will accept people who are medically stable but are still requiring acute care. Both ASRU and BSU have a registrar and a house surgeon to assist the consultant(s) in providing acute medical care.
- An interdisciplinary service is offered by ASRU and BSU. Both spinal rehabilitation units have an interdisciplinary team which includes core disciplines and also include peer support, cultural support, speech and language therapy, urology services and psychology services. BSU has a larger multidisciplinary team due to the associated on site rehabilitation hospital.
- ASRU and BSU provide a patient goal based rehabilitation programme. BSU utilises the assigned keyworker while ASRU has a single Rehabilitation Coordinator. Both roles work to coordinate inpatient rehabilitation with the IDT and patient/family/Whanau to ensure a smooth transition through inpatient rehabilitation. Although models are similar they have some key differences.
- BSU provides a national service for people who are ventilated and those requiring highly specialised procedures.
- Both ASRU and BSU accept people transitioning from paediatric services to adult rehabilitation services however, ASRU does not currently accept persons with Spina Bifida.
- Early advice to other DHB acute services is not always requested from spinal rehabilitation units and when requested or given, is not always followed.
- The Wilson Centre for children provides a comprehensive interdisciplinary rehabilitation service including one for children with SCI. The service is not well utilised outside of the Auckland Region.

#### **Opportunities for improvement:**

- Clear admission criteria, referral pathways and transfer/discharge guidelines to other DHBs from the spinal units could be developed to ensure national consistency and improve continuity and coordination across other services that interface with the spinal rehabilitation units and the Wilson Centre for children.
- Addressing delays in equipment provision and housing modifications would positively impact on discharge arrangements, costs and emotional and safety wellbeing of the person and their family.
- Developing a clear pathway for transitioning people from paediatric to adult rehabilitation services would be beneficial.
- Increasing travel assistance for families of health funded people with SCI would be of assistance.
- Engagement with ACC case managers for ACC clients can be improved especially where they are not part of the NSIS.
- Wider coordination that has a community/multi-agency focus is required for people who are health funded.

- Addressing the Wilson Centre funding system for personal health and DSS funding would remove a barrier to referrals.
- Changing entry criteria to a specialised rehabilitation programme (either through adult or children's services, such as those with Spina Bifida) would increase access to these services.
- A formalised hub and spoke model for rehabilitation of children with SCI could be considered.

### 3.1 Adults

ACC data found not all people were transferred to a spinal rehabilitation unit following acute admission with a small proportion of ACC serious injury clients either transferred to other inpatient rehabilitation or received no inpatient rehabilitation. A high proportion of non-serious injury ACC clients were not transferred to a spinal rehabilitation unit for rehabilitation but data inaccuracies and the nature of the injuries concerned may mean this is not a negative finding. AROC data also identified 10 people in the last year with a SCI that did not receive rehabilitation at either the ASRU or BSU.

There are two specialised spinal rehabilitation units in New Zealand, one based in Auckland and the other in Christchurch. Both units receive ACC funding and personal health funding including non-case weight inter-district flow funding for people not domiciled within their DHB region. There is no direct funding from Disability Support Services; however there is funding for equipment and housing modifications for individuals as they move back in to the community.

The Consumer Perspectives Report (UMR Research, 2013) included examples of people's favourable experiences in the spinal rehabilitation units.

A diagram of the catchment area is shown below. The catchment area for each unit has in some respects been a pragmatic split that has changed over the years with the most recent change being the inclusion of Tairāwhiti into the Auckland catchment area.



A brief overview of both spinal rehabilitation services is presented below:

### 3.1.1 Auckland Spinal Rehabilitation Unit (ASRU)

The ASRU provides an inpatient SCI rehabilitation service and lifelong follow-up service through Auckland based clinics and outreach clinics. It is a regional service with a catchment area of the central and upper North Island.

The inpatient service comprises a 20 bed stand-alone unit for people aged 14 and over who have sustained an acquired spinal cord injury/impairment with resultant neurological deficit. Patients with SCI under the spinal teams in the acute services and ICU services of Middlemore Hospital (CMDHB), Auckland City Hospital (Auckland DHB) and North Shore Hospital (Waitamata DHB) are seen, evaluated and followed by the ASRU Consultant, the admissions coordinator and occasionally other inpatient IDT members as support for the outside hospital's allied health therapists or nurses. ASRU provides, amongst other services: upper limb rehabilitation after specialist surgery, serial casting/splinting, urological investigations (cystoscopy, urodynamic studies, placement of suprapubic catheters, intravesicular botulinum toxin injections), sexuality and intimacy after SCI support and education, spasticity management clinic with inpatient and outpatient management, plastic surgery (through Middlemore Hospital), post plastic surgery management, seating and wheelchair assessment with pressure mapping, and chronic pressure area healing/management. Outpatient clinics including medical, urology, counselling, dietician, social work, clinical nurse specialist and IDT team assessment are also provided. Both inpatients and outpatients have the opportunity to learn and participate in open water sailing through Sail Ability and there are numerous opportunities for participation in SCI research through ASRU.

Paediatric SCI rehabilitation is provided at the Wilson Centre for children. Communication between the paediatric rehabilitation specialist at Wilson Centre and the adult rehabilitation specialists at ASRU ensures admission to the most appropriate facility for rehabilitation and ensures appropriate transitional rehabilitation follow up of young persons with an acquired spinal impairment. The ASRU is not set up for people requiring on-going ventilation. The demographic within the unit has changed over the years having been 65% injury related to now averaging 57% injury to 43% non-injury split.

Data provided by Counties Manukau DHB indicates an average of 80-90 people are admitted to ASRU each year. Of these patients, 23% are from the Counties Manukau DHB, 21% from Waitemata DHB, 16 % from Auckland DHB and 11% from Waikato DHB. Other referring DHBs include those in the catchment area and isolated admissions from outside of the catchment area.

The outpatient service includes interdisciplinary team assessments and Medicine Specialist appointments at the ASRU site and at 9 centres within its catchment area, with the majority of these clinics occurring in Whangarei, Tauranga and Hamilton. See section 5.3 for more detail on these services.

ASRU provides a person-centred interdisciplinary service where services are developed through a patient goal based programme. The interdisciplinary team is comprised of rehabilitation medical specialists, rehabilitation nurses, clinical nurse specialist, physiotherapists, occupational therapists, social workers, a counsellor, a rehabilitation neuropsychologist, a dietician, a speech and language

therapist, site pharmacist and urologist. Cultural Support Services, Peer support, Behavioural Health Services and Psychiatry Services are available when indicated. Medical services include four rehabilitation consultants (three part time), a fulltime rehabilitation registrar, a fulltime house officer, urologist, and orthopaedic surgeons and plastic surgeons from Middlemore Hospital. In addition, an Orthopaedic Upper Limb Surgeon from Christchurch Hospital has been providing upper limb surgery evaluations and surgical follow up in an ASRU outpatient clinic with ASRU therapy staff on a twice yearly basis. ASRU clinical staff are supported by a service manager and an administrative team. As additional source for persons with SCI, the ASRU-developed website [www.sexsci.me](http://www.sexsci.me) ([info@sexsci.me](mailto:info@sexsci.me)), accessed through the ASRU website, provides a place for consumers, partners and health professionals to discuss and learn about sexuality, intimacy and spinal cord injury. Co-located support services on the ASRU site include Parafed, TASC and Kaleidoscope which participate in inpatient and outpatient activities and vocational rehabilitation in conjunction with the interdisciplinary team. Referrals are accepted within ASRU's catchment area from other DHBs for newly injured people who have completed their acute surgical care and are considered medically able to participate in SCI education and rehabilitation. For people located in the Auckland Region, an ASRU rehabilitation consultant and/or nurse admissions coordinator visits people in acute care as part of the initial consultation, evaluation and transition process to ASRU rehabilitation services. For people who are outside of the Auckland region, assessment for admission is through review of their current medical documentation and referral information. If medical or respiratory stability is questioned, the person may be first transferred to Middlemore Hospital Emergency Department or Orthopaedic Ward for assessment before they are received by the ASRU.

ASRU also accept referrals for people with sub-acute/chronic SCI that have developed a complication that requires a specialist inpatient assessment, medical management and rehabilitation services.

Bed availability, due to gender and isolation requirements, can impact on the ability to accept referrals. Occupancy averages 75-80% (2011-12). Historically, ASRU has not accepted referrals for people with spina bifida or for those whose SCI is due to an aggressive cancer in which life expectancy is less than 4 months. An interdisciplinary team will occasionally assess a patient with SCI due to end stage cancer in the home to assess for equipment needs and to provide support and education. For people who have sustained a severe traumatic brain injury in addition to SCI, rehabilitation may first be carried out in a specialized brain injury unit until the individual is able to participate in and understand the educational aspects of SCI rehabilitation.

The staff of ASRU also provide written and verbal specialist advice to other health professionals at referral hospitals when approached and in a proactive manner when a person is moving from the Unit to another health care facility or to the community. It was noted that this advice is not always followed by other DHBs. Formal SCI workshops are held for health professionals and caregivers on a regular basis.

ASRU report the average length of stay in the inpatient unit as being 55 days. This is a downward trend associated with the change of service delivery model that has been implemented over the last year.

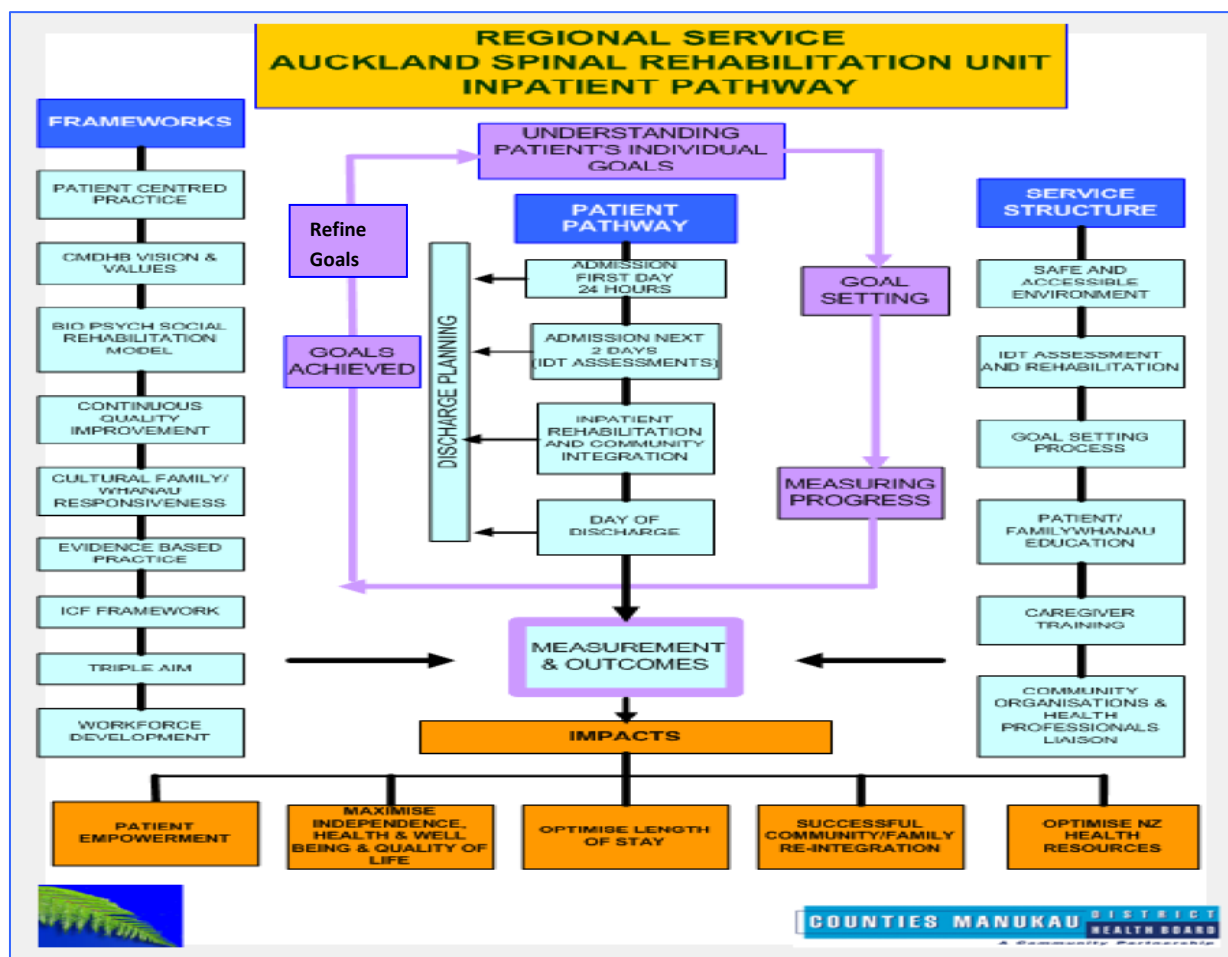
The individual goal based programme of rehabilitation is based on setting goals around activities of daily living, skin management, bladder management, bowel management, mobility, emotional wellbeing, community participation, discharge planning including equipment provision, housing assessment and liaison with other community based agencies along with other goals that may be specific to respiratory, pain, spasticity management and prevention of complications. Family involvement including education is seen as an essential part of the rehabilitation programme.

The patient and staff expectations, intensity and duration of rehabilitation, and the patient's concerns and progress are assessed throughout the inpatient rehabilitation stay through continuous medical monitoring, weekly Interdisciplinary Team meetings, medical ward rounds, goal setting and family meetings. There are limited allied health services available on weekends and public holidays. On call medical coverage is provided after hours, weekends and holidays. Patients with urgent medical concerns are assessed and transported via ambulance services to the appropriate medical facility if indicated.

There is some accommodation available on site for families in self-contained flats. Although not fully accessible, these flats are also used for therapeutic leave to assist people with SCI test their skills and gain independence in anticipation of transitioning to their home environment. Discharge planning is discussed with the person at the first consultation and includes identification of probable discharge destination, identification of the individual's support system, estimated length of stay and identification of barriers to discharge.

ASRU has embarked on a project to redevelop and implement standardised service delivery model for its inpatient unit seeking to lower the length of stay by 10 days, increase Functional Independent Measure (FIM) scores, discharge 85% of people to their usual pre SCI accommodation and establish the optimal frequency, duration and timing of all therapeutic activity. The inpatient pathway developed is shown in the diagram below:





The ASRU is in the process of developing pathways based on injury level. There are existing protocols, for bowel and bladder management and skin management and existing general criteria for admission.

Counties Manukau DHB has prioritised the ASRU to be part of a new development called the Manukau Health Park which will result in its re-location. Timing for this has been delayed by the Christchurch Earthquake re-build.

Areas for improvement identified by staff at ASRU included:

- developing a referral protocol to guide clinicians in referring the right people at the right time to ASRU.
- improving ACC case manager involvement and knowledge of SCI and broadening the criteria for NSIS to include all injured people with SCI, as well as speeding up some ACC systems.
- introducing a case management model and specialist team services for people who receive health funded services.
- identifying people with acute or chronic SCI on hospital admission with a view to involving the ASRU earlier.
- developing a discharge protocol for DHBs of domicile.

- improving access to equipment, transport and intensive therapy in the community for people funded under health.
- having a national SCI database for more proactive health surveillance options over a person's lifetime.
- reducing differences between ACC and Health funded people.
- improving transport options for people with SCI in the community including to be able to access health appointments.
- defining accountabilities for following and following-up on recommendations made by the unit to others such as general practitioners, ACC and other DHBs.
- reducing delays in equipment provision and housing modifications, and housing options.

### 3.1.2 Burwood Spinal Unit (BSU)

BSU is an inpatient spinal and spinal cord service based mainly at Burwood Hospital but also has patients under the spinal team in the acute service including the Orthopaedic Trauma Unit (OTU) and Intensive Care Unit (ICU) of Christchurch Hospital.

The Burwood Hospital campus includes rehabilitation, upper limb, urological and plastics surgery, urodynamics, pressure area management, outpatient clinics, a range of procedures and driving assessments. The Burwood Academy of Independent Living and New Zealand Spinal Trust are also located on the campus.

