



Social Policy Research Centre Report Series

Faculty of Arts and Social Sciences

Research into Maximising Life Choices of People with a Spinal Cord Injury

Final report

For Spinal Cord Injuries Australia

January 2013

SPRC Report 01/13

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Spinal Cord Injuries Australia



Family &
Community Services
Ageing, Disability & Home Care

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Acknowledgements

Thank you to the respondents to the survey and interviews, key informants, research team, Ageing Disability and Home Care, Department of Family and Community Service NSW, and Spinal Cord Injuries Australia.

This research was supported by Ageing Disability and Home Care, Department of Family and Community Service NSW.

Suggested citation

Bates, S., Kayess, R., Fisher, K. R. (2013). *Research into maximising life choices of people with a spinal cord injury* (SPRC Report 01/2013). Sydney: Social Policy Research Centre, The University of New South Wales. Prepared for Spinal Cord Injuries Australia.

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ISSN: 1446-4179

ISBN: 978-0-7334-3264-4

Published: January 2013

The views expressed in this publication do not represent any official position on the part of the Social Policy Research Centre, but the views of the individual authors.

Contents

1	Executive Summary	1
2	Introduction	3
	2.1 What is a spinal cord injury	3
	2.2 Research scope and approach	4
	2.3 The National Disability Insurance Scheme	4
3	Methodology	5
	3.1 Research design.....	5
	3.2 Research stages and methods	5
4	Summary of research participants	7
	4.1 Participants.....	7
	4.2 Survey demographics	7
	4.3 Wellbeing of participants.....	9
5	Framework for analysis	11
	5.1 Appreciative inquiry.....	11
	5.2 Social inclusion framework.....	11
	5.3 Presentation of the research data	12
6	Achievements	14
	6.1 Learning.....	14
	6.2 Working	15
	6.3 Engaging	16
	6.4 Influencing	17
7	What resources facilitate achievements	18
	PART A: INDIVIDUAL RESOURCES.....	18
	7.1 Maintaining and improving physical health and emotional wellbeing	19
	7.2 Setting goals.....	20
	7.3 Qualifications and prior work experience.....	21
	7.4 Financial security	22
	7.5 Social network	23
	PART B: FAMILY RESOURCES.....	26
	7.6 Housing availability and accessibility	26
	7.7 Receiving family and community support.....	28
	PART C: COMMUNITY RESOURCES	30
	7.8 Healthcare services	32
	7.9 Personal care services.....	35
	7.10 Equipment and aids	37
	7.11 Financial support	38
	7.12 Information services.....	40
	7.13 Transport	41
	7.14 Environment and safety	42
	7.15 Economic activity	43
	7.16 Problem solving	45
8	Implications to develop or enhance support services	46
	8.1 Maintaining and improving health.....	47
	8.2 Supporting participation in family and social life	48
	8.3 Providing support to family and friends	48
	8.4 Promoting workforce participation and training.....	49
	8.5 Improving information resources.....	49
	8.6 Increasing financial security	50
	8.7 Continued improvements to government policy.....	51
	8.8 Increasing accessible housing, facilities and transport	52
	8.9 Implications for further research.....	52

Appendix 1 Roundtable	54
Appendix 2 Interviews	56
Appendix 3 Survey	59
Appendix 4 Literature review	67
References.....	68

List of tables and figures

Table 4.1: Sample sizes	7
Table 4.2: Characteristics of survey participants	8
Table 4.3: Location of survey participants by ABS classification of remoteness	9
Table 4.4: Participant Personal Wellbeing Index Scores.....	10
Table 7.1: Highest level of education completed by survey participants compared with Australian average	21

Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ASGC	Australian Standard Geographical Classification (zones)
ASCIR	Australian Spinal Cord Injury Registry
GP	General practitioner
NSW	New South Wales
PWI	Personal Wellbeing Index
SCI	Spinal cord injury
SCIA	Spinal Cord Injury Australia
SPRC	Social Policy Research Centre
UNSW	University of New South Wales

1 Executive Summary

Spinal Cord Injuries Australia (SCIA) commissioned the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW) to carry out research about maximising life choices of people with a spinal cord injury. The research was supported by Ageing Disability and Home Care, Department of Family and Community Service NSW. This report outlines the methods, findings and implications of the research.

The research involved a literature review, one-to-one interviews, roundtables and an on-line survey (Section 3). Total participants were 111, including 83 in the online survey. Hard to reach groups such as Aboriginal and Torres Strait Islanders, people living in regional locations, born overseas or from a culturally and linguistically diverse background, were well represented in the survey. Overrepresented were women, older people and people with higher levels of education (Section 4).

The Personal Wellbeing Index was used to measure people's quality of life. The scores were within the normal range for Australians, although the average score for participants was, as expected, lower than the Australian average in most cases (Section 4).

The research was conducted using a number of methods including appreciative inquiry about people's goals. The findings of the research have been analysed and organised using the social inclusion framework in order to identify whether people have the opportunity to participate fully in society and how they are able to maximise their life choices (Section 5).

The data presented in this report (Section 6 and 7) are from the interviews, roundtables and on-line survey; they are qualitative (interviews, roundtables, survey) and quantitative (survey). We were able to quantify from some of the qualitative data because of the common responses. This data should be used with caution because the responses were not from a closed list of prompts. The breadth of the analysis is based on the information provided by participants and therefore may not be comprehensive across all themes of social inclusion.

Access to resources to maximise opportunities and capabilities are necessary for people to be able to make life choices and experience social inclusion. Research participants said that physical and emotional wellbeing are fundamental to being able to access opportunities. Furthermore, two-thirds of participants said the role of the family in terms of emotional, physical and financial support was the most important resource in being able to achieve goals.

The key implications arising from this research (Section 8) are the need to:

- support to maintain and improve health
- support participation in family and social life
- provide support to family and friends

Maximising life choices of people with a spinal cord injury

- promote workforce participation and training
- improve information resources
- increase financial security
- improve government policy
- increase accessible housing, facilities and transport.

The implications are of equal importance in terms of supporting a menu of resources for people with a spinal cord injury to enable them to maximise life choices. People have different priorities depending on their individual situation, which changes over their life time.

2 Introduction

Spinal Cord Injuries Australia (SCIA) commissioned the Social Policy Research Centre (SPRC) at the University of New South Wales (UNSW) to carry out research about maximising life choices of people with a spinal cord injury. This report presents the methods, findings and implications of the research.

2.1 What is a spinal cord injury

A spinal cord injury is damage to the spinal cord that results in a loss of function, including mobility and feeling. Australia uses the US Centers for Disease Control and Prevention's definition:

the occurrence of an acute, traumatic lesion of the neural elements of the spinal canal (spinal cord and cauda quina) resulting in temporary or permanent sensory deficit, motor deficit, or bladder/bowel disfunction. (Thurman et al., 1995)

Injuries may be traumatic, e.g. car accident or fall, or non-traumatic, e.g. caused by illness. Common terms associated with spinal cord injuries are tetraplegia (also referred to as quadraplegia) concerning the loss of function below the neck, and paraplegia concerning the loss of function below the chest.¹

The extent of an injury is classified by the location of the spinal cord segment damaged and functionality lost. Injury classification for the purpose of this report is C1 to C8 representing the cervical nerves – an injury here is termed tetraplegia; T1 to T12 representing the thoracic nerves; L1 to L5 representing the lumbar nerves; and S1 to S5 representing the sacral nerves. The terms complete and incomplete are often used to describe whether the loss of function is complete or incomplete below the injury site.

More than 10,000 people in Australia have a spinal cord injury.² One new injury is sustained every day, mostly in males in the age group 15-24 years old; lengthy hospitalisations are common, with a median stay of 133 days (AIHW³: Norton, 2010).

Advances in critical care and rehabilitation mean that life expectancy is comparable with the general population; however, there is still some progress to be made in improving quality of life. Some people may require full-time 24 hour support; some people require little or no support. Support may be provided by formal care providers, family or community members, or a combination. In addition to emotional and physical support, the day-to-day financial costs associated with an injury can be large.

The Australian Spinal Cord Injury Registry (ASCIR) records injuries which are then reported periodically by the Australian Government (for latest report, see AIHW:

¹ SCIA website, <http://scia.org.au/health-sci-facts> (date accessed 25 June 2012)

² Spinal Network Australia and New Zealand website, <https://spinalnetwork.org.au/node/42> (date accessed 2 July 2012)

³ Australian Institute of Health and Welfare

Norton, 2010 for the reporting period 2007-2008). There are six spinal units across the country; they treat new incidents of SCIs, as well as provide outpatient and outreach care.

2.2 Research scope and approach

SCIA engaged SPRC to conduct research to identify how to maximise life choices of people with a spinal cord injury. The research draws on data collected from people with a spinal cord injury and reflects their life experiences since their injury, in particular by examining achievements and understanding about what made the achievements possible.

The SPRC has developed this research by gaining an understanding of issues faced through one-to-one interviews or group discussions, and then by exploring and quantifying the issues through an on-line survey.

The research and analysis distinguishes between informal and formal support. Informal support includes assistance from family, friends, networks and the broader community; whereas formal support includes paid support available through government, non-government and private services.

The purpose of the research is to inform SCIA about future directions for policy and services required to maximise the opportunities for people with a spinal cord injury to achieve their goals and aspirations, across a range of personal needs.

2.3 The National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) is being developed to provide a lifetime approach to providing long-term, high quality support for people who have a permanent disability that significantly affects their communication, mobility, self-care or self-management. The five launch sites will commence in July 2013. The scheme aims to provide:

- a lifetime approach, providing long-term funding that will change with needs
- choice and control, allowing people to control what support they receive and when
- social and economic participation, encouraging people to live to their full potential within the community
- early intervention, investing in remedial and preventative intervention.

This report is a useful reference for NDIS and other service design about considerations for people with a spinal cord injury.

3 Methodology

3.1 Research design

The research was designed to investigate the life choices of people with a spinal cord injury. The research included qualitative data from roundtables (Appendix 1); in-depth interviews (Appendix 2); a survey (Appendix 3); and a literature review (Appendix 4). Each stage of the research informed the subsequent stage.

3.2 Research stages and methods

The research was conducted in four phases, which overlapped during implementation.

Phase 1: Project plan and preliminary literature review

The initial stages of the research included planning and refining the scope and focus of the research questions and methodology, based on consultation with the SCIA and a literature review. Ethics approval was obtained from the UNSW Human Research Ethics Committee (Approval Reference 11382).

Phase 2: Fieldwork data collection and analysis

The purpose of the fieldwork is to understand the lived experience of people with a spinal cord injury in terms of quality of life, life choices, support needs, experience of good support and gaps in support. The fieldwork involved three components: two roundtables, in-depth interviews, and a survey. The roundtables were held to inform the design of the survey, and upon the completion of the fieldwork to confirm research findings and explore implications.

Interviews were conducted with 14 people living in urban and regional areas, recruited by SCIA through their newsletter, website and direct contact. The interviews were based on the discovery method to encourage informants to tell the story of their experience rather than answer questions. The first roundtable provided an opportunity to discuss the preliminary findings of the interviews with a small group of participants in order to clarify the findings and to help develop the framework of the survey (See Appendix 1).

The survey was designed to explore, clarify, confirm and quantify the findings of the interviews, and was offered to anyone in Australia with a spinal cord injury (Appendix 3). The survey was sent to SCIA for distribution to both members and clients; SCIA also sent the survey to partner organisations including Hearts in Union, Spinal Injuries Association Queensland, AQA Victoria, AQA South Australia, the Paraplegic and Quadriplegic Association of Western Australia, Paraquad NSW, the Agency for Clinical Innovation, and the Spinal Cord Injury Network. The SPRC published the survey on the SPRC website and sent it to contacts at People With Disability, Ideas, Community Net, and Australian Policy Online.

The survey investigated:

- goals and aspirations
- general wellbeing
- emotional and physical aspects of day to day life with regard to informal support
- satisfaction with formal support and
- care provided immediately after the injury.

Phase 3: Literature review

The literature review focused on the gaps identified in the fieldwork and in particular, how government and non-government organisations in both Australia and overseas address the gaps either at a policy or service level (Appendix 4). The findings are incorporated in the analysis and recommendations.

Phase 4: Analysis and reporting

Thematic analysis was used for the qualitative data, based on a combined deductive and inductive process, drawing on the aims of the research and the themes and issues evident from the data. The social inclusion framework was used to structure the analysis (Section 5). The analysis was conducted in conjunction with the final roundtable in order to confirm and clarify the emerging findings before the final analysis was confirmed. Survey data were analysed using SPSS⁴ and incorporated with the qualitative findings.

⁴ Statistical Package for Social Sciences

4 Summary of research participants

4.1 Participants

The research included a total of 111 contributions (see Table 4.1) across the roundtables, interviews and surveys, with some people contributing through more than one method. Participation in the research was limited to people with a spinal cord injury; the organisation Spinal Cord Injuries Australia provided guidance to the overall research.

Table 4.1: Sample sizes

Method	Number of participants
Roundtable start*	8
Roundtable end*	6
Interviews	14
Survey**	83
Total	111

Notes: * Does not include carers, members of the SPRC research team or SCIA
 **An additional 83 survey responses were incomplete

4.2 Survey demographics

A total of 166 people attempted to complete the survey, of whom 83 provided complete or mostly complete responses. Not every person completed every question. The survey was made available online and promoted by SCIA as well as SPRC. The option to complete the survey on the phone was offered but not used by participants. Table 4.2 presents the characteristics of survey participants by number of respondents.

Table 4.2: Characteristics of survey participants

Characteristic (n=number of respondents)		Percentage of participants*
Age (n=71)	18-25	5.6
	26-35	5.6
	36-45	15.5
	46-55	32.5
	56-65	31.0
	66-75	5.6
	76+	4.2
Gender (n=73)	Female	41.1
	Male	58.9
Type of injury (n=75)	Non-traumatic	13.3
	traumatic	86.7
Level of injury (n=71)	Cervical nerves (C1-C8)	55.0
	Thoracic nerves (T1-T12)	39.4
	Lumbar nerves (L1-L5)	5.6
	Sacral nerves (S1-S5)	0
Country of birth (n=71)	Australia	76.1
	Overseas	23.9
Years since injury (n=72)	1 to 5 years	23.6
	6 to 10 years	19.4
	11 to 15 years	5.6
	16 to 20 years	2.8
	More than 20 years	48.6
Aboriginal or Torres Strait Islander (n=70)	Yes	2.9
	No	97.1
From a culturally and linguistically diverse background (n=71)	Yes	16.9
	No	83.1
Live in an urban/regional location (n=70)	Urban	50
	Regional	50
Living circumstances (n=72)	Alone	15.3
	Alone with carers	6.9
	With family	72.2
	Other	5.6
Received compensation for injury (n=68)	Yes	20.6
	No	76.5
	Waiting	2.9
Highest level of education completed (n=71)	Primary school or less	4.2
	Some secondary or high school	16.9
	Year 12 (secondary or matriculation)	15.5
	Trade certificate/apprenticeship or similar	25.4
	Bachelor degree	22.5
	Post graduate degree	15.5
Main source of income (n=71)	Private income (job or own business)	40.8
	Public support (disability pension or other)	43.7
	Other income support payment (insurance)	5.6
	Superannuation	8.5
	Other	1.4
Participation in productive activity, can answer more than one (n=65)	Paid work	33.7
	Voluntary work	29.3
	Study	15.2
	Other	21.7

Source: Survey: Section F – About you
 Note: *of people who responded (n)

Most people lived in city (50 per cent) or inner regional (26 per cent) locations (Table 4.3). Due to the methods of survey distribution, most respondents lived in NSW (70 per cent), 24 per cent in Queensland, with the remaining 6 per cent coming from the Northern Territory, South Australia, Victoria, and Western Australia.

