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# **WAYS TO WORK**

## **Exploring employment issues for people with spinal cord injury in Tasmania**

**FINAL REPORT**

*You can't sit back and wait for people to do things - they don't know what needs to be done. You have to get out there and tell them what you need. INT8*

**An initiative of the ParaQuad Association of Tasmania Inc  
Funded by the Motor Accident Insurance Board (MAIB) through the Injury Prevention and Management Foundation**



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## Foreword

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## Executive Summary

This research is an initiative of the ParaQuad Association of Tasmania Inc, funded by the Motor Accident Insurance Board (MAIB) through its Injury Prevention and Management Foundation. The project commenced in September 2006.

The main aims of the project were to:

1. provide a report identifying barriers and enablers to the employment of people with SCI throughout Tasmania. Specific barriers to employment will be identified as well as those factors that act as enablers to employment;
2. develop sets of principles or strategies for people with SCI, government and non-government agencies/providers, employers and peer support networks which would facilitate employment for the research group. These strategies have been developed around the results of the consultations, relevant literature and current policies; and
3. make recommendations to facilitate principles and strategies on the basis of the research results.

Tasmania has a small traumatic spinal cord injury (SCI) population, estimated at around 200-230 with more than half living in regional and rural areas. Tasmanians also experience many months away from home during their rehabilitation at the Austin and Royal Talbot hospitals in Victoria. Both of these factors impact on aspects of the SCI experience including information and service provision, family relationships and support, and the personal employment, family and friendship networks of the person with SCI. All of these factors can ultimately affect the employment prospects for people with SCI.

In this research access to health and community support information and services and the experience of using services were found to be extremely uneven. Some individuals had or were receiving excellent care and support, while others reported quite devastating experiences. The literature on employment of people with SCI and the results of this research highlight the close connections between employment for people with SCI and adequate access to services and support. For example, if you are in pain and do not have other health and social problems under control you are less likely to work or more likely to have your working life interrupted.

Differences in the availability of health related services and community support between metropolitan and regional and rural areas has been a long standing issue throughout Australia and is perhaps exacerbated in this case because of the small scattered population of individuals requiring quite specialized support. Nevertheless, the State of Tasmania is itself quite small and several aspects of service delivery have been identified that would benefit from closer communication and coordination between organizations, people with SCI and their families.

The results of this research highlight the importance of the role played by families. From the very earliest time they provide support which may include financial assistance, personal care, transport, community access and accommodation. While these supports

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may be indirectly related to employment some families were directly supporting the employment and study activities of the person with SCI through the provision of transport and sometimes assisting with actual work tasks. Families are the constant that ‘got people through the SCI experience’.

As families are themselves quite traumatized by the SCI event this research emphasizes the importance of caring for families and presents strategies for their support. Supporting families may be even more important in Tasmania than in other States because of the small number of people with SCI and the uneven spread of services.

The importance of maintaining networks was identified as highly significant in returning to or taking up new employment, training or study. Most interviewees who worked at some time since their injury did so through the assistance of their informal family and friendship networks or previous employment networks. The current system of undergoing rehabilitation outside Tasmania jeopardizes these networks causing people to grow apart and to lose contacts. Among other strategies to maintain networks an early vocational intervention approach is suggested.

At the heart of solving this issue of unevenness in the experience of services is finding ways to empower people with SCI and their families. They themselves need to be able to: share information; know what services are available and how to have maximum involvement in those services; understand what standards of care are appropriate and what to do when it is not. There was so much frustration expressed by individuals about the amount of time and energy they spent trying to find out about things and being given the ‘run around’.

Information, peer support and advocacy are therefore central to the proposed strategies. At the same time suggested strategies for service providers aim to increase information, coordination between agencies and client involvement.

Closer communication between the individual with SCI and their families and service providers should begin at the early rehabilitation stage of care to try to compensate a little for the distance ‘factor’. This would enable early access to information about services available at home and the experiences of other individuals with SCI in Tasmania. It would also assist in maintaining family, friendship and employment networks from the earliest possible time.

The opportunities for people with SCI are changing rapidly as health and rehabilitation care practices and knowledge continue to grow, increasing life expectancy and quality of life. The other area of great social change that must benefit the SCI population are advances in technology, particularly computer technology. All but five people interviewed in this research used computers and the internet for a range of services and information. The literature on employment of people with SCI advocates access to computers and computer training as a means of promoting employment. Emphasis is placed on computer and assistive technology education during the rehabilitation at the Royal Talbot Hospital. Technology can also be utilized in a variety of ways to promote contact via webcams, email and websites during ‘distance’ rehabilitation. Computer technology can facilitate the provision of information specific to services and supports in Tasmania and enhance peer support for people with SCI and their families through internet discussions groups and forums.

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The experiences of vocational rehabilitation and employment services appeared to be as uneven as experiences of health and support programs. Of concern was the number of people who ‘dropped out of the [employment] system’ after being employed or involved in a work trial or study which for various reasons had concluded. Most of these incidents had occurred some years ago but there were at least three individuals currently experiencing difficulty ‘staying in the system’. The importance of long term ongoing support, clarity about the services being offered and the timeframes of support as well as avenues to re-enter the ‘system’ should not be underestimated. Suggested strategies again focus on self-empowerment as well as the provision of outreach programs and workshops providing links to health, community and vocational and employment service providers. The Commonwealth Government’s Welfare Reform program appears to mitigate against return-to-work for those who have been out of the workforce and receiving the Disability Support Pension (DSP) prior to May 2005.

Employers interviewed for this research were very positive about employing people with disabilities in their organizations and several organizations did so. They were prepared to undertake workplace and access modifications ‘at a reasonable cost’. There did not appear to be undue concern about any increased Workers Compensation costs. Most employers had a policy of allowing flexible hours and days of work but were less prepared to support ‘work from home’. Flexible arrangements may be the key to being able to work or study for some people with SCI who may need extra time to attend to the many complex aspects of SCI related well being.

Employers, however, were generally not well informed about government incentives available to organizations employing people with disabilities. Nor did they appear well informed about the kind of supports that might be required by people with disabilities and there were some possibly unfounded concerns around access and capabilities. Generally it seemed to be a case of, ‘of course we are willing to employ people with disabilities but we don’t really know much about the process’. There was little evidence of policies to attract people with disabilities to the workplace and a level of unsureness about the recruitment process. Strategies (including employer workshops) are suggested to increase employer awareness of employment issues for people with disabilities, in particular SCI, and information sources. Importantly the information should be easily accessible, perhaps linked to websites of local organizations.

At the same time individuals with SCI also need to know about the supports and incentives, including workplace modifications, the rights and responsibilities of employers and employees, to help them argue their case for employment and assess their own workplace needs. Two case studies in this report highlight some exceptional employer/employee relations.

In this research those individuals who were working, loved working. Their workplace relations were good and ranged from having close connections to fellow workers to believing that good work relations depended on being able to do the job. Employers believed that people with disabilities made loyal employees. They stated that their staff generally became more aware of life’s challenges when they worked with people with disabilities and also more sensitive to each others needs and those of their clients.

Return to work or study for individuals with SCI was described as daunting and physically and emotionally exhausting. This was particularly so in the early stages of work but continued to a lesser extent over time. There was also concern during those

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early days about how other people would relate to an employee in a wheelchair and whether he or she would be perceived as able to ‘do the job’. A major issue for SCI people in employment may be the extra ‘wear and tear’ on the person with SCI when working or studying and the reduced amount of time to care for oneself. Strategies to assist in return to work focus on empowerment and support through counseling and peer support.

There is paid work and unpaid work: unpaid work includes work trials in preparation for paid employment and also includes volunteer work without an employment goal. While the work trial experiences may not have resulted in ongoing employment they were generally regarded by interviewees as a valuable experience. They were important in allowing participants to assess their physical and emotional response to employment as well as test their skills. Although this research is about paid employment, the contributions to the community being made by people with SCI in an unpaid capacity were great. In addition, as involvement in volunteer work enables skills and confidence to grow, it may well provide a stepping stone to employment when the time is right.

This study has also identified two other areas for future research that relate directly and indirectly to employment. Firstly, research is required to develop and present information about an optimum range of exercise equipment and programs. There was a very big difference in what individuals with SCI knew about equipment and exercise, what they were doing to keep fit and in what equipment they were able to access. Secondly, long term health issues and lack of finance to address health and equipment problems was a concern to several interviewees. Those who were not able to work due to SCI complications or other reasons and who were dependent on the DSP for income support over the long term faced severe financial hardship. These interviewees, some of whom had long expended the medical funding provided by their insurer, were totally reliant on the under-resourced public system for all of their health care and equipment needs. As both these issues can impact on employment as well as quality of life, further research would be useful.

The recommendations and strategies for people with SCI stemming from this research focus on empowering people with SCI and their families and addressing service related issues with the aim of increasing employment opportunities. Recommendations and strategies for service providers and other agencies focus on increasing client inclusiveness, increasing service standards and equity of access. Strategies relevant to employers are about education, information, networking and chipping away at the barriers to employing people with disabilities.

The ParaQuad Assoc of Tasmania Inc is nominated as the ‘driver’ of these strategies and recommendations. The strategies have been developed in close consultation with the organization and, though they are a small organization, the executive believes that through prioritization and partnership with other sectors the strategies are achievable. In fact the core philosophy informing the strategies lies at the heart of ParaQuad Tasmania, the provision of information, support and advocacy aimed at promoting the self-reliance of people with SCI.

I wish to thank the ParaQuad Assoc of Tasmania Inc. for their support during this research. Scott Shaw, Chairperson of the Association and Local Government Councillor, and Jenny Stanzel, AM, Secretary gave unstintingly of their support, wisdom and ideas. Thanks also to Chris Bosworth, EO of ParaQuad Tasmania for his practical support. Both

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Scott and Jenny participated on the Advisory Group for the project and I wish to extend special thanks to other members of the Group: Lawrence Walsh, MAIB; Rodney Squires, Job Futures Tasmania; Annie Wells, consumer representative; Lorraine Clark, vocational rehabilitation provider; Sandy Burton, employer representative; and Colleen Hooper, WISE Employment.

Thanks also to all of the busy service providers who took time to share their thoughts and ideas. Not a single employer organization refused a request to be interviewed so many thanks also to those human resource managers who were so thoughtful and concerned about the employment of people with disabilities. Thanks to the MAIB for funding the project through their Injury Prevention and Management Foundation. Without their assistance it would not have been possible to conduct this research.

But, I particularly want to thank the people with SCI and family members who participated in interviews. They were so open and frank about their lives, experiences and feelings even though the interviews brought back some painful memories. They are the most resilient, imaginative, innovative and determined lot of people I have ever met.

Robyn Wolstenholme  
Co-ordinator

**W**ays to Work Project

Exploring employment issues for people with spinal cord injury in Tasmania

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## **Barriers and Enablers to Employment - Summary**

### **Barriers**

- A lack of information about services and supports in Tasmania
- Differences in service standards in Tasmania
- Negative experiences of vocational rehabilitation services and employment services
- Lack of long term vocational support
- Lack of information for employers

### **Enablers**

- Families supporting people with SCI
- Family, friendship and employment networks
- Early contact with previous employer and early vocational intervention
- Usage and availability of computers
- Long term vocational support for people with SCI returning to work
- Flexibility of work arrangement and hours
- Workplace modifications, access and transport
- Unpaid work placements

### **Possible enabler**

- Other kinds of work

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## Recommendations and Strategies

- ❖ Strategies and recommendations which involve ParaQuad Tasmania are intended for both the organization and people with SCI and their families - the organization's membership.
- ❖ Recommendations refer to those actions that may require a major shift in policy, legislation, practice and partnerships. Strategies refer to those actions which can be undertaken within existing policy and practice frameworks.

### **Recommendation 1 – Increasing access to information and specialized services for people with SCI**

Tasmanian Spinal Teams to develop an integrated program across regions of Tasmania with unified standards of care for all Tasmanians with SCI. Information about the Spinal Teams and its services to be made available on the Tasmanian Department of Health and Human Services web-site.

### **Recommendation 2 – Develop systems across agencies to facilitate the provision of information and peer support for people with SCI and families during acute care and early rehabilitation**

ParaQuad Tasmania to further develop protocols with the Austin and the Royal Talbot Hospitals to facilitate peer contact with the injured person and their family, early contact with Tasmanian service providers, and the provision of information packages developed for Tasmanians.

### **Recommendation 3 – Outreach support across regional areas**

ParaQuad Tasmania to strengthen their outreach/networking program across the regions to ensure information and support is provided to people with SCI throughout Tasmania.

### **Recommendation 4 – Review and complaints mechanisms**

ParaQuad Tasmania to consult with insurers and all relevant service providers and develop an 'easy to use' review/complaints model for agencies.

### **Recommendation 5 – Client inclusiveness and whole-of-life approach**

Insurers and publicly funded service providers review their approach to service delivery of people with SCI and identify ways to increase client inclusiveness. This may include increased use of case management procedures encompassing a whole-of-life approach, ensuring client input and sign-off on reports and reviews and the implementation of easy-to-use complaints/compliments mechanisms. Program exit and re-entry strategies would be clearly defined.

### **Recommendation 6 – Counseling and psychological assistance**

ParaQuad Tasmania to seek funding to develop a counseling service specializing in issues around SCI for those who have been injured and their families. It may be an adjunct to the peer support program and developed along the same lines as the program offered by ParaQuad Victoria or through privately contracted providers with specialist knowledge.

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### **Recommendation 7 – Early intervention vocational rehabilitation pilot**

In consultation with ParaQuad Tasmania and the Tasmanian Office of Post-Compulsory Education and Training (OPCET) a panel of vocational rehabilitation and vocational education providers seek funding to develop and pilot a program of early vocational rehabilitation intervention for Tasmanians with recent spinal cord injuries. The model should take account of the NSW SpinalWorks program and commence during the acute rehabilitation phase with proper regard to the physical and emotional well-being of the injured person. While taking account of the long term needs of some individuals, its aims might include identifying vocational directions, keeping existing networks alive and promoting early return to work and involvement in training programs.

### **Recommendation 8 – A brokerage model for people with SCI seeking work**

In consultation with ParaQuad Tasmania, Disability Employment Network members and the Tasmanian Disability Bureau explore the possibility of a brokerage model pilot to be incorporated into current processes. The aim would be to empower the person seeking work and maximize their control over the process and available resources.

### **Recommendation 9 – Long term support and getting back into the system**

In consultation with ParaQuad Tasmania, Disability Employment Network members and the Disability Bureau monitor long term training and employment needs of individuals with SCI. The group might also identify key areas of opportunity for entry and re-entry into the work force and/or training programs.

Individuals with SCI undergoing vocational rehabilitation to ascertain clear exit and possible re-entry mechanisms with their providers.

### **Recommendation 10 – Regional fora/workshops**

ParaQuad Tasmania to facilitate biennial information workshops in the north and south of Tasmania with themes on employment and community work participation including work and study entry – and SCI ongoing health promotion – at work and at home. Workshops to be held in conjunction with regional service providers from, for example, Job Network and vocational rehabilitation agencies, the Vocational Education and Training (VET) sector and Spinal Teams.

This initiative may build on the ParaQuad Tasmania outreach program recommended above.

### **Recommendation 11 - Workshops for employers about employing people with disabilities**

ParaQuad Tasmania in partnership with Disability Employment Network members, the Tasmanian Disability Bureau, vocational rehabilitation providers and the Tasmanian Chamber of Commerce and Industry (TCCI), to jointly facilitate an annual employer forum to address workplace issues around flexible hours, access, modifications, work at home policies, staged return to work and work relationships.

The forum might include input from people with expertise in the area or who are undertaking significant initiatives eg. Diversity at Work program, Human Rights and Equal Opportunity Commission and the Employers Network

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### **Strategy 1 – Early contact with rehabilitation providers**

The Tasmanian Spinal Teams and insurer funded rehabilitation providers to facilitate early and continuing contact with the injured person during the acute ‘distance’ rehabilitation period. The aim of contact would be to provide information about Tasmanian services and ensure a smooth transition from acute rehabilitation to community living in Tasmania. Contact may be in person, by phone, internet and/or video; and,

ParaQuad Tasmania to investigate transport and accommodation funding sources for the injured person to undertake weekend leave to meet with Tasmanian rehabilitation specialists and providers prior to their discharge from the Royal Talbot.

### **Strategy 2 – Information about care and support services at home**

ParaQuad Tasmania to consult with the Tasmanian Spinal Teams and insurers to update and broaden ParaQuad’s information package for people with SCI and families to be made available to them during the acute rehabilitation phase. The package should focus on:

- all those services and programs (health, community and recreational; private and public) likely to be required by an individual with SCI, families and carers;
- a map of how the system works;
- rights, responsibilities, standards of services and complaints mechanisms; and
- initial information for employers about SCI and the workplace eg. vocational rehabilitation, work modifications, funding available for wage subsidies etc.

Information should be available in hard copy and on the ParaQuad Tasmania and other relevant websites.

### **Strategy 3 – Peer support and mentoring for people with SCI with an on-line forum**

ParaQuad Tasmania continue to develop a peer/mentor support program to support newly injured persons while in the Talbot by assisting in maintenance of personal and family networks and thereafter. The program would be enhanced by the provision of an on-line forum promoting discussion in all relevant aspects of life after SCI including access to services, recreation, use of equipment and self care and going back into vocational training/study and work. The program should be able to support mentor linkages across vocational and interest areas as well as support related to SCI.

### **Strategy 4 – Advocacy**

ParaQuad Tasmania to seek funding to employ an advocate to assist with access to services and standards and complaints issues across a full range of services for people with SCI.

### **Strategy 5 – Hospitalisation**

ParaQuad Tasmania to consult with hospital educators and key Spinal Team members in each region and develop a protocol for care of people with SCI while in hospital. This will include consideration of:

- notes on hospital files to alert staff of the need to contact a spinal team member;
- provision of information sheets to hospital staff by the person with an SCI being hospitalized about the care required ;
- personal carers providing care program during the hospitalization period and/or additional staff for people who are wheelchair dependent.

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### **Strategy 6 – Early information for families**

ParaQuad Tasmania to consult with Spinal Teams across the State, with families and the Austin and Royal Talbot Hospitals and further develop the initiative of the northern Spinal Team. The package could be made available to families prior to leaving for Melbourne or soon after arrival at the Austin Hospital.

Package may contain information about:

- Acute care and rehabilitation program and maps of hospitals
- Accommodation options for family members
- Information about social security and Centrelink
- Information about Workers Compensation and the MAIB claims and benefits
- Information about rights and responsibilities in relation to insurer and government programs and their complaints and appeals mechanisms
- Information about community legal assistance in Tasmania
- Information about travel assistance
- A list of resources and supports relevant to this early stage
- A list of resources and publications for children of parents with SCI
- Resources and packages available through State and Commonwealth disability services.

Information with relevant links should also be made available on ParaQuad Tasmania website

### **Strategy 7 – Supporting families – peer support**

ParaQuad Tasmania to develop a small network of families of individuals with SCI to provide peer support to other families for any aspect of the situation after injury. They may be available by phone or in person.

### **Strategy 8 – Supporting families in the early stages – travel**

ParaQuad Tasmania to negotiate logistics and further options for accommodation and travel to Melbourne for family members while injured person is in the Austin or Royal Talbot hospitals.

### **Strategy 9 – National online forum for families of people with SCI**

In consultation with other State and national SCI organisations, ParaQuad Tasmania to foster the development of a national online forum network for families of individuals with SCI.

### **Strategy 10 - Information for friends and family at home and facilitating contact.**

ParaQuad Tasmania to consult with the Royal Talbot Hospital and Tasmanian Spinal Teams and:

- develop an information package/DVD about SCI for members of the extended family, friends and employment networks of the injured person;
- make weekend leave for the injured person (as physically appropriate) from the Royal Talbot hospital to home in Tasmania an integral part of rehabilitation;
- encourage the injured person to access the Tasmanian peer support program to contact friends; and
- to encourage computer based internet contact – including web cams and YouTube/MySpace - between injured person and those at home. ParaQuad Tasmania to assist families if necessary in the provision of equipment eg computer, web cam and internet connection.

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### **Strategy 11 - Promote use of computer technology and assistive devices in vocational programs.**

ParaQuad Tasmania to promote the value of computer access programs and training for people with SCI as a means of gaining lifestyle independence, facilitating further study and training and promoting employment. The use of computers and internet to be an integral part of vocational programs.

### **Strategy 12 – Information about employment and employment opportunities for people with SCI**

ParaQuad Tasmania to develop a ‘web’ page with information (with a Tasmanian focus) about employment and vocational rehabilitation programs with links to relevant employer, insurer and government web-sites. It could contain case studies of people with SCI working in particular occupations and provide examples of workplace arrangements.

### **Strategy 13 – Welfare Reform**

ParaQuad Tasmania in consultation with other SCI organizations, to monitor the effects of the Commonwealth Government’s Welfare Reform program in relation to review, long term support, access to training, education and employment and a person’s financial situation.

### **Strategy 14 – Information for employers**

ParaQuad Tasmania to consult with the Tasmanian Chamber of Commerce and Industry (TCCI) and develop an appropriate local information package for employers about employing people with disabilities/SCI. Information should appear on websites of both organizations and might encompass:

- Workplace modifications and funding and who to approach
- Access regulations and issues
- Workplace vocational support
- Flexible work arrangements and Worker’s Compensation issues
- Possible carer involvement at work
- Guidelines for selection and interview of people with disabilities
- Links to government sites for work subsidy details

This information page may be an extension of the employment information page for individuals with SCI, Strategy 12.

### **Strategy 15 – Access and Transport**

ParaQuad Tasmania and its members to maintain an involvement in Access Committees and access auditing. Information about access and transport issues in Tasmania could be made available on a dedicated page on the ParaQuad Tasmania website.

## Suggested organisational responsibility for carrying out recommendations and strategies

N.B.\*Suggested drivers of the Recommendations and Strategies are noted in **Bold**

| <b>ParaQuad Tasmania</b>  | <b>ParaQuad Tasmania with other Agencies</b>  | <b>Other Agencies</b>   |
|---|---|---|
| <b>Recommendation 2</b> – Develop systems across agencies to facilitate the provision of information and peer support for people with SCI and families during acute care and early rehabilitation | <b>Recommendation 11</b> - Workshops for employers about employing people with disabilities<br><b>ParaQuad Tasmania, Disability Employment Network members, the Tasmanian Disability Bureau, vocational rehabilitation providers Tasmanian Chamber of Commerce and Industry (TCCI).</b> | <b>Recommendation 1</b> – Increasing access to information and specialized services for people with SCI – <b>Tasmanian Spinal Teams</b>   |
| <b>Recommendation 3</b> – Outreach support across regional areas  | <b>Strategy 1</b> – Early contact with rehabilitation providers<br><b>Tasmanian Spinal Teams and insurer funded rehabilitation providers and ParaQuad Tasmania</b>  | <b>Recommendation 4</b> – Review and complaints mechanisms - <b>All agencies working with people with SCI</b>   |
| <b>Recommendation 6</b> – Counseling and psychological assistance   | <b>Strategy 5</b> – Hospitalisation<br><b>ParaQuad Tasmania</b> in consultation with Nurse Educators and key Spinal Team members  | <b>Recommendation 5</b> – Client inclusiveness and whole-of-life approach – <b>All agencies working with people with SCI</b>  |
| <b>Recommendation 10</b> – Regional fora/workshops  | <b>Strategy 6</b> – Early information for families - <b>ParaQuad Tasmania</b> in consultation with Spinal Teams across the State, with families and the Austin and Royal Talbot Hospitals   | <b>Recommendation 7</b> – Early intervention vocational rehabilitation pilot – <b>Vocational rehabilitation and education providers</b> in consultation with ParaQuad Tasmania and the Tasmanian Office of Post-Compulsory Education and Training (OPCET) |
| <b>Strategy 2</b> – Information about care and support services at home   | <b>Strategy 9</b> – National on-line forum for families of people with SCI – <b>ParaQuad Tasmania and other SCI organizations</b>   | <b>Recommendation 8</b> – A brokerage model for people with SCI seeking work – <b>Disability Employment Network and the Tasmanian Disability Bureau</b>   |
| <b>Strategy 3</b> – Peer support and mentoring for people with SCI with an on-line forum  | <b>Strategy 10</b> - Information for friends and family at home and facilitating contact - <b>ParaQuad Tasmania</b> in consultation with the Royal Talbot Hospital and Tasmanian Spinal Teams   | <b>Recommendation 9</b> – Long term support and getting back into the system - <b>Disability Employment Network and the Tasmanian Disability Bureau</b>   |
| <b>Strategy 4</b> – Advocacy  | <b>Strategy 13</b> – Welfare Reform<br><b>ParaQuad Tasmania and other SCI organizations</b>   |   |
|   | <b>Strategy 14</b> – Information for employers<br><b>ParaQuad Tasmania</b> in consultation with the Tasmanian Chamber of Commerce and Industry (TCCI)   |   |

| <b>(Cont.) ParaQuad Tasmania</b>  | <b>ParaQuad Tasmania with other Agencies</b> | <b>Other Agencies</b> |
|---|--|-----------------------|
| <b>Strategy 7</b> – Supporting families – peer support  |  |                       |
| <b>Strategy 8</b> – Supporting families in the early stages – travel                                  |  |                       |
| <b>Strategy 11</b> – Promote use of computer technology and assistive devices in vocational programs. |  |                       |
| <b>Strategy 12</b> – Information about employment and employment opportunities for people with SCI    |  |                       |
| <b>Strategy 15</b> – Access and Transport   |  |                       |

### **How this report is structured**

This report consists of eight chapters. The first two chapters present methodology and background to the report, a profile of participants as well as information about SCI and its incidence in Tasmania. Chapter 3 outlines some key legislation, policies and key Tasmanian services relating to employment and SCI. Chapter 4 summarizes previous studies about employment of people with SCI. It also outlines employer issues, incentives to employ people with disabilities and some employer initiatives.