BSU provides acute care, comprehensive rehabilitation and long term follow up and reassessment for people with spinal and some spinal cord lesions. It has a catchment south from the central North Island and provides a national service for ventilated patients and people requiring upper limb functional reconstruction surgery and a regional service for intra-thecal baclofen pump insertion. The service includes an outpatient and outreach programme to provide life-long follow-up.

BSU has established admission criteria which include accepting children on a case by case basis. BSU also accepts people with spina bifida and some tumours. BSU attends a paediatric clinic at Christchurch Hospital when people with spina bifida reach 16 and are then being transferred to the BSU service.

The inpatient service comprises a 26 bed ward with a further four transitional rehabilitation beds in the adjacent spinal hostel. There are four self-care units and four accommodation units onsite that may be used by family or patients as they are moving towards discharge. The demographic of the service is estimated by BSU as being a 30-40% health and 60-70% ACC split. Occupancy averages around 80% with 320 patients being admitted each year; of which one third are following an acute event which may be spinal or SCI. Average length of stay is variable but averages 62-78 days for people with paraplegia and six months (78 days – 190 days) for people with tetraplegia.

A multidisciplinary team including four rehabilitation consultants, clinical nurse specialists, registrars, house surgeon, specialist social workers, speech language therapist, occupational therapists, physiotherapists, psychologist, Māori cultural advisor, Independent Living Coaches (peer support), programme coordinator, pharmacist, dietician and an assistive technology team work together to

provide a goal based programme of rehabilitation. They are supported by a service manager and an administrative team and work closely with Kaleidoscope staff who offer vocational rehabilitation.

The rehabilitation model used by BSU includes a transitional rehabilitation programme where people stay in a flatting situation for approximately four weeks prior to discharge. An occupational therapist provides professional oversight for the programme and team which includes physiotherapists, nurses, healthcare assistants and other disciplines, as required. A unique aspect of this programme is the intense input provided by independent living coaches who are people with SCI employed by the DHB and has a strong focus on learning practical living skills and peer support. BSU undertakes driving assessments and has access to two vehicles which allows a person to confidently learn to drive prior to discharge if this is one of their goals.

Areas for improvement identified by staff at BSU included:

- better describing the pathway for people with SCI.
- transition from paediatric service to adult services.
- ACC case management involvement whilst waiting for a person to be accepted by the NSIS.
- information and eligibility for funding family travel for people that are health funded.
- improving access to community based rehabilitation for people that are health funded.
- reducing delays in equipment provision and housing modifications.
- establishing a multi-agency process to assist people without accommodation who are nearing discharge.
- supporting training for home and community support providers as part of discharge planning.
- improving funding for large multidisciplinary teams who provide clinics and home visits.
- defining accountabilities for following and following-up on recommendations made by the unit to others such as general practitioners, ACC and other DHBs.
- defining a paediatric pathway.

### **3.2 Paediatrics**

The Wilson Centre provides a national specialist children's rehabilitation service located in Takapuna. The child rehabilitation service provides a comprehensive family-centred programme for children aged 0-16 years or while still at school. There is an inpatient unit with a maximum capacity for 18 children, outpatient unit and a limited ad hoc outreach service. There is accommodation on site for families.

There is a multidisciplinary team of paediatric rehabilitation specialists, nurses, physiotherapists, occupational therapists, speech language therapists, play specialists, social worker and clinical neuropsychologist. There is also access to other supports from Waitemata and Auckland DHBs including cultural support. Despite having highly specialised staff, staff generally felt they were not acknowledged as being a specialist national service.

The rehabilitation approach for children is significantly different to adult services as there is a whole of family and whānau approach. Family and whānau will often be responsible for carrying out daily activities to support their child and can face financial burdens if leaving paid work as a result of their

child's impairment. As children move through stages of growth and development they will also require additional assessments and intensive bursts of rehabilitation and support.

The Wilson Centre is well appointed which includes a classroom on site, self-contained flats for family and whānau and is co-located with a special needs school.

There is a close working relationship between Starship Hospital and the Wilson Centre. Wilson Centre staff work alongside acute clinicians to support an early rehabilitation plan which includes close contact with family and whānau. It was noted that a further improvement would be to have a daily review of children at Starship Hospital and/or a rehabilitation bed located at Starship Hospital.

Linkages with the spinal rehabilitation units are established which allows for good communication when determining whether a child with SCI would be better managed through an adult or children's service.

Staff from the Wilson Centre outlined several barriers to providing rehabilitation services for children with SCI:

- although offering a national service for rehabilitation, it is not well utilised by DHBs outside of Auckland. Average lengths of stay are likely to be 3-4 months for a child with paraplegia and greater than 6 months for tetraplegia. Where the cause is not injury related, it is unlikely DHBs will refer due to inter-district flow funding. There also seems to be issues with insufficient national funding from DSS<sup>14</sup> and debates as to whether admissions to the Wilson Centre for follow-up or preventative review are funded through personal health or DSS funding. This has also impacted on reduced use of the service.
- they always exceed their Ministry of Health volumes which creates funding pressures
- there is insufficient funding to offer a national outreach service which would be seen as ideal in that it supports a hub and spoke model where regional centres are well supported and up-skilled whilst the Wilson Centre remains the centre of expertise.
- there is insufficient funding to provide a range of web-based resources and information to assist other clinicians.
- although paediatricians work collegially there is not an established network of paediatricians providing rehabilitation services.
- there are no junior medical staff rotations through the Wilson Centre which limits the ability to provide early rehabilitation when a child may still require some acute care.
- staff at the Wilson Centre may need to navigate the different systems for obtaining equipment and supports for children where there are boundary issues between health and education.
- transitioning adolescents to adult services is a major problem because:
  - there are not general adult rehabilitation services with rehabilitation physicians to provide national coverage that they can be referred to. Where there are rehabilitation physicians they tend to work within a narrow scope, for example stroke services.

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<sup>14</sup> Currently capped at a number of days that is not based on demand for services.

- not all adolescents that would benefit from services through the ASRU are accepted as they don't meet referral criteria. This is particularly the case for people with spina bifida.
- general practitioners are usually ill equipped to work without the adolescent receiving specialist support due to the nature of the disability and sequelae.
- even where referrals can be made and accepted the adolescent is usually moving from a comprehensive interdisciplinary support system to a much smaller system of supports where there is an expectation of a higher level of autonomy by the adolescent who may struggle with decision making and feeling supported within this context.

It was also thought that children who are not referred to the Wilson Centre do not get the resources they need for regular small bouts of intensive rehabilitation.

### 3.3 Evidence

The evidential review provides a summary of the clinical practice guidelines (University of South Australia, 2012; University of South Australia, 2012a, 2012b). Please refer directly to these documents for this level of detail.

A key question asked in the project is 'what intensity of rehabilitation is best for recovery?' The evidence is insufficient in this area to make any conclusions about intensity. However in the meantime the UK and USA are moving to seven day rehabilitation and Scandinavia is using 4 to 6 hours a day, 6 days a week.

Stroke literature which might have some general applicability to rehabilitation in general, reports strong evidence for the benefits of higher rehabilitation intensity in both the post-acute and chronic phases after stroke. Greater amounts of rehabilitation (practice time) and greater training intensity, can improve functional outcomes for stroke survivors.

The Rehabilitation Workforce Service Forecast (Wong A, 2011) states New Zealand does not have a comprehensive rehabilitation system. Provision of services is considered fragmented and varies between regions. The Ministry of Health and ACC purchase components of rehabilitation that leads to varied and often inequitable services. The forecast report notes that a rehabilitation programme that supports clients from acute care through to returning to their communities and homes show improved outcomes. Although not specific to SCI, the report made a number of recommendations relevant to SCI. These include developing care coordination support following discharge, providing appropriate dosage intensity of rehabilitation treatment<sup>15</sup> and reviewing the alignment of services purchased by ACC, the Ministry of Health and DHBs to a more equitable and sustainable model.

The CARF Rehabilitation Standards Manual (CARF International, 2012) has established programme standards for a spinal cord system of care which describes a coordinated, case managed, integrated service for people with spinal cord dysfunction whether due to trauma or disease. The system includes

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<sup>15</sup> As noted there is scant evidence on this topic specific to SCI. However, the CARF report of New Zealand services recommended increasing the intensity of rehabilitation.

an inpatient and outpatient component. There are 29 programme standards which outlines requirements as minimum components for SCI rehabilitation services. The standards include protocols for clinical and functional aspects as well as criteria for admission, discharge and transition, multidisciplinary team membership and approach to rehabilitation, comprehensive assessments supported by diagnostics, counselling, education, annual reviews, follow-up, outcomes measurement, advisory services and linkages with research. These standards are widely used across Canada and America.

The United Kingdom (South of England Spinal Cord Injury Board, 2010) also has standards for patients requiring SCI care. There are 17 topic areas that cover the continuum of care, research, information management, communication and a person centred approach. The rehabilitation topic includes the need for a dedicated multidisciplinary team to meet individual needs, use of pathways, coordination and an individual goal planning programme.

A white paper (American Spinal Injury Association, 2012) was written to describe the resource necessary to provide competent care to people with SCI during initial acute rehabilitation and admission. The paper describes the need for an interdisciplinary team approach that addresses medical, physiologic, functional, psychological and social issues and has the patient and family/support people as central members of the team. The physician must develop treatment plans to prevent medical complications and be skilled at neurologic assessment noting that these skills are acquired with experience obtained from working regularly with people with SCI. The patient should have an assigned case manager who is usually a nurse or social worker. The paper outlines the various skill sets required by each professional group.

A recent Australian retrospective study of rehabilitation outcomes for people with spinal tumours found that people with SCI due to a tumour have the potential to benefit from a focused specialised SCI rehabilitation programme (Tan M. New P, 2012). The rehabilitation programme will optimise their outcomes but requires careful patient selection, modifying the focus of goals and maintaining a close relationship with treating oncologists and palliative care teams. The evidential review also support this with evidence sited from expert consensus guidelines.

The evidential review (Univeristy of South Australia, 2012) supports not having an arbitrary cut off that determines eligibility for either children's and adult services. The review also found the paediatric rehabilitation team should become involved at the acute phase of admission and that rehabilitation for children should be provided through coordinated networks to provide services as close to home as possible.

Evidence sought in relation to children's models of rehabilitation (University of South Australia, 2012b) found little evidence other than the NHS Clinical Advisory Group Paediatric Trauma report which recommends early engagement of a paediatric rehabilitation team, good coordination, equal access to rehabilitation as adults and specialist school services that support re-integration.

Comments from people who have experienced rehabilitation services in the spinal rehabilitation units were generally very positive (UMR Research, 2013). Comments from two mothers with children with

spina bifida were complementary about the level of support provided by health professionals they interacted with.

## SECTION 4: Current situation - living in the community

### Overview:

- This is about a person's whole of life – their basic needs, social and personal roles, personal and mental wellbeing, participation, medical needs and activities.
- Links with family / whānau, community friends and significant others are vital for wellbeing and quality of life.
- Carers (unpaid and paid) are a vital link in supporting quality of life, or not. People with SCI often experience significant barriers to access and participation in a range of aspects of living in the community.
- Transport is a major barrier to community, including employment, access.
- Pain management is an issue.
- Health and community support services frequently do not have enough SCI specific knowledge and can miss opportunities to prevent secondary complications.
- Home and community services have contractual rules that mean there are gaps in how they support people with SCI
- The issues of differences are very prevalent with community supports
- People can feel isolated when discharged from rehabilitation units especially where there is no on-going rehabilitation / habilitation programme established for them

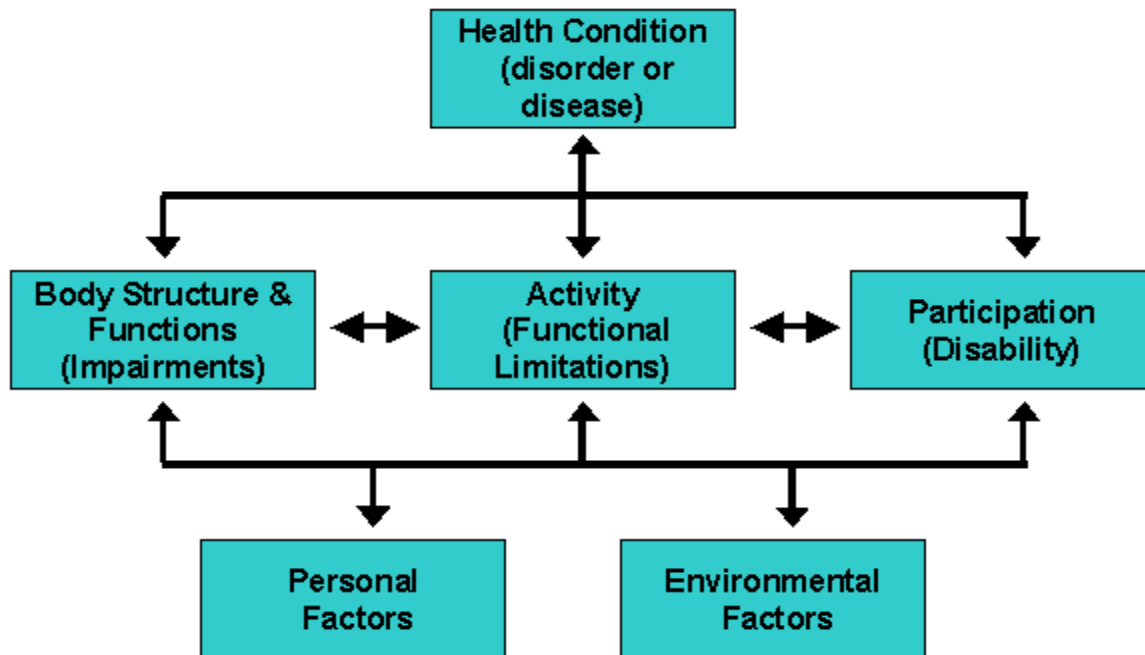
### Opportunities for Improvement:

- Mental wellbeing for the person and the family / whānau
- Practical support of family / whānau and paid carers.
- Up-skilling in SCI expertise in the community.
- Connecting the person with people (including health professionals) and resources available in their communities
- Providing rehabilitation services in the community.
- Prevention of secondary complications.
- Transport options.

People with SCI live in their community for life. The acute and inpatient rehabilitation phase is very important for setting up lifelong outcomes, however by far the majority of time is the rest of the person's life. The wellbeing and quality of life for people is paramount.

A useful way of framing all aspects of life in the community can be seen by using the International Classification of Functioning Model (ICF). A diagrammatic view of this is seen below.





Source: [www.who.int/classifications/icf/site/beginners/bg.pdf](http://www.who.int/classifications/icf/site/beginners/bg.pdf)

The following section is set out in six domains of life which can be loosely matched to and cover the ICF areas.

## 1 Domains of life by life phases

### Overview:

- Some needs remain constant over time and others change.
- Transport, housing and accessing community remain constant over time.
- There are challenges to life roles and relationships for the person, their family and whānau.
- Quality of carers is a significant issue for whole of life.

### Opportunities for improvement:

- Carer considerations.
- Support with housing and transport.

Through the reference group, focus groups and from the UMR research (UMR Research, 2013) we can see changes in need and experiences over time as people work on and adjust to their life post SCI, in the community. The following table is based on the domains of life as set out in the UMR report and includes detail from all inputs. The splits of 0 to 5 years, 5 to 15 year and 15 years plus are unilateral, therefore there will be some overlap at the margins as well as some individual varying situations, but provide for very useful themes at different parts of the life journey.

Note:

- the Consumer Perspectives Report (UMR Research, 2013) used the terms of 0 to 2 years, 2 to 15 years, and 15 years plus, however inputs from the reference group and focus groups have clearly said that for many the first five years is the term so the authors have chosen to use that as the guide
- the evidential review did not break the information down in this format but overall the themes are supported by the review.