Table 4.3: Location of survey participants by ABS classification of remoteness

Location	Per cent of participants*
City	50
Inner regional	26
Outer regional	21
Remote	3
Very remote	0

Source: Survey Section F – About you, converted to Australian Standard Geographical Classification Zones (ABS) ⁵

Note: * of people who responded to this question (n=70)

Hard to reach groups

Some groups were more difficult to reach in the interviews. This was anticipated, and effort was made at purposive sampling through key service providers, networks and contacts; this was not fully successful, consistent with other social research (Brackertz, 2005). People from Aboriginal and Torres Strait Island backgrounds were hard to access, even when contact was made through SCIA. In addition, although the researchers actively sought interviews with people living in regional areas, these were still limited.

Due to the way in which the survey was distributed, to existing members of SCIA and other organisations, the results of the study is not representative of all people with a spinal cord injury.

Tables 4.2 and 4.3 show that some hard to reach groups were reasonably represented in the survey (e.g. Aboriginal or Torres Strait Islander, people living in a regional location, born overseas, or from a culturally and linguistically diverse background). Women were over represented in the survey (41 per cent, compared to new injury rates of 16 per cent women; 2007/2008 AIHW: Norton L, 2010; and SCIA membership 32 per cent women⁶). In addition, the survey participants were generally older and more highly educated than the general population. Nonetheless, important contributions to the research were made and this is constructive in the formulation of any new directions for spinal cord injury policy.

4.3 Wellbeing of participants

The research investigates how satisfied participants are in their daily life, both in terms of overall satisfaction and about satisfaction with specific aspects of it, to

⁵ The ABS 'Remoteness Structure' classifies Australia into regions that share common characteristics of remoteness. It is based on the calculated road distances to the nearest service centres in 5 categories of population size. See <http://www.abs.gov.au/websitedbs/D3310114.nsf/home/remoteness+structure>.

⁶ Source: Peter Perry, CEO SCIA, 6 September 2012.

determine their wellbeing. Personal wellbeing can be interpreted as an outcome or goal and can also affect both confidence and resilience, which may be linked to the ability to identify and achieve goals and aspirations, and the ability to maximise life choices.

The Personal Wellbeing Index (the International Wellbeing Group, 2006) was used in the survey to measure people’s feelings about themselves to determine their quality of life and compared to the general population (Table 4.4).

Table 4.4: Participant Personal Wellbeing Index Scores

	Participants	Australian general population [§]
Life as a whole ***	64	78
Personal Wellbeing Index***	68	75
Standard of living*	73	78
Health***	57	75
Achieving in life***	65	74
Personal relationships***	70	79
How safe you feel	75	79
Community connectedness	67	71
Future security***	60	71
Spiritual/religious***	71	78

Notes: Scale 0-100. *_*** denoted significant difference in scores with *** being most significant - Significance tested using t-tests of survey responses compared with normative population, significance * p<0.05, ** p<0.01 and *** p<0.001

[§] Normative scores taken from Australian Unity Wellbeing Index report 26, September 2011 (Cummins & Schaefer 2011)

Most people had wellbeing scores within the normal range for Australians (50-100); the average score for this group (67.78) was, as expected, lower than the Australian average, both on the combined PWI score (75.23) and on specific items with two exceptions. The ‘feelings for safety’ and ‘community connectedness’ were not significantly lower than the general population – this may be because people responding to the survey have already become connected within the community (possibly demonstrating survey bias).

In preparing the survey, the research team formed a number of hypotheses about the factors likely to have an impact on wellbeing, including presence of a spinal cord injury; severity of injury; years since injury; amount of activity and social participation; living situation; and whether compensation had been received. However, no demographic or injury-related variable such as level of injury, time since injury, level of education, activity, living situation, or financial compensation, were associated with a significant difference in PWI scores. This could be because the sample is small, or that the difference within the group is explained by variables not collected by the data. Other research also concurs that the level of injury has no impact on people’s feelings about themselves in the longer term; whilst feelings may change initially after the event, many soon return to normal (Brickman et al., 1978).

Whilst it was useful to measure wellbeing to provide a context for other elements of the research, the size of the sample means that the data should be understood in the context of the qualitative responses. The majority of the findings from this research are based on the open questions included in the survey and the narrative discussion provided during interviews, supplemented by the data captured here.

5 Framework for analysis

The research was designed using appreciative inquiry. The findings have been analysed and organised using the social inclusion framework in order to identify whether people have the opportunity to participate fully in their communities and how they are able to maximise their life choices.

5.1 Appreciative inquiry

In considering how to maximise life choices, this research uses appreciative inquiry to better understand:

- achievements, in terms of learning, working, engaging and influencing (Section 6)
- what made achievements possible in terms of resources, and the opportunities or capabilities to use the resources (Section 7).

Appreciative inquiry is a form of analysis that seeks to identify what is working rather than merely identifying problems (Rogers & Fraser 2003). Appreciative inquiry begins by using stories of positive experiences to identify themes, identifying what has helped to achieve goals. The participants are not directed or led in any way. Analysis then identifies themes, which in this research were grouped according to the themes identified in the social inclusion framework (Section 5.2).

Stakeholders are generally more interested in appreciative inquiry and are more forthcoming with information. Appreciative inquiry also stresses the use of findings for decision making and action, and is often used as part of a process whereby the themes are taken back to participants with proposed strategies, processes and systems to address issues raised (in this case the roundtables and post research report).

This method cannot always be relied upon to gain an understanding of all weaknesses in a system. However, it was considered a useful tool in this research when used in conjunction with other methods of evaluation (personal well being index and broader questions).

5.2 Social inclusion framework

Social participation is increasingly considered a pivotal outcome of successful rehabilitation (Noreau et al., 2004). Levasseur, Desrosiers and Noreau (2004) explore the relationships between subjective quality of life and social participation of older adults with physical disabilities using 'LIFE-H', an instrument that documents the quality of social participation by assessing a person's performance in daily activities and social roles (life habits). Only a weak relationship was found between total scores of quality of life and social participation; however, they found that:

- interpersonal relationships, responsibilities, fitness and recreation were the categories of social participation most associated with quality of life
- social roles were more associated with quality of life than daily activities and

- satisfaction with the accomplishment of life habits were also more associated with quality of life than the performance itself.

The Australian Government's vision of a socially inclusive society is one in which all Australians feel valued and have the opportunity to participate fully in the life of our society:

Being socially included means that people have the resources, opportunities and capabilities they need to:

Learn – participate in education and training

Work – participate in employment, unpaid or voluntary work including family and carer responsibilities

Engage – connect with people, use local services and participate in local, cultural, civic and recreational activities

Have a voice – influence decisions that affect them

Resources refer to the skills and assets people have (or various types of capital, including human, social and economic capital).

Capabilities refer to an individual's ability (or agency) to use resource and opportunities to achieve the outcomes they wish.

Opportunities refer to the environment (or structure) that enables the individuals to use their capabilities and resources to achieve the outcomes they wish. (Australian Government, 2012: 12)

The notion of social inclusion also provides for a definition of social exclusion, in that where a person has multiple disadvantages they become or are at risk of becoming socially excluded.

The implications of the analysis are presented in Section 8 of this report.

5.3 Presentation of the research data

The data contained in this report include qualitative data (interviews, roundtable meetings and survey) and quantitative data (survey). The data have been analysed in terms of the social inclusion framework – quotes from participants illustrate key points in terms of achievements and resources.

As there was a lot of commonality in the qualitative data in the survey, the research team chose to quantify some of this data – this is described as data that are quantified from the qualitative responses. The source of the quantitative data is identified in this report according to the survey question. The data quantified from qualitative responses should be used with caution.

Comments made by participants, whether in relation to achievements or resources, were identified individually and not selected from a pre-determined list. Participants

in the survey were not prompted in any way. The breadth of the analysis is based on what information was provided by participants and therefore may not be comprehensive across all themes of social inclusion. Discussion is representative of their knowledge and use of resources and services available to them.

Note that the implications identified are not prioritised – they are of equal importance in terms of the menu of services available to support people with a spinal cord injury to maximise life choices. Individuals accessing the services will have different priorities depending on their individual situation and these priorities are likely to change over time as their personal circumstances change, e.g. time since injury, health, age (e.g. health or workforce participation), family, etc. In addition, most implications are interrelated, i.e. they support each other. For example, improving information resources supports all the other areas identified.

6 Achievements

Survey participants identified a number of achievements they had made in different areas of their lives – some of which lead to the achievement of other goals. Achievements are organised in terms of learning, working, engaging and influencing, as identified in the social inclusion framework outlined in Section 5 above. Section 7 includes further examples of achievements in terms of what resources make achievements possible. The data presented are sourced from the survey and interviews (Section 5.3).

6.1 Learning

'Education is ... fundamental to achieving a socially inclusive society, and for many, it can provide a pathway out of disadvantage' (Australian Government, 2012: 5). 'Higher education provides greater employment opportunities... [people perceive] greater control and encountered fewer handicaps' (Chase, Cornille & English, 2000: 18). Pflaum et al. (2006) also reported that higher education greatly increases the likelihood of employment post-injury but is also influenced by the level of injury, age, marital status and pre-injury employment.

A quarter of survey participants identified carrying out further study as a key achievement (survey question 3 - quantified from qualitative responses). People completed further study either to increase employment opportunities, retrain or pursue interests.

[The] biggest "life goal" I achieved was to complete a degree After completing I did feel a sense of achievement and it was the first real concrete goal that I had set out to achieve. It took me six years part-time study and I was also working part-time. I gained a lot from attending university as a student with a disability and it did give me confidence generally in my life.

I'd rather get the qualifications now ... so I can either get a job and get sort of life going, and then when medical science gets to the point where it can fix me, then I'll have the money and I'll have the qualifications; I will be better off than sitting around doing nothing now.

I would like to do more postgraduate study ... it keeps me sane and absorbed ... so I'm looking for something to study next that is physically feasible but real enough to still be an intellectual stretch ... and an achievement if I get through it.

A further 5 per cent of participants also identified study as a future goal (question 4 - quantified from qualitative responses), indicating that not all needs are currently being met.

See also Section 7.3 – Qualifications and prior work experience.

6.2 Working

‘Employment is a powerful vehicle to increase social inclusion, and more Australians than ever are now experiencing the benefits of work’ (Australian Government, 2012: 5). Chase, Cornille and English (2000: 18) report that people ‘employed at least part time were found to perceive more control, experience less handicap, and perceive more satisfaction with life. Economically, the availability of more disposable income, as compared to non-workers, provides the financial resources to reduce or remove barriers’. Krause and Anson (1997: 207) also report a strong association of education and employment with quality of life after a spinal cord injury.

Almost half of the survey participants (48 per cent) identified participating in the workforce as a key achievement, and a further 8 per cent identified participating in the workforce as a key future goal (survey questions 3 and 4 respectively - quantified from qualitative responses). Participation in the workforce can have a number of positive outcomes, including social participation, and provides an income that has a positive impact on other aspects of lifestyle, e.g. housing, aids and equipment, and holidays.

Work is my main source of formal support as it enables me to earn a living and get on with my life.

Some people were able to return to previous employment, either full time or part time. Some set up their own businesses and others had to retrain as their original employment was no longer suitable.

I have retrained as a social welfare worker as I could not return to my pre-accident career of nursing.

Pflaum et al. (2006) report that participation in the workforce prior to injury is an important predictor, but not the only predictor, of post-injury participation. They also found that whilst people with a spinal cord injury are far more likely to work than has been suggested by previous studies, with the possible exception of people with professional degrees, they do have significantly reduced work lives.

The average labour force participation rate for the general population of Australia is 65 per cent.⁷ Of the survey participants, 33.7 per cent were currently in paid employment and 29.3 per cent worked in a voluntary role (Table 4.2 – note that participants could select more than one and that 10 per cent of the participants were over 65 years old).

See also Section 6.3 – qualifications and prior work experience, and Section 7.15 – economic activity.

⁷ ABS 6202.00, August 2012, www.abs.gov.au/ausstats/abs@.nsf/mf/6202.0, date accessed 10 September 2012

6.3 Engaging

Engaging in social inclusion terms, includes connecting with people, using local services, and participating in local, cultural, civic and recreational activities (Australian Government, 2012). For most people, engaging and connecting with people is part of everyday life and requires little effort. For someone with a spinal cord injury, engaging and connecting with people can be a massive achievement due to the physical, financial and social barriers that must be overcome.

Of the survey participants, 66 per cent (survey question 3 – quantified from qualitative responses) identified the support of family and friends as the reason why they had achieved their goals. The emotional and physical support provided by family and friends was identified as critical to achieving goals. Some participants also identified the need to participate more in family life and participate more in the community (11 per cent: survey question 4 – quantified from qualitative responses). In particular, they identified that social participation was difficult to achieve when relying so much upon family and friends for support – they identified that the role of family and carer had become blurred.

[I would like to] participate in community [life] without having to rely on my wife or family to assist me when I want to work, volunteer or in recreation.

Achievements in terms of local, cultural, civic and recreational activities were constrained by access problems (Section 7.6 – Housing availability and accessibility and Section 7.14 – Environment and Safety). Achievements identified focused on structured activities, such as participating in sports, and travel. The importance of social networks is discussed further in Section 7.5.

Travel was identified by 17 per cent of participants as a recent achievement (survey question 3 – quantified from qualitative responses), although not everyone indicated that it was a rewarding experience due to the lack of accessible services.

I travelled alone ... and the outgoing trip, especially, was a bit of a nightmare. I would hesitate to travel alone again if at all ... there was virtually no service for a disabled person ... I managed it, but not I sure will do it again, too much stress.