Chapters 5 to 8 present the findings of the research and identify the issues that provide barriers to employment and those factors that enable employment for people with SCI in Tasmania. Quotes from interviews are presented and arguments are put forward for recommendations and strategies to address each barrier and enhance each enabling factor. Finally there are suggestions for further research followed by the Conclusion.

Appendices contain the open ended interview schedules used when interviewing individuals with SCI and employers.



## Chapter 1 - Background to Research and Methodology

### 1.1 Introduction

This research is an initiative of the ParaQuad Association of Tasmania Inc, (hereafter referred to as ParaQuad Tasmania) funded by the Motor Accident Insurance Board (MAIB) through its Injury Prevention Management Foundation. The project commenced in September 2006.

ParaQuad Tasmania provides a wide range of services to individuals with SCI. These include:

- peer support / mentoring / advocacy
- sale of medical and continence products
- provision of information about product and services
- hiring of equipment
- access audits
- SpineSafe Education Program
- Liaison with government, business, and service providers.

It is vital, therefore, that ParaQuad Tasmania has a good understanding of the issues facing its members and potential members.

ParaQuad Tasmania and researchers (Dorsett, 2001; Krause, 1992 and 2003) note the importance of employment for people with SCI. Employment offers:

- financial rewards
- personal rewards
- community and social integration
- structure; and
- SELF WORTH - so important for all people with disabilities.

Anecdotal information caused ParaQuad Tasmania to become concerned about the low employment rate of its members and the organization wanted to understand more about the barriers and enablers to employment, the experiences of those who were employed and the kinds of strategies that might facilitate the employment of people with SCI in the future.

ParaQuad Tasmania believed that the knowledge gained from research into this area could lead to productive partnerships with other agencies and employer groups with a shared vision of increasing employment for individuals with SCI.

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## 1.2 Major Objectives

The main aims of the project were to:

1. provide a report identifying barriers and enablers to the employment of people with SCI throughout Tasmania. Specific barriers to employment have been identified as well as those factors that act as enablers to employment.
2. develop sets of principles or strategies for people with SCI, government and non-government agencies/providers, employers and peer support networks which would facilitate employment for the research group. These strategies have been developed around the results of the consultations, relevant literature and current policies.
3. make recommendations to facilitate principles/strategies on the basis of the research results.

## 1.3 Methodology

### 1.3.1 Methodological Framework

Two main concepts that have informed this research. The first, Action Research, is qualitative research carried out in a flexible and collaborative manner that takes account of the social, political and cultural context of individuals and group. The aim is to 'make sense' of a situation through an interactive process in which the views of all participants are taken into account. In short it aims to 'get at the bottom of things' in a co-operative way and find out what is going on (Guba and Lincoln, 1989; Patton, 2001; Whyte, 1991).

The second concept informing this research is identification of the strengths of a program or situation and the knowledge and ideas of its participants (Fetterman and Wandersman, 2004). Both organizations and people are likely to benefit when strengths are recognized and strategies identified to further their development.

The research has been based on in-depth interviews with 27 people with SCI of employment age. Family members participated on only two occasions although it was made clear at the outset they were welcome to participate. The sample has representation from different geographic areas, gender, ethnicity and age cohorts. Although it was anticipated that 30 interviews would be conducted, time constraints made this difficult. However, it is believed that the data from the 27 interviews is extremely rich and presents a continuum of SCI and employment experiences over time with clear emerging patterns and themes.

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The research has focused on those who have severe or profound disability as defined by ABS\* caused by a spinal cord injury due to trauma and who are of employment age. The focus is on this group because:

1. their experiences and common interests are likely to be similar whether injury has been caused by transport, work or recreational incidents. For example, as stated by Cripps (2006) the incidence of persistent SCI age 15 years and over, recorded for 2003-4 was highest in the 15-24 age bracket and higher for males in all age groups. On the other hand, most cases of non-traumatic SCI are secondary to a medical condition such as cancer with an average age of 57 years.
2. higher levels of injury are a significant impediment to entry or re-entry into the workforce. In 2003 people with a profound or severe core-activity limitation had a work participation rate (either employed or unemployed but actively seeking work) of 15.2% and 35.8% respectively compared with 80.6% of people without a disability (ABS, 2005; Human Rights and Equal Opportunity Commission, 2005). The challenge in gaining employment is therefore quite high.

People with SCI who were interviewed were sourced in several ways. Some responded to newspaper advertisements, some to letters of invitation by ParaQuad Tasmania while others were directly contacted by the organization. Two people were referred by service providers. Interviewees with SCI were offered a payment of \$120.00 as a gesture of thanks for their participation.

Because we wanted to find out what was 'going on' and to explore the parameters of issues on employment the research has been based on in-depth interviews during which people told their story with open-ended questions guiding the interviewee towards employment issues. The results of their stories has been placed in the context of current policy, service provision practice and the literature on employment and people with SCI.

Interviews were held with 10 employing organizations to gain a 'snapshot' of their experiences in employing people with disabilities. Discussions were held with key service providers and organizations to gain their views and ideas. These discussions have provided greater understanding of the employment and service context for individuals with SCI in Tasmania.

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\* People with a **profound core-activity limitation** always need help with self care, mobility or communication, or are unable to do these tasks. People with a **severe core-activity limitation** sometimes need help with self care, mobility or communication; or have difficulty understanding or being understood by family or friends; or communicate more easily using sign language or other non-spoken forms of communication (ABS, 2005). These definitions would most appropriately cover individuals with SCI.

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## 1.4 Confidentiality

Tasmania is a small State with a small and linked community of people with disabilities. It was anticipated that much of the information collected from and about people with SCI would be of a private and sensitive nature and this was the case. Data from the SCI interviews has been coded for reporting and data storage purposes. All participants were provided with written information about the research and signed a participation consent form prior to their interviews. A draft interim report containing the ideas and quotes attributed to the interviewees, proposed recommendations and strategies was sent to participants for their approval prior to publication of the final report.

## 1.5 Research Stage 1, 2, 3 Project Tasks

- a) A small Advisory Group was established to oversight research. The Group included representatives from ParaQuad Tasmania, the MAIB, Local Government and employment agencies. The Group also had employer and consumer representation. Four members of the Group had sustained an SCI.
- b) Literature relating to employment of people with SCI has been reviewed and analysed.
- c) Government policies regarding disability and employment have been outlined.
- d) Insurer policies and guidelines have been outlined.
- e) Focused but open interview schedules informed by literature and policy were developed for interviews with people with SCI. As new ideas/issues were raised they were included in future discussion. Information from people with SCI gathered during interviews has been central to discussions with agencies and employers.
- f) Interviews have been held with 27 people with SCI from around Tasmania. Each interviewee received a participation fee of \$120.00
- g) Interviews/consultations with representatives from 18 agencies and 10 employing organisations have been conducted.
- h) Using text analysis software CDC EZ Text, (Carey et al., 1998) data from interviews has been analysed and related to ideas/strategies for overcoming barriers and enhancing strengths that have been identified in the study.
- i) Sets of strategies and recommendations have been developed. Strategies are those actions that can be accommodated relatively easily within current frameworks. Recommendations are those actions that will require a change in policy or legislation and/or a substantial change to current practice.

- j) A draft report outlining key factors providing barriers and enablers to the employment of SCI as well as quotes and ideas from interviews was sent to all interviewees for comment. They have been asked whether or not the key points and strategies ring true to them and would be useful in the future. In addition, with the permission of interviewees, case studies highlighting employment experiences are provided.

## 1.6 Profile of Research Participants

| Characteristic                                   | Number               | Characteristic   | Number |
|--|----------------------|--|--------|
| Male   | 20                   | Currently students   | 4      |
| Female   | 7                    | Employed as a professional                                     | 7***   |
| Age range  | 18-55                | Employed in administration                                     | 2      |
| Cervical injury                                  | 12                   | Employed in trade  | 1      |
| Thoracic injury                                  | 13                   | Have been employed at some time since injury                   | 16     |
| Lumbar injury                                    | 2                    | Have undertaken some form of training/education post injury    | 14     |
| Time since injury                                | 18 months – 27 years | Have tertiary (or part) education                              | 10     |
| Average time since injury                        | 11.3 yrs             | Have trade qualifications                                      | 5      |
| Reside in North/Northwest                        | 10                   | Have HSC level   | 4      |
| Reside in South                                  | 17                   | Have year 9 – 11 education                                     | 8      |
| Have dependent children                          | 12                   | Not working but volunteer or full time parents/carers          | 10     |
| Had been employed part/full time prior to injury | 21*                  | Identifies as an Aboriginal person                             | 1      |
| Full time students prior to injury               | 6**                  | From a non-English speaking background                         | 1      |
| Currently employed                               | 10                   | Current family involvement in care, transport or accommodation | 14     |

\* does not include students employed part-time

\*\*4 students were also employed part-time \*\*\*includes 1 self-employed person

Sixteen people were injured in land transport accidents (including an unprotected road user) and four of these accidents were work or sport related, five people were injured through falls (one of which was work related), three through diving accidents, two people sustained injuries due to acute medical conditions and two people sustained crushing injuries while at work (one incident involving an off road transport vehicle).

In addition discussions/interviews have been held with 17 service providers/agencies involved in various support eg, employment, occupational and vocational therapy, insurance, personal care, disability support and spinal care. Ten representatives of employing organizations have been interviewed. These employing organizations were selected either for their State wide focus, contact with people with SCI and different interest and type. The aim

was to obtain a ‘snapshot’ of the issues for Tasmanian employers. No employer contacted refused to be interviewed.

Service providers were asked about the services they provided and their experience working with people with SCI. There was no set interview schedule for this group. Employers were asked about their knowledge and experience of employing people with disabilities and people with SCI.

| <b>Organisations participating in employer interviews</b> | <b>Agencies/individuals consulted</b>                |
|---|--|
| University of Tasmania                                    | ParaQuad Association of Tasmania Inc                 |
| Myer Ltd Hobart   | University of Tasmania, Disability Services          |
| Hobart City Council                                       | Motor Accident Insurance Board                       |
| Launceston City Council                                   | Spinal Teams   |
| Roberts Limited   | North  |
| Webster Fresh   | South  |
| Hobart Pathology  | North-west   |
| Connect Credit Union                                      | Tasmanian Redeployment Service                       |
| Calvary Health Care Tasmania                              | Commonwealth Rehabilitation Service                  |
| Tasmanian Disability Bureau                               | WISE Employment, Devonport and Hobart                |
|   | Job Futures Tasmania                                 |
|   | WorkCover Tasmania                                   |
|   | Royal Talbot Hospital Victoria                       |
|   | ParaQuad Victoria                                    |
|   | Lorraine Clark, Vocational Rehabilitation Consultant |
|   | Andrea Bucher, Occupational Therapist                |
|   | Anglicare Home Support Service                       |
|   | Tasmanian Disability Bureau                          |

Appendix 1 contains interview schedules for participants with spinal cord injury and employers.

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## Chapter 2 - About Spinal Cord Injury

### 2.1 What is spinal cord injury?

The spine travels from the base of the skull down to the coccyx or tailbone. It consists of seven cervical, twelve thoracic, five lumbar, five sacral and four coccygeal vertebrae. These vertebrae surround and protect the spinal cord within a canal like structure. The cord itself is made up of millions of nerve fibres, rather like a mass of telegraph wires, transmitting messages all over the body.

These messages pass through our somatic or voluntary nervous system which controls movement in our arms and legs, muscles and joints and the feeling in our skin. Messages also pass through our autonomic or involuntary nervous system which governs our blood vessels, body temperature, breathing and aspects of bladder, bowel and sexual functions (ParaQuad Victoria, 2006).

The spinal cord is injured when its blood and oxygen supply are disrupted by a severe injury to the spinal column or vertebrae. Injury to the spinal cord will result in paralysis and loss of sensory function below the level of SCI (ParaQuad Victoria, 2006).

Injuries to the spinal cord may, however, be either complete or incomplete depending on the extent of damage to the cord. A person with a complete injury will experience loss of motor and sensory function below the level of injury and on both sides of the body. If the injury is incomplete some messages will get through and a person may be able to feel parts of the body that cannot be moved and/or one side of the body may function more than the other (Paraplegic and Quadriplegic Assoc of NSW, 2006; ParaQuad Victoria, 2006).

The closer the damage is to the brain the greater the level of injury. Damage at the neck or cervical level will result in quadriplegia\*<sup>1</sup> or tetraplegia which is the preferred medical term. This means that all four limbs, the hands and trunk will be paralysed. People with injuries to the C1 - C4 level may require a ventilator to breathe. At C5 they may have shoulder and bicep control but none over wrist and hand movements. An injury at C6 may leave wrist control but no hand control and at C7 and T1 individuals may be able to straighten their arms but have lost the dexterity of hands and fingers (Paraplegic and Quadriplegic Assoc of NSW, 2006; ParaQuad Victoria, 2006).

Injury to the spinal cord at the thoracic level and below will result in paraplegia, where the hands and arms are not affected. At T1 through to T8 there may be poor trunk control as a result of the lack of abdominal muscle control but lower injuries of T9 to T12 allow for good sitting balance and trunk control while injuries to the lumbar and sacral regions mean a decrease in control of the hip flexors and legs (ParaQuad Victoria, 2006).

As well as loss of movement and sensation people with spinal cord injuries may experience a loss of bowel and bladder control and also changes in sexual function. Blood pressure may be

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<sup>1</sup> As quadriplegia remains the popular term it will be used throughout this report.

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lowered and there may be reduced control of body temperature and an inability to sweat below the level of injury. People with spinal cord injury may also experience chronic pain (ParaQuad Victoria, 2006).

Quadriplegia is the most common traumatic SCI. In 2003-4 fifty-five per cent of SCI injuries affected the cervical segments resulting in quadriplegia. Forty-five percent involved the thoracic, lumbar or sacral segments resulting in paraplegia. The most common category of injury was incomplete quadriplegia (41%) (Cripps, 2006).

The onset of traumatic spinal cord injury is sudden and, given the extent of the consequences described above, is a devastating and life changing event for anyone sustaining such an injury. At this stage there is no cure and the injuries will last life long (Dorsett, 2001).

The time spent in a Spinal Unit at the commencement of the road to recovery is a clear indicator of the impact on people's lives. The average time in a Spinal Unit before discharge to home or community accommodation is 136 days (about four and half months) ranging from 51 days for incomplete paraplegia to 261 days for complete quadriplegia (Cripps, 2006).

These life changing events mean that, unless the injury is at a low level, a person will require a wheel chair for their mobility. Even a lower level injury, eg. at L4, will result in the injured person needing some facility such as crutches or braces to assist in mobility (ParaQuad Assoc of Tasmania Inc: undated). Depending on the level of injury the injured person may be dependent on others for many tasks of daily living such as toileting, washing and dressing. Assistance may be needed to manage the loss of control over bowel and bladder functions. Assistance may also be required to access employment, community and recreational activities (Dorsett, 2001).

These changes will also have a profound effect on relationships within the injured person's family and circle of friends. Family members may become carers. As interests change friendships are also likely to undergo changes (Dorsett, 2001; ParaQuad Assoc of Tasmania Inc, undated).

## **2.2 Who sustains a spinal cord injury?**

Statistical reports based on data collected from the Australian Spinal Cord Injury Register cover the years since 1995. In the most recent report Cripps (2006) has examined data from those sustaining a persistent traumatic spinal injury in financial year 2003-2004. His report provides us with an up to date picture of the incidence and causes of injury and the demographics of those who have been injured.

Between 300 and 400 Australians sustain a new traumatic SCI every year and there is an estimated prevalent population of 8,500 people who have sustained an SCI. The reported population in the north and north-west of Tasmania is 66 and 50 respectively but the population figure for the southern region of Tasmania was not available. However, using the known national and State data as a baseline to compare with general population figures, the estimated prevalent SCI population for Tasmania would be around 200-230 people. In Tasmania for the three years 2001-2004 there were 23 reported cases of SCI.

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The age adjusted rate of SCI caused by trauma 2003-4 in Australia was 15.3 new cases per million aged 15 years and older. The highest case counts occur in the 15-24 age group accounting for 27% of SCI caused by trauma 2003-4.

Of all cases of SCI due to trauma 2003-4, 82% were male and 18% female, the difference greatest in young adults. For example, the male to female ratio was 9.7:1 in the age group with the highest case counts of SCI, 15-24.

Almost half of all people sustaining an SCI in 2003-4 were married. However, one third had never married and 65% of these people were in the age group 15-24 years. Spouses and parents or other relatives are important providers of care during rehabilitation and after. A recent Queensland study of individuals with SCI found that families provided an average of 71.3 hours per fortnight (Rowell, 2006).

Fifty per cent of SCI individuals were employed at time of injury, 15% had a tertiary or post graduate education and 30% had a trade qualification.

Marital status, education levels and employment experience are important predictors of gaining employment after the occurrence of SCI.

The major causes of SCI are transport accidents of motor vehicle occupants and unprotected road users – 41%; falls below and above one metre – 34%; water and sport related – 16% and other causes 9% (Cripps, 2006).

Based on current statistics it is predicted that there will be an increasing number of elderly SCI cases in Australia as the population ages (O'Connor, 2004).

### **2.3 What happens when someone in Tasmania sustains an SCI**

Tasmania, like other small jurisdictions, the Australian Capital Territory and Northern Territory does not have its own Spinal Unit. People who sustain a spinal cord injury within Tasmania will be flown by Air Ambulance to the Spinal Unit at the Austin Hospital at Heidelberg, Melbourne for acute care. Following the acute phase they will receive rehabilitation at the Royal Talbot Hospital in the Melbourne suburb of Kew.

Rehabilitation is a complex and lengthy process during which the injured person learns to manage the many complications of spinal cord injury. These include bladder and bowel management as well as management and prevention of a wide range of medical problems such as spasticity, infections, and hyper-reflexia. At the same time the newly injured person will be assisted to maximize their functional skills and movement and learn new ways of managing the tasks of daily living (Dorsett, 2001).

As noted above, the average time spent in acute and rehabilitation care is four and a half months, but can be considerably longer.

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For Tasmanians, as for people from rural areas across Australia, rehabilitation after SCI means a lengthy separation from family, home, friends and employment networks. Tasmanians, however, are not only separated by distance but also by the sea. Friends cannot jump in a car and share travel costs for a quick Saturday visit to the rehabilitation centre. Family members face the cost of air and/or sea travel with usually one member needing to reside in Melbourne close to the injured person. Weekend leave for the Tasmanian injured person is harder to achieve and not common. You can't, at the drop of a hat, go home and see if you can still get into the local pub.

Following discharge from the Royal Talbot, the person will return to Tasmania into the care of one of three regional Spinal Teams located in different sections of the Tasmanian Department of Health and Human Services and/or, if applicable, supported by a care plan arranged by their insurer. The Teams include a spinal nurse, occupational and physiotherapists, social worker, and medical specialists, including visiting specialists from Victoria. Insurers may provide support through contracted rehabilitation professionals and a case management program.

Initial discussions with service providers indicated that distance rehabilitation affected family and friendship networks and limited or prevented early contact with rehabilitation providers. All of these things were confirmed in the interviews with individuals who had sustained an SCI. What also emerged were the crucial links between future employment and family, friendship and employment networks as well as information and service access.

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## Chapter 3 - Key Legislation and Services Related to Employment of People with Spinal Cord Injury

### 3.1 Key legislation

#### 3.1.1 Responsibility

The Commonwealth State Territory Disability Agreement (CSTDA) provides the national framework for the delivery, funding and development of specialist disability services for people with disabilities.

Under the three agreements signed so far (the first in 1991) all parties are responsible for funding specialist services for people with disabilities:

- the Australian Government has responsibility for the planning, policy setting and management of specialised employment assistance;
- state and territory governments have similar responsibilities for accommodation support, community support, community access and respite; and
- support for advocacy and print disability is a shared responsibility.

Through the Agreement, the Australian, State and Territory Governments strive to enhance the quality of life experienced by people with disabilities through assisting them to live as valued and participating members of the community (Responsibilities quoted from the website of the Commonwealth Department of Family and Community Services, 2007).

Policy priorities in the current multilateral agreement are relevant to this research. They aim to:

- strengthen access to mainstream and generic services for people with disabilities
- strengthen across government linkages
- strengthen individuals and families
- improve long-term strategies to respond to, and manage demand for, specialist disability services and
- improve accountability, performance reporting and quality of specialist disability services.

(Priorities quoted from the website of the Commonwealth Department of Family and Community Services, 2007).

Although the Commonwealth has direct responsibility for employment of people with disabilities, the role of the States and Territories cannot be underestimated. Accommodation, care and community access and access to specialist services are vital supports for people with SCI who are seeking employment or participating in training, education and work

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### **3.1.2 Commonwealth and State legislation relevant to service standards and accountability**

The *Home and Community Care Act 1985* provides for the Commonwealth and State Governments to develop and deliver a range of integrated home and community care services for frail or at risk aged persons and younger people with disabilities to assist these people to remain in their own homes. The Act emphasizes provision of services in an equitable manner, the enhancement of independence for those receiving services and the importance of co-ordination with other agencies.

The *Disability Services Act 1986* provides the legislative base and framework for the funding and provision and standards of disability support services funded by the Commonwealth.

The *Disability Services Act Tasmania 1992* aims to increase service accountability and consumer focus in state based services. It outlines service standards, basic principles and objectives of service delivery to people with disabilities. Among other things, the Act promotes client inclusiveness, ease of access to services, access to advocacy and client independence.

The Tasmanian Government has implemented a *Disability Framework for Action 2005-2010*. It promotes a 'whole of government' approach with a focus on access and equity, the provision of a high standard of services and collaborative working principles. It is overseen by the Premier who will receive advice from a Disability Advisory Council with a 50% membership of people with disabilities, their families and carers. The Framework has also implemented a disability employment initiative to increase employment of people with disabilities in the State Service (Tasmanian Department of Premier and Cabinet, 2006).

*Tasmania Together 2020* is a strategic policy which has been accepted as a long term vision for Tasmania's future. A new version of *Tasmania Together* which better reflects and incorporates the experiences of people with disabilities is to be launched in 2007 (Tasmania Together Progress Board, 2006).

### **3.1.3 Discrimination**

The *Disability Discrimination Act (DDA) 1992* is a Commonwealth law governing the rights of people with a disability. Discrimination on the grounds of disability is unlawful. This Act has application to areas of great relevance to this research including: getting a job, aspects of employment such as promotion and , getting 'reasonable adjustment' for a disability. It also applies to education, enrolling in courses at TAFE, university or other colleges. It governs access to the community (eg. shops, banks, theatres public transport) and access to insurance, superannuation and government services and renting or buying a house or flat. The Disability Discrimination Act may also be applied in cases of harassment because of disability.

Under the Act employers must have 'considered whether the person could perform the requirements of the job with 'reasonable adjustment' for the disability'. If not, then it is not unlawful not to employ the person with a disability. Reasonable adjustment and

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‘unjustifiable hardship’ may also be applied to other areas covered by the Act such as ‘education, access to premises and the provision of goods, services and facilities’ (Human Rights and Equal Opportunity Commission, 2007).

The Commonwealth Disability Strategy was introduced in 1994 as a ‘whole of government’ approach to enable the full participation of people with disabilities and assist Commonwealth agencies to meet their obligations under the *DDA 1992*.

The Commonwealth’s *Anti-Discrimination Act 1998* promotes the principle that all people have a basic right to participate in public and social life regardless of any specific personal attribute, eg. race, disability or gender. It prohibits discrimination and provides for inquiry into complaints of discrimination as well as promoting a conciliation process.

### **3.1.4 Welfare Reform**

The Commonwealth Government provides a range of income supports specifically for people with disabilities. They include a living allowance, the Disability Support Pension (DSP) and other ancillary payments such as the Mobility allowance and the Pension Education Supplement and Youth Disability Supplement. People with disabilities who are not entitled to the DSP may receive Newstart, Youth Allowance or Austudy (Australian Council of Social Services, 2006; Centrelink, 2007).

Following the introduction of the Welfare Reform Program on 1 July 2006, people with disabilities including SCI, who are newly injured or have applied for the DSP since May 2005 and who are assessed or reassessed as having the capacity to work 15 or more hours per week within a 2 year period will **not** be eligible for DSP. Previously the cut-off point for eligibility for the DSP was the ability to work 30 hours per week. They may however be eligible for payments such as Newstart Allowance or Youth Allowance which are lesser amounts and do not enable access to concessions available to those on DSP. They will also be subject to activity requirements.

People with disabilities who study full time will receive Austudy and not the DSP which will mean less per fortnight than they would have received prior to 1 July 2006. They will also lose their eligibility to access the Pensioner Education Supplement for full time study (ACOSS, 2006).

#### **3.1.4.1 Some exemptions and implications for people with longer term disabilities**

People already on the DSP are to be ‘grandfathered’ or protected so their payment conditions remain the same. However, those who applied between 1 May 2005 & 1 July 2006 will have their capacity to work reviewed after 2 years.

If a person on DSP, including those who are ‘grandfathered’, finds full time work that lasts over two years then they may have to reapply for payments when employment ends. Under the new rules they may no longer be eligible for the DSP and would receive one of the lower Allowance payments (ACOSS, 2006).

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### **3.1.5 Legislation covering insurance schemes for Tasmanians**

#### **3.1.5.1 The Motor Accidents Insurance Board (MAIB) of Tasmania**

The scheme is a Tasmanian Government Business Enterprise operating since 1974 and governed and regulated by the *Motor Accidents (Liabilities and Compensation) Act 1973* and the *Motor Accidents (Liabilities and Compensation) regulations 2000*. It is a compulsory third party personal injury insurance scheme providing medical and income benefits to persons injured in motor accidents regardless of fault. It also provides access to common law whereby a person can claim damages if they believe they have been wronged.

Benefits include medical costs such as hospital treatment, ambulance transport, travel costs to attend medical treatment, modifications to accommodation and vehicles and attendant care. The maximum total sum payable for medical and related expenses occurring on or after 23<sup>rd</sup> November 2005 is \$400,000. Prior to this date the sum was \$300,000 for injury on or after 29 December 2004 and only \$200,000 from 5<sup>th</sup> August 1992 until the December date.