Domain of Life	0 to 5 years	5 to 15 years	15 Years plus
<b>Basic needs (carers, housing, transport, money)</b>	<ul style="list-style-type: none"> <li>• Major transition to home issues including adjustment challenges and finding a routine</li> <li>• Delays in supports or physical adaptations very stressful</li> <li>• Housing issues</li> <li>• Transport issues</li> <li>• Issues with quality of carers</li> <li>• The relationships with ACC or MoH (health provider) very important</li> <li>• Financial uncertainty</li> <li>• Confusing systems and process and not knowing where to get what</li> <li>• Need more practical information related to individual circumstances</li> <li>• Need on-going and frequent emotional and physical follow ups</li> </ul>	<ul style="list-style-type: none"> <li>• In a routine now</li> <li>• Housing issues continue particularly for people in rental accommodation</li> <li>• Transport issues continue</li> <li>• Issues with quality of carers continue</li> </ul>	<ul style="list-style-type: none"> <li>• Overall people are more settled and have found a way of life / niche</li> <li>• Housing issues continue for some, especially costs of housing on reduced income and those in rental accommodation</li> <li>• Transport issues continue</li> <li>• Issues with quality of carers continue</li> <li>• Need for equipment and care hours can increase due to issues relating to aging, however income may decrease when retirement age is reached</li> <li>• Family carers may also be facing issues related to ageing</li> </ul>
<b>Social roles (partners, family, friends, peers)</b>	<ul style="list-style-type: none"> <li>• Huge relationship challenges and adjustments – partners<sup>16</sup>, family, friends and employers</li> <li>• Emotional challenges e.g. feelings of guilt or</li> </ul>	<ul style="list-style-type: none"> <li>• Marriage / relationship challenges and breakdowns</li> <li>• Frustration at focus on individual and not in the context of</li> </ul>	<ul style="list-style-type: none"> <li>• Gap in supports for relationships and partners continues</li> <li>• Frustration at focus on individual and not in the context of their family / whānau or</li> </ul>

<sup>16</sup> Partners can include spouses, civil union partners, boyfriend / girlfriend and other significant intimate relationships

Domain of Life	0 to 5 years	5 to 15 years	15 Years plus
	frustration at seeing what their partner or other family has to adjust to as well (roles, intimacy, carer role, household activities etc.) <ul style="list-style-type: none"> <li>Financial pressures if income situation has changed</li> <li>Partners and children need support too, but cannot get it</li> <li>Transport issues impact on social roles</li> <li>Family carers acquire skills to manage</li> </ul>	their family / whānau or life <ul style="list-style-type: none"> <li>Transport issues remain</li> <li>Partners and children need support too, but cannot get it</li> <li>Challenges for some life roles e.g. being a grandparent</li> </ul>	life <ul style="list-style-type: none"> <li>Transport issues remain</li> </ul>
<b>Personal (mental wellbeing, intimacy/ sex, having children)</b>	<ul style="list-style-type: none"> <li>Mental health is fragile</li> <li>Sexual intimacy changes can be challenging (personally and for relationships)</li> </ul>	<ul style="list-style-type: none"> <li>Reality sets in and grieving for loss of former life</li> <li>Pain issues</li> <li>Bowel, bladder and skin issues which cumulatively can be major challenge</li> <li>When in place counselling and natural supports are a major source of help and support</li> <li>Family need counselling access also</li> </ul>	<ul style="list-style-type: none"> <li>More acceptance and focussing on staying positive</li> </ul>
<b>Participation (employment, volunteering, education, house care)</b>	<ul style="list-style-type: none"> <li>Return to work can be an issue for a variety of reasons including lack of workplace readiness (e.g. physical, education for employer and colleagues)</li> <li>Transport is a barrier to participation</li> </ul>	<ul style="list-style-type: none"> <li>Many of those back working are part time and it is tiring but important</li> <li>Volunteer activity can be important for some and provides access to community participation and adds to quality of life</li> <li>School is important for children</li> </ul>	<ul style="list-style-type: none"> <li>Those in work report more feeling of being positive, quality of life and are more financially secure</li> <li>Transport issues remain</li> </ul>

Domain of Life	0 to 5 years	5 to 15 years	15 Years plus
		<ul style="list-style-type: none"> <li>Transport issues remain</li> </ul>	
<b>Medical (personal care, bowel/ bladder, pressure sores/ skin irritations, pain)</b>	<ul style="list-style-type: none"> <li>Major trial and error issues: personal and by carers, as well as medical staff if need to attend hospital</li> <li>Need more information and guidance</li> <li>Need higher quality carers (and to pay them more)</li> </ul>	<ul style="list-style-type: none"> <li>Personal cares are still a burden</li> <li>Don't always have access to adequate supports, cares or supplies (consumables)</li> <li>Pain management is an issue</li> </ul>	<ul style="list-style-type: none"> <li>More focus on looking after self and preventative actions</li> </ul>
<b>Activities (sport/ exercise, cultural/ church, recreation)</b>	<ul style="list-style-type: none"> <li>Typically overcoming challenges of the new life and not yet accessing other activities</li> </ul>	<ul style="list-style-type: none"> <li>Need a variety of activities to keep active</li> <li>Transport is a barrier to participation</li> </ul>	<ul style="list-style-type: none"> <li>More activities in place</li> </ul>

The most common and enduring issues reported in the Consumer Perspectives Report (UMR Research, 2013) are:

1. Lack of access to quality carers (i.e. knowledge of SCI, respect for the person and their situation) which can reduce independence, reduce participation and increase risks and causes of secondary complications
2. Lack of access to counselling or emotional support for the person in the early years and for the partner and family up to the 15 year mark. There were many examples of the enormous strain SCI can put on relationships.
3. Pain management
4. Housing and;
5. Transport (linked to several domains of life, reported as much more an issue for health funded people). The importance of accessible transport and the enormity of independence offered by having a car was seen as one of the single most important things that can support a person with SCI. Difficulties in parenting and maintaining relationships with children once they left home was also commonly linked to transport difficulties.

The Consumer Perspectives Report (UMR Research, 2013) also noted people often felt “dumped” or alone when transitioning home from the spinal rehabilitation unit.

In addition at all phases of living in the community, reports of differences between what people supported by ACC can receive compared to Health is seen as inequitable and leading to poorer health and wellbeing outcomes for those in Health.

## 2 Primary Care and Community Services

### **Overview:**

- People with SCI access on average more primary and community care than others.
- There is a gap in SCI knowledge in primary and community services and this can cause significant secondary complications.

### **Opportunities for improvement:**

- SCI knowledge in primary and community services.
- Defining the role of primary healthcare in SCI and how this should interface with spinal rehabilitation unit monitoring, follow-up and advisory services.

People with SCI living in the community access a range of primary and community health services. There are differences between the level of support and services dependent on the mechanism of funding.

The Cultural Perspectives Report (Accident Compensation Corporation, 2012a) noted that for people outside the mainstream culture, difficulties navigating through the fragmented range of services and service providers in the community could be a barrier to access.

### **2.1 Home and Community Support services (HCSS)**

There are differing levels of support available to people with SCI based on an assessment of need. The level of support provided through funded services impacts on families and whānau and their life roles.

A common issue for people with SCI is the competence of staff providing these services.

Three major issues were identified by the reference group and Consumer Perspectives Research (UMR Research, 2013) with the current provision of HCSS:

- staff generally lack specific knowledge of SCI (particularly skin, bowel, bladder management), including their role in preventing avoidable secondary complications.
- some suppliers have rules or policies that prevent the effective delivery of services. For example some carers are not able to provide bowel cares which puts people at risk.
- the recent change in the procurement of HCSS by ACC has left some people feeling dissatisfied as there is a perception this has eroded what SCI specialist knowledge there may have been in the sector.

Examples were provided where people have been admitted to hospital with pressure areas that had been initially undetected by their HCSS provider.

### **2.2 Community based rehabilitation**

There are a wide range of community based rehabilitation services available to ACC clients. These may include counselling and social work.

There are no community based rehabilitation services provided to health funded people other than those delivered through the DHB Community Services which are generally limited to a few appointments.

### **2.3 Community based assessment services**

Health funded people may receive assessment services through the Needs Assessment Coordination Service (NASC). In addition, there are specialist assessment services available for housing and vehicle modifications; wheelchairs and seating; and communication assistive technology.

ACC clients receive a range of social and vocational assessment services through contracted suppliers.

### **2.4 Primary Healthcare**

Reference group members were concerned that in primary healthcare there is little or no understanding of SCI as it is very specialised and the number of patients any on practice or general practitioner may have would be extremely low. The group recommended caution in suggesting a role for primary healthcare as members of the group could provide numerous examples of major problems that were undetected by general practitioners.

It was suggested that when people are diagnosed with a SCI that they are directed to receive primary healthcare services from general practitioners or practices that have a special interest in SCI, or alternatively that specific information is then given to these general practitioners by the spinal rehabilitation units as to ensure they know what to look out for and how to handle situations as they arise.

### **2.5 Evidence**

There are various models of primary healthcare internationally where primary health care is either provided by rehabilitation physicians or general practitioners. High duplication in services has been reported in Canada, the US and UK. High consumer satisfaction has been reported for both models (University of South Australia, 2012).

There is evidence that where staff have specific SCI knowledge and expertise then avoidable secondary complications, especially with skin, bladder and bowel, can be prevented (University of South Australia, 2012b).

The Consumer Perspectives Report (UMR Research, 2013) also noted the need for supports to be tailored to the individual physical and emotional needs of clients.

The Consumer Perspectives Report (UMR Research, 2013) had many examples of where a family member is also the carer, and how being a partner or family member with that responsibility causes a lot of stress. Many reported not being able to work full time due to caring responsibilities.

## 3 Outpatient and Outreach

### Overview:

- Outpatient and outreach services are important for wellness and prevention of other issues.
- There are a variety of services occurring currently.
- Not all people with SCI are linked in to outpatient or outreach opportunities.
- Funding is limited for a full outreach service for both children and adults.

### Opportunities for improvement:

- Data base to improve follow-up opportunities.
- Extending the role for outpatient and outreach services, particularly for children.

### 3.1 Adults

ASRU and BSU provide outpatient and outreach services. In addition both have telephone consultations, either planned (scheduled) or ad hoc as people phone in. Once people are discharged, BSU bring people in for a one-off, three day inpatient multidisciplinary reassessment approximately six months following initial discharge and as required if there are complex issues to be resolved. ASRU follow up interdisciplinary team assessments are done at an hour and a half outpatient clinic appointment either at ASRU or at the outreach clinics outside of Auckland.

ASRU and BSU proactively follow-up people with SCI to prevent and manage secondary complications, prevent avoidable hospitalisations, assist in managing issues related to ageing and to promote independence and participation in the community. They often make referrals to other health professionals and provide recommendations to general practitioners and others involved in supporting a person with SCI. On-going education to the person and their family also occurs through these follow-up appointments.

Both ARSU and BSU noted that funding is insufficient for these follow-up clinics whether in an outpatient or outreach setting as a multidisciplinary team is required. There are also issues of people being lost to follow-up and an inability to proactively re-call people who may not have been involved with the service but are ageing with SCI and would benefit from the opportunity of being seen.

A few participants involved in the UMR consumer perspectives research (UMR Research, 2013) reported that they had not been assessed for decades.

People reported liking the contact they had when they went back to the units for reassessment. They found it valuable for information sharing.

#### 3.1.1 Auckland Spinal Rehabilitation Unit (ASRU)

Post discharge ASRU have a routine of:

- 2 weeks post discharge a telephone follow up from either the clinical nurse specialist or another IDT member.
- 6 months post discharge a team assessment at ASRU or an outreach clinic outside of Auckland

- 18 months post discharge a team assessment at ASRU or an outreach clinic outside of Auckland
- Every 3 to 5 years IDT team assessment
- specialist medical clinics (face to face) as required e.g. spasticity, bladder, bowel, medical concerns related to SCI.
- where required a three day inpatient team reassessment based on complexity of need (very rarely utilised as most people are able to be assessed in a clinic type environment in Auckland or on outreach).
- Remote Assessment mailed to patients on years when a team assessment is not scheduled to assess for new or chronic SCI related (including psychosocial) concerns. Follow up phone call with prompted script to ensure appropriate triage to ASRU providers or community providers for addressing raised concerns.
- Team assessments and/or clinical nurse specialist home visits occur when the patient is unable to leave the home and requires ASRU specialist input or follow up.

ASRU run approximately 15 outreach clinics of two to three days duration per year. ASRU has a dedicated outpatient coordinator. In the 2012 calendar year 321 patients received outreach services.

An Orthopaedic Surgeon from Canterbury DHB visits ASRU twice per annum to undertake assessments and follow up clinics for forearm tendon transfers and shoulder surgery.

### 3.1.2 Burwood Spinal Unit (BSU)

BSU run approximately 18-20 outreach clinics per year across its catchment area. The role of the outreach clinics are to assess the patient and make recommendations to the GP or ACC case manager to progress. Primary and community care staff are invited to join the clinic for their patients. Local reassessments are held at the BSU on an outpatient basis.

Remote consultation by telephone or mail is undertaken annually.

For newly discharge people, there is a three day inpatient reassessment at six months following discharge.

There are also outpatient clinics specific to urology, upper limb, fertility, bowel, sexual health and spasticity available to people based on need.

A review has been recently been completed which is looking at the interface between the service and community including outpatients. The second phase of this project is being undertaken at the time of this report, looking at turning those recommendations in to practice.

## 3.2 Paediatrics

The Wilson Centre for children provides an outpatient service but is unable to offer a full outreach service due to insufficient funding. (Refer to section 4.3.2).

Paediatricians and paediatric surgeons at Starship Hospital commented that a multidisciplinary outpatient service would provide a more holistic and integrated approach by the Starship Hospital and



Wilson Centre team would be beneficial. Coordination and funding that acknowledges the resources to achieve this would be required.

Where children are located outside of Auckland, they are most likely to attend outpatient clinics at their local DHB which may or may not have the right level of expertise for specialised SCI. It was noted that emerging bladder issues are often missed where the paediatrician does not have a special interest in SCI.

It was widely thought by paediatricians and paediatric surgeons interviewed that as part of a hub and spoke model an ideal outreach service would support up-skilling health professionals locally through joint clinics and resources such as guidelines developed for on-going monitoring. In order to maximise the value of an outreach service, a multidisciplinary team would run attend the outreach clinics. Health professionals working outside of the specialist rehabilitation services also need good access to specialised advice that is nationally consistent. To achieve a sustainable hub and spoke model, it would need to be formalised and appropriately funded.

### 3.3 Evidence

The evidence is variable in terms of frequency required for follow up. But it is noted that access to specialist services such as outpatient or outreach is desirable.

It was found that ACC clients tended to be more likely to have their needs reassessed through outpatient and outreach services than health funded people (UMR Research, 2013).

The Consumer Perspectives Report (UMR Research, 2013) noted:

*“This study also shows that long-term follow up with SCI persons is important. This was necessary so SCI persons did not feel abandoned in the community and did not miss out on opportunities that could improve their quality of life. Also, as they aged, needs changed, and they were keen for ongoing reassessments to help proactively identify and manage emerging issues”, page 18.*

## 4 Employment post SCI

### Overview

- In general Westernised adults regard work (employment) as an integral part of life.
- Work can be full time or part time and for some voluntary work is as beneficial as paid employment.
- There are various benefits of work such as social connections, being occupied, sense of worth and earning a living.
- There are many complex barriers and personal factors to gaining or re-entering work such as motivation, physical issues such as pain, fatigue and the environment, attitudes and stigma. Concern regarding loss of benefit or supports can also be a barrier.
- Personal need, perception of benefit of work and other life pressures that may impact on work.
- Enablers to gaining work include having hope, being supported and retaining a commitment to

work.

- Ensuring supports and accessible environments are in place is important.
- Not all people with SCI have access to supports to assist with return to or accessing work.
- Lack of transport, language barriers, cultural issues, multi-generational unemployment and non-modified workplaces are significant barriers, especially for health funded people.
- There are discrepancies in compensation levels post SCI, before work, for those on ACC and those who are not.

**Opportunities for improvement**

- Consistent access to quality vocational supports for return to work or begin to work could be put in place.
- More work could occur with employers to improve their knowledge of SCI.
- Barriers to accessible and reliable transport to get to and from employment could be addressed.
- Education for employers is variable and could be improved.
- Being able to return to work with supports from employers, vocational rehabilitation people, colleagues and / or family and friends.

Access to supports for entering or return to work is varied in New Zealand, particularly between ACC and Health funded people. For those with ACC they have the support of case managers as well as contracted vocational rehabilitation services, whereas in Health there is not a similar structure. This prevents continuity of service for people on the health funded system. Some people may have some supports via MSD if they are on certain benefits.

There is some anecdotal evidence from the Advisory Groups to the SCI project that for ACC clients there is variation between the quality of vocational rehabilitation supports and further differences between urban and rural.