A further 28 per cent of participants identified travel as a goal, the most common goal identified in the survey (survey question 4 - quantified from qualitative responses), suggesting that to date travel had not necessarily been feasible. The language used in the responses related mainly to travel, i.e. exploring new places, as opposed to seeking respite.

My goal is to do some trips (smaller ones in Australia then I'd love to do a river cruise in Europe).

A further 14 per cent (survey question 4 - quantified from qualitative responses) identified participating in sports as a key achievement, ranging from representing the country to participating in sport at a social level. Again, others identify participating in

more sport as a goal, suggesting that where more sport was available, the participation rate would be higher (see also Section 7.1).

6.4 Influencing

Participants actively influence a number of areas of their lives, from personal daily needs to broader issues of access and inclusion. Most people with a spinal cord injury require some assistance, either from care providers or from family and community. Chase, Cornille and English (2000) noted that where people took sole responsibility for directing their care, they were found to perceive more control over their lives (Chase, Cornille & English, 2000: 18). This was also found true in this research, where the level of satisfaction seemed higher for people who had more control over their care and where there was more continuity of care as a result.

Personal care is the most fundamental aspect of influencing for someone with a spinal cord injury; if they have no control over their care they are very disempowered – this goes on to affect every other aspect of their life. Chase, Cornille and English (2000) recommend that it is important to provide skills to direct the services of personal carers – this seems particularly relevant where Australia moves towards the National Disability Insurance Scheme (NDIS). They also reported greater satisfaction of care when provided by family members as opposed to formal care services. Again, this research substantiated their finding, with the caveat that many felt that the burden on family was too great (see Section 7.7).

A number of participants took on a role advocating for the rights of people with a spinal cord injury and with other disabilities, including volunteering in the community, raising awareness aimed at preventing future injuries, mentoring others, and advocating access issues at specific locations or more generically in the community.

The bane of my existence is parking ... I've had a lot of fights with people about that – shopping centres, councils and so on. I took [one company] to the Human Rights Commission with some success ... I wish there was some kind of process that didn't involve that. The Human Rights Commission don't have any teeth either, they can't enforce anything. They did a review on the national accessible parking thing a couple of years ago ... The draft premises standards – I submitted a paper to that. Government ignores you basically.

Every concession that we have is something somebody fought for ... you've got to be willing to take it to court.

Participants commented that making a complaint or advocating for rights takes time and energy and it would be good if someone else could do this on their behalf, or help in some way.

7 What resources facilitate achievements

Participants in the study identified a number of resources that provide them with the opportunities and capabilities to achieve their goals. Resources include human, social and economic capital that may come from individual resources (Part A below); family resources (Part B); and community resources (Part C). Participants also identified resources that were missing, or that were being threatened, therefore presenting a risk to opportunities and capabilities to achieve goals, potentially leading to social exclusion. The data are from the survey and interviews (Section 5.3).

PART A: INDIVIDUAL RESOURCES

Individual resources include physical and emotional wellbeing, setting goals, qualifications and prior work experience, financial security and social networks.

Key points:

- maintaining and improving health is critical to achieving other goals – this includes general health, physical (i.e. strength) and emotional wellbeing
- the capacity to achieve personal goals usually relies on other things, including people or resources
- education and work experience are critical in finding employment
- financial security continues to be a threat for many people, from meeting everyday living expenses to achieving goals
- participating in a social network, including family and community life, is vitally important for wellbeing; however, physical barriers can prevent participation

Implications:

- encourage proactive healthcare management by healthcare practitioners
- provide better access to healthcare services, including emergency healthcare, physiotherapy and counselling
- increase access for physical activities
- increase and facilitate access to community resources to achieve goals (Part C: Community Resources)
- maintain support for further education, and include assistance to identify and source appropriate courses and advocate for more accessible courses
- improve access to financial advice in terms of the cost of living with an injury and the financial resources available
- continue to advocate for the removal of barriers to allow participation in a social network; this may include increasing access in public places, providing support to participate in family life, increasing access to social and sporting activities, increasing access to travel

7.1 Maintaining and improving physical health and emotional wellbeing

Maintaining and improving physical health and emotional wellbeing was identified by participants as both a key achievement and a key resource to achieve other goals. This ranges from monitoring and maintaining, to improving basic health and function, and includes emotional wellbeing.

I diarise ... everything that I do and I have done ... since I came out of hospital ... You can see the progress, you can see if you're having a bad day it's not the end of the world.

More hours of care would improve my physical health and wellbeing, and hence my emotional health and reduce my burden and future burden on society.

Many participants engaged in additional physiotherapy or sports activities to improve strength and found that it had a positive impact on their general wellbeing; 7 per cent of survey participants identified physical improvements in health and function as key achievements (survey question 3 - quantified from qualitative responses). This is important given that many people have been told that these achievements would not be possible.

I continue to be as active as I possibly can. There is nothing better to feel physically exhausted from exercise at the end of the day rather than feeling emotionally exhausted from not doing anything.

Working with a physio and a fitness trainer to achieve a fitness level I did not think I was capable of ... I feel more confident, stronger and more healthy.

I exercise every moment I can. I can breathe by myself now for up to 6 hours a day [a person with a C1 injury – ventilated].

Guttmann (Whitteridge, 1983) introduced the benefits of physical activity early in the care of spinal cord injured patients, claiming that sport was a way to regain fitness, boost self esteem and restore personal dignity. Many participants recognised the importance of sports and organised physical activities on general wellbeing and identified the need for more organised sports activities across the country, whether group activities or providing better access (physically and financially) to gym and sports facilities.

I think we could do with some more sports, etc. for wheelchairs. Exercise is a whole lot easier if you are having fun rather than doing it by yourself.

A number of participants highlighted the Walk On program and commented on the physical improvements that had been made under this program. However, the cost, frequency and location of the program meant that it was not accessed as often as they desired.

Last year I commenced the Walk On program and this made a big difference to my improvement.

The personal wellbeing index quantified how satisfied participants are in their daily life (Section 4.3). Within the limits of a small sample, the results were that no individual demographic or level of spinal injury related variables were associated with any significant difference in personal wellbeing scores.

Some participants in the research commented on their psychological wellbeing, although this aspect was not a focus of the study (see Elliot et al., 1991 for tools to investigate psychological adjustment and psychological wellbeing).

Depression and residual grief about losses and what is still missing in my life are what I grapple with daily.

I needed professional emotional support.

Physical and emotional wellbeing require continual management – they are fundamental to maximising life choices. Physical wellbeing cannot be ignored after rehabilitation as the body and a person's needs continue to change over time. Equally, emotional wellbeing must be continually managed as physical wellbeing and life circumstances change.

Participants in the study identified family and friends as providing emotional support, as well as physical support and financial support. They also identified the need for more professional emotional support and counselling. See also Section 7.8 – healthcare services, access to counselling.

7.2 Setting goals

Participants in the survey were asked about their goals for the future and what was needed to achieve them. People have various levels of impairment relating to mobility and carrying out day-to-day activities. Personal goals and achievements can include things that other members of society take for granted, such as eating, bathing, and maintaining normal body functions, and may extend to the broader aspirations of the rest of society, including employment and travel.

Most people (98 per cent) of survey participants had clear goals (survey question 3) and knew what was needed to achieve them. They include improving health and independence, participating more in the community, participating in work or study, having financial security, participating more in family life, and taking a holiday with family or friends. All of the goals required improvements to community resources in able to be achieved (see Section C).

My goals are to live life and access my community the same as those who do not have a disability.

I look forward to the day when I obtain casual or part-time employment which will give me more independence.

Travel within Australia and short distances overseas; spend more time with my grandchildren; assist others where necessary to achieve their own goals.

My goals are no different than before my accident, just a lot harder to achieve.

To retain my independence, I dream of becoming continent, to be pain free and stop the deterioration of my body. To wake up one morning and saying to my wife let's go and see the kids without the nagging problem of having a bowel accident. To be able to leave the house without taking medication to prevent bowel accidents, to have a coffee, see my GP, go on a holiday and be able to leave the room.

7.3 Qualifications and prior work experience

Participants were asked what level of education they had achieved; it became apparent during the interviews and survey that some participants had gone on to complete further education since the time of their injury – this was not measured separately. Factors influencing whether participants had sought further education include how old the person was at the time of injury, e.g. whether they were injured before completing their education, whether they needed to retrain post-injury, or whether they simply chose to further their education out of interest.

I'm pretty lucky that I was three months away from being a qualified accountant, I could return to work for what I was educated and trained for before my accident ... I was lucky that I could have an income after my accident and didn't have to rely on the Disability Support Pension, which isn't that much anyway, to live off.

In comparison with the general population, the survey participants appear not to be in any way disadvantaged by their level of education (Table 7.1). Due to sample size, this is not necessarily representative.

Table 7.1: Highest level of education completed by survey participants compared with Australian average

Highest level of education completed	Per cent	
	Australian population	Survey participants (n=71)
Some secondary school or less	29.1	21.1
Year 12 (secondary or matriculation)	20.6	21.1
Trade certificate/apprenticeship or similar	26.5	25.4
Bachelor degree	17.0	22.5
Post graduate qualification	6.7	15.5

Source: Survey question 27 and ABS 2011, ABS 6227.0 – Education and Work

Further education was still being sought by some people; whilst the barriers to further education had been reduced significantly over the years, barriers still exist.

Individual teachers at university during recent study have been very supportive ... but the services for disabled students are still laborious, and often far too late in being delivered ... if at all. Improvements in these would help ... Also, the selection of courses

available online/distance is very meagre. If institutions could get their heads around allowing entry into wider range it would be wonderful.

Assistance could be provided in terms of identifying accessible courses and educational institutions, as well as advocating for more accessible courses and venues.

People with little or no work experience found it very difficult to find employment; this is reflective of the general population. This research did not determine whether or not first time job-seekers found it more or less difficult to gain employment than the general population. The findings of this research highlight that the needs of first time job-seekers may be different to people who have prior work experience, not just in finding employment, but also in adapting to work spaces, and that employment services need to take account of these differences. See also Section 7.15 economic activity.

7.4 Financial security

Participants said financial insecurity was a threat to achieving their goals. The financial impact of a spinal cord injury can be two-fold: the costs of living with a spinal cord injury are high; and the injury may prevent or limit a person's ability to earn income or the amount of time they spend at work.

Of the participants in the survey, 44 per cent relied on government support (Table 4.2) and many commented that it was difficult to live on the disability pension alone. Some identified that additional financial support had been provided by family or the community, particularly for large expenditures such as equipment or home modifications.

Only 21 per cent of participants had received any form of financial compensation for their injury (Table 4.2). Financial compensation was not always immediate or forthcoming.

I received financial support in the way of compensation 3 years after my accident – which made life much easier.

I was involved in my own civil litigation action seeking compensation for my injuries. The lawsuit was fought in the Federal Court and the High Court of Australia. That in itself was extremely draining.

The survey identified a number of aspects of financial security that could be further explored, including identifying the costs of living with an spinal cord injury; understanding the ongoing financial assistance available, either through compensation, superannuation, insurance or government assistance; and identifying ways to pay for one-off expenditures such as home/car modifications, travel and respite (see also Section 7.11 – financial support)

In addition to income support for higher living expenses and loss of income, some people identified transport and car modifications as something that would provide a high return on investment.

A lot of people don't have insurance or aren't covered by lifetime care that are trapped relying on family for transport. I'm perfectly fit to drive yet cannot afford to.

One survey participant has set up a business providing financial advice to peers.

So there's the financial side of things ... doing a very basic budget for them to make sure that they're going to earn more income than they're going to spend. If they do have a compensation payout, it's about investing their money wisely so they don't pay too much tax and it'll protect them for the rest of their life. ... I'm a chartered accountant but I've sort of branched out and diversified to specialise in spinal cord injuries.

Another participant recommended providing financial counselling for people in receipt of large compensation payments to ensure that they were not exploited and the payment was managed to cover ongoing costs.

7.5 Social network

Involvement in the social network includes the basic relationships we form with our family and friends, and engaging in everyday social activities such as basic errands, participating in a community organised activity, and travel. They can be difficult to measure and assess as they are not necessarily performed everyday (Noreau et al., 2004).

In addition, 'in line with the UN Convention on the Rights of People with Disabilities, the concept of citizenship is synonymous with the whole-of-life approach, where the rights to participation in the arts, leisure, sport and tourism are central to any notions of citizenship' (Darcy & Dickson, 2009).

The quality of relationships with family and friends depends very much on the person, but most participants in this research reported very positively on the strength of the relationships, particularly with family. These relationships were challenged by issues of access, i.e. not being able to visit family or friends, or join them in social situations, and also challenged when people moved away from those networks (see Section 7.6 – housing accessibility). Additional support may be required where the family and social networks are weak, or in circumstances where they need to be reformed.

I would like advice on relationship maintenance and how to meet people.

A lot of reliance is placed on family and friends providing care and support (Section 7.7 – receiving family and community support), but the two-way relationship of family and friends can be easily overlooked. Participants identified the need to be able to participate more in family and community life, assisted where necessary by formal care. Participating in every day family life may include raising children or helping with grandchildren, maintaining partner/family relationships, contributing to household tasks, and caring for relatives.

[I was] able to support my elderly mother who has supported me to hell and back [after my] injury to my spine, but unfortunately have had to put my mum in a home – it was getting too much for me as she has dementia but I am so proud of giving that back to a very special person my mum ...

I don't have any great goals, just to be able to get my wife to visit her family, visit our family and friends, and keep in contact with all our friends scattered all over the state. The pension does not cover extra petrol costs so our travel is restricted.

I think the ones that it affects most are the ones around you, your family. It's certainly made a huge difference to my wife.

Participating in family life is not limited to the home, but may include accessing events at schools or sports grounds as well as other public places. Equally, participating in community life will extend beyond the family unit and may include work life (Section 7.15), study, social activities, sport and travel.

[Getting out, with the assistance of my carers] makes me feel alive and part of the community.

I would just like to spend more time "out and about".

My children had to learn to adapt to my disability as much as myself. It's restricted things I could be involved with. A lot of school assembly areas weren't accessible so you couldn't be involved with their general schooling. I could go and watch my son's soccer match from the car – if you were getting out in the wheelchair, there were often just rough fields so you couldn't get on the sideline and follow the course of the match. [Access] put restrictions on how I was involved with her as a child as she's grown up.

It changes the whole dynamic of the family; what we can and what we haven't been able to do. We don't do everything as a family anymore.

Most survey participants were engaged in some sort of activity, whether paid work, voluntary work, study, or other hobbies. Nonetheless, many commented on how difficult it is to get paid or unpaid employment, or study. Participants identified physical recreational activities as important, particularly when they had been sporty prior to injury.