The MAIB also provides disability allowances for loss of income and the inability to perform housekeeping duties. In addition, the MAIB contracts professional case management, rehabilitation and personal care providers to assist the injured person in returning to pre-injury activities whether at home, in the community at work or study.

A Future or Long Term Care program is available to those who require or are likely to require, daily care for at least two hours per day for an indefinite period. The program must be assessed and commenced within a year of the date of the accident. The statutory limit of \$400,000 for medical and associated expenses is removed for those who qualify for the Future Care Program (The Motor Accidents Insurance Board (MAIB), 2007).

#### **3.1.7.2 Workers Compensation**

Workers Compensation in Tasmania is governed by the *Workers Rehabilitation and Compensation Act 1988* and administered by WorkCover Tasmania, whose responsibilities include monitoring health and safety in the workplace, injury management and performance of insurers. Under the Act it is compulsory for every employer to have a current workers compensation policy through a nominated insurer or to hold a permit to self-insure.

A worker who is incapacitated and unable to work as a result of a work injury or disease caused by work and has an accepted claim may be entitled to benefits or to make a common law claim to compensate for areas not covered in the Act.

Benefits may include weekly payments based on a current wage which are stepped within a specified timeframe but which may be available for up to 9 years from the date of the injury. Benefits also include the coverage of reasonable medical and associated expenses incurred as a result of the injury for a period of 10 years from the initial injury.

The rehabilitation expenses of the injured person are also provided for up to 10 years and include training, attendant care, workplace, home and vehicle modifications and counseling. Rehabilitation providers are contracted by the nominated insurers to carry out rehabilitation programs.

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In addition to the above entitlements, a worker who suffers a permanent impairment may be entitled to receive a lump sum payment for the permanent impairment involved. It is also possible in some circumstances for the worker to settle a claim by agreement such as the redemption of the entitlement to weekly payments (Work Cover Tasmania, 2007).

## **3.2 Key vocational and employment services**

### **3.2.1 Centrelink**

Centrelink may be pivotal to both the provision of financial support and employment assistance for people with SCI not eligible for insurer income support. It is the 'gateway to Job Network services', including Disability Employment Networks and undertakes income support and capacity to work assessments as well as referral of job seekers to appropriate assistance (Centrelink, 2007).

### **3.2.2 Commonwealth Rehabilitation Services**

A key provider of vocational rehabilitation, particularly for people with SCI not covered by insurance, is the Commonwealth Rehabilitation Service (CRS) which will provide rehabilitation, assist in finding retraining programs and employment, arrange workplace modifications and provide support into the workforce.

Its timeframe for support once the person has returned to the workforce is limited to six months. Services are free to those on a DSP, however, if compensation is received at a later date, costs will have to be repaid to the organization. Referrals to CRS may be made by rehabilitation and employment providers, Centrelink, or the organization may be approached directly by the person with SCI, their employer or potential employer.

People with SCI who are covered by an insurer or who are compensable may receive vocational rehabilitation as a full cost service from CRS or through private rehabilitation providers (Commonwealth Rehabilitation Service, 2007).

Although CRS will remain a key rehabilitation organization the Commonwealth Government is in the process of contracting private agencies to provide vocational rehabilitation services.

### **3.2.3 Job Capacity Assessments**

People with disabilities who do not qualify for the DSP or have received the payment since 2004 may be referred for a Job Capacity Assessment (JCA). This assessment is carried out in order to identify services needed to overcome any medical conditions or problems that might prevent the job seeker from finding or keeping employment. Depending on their assessed capacity, the job seeker may be required to undertake vocational training, or to look for part-time work and/or have participation requirements. These may involve participating in an employment program, undertaking education/training or participating in community work or Work for the Dole.

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At the assessment, the person can be directly referred to the Commonwealth Government Job Network which includes an Open Employment Service or Disability Employment Network (DEN) that assists job seekers with a disability to gain and maintain employment in the open employment market or to become self-employed.

Places in vocational rehabilitation and employment services are guaranteed for people with disabilities on Newstart Allowance and Youth Allowance.

Most assessments will be done by government providers - Centrelink, CRS Australia and Health Services Australia with the remainder being done by private providers (Commonwealth Department of Human Services, 2007; Australian Government Job Capacity Assessment, 2007).

### **3.2.4 Disability Employment Network**

The Disability Employment Network (DEN) or Open Employment Network provides specialist assistance to job seekers with disabilities who require ongoing support to find and maintain employment. DEN is delivered by a network of organisations – large and small – around Australia. They provide training, job placement and on-the-job support. Tasmanian agencies can be found at <http://www.workplace.gov.au>

A job seeker can be referred to DEN if they:

- have a permanent (or likely to be permanent) disability
- have a reduced capacity for communication, learning or mobility
- require support for more than six months after placement in employment
- require specialist assistance to build capacity in order to share the financial, social and personal benefits that employment offers

(Job Access, 2007).

### **3.2.5 Disability Supported Employment Services**

Disability Supported Employment services are provided through a network of organisations contracted by the Department of Families Community Services and Indigenous Affairs. Disability Supported Employment services employ and support people with disabilities, often in specialist working environments. Wherever possible employees will be assisted to work towards open employment (Centrelink, 2007).

### **3.2.6 Self Employment**

The New Enterprise Incentive Scheme (NEIS) assists eligible unemployed people to start and run their own small business.

For the first year of the business, the New Enterprise Incentive Scheme (NEIS) is there to train, support and help participants become self-supporting and independent. Providers of the Scheme are local organisations such as Business Enterprise Centres, TAFE Small Business Centres, community and private sector organisations.

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This scheme may present people with disabilities with a viable alternative to employment (Job Access, 2007).

### **3.3 Key Tasmanian services for people with SCI**

#### **3.3.1 The Spinal Teams**

Each region of Tasmania (south, north and north-west) has a Spinal Team providing specialist services to people with SCI. Each Team includes a spinal nurse and occupational therapist and either includes or provide access to a social worker, physiotherapist, dietician and continence nurse. In the southern region individuals with SCI have access to weekly clinics with a specialist rehabilitation physician as well as visiting specialists/surgeons. In the north-west a specialist physician with links to the Austin Hospital in Victoria is available to SCI clients and both the north and north-west have access, every year, to visiting specialists from the Austin Hospital.

These Team positions have only a limited number of hours set aside each week for spinal work and hours vary across regions. The Teams are also located in different areas of the health service and can be found in the Rehabilitation Unit in the South, within the Specialist Clinics at Launceston Hospital in the north and within Community Health at Latrobe and Burnie Hospitals. The north-west Team location is split with the spinal nurse position based at Burnie hospital and an occupational therapist and physiotherapist at Latrobe Hospital. At the time of writing the position of spinal nurse for the north-west was vacant and duties were covered by the specialist physician working one day a week.

The geographic area to be covered by the Teams in their limited hours is enormous. Consider the difficulty in providing complex and individual services in the north-west region which encompasses King Island, the west coast of Tasmania and east to Elizabeth Town. The northern Team services the north and the east coast and the south the remainder.

Team members reported that there was little interaction between regional teams. This may account for the differences in policy and service access across the regions as might the differences in working hours and geographic coverage. At the time of writing no information about the Spinal Teams or the Spinal Account (below) can be found on the Department of Health and Human Services website.

#### **3.3.2 Spinal Accounts**

In each region the Spinal Teams have access to a Spinal Account, a pool of money available for equipment, including wheelchairs, minor home modifications and a 'top-up' for continence aids. While funding for continence aids of up to \$470.00 is available through the Continence Aids Assistance Scheme (CAAS), service providers and interviewees reported that this amount might last only a couple of months for some SCI clients.

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The Account might also cover wheelchair tyres and repairs in some instances but just what the Account might cover varies between the regions. At the present time the Account is not means tested and is usually available to all those with traumatic SCI who are not compensable, ie eligible for compensation under common-law. A system of review of the needs of compensable clients is taking place in the northern region as it is recognized that over years there can be a considerable erosion of funds.

### **3.3.3 Other necessary services**

Disability Services provides a gateway to personal care for non-insured clients. This care is funded through the Home and Community Care program which, in Tasmania, is delivered through various community based organizations. Individual support packages (ISPs) of up to 34 hours a week of personal support/respite are available to people with disabilities living in their own home. These packages enable a flexible approach to care and can be blended with other HACC services such as home support and respite. Hours can also be banked enabling the person with disabilities to plan (Hinton, 2006).

Other services provided by the Home and Community Care program include home help, transport, respite care and home maintenance and modification.

Hospitalization was a major issue for individuals with SCI. Because of the small numbers of people in Tasmania with SCI, hospital staff may be inexperienced in relation to SCI care and individuals with SCI are likely to require additional hours and/or specialized care. Yet being able to receive adequate acute health care can play a big part in returning to and maintaining work and community commitments.

In addition to health related services there are a limited range of specialist sporting, community and recreational activities available to people to with SCI.

### **3.3.4 Insurer Services for SCI clients**

People with SCI who are covered by insurance may receive insurer funded case management programs, rehabilitation, personal care and other services through private providers as noted above. The insurer will also cover the cost of medical, modification and equipment expenses up to a specified amount.

The MAIB clients on the Future Care program had access to considerably more hours than those people with SCI in the State system. These hours could be increased if required to support the person in the workplace and provide transport, thus making employment a real possibility particularly for people with a high level SCI.

In addition, insurer covered interviewees also accessed the Spinal Teams for services and/or advice and private rehabilitation providers consulted with members of the Spinal Team during the course of rehabilitation programs. When the MAIB funded expenditure for medical care/equipment etc reaches its limits (now \$400,000) for non Future Care clients, the Spinal Teams begin to take over funding for equipment and aids through the Spinal Account. 'We usually know when their money is starting to run out and that is when we step in' (Spinal Team member).

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In this research, two interviewees were covered by Workers Compensation, but a different scheme to what now exists, and were provided with life long medical care. Three people who were self-employed were covered by their own private insurance policies, all of which differed: one paid a small lump sum, one paid medical and rehabilitation expenses and the other paid a percentage of loss of income for life. Eleven people were or had been covered by the MAIB insurance.

As noted earlier 41% of traumatic cases of SCI relate to land transport. The MAIB of Tasmania is therefore of crucial importance to many people with SCI immediately after the accident and long term.

Work related SCI accounted for about 13% of all traumatic cases of SCI over the period 1986–97. This proportion includes work related motor vehicle accidents (O'Connor P, 2001).



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## **Chapter 4 - Employment for People with SCI – Literature and Issues for Employers**

### **4.1 Introduction**

Employment after spinal cord injury is related to better general health, increased activity and greater life satisfaction (Hess et al., 2000; Dorsett, 2001; Krause, 2003). A recent issue of the *ParaQuad News* provides further confirmation of this through the employment stories of six people with SCI. Some of the stories illustrate the kind of enablers for return to work described in the literature below. These include return to previous employment or area of occupation, being young at the time of injury, having a higher level of education and undertaking further education post-injury. All six interviewees were passionate about their work as well as employment and disability issues. Overcoming the many obstacles in their paths cannot have been easy but ParaQuad Assoc of NSW Chairperson, Wendy Potter (one of the six) sums it up when she says that in spite of the difficulties, including discrimination, ‘...there’s not a single day I regret working. It gives you independence, assurance, and gave me the ability to live in the community’. ‘Would I do it again? In a heartbeat’ (Paraplegic and Quadriplegic Assoc of NSW, 2006).

### **4.2 How many people with SCI enter the workforce**

Murphy et al. (2003) in TAFE NSW Western Sydney, (2005), estimates re-employment rate at around 47% for people with SCI in Australia. In a study of adjustment after SCI of patients from the Queensland Spinal Unit, Dorsett (2001) found that 51.7% of the studied group were employed 3 years after injury and 6.5% engaged in study or training.

Krause (2003) suggests that long term research might reflect a truer picture of employment after SCI. He cites US studies showing the employment rate increasing from 13.8% after 1 year post SCI to 38.4% in year 15 indicating that 90% of research participants 25 or more years post injury had worked at some time since the onset of SCI.

It is useful to bear in mind the statistics relating to the employment of people with profound or severe disability or core restriction, which would include paraplegia and quadriplegia. The Australian labour force participation rates in 2003 for profound and severe disability groups, ie. those working or actively looking for work, was 15.2% and 35.8% respectively compared with 80.6% for people without a disability. The unemployment rate for these two small participating groups was 13.9% for those with a profound disability and 9.5% for those whose disability was severe. This was compared with a 5% unemployment rate for people without disabilities (ABS, 2003; Productivity Commission, 2004; Human Rights and Equal Opportunity Commission, 2005).

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### **4.3 How many years before employment?**

Krause (2003) studied 259 participants with traumatic SCI who had worked at some time since their injury and averaging 23.5 years since onset. The average time from the onset of injury to part time employment was 4.8 years and the time from injury onset to full time work averaged 6.3 years.

He concluded that there was both a fast and slow track to employment. Those on the fast track were highly educated, had worked as professionals and possibly been able to return to original employment. Those on the slower track tended to be younger and needed to gain further education and training. Employment for this group could be delayed up to a decade (Krause, 2003). Such a lengthy time frame is indicative of the need for long term rehabilitation support.

### **4.4 Factors Enabling Employment**

Dorsett (2001) has summarized literature relating to employment and SCI up to the year 2000 and identified some consistent factors in research that promote employment following SCI. The reverse of course also applies: when certain factors are not present then access to employment may be inhibited. The summary of literature presented below is based on Dorsett's work to 2000 but adjusted to take account of sources available to this study and research published after 2000.

It is useful to separate the biographical factors, things that cannot be changed, from environmental factors, areas where service providers can intervene to provide training, education, community and social supports that will assist the injured person in gaining employment (Dorsett, 2001).

### **4.5 Biographical Factors enabling employment**

- the extent of injury (those with incomplete injuries or paraplegia and greater functional independence were more likely to find work) (Krause et al., 1999; Conroy & McKenna, 1999; Murphy et al. 1997). However, as noted in the literature review (TAFE NSW Western Sydney, 2005) Murphy et al., 2003, has indicated that links between the level of impairment and employment are not conclusive.
- being younger at time of injury (Krause et al., 1998; Conroy & McKenna; Hess et al., 2000; Yasuda et al. 2002).
- being male (Tomassen et al., 2000; Yasuda et al., 2002).
- having higher levels of education at the time of injury (also associated with working in less physically demanding role and expectations of return to work) and working as a professional at time of injury (Murphy et al., 1997; Hess et al., 2000; Tomassen et al., 2000; Yasuda, et al. 2002; Krause, 2003; Schonherr et al., 2005).
- being married (Hess et al., 2000).

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- having been employed prior to injury, particularly in lighter occupations (Krause et al., 1998; Tomassen et al., 2000; Yasuda et al., 2002).
  - being highly motivated to be employed (DeVivo, Richards et al., 1991; McShane & Karp, 1993).

#### **4.6 Environmental Factors enabling employment**

- Returning to the same job (Berghammer et al., 1997; Krause, 2003).
- Informal networks and support from previous employer (Dorsett, 2001; Athanasou et al., 1996; Krause, 2003).
- Expectation of return to work (Schonherr et al., 2004).
- Undertaking education and vocational training post-injury (Murphy et al., 1997; Tomassen et al., 2000; Krause, 2003; Schonherr et al., 2004).
- Early intervention vocational rehabilitation (Krause, 2003; Murphy et al. 2003)
- Access to transport (particularly being able to drive oneself or travel independently) and community mobility (McShane & Karp, 1993; Conroy & McKenna; Yasuda et al., 2002; Jang et al., 2005).
- Functional independence and control over the environment (Yasuda et al., 2002; Jang et al., 2005; Valtonen et al., 2006; Wehman et al., 2000).
- Absence of pain and decreased medical complications (Anderson CJ, Vogel LC, 2002; Valtonen et al., 2006).
- Having social supports; support from friends and family (McShane & Karp, 1993; Yasuda et al., 2002).
- Access to and use of computers (Krause et al., 1996; McKinley et al., 2004).
- Computer training and use of computers (Pell et al., 1997; TAFE NSW Western Sydney Institute-OTEN, 2005; WestWoodSpice, 2005).
- Use of assistive devices (this includes a full range of devices from wheelchairs to communication devices) (McKinley et al., 2004; Hedrick et al., 2006).
- Employment in telework or homebased IT work (Bricout, 2004).
- Not being afraid of losing financial security (Wehman et al., 2000).
- Workplace modifications (Schonherr et al., 2004; Jang et al. 2005).

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## 4.7 Employing people with Disabilities

### 4.7.1 Employer perceptions

The Australian Human Rights and Equal Opportunity Commission (HREOC) conducted a national inquiry into employment and disability commencing in 2005. As a basis for discussion the Commission compiled an Issues Paper of commonly identified factors that impact on employers when employing people with disabilities with additional factors coming to light during the inquiry. All of these factors are relevant to the employment of people with SCI.

#### Barriers include

- lack of information, advice and ongoing support – no ‘one stop’ shop;
- lack of coordination between government agencies and employers are unsure which areas are State or Commonwealth responsibility;
- mechanisms for recruiting people with disabilities not clearly defined;
- lack of advice about the employer’s legal rights and responsibilities under State and Commonwealth law;
- concern about the cost of modification to the workplace;
- possible higher cost of workers compensation and occupational health and safety;
- some employees with disabilities may require ongoing support and/or may be less productive in the workplace than those without disabilities.
- concern about the impact on the person with a disability if the employment arrangement does not work out.

Lack of information exacerbates the barriers making it difficult to discern between real and perceived costs and risks (HREOC, 2005 and 2006).

#### Benefits include

- possible economic benefits to employers and financial incentives from Government (these have been outlined above);
- productivity of people with disabilities is as good as those without a disability when the job is appropriate;
- people with disabilities may be more innovative;
- good corporate reputation: customers and staff appreciate that the organization is employing people with disabilities (HREOC, 2005).

Information published on the Commonwealth Government’s Work Choices website supports a business case for the employment of people with disabilities. It reports that 90% of employers with experience of employing people with a disability would continue to do so; that employers (78%) were happy with the match between their employee and the job; 65% of employers found cost of employment to be cost neutral and 20% identified a financial benefit. Recruitment costs were less for employees with disabilities and there were less occupational health and safety incidents. For most (86%), attendance was at least average or better and for 90% of employees with a disability productivity rates were equal or greater (Australian Government, Work Choices, 2006).

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#### **4.7.2 HREOC recommendations**

The comprehensive recommendations made by the HREOC Inquiry would address many of the difficulties faced by employers and by people with disabilities seeking employment. The overall vision coming out of the inquiry was a call for a National Disability Employment Strategy. It would be led by the Commonwealth and would encompass a whole of government approach focused on providing true equal opportunity for people with disabilities and information addressing concerns about costs and risks. The report made 30 recommendations, 29 of which addressed specific barriers and the final outlining a National Strategy.

Specifically, the Inquiry recommended increased recruitment of people with disabilities into the public sector particularly at the Commonwealth level. In addition a whole of government approach should ensure adequate financial and personal support for people with disabilities, including income support, transport, equipment and health care subsidies, modifications to work places and personal care in the work place.

It recommended business and employer peaks do more to address barriers to employing people with disabilities. It also recommended closer coordination between community, training and employment and support services to provide greater equality of opportunity for people with disabilities (HREOC, 2006).

The HREOC approach has been outlined in detail here as it is compatible with the findings and suggested strategies put forward in this study.

#### **4.7.3 Innovative initiatives for and by employers**

There is a growing awareness of the importance of diversity in the workplace. Pressures at work arise from personal issues such as disability, gender roles and cultural difference. Being able to address these issues from the onset can prevent deterioration in work relations that may have led to harassment of certain workers and even illness. The Age has produced advertising features which allow organizations to showcase their best practices and philosophies. Diversity features prominently.

Diversity@work is an independent business providing a wide range of information and support in diversity management for business. Its CEO states that the benefits of diversity include increased morale, productivity and creativity. There is also a reduced risk of litigation and claims of discrimination.

In the area of disability, Diversity@work assists employers with Disability Action Plans, access audits, mobility maps, workplace modifications and disability awareness training. They provide a range of other courses such as ‘train the trainer’, staff mentoring and executive coaching. Programs and training are tailored to the needs of the organization and also include ongoing support and equal opportunity risk management (The Age, 2006).

WISE Employment is a member of the Government’s Job Network program assisting people with disabilities to find work. The organization is, of course, also an employer in its own right and employs people with disabilities within its organization and contracted businesses.

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Its operations manager states that, 'with staff from a broad range of backgrounds your organization can understand and communicate more effectively with a diverse customer base.' One of its business customers stated that they like to support an organization that in turn supports the community (The Age, 2007).

Westpac sees flexibility of the workplace as the key to the future. They aim to provide staff with choices to suit the diversity of need such as family responsibility and health and well being. Staff members are increasingly working from home on a regular basis and there are opportunities for job sharing. Mentoring and leadership training are also available to employees (The Age, 2007).

The Australian Employers Network on Disability is a not-for-profit organisation funded by its members to take a leadership role in advancing employment for people with disability. It assists organizations in a range of disability issues relating to employees and customers. Its stated aims are to:

- Create opportunities of mutual benefit for people with a disability and organisations.
- Facilitate an employer network on disability for mutual learning and information sharing.
- Help organisations become compliant with the Disability Discrimination Act.
- Assist businesses to implement the Charter for the Employment of People with a Disability, a set of 10 principles that assist in achieving best practice.
- Hold events that provide knowledge and networking opportunities.
- Develop customised tools and specialist publications.
- Provide an information line on disability.
- Provide equality training.

The organization stresses the benefits of corporate social responsibility in enhancing corporate reputation and value thereby increasing the desire for a service that is associated with a cause. They also note that it improves employee and customer loyalty and improved culture within organizations.

Current key initiatives include the "Stepping into ....." series providing paid, four week internships for students with disability in their final year of their tertiary study to experience working in law firms, banking and business. It is a structured program that provides support and encouragement to participating managers. Its foundation charter members include: Australian National University, IBM Australia Ltd., McDonald's Australia Ltd, and the Westpac Corporation. Members' names are listed on the organizations website. [www.employersnetworkondisability.com.au](http://www.employersnetworkondisability.com.au) (The Australian Employers Network on Disability, 2007).

#### **4.7.4 Incentives for employers**

Employers may be eligible to take advantage of a number of financial incentives offered by the Australian Government through its Department of Employment and Workplace Relations (DEWR) for employing a person with disability. These may be accessed through Commonwealth Rehabilitation Service and Job Network agencies. These include funds for workplace modifications and wage subsidies.

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#### **4.7.4.1 Workplace Modification Scheme**

The Workplace Modifications is a pool of funds available through the Commonwealth's JobAccess Program to reimburse the employer for the cost of any workplace adjustment that is needed to accommodate a worker with a disability. These may include alternative lighting, ramps, noise management, workstation height adjustments, etc. The cost of any building modifications cannot exceed \$25,000 (GST exclusive) and funding requirements greater than \$10,000 will require a workplace assessment. Employers may be assisted by service providers when making application for funding.

Under the scheme, special equipment, software not normally used by the employer and training in their use may also be funded (DEWR, 2007).

#### **4.7.4.2. Supported Wage System and Wage Subsidies**

Under the Supported Wage System (SWS) employees with a disability may be paid a lower wage according to their productivity. Wage assessments to determine fair pay for fair work are conducted by independent assessors and reviewed at regular intervals (HREOC, 2005; DEWR, 2007).

When employing a person with a disability through the Disability Employment Network or Commonwealth Rehabilitation Service, employers may be eligible to receive a wage subsidy for that person for 13 weeks (HREOC, 2005; DEWR, 2007).

#### **4.7.4.3 General**

In addition, there are provisions for employers to receive assistance for various training services when employing people with disabilities under apprenticeship schemes (HREOC, 2005; DEWR, 2007) The Commonwealth Government also provides a one stop shop information service 'JobAccess' as well as a personal advice service to employers.



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## **Chapter 5 - Important Influences on Employment – Information and Access to Services**

*There's nothing out there mate and  
Not walking is the easy part.* INT14 and INT13

These comments were made by two interviewees about their situation after coming home to Tasmania from the Royal Talbot in Victoria.

### **5.1 Introduction**

This chapter argues that return to work or study is dependent upon finding solutions, or at least partial solutions, to the range of life and health issues that must be dealt with after an SCI. Finding ways to access transport, equipment and health care, personal care, community support and suitable accommodation are more than likely to take precedence over finding work.

As discussed at 2.3 above, the immediate care arrangements for Tasmanians who sustain an SCI involve months of separation from their home, their family and friends, far away from the services they will eventually access. Interviews revealed that distance rehabilitation has implications for access to information and future service provision and, ultimately, for employment.

Perhaps because of the small SCI population and the fragmented nature of some services, the experiences of individuals using services from the time of coming home to Tasmania were quite varied: some were excellent and some quite poor. The variations occurred in both insurer and publicly funded services and are illustrated by quotes from interviewees.

Two barriers to employment are identified: firstly, a lack of access to information and services and secondly, differences in service standards in Tasmania. Strategies and recommendations are suggested. A key strategy, the provision of peer support throughout the SCI journey, is discussed and illustrated in some detail.

### **5.2 The link between service provision and employment**

The view that being able to work with a severe disability is dependent in many ways on the provision of essential care and services is something we feel intuitively from our own everyday experience about the kind of things that can disrupt our working life. It is a view expressed in discussions with key service providers in Tasmania and is also supported by literature. Buys et al. (1999) notes the importance of addressing issues such as housing, care, transport and support while assisting people with disabilities undertaking training courses. Unresolved issues around home modifications and support for potential students with SCI was found to impede early entry into vocational programs (TAFE NSW Western Sydney Institute-OTEN, 2005). The need for increased flexibility and availability of services ensuring access to essential care was among the conclusions reached by Wehman et al.