The New Zealand Spinal Trust operates the Kaleidoscope Vocational Rehabilitation Programme out of the BSU and Auckland Regional Spinal Unit. Kaleidoscope services are contracted to Canterbury, greater Auckland, the lower half of the South Island and areas within the lower half of the North Island.

Kaleidoscope was initiated in 2003 when there was a return to work rate of 12.3%. Kaleidoscope figures today report a return to work rate of 56% with a further 11% in tertiary education<sup>17</sup>. Kaleidoscope is the only specialist SCI Vocational Rehabilitation Programme in New Zealand

The reality of time personal cares take in the mornings, or during the day, can impact on when people can work. Therefore those who are in more successful employment relationships report having a more flexible workplace approach supported by their employer.

Some people choose not to work as the strain and fatigue of working can mean detrimental and long term poor health outcomes. People undertaking voluntary or community work also report the same benefits as employment, other than income.

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<sup>17</sup> Information provided by the NZ Spinal Trust

Some people interviewed by UMR (UMR Research, 2013) felt that returning to work was difficult as they felt ACC or MSD might cut their supports and financial income and then if the work did not work out then they would lose everything. The other disincentive seen as starting work, particularly for ACC clients, is that all other supports will be cut off, yet in reality they are not mutually exclusive. For example, on-going physiotherapy, contact from the ACC case manager or others.

Access to reliable and accessible transport options is a barrier to employment as well.

## **4.1 Evidence**

Employment or work can be paid full time or part time, or for some, unpaid activity.

Employment is shown as having positive benefits for people in terms of quality of life measures, being socially connected, feelings of hope and purpose, having a sense of worth and being occupied. In addition, although not top of the list, is earning a living (University of South Australia, 2012b).

There are a complex set of enablers and barriers, interrelated, that may motivate or limit people to access work.

Enablers to accessing employment include having physical and psychosocial supports, including having support from others to want to be in employment. Support can be from one or many sources such as family and friends, employer, colleagues, ACC or vocational rehabilitation services.

The Consumer Perspectives Report (UMR Research, 2013) found ACC have supports in place to support employment including paying for significant modifications of the work environment where these were required.

One study (Dickson B. Sinnott KA. Nunnerley J. Hay-Smith J, 2012) referred to those not being employed as having an emphasis on their health issues and concerns, which were seen as a barrier to accessing work. The statement is supported in the Consumer Perspectives Report (UMR Research, 2013).

Participants were struggling to find work that would be suitable to their condition. Many had tried going back to work, but it had been difficult to sustain and they were either trying to find new opportunities or deciding if they could work at all. A few were also frustrated by a lack of proactive support from vocational agencies to help them get back into work.

Barriers to accessing work include staying motivated, stigma, pain and feeling unsupported. There are also environmental barriers. People need to feel that the work in question is purposeful to them and provides enough benefits to pursue (University of South Australia, 2012b).

In Consumer Perspectives Report (UMR Research, 2013) many reported looking after themselves and their health was a barrier to being able to work full time.

## **5 Peer Support**

**Overview**

- There is an increasing body of evidence on the importance of peer supports for improved outcomes.
- Peer support definitions can include both paid and unpaid roles, however it needs to be clear they have different functions and responsibilities.
- Peer support can occur in a myriad of ways and at all stages in the life of a person with SCI.
- There is use of social media and e-options for peer support through the New Zealand Spinal Trust and TASC which both have face-book groups.

**Opportunities for improvement**

- Access to peers for support is not a formalised process.
- Use of social media and e-options for peer support could be extended.

The following section is abridged and summarised from a paper by Dyson Consulting Group (Dyson M, 2012). In addition some aspects from the reference group and focus groups as well aspects from the UMR consumer perspectives report (UMR Research, 2013) have been added.

## 5.1 Unpaid (Voluntary) Peer Support

There is little literature on peer support that would meet statistical and methodological requirements for evidence based health care. However there is a lot of material on the importance of peer support and how it can benefit the recovery and living of those with a SCI.

It is noted that peer support is important to support the transition from rehabilitation to living in the community especially for:

- practical solutions or strategies for activities of daily life
- preventing isolation and loneliness.
- psychosocial supports (e.g. preventing depression).
- sexuality and personal and intimate relationships.
- family supports.

Peer support is also valuable for:

- support to participate in valued life roles e.g. Family roles and friends.
- support to access education and employment.
- reduction of both physical and social barriers to participation.
- assisting to access primary health care and support.

There is a need for organisations to have a common understanding of what peer support is. Themes that characterise peer support are:

- a paid and voluntary system of giving and receiving of assistance, encouragement and social-emotional support;
- addressing common problems or shared concerns;
- provided by an equal (someone in a similar situation, preferably with lived experience);

- a relationship based on respect, shared responsibility, and mutual agreement of what is helpful; and,
- supporting autonomy and community rather than a professionalised role.

Conceptual theories regarding peer support consider the way people take on new attitudes and form new behaviours and have been described as emphasizing four themes:

- the importance of learning from others who have had 'lived experience' – be that a peer with a similar level SCI or someone who is a family member of someone with an SCI
- the importance of learning by observing others who are respected by or somehow similar to the observers – this is an important point in terms of a peer who the person can relate to;
- the impact of beliefs, attitudes, intentions, self-efficacy, skills, and social norms on the adoption of any given behaviour; and,
- the recognition that people in like situations themselves can play a useful role in promoting positive behaviours among their peers.

For those considering the development and implementation of peer support programmes, success is based on having mentors who are similar to, and respected by the peer group.

Regardless of the mechanism by which support is delivered, the actual provision of peer support comprises of a number of specific, common attributes and notes three critical attributes; emotional support, information support and appraisal support (also known as affirmational support) emerging repeatedly in the descriptors of peer interventions.

Various models of peer support can include:

- face to face or one on one peer support.
- on-line support. This includes the growing use of social media including text, Facebook, chat rooms etc.
- group support.
- self-help groups.
- telephone support
- provision of information which enables people with SCI and their families to gain knowledge about SCI and learn to become more confident and empowered to take control of their own lives.

All input groups and evidence for this project have noted the importance of peer supports and how they assist with the day to day as well as aspirational and hope aspects for a person.

In addition there has been some input and extensive anecdotal evidence from families about the importance for them in linking with their 'peers', as in other families. This can help with problem resolution, relationship tools and feelings of acceptance and others understanding their situation.

However it is also important to note that people with SCI have also said that there is a time and place for peer support and that they do not always need or want that. Generally people found peer support more

important early after diagnosis, rather than later as illustrated in the Consumer Perspectives Report (UMR Research, 2013). The stages of peer support are as follows:

- Acute and inpatient rehabilitation phase: support & service
- Post discharge/Early years: support & service. Recruit mentors
- Middle Years: Maintain connection through meaningful, regular but infrequent communications.
- Later Years: support & service

## 5.2 Paid Model of Peer Support

BSU Transitional Rehabilitation Programme has a role called Independent Living Coach (ILC) which is a paid peer support role. This began in 2009. In a 2010 report (Sinnott K.A, 2010) on the role it was stated as:

*“People with SCI unanimously describe the ILC role with words that include ‘natural’, ‘profoundly useful’ and ‘positively influential’”.*

A quote from the Transitionz review (Sinnott K.A, 2010) reinforced the benefits of peer support:

*“You get an insight by being around those guys... into what’s achievable if you want to stick at it rather than being told by someone who’s walking around freely that you should be able to do this and that, you just actually see him out there doing it.”Page 8.*

From the 2008 proposal to ACC for the Burwood Transitionz programme (Burwood Academy of Independent Living, 2008) it was noted that although also a peer, when being in a paid position the following skills are needed:

*“The IL Coaching position is a critical component of the IL programme and the individual must be carefully selected to maximise the benefits of the intervention. The individual must be themselves highly independent and organised. They must be a skilled listener who can identify strongly with the emotions and experiences of the IL students. They must have a background in counselling techniques, specifically motivational interviewing and they must be able to work with people from all demographic diversities”, page 13.*

The New Zealand Spinal Trust operates the ‘Connecting People – Peer & Family Support’ Programme initiated in 2009. This service provides peer & family Support throughout the continuum of care for people with a Spinal Cord Impairment in the Burwood Hospital catchment.

Services are provided from early intervention inpatient rehabilitation, discharge, early community, long term community and re-connecting clients.

This programme has been funded solely by the New Zealand Spinal Trust since its inception.

The Association of Spinal Concerns (TASC) is a non-profit organisation providing a buddy system for people with spinal cord impairment. The buddy system has been operating successfully for several years with coordinators visiting every new in-patient in the Auckland Regional Spinal Unit to explain

what the system is about. For those interested in the system TASC connects the person with a buddy who can visit the person several times whilst in the unit and if possible again following discharge. Spouses, parents, children and other family members can also ask for a buddy.

TASC also runs 'Back on Track' meetings twice a month at the Auckland Regional Spinal Unit. Guest speakers share their experience on a wide range of subjects.

### 5.3 Evidence

Throughout the input gathering phase for the SCI Initiative and Implementation Plan Project the immense value of peer supports, in a variety of ways at various stages of the person's experience of SCI, has repeatedly arisen. There has been much anecdotal input to the SCI Initiative and Implementation Plan development process of the importance and success of peer support. There are a variety of ways peer support can be undertaken from ad hoc through to organised, and may be paid and unpaid. There are a variety of opinions on whether paid peers can be classed as "peer support" so terminology needs to be defined. What is not in dispute is the benefit of peers being available and involved, whether paid or unpaid, as long as the person with SCI wants them in their life and there is a match for need and personality (which may include a range or mix of age, stage, cultural, life experience, and other life experience or understandings).

Currently there are three paid approaches to peer support which are via;

- The BSU for Transitional Rehabilitation Programme Life Coaches.
- The New Zealand Spinal Trust
- TASC (The Association of Spinal Concerns)

There is increasing use of social media for people with SCI to seek and receive solutions to everyday problems as well as medical concerns. Both the New Zealand Spinal Trust and TASC operate a forum style Facebook group. The New Zealand Spinal Trust has in excess of 350 members.

It has been demonstrated in these groups, and those mirrored in Australian Peer Support Networks that peers have become more powerful as use quickly enables people to link in with others and be in touch more readily. It also allows for some "group" discussion on any particular issue including those that are incredibly sensitive to those without an SCI.

## 6 Compulsory Education

### Overview

- Schools vary in how they accept and support children with SCI.
- Families feel like they have to fight for any supports and don't have the right information.
- Working across different funding streams and knowing what was available is very difficult for families.

**Opportunities for improvement**

- Coordination and easy to access information.

For younger people (can be up to age 21 years) with SCI school is an important part of their life in the community. As previously noted the Ministry of Education via Special Education can fund additional supports and facility modifications to schools to enable a child or youth with SCI to access the curriculum.

However families report that getting access to these supports or modifications can be extremely difficult and not timely. Families reported wanting a coordination or “umbrella” organisation so they could be sure they were accessing all they are entitled to and knew where to go to get information and support, as well as advocacy, from across a range of funding streams (non ACC).

Many families felt that they didn’t get all the information they needed to make informed decisions in a timely manner.

Both the advisory groups and the Consumer Perspectives Report (UMR Research, 2013) noted there is variance in schools and how they work with children and families with disabilities. Some are more inclusive than others.

## 7 Prevention: Follow up, reassessment, readmission

**Overview**

- Although there is evidence on the benefits of health reviews, there is variable to no evidence on the frequency of reviews and monitoring / health surveillance, but better evidence for some than others.
- Overall it leads to a conclusion that review type and frequency are important and should be individualised as risk factors can vary by person and circumstances.
- There is no conclusion as to the model of review that is best, but clear statements on the fact that people with SCI living in the community access primary care more than others and that it is advantageous if primary care understand red flags for issues for people with SCI and what to do about it.

**Opportunities for improvement**

- An agreed consistently coordinated planned review programme could be put in place for New Zealand.
- Improving quality of life thorough preventing secondary issues can be improved.

Current review and monitoring practice in New Zealand is variable, does not include all people with a SCI living in the community and utilises a range of methods. For example, monitoring may occur through outpatients therapy services, outpatient spinal rehabilitation services through the two spinal rehabilitation units, inpatients at specialist rehabilitation units (BSU mainly with few at ASRU), GP, specialist spinal rehabilitation unit outreach and telephone advice. There is consensus from the



reference group and advisory groups that a more structured consistent review or surveillance programme is needed in New Zealand and is beneficial in improving quality of life, overall health outcomes and in preventing secondary complications with avoidable health interventions. ASRU and BSU have a structured review timetable. Priority is given to those with urgent or current SCI related concerns.

Wheelchair and seating assessments and reassessments occur in the community in addition to the above. For ACC these are by contracted providers and for health funded people by either a DHB allied health team or contracts with specialised assessor services.

The first assessment begins while the person is still in specialist rehabilitation. For outpatient reassessments for ACC clients, the ACC case manager determines the frequency, albeit part influenced by the specialist assessor recommendation, which may or may not be adopted. This is seen by some assessors and clients to be problematic, especially where there are changing needs. Whereas, for health funded people, the specialist assessor determines the frequency of reassessment. Where wheelchair and seating assessments are undertaken for health funded people that these may be the trigger for other assessments.

Conversely for ACC clients once reassessments have occurred they are more likely to get the equipment and seating they need than health funded people, where there is more budget prioritisation and rules around eligibility.

Frequency can be both with planned follow up and / or on an as needed basis, and like any health screening programme, should be voluntary for people to choose to participate in, or not.

It is reported by members of the reference group and focus groups, that without a national database it will be impossible to ensure all people with SCI living in the community can be offered the opportunity to follow up and advice, with a preventative focus for better health and quality of life outcomes.

The Pacific peoples focus group conducted as part of the Consumer Perspectives research found that those who did not receive follow-up care were admitted to hospital fairly frequently due to pressure areas. This was seen as an opportunity to re-connect and receive follow-up care.

There are a variety of opinions on when follow up or review should happen. A common opinion by members of the reference group and focus groups, as well as in the evidential review, is that in the first two to five years post discharge there is a need to see the person regularly for follow up. The rationale is that post SCI is a time of adaption and a changing time and people need more support and information. From 5-15 years would be individualised timeframes with upper limits, for example contact made no less than every three years. Post 15 years there is more support for annual contact.

There was strong support from the reference group that a 0800 number or web-based information service that provided immediate advice would be helpful.

As noted in the ageing with SCI section there is a need for more proactive work re preventing SCI related issues with those that are ageing.

## 7.1 Evidence

A question asked in the evidence review related to the evidence for frequency and type of review or monitoring and the outcome for the person with SCI, for proactive health surveillance.

There was little evidence to determine what type, model or frequency of review was best or if improved outcomes did ensue. There were four models identified (University of South Australia, 2012b):

1. GP and then referral to secondary
2. Specialist management via specialist centre with less of a role for the GP
3. Specialist outreach teams
4. Tele-health.

There is no evidence as to which or how many of these models provide for better outcomes. The evidence does note that people with SCI (as are many people living with long term conditions) are at greater risk of various complications (e.g. respiratory, cardiovascular, diabetes, stroke, urinary, bowel, suicide etc.) and that proactive review may assist with preventing some of these and increasing quality of life and community participation.

The evidence also notes that people with SCI are higher users of primary care and that mainly people are happy with their GP care, even when acknowledging they may not have the specialist SCI expertise needed. One option raised by the reference group, focus group and in the evidential review is giving and educating GPs on “red flags” for people with SCI e.g. 3 or more urinary tract episodes within a year, and what to do, where to refer.

There is comment, but without evidence, that frequency of review should be individual based but not left for periods of longer than three years (University of South Australia, 2012b). The paper then went on to list specific health conditions that might require monitoring and made comment on these. This is summarised below.