The impact was greater outside of work. There was really not a structured sporting activity for people using wheelchairs [in the region], except for basketball.

It is still hard to go and watch my mates play [rugby league and touch football] knowing that I would still be good enough at 38 years of age to play competitive sport. I had to learn new sports. I concentrated on basketball and tennis, but because I'm so disabled

... I couldn't compete at the elite level with elite wheelchair athletes because I was more disabled than them. It was a very un-level playing field.

Being able to travel, whether for work or pleasure, is an important part of life – 'tourism is seen as important component of [the] quest for life experiences' (Darcy & Dickson, 2009); 17 per cent of survey participants identified travel as a key achievement, and 27 per cent identified travel as a future goal (survey questions 3 and 4 – quantified from qualitative responses). Additional support required for travel may vary depending on personal needs; however, the cost and logistics of travel are significantly more than the general population. Some funds are available to help meet these additional costs, but the availability of carers and complexities of travelling mean that options for travel are limited. Targeted services could be developed to assist people travelling for business or leisure.

One goal I would like to achieve is an overseas holiday ... One of the barriers to this goal is a lack of funding or more correctly, a lack of flexibility in the personal care service I currently receive. It does not include the ability to use the hours that I am entitled to for an overseas holiday. So in order for me to take a carer with me I would need to pay them myself. This is a significant financial hurdle – as you can appreciate living life with a physical disability comes with additional costs already without making them any worse..

Varying experiences of travel were also reported. Sharing information about these experiences would inform other people with a spinal cord injury.

Some help with planning and managing these trips would be of benefit. Getting information on air travel, knowing what accommodation is wheelchair friendly and just knowing if it is possible.

I travelled alone ... and the outgoing trip, especially, was a bit of a nightmare. I would hesitate to travel alone again, if at all. There were not enough wheel chairs or personnel at the stopovers ... they forgot about me in the departure lounge ... there was virtually no service for a disable person.

PART B: FAMILY RESOURCES

Family resources include housing availability and accessibility as well as the support provided by family and the community.

Key points:

- the shortage of accessible accommodation to either rent or buy forces people to move out of area (away from their social network) or into accommodation with others (family or transitional accommodation)
- home modifications can be costly and may not be feasible in rental accommodation
- for most people family and community continue to be the most important sources of emotional, physical and sometimes financial support

Implications:

- provide assistance in finding accommodation that is accessible; where a person moves out of area, provide assistance in engaging in the new social network
- increase advocacy for government funding of home modifications and reducing the bureaucracy of accessing funds
- increase advocacy for financing of care services to reduce impact on family and community and to allow them to focus on the relationships
- encourage community support by facilitating more peer to peer services

7.6 Housing availability and accessibility

There has been an emphasis on independent living since the late 1970s and early 1980s. DeJong (1981) defines independent living in terms of consumer control and self-direction, social and economic productivity, and living in the least restrictive environment; outcomes that can be achieved through advocacy, self-help, peer counselling and the removal of social and environmental barriers and distinctions. Research by Mattson-Prince (1997) suggests that it is better for both the person and society to live independently as opposed to in a care facility. Benefits include significantly better health outcomes, fewer hospitalisations, and despite more hours of paid assistance, lower average costs.

The hospitalisation period after injury (for traumatic injuries) may be lengthy; AIHW:Norton (2010) report a median stay of 133 days. In some cases, where participants were living alone in rental properties, they gave up their accommodation when they were in hospital. However, when leaving hospital, accessible rental accommodation was difficult to find. Others found that the instability of renting meant that they were required to find alternative accommodation at short notice when leases were not renewed. It is difficult to modify a rental property to allow for access. The age and size of many properties in inner-city areas mean that they are not accessible and cannot feasibly be modified. This requires people to move to a different area, possibly leaving social and family networks.

Finding accommodation is a nightmare, an absolute nightmare... it's hard just looking for a house full stop. But add accessibility to it and it just becomes impossible.

The lease ran out where I was living ... We had to find somewhere at short notice. This was the only flat house in Sydney! ... All the information [about accessible services] ... it's just such a headache when you move [suburbs]. You don't know where you can shop, or finding a GP who has any sort of SCI experience ... It would be good to talk to people with local knowledge.

It is a challenge living in rental accommodation [on a short-term basis when looking for a property to buy] as I don't want to spend money on things like a rail in the bathroom, ramp into the house etc. Access to houses, buildings, of any sort, is a challenge and I have to pay more than I would without a disability.

Where accessible rental accommodation is unavailable, people either have to buy a property and modify it, move back to a family home, or move into public housing. Access issues affect all three options. Purchasing a property may be difficult at the time or just after injury, either because of finances due to impact on work life or knowing what modifications to make.

Others lived in transitional accommodation or moved back in with family.

I moved back in with my parents as I couldn't live independently by myself ... some two years later, I felt I was ready to live independently again.

Where partners or family shared accommodation, participants had greater stability in accommodation and therefore also their social networks. However, most properties still remained inaccessible and investment was required to modify them prior to discharge from hospital.

I was able to return home, however, at a cost to my parents as to do so they needed to go into debt to make necessary alterations to the house.

Some participants reported making major changes to their accommodation, often a cost met by their family, and others designed and built purpose built homes.

We were very disappointed with the options that we were given regarding assistance to modifying the previous house. In the end we were very very fortunate with assistance we got from my family that allowed us to move ... We did it out of our own pocket rather than waiting for the government agencies, who tended to put up so many roadblocks and obstacles and made things difficult. The amount of occupational therapists that were involved in the situation was beginning to really annoy me. The bureaucracy of the whole process was unbelievable.

[Without assistance from somewhere] you'd still be in institutionalised care of one form or another.

Seven per cent of survey participants identified modifying a home to make it more accessible as a key achievement (survey question 3 - quantified from qualitative responses). This is a low figure considering that most homes require some form of modification to make them accessible. The level identified may be due to the importance attached to the outcome by the person, how recently the modification took place, as well as the barrier of funding extensive modifications.

7.7 Receiving family and community support

The support of family, friends and people within the community is important in providing emotional, physical and sometimes financial support. This is identified in the literature (Elliot et al., 1991) and confirmed by the survey participants.

Of the survey participants, 66 per cent identified the support of family and friends as the most important resource in achieving goals (survey question 3 - quantified from qualitative responses). The support and the stability of that support from family and friends leads to greater confidence and willingness to try new things.

I would not have survived without ongoing support of my family who supported me in the family home after discharge.

[My achievements] would [not] have been possible without the love and support of my family and especially my wife.

I attribute my situation to help from friends and family and community support.

[My] family was very supportive and understanding of my limitations but encouraged me to do what I thought I could do.

I have great friends and a supportive family, all which have made the transition a whole lot easier.

My husband is the only source of physical support I have. If it wasn't for him, I'd probably be in a nursing home.

Friends and family have been my major support. Giving up or sitting in the corner feeling sorry for myself was not an option. All my close friends and family have been extremely supportive in getting me home and including me in their lives. Helping me get around and overcoming obstacles along the way. They have tried to understand what I go through on a day to day basis, but also treat me like a normal person. They don't let me get away with too much either.

Without family and friends' support, it's pretty hard to live independently in society.

Support provided from family and friends varies, but is sometimes exclusively relied upon by people with smaller needs.

I don't fall into the category of being totally dependent on others to do everything. There are lots and lots of things that I need help with and there's nobody but my husband to do these things. It puts loads of pressure on him. There are no support services available to people who only need a little bit of help

The participants said they would like to reduce their dependence on partners and family, and to savour that personal relationship rather than it becoming one of reliance for support. Where care is provided by family and friends – 72 per cent of participants live with family (survey question 28) – increased support is required to fulfil that role. This may include support for the family at the time of the injury, in terms of travel, accommodation and emotional support; and for ongoing emotional, physical and financial support post-injury.

I also received financial and accommodation support from my family.

Overall my goal is to keep busy and happy with the help of lots of people. To do this I use my wife and family, my friends, my carers and external people I pay to help me with everything I can't do for myself. By sharing all of the help I need I am not too much of a burden on my family. If only I didn't have to battle so hard to get two hours of help a week from a carer ... to help me with my personal showering and general help around the house that would be very good.

Although we have a lack of access to services [in a country town], we get a lot of help financially, emotionally and that from the community, whereas when you're in Sydney you're just a little fish in a big pond.

The importance of the support of family and friends was reaffirmed when participants were asked about the most effective sources of information available concerning emotional and physical support; 58 per cent identified partner/family, friends and community, and peer support groups as their most effective sources of support (survey question 9 – quantified from qualitative responses). Participants identified that partners/family or peers better understand their needs, can provide more appropriate information on a personal basis, and allow for privacy. Peer support was also considered important as peers are living the experience, provide great support and encouragement, and provide useful tips with day to day living.

No matter how well able bodied people try to understand, unless you are actually dealing with something yourself, I don't think you totally understand.

Peer support is always valuable as it is sharing information with people who have been through similar experiences but who may have sourced different answers to similar problems. I feel a special connection to peers.

Survey data show that community support, whether face to face or online, can help overcome feelings of isolation often associated with a disability, as well as provide advice in which to overcome physical, emotional or financial problems. Having access to good peer to peer support services was identified as a way in which to overcome issues as well as reduce the feeling of isolation.

I want to contribute more to other people with a spinal cord injury - peer support is a vital ingredient in the rehabilitation process and beyond. More peer support programs [are required] at the rehabilitation level and most importantly when people return to their communities.

Some participants suggested that peer to peer support programs should not necessarily be confined to issues of disability support, but may also extend to hobbies, work, or other interests.

I am attempting to write a memoir and fight daily against procrastination. It would be good to have a writing group/writing buddy to share the writing process with. Preferably composed of other people with disabilities who could understand better what I am trying to say.

PART C: COMMUNITY RESOURCES

Community resources include services, healthcare, personal care, equipment and aids, financial support, information services, transport, environment and safety, and economic activity.

Key points:

- some people are unclear as to what services and resources are available
- professionals in the healthcare sector have different experience and knowledge of spinal cord injuries
- some people did not receive enough information or emotional care at the time of injury
- specialist healthcare services are not available in regional or remote areas either at all or to the extent required; the healthcare provided depends on the knowledge of the individual and the individual skills of GPs
- some people commented that healthcare services are disjointed
- some people experienced uncertainty in receiving future support services at the level, quality and certainty that they needed
- equipment and aids can increase the quality of life and assist people to live independently, yet are expensive and not always easily accessible to many

- financial support remains inadequate, confusing (in terms of what is available), and in some cases difficult to access (in terms of bureaucracy)
- general information about living day to day with a spinal cord injury was identified as a key resource that can be improved
- a large proportion of participants are participating in the workforce - others want to participate and need help finding work
- physical accessibility of public and private places remains an issue preventing social participation

Implications:

- provide a clear central guide to outline what services are available
- increase the knowledge and understanding of spinal cord injuries and associated health issues for GPs and emergency departments
- advocate for an increase in emotional care provided to the person and family at the time of injury, and post injury, possibly through greater peer support
- increase outreach services by spinal units
- encourage a holistic approach to healthcare management
- advocate, where required, for an increase in and then a stability of personal care services
- increase access to equipment and aids
- increase financial support available commensurate with the costs of living with an injury and make it accessible to people who need it to relieve pressure on family
- provide accessible (internet and personal), relevant and current information on spinal cord injuries in relation to general health and wellbeing, support services, participating in the workplace, travel, 'how to' information, and details of new equipment
- advocate for greater employment services and opportunities, from support in looking for work, access to part-time or flexible work, removal of barriers to employment and work environments, support for first time employees, and encouragement and support for new businesses
- encourage the enforcement of planning requirements in terms of access and provisions for people with disabilities

Services include healthcare, formal care services, access to equipment and aids, financial support, and information. Services may be provided directly or indirectly by the local, regional and national governments, or be sourced privately.

Participants in the research recognised that a range of services are available; however, they identify a lack of clarity and an opportunity to consolidate and coordinate services.

I think we need possibly a contact or service that is designed to provide all the information on the services available to those that are entitled to them. They may then act as an advocate, to assist the person gain the supports they need and also and also to assist further with any ongoing problems.

Better Government assistance e.g. making people aware of what is available without having to stumble across it yourself by accident.

A 'one stop shop' to get information in ENGLISH rather than having to check any number of sub sub paragraphs.

7.8 Healthcare services

There is a need for specialist healthcare, not just related to the injury, but also in terms of ongoing associated health issues. Specialist healthcare is usually provided at the time of injury in specialist facilities; experiences of these services have varied and some potential improvements to services are identified. Ongoing healthcare requirements are often left to general practitioners (GPs), emergency departments, and specialists (not spinal injury specialists), where experience and knowledge of spinal cord injury varies. Participants in the research identified scope for improving healthcare resources by increasing healthcare practitioner knowledge and providing a more holistic and coordinated approach to healthcare across all levels of injuries, from initial aftercare onwards.

I think the health department needs to communicate better with the services that are set up to assist people with disabilities so that there is a more seamless approach. This way when there is a problem with one, there is understanding and support from the other, i.e. if I'm in hospital due to some problem related to my disability then on discharge there needs to be greater support and communication with disability service providers to assist me in the home. Otherwise people are vulnerable to further health problems.

Rating of injuries should not have an effect on the way you are treated but unfortunately does.

Initial care

The initial care provided at the time of injury and the initial aftercare is critical both in terms of the initial recovery as well as the physical, emotional and practical preparation for returning home after rehabilitation. Participants in the research were asked about the care received at the time of their injury. Responses varied significantly, from good quality care but not enough of it, to poor quality of care overall.

The two main concerns raised during the research are the lack of information about ongoing and associated health care issues, and the need to provide support for the emotional and mental wellbeing for the person with the injury as well as their family.

Some psychological counselling [is needed]. The poor nurses in the spinal ward wear the brunt of all the psychology issues from all the patients. It's not fair on either party

[I needed to know] what to expect from life. Not from a health professional's perspective but from someone with SCI who was working etc and who could give an unbiased, balanced view of what may lie ahead. In my case it was the bastard dog in me that wouldn't say no that has seen me succeed beyond all expectations.

[They needed to provide] family support. Educating my husband and teenage daughters about my condition and the physical and emotional support I required. I did not receive any financial advice about payments I was entitled to. I was eligible for payments from my Super fund, but this was never mentioned to me either by the hospital or my employer, so I missed out on temporary disability payment and now currently, permanent disability payment. I did not receive any government payment for equipment which cost me a lot to purchase a wheelchair, wheelie frame, sticks, commode stool, etc.

[I was] sent home knowing nothing.