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(2000) in their SCI employment study. Yasuda et al. (2002) Anderson and Vogel (2002) and Yang et al. (2005) also describe the association between community mobility, functional independence, self care ability, decreased medical complications and employment for people with SCI. All of these areas depend on satisfactory access to service provision if they are to be successfully addressed.

The effect of inadequate access to services and support on coming home is summed up by INT4:

*Seemed like I had to fight for everything and they never really helped. Centrelink is good now. They should understand peoples needs - would love to come back and found a house, a job, a lady and mates but it doesn't work like that in the real world.....Work is one of the last things on your mind while you are sorting all this out. Still got Drs appointments and physios and at that time couldn't drive....Nice to have a big folder when you come back. INT4*

### **5.3 Barrier to employment 1: A lack of information about services and supports in Tasmania**

#### **5.3.1 Information about services at home in Tasmania**

Undergoing rehabilitation away from home emerges as a key factor in limiting information about services in Tasmania and standards to expect. Before the SCI event most interviewees, particularly younger people, knew little about health and community service provision generally or about Tasmanian services in particular. This makes the provision of information to this isolated group even more important.

This research showed clearly however, that, right from the earliest rehabilitation phase, interviewees could lack information about services and supports at home.

##### **5.3.1.1 On what interviewees would like to have known while undergoing early rehabilitation**

*Some things would like to have known - was things - being that distance between Hobart and Melbourne - things done differently. INT11*

*Fend for yourself. Difficult to organize modifications over phone, bathroom. Had to organize other accommodation when I first came home.... When it came to going home... Melbourne flat... trying to think what it would be like in Hobart - Melbourne easier. Wonder if I can still go down there. INT13*

*Tas knew about me so I kept them up to date - no updating by the Talbot on progress - up date was from my end. Needed to know about equipment...there's a big gap between Tas spinal patient and spinal team - you are scared shitless - how are you going to cope - 20 percent Tasmanians in the unit - 4 out of 20. INT16*

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This lack of information continued upon arriving home and was reflected in the difficulty experienced in accessing services. The overall impression of the experience of individuals with SCI arriving back in Tasmania is that it was very, very difficult to find out about the services that were needed. It is the very ‘aleness’ of the individuals coming home from the Royal Talbot that came through so strongly during interviews. It is also important to bear in mind that the injured person will be going through a massive adjustment process at this time making easy access to information even more important.

### 5.3.1.2 The need for information on coming home and ‘ongoing’

*Basic wheelchair skills at Talbot. Come back to Tas - fend for yourself - find whatever you can - nothing set up here - went to the pictures and snorkeling in Talbot. Nothing in Tas. You have to find it all yourself. Things getting better - hard at first - Sailability - met someone - rowing - happen to find something somewhere but nothing organized. Do it all yourself. No one tells you nothing. INT13*

*It did all work out and people contacted you but I thought that what was needed was an information package with all the things you might need – if you want to play sport talk to these people – wheelchairs contact this person - medical needs – even now - do not really know how it all works. INT8*

Importantly, information needs to be readily available at this early stage and ongoing. One man injured more than 20 years previously was not aware of aspects of funding for continence aids and wheel chair maintenance. INT10 is a young man injured some years ago. He stated that there are so many names he really has no idea who does what. Just can’t remember them all.

In this study, the most extreme situation resulting from a lack of information and referral but unrelated to distance was the case of a Sudanese person, INT27, who had been accepted in Tasmania as a refugee. He was injured nearly five years ago in a fall while working in an orchard. His employer told him to go home, which he did, and spent a week in bed before seeking medical help. Today he walks with the aid of sticks, has considerable back pain and receives the Disability Support Pension. This man, even today, speaks very little English and requires an interpreter. Probably because of communication difficulties he was apparently never provided with information about Workers Compensation by his employer, GP or Centrelink. Nor was he referred for specialist spinal medical assessment.

As a result of his being involved in this research his interpreter, provided by the Migrant Resource Centre, has organized a referral to the Spinal Team and provided information about the possibility of lodging a Workers Compensation claim. However, if information about SCI services had been available on an ongoing basis then his situation may have been identified at an earlier stage by his providers.

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## 5.4 Barrier to employment 2: *Differences in service standards in Tasmania*

### 5.4.1 Accessing services on coming home

Accessing services on coming home was also somewhat problematic. The type of service and standard of care were not always satisfactory and there was a serendipity quality about the experience. This could be the case for both insurer and non-insurer clients and would surely impact on any plans to return to work and study. As noted earlier this quality of care may be due to the small and scattered SCI population. The differences in the services provided by the Spinal Teams across the State and the separate nature of their service delivery may also have an effect as would the lack of information about services prior to coming home.

The descriptions of the experiences of the two people below highlight the haphazard nature of information and service access and the confusion that must be felt in the process of finding care.

#### 5.4.1.1 The experience of coming home

This young man had sustained a high level injury and was highly dependent on care.

*Social worker from Talbot organized care when I came home. Spent a couple of weeks in X hospital and that's where I got in contact with (personal care organization) and community health care came to see me. The hospital didn't have the equipment - staff didn't know about spinal injury. INT6*

*Seemed like care wouldn't be too much of an issue but seemed like when I got here –no. Care should be a lot better than it is. Mother is passionate about it - seemed like they had never had anyone like me before. INT6*

This man (INT16) did have connections and some background knowledge of the system that enabled him to do his own research. But if he hadn't.....

*Knew a lot of the nurses .... so had a connection - came home with an out of date pamphlet with spinal names on it with old analogue numbers from social worker.... did my own research from the Talbot to find out what was going on. INT16*

Access to information and services was sometimes dependent on a key person.

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#### 5.4.1.2 On - it can work

*Sees x - she is good - doesn't just drop in and comes when I need her. Always speaks to x first and she refers on - already doing physio. Always room for improvement. INT9*

A particular member of the spinal team was mentioned over and over again by interviewees as being caring, compassionate and knowledgeable. He was also a key person for information and referral to services. *He is my mentor. INT16*

While this kind of connection is excellent, given the previous quotes, it is obviously not happening to everyone. It is also the case that even when key service providers are involved, they cannot solve all the access problems to all the services all of the time. The two interviewees noted above still had considerable issues accessing certain services.

There was an interesting contrast between the experiences of three people who had completed their rehabilitation in Tasmania before the rehabilitation unit at 'Tower Road' was closed approximately nine years ago. Three out of the four individuals in this category who were interviewed experienced a transition to the community that appeared to be much smoother than that of individuals who now undergo rehabilitation in Victoria. They were very familiar with the relevant service providers and services offered and they were in contact with other people with SCI receiving in-patient and outpatient care. This contrast perhaps illustrates the argument for early contact with rehabilitation providers as does the quote below.

#### 5.4.1.3 And when things go well how much easier it is.

One interviewee had enormous support from her employer who developed links between the Royal Talbot and Tasmanian spinal team. INT5 was included in teleconferences with spinal team about renovations and modifications to house. When she came home she was already familiar with the team and they with her. *They were like a family. INT5*

#### 5.4.2 Ongoing service delivery and client inclusiveness across services

The differences in the ongoing experience of access to services and care provided within the public system and also through insurers remained after the initial coming home period. There were differences across the regions in services available to clients, difficulties accessing services and long, sometimes unexplained waiting times following requests for equipment and services.

On re-reading the transcripts of interviews, the concerns and battles over care arrangements appear to settle down somewhat after the first three or four years – years of great importance in relation to return to work. But there could still be occasions after this when problems arose. For example, a new injury or health problem might need to be addressed or new

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equipment required and this could again cause some difficulty. Some interviewees appeared to have reached a level of acceptance of some remaining long standing problems.

Overall, however, there seemed to be a lack of **‘easy-to-use - we encourage you tell us about any problems you have with our service’**– type of complaints and review mechanisms in both insurer and publicly funded services. There also appeared to be a lack of client involvement in the delivery of services.

Several interviewees expressed their reluctance to make a complaint and others stated that when they did the complaint did not receive attention. The MAIB contracted agents, case managers and vocational rehabilitation providers, have their own complaints mechanisms, but not all interviewees using these services seemed aware of this.

Some individuals with SCI who had very complex needs in the early years had not been offered any ‘case conferencing’ facility and it was not clear whether or not it was automatically the case that the client would be present if and when a case conference was held. Individuals working with the MAIB vocational rehabilitation providers had input into the development of their goals and signed off on their plans but were apparently less involved in progress assessments.

The MAIB is currently reviewing its vocational rehabilitation policies to ensure clients are aware of their right to be involved in the development and implementation of their care plan as well as their responsibilities to their providers and the MAIB.

#### 5.4.2.1 On ‘it can be a battle’

*Used to pray I wouldn't wake up in the morning. Knowing you had to fight tooth and nail for stuff to go to the toilet. INT18*

*X does not respond well to complaints - 'We are doing it right'. Not the best attitude - at the moment its good.....Might need to be more assertive sometimes. INT6*

INT25 talked about his reluctance to complain because he was so grateful for the care he did receive.

When INT16 requested another rehabilitation service he was told he had to have a goal. He said his goal was to walk but was told it had to be achievable. He did not make a formal complaint. INT16

*Very vulnerable. My carers are employed through x. Never check up to see if ok - not in two years. Needed extra care after an operation on my hand but this never happened. Had to stay in hospital until medical staff intervened. INT9*

*Battles big time to get equipment/clothing he needs. (Insurer's) rehab person - too far away - didn't do nothing. I had to do it. INT14*

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But there were exceptions. The University of Tasmania provides an excellent ‘complaints mechanism’ model for students and staff with an emphasis on informal approaches in the first instance and mediation if required.

One organization providing personal care services to both insurer and public clients held face-to-face reviews every two months with their clients encouraging them to discuss any changes they wanted to make and to talk about any issues of care that arisen. Four clients using this service were interviewed and, refreshingly, all were more than happy with the care they received and their rights to make changes. This service combined both client involvement and an easy-to-use complaints mechanism.

#### **5.4.2.2 On with greater involvement it can work**

*X sends carers to be interviewed. I can pick a good carer now - didn't bother before (with other organization) just put up with it - now if there's a problem just let the case manager know. His mother said, 'things are really turning around'.  
INT10*

#### **5.4.3 Advocacy role of insurer contracted providers**

There was some evidence (four individuals) of their contracted case managers acting or expected to act on the clients behalf in an advocacy role to the insurer. A ‘good’ case manager was seen as one who would assist the client to gain a piece of equipment (eg. from their medical allowance fund) or increased attendant care hours from the insurer. This seemed to indicate an adversarial relationship could exist between the insurer and the insured with the case manager acting as a go-between. The result was that if the case manager was ‘good’ the client had a strong advocate and gained the equipment or hours required, but if the situation was reversed the client could be disadvantaged. Although the entitlements of the insured are covered by legislation it may still be necessary to argue the value of the requested equipment or hours.

In a report of a review of Workers Compensation practices for WorkCover Tasmania, its author Rutherford (2004) expressed concern that the role of the rehabilitation provider in delivering effective rehabilitation and injury management could be compromised if the provider becomes involved with insurer interests. One result may be a lessening in the trust between the provider and client. The report stated that any system, in which the rehabilitation provider is paid by the insurer either directly or through a contractual relationship, will face potential conflicts.

The recommended solution lay in clear separation of roles and clear ethical commitments and accreditation standards for service providers. A structure that enabled clients a certain amount of choice between providers was recommended. The review also noted the importance of clients understanding the relationship between the provider and the insurer (WorkCover, 2004). WorkCover Tasmania is currently working on the implementation of the recommendations of the Rutherford Report. The MAIB policy review also aims to clarify the relationship of providers with the MAIB and provides for client choice of provider.

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#### 5.4.4 Hospitalisation – the need for strategies

Hospitalisation was a major issue for several individuals with SCI. Because of the small numbers of people with SCI, hospital staff are likely to be inexperienced in relation to SCI care. Yet being able to receive adequate acute health care can play a big part in returning to and maintaining work and community commitments. Difficulties were most likely to occur in public hospitals. Three interviewees stated that they were very happy with the care they had received as private patients.

The northern Spinal Team has developed a system of note on file of SCI clients so that a member of the Team can be contacted if hospitalization occurs. One interviewee stated that it was a good idea for people with SCI to take their own care instructions to hospital with them.

There is also consideration being given to allow personal care workers to continue working with public clients while they are in hospital. The MAIB already supports such a service for its clients during hospitalization.

##### 5.4.4.1 On hospitalisation

*...a big problem is hospitals - He was in X for a hand operation and got a pressure area the first night. INT10*

*Had to show people at X how to look after me. Talbot thought X up to speed with skill and equipment - terrible the comparison between what was happening at the Talbot...Standing frame at hospital - they didn't use it. Wouldn't give me a sheepskin - wouldn't listen to what was needed. INT14*

*Hospitals are pretty scary places to be...Absolutely terrible for spinal - dread the day I might turn up with hyper-reflexia. INT6*

*Classical example, top surgeon - in 30 years I was first person - had to provide info about hyper-reflexia. INT20*

#### 5.4.5 Accommodation and Home modifications – the importance of inclusiveness

The literature on employment for SCI stresses the importance of having accommodation in place before a return to work program is commenced. Service providers indicated that finding accommodation could be a huge problem which if not solved could extend the rehabilitation hospital period for the injured person.

Some interviewees spent time in Tasmanian hospitals or motels or interim insurer accommodation while the modifications were being completed or permanent accommodation found. The extent of modifications depended on available personal and insurer finances and did not always meet the ideal vision of the client. However, as shown in the quotes from interviews below, inclusiveness in design and decision making by the person with SCI and their families was always important.

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Families of injured young people play an important role in providing accommodation. In five instances interviewees lived in specifically modified or constructed apartments attached to their parents' houses. Others lived with, or close by parents while several individuals had lived with their family in the past.

Input into modifications could be facilitated if the injured person had weekend leave to return home to Tasmania prior to the end of acute rehabilitation.

#### 5.4.5.1 On home modifications and the need for client inclusiveness

INT18's insurer paid \$7000 for a ramp but didn't consult with the family on the cost..... The family believed some tradesmen charge more because an insurer is paying the bill. (In fact it comes from limited funds set aside by the insurer for a person's medical and rehabilitation expenses). *Had to modify bathroom a little – take off a corner and put in a vanity. Cost a fortune and not done well.* INT18

*Family had trouble accepting what had happened. Coming on board now. Were going sell everything - if I'd come home to nothing... needed to come home and see what I could do.* INT14

After an unsatisfactory bathroom modification, *I told them I would design my own kitchen and send them the bill.* INT14

*I designed my own bathroom and it worked really well.* INT8

*Went to Phillips Avenue for about 3 months to learn to manage at home. Just great to be out of hospital. Mates came to house. Hospital makes it difficult for mates. Everyone running around trying to help. Very hard to find accessible accommodation.* INT14

## 5.5 Discussion

### 5.5.1 Addressing barrier to employment 1: ***A lack of information about services and supports in Tasmania***

Providing information about services and supports available in Tasmania during the early rehabilitation phase would be a simple and effective way of enabling future planning to commence. Four key approaches are suggested to help in addressing the initial lack of information and resulting difficulty in accessing services.

- 1) The first is the integration of the regional Tasmanian Spinal Teams. This would enable a more coordinated approach to the provision of information about services available in Tasmania on Statewide basis and place a focus on service equity. It would also assist in developing mechanisms to increase early contact between Spinal Team members and individuals with SCI during the acute rehabilitation phase.

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Discussions with members of the Spinal Teams indicate that integration of the teams is currently being planned.

- 2) The second is early contact with service providers in Tasmania. Rehabilitation in Victoria means that there is isolation from future community care and rehabilitation providers. Contact with spinal team members and private rehabilitation specialists prior to coming home would be valuable in addressing information needs and future access to services in Tasmania. Knowing about these things in advance can only free up energy and time during rehabilitation to focus on vocational and community activities.
- 3) The third is the development of an information package about Tasmanian services that should be readily available to individuals with SCI on the internet and in hardcopy from the acute rehabilitation period and onwards.

Early contact may be by phone, internet, video and in person. Weekend leave for Tasmanians from the Royal Talbot could assist this early contact. Being able to return home prior to home modifications being completed will enable client involvement in this very important and personal area.

- 4) The fourth suggested approach is peer support from Tasmania that could co-exist with the peer support program offered during acute rehabilitation at the Royal Talbot. Through communication with peers the newly injured person could find out about services and access issues at home and have contacts and support on arrival back into the Tasmanian community. Importantly they can also find out what 'going home' was like for others before them.

Tasmanian service providers indicated that confidentiality issues can prevent ParaQuad Tasmania from directly approaching newly injured people and families to provide information and peer support while in the Austin/Talbot rehabilitation complex. In order to implement the above strategies, a system needs to be put in place to enable an information flow between Tasmanian service providers and Tasmanians with SCI while patients are at the Austin and the Royal Talbot Hospitals.

Discussions with the social worker at the Royal Talbot spinal unit indicate that all three of these strategies were more than likely to receive their support. It was also indicated that there should be no difficulty in working out a referral protocol to ParaQuad's peer support programs and ensuring Tasmanian information packages were provided.

The internet can be a powerful tool in extending the peer support and information models for people with SCI and families. This kind of tool could be particularly important given Tasmania's small scattered SCI population.

Internet forums are now part of our everyday use and culture and can enable sharing of information about services, access, and the standards to expect. They are widely used by SCI organizations to provide information and support. An internet forum hosted by ParaQuad Tasmania for Tasmanians with SCI about Tasmania's services and opportunities would be a

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valuable resource for people with SCI. It could have discussion threads on health and community care, equipment as well as access to training, further study and employment.

### **5.5.2 About Peer Support**

ParaQuad Tasmania is currently developing its peer support program to include an early support focus as well as providing continued longer term support and mentoring. Peer support is recognized as an essential program in SCI recovery and is an important service provided by most SCI organizations.

Peer support networks would enable people with SCI to know more about what services were available (and not available) in their regions before and after coming home; where and how to access services as they are required on the SCI journey, and what standards of care they can expect. The peer support program can be strengthened through the use of an on-line forum allowing experiences of situations to be shared with others.

The quotes below indicate the value of peer support firstly during the recovery phase at the Royal Talbot and secondly, on coming home.

#### **5.5.2.1 On peer support at the Royal Talbot hospital**

*Made friends with two people there about same age - hung out together. Did a fortnightly excursion - comedy festival. They were good mates to go out with. Care was great. Kept in touch with friends for a couple of years. INT2*

*Good thing about rehab 44 patients all with same thing and that helped. A year later spent 2 weeks in Burnie hospital - that was worse cause I was the only one in a wheel chair. INT15*

*Leisure stuff at Talbot was wonderful. Went out for tea, and to rugby and this got you ready for going home..... Get used to people looking at you. INT3*

#### **5.5.2.2 On the need for peer support at home**

*No problem at Talbot - only when I came back - known how to push to become a better advocate for self. Tell me the pitfalls - I could talk to them all day. Need a mentoring system - it would have been great. The hurt and the hate when you come home is horrible. INT16*

*Just having someone there to talk to about things. I was lucky I had family to talk to but if you didn't - I hate to think. INT23*

*Probably the loneliness – not having people in my situation to talk to – yeah – peer support it's called now. People say they know how you feel but the only person that does have some idea is the person sitting beside me in a chair.....The person who knows the trials and tribulations of being in a chair is the person who uses one. INT22*

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*Best to talk to other people in wheelchairs. No problem talking to others about personal things - guy in Burnie advised me about leg bags and sent some. I sent him condoms for drainage.....Harder to talk to nurses about it than other SCI.*  
INT15

And from the same person-

*First 12 months didn't really want anything to do with a wheelchair person – thought it was crap - that it could get better.* INT15

Not everyone will want to be part of a peer support program. The interviewee above (INT15) took about 12 months before he was ready to talk with others about SCI and life in a wheelchair. Others took an even longer time. But it will still be important for this group to have a program in place for when they feel it is needed.

### **5.5.3 Recommendations and strategies to address a lack of information about services in Tasmania**

#### **Recommendation 1 – Increasing access to information and specialized services for people with SCI**

Tasmanian Spinal Teams to develop an integrated program across regions of Tasmania with unified standards of care for all Tasmanians with SCI. Information about the Spinal Teams and its services to be made available on the Tasmanian Department of Health and Human Services web-site.

#### **Recommendation 2 – Develop systems across agencies to facilitate the provision of information and peer support for people with SCI and families during acute care and early rehabilitation**

ParaQuad Tasmania to further develop protocols with the Austin and the Royal Talbot Hospitals to facilitate peer contact with the injured person and their family, early contact with Tasmanian service providers, and the provision of information packages developed for Tasmanians.

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**Strategy 1 – Early contact with rehabilitation providers**

Members of the Tasmanian Spinal Teams and insurer funded rehabilitation providers to make and maintain early contact with injured person by phone, internet and video during the acute ‘distance’ rehabilitation period and be available to answer questions about service provision as they arise; and, ParaQuad Tasmania to investigate transport and accommodation funding sources for the injured person to undertake weekend leave to meet with Tasmanian rehabilitation specialists and providers prior to their discharge from the Royal Talbot.

**Strategy 2 – Information about care and support services at home**

ParaQuad Tasmania to consult with the Tasmanian Spinal Teams and insurers to update and broaden ParaQuad’s information package for people with SCI and families to be made available to them during the acute rehabilitation phase. The package should focus on:

- all those services and programs (health, community and recreational; private and public) likely to be required by an individual with SCI, families and carers;
- a map of how the system works;
- rights, responsibilities, standards of services and complaints mechanisms; and
- initial information for employers about SCI and the workplace eg. vocational rehabilitation, work modifications, funding available for wage subsidies etc.

Information should be available in hard copy and on the ParaQuad Tasmania and other relevant websites.

**Strategy 3 – Peer support and mentoring for people with SCI with an on-line forum**

ParaQuad Tasmania continue to develop a peer/mentor support program to support newly injured persons while in the Talbot by assisting in maintenance of personal and family networks and thereafter. The program would be enhanced by the provision of an on-line forum promoting discussion in all relevant aspects of life after SCI including access to services, recreation, use of equipment and self care and going back into vocational training/study and work. The program should be able to support mentor linkages across vocational and interest areas as well as support related to SCI.

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#### **5.5.4 Addressing barrier to employment 2: *Differences in service standards in Tasmania***

There is clearly a need for closer regional co-operation and advocacy in relation to services to help combat the tyranny of distance in Tasmania and the dispersed SCI population.

An integrated statewide Spinal Team and further development of ParaQuad Tasmania's Outreach program are likely to increase access and equity in relation to services and information across the regions. Discussions with ParaQuad Tasmania and (as noted earlier) key Spinal Team members, indicate that this is the intention of both organizations.

Increasing the input of both public and insurer clients into care plans and clarifying the role of insurer funded providers may assist in improving experiences of care. For example, in spite of the complexity of the care needs of people with SCI, there appeared to be little involvement of SCI clients in case conferencing. In some instances there could be increased client input into reporting mechanisms for those receiving rehabilitation care through insurers as well as in public care.

A more client inclusive process would also increase client access to information and knowledge about service delivery and standards and further contribute to a whole-of-life approach.

In addition, changes in the following areas are likely to promote easier access to services and knowledge of service standards:

making complaints mechanisms 'easy-to-use';

providing an advocate to assist client access to services and promote equity;

clarifying the roles of insurer funded providers; and,

further developing a Tasmanian peer support program with an on-line forum are all areas that. As hospitalization is such a major concern for individuals with SCI suggested strategies involve increasing awareness of these issues, nurse education and increasing hours of care/support.

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#### 5.5.4 Recommendations and strategies to overcome differences in service standards

**Recommendation 1 – Increase access to information and specialized services for people with SCI**

This strategy has been outlined previously (see page 41)

**Recommendation 3 – Outreach support across regional areas**

ParaQuad Tasmania to strengthen their outreach/networking program across the regions to ensure information and support is provided to people with SCI throughout Tasmania.

**Recommendation 4 – Review and complaints mechanisms**

ParaQuad Tasmania to consult with insurers and all relevant service providers and develop an ‘easy to use’ review/complaints model for agencies.

**Recommendation 5 – Client inclusiveness and whole-of-life approach**

Insurers and publicly funded service providers review their approach to service delivery of people with SCI and identify ways to increase client inclusiveness. This may include increased use of case management procedures encompassing a whole-of-life approach, ensuring client input and sign-off on reports and reviews and the implementation of easy-to-use complaints/compliments mechanisms. Program exit and re-entry strategies would be clearly defined.

**Strategy 4 – Advocacy**

ParaQuad Tasmania to seek funding to employ an advocate to assist with access to services and standards and complaints issues across a full range of services for people with SCI.

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**Strategy 5 – Hospitalisation**

ParaQuad Tasmania to consult with hospital educators and key Spinal Team members in each region and develop a protocol for care of people with SCI while in hospital. This will include consideration of:

- notes on hospital files to alert staff of the need to contact a spinal team member;
- provision of information sheets to hospital staff by the person with an SCI being hospitalized about the care required ;
- personal carers providing care program during the hospitalization period and/or additional staff for people who are wheelchair dependent.

**Strategy 3 – Peer support and mentoring for people with SCI with an on-line forum**

This strategy has been outlined previously (see page 41)

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## **Chapter 6 - Important Influences on Employment – Families**

### **6.1 Introduction**

This chapter examines the support role played by families of individuals with SCI and throws a small light on just some of their experiences. Families provide support to the injured person from the time of the initial injury and in many cases this early support continues on into long term care. It is also apparent that family support is a positive factor in enabling and/or maintaining employment either directly or indirectly. The impact of ‘distance’ rehabilitation on families and the individual with SCI is also shown to be an important factor for consideration.

Strategies to support families are suggested.

### **6.2 What Families do**

Having social supports and being married are positively linked to employment after SCI. (McShane and Karp, 1993; Yasuda et al., 2002; Hess et al., 2000). Many families provide social supports and they also do so much more.