Health Consideration	Comment
1. Cardiovascular	<ul style="list-style-type: none"><li>• Suggested annual monitoring yet there is no consensus on this</li></ul>
2. Respiratory	<ul style="list-style-type: none"><li>• Major cause of morbidity and mortality so needs active lifetime management</li><li>• Some evidence on the benefits of physical training but ideal training regimes are not identified</li></ul>
3. Urological health	<ul style="list-style-type: none"><li>• Strong evidence for urological follow up; less clarity on frequency</li><li>• However an annual review appears to be the minimum with more frequent reviews in the first year</li><li>• No New Zealand consensus on the types of screening required; NZ practice is generally consistent with UK consortium consensus.</li></ul>
4. Neurogenic bowel	<ul style="list-style-type: none"><li>• Major source of morbidity in people with SCI</li><li>• Therefore evident that the bowel requires regular long term management</li></ul>

Health Consideration	Comment
management	<p>and review; No evidence on frequency</p> <ul style="list-style-type: none"> <li>• There is evidence that a multi-faceted management regime is important e.g. diet, medications, fluid intake, evacuation techniques and schedules</li> </ul>
5. Skin and pressure care	<ul style="list-style-type: none"> <li>• Significant negative consequences for people who develop pressure ulcers in terms of general physical health, socialisation, personal control, financial status and health care costs</li> <li>• There is evidence that strategies for pressure ulcer prevention can be effective and strategies must be individualised due to varying risk factors</li> <li>• No evidence on frequency</li> </ul>
6. Autonomic dysreflexia prevention	<ul style="list-style-type: none"> <li>• Autonomic dysreflexia is a life threatening emergency</li> <li>• There is some evidence of prevention of autonomic dysreflexia</li> </ul>
7. Physical activity for the prevention and management of secondary conditions	<ul style="list-style-type: none"> <li>• Strong evidence that physical activity can improve functional and physical performance, subjective well-being (Quality of life, mental wellbeing), cardiovascular health factors, respiratory health, and body composition, muscle strength, aerobic capacity</li> <li>• There is little evidence describing effective exercise parameters</li> </ul>
8. Bone health	<ul style="list-style-type: none"> <li>• While there is strong evidence for the importance of preventative bone health measures, especially early after SCI, the evidence of the effectiveness of preventative pharmacology is limited</li> <li>• There is some evidence for the use of Alendronate, Calcium (one RCT) and Vitamin D (one RCT) to treat bone loss following SCI</li> <li>• There is a lack of evidence to support non-pharmacological interventions for either prevention or treatment of bone loss after SCI</li> </ul>
9. Pain	<ul style="list-style-type: none"> <li>• Pain is a frequent complication of traumatic spinal cord injury and is often reported as the most important factor affecting quality of life</li> <li>• The evidence base for non-pharmacological pain management is variable</li> <li>• Several pharmaceutical agents have strong evidence to support their use</li> <li>• There is very little evidence to support surgical interventions</li> <li>• No recommendations were found for the frequency or mode of pain management review</li> </ul>
10. Heterotopic Ossification	<ul style="list-style-type: none"> <li>• Excess bone formation at abnormal sites on bone</li> <li>• There is strong evidence that pharmacological interventions commenced early after injury can prevent heterotopic ossification</li> <li>• There is less evidence that once HO has developed its progression may be slowed by strategies</li> </ul>
11. Mental health	<ul style="list-style-type: none"> <li>• Reviews reported that Cognitive Behavioural Therapy was an effective intervention for depression, anxiety, adjustment, coping, assertiveness, quality of life, self-efficacy, mood and chronic pain following SCI</li> </ul>

Health Consideration	Comment
12. Sexual reproductive health	<ul style="list-style-type: none"> <li>• Little and poor evidence on this topic</li> </ul>
13. Spinal deformity in paediatric and adolescent people with SCI	<ul style="list-style-type: none"> <li>• Satisfactory evidence to recommend that children should be monitored for the development of scoliosis and actively managed if this occurs</li> <li>• Children with traumatic spinal injuries are at particular risk of spinal deformity at the time of the adolescent growth spurt, while children with spina bifida may develop scoliosis at any age up to 15yrs.</li> </ul>

No studies were found that compared the effectiveness of different models. However proactive involvement in health surveillance has been shown to reduce complications, prevent rehospitalisation and improve community participation as well as quality of life for people with chronic conditions (Engel S. Leong D, 2008).

The NSW State Spinal Injury Service Guideline (Engel S. Leong D, 2008) makes several recommendations for a comprehensive program of health review and monitoring. This includes a review programme that sets out what monitoring should occur across one year, two year and three-five year periods. 'Red Flags' are identified through the monitoring and information is provided to alert GPs to important symptomology and changes that require expedient attention and further investigation. A summary of key recommendations are shown in the box below.

*At hospital discharge:* The Spinal Cord Injury Units should encourage patients to consult with their GP shortly after discharge, and then on a regular basis to modify and individualise their health maintenance plan.

*Every year* the following SCI-specific reviews should be made:

- Urinary tract review. A history of > 3 urinary tract infections in the last year, haematuria, or increased incontinence should prompt further investigation. Review electrolytes and renal function. Image the urinary tract annually for the first 3 years post-injury, then bi-annually. Abnormalities should be referred to a spinal cord injury clinic or urologist.
- Bowel program review. Assess regularity, stool consistency, aperients use, time taken to defecate, blood or mucous in the stool.
- Skin review. Integrity of skin on the feet and bony prominences should be checked regularly.
- Respiratory review. Check respiratory function, resting rate and peak flow, or FVC if spirometry available.
- Cardiovascular review. Check triglycerides, cholesterol and fasting BSL to screen for diabetes every 1-2 years from age 45yrs.
- Neuromuscular review. Assess for altered sensation, muscle strength or onset of worsening pain &/or spasticity. Review any changes in function &/or loss or range of motion at joints. Be aware of upper limb over-use syndrome.
- Mental health review annually.
- Carer and environment issues must be considered particularly if the individual with SCI is unwell or changes in functional capacity.

*Every 3 – 5 years:*

A comprehensive multi-disciplinary review is recommended to:

- Determine adequacy of equipment and home modifications, function and independence.
- Assess changes in life situation, social supports, attendant care, coping & adjustment, community access & participation.
- Perform a comprehensive physical & neurological examination, review pain, spasm, posture & skin integrity.
- Recommendations are also made for aspects of general health promotion, and specific reasons for prompt medical review.

CARF Standards includes the spinal rehabilitation unit offering a comprehensive annual review for people that addresses the person's community living status, equipment status, functional status, life-long care plans, medical status, psychological needs and vocational needs. Recommendations are then required to be made to the person and other relevant stakeholders (CARF International, 2012).

## 8 Additional areas or aspects of life

### Overview

- Pain management is a significant daily issue for many.
- Sexual function and intimacy are issues for many and changes relationships.
- Mental wellbeing is a very important aspect of quality of life.
- Rights and responsibilities of the person and their families/whānau need to be balanced
- Partners and families are also impacted and would benefit from being able to access counselling or psychological assistance.

### Opportunities for improvement

- Supporting overall mental wellbeing for the person with SCI and their family/whānau could be undertaken consistently and include a proactive approach so everyone feels they are supported.
- Pain management strategies may need strengthening.

### 8.1 Pain Management

Pain management was a significant issue identified in the Consumer Perspectives Report (UMR Research, 2013). For most people the length of time since their injury or impairment was irrelevant in terms of pain.

There are a variety of medication regimes and mental strategies such as meditation are used to manage pain in SCI. However, even those who had managed it felt it was only partially under control.

### 8.2 Intimacy and Sexual Function

Intimacy and sexual function are topics covered at the rehabilitation units but people report (UMR Research, 2013) that for many it is an ongoing life issue. Some try medications to assist but for others there is a lifelong change in their intimate relationships and sexual function.

### 8.3 Mental Wellbeing

For many people the early days of living with SCI were extremely difficult (UMR Research, 2013). People report feelings of loss and grief, embarrassment, loss of hope and suicidal thoughts. Dealing with the bladder and bowel issues and at times the embarrassment this can cause is significant for many.

For some people who had received counselling it had been very valuable. However people report also that they are seen as isolated and their families are not offered the same supports. Not everyone can access funded counselling and this is especially the case for health funded people.

The link between functional changes and emotional wellbeing is illustrated in the Consumer Perspectives Report (UMR Research, 2013).

## SECTION 5: Additional issues for service planning

In addition to identifying issues identified in previous sections of this report, there are a number of additional factors that influence service planning. These are:

- Transitioning from adult services
- Ageing with SCI
- Workforce
- Highly specialised procedures
- Long term ventilation
- Research

Note: The following list is in no particular order.

### 1 Transitioning to adult services

#### Overview:

- Transitioning to appropriate adult services is challenging given differences in referral acceptance by the spinal rehabilitation units

#### Opportunities for improvement:

- There is not a clear pathway for transition to adult services.
- Follow-on services if not provided by a spinal rehabilitation unit are likely to be single discipline and episodic rather than a whole of life approach.
- The role of the NASC for non-injured people is unclear and lacks national consistency.

There are well known and established issues related to the transition of youth from paediatric to adult services where on-going monitoring and rehabilitation is required. This is most obvious in youth with congenital causes of SCI as both spinal rehabilitation units have different referral criteria and although BSU has a transition process for youth with spina bifida attending Christchurch based paediatric services it is not a process available to youth within the BSU catchment area. It was noted by clinicians participating in the transitional focus group that both ASRU and BSU are always happy to provide advice where they are not directly accepting a referral.

Currently youth, if not accepted by either spinal rehabilitation unit or for those that would not benefit from referrals are transitioned to adult medical physicians or are referred back to their general practitioner who will then make referrals on an episodic basis. Both Spinal Rehabilitation Units provide SCI resources and are available for phone or letter/email consultation.

It is seen as a major gap that there are no community based rehabilitation physicians or specialist nurses to refer to when transitioning from paediatric services. Where there are physicians to refer to it is unlikely they will include the multidisciplinary service required. This is especially difficult for youth and their families and whānau when they have become adapted to paediatric services which provide a high level of support.

Youth, families and whānau are often confused and frustrated with the differences in accessibility of services between those offered in a paediatric setting and those in an adult setting.

The role undertaken by NASCs for non-injured people in supporting the transition process and coordinating services and supports is unclear as wide ranging variability was identified by clinicians.

One issue raised by participants affected by spina bifida in the Consumer Perspectives Report (UMR Research, 2013) was that while they tended to be satisfied with the levels of support available for children, this support, including regular health assessments dropped away once they were 18 years old.

## 2 Older people and ageing with SCI

### Overview

- Part of the cohort with SCI are older than they used to be due to increased life expectancy and also being older when having a SCI.
- People are living longer with SCI therefore ageing with SCI.
- There needs to be consideration given to the implications for how supports and services work in getting best outcomes for people with SCI who are older and / or who have lived a long time (e.g. 15+ years) with SCI.
- There is strong evidence that people with SCI age prematurely.
- People living with longer term SCI report difficulty in saving for retirement due to employment changes or issues.

### Opportunities for improvement

- Consistent pathways in New Zealand for assessment treatment and rehabilitation for older people with newly acquired SCI could be developed.
- There is consensus on the need for a proactive approach, but no consensus on frequency or type of review / follow up services, for health surveillance.

### 2.1 New SCI in an Older Person

Anecdotally the age of people acquiring SCI is increasing. This poses additional considerations for treatment, rehabilitation and on-going management of their needs. People may often have co-morbidities. Older persons with SCI are included in current methods of SCI rehabilitation, management and follow up at ASRU, in collaboration with a geriatrician specialist when indicated. Persons as old as 94 with a new SCI have completed rehabilitation at ASRU and returned to their home with support.

### 2.2 Evidence

Key points from the evidential review were that high rates of hospital admissions have been reported in older adults with SCI. Damage as a result of non-traumatic aetiologies is also common necessitating admission to rehabilitation facilities. Older adults are likely to have a longer length of stay in rehabilitation and have lesser functional gains than younger people (Univeristy of South Australia, 2012).

Expert group developed guidelines suggest older people with SCI should be offered the same access rights to specialist SCI services as younger patients including outreach, initial rehabilitation, re-admission



and outpatient services for lifelong support but should also be offered alternative services on an individual basis to allow them to return to home and their community as soon as possible (University of South Australia, 2012). The paper also stated all patients over the age of 65 should have cognitive assessment on admission to allow early identification and individual management of impairments. Clinicians should be aware of the physiological changes that occur with normal ageing, and the pharmacokinetics and pharmacodynamics in older adults and prescribe accordingly.

## **2.3 Living longer with SCI**

There is an increasing evidence base related to different aspects of ageing, including bladder, bowel, skin and shoulders and long term chair use with common complications of SCI often heralding the recurrence of the same complications at a later point in time. This highlights the importance of early intervention to prevent future health and psychosocial difficulties (Charliffe Susan, 2004). In addition, it has been found that the person with SCI ages prematurely (University of South Australia, 2012b).

It was found that the average cost of healthcare for a veteran in the United States with SCI was double the cost of an average individual without SCI in the last year of life. The difference in costs between veterans with SCI and other veterans for both routine and end-of-life costs was concluded to be large and most likely reflecting the complex care veterans with SCI require (Yu Wei, 2008).

As in the general population, reported personal experience is that new issues seem to develop every five years (or thereabouts) for people living longer with SCI.

The Consumer Perspectives Report (UMR Research, 2013) found that ageing with SCI meant loss of strength in participants' upper bodies and skin thinning which meant loss of independence and higher risk of pressure sores. Increased need for equipment and carer hours often came at a time when income was reduced due to leaving the ACC compensation scheme upon reaching 65 years of age.

The tipping point is when the time it takes to do your care begins to increase. When things start to take longer (i.e. get out of bed, bowel management, etc.) reassessment should be triggered. It is important to be more proactive with issues so they don't become big problems.

It is reported by members of various focus groups for the SCI project there are some issues with people not having connections with the spinal rehabilitation units so they don't know who to contact when issues arise. They believe it would be good to try and contact these people to start a national register. Conversely the spinal rehabilitation units report a lot of telephone contacts from people who are not on their register or their GPs, so some people are aware of their presence for advice.

Regarding the prospect of retirement for people with SCI, the Consumer Perspectives Report (UMR Research, 2013) made an observation that only long-term people were thinking about the prospect of retirement. This had implications for ACC clients that will move to a pension and significant drop in income.

## **2.4 Evidence**

There is strong evidence presented in one high quality guideline (University of South Australia, 2012b) that individuals with SCI undergo premature aging processes. This has implications for the monitoring

and preventative health strategies required to optimise the health and quality of life for this part of the SCI population; and consideration as to specialist long term residential care if required.

## **3 Workforce**

### **3.1 Rehabilitation Workforce Service Forecast**

The Rehabilitation Workforce Service Forecast (Wong A, 2011) outlined a vision for world-class rehabilitation system which could improve outcomes for people with disabling conditions. Although not specific to SCI it is relevant to SCI.

Key elements identified for effective rehabilitation included early intervention, a person and family-centred approach, providing culturally appropriate services, reducing inequalities, appropriate intensity of response and care coordination. The forecast noted that there is currently no comprehensive rehabilitation system in New Zealand resulting in provision of and access to fragmented services that vary greatly between regions. The forecast found that the current rehabilitation workforce faces issues of recruitment and retention across the full workforce comprising support workers and health professionals including rehabilitation medicine specialists. Training in rehabilitation is limited and uptake is not currently adequate to meet the needs of a comprehensive system.

The forecast predicted a positive influence on rehabilitation with the introduction Whānau Ora and provided evidence that rehabilitation can significantly reduce the costs to the health system and increase a return to productivity for many of those affected by disabling injury or illness.

In order to improve rehabilitation systems in New Zealand the forecast report made recommendations to:

- raise the profile of rehabilitation in New Zealand.
- increase the provision and opportunities to undertake rehabilitation training and increase the rehabilitation workforce.
- recognise and implement the funding requirements to support additional basic rehabilitation trainees and specialist rehabilitation trainees of rehabilitation medicine and allied health
- develop care coordination to support client following discharge from an acute facility.
- provide appropriate dosage intensity of rehabilitation treatment.
- support the review and alignment of services purchased by ACC, the Ministry of Health and DHBs to a more equitable and sustainable model.

DHB Workforce Strategies and Action Plans include reference to activities that support SCI as a sub-speciality such as supervision, journal clubs and Faculty of Rehabilitation Medicine activities. Some activities are undertaken regionally to ensure opportunities for maximising rehabilitation.

Counties Manukau DHB suggested a review of the rehabilitation workforce (Doctors, Nursing and Allied Health) and sub-specialities across the public and private rehabilitation providers is conducted to identify existing infrastructures to leverage off to support the specialist workforce. For example, there

may be Rehabilitation Specialists in the sectors who are not working in SCI, but who may be able to provide cross cover after hours and assist with cross pollination of information. There may also be informal relationships in place amongst public and private Rehabilitation Specialists in relation to triage and cross cover which need to be recognised and incorporated into the project work.