I don't think I was in any sort of state to make any decisions on my life ahead or know what I needed.

Ongoing medical care

Many participants identified weaknesses in the resources currently available to provide ongoing medical care. This relates to the knowledge and understanding of spinal cord injuries for GPs, emergency departments and specialists; the speed of response; and the lack of coordination between services. Some participants reported very good experiences and relationships with their GP who understood their healthcare requirements and were responsive to their needs.

[There should be] greater access to expert medical care without long delays for consultations with neurosurgeons and rehabilitation specialists.

[It would help] knowing that the services I have support from are experienced in SCI. More education on SCI is needed as it seems a lot of nurses and people in the medical field don't have much knowledge on Paraplegia or Quadriplegia.

Participants recognise the change in healthcare requirements as the ordinary aging process takes place, but commented that they were discovering and managing these changes themselves.

36 years post injury means aging with a spinal cord injury and my information needs change - how are other people who are ageing with a spinal cord injury getting on? Being out of the hospital system for years is a good thing; however, it can also mean being out of touch with medical changes in the clinical management of spinal cord injury. I feel there should be some form of follow up for people with a spinal cord injury who have not had contact with their respective spinal outpatients every 5 years.

I would like more regular assessment of my physical progress and exercise program.

As I am approaching old-age, I am losing a lot of the functions I had in the first 40 years post injury... I am needing greater support.

For people living away from the major cities (50 per cent of survey participants), specialist health care services may also be difficult to access. Specialist healthcare services, as well as other support services, should also be made more available to remote locations, rather than requiring patients and carers to travel into cities.

Living in rural NSW we do not I believe have the same support as those in the city.

There is no support for people with spinal injuries in [regional towns]. We just have a GP here.

The Spinal Outreach Service now comes to the country every two years, which is not enough. It would be great if that could come at least once a year.... Have to travel to Sydney every 5 weeks to get it [suprapubic catheter] changed up there.

In addition, services may differ from one region to another, and whether the injury is related to a traumatic or non-traumatic injury.

I was hospitalised in Qld but lived in NSW so the staff weren't too familiar with NSW services

Eleven per cent of survey participants identified physical improvements in health and function as achievements as well as being able to facilitate other aspects of life (survey question 3 – quantified from qualitative responses). This was described as extra-ordinary efforts taken to improve health that had lead to positive outcomes. Proactive health care or proactive management of health could lead to a reduction in reactive healthcare requirements and lead to a better quality of life. Opportunities to access to physiotherapy and other means of proactive health care should be provided as a means to maintain and improve health.

I would like more regular assessment of my physical progress and exercise program. It has been left up to me to try and access a gym with equipment I can use (safely) and a program that is beneficial and to access treatments that have made a difference to my

paralysis, neuropathy and mobility such as acupuncture, which are not part of Medicare.

Further information could be provided as to managing health issues as well as new research.

Compared with the US there seems to be limited info re spinal cord injury, current treatments, recovery programs, ongoing social, emotional and wellbeing and exercise programs.

A site or organisation where all parties work together and pool information to try and find a cure for spinal cord injury.

Access to counselling

The need for ongoing counselling, including for immediate family, was identified as a key resource required both at the time of injury and post-injury. The need for counselling could be reduced by improving the information and care provided at the time of injury to manage expectations. However, over the course of life, there are changes in function, mobility and health, therefore the opportunities to receive counselling should be ongoing.

[I need] access to counselling. This would help me discuss and hopefully solve my problems rather than dwelling on them.

[I need] emotional support for my family and me.

Psychiatric hospitals are definitely not wheelchair accessible... it would be great if they had a psychiatric hospital in Sydney that was just totally disabled clients... because they could talk about their problems with each other.

7.9 Personal care services

The emphasis in the responses provided to the survey has been on increasing the amount and the quality of personal care resources available, and increasing their flexibility. Participants in both the survey and the interviews commented on the continuing threat of reducing personal care services.

Every year the funding for nursing care is reviewed. For 4 years I was told that my nursing staff would be cut and I would lose the registered nurse hours. This is one of my greatest stressors for I have excellent nurses ... and I know the difference between good and average nurse. ... So you can imagine my concern when they want to cut my hours and the staff who keep me well. I have never had a pressure area The statistics say that C1s usually have a life span of 5 to 7 years and infection commonly from pressure sores are the cause of death. My wellbeing relies on my nursing team. If I lost them all my aspirations also are lost.

Stability is required in the personal care sector to attract and retain quality staff for continuity of care. The importance of personal care services cannot be undervalued; for some it may mean the difference between life or death, or living at home or in hospital. The provision of personal care services for all will reduce the burden of physical care on families and allow them to focus on family life and emotional support. Funding for personal care services should be increased and be flexible to meet continually changing needs.

[What is required is] flexibility and an acknowledgement of the changeability in people's lives and a broader understanding of a person's diverse life so that services do not hinder but rather empower.

An increase in carer hours was crucial to my remaining in my own home and not having to return to nursing home

I only receive 15hrs a week since 1999 and would like this increased as my needs have changed dramatically during this time, but no funding.

Participants in the survey provided constructive criticism about personal care services, both in terms of quality and availability. Some also spoke favourably about a program or service: for example, individuals made positive comments about the Attendant Care program, Australian Home Care Daily, HSCI, Lifetime Care Services, Homecare CAPS, community nurses, GPs, etc. However, it was not possible to analyse whether one program or service was more successful than another due to limited sample.

The Lifetime Care Services scheme works well on some levels, e.g. home modification; however, it is not designed to promote independence and self-reliance. Although you are encouraged to participate in the community independently, all the decision making as to what is 'reasonable and necessary' is determined by clinical staff... I have found my case has been extremely overmanaged...9 times out of 10 my opinion has been overlooked. This has made me feel patronised and very unhappy about the services...

There are no effective sources of formal support in my 42 years of disability experience – with the exception of our fantastic local GPs.

The government needs to hurry up with self funding management so that we can choose our carers and home helpers our self.

Enable for equipment, SCIA for advice and support funding.

Enable – they're probably the only financial support that was ever available to me.

Most respondents identified the important role of personal care services and highlighted the need for additional or improved services.

I now live at home with care from spinal injury supplied support workers – they are the greatest asset I now have apart from some family and friends.

I was relying on Homecare service of NSW. Without these basic services I would not be able to live and independent life and participate as an equal member in society. ... to some degree these services are taken for granted. But without them life for people with disabilities would be decidedly different. The important thing now for myself and others is to improve the services that are available so that there is no hint of a barrier to achieve goals.

In some cases it may be that services are unknown to someone needing them, or are unavailable, or are unavailable to the extent sought by someone.

7.10 Equipment and aids

The cost of equipment and aids can be high. Participants commented on the difference in availability and price of aids in Australia compared to the US and other countries; one person interviewed has established an online company to provide a number of aids at a reduced cost to people in Australia.

Hearing from customers that they're having to choose between buying food and buying catheters which frightening... so I'm selling mine at half price. I was spending \$2000 a year on urinary catheters prior to starting this business. This cushion that I'm sitting on, \$900 and its inflatable so they get punctures... I go through one of these about every 12 months... in the US you can buy them for \$350.

Participants in the study identified that assistive technology can increase quality of life, assist people to live independently, and may reduce other healthcare requirements. There is a clear need to provide more information about, improve access to, and increase funding and support for assistive technology, from basic daily disposables, to wheelchairs, adjustable beds and lifting equipment.

The right tools make everything easier.

Got to go to Sydney for that [wheelchair repairs] as well.

As people with physical disability require a lot of assistive technology including wheelchairs, electric adjustable beds, pressure carer equipment to prevent pressure sores, lifting equipment, etc. there is currently inadequate government funding to provide the appropriate equipment in a timely manner. Furthermore, such assistive technology generally breaks down on Friday afternoons and there is a need for 24/7 emergency repairs services and backup with the possibility of replacement parts or equipment.

Better access to equipment and repair would be beneficial for essential items such as wheelchairs and worn out items.

Someone in Treasury should do the analysis to say well, if we provide people with specialist equipment we're going to keep them out of hospital which is going to save us money. I've been able to work to fund my equipment but I try and keep up to date and buy the best gear to keep my body fit and health so I don't have to spend time in hospital.

7.11 Financial support

Participants considered financial insecurity to be a major threat to wellbeing (Section 7.4). Forty-four per cent of survey participants identified that they were managing on government support, e.g. in the form of a disability pension (survey question 30).

Participants identified additional costs of living, including utilities, medical expenses, transport and personal care services.

The actual costs of equipment compared to what is subsidised, increasing costs of electricity etc because of needing to use reverse cycle air conditioners to control body temperature, the cost of purchasing wheelchair accessible vehicle, the additional costs of accommodation and transport when travelling...

The cost [of physiotherapy] is a big issue as my super was spent on our home and the many expenses involved in my care, simple day to day things like the enormous electricity bill. It all adds up.

Some participants commented that they were not sure about what payments they were entitled to.

I did not receive any financial advice about payments I was entitled to. I was eligible for payments from my Super fund, but this was never mentioned to me either by the hospital or my employer... I did not receive any government payment for equipment which cost me a lot to purchase.

Others commented that different schemes offered different levels of support and flexibility; and also that support varied depending on where you live, who the support is provided by, and the reason for the injury (traumatic as opposed to non-traumatic). Many commented that the money received was inadequate to meet basic needs.

Recently I found out that there is financial assistance for various needs. A lot of people with SCI just haven't got the finance to help them to help themselves make their lives easier... Something like a computer can make a difference in preventing them from becoming isolated, allowing them to shop and pay bills etc ... people need to be aware of assistance that is available and at the moment a lot of information is through word of mouth.

One list [is needed] of constantly updated "Entitlements" for those with a spinal cord injury. It would be great to be able to type in an online survey, stating your situation, i.e. where you live, level of

disability, compensation or not, working or not, etc., and at the end of the survey get a list of "You are entitled to the following..." Rather than have to trawl through all the various individual sites

The National part [of NDIS] being the key since there is such a discrepancy of service provision to PWD's depending on where you live – State, suburb, local council, etc.

There definitely seems to be a discrepancy between payment for traumatic spinal cord injury and non-traumatic SCI . I have received no payment towards anything except incontinence products and my neurologist gave me free botox injections in my legs from money he personally fund raised. Every little bit helps when being a disabled person is so much more expensive than being an able bodied person.

Better funding mechanisms [are needed] and an acknowledgement that this could be improved to assist people to live independently through personal care services and also greater financial support to assist people with equipment they need to live independently such as through Enable NSW.

You rely a lot on the technology in a computer and access to that. Without that, I think life would be really boring and tedious. The internet suddenly becomes a gateway into the outside world. It's a communication device; it's your entertainment quite a lot of the time.

For people with a spinal injury [with an existing injury] there is very little government funding available to receive recurrent personal care funding despite many lobbying for years. Personal care is not a luxury – it is a basic need.

Whilst there are some policies in place to provide rebates for energy bills for people living with thermo-regulatory dysfunction, they are not considered to be adequate.

The very trivial medical discount on electricity bills for thermo-regulatory dysfunction could be increased. My winter quarter electricity costs are over \$4k and the rebate is about \$86!! Rebate should also be available if one uses gas for heating! Carbon tax 'handouts' to taxpayers, pensioners and families on benefits bypass me as I'm no longer earning enough to pay tax now, not on a pension or family benefits....yet my next electricity bill with carbon tax added will probably wipe out most of the savings I've been living on recently. So where do significantly disabled people get relief from these ever-rising costs if they're in none of the above categories?

Additional mechanisms are needed to support people financially and logistically to allow them to be more mobile, whether that is travelling for work or recreation, to allow people to participate fully in family and work life.

Need appropriate levels of government funding allocated to enable people with disability to take a holiday or travel.

7.12 Information services

Of the survey participants, 63 per cent identified additional information resources required or made suggestions for improvements in the provision of information relating to: general health and wellbeing; formal support services; participating in the work place; and travel (survey question 11 – quantified from qualitative responses). Ease of access, scope and currency of information were common concerns across all areas.

Any information designed to assist and empower people with disabilities needs to be readily available and easy to gain. It needs to be available in many formats such as hardcopy, online and other digital formats. As for individuals who might be the source of the information, they need to be easily approachable through the phone or in person. Any service needs to be made available so that it reaches as wide an audience as possible.

Successful information resources are those that are clearly expressed, on the ball/up-to-date on government/community based services and initiatives. Publications that alert me to events, meetings, conferences, courses that will assist me in my daily life or stimulate thought and discussion about current events that have a direct impact on my life.

One website like a Lonely Planet Guide for people with disabilities where we could access information about Australian and overseas destinations regarding: disabled facilities such as clean disabled toilets, easily accessed places to visit, accommodation with good disabled facilities for most locations in Australia, places or activities of interest that provide good help and facilities for people with disabilities;* tips about suitable travel destinations from people with SCI who have travelled there; information about hire of aids and cars with hand controls in various locations.

Overall, participants would like improvements to online information sources. They also highlighted the importance of personal contact and that contact having the time to provide more information to them. In addition, with high living costs associated with spinal cord injuries, some people do not have enough funds to buy or update a computer to access information that is there, increasing the feeling of isolation.

I have just discovered the existence of SCI Australia, did not come up in previous searches... I am on the email list for People with Disabilities Australia and the Physical Disability Council and receive support and information re disability issues through this service, but would still like to physically attend a support group, it is finding one that is the issue. Websites are not always easy to navigate or are very outdated. There should be some sort of updated manual for people with SCI re: services, groups, government subsidies, etc. My

local hospital did one but that was 8 years ago and the info is outdated.

As identified previously, family and carers are often the main or first source of information – the information and support available should be accessible to both people with an injury or people supporting them. Family and carers may have limited time to access information so it must be as easy to find and access as possible.

[Ideas for improvements to information] Websites kept updated. A Yellow Pages type of directory for services for disabled people in each state. Newsletters from orgs such as SCI Australia. Rehab hospitals should have manuals about basic services, support groups, etc. Better access to info re current treatment for SCI in Australia.

As with other aspects of this research, the information or support services may already exist but targeted end users may not be aware of them. It is not enough to provide an information resource without making that resource known.

I do feel that SCIA and spinal outreach programs could be better advertised as it took us years to find them.

If you don't know what support is available how can it help you?

7.13 Transport

Transport issues include public and private transport either across short distances, e.g. from home to work, or home to the community, or longer distances, e.g. within the state, interstate or overseas. Travel may be required for one of a number of reasons including work, recreation, social activities, sports, health reasons, maintaining family relationships, shopping, etc.

In addition to meeting logistical requirements, the ability to move around in the community gives people a sense of independence and reduces feelings of isolation.