This study revealed that families play a crucial support role for people with SCI. In at least ten cases families were, at some time, involved in providing varying degrees of personal care. Fourteen interviewees indicated that families were currently involved in some capacity in the provision of care, transport and/or assistance with temporary or permanent accommodation arrangements. In twelve instances families provided transport enabling access to the community. Six interviewees depended at some time on their families for transport to employment/study/training activities and in at least one case family members assisted with actual work tasks. As noted above Rowell (2006), in his study of 181 individuals with SCI, found that families provided an average of 71.3 hours per fortnight of care with several families providing 24 hour care.

In this study, in addition to providing care, families and their networks were a key factor in finding employment for the individual with SCI in at least four instances.

It would never be possible to quantify the importance of the emotional support and care provided by families at a time when lives are turned upside down. Almost all of the SCI interviewees indicated that ‘my family’ was the key factor in helping them to recover after SCI.

If we accept that access to accommodation, transport and social support are factors that can promote employment as argued in the previous chapter, then it follows that providing support to families is an important element in enabling people with SCI to take up employment and training. Yasuda et al. (2002) state that supporting families is critical as their support enhances the likelihood of returning to work.

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It may be the case, given the small and dispersed SCI population in Tasmania and the unevenness of service delivery that the role played by Tasmanian families is even more important to the recovery and community re-entry of the individual with SCI than it would be for their counterparts on the mainland.

Caring for carers, recognition of the important role they play in supporting people with disabilities in the community has long been a policy of Commonwealth and State governments. The importance of family care is recognized in funding arrangements for Carer's pensions and programs for carers within the Home and Community Care Program.

### **6.3 Enabling employment 1: *Families supporting people with SCI.***

#### **6.3.1 The earliest stage and the need for information**

Dorsett, 2001, discusses the enormity of the adjustment process that families face at the time one of its member's sustains an SCI. A US publication on family adjustment after SCI describes the shock and horror of the situation and the numbness, confusion and disbelief experienced by family members at the time of the injury to their loved one. Those who had experienced the situation would have liked to talk to someone with similar experiences at this early stage (Jaworski and Richards, 1998).

Even at this very anxious time, however, families will need to make decisions about practical matters with short and long term implications.

*When a family member becomes spinal cord injured, there are many stresses and changes to deal with. First is the worry and concern for the individual's recovery and medical care. Next are problems dealing with money, transportation, and making the home accessible. The caregiver may have to take time off work, change their work schedule, make a job change, or even quit working so they can take on their new role of caregiver.*

Department of Physical Medicine and Rehabilitation, University of Alabama, 1998

For Tasmanian families, the situation has that additional edge, the 'distance factor'. A member of the Tasmanian Spinal Unit spoke about the extremeness of the experience for families when one of its members sustained an SCI. They might arrive at the hospital with nothing but their wallet and then proceed immediately to Melbourne by air ambulance, catapulted into a dozen unknown situations at a time when their whole being is taken up with concern and fear for the well being of the injured person.

The provision of an information package for families at this early stage which may include information specific to Tasmania, would be a simple way of providing some support in the most confusing of times as illustrated by the quotes below of both families and individuals with SCI.

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### 6.3.2 On the need for information

*I didn't know what we were entitled to – rebates on rates and stuff – only learned later from people in the system – Centrelink paid us as though we were separated and then sent us a bill for \$5000. We didn't know what payments we should get because we had never been on social security before..... Should have a booklet to let everyone what they are entitled to. Such a confusing time. INT17*

*I was putting in receipts (to the insurer) to claim taxis from the airport. I had no idea it was coming out of X's money – that I was spending X's future. INT18*

*I would have liked more information from (my insurer) about what I could have, before and after I came home. INT3*

Years after injury, INT9 is still paying off a tax bill incurred at the time of his accident when unbeknown to him no tax was taken from the living allowance paid to his partner. INT9

### 6.3.3 Effects of 'distance' rehabilitation

After the initial shock of the injury, the impact of distance and isolation during the months of rehabilitation in Victoria can adversely affect both the person with SCI and their families. In some cases family members were able to stay in Melbourne in accommodation provided by the Austin and the Royal Talbot. Although this accommodation is limited it is free of charge. However, there can be long periods of separation, when perhaps due to lack of finance or other family commitments spouses/parents are prevented from being with the injured person. Insurers may cover cost of travel for a family member of eligible clients from the injured person's medical funds. Some travel costs for families may also be assisted under the Patient Transport Travel Scheme. In spite of this assistance however several interviewees stated that meeting the cost of travel was very hard for families.

Situations and relationship dynamics can be further complicated when parents of the injured person are divorced or the injured person is separated/divorced. All this puts great pressure on the recovering person and family members.

#### 6.3.3.1 On distance rehabilitation and separation – effect on family

*My mother stayed the whole time so the other children missed out. I felt very isolated away from the family but – just lucky they could afford it. INT1*

*One son came – the other son couldn't come to terms – he was affected emotionally - took about eight months to accept. I got very close to other patients and their parents at the Talbot. They were like my family. (Cont.)*

This person was so concerned about his son that he left rehabilitation perhaps earlier than he should. *They didn't take me seriously about coming home. I booked into X hospital and flew home myself. INT14*

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INT25 had been raised by a loving foster mother. When his accident occurred his estranged natural mother returned and, rather than his foster mother, it was she who took up the accommodation offered by the Austin Hospital. INT25 could not sort out the situation until his 'trachy' was removed and he could speak. INT25

*I was there for seven months and the distance was very hard on the family. Mum and Dad are divorced – they swapped over – have two brothers and a sister and they came occasionally. INT6*

*In hospital for one year and this was very bad for family relationship... Children came only twice in the year. INT9*

Injury to a parent can be a very frightening experience for sons and daughters, younger and older. Once again this puts further strain on the injured person. The Royal Talbot Hospital now provides resources for families to give to young children and adolescents to help them to come to terms with the injury.

#### **6.3.3.2 On distance rehabilitation and separation – effect on children**

*The children took it hard - saw them with the halo on and hadn't been able to shower or wash my hair ..... looked a mess. Could not talk in the Austin so we had no phone contact. May be books with wheelchair, and halo - should be something gradual. INT9*

One injured woman who was separated from her husband saw her children only rarely during her rehabilitation period and experienced great difficulty in achieving these arrangements. The children were aged between 11 and 5. When she did see them she couldn't talk because of her 'trachy' and when away from them she could not talk to them on the phone. Her children lived with her before the accident but when she returned home she had to fight for access in the courts. INT19

*My son fainted when he saw me in ICU – fainted 4 times. Very distressing for whole family – life turned upside down. INT16*

My kids came over so we could be together as a family. I said to my daughter can you put my shoes on for me. She said 'Mummy lift your foot up'. I said 'I can't darling' and she couldn't understand. But then she did lift my foot and after that she was fine. INT27

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## **6.4 Support for families - Coming Home**

### **6.4.1 Adjustment in relationships**

The massive disruption to family life continues after coming home as spouses come to terms with changes in their relationships and young people move back in with families. In this research SCI was attributed to be the cause of three marriage breakdowns.

Marriage break-down for a person with an SCI can bring with it similar problems to those experienced by general population – and more. De Vivo et al. (1991) found the divorce rate was greatest in the first years following SCI. For SCI individuals who already have to contend with mobility, health and adjustment difficulties the effect can be devastating. During one interview, the respondent continually returned to the situation of marriage break-down that had occurred some years previously. It had affected most areas of his life and seemed to remain uppermost in his consciousness.

The flow-on effects of marriage break-down mean that things can become tougher financially as the departing spouse may claim their share of the house, compensation or sale of the family business proceeds. There may be no spare cash to improve access around the house or maintenance or replace furniture allocated to the departing spouse. In this study some modifications were incomplete at the time of the marriage breakdown and remained so. Three interviewees experienced problems with access to their children and had to fight for this in the courts.

Marriage breakdown also means the person with SCI is left with less support, both physical and emotional. Being married has been identified as a factor promoting employment for individuals with SCI.

### **6.4.2 The Bright Side**

But many families are able to ride through these difficulties. Spouses and parents take up a carer role, remaining loving and respectful and doing what they can to assist the injured person to develop and maintain as much independence as possible.

Five interviewees lived in premises adjoining their parents' house or were in the process of building close by. The reverse scenario also occurred in which a parent lived in an apartment adjoining the injured person's home in order to provide support for the household as required. Several interviewees lived in the same house as their parents or had done so in the past.

In addition, new intimate and friendship relationships commence and grow and this stability may assist in both employment and leading fulfilling lives in the community.

But the bright side is not always easy. The health of carers may suffer because of the stress and anxiety they feel (Kolalowsky et al., 1999 in Yasuda et al., 2002; University of Alabama at Birmingham, 1998). Several SCI interviewees talked about the difficulty finding a balance in their family relationships between dependence and independence. Loving parents may be filled with concern for the safety and well being of their injured son or daughter and their

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need to try to protect them. At the same time the injured person may feel guilt at requiring assistance and want to maximize their independent activities without causing their family members undue concern.

SCI leads to a massive disruption of family life. In the first instance noted in the earlier chapter there is separation between spouses, parents, children and siblings in various degrees. Then there is the adjustment phase in coming home. Young people who had flown the nest return, spouses might leave and children need time for adjustment. Overshadowing all of these relationships is a financial one. Parents and spouses have their working life disrupted in the short or long term, compensation and insurer issues have to be resolved.

### 6.4.3 On adjusting to life after SCI

*No support for me – it was very hard – I was trying to get x back to school and to appointments - physio at St Giles - and did do swimming at early stage but very afraid because of trachy hole and not really got back to it. INT10 (Mother)*

This mother was the only adult support for the injured young man. She then talked about the intrusiveness of carers in their lives and how her household relationships had been discussed between members of the service organization. INT10

INT5 talked about how it seemed harder for her husband than for her while she was undergoing rehabilitation. She felt he closed up and seemed more worried than she did. INT5

All this at a time when the person with SCI is struggling to forge a new life and come to terms with a new image and the loss of many things.

*I was very pissed off with myself. ...Still coming to terms with it. INT24*

*Basic stuff really hard. Get into bed and find you want a drink of water and spend half an hour getting up then spasm and end up falling on the floor. You hate yourself and end up punching yourself. Really hard by yourself - really hard starting out. Basic stuff. INT4*

INT25 talked about his anger and depression on coming home. He felt a burden to his family.

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## **6.5 Discussion**

### **6.5.1 Addressing ways to enable employment 1: *Families supporting people with SCI.***

#### **6.5.1.1 Early Information needs**

The northern Tasmanian Spinal Team has assembled an information package aimed at meeting the needs of families and people with SCI in the early stages. It provides hospital maps and information about the care provided at the Austin and the Royal Talbot, accommodation options and insurer and social security information to meet immediate needs.

The package could be further developed in conjunction with social workers at the Austin and Royal Talbot hospitals and with input from families affected by SCI in the past. It could be provided to families when leaving Tasmania and also be available at the Austin Hospital and on relevant websites. The package might also contain information on Tasmanian supports for families, lists of resources available for children, and community legal assistance.

#### **6.5.1.2 Supporting families during ‘distance’ rehabilitation**

There are a number of resources available for children of injured parents and these can be made available in the early stages.

Families may be assisted by having access to a support network of other Tasmanian families who have been through a similar experience. ParaQuad Victoria in conjunction with the Royal Talbot offers a support program for families to provide emotional support and information about care and services (ParaQuad Victoria, 2007). Being able to talk to other people about the experience is believed to be essential for families of people with SCI. (University of Alabama, 1998). Contact with other families at this early time will also assist in gaining information about services available in Tasmania. Teenagers and young adults may also benefit from interaction with members of the family peer support program.

ParaQuad Tasmania is currently investigating the possibility of making stand-by airline fares at reduced rates available to family members visiting injured relatives during rehabilitation in Victoria. If successful this may help to ease some of the emotional and financial burden and provide support for those important family networks.

#### **6.5.1.3 Support for families – coming home**

In the longer term ParaQuad Tasmania might build on the personalized Tasmanian peer support program and work with other state and national SCI organizations to develop an online forum for ‘peer support’ for families affected by SCI. A greater number of participants could promote discussion around broader issues, give increased freedom from confidentiality issues and enable comparisons to be made of services and initiatives offered in different states.

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Assisting people with SCI and their families by providing counseling in the period of adjustment and beyond may help resolve conflict and confidence issues and lead to earlier employment. This kind of program is offered by ParaQuad Victoria. The Carers Association of Tasmania provides telephone counseling for carers on general issues of caring. However, supportive family members do not necessarily identify as carers. As some areas of SCI are so unique there may be times when a special approach is necessary and available to family members as well as to the injured person.

One employer interviewed in this research stated that a counseling service with expertise in SCI issues would be a useful tool for employees with SCI and families. This person also noted that she would have no idea where to seek help in this specialized area.

At the present time, insurer clients who identify a need for psychological counseling are likely to be funded by their insurer. However, there is apparently no specialized counseling service for people with SCI. For those not funded by an insurer, the cost of a counseling program may be prohibitive.

#### **6.5.2 Recommendations and strategies – supporting families to support individuals with SCI**

##### **Recommendation 6 – Counseling and psychological assistance**

ParaQuad Tasmania to seek funding to develop a counseling service specializing in issues around SCI for those who have been injured and their families. It may be an adjunct to the peer support program and developed along the same lines as the program offered by ParaQuad Victoria or through privately contracted providers with specialist knowledge.

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**Strategy 6 – Early information for families**

ParaQuad Tasmania to consult with Spinal Teams across the State, with families and the Austin and Royal Talbot Hospitals and further develop the initiative of the northern Spinal Team. The package could be made available to families prior to leaving for Melbourne or soon after arrival at the Austin Hospital. Package may contain information about:

- Acute care and rehabilitation program and maps of hospitals
- Accommodation options for family members
- Information about social security and Centrelink
- Information about Workers Compensation and the MAIB claims and benefits
- Information about rights and responsibilities in relation to insurer and government programs and their complaints and appeals mechanisms
- Information about community legal assistance in Tasmania
- Information about travel assistance
- A list of resources and supports relevant to this early stage
- A list of resources and publications for children of parents with SCI
- Resources and packages available through State and Commonwealth disability services.

Information with relevant links should also be made available on ParaQuad Tasmania's website

**Strategy 7 – Supporting families – peer support**

ParaQuad Tasmania to develop a small network of families of individuals with SCI to provide peer support to other families for any aspect of the situation after injury. They may be available by phone or in person.

**Strategy 8 – Supporting families in the early stages – travel**

ParaQuad Tasmania to negotiate logistics and further options for accommodation and travel to Melbourne for family members while injured person is in the Austin or Royal Talbot hospitals.

**Strategy 9 – National on-line forum for families of people with SCI**

In consultation with other State and national SCI organizations, ParaQuad Tasmania to foster the development of a national on-line forum network for families of people with SCI.



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## **Chapter 7 - Work, Study and Training – Finding the Way**

### **7.1 Introduction**

This chapter outlines some of the key factors associated with return to work or study identified in this research. It describes the experiences of the interviewees in finding their way into the workforce or taking up training and study. It also provides case studies illustrating some outstanding achievements by individuals with SCI. Strategies are suggested to further develop identified employment enablers and increase vocational opportunities as well as ways to overcome some of the barriers described by interviewees. Strategies also aim to empower individuals, increase their access to information and develop closer linkages between individuals with SCI and vocational and employment service providers and employers.

### **7.2 Key factors associated with employment and training/study**

Family and friendship networks and early contact with former employers were two of the most positive influences on employment for people with SCI emerging in the course of this project. The case is argued for strengthening these ties and, based on the positive outcomes from early contact with previous employers and research literature, a case is also put forward for an early vocational intervention program.

Almost all interviewees had access to a computer and the internet and used their equipment for information, banking and services as well as work related activities. The use of computer technology is positively associated with employment in literature and can be a key strategy in promoting return to work and for vocational rehabilitation.

Barriers to work included the difficulty of re-entry if a job was lost or study program interrupted. As with the experience of health and community support services described in Ch 5 the experiences of accessing information about and using vocational rehabilitation and employment provider networks were uneven and sometimes unsatisfactory.

The literature about employment and SCI and discussions with Tasmanian service providers indicated that being financially compensated for an injury might be an impediment to a person's desire to return to work (Tomassen, et al., 2000; Engel et al.,1998). This did not appear to be the case in this research as seven interviewees who had received compensation worked, studied or were seeking work. This may indicate that being compensated may even promote employment because individuals are more financially secure and able to take risks. Conversely, fear of losing financial security was identified by Yasuda et al. (2002) and Wehman et al. (2000) as a barrier to taking up employment. Fear of losing the Disability Support Pension (DSP) was a factor deterring at least three individuals from taking up training or work in this study.

On the other hand several interviewees stated that the desire to earn money was a motivating factor in seeking work.

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Poor health, pain and other SCI complications were the most commonly expressed reasons for not working or making work difficult. This adds further support to the necessity for easy access to support and care services for people with SCI.

### **7.3 Enabling employment: *Family, friendship and employment networks***

#### **7.3.1. Importance of networks**

Almost every interviewee (13 of the 16) who had been employed at some time since their accident, had found employment, on at least one occasion, either through their previous employment contacts or family and friendship networks. In only three cases interviewees reported finding work (at some time) through generic job placement agencies. Networks were also important in securing unpaid job placements or work trials sometimes with the support of a vocational rehabilitation provider assisting in negotiations and workplace modifications. Networks formed post-injury were also influential in gaining employment.

The importance of networks in obtaining employment after SCI was noted in discussion with key service providers and is supported in the literature (Krause, 2003). A study by Athanasou et al. (1996) found that most individuals with SCI found work through informal means.

In addition to the importance of family and friendship networks in directly influencing employment, these networks also provide positive indirect support. McShane & Karp (1993) identified social support as a positive factor in gaining employment after SCI. Dorsett (2001), in her summary of literature on adjustment after SCI, notes a number of studies identifying the importance of social supports in coming to terms with SCI and contributing to positive outcomes.

‘Distance’ rehabilitation again emerges as a factor that can negatively affect network relationships. Friends, including workmates, employers and extended family members in Tasmania can become isolated from the injured person during the distance rehabilitation period. The progress and experience of the injured person is not seen; people grow apart; some may have outdated expectations of what can be achieved by people with SCI. Most will have very little knowledge of what it means to have a spinal cord injury. One service provider noted that expectations of friends and family at home may have a bearing on what the injured person will achieve. An expectation of return to work is among those factors that can promote employment (Schonherr, 2004).

##### **7.3.1.1 On separation and relationships**

*I didn't like being separated - no friends or family in Melbourne. No one knows what has happened. I went to a party when I came home – (they) can't understand what you have been through. INT12*

*My mates thought will we be able to camp again. Lost a couple of friends – never heard from them – they just wave... One friend asked mum what to say – she said 'just whatever'. INT15*

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## **7.4 Enabling employment: *Early contact with previous employer***

### **7.4.1 Early contact with previous employers**

A second related factor in gaining employment after an SCI, was knowing, at the early rehabilitation stage, that a former position or place of work remained open and welcoming. A part of one's life - a very large and important part - would still be there when everything else had changed profoundly.

Of the five interviewees who returned to their former place of work, either in the same or different job situation, four were approached by their employer during the early rehabilitation period. This assurance appeared to give these individuals the freedom to concentrate on rehabilitation. Something in the balance shifted from a focus on regaining independence for some shadowy possibility to regaining independence for a very concrete reason. Case Study A below provides a very special example of how early support from an employer can affect the employment outcome for an individual with SCI.

The fifth person was approached by a previous employer soon after returning home and told that there would be an opening for him, with all the flexibility he needed, when he was ready. Prior to this offer, this person had been very concerned about what kind of work he would be able to do. As his health improved he gradually became more confident and accepted the position. His story is presented in Case Study D in the next Chapter.

Berghammer et al. (1997) and Dorsett (2001) identified return to the previous workplace and support from employers as positive factors in gaining employment after SCI. Krause (2003) states that returning to one's previous position or workplace is a fast track to employment and describes a slower track for those who need to pursue some kind of retraining. He states 'the need is great for intervention studies that aggressively work to maintain the bridge with the pre-injury employer.' He warns that if this 'window of opportunity' closes, return to work may take years. Schonherr et al. (2004), as noted above, cites the expectation of return to work as a positive influence in gaining employment.

One employer interviewee stated their need, at the early rehabilitation stage, for information that would have assisted in planning for their employee's return to the workplace. In spite of the Commonwealth Government's 'one-stop shop' JobAccess, few employers were aware of where to obtain information about work modification funding, wage subsidies and vocational rehabilitation support. Krause (2003) states the importance of providing information and support to potential employers in the early stages after injury.

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#### 7.4.1.1 On early contact with employers

*A couple of lecturers came and talked about the future and (my supervisor) came to see me. Felt they wanted it to happen for me - no one said 'think you can do this?' They all said, ' come and do this and we will help you' . INT1*

*(I was) fortunate - had just changed jobs - about a month before ....they let me know that they would keep the job open. My previous employer also contacted me and said they would be happy for me to come back to them. This happened in the first week of rehab - after that it was a breeze - to me it was the biggest help to my rehabilitation knowing I had a full time job to come back to. Rehab was all about setting goals and my ultimate goal was getting back to work and that was already set up. So I concentrated on goals in between - was only in rehab 3 months - went back after Xmas but just stayed in flats - Austin said you are ok 'you're done'. INT8*

#### 7.4.2 Early vocational rehabilitation

Although there is a general lack of consensus as to when vocational rehabilitation programs should commence (Young et al., 2003), there is a growing body of evidence indicating that early intervention vocational rehabilitation can promote a successful return to work for people with SCI. Murphy et al. (2003) in TAFE NSW Western Sydney, (2005) supports vocational rehabilitation commencing as soon as possible. Krause (2003) indicated the need for early intervention to promote a speedy return to work. He argued that career counseling would benefit from exploring links between past and future employment at this early stage.

Murphy et al. (1996) states that vocational rehabilitation occurring in fits and spurts. Young et al. (2003) found the best time to offer vocational intervention varies with each individual. Krause (2003) suggests that if there is any possibility of returning to the pre-injury job then early intervention should occur even if it causes some discomfort for the injured person and their rehabilitation providers.

The NSW early intervention model *SpinalWorks*, is recognized as an effective approach into training and employment for individuals with SCI. (WestWoodSpice, 2002; 2005). In considering the timing of the introduction of vocational rehabilitation the final evaluation report recommends:

*...It is important to introduce them (individuals) to the idea early, but not necessarily start teaching early. Work on the premise that adjustment periods for some individuals can take months or sometimes years and early exposure can facilitate a return at this point.*

WestWoodSpice (2005, p. 29).

While there were some interviewees who stated that they had not wanted to think about employment and training during their early rehabilitation, some interviewees did. Had vocational support been offered at this early time, and in the manner suggested in above quote, this may have facilitated entry into work or study at a later date.

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#### 7.4.2.1 On the need and the possible lost opportunity

*Always thinking what am I going to do when I get out of here. Used to work 7 days a week* INT15. This person's previous employer did contact him soon after he came home and he returned to work.

Three individuals were planning the continuation of their University courses during acute rehabilitation.

INT17 thought he would be contacted by his previous employer but it didn't happen. When he contacted them over a year after coming home he did go back to work for them but the work was casual, unsupported and physically unsuitable and eventually he left. INT17

Perhaps with earlier contact with his employer and the right assistance the employment could have worked out.

#### 7.4.3 Case Study A – Early contact and support from an employer

A sustained a spinal injury in a fall about four years ago which left her with paraplegia. The accident occurred at home and was unrelated to work. Like other Tasmanians A was flown to the Austin Hospital in Melbourne for acute care and then to the Royal Talbot hospital for early rehabilitation. Even though her husband was able to be with her she nevertheless describes the experience of 'distance rehabilitation' as 'shocking'.

What happened for A during this time however, was unlike the experience of most injured people. A's employer has a strong culture of pastoral care towards its employees and provided immense support for A during this time.

A was visited by her employer's Human Resources (HR) Manager early in rehabilitation and on several further occasions and was told that she would have a job when she came home. The Manager couldn't be sure exactly what it would be but there would definitely be a position for A. For A this meant that 'things were taken care of - life seemed to be preserved or cushioned in some way'. She said she developed a sort of tunnel vision that enabled her to gradually work through the things that needed to be done.

A's employer, through the HR Manager, also liaised with the Royal Talbot and the Spinal Team in Tasmania to oversee the modifications in A's bathroom and the building of ramped entries into the house. This early contact with the Spinal Team was also a 'plus' for A as when she came home she felt as though the Team members were 'like a family'. (Cont.)

A had been part of a team in her former job. A's employer paid for the team, 10 in all, to fly to Melbourne – as a team - to visit A. It was a surprise and when A entered the room she said she just didn't really know where she was. A's employer stated that these visits were invaluable in allowing A's team members to come to terms with what had happened to their colleague. After five months of rehabilitation A returned home and was invited to an afternoon tea along with her husband where work mates presented A and her husband with a quilt with messages embroidered by each of them. It now has pride of place at the entry to A's house.

About nine months after the accident A began a slow return to work, starting at about two hours a day. It wasn't easy as A was still learning to manage the various complications of spinal cord injury. During this time she was supported by a rehabilitation provider, contracted by her employer, over a three or four month period and after that by phone as necessary.

A heard about CRS through another person with SCI and organized the funding for modification to a desk and toilet at her workplace. She was pleased to be able to take this initiative and felt this was a way of showing gratitude to her employers for their support.

A's work has changed from one that required a lot of physical mobility and community access to a clerical position. She now works four hours a day and has been employed continuously since her return.

Her employer stated that being involved in A's rehabilitation and return to the workplace has made the organization much more conscious of access issues for staff and customers. The organization has an ethos of encouraging diversity and believes that working with people with disabilities makes people stop and think what they would do in that situation; it opens another world and develops tolerance. She has also found that caring for staff encourages loyalty – 'a two way thing'.