### **3.2 Nursing and allied health survey**

The nursing and allied health survey (Ministry of Health & Accident Compensation Corporation, 2012b) requested information from nurses and allied health staff working to provide SCI services and supports whether in an acute or community setting. Over 300 responses were received, 90% were from nurses and 60% were from staff directly involved in providing specialist services or supports.

People working in the spinal rehabilitation units, the Christchurch Hospital Orthopaedic Trauma Unit and selected ICUs felt they were sufficiently skilled and experienced but commented on the interface between their service and others where gaps were apparent to them.

In summary, the survey found there are opportunities for better supporting staff irrespective where they worked with guidance, pathways and protocols. There was also a perceived benefit in developing a career pathway specific to SCI which could include additions to existing post-basic courses or certificates.

Respondents were well aware that low volumes impacted on their ability to provide optimal care and that high staff turnover rates had a further impact.

Workforce gaps identified included the lack of:

- social workers and psychologists in the acute and community settings.
- physiotherapists with specialist skills in SCI in community settings.
- advanced practitioner roles for physiotherapists working in SCI.
- a trained unregulated workforce in the community (i.e. home and community support services)
- a community based health professional workforce with specialist skills in SCI.
- credentialing of occupational therapists and physiotherapists undertaking wheelchair and seating assessments on behalf of ACC (noting that the Ministry of Health requires this when assessing people funded through DSS).
- advisory services or nurse specialists within a DHB to get advice

Respondents to the survey recommended nationally consistent services and guidelines, improved coordination and continuity of services, provision of more support for family and whānau, a greater emphasis on community services including outpatients, outreach, follow-up, community based rehabilitation and equity for people requiring services.

### **3.3 Home and Community Support Services**

HCSS are funded by ACC, DSS and DHBs. All expect these providers to work to the Home and Community Support Sector Standard NZS 8158:2003 (Standards New Zealand, 2012). This is a general

quality standard that includes a requirement for staff to be assessed as competent in providing the level of care and support required and to receive appropriate supervision.

Both spinal rehabilitation units provide advice and information training to home and community support providers either on an individual or group basis. However, not all support workers will receive training directly from one of the spinal rehabilitation units. There is also no direct funding for the training provided by the spinal rehabilitation units. Trained or untrained, attrition rate is high among carers of persons with SCI.

The reference group were concerned that the National Foundation Skills training programmes for support workers do not adequately prepare a support worker to competently work with a person with SCI. It was suggested that a level four add-in programme could be developed.

Remuneration levels (advice from the advisory groups and noted in the UMR (2013) report) for support workers are also seen as a barrier to retaining staff and attracting staff of the right calibre to work with people with SCI.

The reference group felt the role for registered nurses, physiotherapists, occupational therapists and social workers within HCSS providers is not explicit within current contracts. Currently this can result in a person not receiving these services or receiving them either within a supervisory context or through other providers such as community or district nursing services which creates a lack of continuity for the person with SCI. This is seen as a gap by the reference group.

The rules around what HCSS providers can do are seen by many to be restrictive and providing barriers to wellbeing living in the community. Examples given by people with SCI and members of the reference group included:

- not being able to get lawns mowed or gardens done so having to pay for this themselves
- minor home maintenance not being able to be done e.g. changing light bulbs
- bowel cares
- bringing in fire wood
- cleaning windows
- getting up on a chair or a stepladder

In addition many in the advisory groups and in the UMR 2103 report noted that they are not in favour of the new ACC limited vendor model as it is seen as taking away smaller and more specialised providers.

## **4 Highly specialised procedures**

### **4.1 Tendon Transfer**

As part of its national service, BSU offer upper limb reconstructive surgery for people with tetraplegia.. This is a highly specialised surgical procedure that involves transferring functioning muscles into paralysed muscles to provide active elbow extension, pinch and grip functions of the hand for people with C5 – C7 tetraplegia. It often requires multiple surgeries and a large surgical and rehabilitation

team. An intensive period of rehabilitation is required following each surgery which is, depending on the procedure performed is between 10 days to 10 weeks. The surgery is performed at BSU, while rehabilitation occurs at either ASRU or BSU, depending on the patient's geographical location. BSU report that some people have a longer length of stay in a spinal rehabilitation unit than would be otherwise necessary due to lack of support or equipment available to people in their own homes. People then receive life-long follow-up.

A detailed pre-assessment is required to determine suitability for the procedure. Not everyone is assessed as suitable and some who are suitable decline after learning more. The procedure can be undertaken on all age groups. Approximately 10-12 people with SCI receive surgery each year, often this is bilateral simultaneous surgery. Volumes have remained constant over recent years.

There is a 12-18 month waiting list for this surgery. The main constraints impacting on the waiting list times are theatre time and bed capacity at BSU. It is not uncommon that people previously assessed as suitable for the surgery have a change in health status during the 12 month waiting time which can result in cancellations and further delays.

New Zealand is seen as a world leader in the provision of this procedure and has been offering it since 1983. There is an upper limb registry maintained by BSU. Extensive NZ outcome data has been published for these procedures (Dunn J. A, 2008, 2010, 2012a, 2012b; Mohammed K D, 1992; Sinnott K A, 2004) .

Of significance to service planning is funding for this procedure. BSU report that funding is currently insufficient to meet the costs associated with the pre-assessment, surgical procedure which is long and has multiple surgeons involved, a large multidisciplinary team and early discharge. Long waiting times due to lack of resources also impacts on people's general wellbeing and can for a few mean they are no longer suitable for the procedure when they are offered a date for surgery.

## **4.2   Implants**

People with SCI often have on-going spasticity. Where oral medication regimes have proven to be unsuccessful intra-thecal baclofen may be offered. There are approximately six-eight people a year that benefit from this therapy which requires a surgical implant for the administration of baclofen. The implants cost approximately \$25,000 and last around eight years. Refills of baclofen which are renewed every three-six months cost approximately \$1000. Prior to the surgical implant of the baclofen pump, people receive a trial where baclofen is administered by a lumbar spinal injection at BSU. Approval for funding of the pump and refills is also sought.

People receiving intra-thecal baclofen therapy are assessed at outreach clinics and receive their refills from their local hospital where able.

There are also other similar implants used in New Zealand such as spinal cord stimulators for pain management and spasticity management and Brindley Implants for urological management.

### **4.3 Emerging technologies and procedures**

An example of an emerging technology not currently used in New Zealand is diaphragmatic pacing. BSU identified that there are three or four people who could potentially benefit from this. Diaphragmatic pacing requires an invasive procedure to test whether a person might be suitable. At present an interested person would need to go to Australia for an assessment and then insertion of a pacer if deemed suitable. There are questions as to how this would be funded and whether there is suitable expertise or demand in New Zealand to provide such a service. BSU report that there is interest from individuals with SCI in New Zealand and that internationally this procedure is being offered more often.

### **4.4 Long term ventilation**

As part of its service, BSU manage inpatients from across New Zealand with SCI requiring long-term ventilation or where ICU's have been unable to wean patients and a prolonged weaning programme is required. Numbers of people requiring prolonged ventilation associated with SCI are small, usually 3-5 per year. Not all people who are ventilated go on to be long term ventilated at home as they are weaned in the BSU. Currently BSU provide ad hoc oversight and advice to approximately six people who are home ventilated of which three have been ventilated for many years. ASRU patients requiring weaning or prolonged ventilation with expectations for weaning are managed at the Middlemore Hospital ICU. Currently ASRU provides oversight to one person with SCI who is on home mechanical ventilation. Internationally, numbers of people with SCI that will be home ventilated is expected to increase. Increasing numbers are attributed to more people surviving the acute insult and an ageing cohort of people with SCI that lose respiratory function over time and will eventually require ventilator support (New South Wales Department of Health, 2010).

### **4.5 Acute management and initial rehabilitation**

Weaning a person with a SCI from a ventilator is different from usual practice in ventilator weaning where the person does not have a SCI. This means that for people in ICU's outside of Christchurch specialist advice may need to be provided to those centres. As there is no visibility by BSU of people receiving acute services, especially outside of their catchment area, it is possible no advice can be proactively provided by BSU to other hospital ICUs. BSU noted that where there have been failed attempts at weaning a person from a ventilator at other hospitals they have often been slow to request advice. Hospitals can also strike problems where a person with SCI has a tracheostomy requiring decannulation which requires specialist expertise of which BSU feels that this should be provided only by centres with specialist skills and currently Christchurch are best able to provide this service.

There can also be delays in accepting the transfer of a ventilated person whether due to Christchurch ICU bed availability, staffing or equipment. There is no funding available for a member of the BSU team to visit a patient in another ICU or to provide advice on ventilator management and weaning protocol.

Ideally, people with SCI who are ventilator dependent should be transferred to Christchurch Hospital ICU or Middlemore ICU and then on to the respective Rehabilitation Units when indicated. If a patient is admitted from the ASRU catchment area and successfully weaned, they are generally transferred back to ASRU for the remainder of their rehabilitation.

BSU reported that there have been examples of people that were likely to remain ventilator dependent if not for the expertise of their interdisciplinary team.

If a person with SCI is ventilated and the cause is not injury related, there can be delays in accepting the person for transfer to BSU as the DHB of domicile needs to fund equipment including a ventilator prior to the person's transfer.

BSU have a limited supply of portable ventilators. They can only manage two acute ventilated people at any one time and an additional person if they are an established ventilated person that has their own machines. They sometimes rely on the distributor to loan them portable ventilators on the basis that they will be eventually purchased for the people requiring them.

People who are ventilated have a longer length of stay in BSU than for other people with SCI. There can be additional delays if suitable accommodation needs to be found for the person on discharge.

#### 4.6 Community

BSU and the ICU technologist provide training to family and carers about home ventilation that requires instruction and hands on training at the BSU prior to discharge/transfer to ICU of domicile. Training will usually be for the week prior to discharge where the carers get to know the person and work with the interdisciplinary team.

BSU contact the local hospital, general practitioner, pharmacist, ambulance service, oxygen suppliers and electricity company in preparing for a person's discharge. In working with the local hospital arrangements are made for bypassing the emergency department should the person require admission to ICU<sup>18</sup> and identify a range of other services the person might need such as district nurses for tracheostomy management or peg tube changes. Arrangements are also put into place for the range of consumable products and equipment the person will require. This includes having two ventilators and two suction units with battery backup. Usually one ventilator is set up for the being in bed and the other for being in a chair.

When transferred home, the person will go via the local hospital ICU staying the first night in ICU. The purpose is to ensure ICU staff meet the person and can provide advice at a local level. Members of the BSU interdisciplinary team also accompany the person on their journey home spending the first week providing additional coaching and support to the person, family and carers. This is labour intensive as at least two members of the interdisciplinary team are required. For Māori it would be ideal for a staff member of Ranga Hauora team to be included, however resourcing issues have prevented this.

BSU keep in contact with people which usually includes a home visit on an as required basis if approved by ACC where the ICU technologist and a registered nurse will visit. This visit includes regular maintenance of the ventilators completed by the ICU technologist, up-skilling the carer team, liaising with the local ICU and clinical team. There is no funding for this service for non-ACC people. ASRU

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<sup>18</sup> Usually as a result of recurrent chest infections

team assessments are provided to persons on home based mechanical ventilation either in the home or at an outpatient clinic.

Issues identified in the provision of services for people requiring long-term ventilation include:

- no formalised structure or funding around the coordination of people in the community. Although BSU identify who they need to link with on a case by case basis this is difficult as BSU are unlikely to have local knowledge of the person's home community. The role of the ACC case manager is unclear in relation to discharge planning as is the role of the NASC for non-injured people.
- variable funding is available for carer training. This can result in limitations in the number of home and community support service staff that will be trained.
- ad hoc training is provided to individuals providing community services by BSU.
- few if any locally available speech language therapists and physiotherapists with the right level of expertise to assist the person and keep them well in the community. Funding of these therapists can be difficult if the DHB of domicile is not providing them.
- delegations for approval of the purchase of ventilators create delays for both ACC and health funded people.
- there is no funding available to the Spinal rehabilitation units for the time required to provide advice. This can be extensive in both the acute and community setting.
- funding constraints can limit the number of home visits and the composition of the team that visits.
- people often become socially isolated and strategies are required to try to address this. BSU were aware of people who were home ventilated who only left their property to go to the local hospital.

## 4.7 Research

New Zealand is an active participant in research which is led by Universities, Trusts, Societies and the Burwood Academy of Independent Living. New Zealand is also part of the Australia New Zealand Spinal Cord Injury Network that aims to advance research and translate information into improved SCI care. Worldwide there is a lot of research being undertaken across the field of SCI. The breadth of the research is very broad from new exercise programmes to stem cell treatment.

Internationally, it is recognised that there should be a strong role for research related to SCI, including treatments, services and supports for living as independently as possible with SCI.

There are current challenges in keeping abreast of research activities and determining how these apply within a New Zealand context and when or if they should be adopted especially where there are ethical considerations and high costs involved.

A summary of changes in clinical practice and research including difficulties in implementing new rehabilitation modalities within resource constraints is provided in the New South Wales State wide Service Plan for Spinal Cord Injury (New South Wales Department of Health, 2010).



## 5 Cultural Applied Research

### Overview

- Currently there is variation in how culture needs and differences are dealt with by health and disability providers, as well as ACC, across New Zealand.
- There is only one commonality, that is, all can see room for improvement in meeting the needs of people from culturally diverse backgrounds.
- There is a distinct need to consider and support wider whānau and family not just the person with the SCI.

### Opportunities for Improvement

- Services and supports could generally have a gap improve their awareness and responsiveness to cultural needs.

ACC Research undertook to provide an applied research report on cultural needs relating to SCI. The purpose of the report was to provide cultural input to inform the National Spinal Cord Impairment (SCI) strategy. Throughout the interviews of other stakeholder cultural specific needs were also raised.

Current general opinion is that cultural needs are not considered or met well anywhere along the continuum or in a whole of life manner when people interact with services and supports, other than family / whānau.

The cultural input covers Māori, Pacific peoples and Asian/other.

Note the following is a summarised from the full document (Accident Compensation Corporation, 2012a).

### 5.1 Findings

Currently there is variation in how culture differences are dealt with by health and disability providers, as well as ACC, across New Zealand. There is a lack of a framework or model that can guide and inform organisations and providers and a fragmentation of culturally appropriate services and supports. There is only one commonality, that is, all can see room for improvement in meeting the needs of people from culturally diverse backgrounds.

Cultural considerations are part of best practice in treatment and rehabilitation. Culture can have an effect on the whole continuum of care from how the SCI is interpreted by the individual and/or family, how they respond to care, their understanding, communication of needs, engagement with the process, to the opportunities to re-connect and participate within their communities.

The different cultures examined in the report have both commonalities and differences. Commonalities include that overall people from these cultural groups are a younger population, tend to have low socio-economic status (particularly Maori and Pacific Peoples), their cultural beliefs may mean a different world view on disability, have more of a family / whānau/ collective focus, have low rates of access to

services and supports, and face similar difficulties including language, communication and health literacy issues, cost barriers, problems accessing information and navigating the health system.

There was a high level of consistency in the literature and from cultural informants suggesting issues are well known. There is an effort to deliver culturally appropriate care to disabled members of communities by community organisations and providers. However, they report issues and barriers in meeting the needs of this population. The lack of adequate resourcing to meet the needs of their community was the most commonly reported issue.

Recommendations relating to each of the ethnic groups included in the report were included at the conclusion of relevant chapters on Māori, Pacific peoples and Asian/Other.

Broad high-level recommendations include frameworks and established procedures to meet the needs of different cultural groups. This includes; cultural competency training for all providers and staff, development of relationships and links to cultural support both inpatient and in the community and increased utilisation of cultural brokers.

Notably the BSU, the ASRU and the Wilson Centre all have specific access to Māori and Pacific Island cultural supports.