I commute everywhere by bus and train... It's a little bit annoying when you have some stations that aren't accessible.

The 0200 network [taxis] in principle sounds great. When you apply it practically she's not so good. It's alright I think if you get on a regular run type thing, but I never seem to.... It was an issue getting to and from work.

The government needs to subsidise and do everything possible to help the disabled to buy and modify their own vehicle. The ability to visit my friends, to go to doctors, to go shopping, to go to work, to go to activities and events etc without the need for someone else to drive me is paramount to my happiness and feeling worthwhile as a productive member of society.

You can hire cars with hand controls now. Mainly in the capital cities.

Participants identified the need to improve transport options, including personal, public and community transport.

Wheelchair taxis [are needed] that are physically appropriate, reliable, safe (already been injured in one!) and affordable.

The taxi rebate was not considered adequate. Participants also identified the need to increase flexible community transport services to allow people to use the services socially, e.g. in the evenings and on weekends.

In terms of private transport, 7 per cent of survey participants identified either passing a driving test or owning a car as a key achievement (survey question 3 – quantified from qualitative responses).

The biggest thing that impacted our lives was having an adapted vehicle and not relying on taxis [the car was funded by community and family]

The last car I got modified was \$7500, which a lot of people can't afford.

A lot of people don't have insurance or aren't covered by lifetime care that are trapped relying on family for transport. I'm perfectly fit to drive yet cannot afford to. The main reason is how much vehicle modifiers charge. ... I would want to see organisations such as SCIA push to lower or subsidise vehicle modification rates for those with no insurance or financial support. Ideally not cover the cost, but fight to lower it at the root.

Issues of transport are also raised in terms of access to employment (see Section 7.15 – economic activity), general access to the environment (see Section 7.14 – environment and safety), as well as financial support (see Section 7.11).

7.14 Environment and safety

Government has a role in improving access to public places, including transport and services. It does this through predominantly through planning policies, as well as other policies relating to transport. Planning requirements for access may vary between authorities and across states, and may be enforced by different authorities depending on the scale of the development. Planning requirements only affect new developments and are generally not retrospectively enforced on existing developments.

Access, in shops, accessible accommodation, larger shopping precincts, car parks, schools and recreational facilities continues to be a problem. This may relate to parking, toilet facilities, and general access.

Legislation for new buildings throughout Australia which are supposed to provide parking, ramps, lifts, disabled toilets, doors wide enough for wheelchairs etc. should be legally enforceable, which at present they are not. It takes protests or appeals from disabled

people before anything happens in many cases. The needs of people in wheelchairs or severe mobility issues such as mine are very rarely considered when buildings are designed or redeveloped.

Staying in accommodation can be interesting at times... Different states seem to have slight variations on how they interpret the standards and sometimes even local councils. A room advertised as a disabled room (more rightly called an accessible room) was generally accessible. But the bathroom had been modified from a standard bathroom and the shower wasn't accessible. The reception wasn't accessible. But... the local council had approved it... It's education of the planning department and the council inspectors and things like that.

With a lot of public toilet facilities... it's set up as a baby change room.

Most of the shops are not quite as accommodating for wheelchairs. A lot of the old shops in the town and the suburbs still have steps... I'd say well in excess of 50 per cent.

99.9 per cent of your friend's places are not accessible. So you can't just go to somebody's place.

I think the main thing for me is the accessible environment and that includes buildings, it includes transport. But if all those things were universally available 100 per cent across the nation, then the other issues of disability I think would be greatly diminished.

Talking to people with manual chairs, they have completely different barriers. So... whilst we all have the same sort of problems, there are different problems associated. [If] it has been raining, all of a sudden the floor is very slippery and the wheelchair won't actually go up the bit of the hill. The weather is a problem.

The biggest thing is not being able to get into the ocean.

7.15 Economic activity

Thirty-four per cent of survey participants currently participate in the work force (see Table 4.2).

I was able to go back to work, made possible by my employer being flexible with the hours I work. It makes my life more fulfilling and feels like you contribute to society.

However, there are a number still seeking employment. Participants in the survey identified a number of concerns relating to current access to economic activity through employment services. Over a quarter of survey participants work in a voluntary capacity (29 per cent); some may use this as a stepping stone to paid employment. Others have identified employment as a future goal; this includes

people with little or no work experience, or people who have had a change in career due to their injury.

Government agencies for job seekers with a disability could be doing more to help find a job for people rather than supporting you once in a job. After I finished in job that lasted 9 years, I registered with Scope, but they were of virtually no help in finding me a job. They revised my CV and that was about that. They do not seem to really cater for professionals. These agencies could be forming closer networks and links with business and the health sector industries as well as government agencies. It is difficult to find work that is ACCESSIBLE. You need be able to get to a job, park if driving, get inside and around a building. You need access to toilets, computers, a kitchen, etc.

Most employment agencies are not equipped and were not interested in assisting me (over 60 and with a spinal injury) in finding employment.

People who had returned to work after injury recognised that physically going to work required a lot more effort, and depending on care needs, required additional resources to get to the workplace and access the workplace. Full time employment is also constrained by ongoing medical appointments and additional care requirements; flexible terms of employment were not always available.

People who work are not able to pay for this care privately as living costs are too high to include personal care to the budget. We stay employed to keep participating and contributing to society yet if we can't have our personal care needs met then we can only be unemployed as we are not able to get ready for work, making us be on welfare payments. A further burden on society if government can only see that if we had access to our basic care needs through funding then more us can be employed and contribute – this has to be more economical to society, for the individual, and Australia.

I've tried to find part time work and there is just so very little part time work out there... if you can't find any part time jobs, you started full time and then make sure they liked you and then convinced them [to allow you to work part time].

I lost a day a week [attending medical appointments].

A number of people not yet participating in the workforce identified additional resources to help provide more targeted assistance in finding employment and finding part-time or professional work.

Employment agencies and employment consultants [need to receive] more training to assist potential employees.

I have the dilemma in completing job applications especially on-line, which ask questions about physical and mental ability to do the job

safely. ... Whenever I have mentioned that I have a mobility disability but have successfully worked since acquiring it, I have not even got to interview stage for jobs I am easily qualified to do. There should be less discriminatory questions on application forms.

Any assistance in returning to the workforce must also include people joining the workforce for the first time.

Being a young person at the time (16) it is vital to have some sort of "starting work with a disability", "looking for work with a disability", "appealing to employers" workshops or courses. There is a dominant "back-to-work" focus among the spinal cord injury bodies that does little to help those people who never worked before and have zero experience. Talking to employers about getting you working again and optimising the workplace to accommodate your disability means nothing when you've never had a workplace. To avoid being stuck perpetually studying at TAFE or Uni and relying on the measly disability support pension I'd have really needed support regarding starting and looking for work while I was in the late rehabilitation phase.

Interestingly, a number of participants have set up their own small business. However, this had been achieved with relatively little formal support – it was noted that support services for establishing or supporting small businesses do not match services provided for other disadvantaged groups.

There's no support for people with disabilities to start businesses. Whereas there are investors in business support programs for, say, if you're an Indigenous Australian. There's a little bit of support for women, but nothing for disabilities. It's all targeted at employers to take on just people with disabilities as employees... government support is pitched too low. They just think that we're capable of being employees but not employers.

One of the biggest things in Australia right now is employment opportunities for people with disabilities... people need flexible working arrangements, they need part time work and there's just nothing... so it makes sense to me for us to be able to do online business because it is flexible... I always think we're positioned to provide services to our own community.

7.16 Problem solving

Every person has specific needs relating to their injury, and have different physical, emotional and financial circumstances; however, many come across the same problems. A number of research participants identified the use of internet discussion forums, including the use of YouTube, to share how different problems have been overcome – literally including a 'how to' video approach to problem solving.

See also Section 6.4 – Influencing.

8 Implications to develop or enhance support services

To be socially included, and to therefore maximise life choices, people need resources to maximise their opportunities and capabilities. The resources cannot be provided in isolation of each other, but need to be mutually reinforcing.

Resources help to support capabilities and opportunities, allowing people to make choices about how they wish to participate in society. In turn, participation, such as in work, training or connecting with friends, can then help to build people's resources such as work experience, qualifications or support networks, which assist further participation. [Australian Government, 2012: 12]

Assistance is required to build the capabilities of people to identify and use resources, and to provide an environment in which these resources can be used.

The risk of not addressing gaps in resources, and building the bridge with capacity building and opportunities, may mean that people have a lower rate of social participation, potentially leading to social exclusion.

This research has identified a number of areas to possibly develop or enhance individual, family and social resources in order to maximise life choices for people with a spinal cord injury and to support their family members/carers. The findings of the research have been further substantiated in discussion with the participants of the second roundtable.

The implications of the findings identified in Sections 6 and 7 overlap and are therefore grouped into eight key areas:

- maintaining and improving health
- supporting participation in family and social life
- providing support to family and friends
- promoting workforce participation and training
- improving information resources
- increasing financial security
- improving government policy
- increasing accessible housing, facilities and transport

The implications are accompanied by a possible action by SCIA in terms of advocacy (system rather than individual), collaboration, facilitation, and information resources. The findings and implications of this report are particularly relevant in the development and implementation of the NDIS.

The implications are of equal importance in terms of supporting a menu of services for people with a spinal cord injury to enable them to maximise life choices.

Individuals accessing the services will have different priorities depending on their individual situation and these priorities are likely to change over time as their personal circumstances change, e.g. time since injury, health, age (e.g. health or workforce participation), family, etc. In addition, most implications are interrelated, i.e. they support each other. For example, improving information resources will support all of the other areas identified.

8.1 Maintaining and improving health

The research identified a number of on-going health issues. People who took a proactive approach to their healthcare did see benefits. However, most people identified issues of concern with ongoing healthcare and care in general.

Areas to develop or enhance health services include:

improving the initial rehabilitation process to achieve better outcomes for physical and emotional wellbeing

improving the financial support and availability of on-going health care and care support services, including physical and emotional wellbeing

improving access to emergency health care and ensuring emergency departments have someone knowledgeable in spinal cord injuries and that paramedics receive appropriate training or access to advice

improving the access to therapeutic care

providing flexible care services, in particular, providing additional care as required and in locations required (e.g. regional areas)

improving the quality of health care, and in particular, the understanding of SCI and its' impact on health through training, peer support and information for health care staff including staff in regional areas

improving physical access to general and mental health services to relieve pressure on hospital clinics

recognising the needs of an aging population and the needs of an older age group in all of the above

Recognising the impact of support services also have on health, areas to enhance support services to complement health services include:

increasing access to appropriate aids and equipment and providing better access to equipment repairs

improving the future certainty of support services

8.2 Supporting participation in family and social life

Relationships with family, friends and the broader community were identified in this research as critical to the ongoing wellbeing and achievements of the person. In addition to supporting family and primary care-givers, people with a spinal cord injury want to be supported to maintain their role in their family and community. This may include support for the care of children or the elderly, or increasing access to public places where normal family activities are located, e.g. in schools, sports venues and other community facilities. This will allow people with injuries to spend more time in the community and help maintain and develop basic social networks.

There may also be additional costs of social activities due to access or transport requirements. See also Section 8.6 – Financial security.

Areas to develop or enhance support services include:

improving the assessment process for support services to reduce reliance on family to prevent the breakdown of relationships

providing assistance in supporting participation in family responsibilities (e.g. care of children and other people), including the provision of aids or occupational therapy, advice and physical support

increasing access in public places, schools, transport and services, to enable access to the community - human rights; increasing access in private dwellings

providing access to a broader community of peers to access and provide peer support services

increasing access to recreational facilities and organised activities

increasing support and information to facilitate travel

increasing support and information to facilitate commuting

increasing support for building and maintaining relationships, particularly for women

8.3 Providing support to family and friends

The support provided by family and friends is critical to the emotional, physical and often financial wellbeing of the person. This research demonstrated that most people attribute their achievements, confidence and ambition to the support, and the consistency of support, from family and friends. Services should be strengthened to prepare family and friends for this role and relieve as much pressure from family and friends as possible in order for the relationship and emotional support to continue. People would like to reduce dependence on partners, family and friends, and to allow that to remain a social relationship as opposed to becoming a relationship with a carer.

Areas to develop or enhance support family and friends include:

providing more emotional and financial support to the person, family and friends during the initial hospitalisation period

providing more physical, emotional and financial support post-injury, reducing the pressure on family and the personal support network

providing information and methods to share information

providing peer support networks for the person with injury and their family

recognising the primary carer role

providing assistance in forming, strengthening or extending social networks if these are weak

8.4 Promoting workforce participation and training

Participation in the workforce was identified as a key achievement for half of the participants in the survey. They attributed this to the importance of a sense of worth, empowerment, financial independence, and social interaction. In addition, people participating in paid work were able to use their income to make choices to improve other aspects of their lives. Some survey participants were able to continue in their existing profession, and others, due to their disability, had retrained.

Areas to develop or enhance workforce participation include:

providing more targeted assistance to rejoin the workforce to increase workforce participation – gaps identified included part time and/or professional work

removing barriers to participation in the workforce, from application processes to physical access, from employers to individuals to job capacity assessors, and changing community expectations

increasing access and financial support for further skilling to allow re-entry into workforce

providing support for people wishing to start or further their own small business to at least match that of other disadvantaged groups

8.5 Improving information resources

Life with a spinal cord injury can be difficult and costly; people need access to relevant and up to date information to overcome the physical, emotional and financial difficulties. Information is either sought directly by the person, or by family or carers.

This research identified a number of areas in which the provision of information could be improved. It may be that the information sources exist but are not known to the person.

Areas to develop or enhance information resources include:

improving ease of access, scope and currency of information for general health issues, formal support services, participation in the workplace, and travel; provide single source of information

providing information on equipment and services relating to spinal cord injuries and independent living, including 'how to do it' information and information about new equipment

providing more general information about living with an SCI, including home modifications

encouraging discussion forums to share information

providing information and resources about participating in the workforce

providing and sharing information on travelling with a disability

Access to information may be facilitated by an intermediary, for example a virtual case manager; alternatively, a broker or facilitator might direct someone to the appropriate services. Both options would require information resources to be comprehensive and staff to be knowledgeable as to what is available.

Further work is also required to raise the profile of SCIA across the community, including at both public and private rehabilitation units.

Whilst participants would like improvements to online information sources, it was noted that not everyone had access to a computer. They also highlighted the importance of personal contact and that contact having the time to provide information to them.

Information must also be accessible to family and carers.

8.6 Increasing financial security

Some participants identified financial insecurity as a threat to their wellbeing, and others sought financial advice to manage the costs of their condition in the long-term. The research also identified potential financial exploitation of individuals.