### **7.5 Enabling employment: *Usage and availability of computers***

As stated earlier all except five individuals with SCI participating in this research had access to and use of the internet. Three people were in the process of gaining access. Computer technology assisted them with work that was conducted from home as well as in the workplace and was also used for personal and SCI information and services such as banking and paying bills. One individual, with a high level injury, described how he had been totally resistant to using a computer until a friend showed him just what could be done. He was hooked.

Several individuals participating in this research had undertaken computer courses either privately or through TAFE or another training provider. Younger people, particularly those

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who were studying at the time of their injury, already had substantial computer skills. In a few cases voice software and other assistive devices were used.

While there may be some resistance to 'working in an office', especially among those who previously worked outdoors, discussions with rehabilitation providers indicated that when computer based training and work was linked to an area of experience and interest it became more acceptable. Computer and assistive technology training is an integral part of the Royal Talbot rehabilitation program. The aim is to develop skills that can promote lifestyle independence and which may also promote employment opportunities.

Pell et al. (1997), found that level of computer skills and training was a significant factor in predicting employment in a study of people with physical disabilities, including SCI, living in the Brisbane area. Results from the same study published in 1999 found that people with quadriplegia had higher levels of computer skills than those with paraplegia but there was concern over the low rate of assistive devices used by people with quadriplegia. McKinley et al. (2004) states the importance of the availability of assistive technology in facilitating computer access and increasing employment opportunities. Kruse et al. (1996) also emphasized the importance of computer access for people with SCI as a means of enhancing employment. At that time, however, he found that computer use among people with SCI was lower than for the general community and recommended policies of increasing access to computers and training.

Bricout (2004) discusses the opportunities that telework provides for home-based work for people with SCI through the use of information and communications technology. He emphasizes that such employment should be part of a carefully managed 'back-to-work' program involving rehabilitation professionals and the employer.

The early intervention NSW SpinalWorks Project incorporates a focus on computer training for people with SCI. The project reported a high success rate in assisting individuals with SCI into further study and training thereby increasing opportunities for employment in the future. The project also emphasizes the importance of computer skills in contributing to a 'whole-of-life improvement' for individuals with SCI (WestWoodSpice, 2005).

The case study below highlights the importance of computer technology for people with higher levels of SCI to assist them in maintaining control of their environment. Control over the environment also opens the doors to employment and enabling individuals to study and work from home independently. The kind of controls described below could also be adapted for an office situation increasing employee opportunities and independence.

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### 7.5.1 Case Study B – The importance of computer technology and environmental controls.

B has a purpose built apartment attached to his family home and was able to put a lot of thought and effort into establishing environmental controls to maximize his independence. Environmental systems can be prohibitively expensive. What B has developed is not only innovative but also economical as he worked out ways to use off-the-shelf software and hardware to manage his environmental controls.

The controls which B has developed have enabled him to work and study as independently as possible in a home environment.

These controls include:

- a powered chair with a radio transmitter to open and close doors;
- an intercom to the house via radio for contact with family;
- an X-10 system over the power cable to turn lights and heater off and on. This is controlled through a computer or programmable infrared transmitter. All of this is set up in B's computer and activated using voice commands with Dragon Naturally Speaking (DNS) software.

Using this software B has worked out a way of using voice control for other important objects in his environment: tv, phone and lights – the system works well. B can't understand why other people aren't using a similar setup as most disabled-specific voice controls are very expensive.

B's computer is set up all the time so this accommodates his environmental system. Even in bed at night he can still yell commands through microphone (if too far away software cannot respond to dictation but will still recognize commands). B has version 8 of DNS and says is very good with about 95% accuracy.

B has a desk top microphone which does take away some accuracy but allows more freedom than a headset microphone – a trade-off.

B's hands-free phone is also controlled through his computer and he has a track-ball to use with a mouth stick. B also has an infrared head-tracking mouse, called Smartnav, which can be used from a bed some distance from the computer. This has a reflective dot controlled by head movement which is used in conjunction with DNS voice commands mentioned above.

There is also a device called USB-UIRT which is another programmable infrared transmitter/emitter capable of controlling TVs, air-conditioners and other electrical appliances. This is also controlled from the computer. B has written his own software to make it more user friendly. Instead of being controlled through a series of numbers his program displays actual function names for each device. (Cont.)

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The same program also simplifies the function of telephone dialing. He can just click on a name out of his address book. Infrared extenders (devices that extend the reach of infrared signals by using radio waves) make sure devices not near the computer can be controlled.

B has not been able to find people doing similar things and stresses the importance of looking at off-the-shelf products as these are much cheaper – for example the infrared mouse was aimed at the games market and cost about \$400.00 compared with thousands for a similar ‘disabled specific’ device.

B’s set up has grown gradually over time and is still evolving.



Figure 1



Figure 2



Figure 3



Figure 4



Figure 5

**Figure 1:** The “PROG”, controls heaters, doors, and other equipment via Infra-red signals. It is operated directly from the computer.

**Figure 2:** a second Infra-red emitter, controlled from the computer

**Figure 3:**

**(left)** Infra-red extender: converts infra-red signals to radio signals and vice-versa. Used to extend control to areas outside infra-red range

**(right)** Light/power control box: switches lights and power points on and off. It is in turn controlled by the “PROG”

**Figure 4:** Phone dialer: controlled via infra-red from computer

**Figure 5:** Track pad: operated with a mouth-stick to control the computer

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## **7.6 Employment Barrier: *Negative experiences of vocational rehabilitation and employment services***

### **7.6.1 Experiences of vocational rehabilitation and employment services**

Chapter 3, Section 2 sets out a brief description of vocational and employment services available to people with SCI. To re-iterate, the key generic vocational service is the Commonwealth Rehabilitation Service (CRS). The MAIB contracts private vocational rehabilitation providers to work with its clients as do Workers Compensation insurers regulated by WorkCover Tasmania. The Disability Employment Network (DEN), part of the Job Network program, can provide specialist assistance to job seekers with disabilities and provide support past the six months limit allowable through CRS. Access to CRS and the DEN is determined by Centrelink through a Job Capacity Assessor (JCA).

As with other services accessed by individuals with SCI described in Ch 5, there were also distinct differences in the experiences of interviewees using vocational rehabilitation and employment services. There was an overall tone of disempowerment which is illustrated by the quotes below. Several interviewees reported that their work and study preferences were not acknowledged by vocational rehabilitation/employment providers. There was frustration expressed at the apparently over-long preparation times prior to job-seeking in both vocational and employment programs. Supports provided by individuals and agencies were sometimes described as poor and several interviewees stated that their complaints about service delivery were ignored.

There was, once again, unevenness in the experience of availability of information and access to services. One individual with a high level SCI injured three years ago and who is now working was never referred for any vocational rehabilitation. In another case a service provider just happened to mention the existence of CRS to an individual with SCI who had just returned from Victoria. However no referral or follow-up was made. One interviewee reported 'shopping around', trying to find out just what services he was entitled to use.

There also appeared to be a lack of clarity about the timeframes for vocational rehabilitation programs – when did they end and when could you re-enter - and this was the case for both the mainstream and insurer systems and up to the present time. At least three people interviewed appeared to be at some risk of 'slipping out of the system'.

To make things more difficult the system of rehabilitation and employment is itself very complicated and probably contributes to the, again, somewhat serendipity nature of service access and experience. Linkages between social security and vocational systems are complex at the best of times but become more complicated when insurer clients pass from insurer provided income replacement to social security payments. At the same time the client may also change from insurer funded vocational rehabilitation programs to the CRS or a JobNetwork member as decided by the Centrelink Job Capacity Assessor.

But probably of greatest concern is that the difficulties being experienced seem to be long standing and continuing today.

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#### 7.6.1.1 On situations occurring some years ago.

*Didn't really ask what I wanted to do - very little say - no liaison to see how you are going. X talked to employer more. Employer told me more about it than X about entitlements. Was with this one for about 18 months. Said they were having financial problems - impression no more government money.....People at work were good. INT12*

*When first started looking for work was like when you sell a house - gangbusters at first but then it changes - your file is in another cabinet and someone else has got your file. INT21*

#### 7.6.1.2 On a situation three years ago

*They never came up with anything in twelve months. I found it extremely frustrating – they look at you for the answers – basically threw a big fat text book at me and said ‘see if there is something here you want to do’. And that was basically it. They said ‘you know you’re going to have to work in an office’ and I thought this is not me- this is not what I want to do. INT23*

#### 7.6.1.3 On a situation about 18 months ago.

*Went to a Job Network program - advertised. Went for interview. Told they had to apply to Centrelink for funding - they got approval after 6 weeks. Went back for interview. Two people - one taking notes. Told I was too hard but they had the money. Did they keep the money and put me at the bottom of the list - still going through healing process - all cosmetic - probably charge \$500 for the assessment. Lovely brochures - put me in a room and - nothing - went to Managers but told I was lying - two witnesses there.... Went to politicians...do they do an audit on these people? He didn't know. ID14*

#### 7.6.1.4 An example from the complicated system

INT13 received income replacement from his insurer for two years as well as assistance from a vocational rehabilitation provider contracted by the insurer. The provider had worked with him to set up some temporary part time work as well as work trials. They were in the process of setting up a traineeship when INT13's insurer income support concluded. INT13 then became a Centrelink client and received the Disability Support Pension (DSP). Centrelink referred him to the CRS for vocational rehabilitation and they continued, with him, to work towards attaining the traineeship.

Recently, during a Centrelink review INT13 was told he should have left CRS some time ago and was placed with a Job Network agency. He feels he has gone back to square one – back to identifying his training and work goals – and is still pursuing the traineeship independently of the Job Network agency. His understanding is that it will be up to Centrelink to decide whether he takes up the traineeship if it is offered. INT13

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### 7.6.1.5 On a positive experience

*Employer suggested I contacted a Job Network agency - they can get grants to help people in this situation... Interwork – now WISE...signed up with them and they got a \$5000 grant and put in a ramp and modifications. They come and see me every now and then to see how I am going...they call in fortnightly or ring to see if I'm ok - how I'm going with hours. Keep an eye out.... INT15*

## 7.7 Employment Barrier: *Lack of long term vocational support*

### 7.7.1 Experiences of vocational support

Several interviewees talked about how they had drifted away from employment possibilities and been given little or no ongoing support. There were instances where individuals (both insured and non-insured clients) just fell out of the system, (work, work trials and study), for various reasons, including health, family commitments and lack of support, and perhaps did not have the confidence, skill and knowledge to help them 'get back in there'.

In some cases interviewees in this category were no longer contemplating employment. But others retained some interest in employment provided the right supports and flexibility of arrangements could be met.

Krause (2003) talks about a 'slow track' of many years for people who need to retrain for a new occupation and the importance of their having access to long term support. Yasuda et al., (2002), states, 'it becomes critical to provide ongoing assistance in addition to effective rehabilitation programs'. Any early vocational program should also take account of these longer term needs.

The experience of this woman is illustrative of the need for long-term support and a way back into the system. Eleven years from injury INT19, on her own initiative enrolled in a pre-employment course at TAFE and found her computer skills were greater than she had thought. While at TAFE she, by chance, met and signed up with a Job Network agency. She is now seeking work and is also enrolled in a more advanced Certificate Course.

#### 7.7.1.1 On why people leave the system

*CRS arranged a job in mechanic shop but as an employer myself I know what people want and could not do that. Spasms, bowel and bladder problems meant that sometimes just could not be there. Sometimes perfect to be there at 9am and other days not. INT9*

*When at uni had a couple of injuries and at the time was questioning what I was doing -why all the effort. So stopped that and thought I'd put the effort into something else. But didn't – thought I'd go back and then got another injury. INT7*

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*In some ways would like to (retrain) but a bit lazy – not being able to find something I really wants to do... always had problems at school with exams – going back and doing exams put me off - But might change. INT11*

#### **7.7.1.2 On being out of the system**

*Come and see us when you know - didn't say we could help look at different avenues. Were they interested - yes and no - like other government departments - say we are doing things but not really - nothing was completely cut and dry. INT11*

*Upset when that first job finished. Whole life ahead – was going to do this and that but it didn't happen. INT12*

*Loved studying but stopped because of campus. INT12*

*Has given up to be honest – love to earn some money – in debt more and more would like to be able to earn money – but got a lot out of life and am happy with that. INT4*

However, INT4 also said that he should be able to work somewhere like Cadbury's, even for a few hours a week. But he was afraid that if it didn't work out he would not be able to go back to receiving the DSP. INT4

The difficulties experienced with vocational and employment programs and the complexity of the system itself as described above may make long-term support problematic and also re-entry into a vocational program if a job is lost or study program disrupted. As noted earlier, the time frame for support by CRS the vocational rehabilitation specialists, is six months. It is understood that the proposed private rehabilitation services to be funded by the Government will also be limited to a six month timeframe.

The Disability Employment Network, however, can provide long term employment support to their clients when seeking work and when in an employed position. While some network members provide an excellent service this is not always the case as shown above. In addition the Australian Council of Social Services has expressed concern that, under the Welfare Reform Program it may become more difficult for people with disabilities with complex needs to access the system. The organization states that, 'Although the numbers of people seeking assistance will increase, due to a cut of \$450 million in Job Network funding announced in the Budget, 'Customised Assistance', the highest level of Job Network help, will be more strictly rationed' (ACOSS, 2006, p5).

Discussions with MAIB funds management staff indicate that their vocational rehabilitation program is usually limited to the time (two years) a person is receiving a disability allowance. However in the case of those clients who are part of the Future Care program, the timeframe may be longer ie. up to five years. It was also stated that consideration could be given to providing support after this time if circumstances of the person changed. Within the

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Workers Compensation framework, provided a claim had not been settled, it may be possible to access vocational rehabilitation services, if required, during the ten year support period following the injury.

In this study those working in professional jobs stated their intention of using their own skills and networks if they changed jobs in the future. INT15 and INT21 would use the Job Network programs which had been successful for them in the past.

#### 7.7.1.3 On a suggestion for a national online database

*After I stopped Uni got in contact with CRS to get ideas about direction to go but they couldn't - thought there would be some national database about what work worked for quads but nothing. Came back with not much - quite depressing - in terms of employment - if qualified beforehand I would have a better opportunity - so hard to see what the options are when first you have to get the degree. INT6*

#### 7.7.2 Case Study C: Determination to get back into the workforce

C had an accident that left him with paraplegia mid year 2005. He is 49 years old and was a self employed contractor working with heavy machinery in rural areas before his accident – ‘doing everything, you name it, tree-felling, power poles, fencing’.

C started looking for work almost as soon as he came home from the Royal Talbot Hospital. One possibility was work driving a ‘semi’, but to do this he needed to be reassessed with a hand controlled vehicle to regain his license.

He went to the Tasmanian Department of Transport but they said ‘no, no mate you wouldn’t be able to drive a truck, it would be too much for you’ – ‘I was s’posed to be able to change a truck tyre, strap the load and a whole page of things they said I couldn’t do. But the load would be strapped down before I left and companies now-a-days won’t let the driver change the tyre’.

I told them other people in Australia had their license and they said ‘Ah!’ C went to other organizations and politicians but he found he was in the too hard basket. It seemed the only way was to travel to NSW to get his license – no modified vehicle was available in Tasmania even if he got the go ahead for reassessment. C felt this was discriminatory as it would have involved him in a great deal of additional expense.

Then C met a lady (an OT) who did reassessment for hand control car driving – ‘she was excellent - looked outside the box – can’t thank her enough – she went to the Department of Transport and came back and said, ‘this is what you do’’.

(Cont.)

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C now had to locate a modified truck for his reassessment and had heard of a colleague with paraplegia who had his own trucking business delivering swimming pools around Australia. (This person had previously taken the NSW Department of Transport to court for the right to get his license back) This man agreed to help C and rang one day and said 'I'm coming to Tas with a pool'. C organized to have the reassessment done at that time.

'My papers turned up the other day – so now I'm accredited to drive a semi - first bloke (in a wheelchair) in Tasmania'.

## 7.8 Possible effects of the Welfare Reform Program

The Welfare Reform Program may have a mixed effect on the employment prospects of people with SCI. On the one hand it may prevent people with long term disabilities from 'slipping through the net' by its introduction of a system of two yearly review of all clients eligible to receive the DSP after May 2005. On the other hand the changes to the system in relation to eligibility for the DSP might prevent those receiving the DSP prior to this date from seeking work in the future. For example, returning to work 15 or more hours per week over a 2 year period may preclude a person from claiming the DSP should he or she become unemployed after that time. Instead they may receive an allowance such as New Start with few benefits and lower payments. For many people with long term disabilities this could present a real risk to what little financial security they have.

As noted above changes to the Welfare Reform Program may also affect the number of people with longer term complex needs from accessing high level employment assistance.

*Would love to undertake some training program or get work but terrified of losing the DSP. Would be a disaster as need so much.....INT12*

## 7.9 Discussion

### 7.9.1 Addressing ways to enable employment: *Maintaining family, friendship and employment networks*

Given the importance of family and friendship contacts and support the strategies below aim to keep alive contacts and networks at home as well as smoothing the transition from rehabilitation to home. The first is to make available an appropriate information package about SCI for family and friends and to facilitate contact, both personal and via the internet, from the earliest possible time.

The Royal Talbot Hospital has computers with internet connections and assistive technology and software for people with SCI undergoing rehabilitation. In addition, individuals with SCI who have their own computers can also purchase internet 'time' from providers. Staff at the Royal Talbot also indicated they would welcome technology such as Web Cams that enabled closer contact between their Tasmanian SCI patients and friends and family at home. 'YouTube' and 'MySpace' also presents opportunities for maintaining contacts.

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The second has already been outlined: support through a peer support network to be made available from early rehabilitation. Such a network has the potential to provide a link between the injured person and those at home by families, sporting groups, and possibly employers as well as providing support and information about SCI.

### 7.9.2 Strategies to maintain networks

**Strategy 10 - Information for friends and family at home and facilitating contact.**

ParaQuad Tasmania to work with the Royal Talbot and Tasmanian Spinal Teams to:

- develop an information package/DVD about SCI for members of the extended family, friends and employment networks of the injured person;
- make weekend leave from the Talbot to home in Tasmania an integral part of rehabilitation;
- encourage the injured person to access the Tasmanian peer support program to contact friends; and
- to encourage computer based internet contact – including web cams and YouTube/MySpace - between injured person and those at home. ParaQuad Tasmania to assist families if necessary in the provision of equipment eg computer, web cam and internet connection.

**Strategy 3 – Peer support and mentoring for people with SCI with an on-line forum**

This strategy has been outlined previously (see page 41)

### 7.9.3 Addressing ways to enable employment: *Early contact with previous employer and vocational intervention*

The successful outcomes for people with SCI that followed early contact with employers and the recent literature on early intervention rehabilitation for people with SCI is surely an indicator of the need for early interventions that can maintain and further develop linkages within these networks from an early stage. An early intervention vocational program could maintain and explore other possible employment links through family and friends of the injured person, an area so rich in possibilities. It could also assist individuals into training programs, a significant predictor of obtaining employment after SCI (Murphy et al., 1997; Tomassen, 2000).

As noted above, rehabilitation at a distance creates just that much more of a barrier for Tasmanians with SCI. An early intervention vocational model may help to further overcome some of the difficulties of separation. Any model should take account of the NSW SpinalWorks program particularly in relation to the timing of intervention. Discussions with

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staff at the Royal Talbot indicated that a model is likely to be supported during the acute rehabilitation period provided that it gives priority to the individual’s SCI rehabilitation needs.

The number of people involved in such a program is likely to be quite small (hopefully) therefore expenditure would not be great. If the program was conducted over say five years it would allow a reasonable assessment of the result. It should be available to all Tasmanians with SCI, whether or not they are covered by insurance. Such an approach, while commencing early, should also give recognition to the fact that some people with SCI may require longer term support. The Recommendation below suggests the development of an early intervention approach.

It has already been suggested that the Information Package about Services in Tasmania would contain information for employers and people with SCI about vocational rehabilitation and employment. This will better prepare the individual with SCI when employment opportunities arise as well as having information ‘on the table’ for the employer.

#### **7.9.4 Recommendations and strategies to promote early intervention**

**Recommendation 7 – Early intervention vocational rehabilitation pilot**

In consultation with ParaQuad Tasmania and the Tasmanian Office of Post-Compulsory Education and Training (OPCET) a panel of vocational rehabilitation and vocational education providers seek funding to develop and pilot a program of early vocational rehabilitation intervention for Tasmanians with recent spinal cord injuries. The model should take account of the NSW SpinalWorks program and commence during the acute rehabilitation phase with proper regard to the physical and emotional well-being of the injured person. While taking account of the long term needs of some individuals, its aims might include identifying vocational directions, keeping existing networks alive and promoting early return to work and involvement in training programs.

**Strategy 2 – Information about care and support services at home**

This strategy has been outlined previously (see page 41)

#### **7.9.5 Addressing ways to enable employment: *Usage and availability of computers***

The success of the NSW SpinalWorks program with its focus on computer training within their early vocational intervention program is an indicator of just how important this area is for people with SCI. Computer and assistive technology and community computer uptake is moving so quickly that we may not have caught up with the opportunities it presents, not only for employment opportunities but also for increasing lifestyle information and choices

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for individuals with SCI. As noted above the Royal Talbot Hospital provides access to computers, the internet and assistive technology as part of its rehabilitation program. The Case Study B highlights the importance of computers for environmental controls which may be a key factor in enabling some individuals with SCI to work.

#### 7.9.6 Strategy to promote computer use

**Strategy 11: Promote use of computer technology and assistive devices in vocational programs.**

ParaQuad Tasmania to promote the value of computer access programs and training for people with SCI as a means of gaining lifestyle independence, facilitating further study and training and promoting employment. The use of computers and internet to be an integral part of vocational programs.

#### 7.9.7 Addressing employment barriers: *Negative experiences of vocational rehabilitation and employment services*

The experience of people with SCI accessing vocational and employment services may be improved through the same process of empowerment recommended in relation to other health and support services outlined in Chapter 5. The need for peer support is crucial as is the ability to access information and participate in discussion on-line. This support can enable individuals with SCI to be better able to monitor and compare ‘what is going on’ in relation to the services they are being offered. Access to advocacy and the availability of easy-to-use complaints mechanisms are crucial factors that can bring about changes and enable providers to better understand what is required by people with SCI.

Empowerment can also be enhanced by increasing access to information about employment possibilities for people with SCI through the development of a web page with a Tasmanian focus on employment issues. It might contain information for employers and vocational rehabilitation providers with suggestions and case studies illustrating successful working situations of people with SCI. This might incorporate the suggestion made above for an on-line data base of jobs for people with SCI. Readily available information may address some of the issues for those who are outside the system but may want to return.

A suggestion for a brokerage model was made by one interviewee – *give me the money and let me go and find my own employer. [I would say] here’s a wage subsidy and money for Workers Comp for 12 months – take me on.* ID14

While this may be a very difficult thing to achieve within the current system, brokerage models have been used in other areas of the disability service provision. The suggested employment brokerage model is a valuable idea and one that should be ‘left on the table’ for further consideration.

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### 7.9.8 Recommendations and strategies to increase vocational service access and delivery

**Recommendation 8 – A brokerage model for people with SCI seeking work**

In consultation with ParaQuad Tasmania, Disability Employment Network members and the Tasmanian Disability Bureau explore the possibility of a brokerage model pilot to be incorporated into current processes. The aim would be to empower the person seeking work and maximize their control over the process and available resources.

**Recommendation 4 – Review and complaints mechanisms**

This recommendation has been outlined previously (see page 43)

**Strategy 12 – Information about employment and employment opportunities for people with SCI**

ParaQuad Tasmania to develop a ‘web’ page with information (with a Tasmanian focus) about employment and vocational rehabilitation programs with links to relevant employer, insurer and government web-sites. It could contain case studies of people with SCI working in particular occupations and provide examples of workplace arrangements.

**Strategy 3 – Peer support and mentoring for people with SCI with an on-line forum**

This strategy has been outlined previously (see page 41)

**Strategy 4 – Advocacy**

This strategy has been outlined previously (see page 43)

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### **7.9.9 Addressing employment barrier: Lack of long term vocational/employment support**

The brokerage model might be considered by a group of expert providers such as ParaQuad Tasmania, a Disability Employment network member and the Tasmanian Disability Bureau. The group could also monitor long term vocational and employment support needs of individuals with SCI and ways to encourage entry or re-entry into training, education or the workforce. Early intervention programs should also take account of long term needs of individuals and program support required.

Information forums about all SCI related services, including community, health and employment and rehabilitation programs, in each region of Tasmania could provide an opportunity for individuals with SCI to participate in seminars with local employment and vocational providers and discuss relevant employment and vocational issues. Seminars might address issues for return to training/employment for longer term unemployed, provide an opportunity for peer support and information about health and well-being that might affect employment and quality of life. Discussions with ParaQuad Tasmania indicate that their resources would allow biennial workshops in the north and south of the State.

The impact of the Welfare Reform Program on the work opportunities of people with disabilities requires monitoring in order to gauge the short and long term effects on access to jobs, the effect of two yearly reviews, access to employment services and long-term support.

### **7.9.10 Recommendations and strategies to improve long term support and a way back into the system (vocational rehabilitation and employment programs)**

#### **Recommendation 9 – Long term support and getting back into the system**

In consultation with ParaQuad Tasmania, Disability Employment Network members and the Disability Bureau monitor long term training and employment needs of individuals with SCI. The group might also identify key areas of opportunity for entry and re-entry into the work force and/or training programs.

#### **Recommendation 10 – Regional fora/workshops**

ParaQuad Tasmania to facilitate biennial information workshops in the north and south of Tasmania with themes on employment and community work participation including work and study entry – and SCI ongoing health promotion – at work and at home. Workshops to be held in conjunction with regional service providers from, for example, Job Network and vocational rehabilitation agencies, the Vocational Education and Training (VET) sector and Spinal Teams.