## Appendix 1 – Strategy and policy context

### 1 Strategic context

There are four key strategies that provide a framework for the health and disability system in New Zealand:

- the New Zealand Health Strategy (Ministry of Health, 2000) which sets out seven underlying principles that the Government sees as fundamental and should be applied across the health and disability sector and be reflected in any new strategies or developments.
- the New Zealand Disability Strategy (Ministry of Health, 2001b) which presents a vision for changing New Zealand from a disabling to an inclusive society.
- He Korowai Oranga: the Māori Health Strategy (Ministry of Health, 2002) which recognises whānau as the foundation of Māori Society and sets the direction for Māori health development in the health and disability sector to increase the life span of Maori, improve their health and quality of life and reduce disparities with other New Zealanders.
- the Primary Health Care Strategy (Ministry of Health, 2001c) which presents a vision for people to be part of local primary health care services that improve their health, keep them well, are easy to get to and coordinate their on-going care focusing on better health for a population and actively work to reduce health inequalities between different groups.

These strategies provide direction to policy makers and funders in how services and supports should be delivered. A central theme within these strategies is improving health and wellbeing, providing equitable access to services, addressing disparities, acknowledging the Treaty of Waitangi and involving consumers.

Also relevant in the context of SCI are the following key documents:

- the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006) that reaffirms the human rights and fundamental freedoms for people with all types of disabilities
- Disability Action Plan<sup>19</sup> which is a framework for agencies to collaborate on implementing the New Zealand Disability Strategy and the United Nations Convention on the Rights of Persons with Disabilities.
- Whaia Te Ao Marama: The Māori Disability Action Plan for Disability Support Services (Ministry of Health, 2012d) which establishes four priority areas of action to enable Māori disabled to achieve their aspirations, and to reduce barriers that may impede Māori disabled and their whānau from gaining better outcomes.

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<sup>19</sup> <http://www.odi.govt.nz/what-we-do/ministerial-committee-on-disability-issues/disability-action-plan-diagram.html>

- Faiva Ora National Pasifika Disability Action Plan (Ministry of Health, 2010) looks at improving the training and career path for Pacific disability workers ensuring support services meet the needs of Pacific disabled people and increasing locally delivered services.
- Lu'i Ola Strategic Framework for Action 2009-2013 (Ministry of Health, 2012c) is an interagency project that aims to better serve the needs of Pacific peoples with disabilities, their families or aiga and their caregivers.
- the Social Services Select Committee's Inquiry into the Quality of Care and Service Provision for People with Disabilities (Social Services Committee, 2008) and the Government's response (New Zealand Government, 2009) which has specific reference to improving information and information sharing, building local coordination systems, providing more choices for people with disabilities, providing flexible streamlined funding for housing modifications and equipment, improving workforce capability and pay rates.
- Whānau Ora: Report of the Taskforce on Whānau Centered Initiatives that identifies the need for Whānau Ora to demonstrate a 'Māori heart', ensure local representation in decision making, minimal bureaucracy, sustainability and adequate resourcing, a research and evaluation component, and quality relationships between whānau, providers and iwi.
- Ala Mo'ui: Pathways to Pacific Health and Wellbeing (Minister of Health and Minister of Pacific Island Affairs, 2010) that sets out the priority outcomes that will contribute towards achieving better health outcomes for Pacific people, families and communities which can be used by the health and disability sector as a tool for planning, prioritising actions and developing new and innovative methods of delivering results and value for money.
- Health of Older People Strategy (Ministry of Health, 2001a) which sets eight objectives to identify areas where change is essential to ensure older people are able to participate to their fullest ability in decisions about their health and wellbeing and in family, whānau and community life.
- New Zealand Carers Strategy (Ministry of Social Development, 2008) outlines the Government's vision for carers in New Zealand where carers have choices and opportunities to participate in family life, social activities employment and education and have their voices heard in decision making that affects them.
- ACC Statement of Intent which commits to a focus on developing capability to deliver the highest quality rehabilitation outcomes (Accident Compensation Corporation, 2012b).
- the Rehabilitation Service and Workforce Forecast Report (Wong A, 2011) that recommends the development of a comprehensive rehabilitation system in New Zealand and outlines how this can be achieved.
- the National Health IT Plan (IT Health Board, 2010) which sets priorities for regional and national IT investments over a five year period to consolidate IT platforms and enable shared care capability.

## 2 Policy

Improving health outcomes and raising the quality of health services while living in a lower economic growth path are the main challenges for the health and disability sector at present (Ministry of Health,

2012a). To accelerate the pace of change in meeting the sustainability challenge the Ministry identified seven priorities. Relevant to the strategy development work is a desire to:

- focus on proven preventative measures and earlier intervention
- meet the diversity of needs within the population
- design services to meet individuals needs through better models of care that guide investment in workforce, capital and information systems
- integrate services through better coordination placing the person and carers at the centre of service delivery and addressing variation in quality and service performance
- consider new incentives to deliver better performance
- strengthen leadership to ensure the sector is cohesive and moves in the same direction
- work across government to address health and other priorities.

Disability Support Services in its Strategic Plan (Ministry of Health, 2012b) aims to manage the overall costs within its available budget as it implements the New Model for supporting disabled people. The New Model is aimed at increasing consumer choice and flexibility of service provision through increased information and assistance through local area coordination, individualised funding, offering an option of supported self-assessment and allocating funding rather than services.

The Ministry of Health released a discussion paper that is guiding primary health care in New Zealand called “Better, Sooner, More Convenient Health Care in the Community”(Ministry of Health, 2011). Health policy and planning considers this when making plans with an emphasis on delivering health care in a coordinated and cooperative manner, as much as possible in the community.

ACC has a continued focus on reducing injuries and helping people to get back to work and community participation as soon as possible (Accident Compensation Corporation, 2012b). ACC is currently making improvements in its claims management operations aimed at improving clients’ experience, rehabilitation rates and supporting people to return to a productive life sooner.

In 2008, ACC established the National Serious Injury Service (NSIS) with dedicated staff with the aim to improve financials and deliver better client outcomes by moving from a service based planning model to a person-centred planning model. This included in the introduction of Functional Independence Measures (FIM). There are approximately 4500 clients in the NSIS of which 40% are people with a SCI. Note that not all people with SCI qualify to be managed within the NSIS due to its eligibility rules.

### 3 Funding models

There are three main funding streams that may support people with spinal cord impairment. These are:

- ACC funding where there is an injury cause (retrieval, treatment, supports and weekly compensation where entitled).
- Ministry of health funding where there is a non-injury cause either from personal health, disability support services and mental health funding streams (retrieval, treatment and supports).

- Ministry of Social Development funding where a person is not eligible for ACC funding and requires income support.

In addition, people may self-fund some services and supports either individually or through insurances.

Children and young people can also receive services through the Ministry of Education.

### 3.1 ACC funding

Under the Accident Compensation Act 2001, ACC funds injury prevention, treatment, medical rehabilitation, social rehabilitation, vocational rehabilitation and provides compensation.

Acute hospital services for people who have sustained an injury are funded via ACC under a funding stream termed Public Health Acute Services (PHAS). This goes as a bulk amount from ACC to the Ministry of Health under a service agreement between the Minister for ACC and Minister of Health. Acute services are then provided by District Health Boards (DHBs) under service specifications for Emergency Services and Medical and Surgical Services issued by the Ministry of Health as part of the National Services Framework.

Rehabilitation services are delivered by a range of public and private suppliers on a contracted basis as specified in service schedules. Services most likely to be accessed by SCI clients include:

- conveyance for treatment (ambulance/air)
- medical treatment including pharmaceuticals
- social rehabilitation, for example housing modifications, vehicle modifications, home and community support services, orthotics, travel and accommodation, aids and appliances, training for independent living, physiotherapy, pain management
- vocational rehabilitation
- surgical treatment (elective)
- mental health assistance e.g. depression.

Spinal rehabilitation units receive funding via the specialised spinal cord active rehabilitation services (inpatient and outpatient) contracts.

Under existing ACC policy, support people can be provided with travel and accommodation assistance.

ACC provides compensation to clients for loss of income and permanent impairment (lump sums) operating under a social insurance model.

ACC clients eligible for weekly compensation usually lose this entitlement when they turn 65 as they then qualify for superannuation. More information is available in the Accident Compensation Act 2001 on this matter.

## 3.2 Ministry of Health funding

### 3.2.1 Personal Health

Public health funds are devolved to DHBs by the Ministry of Health mostly on a population basis. They are usually adjusted annually for inflation and demographic change. DHBs in turn determine how the funds are spent working within the National Service Framework which specifies service requirements and for some services, levels. This means that there may not be consistent funding and service delivery models for SCI in each DHB as there is flexibility around the allocation of funding to specific services and over service volumes to reflect the needs of each DHB population.

Funding for SCI is not dedicated as it sits in general personal health lines and is allocated by the DHBs to various services. The spinal rehabilitation units are allocated funding from their respective DHBs and also receive some funding from other DHBs through inter-district flow funding. These units also receive some funding from ACC and DSS.

Where a DHB provides services on behalf of another DHB there is either a regional funding agreement to do this at a service level or a payment calculated per individual as part of an inter-district flow arrangement. In practice this means that some DHBs are advantaged or disadvantaged in providing services on behalf of other DHBs or in sending their patients to another DHB. This may have an impact on how DHBs determine access to services for people with SCI as discussed later in this document.

The Ministry of Health has a National Travel Assistance Policy which came into effect in 2006 (Ministry of Health, 2005). The policy sets out how some financial assistance towards actual travel and accommodation costs can be applied. It is targeted at those people who have to travel long distances to access specialist health or disability services and incur high travel costs as a result of frequent visits and have a financial need that might otherwise prevent them from accessing services. Travel and accommodation assistance may be available to a support person and is approved on a case by case basis beyond one return trip per week after the first two weeks of inpatient and/or daily outpatient specialist services. The DHB of domicile funds the travel which is administered through a national system.

### 3.2.2 Disability Support Services

Disability support services (DSS) funding remains centralised with the Ministry of Health, and is generally for people under the age of 65 years, but depending on lifelong need some may be over the age 65 years.

DSS variably fund generic services that may include people with SCI via a range of contracts with public and private suppliers, often purchased as either a programme with no set volumes or a set cost for a limited number of volumes. When purchasing volumes, the allocation is largely based on historic allocations that do not necessarily take into account changing demographics or the cost of inflation.

Some funding for the spinal units comes from DSS funding, either through the Assessment, Treatment and Rehabilitation (AT&R) contract or a specific contract in the case of Counties Manukau DHB.

In addition, DSS funds equipment and modification (housing and vehicles) services. Services funded by DSS most likely to be variably accessed, by people with SCI include:

- Child Development services
- Disability Information and Advisory services
- Equipment and Modification services
- Home and Community Support Services
- Community Day Activity Programme (for post deinstitutionalised people only under the formal Government deinstitutionalisation programme – others access funds via MSD)
- Respite and Carer Support
- Limited amount of orthotics.

There may be some who also access residential care but figures are not available.

### 3.2.3 Mental Health and Primary Healthcare Services

Mental health funds are also devolved to DHBs by the Ministry of Health. Mental health funds are ring-fenced which means spending is targeted to this client group. It is unclear whether people with SCI can access these services as it will be determined on acuity and level of need.

Primary healthcare services are funded by DHBs via primary healthcare organisations. People with SCI can access these alongside the rest of the population. People with SCI may be eligible for Care Plus which is a primary health care initiative targeting people with high health need due to chronic conditions, acute medical or mental health needs or terminal illness. Care Plus allows for a doctor or nurse from the general practice to undertake an initial assessment where health needs are explored in more depth and an individual plan developed to set health and quality of life related goals with regular follow-ups. Care Plus services are provided at a low or reduced cost to the person receiving them. Over time, Care Plus will replace the High Use Health Card as people come up for their annual review.

### 3.2.4 Long Term Support - Chronic Health Conditions (LTS-CHC)

Since November 2006, the Ministry of Health has been administering what was then called the Interim Funding Pool (IFP) to ease pressures created by a gap in funding responsibility for people under the age of 65 with chronic health conditions and high need for long-term support services. This funding stream was subsequently renamed and is now known as the Long Term Support - Chronic Health Conditions (LTS-CHC) funding pool. Responsibility for the fund was devolved to DHBs in 2011 with an intent that the pool would be administered on a regional basis. The devolved funding is based on a two year transition period.

There is some concern that supporting people with SCI from this pool poses significant over spend risks. How this can best be used and managed needs considered as part of the wider SCI strategy.

## 3.3 Ministry of Social Development funding

There are a variety of benefits administered by the Ministry of Social Development (MSD) that a person with a SCI, or their carer, might apply for, if they are not covered by ACC. These include:



1. Invalid's benefit – where the SCI stops the person working, for longer than two years. It is income tested
2. Sickness benefit – for those who can't work as much as they did or had to stop working for a defined period. It is income tested
3. Domestic purposes benefit care of the sick or infirm (DPBCSI) – for people caring full time for someone at home, and who have had to give up employment for this role. There is an income limit for this benefit.
4. Help with extra costs which are income tested including:
  - a. Disability allowance
  - b. Assistance for hardship
  - c. Community services card
  - d. High use health card.

When a person turns 65, they will qualify for superannuation, even if they have been receiving ACC weekly compensation till then, which will cease at age 65.

### **3.4 Ministry of Education**

The Ministry of Education, via Special Education Services, have a range of funding streams to assist children with high level needs. For children with SCI these can include, depending on their needs level and eligibility:

- Physical Disability Services which provides physiotherapy and occupational therapy with children and teachers at school
- On-going Resourcing Scheme (ORS) but this is only for the very severely disabled and those with very complex specialist education needs, which most of those with just SCI would not meet (e.g. usually include major intellectual and / or behavioural and / or health needs)
- assistive technology
- facility alterations
- equipment
- communication services
- transport.

Families have to apply and go through an independent education planning process to get a decision as to whether their child's needs will be met.

Families report difficulties in accessing these supports in a timely manner. There are also policy boundaries between DSS and Education, especially around therapies and equipment, which can cause debate over who is the relevant funder.

### **3.5 Dual systems**

Differences in legislation, systems, policies and available funding can impact on people with SCI. These differences have been previously well described (Stephens. R, 2004; Wong A, 2011).

It is important to understand the context as to why New Zealand's dual system creates differences in income and service provision which is summarised below.

ACC came into operation on the 1<sup>st</sup> April 1974. It was based on an insurance model that provided no-fault injury cover for complete rehabilitation and removed the right to sue. The model was recommended by a Royal Commission in its report, known as the Woodhouse Report (Royal Commission (Woodhouse. O), 1967).

Prior to the Woodhouse Report, the common law action for damages provided a remedy where personal injury could be attributed to negligence. Supplemented by the common law remedy were three statutory systems of compensation through the Workers' Compensation Act 1956, Social Security Act 1964 and Criminal Injuries Compensation Act 1963.

There was concern that the systems for providing compensation in the case of road traffic accidents and industrial accidents was insufficient and that where fault could not be established or the degree of negligence, a person may receive little compensation or the level of compensation was proportionally reduced. Where cases were appealed this resulted in jury trials where awards were not seen as fair and consistent. This resulted in criticism of the current systems and led to the Royal Commission.

The Woodhouse Report acknowledged inequity would occur with the proposed changes to injury based compensation as stated in paragraph 17 of the Report:

*"It may be asked how incapacity arising from sickness and disease can be left aside. In logic there is no answer. A man overcome by ill health is no more able to work and no less afflicted than his neighbour hit by a car. In the industrial field certain diseases are included already. But logic on this occasion must give way to other considerations."*

The Woodhouse Report also rejected recommending the introduction of flat rate payments for compensation on the basis few would accept the scheme despite the social security system which aimed to ensure income sufficient to reach an adequate living standard that was predicated on a flat rate and was not earnings related.

Following the introduction of ACC, the two systems that were effectively created in New Zealand (Health and ACC) are unlike any others internationally as other insurance maintenance schemes:

- are time limited (apart from pensions), with a subsequent fall to a flat rate, means tested benefit.
- usually only compensate for work related injuries.
- do not prevent the ability to sue for damages.

Despite various strategies aiming to eliminate barriers for people with disabilities and promote better public services, there are differences for people with the same disability or medical outcome and level of impairment as an ACC client.

A whole of government approach for policy and programme changes has previously been proposed (Saucier. P, 2002) following the launch of the New Zealand Disability Strategy to:

- promote independence giving more opportunities for participation with flexible service packages to meet the greater expectations of habilitation and rehabilitation
- improve effectiveness of existing services through workforce development and better coordination of services
- simplify access to comprehensive services by developing cross-departmental assessment and service coordination, re-focusing assessment processes to be more comprehensive where people have complex needs and simpler for those with low needs.