Areas to develop or enhance support services include:

providing clear information on the financial support available from the government, insurers and super funds, from any initial compensation process, to day to day living

expenses, to alterations of a vehicle or home – this should include how to achieve the best outcome for money, e.g. what daily living aids provide the most benefit to the user in terms of value for money

providing financial advice concerning the costs associated with a spinal cord injury, including medical care and ongoing treatment – making payments go further

providing financial advice as to the management of any insurance or compensation payment

providing incentives for employment, without loss of other benefits, meeting the additional costs of going to work and potentially reducing any financial support received

SCIA currently refers financial questions elsewhere and recognises that they should be mapped to make this referral better. This includes the costs of living with a spinal cord injury, sources of financial support, how to minimise exploitation, and how to seek and then manage any compensation for injuries.

8.7 Continued improvements to government policy

The research identified opportunities for continued improvements to government policy for formal support services for people with a spinal cord injury. Research and evidence is required to inform policy change – see also Section 8.9 below – Implications for further research.

Areas to explore further include:

removing differences in care and support services between states and regions (potentially addressed by the NDIS)

providing access to health and care services according to needs, including providing new assistance to those who need it, as well as improving the certainty of support services

improving social services, from care services, to health, to financial support; extending SCIA support to a broader area

providing simple, clear financial and support services

increasing access to cost-effective assistive technology

incorporating disability into the design stage (from taxis to residential buildings to care facilities) to make the costs of disability go down

improving consultation processes to ensure people with a spinal cord injury are engaged (e.g. invited to meetings that are accessible and resourced) and well represented (e.g. mixed group with a regular turnover)

8.8 Increasing accessible housing, facilities and transport

The research identified a number of issues concerning the availability and accessibility of housing. Some issues, such as the location of accessible services in the locality, were identified by those that have had to move locations, but are more broadly applicable where accessible service providers such as optometrists, doctors, etc. close and new service providers must be sought.

The research also identified a number of basic access issues relating to facilities (e.g. dentist, post office, shops, cinemas, etc) and transport. See also Section 8.7 – Improving government policy.

Areas to explore further include:

supporting independent living

providing assistance finding accessible rental accommodation or accommodation that can be modified

increasing the amount of accessible housing available

providing support in finding accessible facilities and social networks by location

increasing access to funds for modifications and to knowledge of what is easy to modify, e.g. through access to someone that has this knowledge

identifying transport needs and improving access to existing transport services and subsidies

8.9 Implications for further research

There are a number of implications that would benefit from further research into the scale of a problem or identifying potential solutions. Extending the methodology used in this survey and the representation of those affected by services to reach people who are not already engaged would add to the depth of research findings and application. In addition, it would be useful to engage with a larger group to determine how quality of life changes following injury and whether resources change over time.

In a broader survey, consideration could also be given to whether or not location affects people's goals and achievements and quality of life. From this research it appeared that some fundamental specialist health services were missing in regional locations. In contrast, from the interviews and qualitative aspects of the survey, it appears that there was greater continuity of care, particularly personal care services, in regional areas; however, continuity of care was also seen in urban areas where there was greater control over care, for example due to the way in which the care was funded.

In terms of the findings and implications of this research, possible areas for further investigation include but are not limited to:

- understanding the impact additional costs associated with a spinal cord injury can have on household income and budgets – this may include additional costs of utilities, medical equipment, alterations and modifications, and transport – and to ensure that income support adequately covers these costs
- identifying and analysing the impact of any change in government policies on the additional costs associated with a spinal cord injury, for example the cost of energy
- calculating the cost benefit analysis of investing in vehicles, home modifications, independent living aids and new technology, in terms of improving quality of life and the impact on healthcare and transport system costs – identify the cost of the intervention versus the cost of no intervention
- identifying travel needs, it's impact on quality of life, and the best way of meeting these needs
- identifying the skills required to help people transition to the NDIS in terms of understanding what capacity is required and if additional capacity is required, how to build that capacity, in order to maximise the outcomes from choices within self managed care
- identifying how to best source and then share information about accessible places, to maximise the places that are already accessible; this can include accessible accommodation, facilities (GPs, dentists, optometrists), public places, restaurants and shops
- identifying how to increase accessible places by building awareness of barriers to access and identifying opportunities for access
- finding out what supporting families means in practice – needs will be individual and may include taking pressure off families, supporting families in their caring role, supporting the person in fulfilling their family role, or providing more time away from carers to just spend as a family
- identifying the specific requirements of women in terms of relationships and informal care

The possible research areas identified and any findings are also transferable to other people with high support needs.

Appendix 1 Roundtable

Roundtable 1 – 20 March 2012

In March 2012, SPRC invited SCIA and eight members to a research roundtable. The purpose of this meeting was to provide an overview of preliminary research findings, to discuss the priorities for this research, and to discuss the proposed topics for inclusion in the more detailed survey of SCIA members.

Attendees included Peter Perry (CEO, SCIA); Karen Fisher, Saul Flaxman and Rosemary Kayess of the SPRC project team; and eight people with a spinal cord injury plus two carers.

Participants also discussed the key research questions:

- How might quality of life and life choices be defined by people with a spinal cord injury?
- What barriers and gaps exist for people with a spinal cord injury to achieve their life choices (what do we know already and what do we need to more about)?
- What additional supports are needed to support the life choices of people with a spinal cord injury?

The key areas identified to explore in the survey were:

- Housing and living arrangements
- Participation (social, employment, transport and recreation)
- Care (hospital and home)
- Equipment
- Income and financial support
- Wellbeing
- Service use, information and support

Key outcomes of the round table were the need for:

- social inclusion for those with spinal cord injuries
- equitable access to services and support, and
- employment opportunities and productive activities such as volunteering.

Participants concluded that whilst there had been great improvements in support and opportunities in the years since they had incurred their injuries, other steps were needed to improve social inclusion. They concluded that these steps needed to facilitate the development of individual capacity, environment and system level support.

Roundtable 2 – 20 September 2012

In September 2012, SPRC invited SCIA and six members to a second research roundtable. The purpose of the meeting was to present the findings of the survey and analysis, and to discuss the implications of the research.

Attendees included Peter Perry (CEO, SCIA); Shona Bates, Karen Fisher and Rosemary Kayess of the SPRC project team; and six people with a spinal cord injury plus two carers.

The attendees had been given a copy of a draft Final Report prior to the meeting and discussed the key findings of the research in terms of:

- maintaining and improving health
- supporting participation in family and social life
- providing support to family and friends
- promoting workforce participation
- improving information resources
- increasing financial security
- improving government policy
- increasing accessible housing

The group discussed the implications of this research for SCIA.

Appendix 2 Interviews

Interview questions

The interviews used a discovery interview format, which encourages people to tell the story of their experience rather than answer prescribed questions. Discovery interviews aim to understand the experience of the person with a health problem or disability and the impact this has on their everyday life. They allow participants to tell the 'story of their journey' in their own way, using their own language with minimal prompts from interviewers.

The following structure was used to offer guidance to respondents to assist them to tell their story. It describes the chronological stages of a person's journey through an illness or disability and aims to trigger memories:

- Circumstances of spinal cord injury
- Getting initial help for spinal cord injury
- Receiving help for spinal cord injury
- Leaving hospital/medical treatment setting (if applicable)
- Going home
- Everyday life, living at home
- Lifestyle changes since spinal cord injury
- Aspirations, future plans, goals
- What would be useful/necessary to help maximise life choices (current and planned, aspirational).

Summary of issues raised in interviews

Interviewees either had incurred a serious injury, illness or degenerative condition which has led to their current disability. As such, every member has specific requirements. However, interviewees identified the following that would help with transition:

- Provide more information about health, including the increase in vulnerability to illness, proactive health management and how health issues changes over time.
- Provide support for mental health, including access to psychiatric services as well as activities and forums to help share issues and overcome boredom.
- Provide support for families.
- Provide information to get the most out of support services.

All interviewees had made a transition to life well but highlighted areas that could be improved to reduce the impact of their disability. These include sharing information and networking, and improving infrastructure:

- Provision of peer to peer support – help like minded people to engage, share experiences, etc. Could be topic specific, e.g. travel, activities and sports
- Accessible services such as dentists, GPs, etc. Interactive map? Particularly when you move or travel to a new area. This could include other amenities such as restaurants, post offices, cinemas, hotels/motels, toilets, etc.
- One clear standard for the provision of accessible services, including toilet facilities (less dual usage), shop access, motels/hotels, parking (number and size of spaces) etc.
- More access to transport, both public transport (some train stations are still inaccessible) and private (taxi service and subsidies, and car conversion)
- Greater access to other public facilities and buildings, such as schools, beaches, swimming pools, etc.

In addition, improvements to medical care, home care and financial support were identified:

Medical

- Knowledge of products and aids that make life easier
- More training required for GPs and other care providers around disability and spinal cord injuries
- More training in incontinence and catheters
- Improve knowledge and care of pressure sores
- Different health areas within states and interstate
- Request that medical teams visit regional areas – effort and cost of travel for minor treatment to Sydney is prohibitive for many
- Provide psychiatric services for disabled clients

Care

- Improve the continuity of care and support (support care services less consistent in Sydney than in regional areas)
- Improve communication skills of health care professionals – language requirements
- Improve the competency of carers (varied)
- Need additional care services when sick

Financial

- How to fund ongoing medical costs, e.g. catheters, physio
- Transport costs – either taxi rebate or car conversion
- Different support schemes cover different things, e.g. travel for carers

- Government agencies not helpful, schemes are not timely
- Government funding for equipment would keep people out of hospital

Moving forward, participants identified a number of aspirations they had for the future, including travel, employment and understanding more about their condition and research being undertaken to address their condition.

Travel

- Overcome the logistical aspects of travel as well as the financial

Employment

- Help finding part-time work
- Help in starting up a business (there is support for women and indigenous people)
- Help with career advice and retraining
- Help accessing further education

Finally, a number of support areas were identified that SCIA could Service potential for SCIA

- Providing a knowledge base for government services
- Finding accessible accommodation to live in
- Lobbying government
- Advocating on behalf of members to resolve both national, regional and local issues
- Providing more information to members, including:
 - consulting members on government proposals
 - information on new products
 - information on medical research, including stem cell research and trials
- Providing travel assistance
- Educating on disability, including about designing buildings and facilities for accessibility

Appendix 3 Survey

Survey – maximising life choices of people with a spinal cord injury

This survey is only for people living in Australia with a spinal cord injury. The closing date for this survey is 16 July 2012.

The Social Policy Research Centre at the University of New South Wales invites you to participate in research about maximising life choices of people with a spinal cord injury.

The study has been commissioned by Spinal Cord Injuries Australia (SCIA). We want to learn what helps people achieve self fulfilment, and to know what are the gaps and barriers to this. The research will help SCIA in setting a strategic direction that enables each person with a spinal cord injury to choose from a full menu of life choices.

You have been identified by SCIA as someone living with a spinal cord injury. Completing the survey is voluntary and confidential; your answers will not be disclosed to anyone outside the research team. In any report about the study, information will be provided in such a way that people cannot be identified.

The survey can be saved at any time and you can return later to complete it using the link provided in the invitation email. If you would prefer to complete a hard copy of the survey or arrange to complete this by telephone, please contact Shona Bates at shona.bates@unsw.edu.au (on Mondays or Thursdays) or Karen Fisher at Karen.fisher@unsw.edu.au on (02) 9385 7800 and they will assist you.

Survey participants are invited to give their contact details to go into a draw to win a \$250 Coles Myer voucher. Contact details will only be used to contact the prize winner and distribute summaries of the research finding if you indicate that you are interested in receiving this.

We thank you for your participation in this important research.

-
1. Are you an Australian Resident? (if no – thank you for your participation in the survey)
 2. Do you have a spinal cord injury? (if no – thank you for your participation in the survey)

Section A: Your hopes and aspirations

This is the most important part of the survey and we appreciate you taking the time to answer this section in detail.

We want to learn about your hopes and aspirations. We also want to know what has helped you to achieve your goals. This may include friends, family and community or formal support services; financial support; or your general approach to life.

3. Please describe something you have achieved in your life since your injury that you are proud of. Think about what you did, what you were feeling, who was involved and what made it great. Feel free to use more than one example.

4. Thinking about what you want to do in your life, if you have any goals or aspirations, is there anything that could help make them happen?
 - (a) what are those goals?

 - (b) Is there anything that could help make them happen?

Section B: Your wellbeing

We would like to learn more about your daily life and how satisfied you are with it. This is in terms of overall satisfaction, and about satisfaction with specific aspects of your life.

5. Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole? (please tick)

Completely Dissatisfied						Neutral						Completely Satisfied
0	1	2	3	4	5	6	7	8	9	10		
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6. Please tick one box in each row to show how satisfied you are with the following:

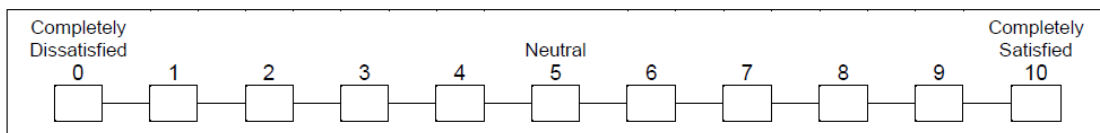
your standard of living	Completely Dissatisfied					Neutral						Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

your health	Completely Dissatisfied					Neutral						Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

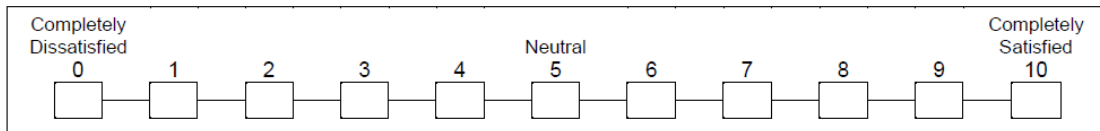
what you are achieving in life	Completely Dissatisfied					Neutral						Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10	
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Maximising life choices of people with a spinal cord injury