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**Strategy 13 – Welfare Reform**

ParaQuad Tasmania in consultation with other SCI organisations to monitor the effects of the Commonwealth Government’s Welfare Reform program in relation to review, long term support, access to training, education and employment and a person’s financial situation

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## Chapter 8 - Work and Study – The Experience

### 8.1 Introduction

This Chapter outlines the experiences of individuals returning to work or study after an SCI and the perceived benefits and costs of working. The quotes drawn from interviews illustrate some of the challenges they face, including extra physical ‘wear and tear’ as well as their positive work relations.

The value of peer support and mentoring is explored as is the value of workplace flexibility around hours and days worked and work-at-home policies. The importance of access, transport and workplace modifications is discussed.

Employer knowledge of disability issues and employer incentives is outlined together with their knowledge of funding sources and experience of workplace modifications.

The positive and negative aspects of unpaid work trials are discussed, as is the possible relevance to employment of community work undertaken by people with SCI.

Barriers and enablers to employment are identified and strategies suggested.

### 8.2 Enabling Employment: *Support for people with SCI returning to work/study*

#### 8.2.1 Commencing work and study

The experience of commencing work or study after an SCI was described as ‘daunting’ and emotionally and physically exhausting. The individual with an SCI may still be coming to terms with being in a wheel-chair, building up their strength following the injury and adjusting to the many health and life-style related side effects of SCI.

The extra physical demands that some work and study venues place on individuals with SCI can also contribute to the difficulty of the experience. As an example, the hilly terrain of the University of Tasmania Sandy Bay campus presents an ongoing challenge for students and staff with disabilities and the disability support staff working to lessen the effects. But heavy doors, locked doors, poor access signage, having to access buildings away from the main entrance, parking areas situated away from the work area and not undercover - all these things made extra demands on an individual with SCI and, especially in those early days, can make working and studying more difficult.

Another aspect of the initial return-to-work/study experience described by interviewees was being unsure about how other people in their new situation might react to someone in a wheelchair. In some cases this concern affected the self-confidence of individuals with SCI. If others were thought not to be confident about the ability of the individual with SCI to do certain things then the confidence that individual had in his or her own ability could be undermined.

### 8.2.1.1 On commencing work and study

*Felt independent but confidence took a long time - probably only became confident in last five years even now a struggle – worries about how I'm perceived. Still do a little bit. INT1*

*Daunting to come back to work not knowing how people would relate to you - never any worry that I could do the work as had even done some computer work while in the Austin - day to day interaction was a bit of a worry - being able to come in and do a bit - a gradual process...INT8*

*Daunting going back (to Uni) – had only been out of hospital for 6 months and not used to being in the real world. I was very nervous and scared. INT2*

*When first started work was buggered was wrecked. Not physically but mentally.....There's a lot of wear and tear - have to get up much earlier - up at 6 to be at work at 8.30 - don't have time to eat, cook and do the washing. INT21*

*INT20 stated was 'absolutely terrified' (starting her new job) It was also exhausting. For the first six weeks I literally came home and cried. But she is glad she didn't chuck it. This interviewee stated current work is also very tiring. She often goes home after work and lies down for an hour - is in bed by 9.30 and out of bed by 7am and there is no pressure relief all day. INT20*

*What I was probably shy about was being at the front desk.....they don't know to start with. And when you have to access a file..... and roll out from behind a desk..... you think 'oh you don't know me – you're about to know me'. You get more confident over the years but its still there. INT23*

As can be seen in the above quotes, 'going to work' not only presents emotional challenges it also places extra pressure on health and wellbeing. There are fewer hours available to care for oneself, yet at the same time, the physical, mental and emotional demands on the person with SCI are increased. Adapting to these changes appeared more difficult in the first months after return to work with the individual with SCI gradually becoming more accustomed to demands. Nevertheless, it was clear that 'going to work' always created greater demands on time and energy. This emphasizes the need for ongoing access to community and health services and support.

### 8.2.1.2 On wear and tear on health

*If you want to work and go to uni you have to give up things. This interviewee works at home part time and makes health and exercise a priority. He exercises every morning until lunchtime. Just don't know how people who work do it. INT7*

*Wear and tear - after 2 or 3 months on more pain killer - knocks you about. The longest day was seven and a half hours and was buggered. INT15*

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*You've got to make the decision 'do you want to work - or do you wanna....' If I did everything everyone wanted me to do [regarding SCI care] I wouldn't do anything else - you have to make the decision.'* INT3

## **8.2.2 Benefits and costs of working**

Interviewees were asked about what they thought were the benefits and costs of working. The costs of working must include the physical costs described above but they were regarded more as a challenge than a cost by the interviewees. Several interviewees talked about the increased cost of transport, organizing car modifications and organizing people to assist with transport if not able to drive oneself. The identified benefits of working related to an increased quality of life.

### **8.2.2.2 On costs and benefits of working**

*Good to be among people - sometimes a struggle to be nice when its all too hard and don't want to be there. Learn your own boundaries - if someone had said you can't work full-time would have done it to spite them. Back then chair was heavy and getting it in the car was hard.* INT1

*The buzz - the weekend - loved it* INT12

*Better than staying home watching tv - drive me mad. A reason to get up in the morning.* INT15

*Made me feel I wasn't stupid anymore... people look at you like they think you are stupid because you are in a wheelchair and even though you know you are not - a job is something to back it up.* INT20

This same person noted that her health was good but that she tended to push herself to breaking point. *Need to have more self knowledge and know when to stop.* INT20

*Keeps mind active –* INT21

*The benefits are quality of life, independence and self-respect - but having said that I am looking forward to retirement.* INT8

## **8.2.3 Workplace relationships and mentors/role models**

In this research those individuals who were working, loved working. Their workplace relations were good and ranged from having close connections to fellow workers to believing that good work relations depended on being able to do the job. If they wanted to change

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aspects of their employment it was almost always some aspect of work that bore no relationship to their disability.

Employers believed that people with disabilities made loyal employees. They stated that staff became more aware of life's challenges when they worked with people with disabilities and also more sensitive to each others needs and those of their clients. There are some subtle access issues explored below in Section 8.5.2 that can affect relationships and these may be reduced with employer/diversity education and training in disability issues.

### 8.2.3.1 On relationships at work

INT20 has all the flexibility she needs in her workplace. She works within a huge department but her actual unit is quite small. This interviewee noted how helpful her workmates were and that they respected her needs. *Quite a close group of people.* INT20

*Never been one to socialize after work hours but they get on well .....As long as you can do your job that is all people worry about.* INT8

*Just one of the workers - you know – I think if you can do your job and do it satisfactorily then shouldn't be any problems.* INT22

*Love my job – work with a great team of four within administrations and across departments.....See yourself growing professionally.* INT1

When asked to comment about the value of role models and mentors in the workplace respondents indicated that mentors need not necessarily be associated with a particular workplace nor need they necessarily be in a wheel chair. They could be people who were admired for their attributes and skills in various fields and for their capacity to mentor. On several occasions, however, it was stated that it would have been helpful to know about the early work experience of other individuals with SCI and/or the kind of work they were doing.

The University of Tasmania offers a mentoring system for their employees with disabilities with regular focus groups and ongoing email contact to address issues as they arise. Discussions with University staff indicated that this mentoring system will be extended to students with disabilities in the future. Peer support for people with SCI returning to work is among the established programs offered by SCI support groups and information networks.

### 8.2.3.2 On mentors and role models

INT5's role model is a younger person in a wheelchair. She was described as being very positive and with lots of interests and great to learn from. INT5

*Met a nurse there who was a wonderful mentor - open minded positive and switched on.* INT1

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## **8.3 Employment Enabler : *Information for employers***

### **8.3.1 Employer knowledge of disability issues**

Employers interviewed for this research were very positive about employing people with disabilities in their organizations and several organizations did so. Employers, however, were generally not well informed about government incentives available to organizations employing people with disabilities. Nor did they appear well informed about the kind of supports that might be required by people with disabilities and there were some possibly unfounded concerns around access and capabilities.

Employers were generally aware of the need for workplace modifications eg installation of ramps, modifications of desks, doorways and toilets when employing an individual in a wheelchair. However, when it came to issues in their workplace that might be harder to solve 'a little wall came up'. One employer stated that a person in a wheelchair could never do a specific task because staff carrying out that task were required to work on a dais. 'It's a technical problem'. Another was concerned about fire safety strategies and thought this might possibly preclude the employment of a person in a wheelchair. Another employer stated that as staff frequently walked up and down stairs - 'a stair based work program' - employing people in wheelchairs would present problems. However, lifts were already in place just not generally used by staff.

Generally it seemed to be a case of, 'of course we are willing to employ people with disabilities but we don't really know much about the process.' Four employers stated they would be happy to employ people with disabilities but in fact they received no applications for employment. Perhaps because of these reasons there was little evidence of policies to actually attract people with disabilities to the workplace.

There was, however, evidence of positive initiatives. The State Government has developed an employment register for people with disabilities, the University of Tasmania as noted is actively supporting employees and students with disabilities through mentoring and ongoing programs to facilitate access. Several employers, including those in case studies A and D were or became acutely aware of disability issues and requirements due to their employment of individuals with SCI. Employers also noted that by caring for their own staff following injury or illness they had gained some experience of workplace supports that might be required when employing people with disabilities.

#### **8.3.1.1 Job application procedures**

Several employers appeared unsure about when they want to be told about a disability by a job applicant. At least two employers thought that knowing about a disability prior to selecting a candidate might influence them in their selection procedures. On the other hand several employers were very clear that they wanted to know about the disability as early as possible with information about any restrictions the person might have.

The University of Tasmania intended introducing a procedure aimed at establishing whether or not prospective employees had any special requirements at interview. This would cover all selected applicants and not just a person with a disability and would prevent the embarrassment described below.

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### 8.3.1.2 On not knowing what to expect

*All the time I wanted to work and even going for jobs – the access was non-existent. At the time I got an interview I should have asked about the access – there were bloody steps there. That happened a few times. INT24*

Some employers were also unsure about asking questions of the person with the disability that may not be applicable to other candidates. One interviewee stated she had never been asked any questions about her disability during interviews. However, one employer stated that she would ask detailed questions about the capability of carrying out each task regardless of ability/disability.

### 8.3.2 Employer knowledge of other government incentives

Most employer interviewees were aware that some incentives were available to assist in the employment of people with disabilities but were not sure how they would go about finding out about the information. In most cases it would have involved an internet search through government department websites. One employer suggested that the Tasmanian Chamber of Commerce and Industry (TCCI) would be their first port of call. This would seem to be a useful suggestion that incorporates local infrastructure and knowledge and which can be developed into a strategy. Closer linkage between employer peaks, disability organizations and employer networks was among those recommendations put forward by the HREOC to increase employment of people with disabilities.

Strategies (including employer workshops) are suggested to increase employer awareness of employment issues for people with disabilities, in particular SCI, and information sources.

## 8.4 Enabling Employment: *Flexibility of work arrangement and hours*

### 8.4.1 Importance of flexibility of hours and work arrangements

The flexibility to work full or part-time and flexi-time and from the workplace or home, may be essential for some individuals with SCI and immensely helpful for others. Flexibility in relation to hours worked and when they are worked will allow individuals with SCI a greater opportunity to manage their SCI care needs. Working from home particularly, can enable employment to become an integrated part of life enabling corresponding flexibility around home, transport and personal care arrangements. It also facilitates control over personal needs within the environment, eg, wet weather arrangements and temperature, particularly important for individuals with a higher level SCI.

Five of the SCI interviewees had worked from home either as an employee or as self-employed persons at some time and on a part-time basis. Two people conducted extensive community work from their home. Three individuals who were not employed, felt that the ability to work flexibly from home would be necessary to their taking up employment. Four interviewees, however, worked or had worked in '9 to 5' workplace based occupations and had done so for several years.

The importance of flexible work arrangements, particularly in the early 'daunting' stages of return to work is illustrated in quotes below and also in Case Study D below.

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#### 8.4.1.1 On gradual return and flexibility

*Went back to work in March (3 mos after coming home)- started coming in Feb so came in part time and would rest in X's office as I needed to - part time for a few weeks then work put pressure on to go full time. Have worked continuously since then. INT8*

One interviewee was supported by a rehabilitation professional provided by her employer. For 3 or 4 months she was given assistance on a weekly basis gradually tapering off but with help remaining available as necessary. She began working for two hours a day and gradually increased her time. Initially it took 3 hours to prepare for work. INT5

*Worked 15 hrs a week from home completely flexible - not always motivated - nice of them to offer the job – INT6*

*(My work) suits me. Don't need to be there 'til 1pm or 4 pm...can read at home...best job I could have ...very flexible - cant think of anything better. INT16*

*Working is good - would like to work 4 days a week - one day to catch up with physios....- problem with service providers coming at a time that suits when you are working. INT3*

INT5 would like more hours but gets physically tired and has neurogenic pain which is worse if tired. She suggested that a place at work to lie down and stretch would be a good idea. It could be done in a tea-break. INT5

#### 8.4.2 Employers and flexible work arrangements

Employers who were interviewed indicated that flexible working time arrangements were relatively easy to accommodate in the workplace (depending on the position) and in most cases a policy was in place that enabled a degree of flexi-time and part-time arrangements. Several employers stated that this was due to the implementation of family-friendly policies enabling a gradual and flexible return to work for women following maternity leave. Several employers also stated that they were experienced in providing rehabilitation support and special work arrangements for their employees who had been injured.

The existence of family friendly policy frameworks could enhance the probability of organizations employing people with disabilities who required flexible work arrangements. One employer suggested, however, that there may be limits to the extent flexible arrangements can be met within an organization. For example, organizations with an ageing workforce with a variety of conditions that needed to be accommodated in the workplace may be less able to employ someone else who also needed flexible working conditions and specific accommodation.

Employer attitudes to work-from-home practices, particularly on a long-term basis, were less flexible due mainly to concern about occupational health and safety issue of ensuring the

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safety of a home workplace. As the representative from one organization commented, 'it is not on our radar yet'. Others were concerned about the cost of a 'fit-out' in the person's home and whether they could be adequately supervised. Four employers, however, indicated that they would allow people to work from home depending on the suitability of the task although not necessarily on a long-term basis.

The concept of carers in the workplace was accepted by most employers but not all. One person indicated that issues of security and safety might prevent this happening as all personnel in a particular area were subject to security screening. Others stated that it would be acceptable provided that there was a suitable place for care arrangements. The availability of a carer to assist people with SCI during working hours and in the workplace was perhaps 'the' factor that enabled some interviewees to work.

#### **8.4.2.1 Case Study D – An ideal flexible work arrangement**

D is a young man injured when he was 32 years old in a tree felling accident. He is one of those adventurous Tasmanian men who fish and shoot and drive a 4WD vehicle with a chain-saw in the back.

D's injury was horrendous and resulted in paraplegia. He spent six months in rehabilitation in the Austin and the Royal Talbot. 'Always thinking what am I going to do when I get out of here. Used to work seven days a week.' There were set-backs in his recovery one of which involved a staphylococcal infection apparently from the metal rods inserted into his back. 'Just wanted to die and not be there anymore'. It took two months of rehabilitation before he was able to get out of bed and when he came home with the rods still in place D had to lie flat 8 hrs a day. He needed morphine to get out of bed and the staphylococcal infection persisted.

This was how things remained when, six months after D came home, the Human Resources (HR) Manager from his previous place of employment (a vegetable processing, packing and exporting plant) approached him and said, 'they could set him up something at work'.

Although not working for them at the time of the accident, D had worked there previously for about seven years in a supervisory role. When the HR Manager heard of the accident, and with the backing of the organization, he decided to find a way to re-employ D. The organisation knew he was a good worker - 'The sort of bloke that goes and cuts wood with a chain-saw by headlights after a full days work'. This organization also had an impressive history of employing people with a diverse range of disabilities.

D wanted to wait until the rods were removed from his back and was worried as to whether he could do the job. However, he was assured by the HR Manager that he could work his own hours, take breaks as he needed and work his own days. D thought, 'I might be able to do this with pain killers'. And when the rods came out D just 'couldn't believe it. I could bend over again'. (Cont.)

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The Manager suggested D work through a Job Network agency to obtain some funding assistance for modifications. A \$6000 grant was allocated to set up a little office for D, with a portable ramp, reverse the toilet door, place sliding doors into the canteen and cement ramps into the main office as well as small handrails here and there.

There was, however, a big hiccup in the installation of some of the modifications. The Commonwealth funding agent insisting on a guideline timeframe that did not suit the employer and negotiations around this consumed an unnecessary amount of the employer's time – about thirty emails!

Apart from this one problem that could easily have been avoided, the outcome has been excellent for D and his employer.

D is assembling electrical fittings. 'Just been going along since – my hourly rate has gone up. I've done a TAFE course and have a Testing and Tagging Certificate. D likes the work although it is different to what he was doing and the flexibility makes it perfect for him. D works with the season, five to six months a year between two and seven hours a day, five days a week.

He can also bring work home and work on specific stages of the assembly process in his shed where the necessary equipment has been provided by his employer. He and the Manager worked out the hours to be paid by the number of at-home finished products. The five to six month time frame is also good as D notices that pain begins to increase after a few months at work. This flexibility of hours that D has allows him to look after himself and work. He ensures that he keeps in front with production then if he does need to take time off because of ill health, he can. He takes responsibility for making sure the work is done.

D's workplace has a strong focus on Occupational Health and Safety issues. All workers are given a medical to ensure that they can safely do the job they are employed to do. They are also encouraged to report any signs of injury or soreness at the earliest stages. D's employer sees no problem with allowing D to work from home, as long as the task is suitable. The Manager added, 'He (D) can do so [work at home] because he is more comfortable'. D agrees, 'It is wonderful'.

D's Manager stated that he thought people with disabilities made loyal employees. But he added, 'they are really no different to anyone else. It's the personality that counts and how well they can adjust to the workplace'.

D said 'I do the same by them as they do good for me'. (Cont.)

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D was recently offered a supervisory role with a lot more hours, still with the ability to work some hours at home, but he is happy doing what he's doing now – 25 to 30 flexible hours a week.

He has also worked out a way to get from his wheelchair into his boat and go fishing again on the mountain lakes.

## **8.5 Enabling Employment: *Workplace modifications, access and transport***

### **8.5.1 Workplace modifications and employer responses**

The Commonwealth Rehabilitation Service (CRS) was the most usual organization consulted about the workplace modification and/or assisting in the funding process although other Job Network members were also involved (See Sec 4.7.4.1). The workplace modifications that had been completed included ramps, the small office mentioned in the case study above, toilets, doors and doorways and desks. At least four organizations undertook workplace modifications using their own funding and expertise.

Employers who were interviewed indicated that would be happy to provide modifications within reasonable cost as required by a person with a disability and within the requirements of discrimination legislation. Although funding for workplace modifications has been available for many years, somewhat surprisingly, half of the employers interviewed were either unaware of government assistance for modifications and/or how to access this incentive.

Two employers involved in providing modifications through government funding were critical of the policy and process. One employer stated that they seemed to be involved in endless meetings. Another, as mentioned in Case Study D, had found that the timelines for the modification were rigidly laid down within funding guidelines and did not suit his organization which was subject to seasonal fluctuations in activity. It took a great deal of employer time and energy before it was agreed to arranging the modifications work around the employer's needs.

Most interviewees were generally satisfied with modifications which were done prior to or soon after their arrival at work. Two employers stated that employing a person in a wheel chair alerted them to issues faced by those clients and volunteer staff who were wheelchair or walking stick dependent. This awareness led to doors being widened, toilets redesigned and automatic controls being place on doors.

Both employer and SCI interviewees stressed the importance of the person with SCI being able to tell the employer what was needed and how to access it. This again emphasizes the importance of the person with SCI having access to information about services and funding possibilities.

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### 8.5.1.1 On workplace modifications

*Mostly happy with modifications but didn't finish the toilet and still haven't.* INT8

*X modified things straight away. Asked him what he needed. Fixed things straight away. Funding for toilet organized through CRS* INT13

INT3 talked about how she could not get through the front door by herself and how this limited her independence. It has since been modified. Having her working there has made her employers more aware of what modifications could be required for better access and support of their clients. INT3

*Got job through friend of family and they were prepared to put ramps in - the grounds were quite rough - to access mobile offices and make them roomy inside. I think I was fortunate that they were friends of family and willing to do it. Further down the track they extended and still put in toilets big enough for me to access.* INT23

INT5 had been told about CRS by another person with SCI and approached them to assist her employer to access funds for her workplace modifications. (Her employer had not been aware of this service/incentive) As a result her desk was modified and a basin installed in the toilet which was big enough to become a disabled toilet. She felt it was a way she could assist her employer. INT5

### 8.5.2 Access, parking and transport

Access, closely linked with modifications, remains an issue on different levels. First there is access into a building the lack of which can prevent a person with SCI working or studying or using services in that venue.

Secondly there is access within the workplace: two employers provided examples of difficulties they thought would make certain jobs impossible but which may well have had a solution.

The third kind of access problem is more subtle and might be called social access. When terrain is difficult and/or the person in a wheelchair has a physical access to a building different to the main access, the possibility of relationships with other people is reduced. One instance may be when staff go off to the 'pub' after work in one direction, but the person in a wheelchair has to travel in a different but more accessible direction and away from the company of workmates. Social access can also be limited due to a reliance on carers and time restrictions.

Sandy Bay campus with its hilly terrain and widespread lecture theatres presents a challenge for individuals with SCI and the staff that work to improve access. The campus did make things much harder for its SCI students interviewed in this research and in two cases was the deciding factor in the decision to discontinue studying and may have influenced others. It is worth mentioning the difficulties of a particular campus because it provides an example of

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just how important access is to community participation by people with SCI. By comparison Launceston University campus was described as wonderful as was Launceston TAFE. About Hobart TAFE, the interviewee said, ‘no worries’.

Discussions with University staff revealed that finding solutions to the access problems and terrain is an ongoing project. Staff work closely with individual students to work out the best access options and these can include modifying lecture theatres and providing transport between lecture theatres.

Parking was an issue in every area of life and several interviewees talked about the difficulties they experienced. These included a lack of awareness by organizations (even Centrelink) to take parking into account when arranging appointments; lack of space to allow hoist operation in some parking stations and just not enough places to park particularly in built up areas. However, those interviewees who were working stated that they had good parking facilities at their workplace. The University of Tasmania has reallocated parking spaces to better suit students with physical disabilities. Two interviewees stated that the ability to park easily and close to work would be a consideration when seeking employment.

The importance of the individual with SCI being aware of their access rights is illustrated by the changes they can bring about. One interviewee insisted on change to footpath impediments and work through the Council Access Committee. Another insisted that his local Council ensure a step was removed from the entrance of a newly renovated building. He noticed the step because he had been interested in applying for a job in that building. This provides a good example of the results that can flow from the empowerment of individuals with SCI.

#### 8.5.2.1 On Access

*School was accessible (middle school) but a change table had to be organized and some other modifications. Kids good the whole way through and still are supportive. INT10*

*It was horrible, horrible, horrible. Not wheelchair friendly - had one subject at the bottom of campus and another at the top..... Once in the building stuck down the front or up the back so didn't have any interaction with anyone. Just on your own. INT20*

*Attending arts school. Very nice, lovely environment – he is getting on well. The place is fully wheelchair accessible – there are lifts and it is very flat. INT10*

*In her first year INT3 was at Launceston and the campus was good. In the following years she attended the Sandy bay campus. They modified areas as I went to make sure there was access to lecture theatres etc. There is a special area with computers for people with disabilities, adjustable tables, somewhere to lie down. INT3*

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INT2 had a lecture in the bottom building of Sandy Bay campus and one in the top. Sometimes he would have to park at the bottom and push back up the hill in his lunch break. When asked if this affected social interaction, he responded with a wry smile, *would have been good to have lunch.* INT2

*Used to have to act as a consultant and would ring people to see if I could get in to the office. Otherwise would ask them to come out to the car.....Worked around it. ....Never really been disadvantaged by access even in a temporary workplace. Have a bit of a grizzle when I can't drive the company car when the boss is away.* INT21

INT22 was a Spine Safe lecturer in schools. When asked about access into schools he replied *you get some nice big male teacher or yr 10 yr or 12 boys and say 'Hey guys I need to get up there - please do not drop me on the way'.* INT22

*Brick walls....no parking at TAFE - talked to TAFE and told nothing to do with them. Went to Council – told nothing to do with them..... But TAFE is ahead of some other places.* INT14

The literature on employment for people with SCI emphasizes the importance of having access to transport. This was a generally positive area for most interviewees who either drove themselves in modified vehicles or owned accessible vans. There was, however, some concern expressed by those who depended on carers or family to drive them. As mentioned earlier families play a crucial role in assisting with provision of transport into the community and to work. Maxi-taxis were also an important part of the transport system and were used by a number of students (including on Sandy Bay campus) and volunteers.

The learn-to-drive process and car modifications seemed to be a relatively smooth operation except in a couple of cases. One person noted that it was harder for people living outside the major centres to have their vehicles checked by the Department of Transport after modification to hand controls. Another experienced difficulty with an Occupational Therapist involved in the relearning to drive process. The high cost of transport, petrol and car maintenance were mentioned regularly throughout the interviews. One interviewee stated that he did not think various tax-emption schemes for people with disabilities to cover some car parts and repairs were widely known.

The MAIB provides extra carer/driver hours to enable its working Future Care clients to travel to and from the workplace and also provides some support at work as necessary. This extra resourcing enables individuals with SCI, particularly those with a high level who are unable to drive to 'go to work'. However, there are no such supports available to people with SCI in the public system and as noted earlier transport assistance is generally provided by families.

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### 8.5.2.2 On transport

*Transport is going to be a major issue - had a maxi-taxi - funded by education department but he is not eligible at TAFE - still costs \$20.00 one way with a voucher - \$40.00 a day - community transport bus only certain days - has a van but needs a driver – I (mother) might do it but shouldn't.*

(This person has since received funding for a maxi-taxi to take him to TAFE. However he was not sure of the source of funding just saying he thought that his Mum arranged it).