The table below summarises differences in access, service and support provision relevant to people with SCI. Note that there are few if any differences in the acute provision of services through DHBs which can be attributed to public health acute funding.

Area	Example under ACC	Example under Health & Disability
Specialised inpatient and outpatient rehabilitation	<ul style="list-style-type: none"> <li>• Spinal rehabilitation units accept all people with spinal cord injuries</li> <li>• The Wilson Centre will accept children and young people with spinal cord injuries</li> </ul>	<ul style="list-style-type: none"> <li>• Spinal rehabilitation units accept <b>all</b> people with spinal cord impairment (with the exception of Spina Bifida and some tumours for ARSU) referred for rehabilitation – though they will provide telephone advice</li> <li>• Some rehabilitation through Assessment Treatment and Rehabilitation (AT&amp;R) units may occur</li> </ul>
Community based rehabilitation	<ul style="list-style-type: none"> <li>• Contracts with a wide range of suppliers to provide assessment and rehabilitation in the community, including access to equipment and modifications</li> </ul>	<ul style="list-style-type: none"> <li>• Limited services provided by the District Health Board under Community Services usually for a limited period</li> <li>• Specialised assessments provided by the District Health Board and very limited assessments provided by private e.g. for seating and wheelchairs, communication devices or NGO suppliers contracted by Disability Support Services Ministry of Health (MoH), including access to equipment and modifications</li> </ul>
Vocational rehabilitation	<ul style="list-style-type: none"> <li>• Contracts with specialist vocational rehabilitation suppliers to provide vocational rehabilitation</li> </ul>	<ul style="list-style-type: none"> <li>• Relies on the limited and non-specialised programme offered by Ministry of Social Development unless the person was part of the defined deinstitutionalisation processes funded by the MoH</li> <li>• Is known to be a gap for both younger and older people</li> </ul>
Promotion of independence	<ul style="list-style-type: none"> <li>• Contracts with specialist suppliers to provide training for independence</li> </ul>	<ul style="list-style-type: none"> <li>• Supported living programme for a very limited few, but not a rehabilitation model</li> </ul>

Area	Example under ACC	Example under Health & Disability
	services	
Coordination of services and supports	<ul style="list-style-type: none"> <li>Has specialised case managers managed through the national serious injury services of ACC</li> <li>For non-serious injury ACC case managers or case coordinators</li> </ul>	<ul style="list-style-type: none"> <li>Relies on the needs assessment and coordination services (NASC) which has a limited role for a few people classed as having a disability under the Ministry's definition or meet the criteria for Health of Older People for DHB NASCs</li> <li>No access for those with health causes that do not meet the definition and eligibility for disability services funding</li> <li>DSS is trialling a new way in one locality of using Local Area Coordinators</li> </ul>
Eligibility to receive services and supports	<ul style="list-style-type: none"> <li>No means testing</li> <li>Includes childcare within home support services</li> </ul>	<ul style="list-style-type: none"> <li>Means testing for some supports</li> <li>Prioritisation tools</li> <li>Limits to levels of supports</li> <li>For DSS have to meet the MoH DSS eligibility criteria<sup>20</sup></li> <li>Does not include childcare services within home support services</li> <li>Changes over life depending on age (e.g. health of older people services versus DSS)</li> </ul>
Ease of access to services	<ul style="list-style-type: none"> <li>Prioritised for elective procedures if required</li> <li>Case management model promotes ease of access to services</li> <li>Can see physicians privately to promote speed of access</li> </ul>	<ul style="list-style-type: none"> <li>Waiting times for access to NASC (e.g. for access to home and community support services) specialised assessments for equipment and modifications</li> <li>Wait listed for clinics and elective procedures if required</li> <li>Reliance on health professionals and community resource centres to point towards access and eligibility</li> </ul>
Access to housing modifications, modified vehicles, equipment and supplies (e.g. continence supplies)	<ul style="list-style-type: none"> <li>Permissive system for housing modifications</li> <li>Modified vehicles purchased for ride on access and drive from chair</li> <li>Equipment purchased and regularly upgraded</li> <li>Full supplies provided</li> </ul>	<ul style="list-style-type: none"> <li>Limits on housing modifications – type and funding amounts including means testing</li> <li>Limits on vehicle modifications and threshold for purchase of a modified vehicle requires complementary funding from others (e.g. Lotteries Grant application)</li> <li>Limits on provision of some equipment</li> <li>Adequate and equitable access to supplies does not occur (e.g. continence supplies and consumables) and is variable</li> </ul>

<sup>20</sup> <http://www.health.govt.nz/yourhealth-topics/disability-services/am-i-eligible-ministry-funded-support-services>

Area	Example under ACC	Example under Health & Disability
		between DHBs
Support for family members	<ul style="list-style-type: none"> <li>• Payment of family as carers</li> </ul>	<ul style="list-style-type: none"> <li>• Family carers are not paid (understand this is currently under review and public consultation closed on 6<sup>th</sup> November)</li> </ul>
Transport assistance	<ul style="list-style-type: none"> <li>• People with SCI can get transport assistance e.g. to employment, school, medical appointments</li> <li>• Travel assistance for family to visit people in spinal rehabilitation units</li> </ul>	<ul style="list-style-type: none"> <li>• Limited travel assistance variably applied by DHBs under the National Travel Assistance Policy</li> <li>• No transport (or if any extremely limited) for the person to attend appointments, employment, vocational supports etc.</li> <li>• Some transport assistance for eligible children for attendance at school via Ministry of Education</li> </ul>
Model	<ul style="list-style-type: none"> <li>• Rehabilitation focus</li> </ul>	<ul style="list-style-type: none"> <li>• Every day living focus in line with the social model of disability</li> </ul>
Income	<ul style="list-style-type: none"> <li>• Workers qualify for weekly compensation until they return to work or reach the age of 65 (when they transfer to superannuation)</li> </ul>	<ul style="list-style-type: none"> <li>• Benefits are available through the Ministry of Social Development and are income tested but not earnings related</li> </ul>

A review of the Medical Rehabilitation Standards (CARF International, 2012) would suggest that ACC is not over servicing clients, although it should be noted that these Standards does not include the level to which environmental supports should be funded.

Consumer perspectives research (UMR Research, 2013) also noted large inequalities between Health and ACC in terms of entitlements. Key findings from this research were that ACC clients receive better coordinated services, have access to more services and receive more within similar services such as home and community support services. The issue of unpaid family carers for non-ACC funded people was also raised in the research which is currently being addressed<sup>21</sup> by the Ministry of Health following a High Court ruling<sup>22</sup>.

Please refer to the Consumer Perspectives Report (UMR Research, 2013) where people have shared their experiences of differences in service provision based on funding models.

<sup>21</sup> <http://www.health.govt.nz/publication/consultation-paying-family-carers-provide-disability-support-2012>

<sup>22</sup> <http://www.health.govt.nz/our-work/disability-services/appeal-court-decision-paid-family-caregivers-litigation>

## 4 Cost per person

There is comprehensive cost information available for people who receive ACC services. There is not equivalent information available for people who are funded through other health services.

The average cost of injury rehabilitation and support (excluding weekly compensation) is \$6.2 m for per person. The average is higher for people under the age of 20 at the time of their injury at \$13.2m and lower for those aged 60 and over at the time of their injury at \$0.9m. Note the acute care costs for injury are not included in these averages.

## References

- Accident Compensation Corporation. (2012a). Report on cultural input to inform the national spinal cord impairment strategy. In D. S. Carne (Ed.). Wellington: Accident Compensation Corporation
- Accident Compensation Corporation. (2012b). *Statement of Intent 2012-2015*. Wellington: ACC.
- Accident Compensation Corporation. (2012c). Traumatic Spinal Cord Impairment: Analysis of ACC and Hospital Discharge Data (draft).
- American Spinal Injury Association. (2012). White Paper on Competent Care and SCI Rehabilitation American Spinal Injury Association, .
- Australian Health Services Research Institute. (2010-2012). NZ Spinal Data: University of Wollongong.
- Burwood Academy of Independent Living. (2008). Independent Living Programme Development Proposal Christchurch Burwood Academy of Independent Living.
- CARF International. (2012). Medical Rehabilitation Standards Manual. Arizona: CARF International, .
- CARF International. (n.d.). Review of Spinal Injury Services in New Zealand CARF International.
- Charlifue Susan, L. D., Adkins Rodney,. (2004). Aging with Spinal Cord Injury: Changes in Selected Health Indices and Life Satisfaction. *Archives of Physical Medicine and Rehabilitation* 85, 1848.
- Counties Manukau District Health Board. (2012). Acute Spinal Patient Integrated Navigator (ASPIN). Auckland: Counties Manukau District Health Board, .
- Derrett S, B. C., Sullivan M, Herbison G, Acland R, Charlotte P. (2012). Traumatic and non-traumatic spinal cord impairment in New Zealand: incidence and characteristics of people admitted to spinal units. *Injury Prevention; Early on-line*.
- Dickson B. Sinnott KA. Nunnerley J. Hay-Smith J. (2012). The experience of employment in New Zealand following spinal cord injury. *Occasional Report*
- Dunn J. A. (2008). Measurement issues related to upper limb interventions in persons who have tetraplegia. *Hand Clinics*, 24(2), 161-168.
- Dunn J. A. (2010). Upper limb reconstructive surgery uptake for persons with tetraplegia in New Zealand: a retrospective case review 2001–2005. . *Spinal Cord*, 48(11), 832-837.
- Dunn J. A. (2012a). Issues influencing the decision to have upper limb surgery for people with tetraplegia. *Spinal Cord*, 48(11), 832-837.
- Dunn J. A. (2012b). Liminality and decision making for upper limb surgery in tetraplegia: a grounded theory. *Disability and Rehabilitation*, 00, 1-9.
- Dyson M. (2012). Peer Support Programs with individuals with SCI: Dyson Consulting Group.
- Engel S. Leong D. (2008). Health Maintenance for Adults with Spinal Cord Injuries. Sydney: New South Wales State Spinal Cord Injury Service,.
- IT Health Board. (2010). *National Health IT Plan*. Wellington: National Health Board, Ministry of Health.
- Krischblum, S. (2009). *Spinal Cord Medicine*. Philadelphia: Lippincott.

- Minister of Health and Minister of Pacific Island Affairs. (2010). 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010-2014. Wellington: Ministry of Health.
- Ministry for Primary Industries. (2012). *The future of folic acid fortification of bread in New Zealand*. Wellington: New Zealand Government.
- Ministry of Health. (1995). Spinal Cord Injury Rehabilitation Services. Wellington: Ministry of Health.
- Ministry of Health. (2000). *The New Zealand Health Strategy*. Wellington: Ministry of Health.
- Ministry of Health. (2001a). *Health of Older People Strategy*.
- Ministry of Health. (2001b). *The New Zealand Disability Strategy: Making a World of Difference Whakanui Oranga*. Wellington: Ministry of Health,.
- Ministry of Health. (2001c). *The Primary Health Care Strategy*. Wellington: Ministry of Health.
- Ministry of Health. (2002). *He Korowai Oranga: Maori Health Strategy*. Wellington: Ministry of Health.
- Ministry of Health. (2005). *National Travel Assistance Policy*. Wellington: Ministry of Health
- Ministry of Health. (2010). Faiva Ora National Pasifika Disability Plan 2009-2013. Wellington: Ministry of Health.
- Ministry of Health. (2011). *Better, Sooner, More Convenient Health Care in the Community*. Wellington: Ministry of Health.
- Ministry of Health. (2012a). *Briefing to the Incoming Minister of Health*. Wellington: Ministry of Health
- Ministry of Health. (2012b). *Disability Support Services Strategic Plan 2010 to 2014*. Wellington: Ministry of Health.
- Ministry of Health. (2012c). Lu'i Ola Auckland Regional Disability Project website: <http://www.health.govt.nz/our-work/disability-services/disability-projects-and-programmes/development-disability-services-pacific-peoples/lu-i-ola-auckland-regional-disability-project>.
- Ministry of Health. (2012d). Whaia Te Ao Marama: The Maori Disability Action Plan for Disability Support Services 2012 to 2017. Wellington: Ministry of Health.
- Ministry of Health & Accident Compensation Corporation. (2012a). *Project Initiation Document: Spinal Cord Impairment Strategy*. Ministry of Health & Accident Compensation Corporation,.
- Ministry of Health & Accident Compensation Corporation. (2012b). *A survey of nursing and allied health staff*. Joint National Spinal Cord Impairment Project,.
- Ministry of Social Development. (2008). *The New Zealand Carers' Strategy and Five-year Action Plan*. New Zealand Government.
- Mohammed K D. (1992). Upper-limb surgery for tetraplegia. *Journal of Bone & Joint Surgery, British Volume*, 74(6), 873-879.
- National Ambulance Sector. (2012). National Helicopter Dispatch Protocols for Ambulance Services (draft for consultation September 2012). Wellington: National Ambulance Sector.
- National Health Services. (2011). Management of People with Spinal Cord Injury NHS Clinical Advisory Groups Report. United Kingdom: National Health Service.
- New South Wales Department of Health. (2010). *Selected Specialty and Statewide Service Plans: Spinal Cord Injury*. Sydney: New South Wales Department of Health,.
- New Zealand Government. (2009). *Government response to Report of the Social Services Select Committee on its Inquiry into the quality of care and services provision for people with disabilities*. Wellington: House of Representatives.
- Royal Australasian College of Surgeons New Zealand Trauma Committee. (2012a). Guidelines for a structured approach to the provision of optimal trauma care, : Royal Australasian College of Surgeons.
- Royal Australasian College of Surgeons New Zealand Trauma Committee. (2012b). Optimal Trauma Care Guidelines.

- Royal Commission (Woodhouse. O). (1967). Compensation for Personal Injury in New Zealand: Report of the Royal Commission of Inquiry. Wellington: Government Printer.
- Saucier. P. (2002). Promoting a National Vision for People with Disabilities: Successful Policies and Enduring Barriers (pp. 74). Wellington.
- Sinnott K A. (2004). Use of the ICF conceptual framework to interpret hand function outcomes following tendon transfer surgery for tetraplegia. *Spinal cord*, 42(7), 396-400.
- Sinnott K.A. (2010). Transitionz Programme 12 month report. Christchurch: Burwood Academy of Independent Living.
- Social Services Committee. (2008). *Inquiry into the quality of care and service provision for people with disabilities*. Wellington: House of Representatives.
- South of England Spinal Cord Injury Board. (2010). Standards for Patients Requiring Spinal Cord Injury Care *Service Standards (Revised 2010)*. England: National Health Services.
- Standards New Zealand. (2012). Home and Community Support Sector Standard NZS 8158:2012. Wellington: Standards New Zealand.
- Stephens. R. (2004). Horizontal equity for disabled people: Incapacity from accident or illness. *Victoria University of Wellington Law Review*, 35(4), 783 - 800.
- Tan M. New P. (2012). Retrospective study of rehabilitation outcomes following spinal cord injury due to tumour. *Spinal Cord*, 50(February), 127 - 131.
- UMR Research. (2013). Spinal Cord Impairment Client Perspectives: UMR Research.
- United Nations. (2006). *Final report of the Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities*. New York: United Nations.
- Univeristy of South Australia. (2012). Scan of secondary evidence for the management of spinal cord injury and related impairments; extraction of key points. *International Centre for Allied Health Evidence Phase two report*: University of South Australia.
- University of South Australia. (2012a). Scoping the currently available secondary evidence along the continuum of care for spinal cord impairment management: informing service delivery improvement. *International Centre for Allied Health Evidence Phase 1 Report*: University of South Australia.
- University of South Australia. (2012b). A systematic review of focused topics for the management of spinal cord injury and impairment *International Centre for Allied Health Evidence Phase three report*: Univeristy of South Australia.
- Wong A. (2011). Rehabilitation Service and Workforce Forecast. Wellington: Health Workforce New Zealand.
- Yu Wei, S. B., Kim Shirley, Chow Adam, Weaver Frances;. (2008). Major medical conditions and VA healthcare costs near end of life for veterans with spinal cord injuries and disorders. *Journal of Rehabilitation Research & Development* 45(6), 831-840.