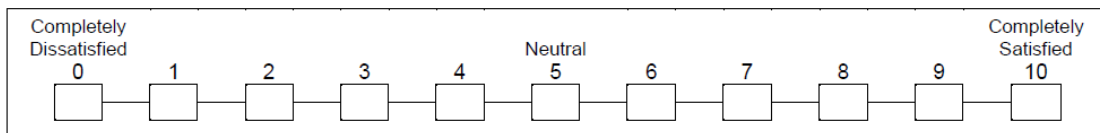
your personal relationships



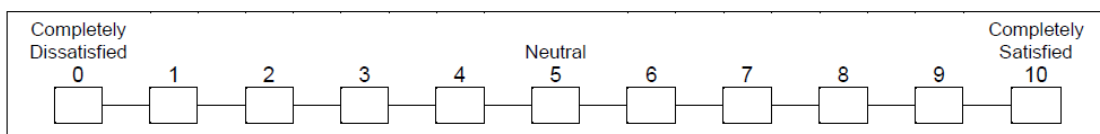
how safe you feel



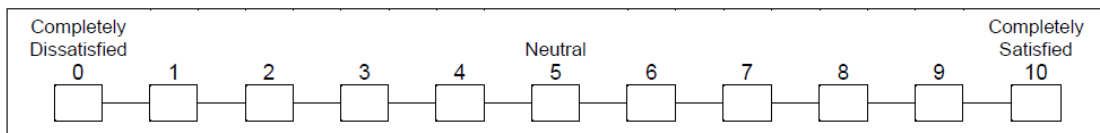
feeling part of the community



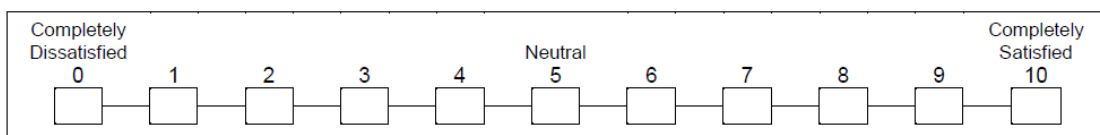
your future security



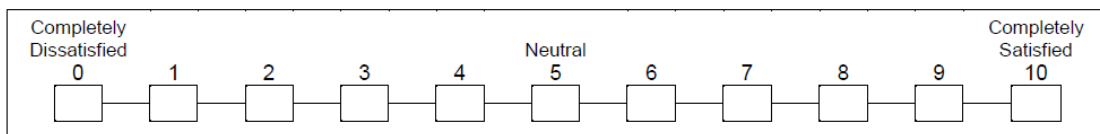
your spirituality or religion



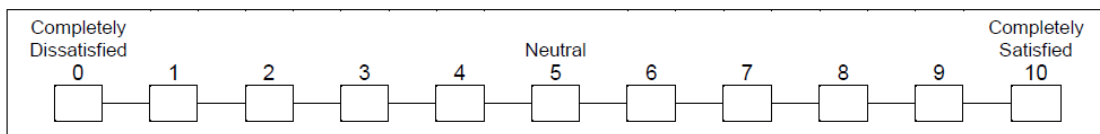
your household arrangements



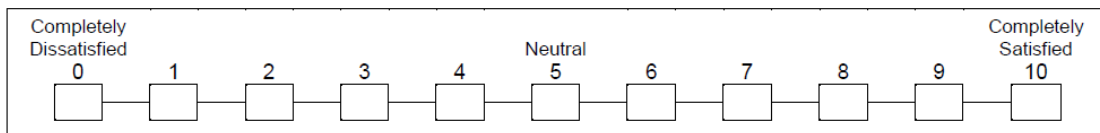
your emotional wellbeing



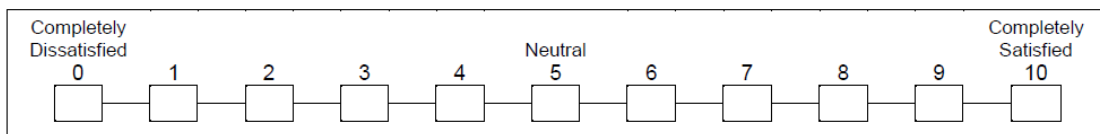
your level of independence



your control over your own life



with the progress you have made following rehabilitation



Section C: Your day-to-day life

We would like to learn more about how you manage your life on a day-to-day basis. This includes emotional and physical aspect, support available, and information that may be provided by your personal connections.

7. Thinking about your day-to-day life, how satisfied are you with the emotional and physical support that is available to you? (please tick one box)

Completely Dissatisfied					Neutral						Completely Satisfied
0	1	2	3	4	5	6	7	8	9	10	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8. How satisfied are you with the emotional and physical support available to you from the following groups: (please tick one box in each row)

Peers with spinal cord injuries	Completely Dissatisfied					Neutral					Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Family & friends	Completely Dissatisfied					Neutral					Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
People living nearby	Completely Dissatisfied					Neutral					Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Formal support services	Completely Dissatisfied					Neutral					Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Others (please specify)	Completely Dissatisfied					Neutral					Completely Satisfied
	0	1	2	3	4	5	6	7	8	9	10
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9. Thinking about the emotional and physical support available, what are the most effective sources or combination of sources of information available to you?

10. What makes these information sources more successful for you?

11. What else could help you with your information needs?

Section D: Your formal support

We would like to learn more about your day-to-day life and about the more formal aspects of support that you rely upon, from financial support to public access and mobility, from housing to medical services, i.e. not from family and friends.

12. Again, thinking about your day-to-day life, how satisfied are you with support for the following (leave blank if N/A):

Your financial situation	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Your paid or unpaid work	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Medical services	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Care support services	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Emotional and mental wellbeing	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Equipment, medical supplies & aids	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Housing	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>
Transport	<div style="border: 1px solid black; padding: 5px;"><p>Completely Dissatisfied 0 1 2 3 4 Neutral 5 6 7 8 9 10 Completely Satisfied</p><p><input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/>—<input type="checkbox"/></p></div>

Maximising life choices of people with a spinal cord injury

Access in public places	Completely Dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely Satisfied 10
Forming social relations	Completely Dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely Satisfied 10
Community participation	Completely Dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely Satisfied 10
Lobbying or advocacy on your behalf	Completely Dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely Satisfied 10
Access to information	Completely Dissatisfied 0	1	2	3	4	Neutral 5	6	7	8	9	Completely Satisfied 10

13. Thinking about your formal support, what are the most effective sources or combination of sources of support for you to manage your lifestyle?

14. What makes these support services more successful for you?

15. What other support services could help you with your lifestyle?

Section E: Your injury & initial aftercare

This section focuses on your injury and the support you received immediately after your injury.

About your injury

16. Is your spinal cord injury the result of an injury or other condition? (traumatic or non-traumatic)

17. Level of injury (vertebrae number) (drop list – vertebrae number)

18. Date of injury

Thinking about the time directly after your injury:

19. Thinking about the time directly after your injury, how satisfied were you about the quality of information provided to you about on-going health care?

Completely Dissatisfied	0	1	2	3	4	5	Neutral	6	7	8	9	10	Completely Satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20. Again, thinking about the time directly after your injury, how satisfied were you with the support provided for your emotional and mental wellbeing?

Completely Dissatisfied	0	1	2	3	4	5	Neutral	6	7	8	9	10	Completely Satisfied
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21. Please specify anything that would have been of use to you directly after your injury that you didn't receive at the time.

Section F: About you

We recognise that everyone's circumstances and needs are different. For that reason we would like to collect a little information about you that will help put your previous answers into context.

About you

22. How old are you? (two figure field)

23. What is your gender? (male, female, prefer not to say)

24. Were you born in Australia? (y/n)

25. Do you identify as an Aboriginal or Torres Strait Islander? (y/n)

26. Do you identify as from a culturally and linguistically diverse background? (y/n)

27. Which of these best describes the HIGHEST qualification you have completed? (primary school or less, some secondary/high school, year 12 (secondary or matriculation), trade certification/apprenticeship or similar, bachelor degree, post graduate degree).

28. Do you live... (alone, alone with carers, with family, or other – please specify)?

29. Have you received any compensation for your injury? (yes, no, waiting)

- 30.** What is your main source of income? (private income, e.g. job or own business; public support, e.g. disability support pension or other; other income support payment, e.g. insurance; or other)
- 31.** Are you regularly involved in a productive activity, for example paid work, voluntary work, study, or other? (select all that apply)
- 32.** What is your postcode?
-

Section G: Conclusion

- 33.** Is there anything we haven't discussed that you would like to add, for example any gaps in support or services?
-

Section H: Your contact details

- 34.** To go into the draw to win a \$250 Coles Myer voucher and/or receive a copy of the summary of the research, please enter your email address here:

Appendix 4 Literature review

A literature review was carried out at the beginning of this research and during the analysis. A number of references to the literature are contained within the report. Additional review findings are included below.

Quality of life

Literature discusses at lengths the differences between the various tools used to measure quality of life, see for example Dijkers (2005), and even the definition of quality of life itself (Cummins, 2000). Some of the literature questions whether they provide data that really are comparable to the broader population, whilst other literature highlights the complexities of measuring and evaluating quality of life without listening to personal stories (Stensman, 1994), and that satisfaction with quality of life is not necessarily correlated to standard of living (Cummins, 2000). The personal wellbeing index developed by the Personal Wellbeing Group is selected for this study as it allows wellbeing of participants to be considered against the broader Australian population, and provides comparative data for the qualitative aspects of the study.

Levasseau, Desrosiers and Noreau (2004) found that interpersonal relations, responsibilities, fitness, and recreation were the categories of social participation most associated with quality of life. Quality of life may decline with disability, but participation in valued activities may be a key factor for a good quality of life.

Use of social inclusion as a framework for the analysis

The approach taken in this research is supported by Lutz and Bowers (2005) who suggest that disability is a multifaceted, complex experience that is integrated into people's lives. The degree to which integration is possible is influenced by three factors: (a) the effects of the disabling condition, (b) other's perceptions of disability, and (c) the need for and use of resources. Lutz and Bowers suggest that achievements are determined by how each person perceives themselves and what is important in their lives, and the influence of the three factors above. This is equivalent in many respects to the social inclusion framework in terms of achievements and the capabilities, opportunities and resources required to deliver them.

The approach to this research is also substantiated by DeJong's theory that independent living is influenced both by living arrangement and productivity status, in terms of work, leisure, schooling, volunteering or other activities (DeJong 1981). Dejong went beyond personal attributes and also looked at what resources and obstacles the broader environment (i.e. family and community) contributed to independent living. Dejong found that living arrangements and productivity status contributed equally to independent living. The tests have been rerun subsequently by Boschen and Gargaro (1998) who demonstrated that living arrangements contributed slightly more than productivity status (58 per cent and 42 per cent respectively) (Boschen and Gargaro, 1998: p. 296).

References

- Australian Bureau of Statistics (ABS) 2011, *ABS 6227.0 - Education and Work*, Australia, May 2011
- Australian Government 2012, *Social Inclusion in Australia – how Australia is faring*, 2nd edition, Australian Social Inclusion Board, Canberra
- Australian Institute of Health and Welfare (AIHW): Norton L 2010, *Spinal cord injury, Australia 2007–08. Injury research and statistics series no. 52. Cat. no. INJCAT 128*. Canberra: Australian Government, Australian Institute of Health and Welfare (AIHW).
- Boschen KA & Gargaro J 1998, 'Independent living long-term outcome variable in spinal cord injury: a replication of DeJong', *International Journal of Rehabilitation Research*, 21, 285-300
- Brackertz N 2005, *Community consultation and the 'hard to reach': concepts and practice in Victorian local government*, Melbourne: Swinburne Institute for Social Research, Swinburne University of Technology.
- Brickman P, Coates D, Janoff-Bulman R 1978, 'Lottery winners and accident victims: is happiness relative?' *Journal Personality and Social Psychology*, 36(8): 917-27
- Chase BW, Cornille TA & English RW 2000, 'Life satisfaction after spinal cord injury – life satisfaction among persons with spinal cord injuries', *Journal of Rehabilitation*, 66 (3): 14-20
- Cummins R 2000, 'Objective and subjective quality of life: an interactive model', *Social Indicators Research*, 52: 52-72
- Cummins R & Schaefer M 2011, Australian Unity Wellbeing Index Survey 26 – Part B Appended Tables: The Wellbeing of Australians, Chronic Health, Australian Centre of Quality of Life, Deakin University, available at <http://www.deakin.edu.au/research/acqol/auwbi/survey-reports/survey-026-report-part-b.pdf>
- Darcy S & Dickson T 2009, 'A whole of life approach to tourism: the case for accessible tourism experiences', *Journal of Hospitality and Tourism Management*, 2009, 16(1):32-44
- DeJong G 1981, *Environmental accessibility and independent living outcomes: directions for disability policy and research*. East Lansing, Michigan: The University Centres for International Rehabilitation
- Dijkers MPJM 2005, 'Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings', *Journal of Rehabilitation Research and Development*, 42(3), May/June 2005 Supplement 1: 87-110

Elliott T R, Herrick SM, Patti AM, Witty TE, Godshall FJ & Spruell M 1991, 'Assertiveness, social support, and psychological adjustment following spinal cord injury', *Behaviour Research and Therapy*, 29(5): 485-93

International Wellbeing Group (2006), *Personal Wellbeing Index: 4th edition*. Melbourne: Australian Centre on Quality of Life, Deakin University <http://www.deakin.edu.au/research/acqol/instruments/> (accessed 17 May 2012)

Krause JS & Anson CA 1997, 'Adjustment after spinal cord injury: relationship to participation in employment or educational activities', *Rehabilitation Counselling Bulletin*, 40(3): 202-14

Levasseur M, Desrosiers J & Noreau L 2004, 'Is social participation associated with quality of life of older adults with physical disabilities?' *Disability and Rehabilitation*, 26 (20): 1206-13

Lutz BJ & Bowers BJ 2005, 'Disability in everyday life', *Qualitative Health Research* 15:1037-54

Mattson-Prince J 1997, 'A rational approach to long-term care: comparing the independent living model with agency-based care for persons with high spinal cord injuries', *Spinal Cord*, 35(5): 326-31

Noreau L, Desrosiers J, Robichaud L, Fougeyrollas P, Rochette A & Viscogliosi C 2004, 'Measuring social participation: reliability of the LIFE-H in older adults with disabilities', *Disability and Rehabilitation*, 26(6), p. 346-352

Pflaum C, McCollister G, Strauss D, Shavelle R & DeVivo M 2006, 'Worklife after traumatic spinal cord injury', *Journal of Spinal Cord Medicine*, 29, p. 377-86

Rogers PJ & Fraser D 2003, 'Appreciating appreciative inquiry', in H Preskill & AT Coghlan (Eds.) *Using appreciative inquiry in evaluation* (pp. 75-84), San Francisco, CA: Jossey-Bass

Stensman R, 1994, 'Adjustment to traumatic spinal cord injury – a longitudinal study of self-reported quality of life', *Paraplegis*, 32: 416-422

Thurman D, Sniezek J, Johnson D, Greenspan A & Smith S 1995, *Guidelines for the surveillance of central nervous system injury*, US Department of Health and Human Services, Centers for Disease Control and Prevention, Atlanta

Whitteridge D 1983, 'Ludwig Guttman. 3 July 1899-18 March 1980', *Biographical Memoirs of the Fellows of the Royal Society*, 1983 29, 226-244