INT6 expressed concern at his dependence on family for all transport needs. He needed all his ISP hours for personal care and was unable to 'bank' extra hours for carers to provide transport for community needs on a regular basis. However he did try to 'bank' hours when he could. INT6

### 8.6 Employment enabler - *Unpaid work placements*

Unpaid work placements presented some difficulties. Some interviewees experienced job placements that were apparently unstructured in time limit and unsupported. Three people had experiences in placements that had just 'fizzled out'. One individual believed his position had been terminated because the necessary paperwork had not been completed by the vocational rehabilitation agency. These kinds of experiences might easily discourage some individuals from seeking work in the future.

On the other hand two people spoke very highly of their work placements and would have liked them to continue, even though they knew they would not become paid jobs.

One individual, currently in a placement situation, identified the place where he wanted to do his work placement and then requested assistance from a vocational rehabilitation service to negotiate the placement. He is really enjoying the work and his relationships with staff who go out of their way to make sure his work is interesting and varied. He wants the work to continue but has not been made aware of any timeframe placed on the program and is no longer in contact with the vocational service. He feels unsure about where he is heading and the status of his job which he knows is not going to become a paid job. He believes that if the position ends he will be badly affected emotionally.

Another interviewee who had an unpaid work placement facilitated by a vocational rehabilitation provider was invited to relieve another worker who was taking leave. However, she was to do so in an unpaid capacity yet she was well qualified to do the work involved in the relief position. She did not accept the offer.

One rehabilitation service provider stated that she always preferred to find paid work for her clients just because of that reward. Unpaid placements, however, she believed did provide valuable experience.

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In spite of not being paid and some jobs ‘fizzling’ out and/or leading no-where, most interviewees found some value in the experience. It would seem however that such placements need to be carefully monitored and part of a planned and specific work program

### 8.6.1 On Unpaid Work-placements

*Got myself a work trial at R and J Motors.....had to argue with CRS not to do modifications until I knew ... in reception area - early after injury - did not enjoy it but hoping it might lead to something else. Asked to do petty stuff that anyone could do - writing out invoices kind of thing. It all fell apart in the end. Got me out for a while - something to get up for. INT4*

*Loved the work - but the boss was locating money to (other sections) - stayed 6 or 7 months - happy for me to keep coming in. INT13*

### 8.7 Possible employment enabler: *Other kinds of work*

Several interviewees stated that they were very happy undertaking volunteer work for ParaQuad Tasmania and providing community access advice. Another interviewee had worked as a volunteer for ParaQuad Tasmania for many years and been involved in peer support as well as website design and desk-top publishing. Other interviewees were involved in different kinds of community work and had their own family commitments. It was also clear during interviews that most people with SCI who were employed were also involved in a variety of community activities.

Participation in volunteer work may provide a valuable step in building confidence for people who have been out of the workforce for a while and who are not confident academically.

#### 8.7.1 On other kinds of work

*The retraining - not a great academic - going back to school put me off a bit. But - may still happen. Doing access stuff and spinal education in schools. INT11*

*Don't like being shut up.....Started driving other quad people to Hobart. INT17*

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## 8.7.2 Case Study E – A Targa Story

E sustained a spinal cord injury at the cervical level while taking part in a motorbike race five years ago. He is a qualified mechanic and boilermaker and something of an entrepreneur, owning and running a successful manufacturing business prior to his accident.

E believes his injury prevents him from working because so many things associated with quadriplegia are unpredictable. ‘Sometimes perfect to be there (at work) at 9am and sometimes not’. E asked himself what he could do – and even though his hand movements will not allow him to do all of the mechanical work he used to do – he still has all that mechanical experience and knowledge. E decided he could use these skills in promoting an awareness of spinal cord injury. He wanted the public to see that people with spinal cord injury could participate fully in life. And this was something that E himself had not really believed prior to his injury.

In 2004 E was approached by a teacher from Launceston College (husband of his carer’s work colleague) to work with College students on building an Elphin Clubman sports car to be driven in the 2005 Targa Tasmania rally. Targa Tasmania is an internationally famous, annual 6 day, 2000km rally event for the touring, sports and GT class cars. While there were some who doubted a person in a wheel chair could carry out such a mammoth task, E ‘got in there’, helped build the car (with hands on assistance from the students) and it raced in Targa Tasmania 2005.

This is when E got talking to a Targa official, ‘Have you ever had a quadriplegic in the race?’ The official thought E meant as a passenger. ‘No,’ said E, ‘I mean as some-body driving’.

‘You should have seen the look on his face’, said E, ‘but he was very careful what he said without saying ‘no’’.

‘Would you be able to race?’ asked the official.

E replied, ‘we both know I can’t do that – in the touring section driving at normal speed just like we do every day. Get out there and raise awareness’ .

E bought a Lexus Soarer SC40 car, prepared it for racing, secured sponsors including the Australian Quadriplegic Association and the Australian Maritime College, negotiated with Octagon, managers and organisers of the Targa event, and brought together a racing team. He even manufactured the car signage from his home computer.

E’s co-driver/navigator for the event also had a spinal cord injury. They required a support car with a carer and a sponsored mechanic to follow them in the race. Targa deemed their support vehicle to be an ‘official car’ to enable carer and mechanic to travel on the closed roads. (Cont.)

E said that as a quadriplegic he is used to many obstacles being placed in front of him, obstacles he says, that are there to make sure you don't get over them. But the Targa officials were supportive throughout and surpassed all E's expectations.

E and his team drove in the 2006 Targa event, raising public awareness about spinal cord injury among the media and the spectators. But that is not all. E thought that children in the north of the State should have the same opportunity to ride in a Targa car as did children in the south. The event that was organised is described so well by the Chairman of Targa Tasmania, Rob McGuire:

*One of the highlights of Targa Tasmania 2006 was the Kids Kick Start Disability Rides for approximately 25 children with physical or mental disabilities which was held prior to the commencement of Targa Tasmania 2006. Eight Targa Tasmania competitors turned up at the Country Club Resort in their competition cars and took the children on a 4 kilometre ride of their lives. The organisation of the cars, the children, the venue for the rides, the media and the necessary police support was all organised by [E]. The experience is something that the children and the Targa competitors involved will never forget.*

E and his team drove again this year, and E once again organised the Kids Kick Start Disability Rides. E stated that 25 Targa Tasmania 2007 competitors made their cars available and 50 children with disabilities had their very own taste of Targa. E said that cars ranging from the latest Porsche to the mighty Austin A30 registered for the Kids Kick Start rides to bring Targa to those who normally would not be able to attend.



## 8.8 Discussion

### 8.8.1 Addressing ways to enable employment: **Support for people with SCI returning to work**

Knowing what the experience of 'return to work' will be like could be extremely helpful for people with SCI returning to work. It would provide some sort of framework for comparison and clarify expectations. It might also help to be able to talk about the nature of physical and emotional stresses that were emphasized at that time. Peer support could play an important role assisting individuals in the return-to-work process whether they are commencing or returning to work/study and whether they are in a paid or unpaid position.

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Interviewees indicated that their role models/mentors could be a fellow worker, friend or high achieving sportsperson, and not necessarily anyone in a wheelchair. Any peer support/mentoring group should take this into account and ensure that it has the ability to make linkages with key people outside the SCI network. For example, it might be more appropriate and useful for someone studying financial planning to be in contact with a person working successfully in this area than with a peer SCI not involved in that field of study. The choice should be available and perhaps he or she might like support from more than one mentor.

Certainly, the interviewees in this research who were working displayed tremendous insight into their experience. They would make wonderful mentors for those individuals with SCI coming into the workplace.

Peer support networks and an internet discussion group with an employment thread could assist in the back to work/study process by providing both support and information about the experience of others. Learning what the experience was like, how to manage the extra activity and ‘wear and tear’ and being able to be put in touch with other people outside the SCI networks may all make the experience of work/study less overwhelming.

A specialized counseling program could also be made available to people with SCI entering the workforce or taking up study to help deal with issues of confidence.

### **8.8.2 Recommendations and strategies promoting support for people with SCI returning to work**

**Recommendation 6 - Counseling and psychological assistance**

This recommendation has been outlined previously (see page 52)

**Strategy 3 – Peer support**

This strategy has been outlined previously (see page 41)

### **8.9 Addressing ways to enable employment: *Information for employers***

The good-will illustrated by the ‘snapshot’ of employers participating in this research is a truly valuable resource which can be enhanced by the provision of information. Information about incentives to employ people with disabilities and employment processes including selection and interview should be easily available at the local level perhaps through website links to the information source. For example interview guidelines are available on the HREOC and Australian Employer Network on Disability websites. Online case studies could

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be used to illustrate ways in which particular problems have been overcome eg information could be provided about the home modification issue mentioned above.

The opportunity for employers, agencies and experts to meet on an annual level and discuss disability employment issues particularly with people at the ‘cutting edge’ of new initiatives, is likely to promote confidence in this area of employment. Promoting closer linkages between employers, employer peaks and agencies in the disability sector was one of the recommendations of the HREOC report on the National Inquiry into Employment and Disability.

### **8.9.1 Recommendations and strategies to increase access to information for employers**

#### **Recommendation 11 - Workshops for employers about employing people with disabilities**

ParaQuad Tasmania in partnership with Disability Employment Network members, the Tasmanian Disability Bureau, vocational rehabilitation providers and the Tasmanian Chamber of Commerce and Industry (TCCI), to jointly facilitate an annual employer forum to address workplace issues around flexible hours, access, modifications, work at home policies, staged return to work and work relationships.

The forum might include input from people with expertise in the area or who are undertaking significant initiatives eg. Diversity at Work program, Human Rights and Equal Opportunity Commission and the Australian Employers Network on Disability.

#### **Strategy 14 – Information for employers**

ParaQuad Tasmania to consult with the Tasmanian Chamber of Commerce and Industry (TCCI) and develop an appropriate local information package for employers about employing people with disabilities/SCI. Information should appear on websites of both organizations and might encompass:

- Workplace modifications and funding and who to approach
- Access regulations and issues
- Workplace vocational support
- Flexible work arrangements and Worker’s Compensation issues
- Possible carer involvement at work
- Guidelines for selection and interview of people with disabilities
- Links to government sites for work subsidy details

This information page may be an extension of the employment information page for individuals with SCI, Strategy 12.

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## **8.10 Addressing ways to enable Employment: *Flexibility of work arrangement and hours***

### **8.10.1 Recommendations and strategies to promote flexibility of work arrangements**

Flexibility in the workplace will be essential for some people with SCI. As employers noted some concern about implementing some aspects of a flexible workplace further education and information about these issues is required. Strategies for information for employers have already been outlined and are relevant to addressing flexibility issues.

There was a clear message from some employer and SCI interviewees that it is important for the person with SCI to know what assistance he or she needs in the workplace. As employers at this point do lack information about disability issues, being able to point employers in the right direction for funding incentives or access issues is likely to have a positive impact on employers.

**Recommendation 11 - Workshops for employers about employing people with disabilities**

This recommendation has been outlined previously (see page 95)

**Strategy 12 – Information about employment and employment opportunities for people with SCI**

This strategy has been outlined previously (see page 74)

**Strategy 14 – Information for employers**

This strategy has been outlined previously (see page 95)

## **8.11 Addressing ways to enable employment: *Workplace modifications and access and transport***

All of these areas are important in facilitating work and study for individuals with SCI. Information should take account of local needs where possible and be made available to employers and prospective employees through linkages and other means on the websites of local organizations. Information about modifications and access issues can be placed on websites as suggested in Strategy 12 and 14 and monitored through the employer group responsible for employer workshops as suggested in Recommendation 11.

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### 8.11.1 Recommendations and strategies to enhance workplace modifications, access and transport

#### **Recommendation 11 - Workshops for employers about employing people with disabilities**

This recommendation has been outlined previously (see page 95)

#### **Strategy 14 – Information for employers**

This strategy has been outlined previously (see page 95)

#### **Strategy 15– Access and Transport**

ParaQuad Tasmania and its members to maintain an involvement in Access Committees and access auditing. Information about access and transport issues in Tasmania could be made available on a dedicated page on the ParaQuad Tasmania website.

### 8.12 Addressing ways to enable employment - *Unpaid work placements*

Strategies to improve and enhance these experiences are those already discussed in relation to the use of services, particularly vocational rehabilitation and employment services. It is important that the person with SCI understands the parameters of arrangements, what his or her rights and responsibilities are and how to access an advocate if necessary. Providers could support this approach by emphasizing client inclusiveness in service delivery.

#### 8.12.1 Recommendations and strategies to enhance the experience of unpaid work placements

#### **Recommendation 5 – Client inclusiveness and whole of life approach**

This strategy has been outlined previously (see page 43)

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**Recommendation 11 - Workshops for employers about employing people with disabilities**

This recommendation has been outlined previously (see page 95)

**Strategy 14 – Information for employers**

This strategy has been outlined previously (see page 95)

**Strategy 4 – Advocacy**

This strategy has been outlined previously (see page 43)

**8.13 Addressing ways to enable employment: *Other kinds of work***

Bringing together people with SCI from a variety of backgrounds, including those engaged in unpaid community work, with key employment and vocational providers will provide an opportunity for information exchange. Those individuals participating in unpaid work may identify skills they have developed and ways to continue their development. Further skill development may assist in enhancing the work they are doing and may also promote involvement in paid employment in the future.

**8.13.1 Recommendation to promote recognition of the value of ‘other kinds of work’**

**Recommendation 10 – Regional fora/workshops**

This recommendation has been outlined previously (see page 75)

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## Suggestions for Future Research

Finally this study has identified two areas related to SCI that would benefit from further research. The first area, access to an optimum exercise regime and equipment, may be closely related to the employment of people with SCI. The second area, long term financial and health care needs for people with SCI is not necessarily related to employment although it may be. Nevertheless, it was such a significant factor emerging in this research, it would seem wrong to ignore it.

### **Optimum exercise regime and equipment**

There were marked differences in what interviewees knew about exercise and their use of equipment. There were such positive reports from some individuals who were using a range of gym equipment it seemed like the information should be shared.

Some individuals were able to buy equipment similar to that used in their rehabilitation at the Royal Talbot. Others had purchased second hand equipment and modified it themselves. Some individuals had little or no equipment and did not seem aware of the benefits that might come from its use. Those individuals who were covered by insurance benefits generally had greater access to equipment but this was not always the case, particularly for those who had expended their medical funding allocation. Individuals with SCI relying on the public system for funding and equipment were much less likely to have the equipment they would have liked. Some individuals also reported difficulties in accessing physiotherapy and/or were constrained by what was affordable.

A good exercise regime can be particularly important for people who are working as they have less time and energy to care for themselves and may be subject to increased demands. Health and well being issues identified by interviewees that may be assisted through exercise included deteriorating shoulders, the maintenance of healthy muscle and tissue thus limiting the possibility of pressure areas and the reduction in leg swelling and neurogenic pain.

It would be useful for all people with SCI to have access to information about optimum exercise equipment and an exercise regime and the ways in which it can improve health and well being.

*I am regaining stomach muscles – spasms down legs all the time – the more I do the more I feel. Can feel toes and feet. If they swell its very painful.* This interviewee noted that exercise takes away swelling and gives a much better quality of life. INT18

### **Future Research – Identifying a program showcasing optimum exercise equipment and exercise regime**

ParaQuad Tasmania to work with allied health professionals in the development of a best practice model for exercise equipment and exercise regime for people with SCI – what they need to know and to have. Results of the project would be placed on relevant Tasmanian health, rehabilitation and SCI websites.

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## Finances and Health

These two issues seem to be linked together, especially in the long term. Deteriorating health will also affect the ability to be employed and affect finances. At the same time access to adequate finances affects the ability to purchase or access specialist equipment and services.

The deterioration of health and strength in years after injury and increasing medical costs was very clearly an issue in this research. People in their 40's (and older but still within working years) reported deteriorating shoulder capacity and sometimes their general health was also an issue. There were instances of increasing pain and the need to switch from manual to power chairs and also to undergo shoulder surgery.

For those who were receiving life-long medical care and support through their insurers the future felt much more secure as they knew their health and well-being needs would be catered for. Those who were working had a salary and could also access the Spinal Account for financial assistance with equipment.

The situation for people who had received compensation under common-law varied. In some cases compensation payouts had been divided due to family breakups leaving the person with SCI with little financial back up. Yet, in most cases these individuals are not eligible to access the Spinal Account because they had received compensation. In other cases interviewees who had received compensation reported being comfortable financially and able to afford the equipment and services they needed.

For those who were not working and reliant on the DSP and the public system for care and equipment the present and the future was a financial battle. These individuals included former MAIB clients who had expended their allocated medical funding. It was very difficult for this group to obtain basic equipment and health care products and pay for medications and for normal living expenses – especially if they had a family. The situation for long term SCI individuals who had received Workers Compensation is not known.

The difference in their situation compared to someone whose medical care was assured was quite stark and financial difficulties were raised throughout the interview with these participants. The poverty and stress for people with disabilities in Tasmania who rely on the DSP for financial support has been identified by Hinton, 2006. She also stresses the extra financial and other emotional and physical costs associated with having a disability.

INT27 stressed the need for people with SCI to think long term about future financial needs for health care and equipment. She has life long medical care provided by her insurer and outlined what some of her needs are now - 19 years after her accident that left her with paraplegia. She is waiting on a shoulder reconstruction which she will have in Victoria. Her husband will travel with her as carer and will be provided with accommodation while she is in hospital. She requires a new chair every two years, a sheepskin every six months, as well as cushions, shower chair, hand control replacement and medication. INT27

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## **Future research – Ongoing health care – consideration of future funding**

ParaQuad Tasmania, the Premier's Disability Bureau and or Disability Council members and a Spinal Team and MAIB representative might undertake to obtain funding to explore the long term financial and care situation of people with SCI. This might include:

- the long term medical care and equipment needs of people with SCI, with either paraplegic quadriplegic or quadriplegic injuries;
- the implications of ageing after an SCI;
- a review of the adequacy of the medical allowance provided by the MAIB for individuals with SCI not on a Future Care program;
- the long term financial effects for people with SCI who had been covered by Workers Compensation policies;
- whether Spinal Account funding is sufficient to cover the needs of people with SCI long term.

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## Conclusion

The early chapters of this research provide information about SCI and its incidence in Australia. Legislation and policies and key services are summarized. The complexity of SCI means that there is a raft of legislation, policies and services that can be relevant to the needs of people sustaining this injury. The literature on employment of individuals with SCI is also summarized and further references to relevant literature are made throughout the study.

There are five case studies included in this research that illustrate important aspects of employment after an SCI. They include: employer support and a flexible return to work; ongoing workplace flexibility; the importance of computer and assistive technology in enabling work after SCI particularly at home; determination to succeed against quite a few barriers; and, the value of volunteer community work.

The literature on employment of people with SCI and the results of this research highlight the close connections between employment for people with SCI and adequate access to services and support. In this study access to health and community support information and services and the experience of using services were found to be extremely uneven. Some individuals had or were receiving excellent care and support, while others experienced services that did not satisfy their requirements.

One reason for this unevenness in service provision may be that Tasmanians experience many months away from home during their rehabilitation at the Austin and Royal Talbot hospitals in Victoria. A second reason may be the small population of people with traumatic SCI population, estimated at around 200-230 with more than half living in regional and rural areas. Being away from Tasmania in the months following the injury puts limits on access to information about service provision and contact with service providers at home. The small scattered population of SCI individuals may impact on service response. Whatever the cause, many individuals returning home experienced great frustration in finding out about and accessing the services they required.

Strategies suggested to overcome some of these effects aim to increase information to newly injured SCI individuals. They include the provision of Tasmanian peer support during rehabilitation and after coming home and the use of internet technology eg internet forums, web-cams and You Tube to enhance contact with service providers prior to returning to Tasmania. Emphasis is placed on the importance of weekend home leave from rehabilitation for Tasmanians with SCI. This will also help to develop links with service providers from an early stage and possibly enable involvement in home modifications. Closer communication and coordination between organizations, people with SCI and their families may also assist in attaining a more even standard in service provision.

The strategies put forward aim to empower people with SCI and their families. They themselves need to be able to: share information; know what services are available and how to have maximum involvement in those services; understand what standards of care are appropriate and what to do when it is not. Information, peer support and advocacy are central

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to the proposed strategies. At the same time, suggested strategies for service providers aim to increase coordination between agencies and client involvement, another empowering aspect.

This study highlights the importance of the role played by families. From the very earliest time they provide support which may include financial assistance, personal care, transport, community access and accommodation. While these supports may be indirectly related to employment, some families were directly supporting the employment and study activities of the person with SCI by providing transport and sometimes assisting with actual work tasks. Families are the constant that 'got people through the SCI experience'. It follows that families who are themselves traumatized by the SCI event, need support for the role they are playing and strategies are put forward to support families from the earliest time. Support may be even more important in Tasmania than in other States because of the small number of people with SCI and the uneven spread of services.

The importance of maintaining networks after an SCI injury was identified as highly significant in returning to or taking up new employment, training or study. Most interviewees who worked at some time since their injury did so through the assistance of their informal family and friendship networks or previous employment networks. The current system of undergoing rehabilitation outside Tasmania jeopardizes these networks causing people to grow apart and to lose contact. Among other strategies to sustain networks including internet technology and peer support, an early vocational intervention approach is suggested.

All except five people interviewed in this research used computers and the internet for a wide range of services and two of these people were in the process of 'connecting'. This presents a great opportunity to enhance information flows to people with SCI, maintain networks in Tasmania during the early acute rehabilitation period and share information with others after coming home.

The delivery of vocational rehabilitation and employment services appeared to be as uneven as experiences of health and support programs. There was evidence of people dropping out of the system in the past and in some jeopardy of doing so in the present. The importance and the possibility of long term ongoing support are discussed together with ways to re-enter the system if unemployed. The need is emphasized for clarity about the services being offered and the timeframes of support. Suggested strategies again focus on self-empowerment as well as the provision of outreach programs and workshops providing links to health, community and vocational and employment service providers.

Employers interviewed for this research were very positive about employing people with disabilities in their organizations and several organizations did so. They were prepared to undertake workplace and access modifications 'at a reasonable cost' were prepared to allow some flexibility in hours and days of work but were less prepared to support 'work from home'. Flexible arrangements may be the key to being able to work or study for some people with SCI who may need extra time to attend to the many complex aspects of SCI related well being.

Employers, however, were generally not well informed about government incentives available to organizations employing people with disabilities. Nor did they appear well informed about the kind of supports that might be required by people with disabilities and

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there were some possibly unfounded concerns around access and capabilities. Generally it seemed to be a case of, ‘of course we are willing to employ people with disabilities but we don’t really know much about the process.’ Strategies (including employer workshops) are suggested to increase employer awareness of employment issues for people with disabilities, in particular SCI, and information sources. Importantly the information should be easily accessible, perhaps linked to websites of local organizations.

At the same time individuals with SCI also need to know about the supports and incentives, including workplace modifications, the rights and responsibilities of employers and employees, to help them argue their case for employment and assess their own workplace needs.

In this research those individuals who were working, loved working. The benefits outweighed the costs. Their workplace relations were good and ranged from having close connections to fellow workers to believing that good work relations depended on being able to do the job. Employers believed that people with disabilities made loyal employees and that staff became more aware of life’s challenges when they worked with people with disabilities and also more sensitive to each others needs and those of their clients.

Return to work or study for individuals with SCI, however, could be daunting and exhausting. This was particularly so in the early stages of work but continued to a lesser extent over time. It also took time to gain confidence in themselves and to be comfortable about the way others related to them. A major issue for individuals with SCI in employment may be the extra ‘wear and tear’ on the person with SCI when working or studying and the reduced amount of time to care for oneself. Strategies to assist in return to work focus on empowerment and support through counseling and peer support.

There is paid work and unpaid work and unpaid work includes both work trials in preparation for paid employment and volunteer work without a paid employment goal. While the work trial experiences were mixed they were generally regarded by interviewees as a valuable experience. Although this research is about paid employment, the contributions to the community being made by people with SCI in an unpaid capacity were great. As involvement in volunteer work fosters skills and confidence, it may well provide a stepping stone to employment when the time is right.

This research has also identified other areas for future research that relate directly and indirectly to employment. They include research to develop and present information on an optimum range of exercise equipment and programs. There was a very big difference in what people were doing to keep fit and the equipment they were able to access. However, several interviewees noted the importance of exercise in areas such as swelling and nerve pain reduction. It would seem that this information should be shared. The second area identified for future research was the long term health issues and lack of finance to address these and other problems. As both these issues can impact on employment as well as quality of life, further research would be useful

The recommendations and strategies for people with SCI stemming from this research focus on empowering people with SCI and their families and addressing service related issues with the aim of increasing employment opportunities. Recommendations and strategies for service

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providers and other agencies focus on increasing client inclusiveness, increasing service standards and equity of access. Strategies relevant to employers are about education, information, networking and chipping away at the barriers to employing people with disabilities.

ParaQuad Tasmania, the organization commissioning this research is the nominated 'driver' of these strategies and recommendations. Although they are a small organization, the Executive believes that through prioritization and partnership with other sectors the strategies are achievable.

In fact the core philosophy informing the strategies lies at the heart of ParaQuad Tasmania, the provision of information, support and advocacy aimed at promoting the self-reliance of people with SCI, a quite remarkable group of people.

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## Appendix 1

### 1.1 Questions for SCI interview participants - Ways to Work Project

#### Demographic/biographic details

- Age
- Gender
- Length of time since injury – age at injury
- Marital status
- Number of children
- Income range
- Cause of injury
- Level of injury
- Have you received any compensation for your injury
- Are expenses covered by an insurer/which scheme
- Educational level
- Employment status and occupation - pre-injury
- Employment status and occupation - now
- Have you been in paid work at all since injury
- Education/training undertaken post injury

#### The road to 'now' – Initial rehabilitation

- What were some of the effects of distance in your early rehabilitation period
- Thinking back to the first stage of rehabilitation what things were most likely to have helped/hindered employment in the future
- When did you start thinking about return to work and the kind of work you might do

- 
- Did you have enough information about what was happening to you and to plan for the future
  - What other supports did you have at this time  
Prompt - Family, friends, employment networks
    - In what ways were they important
  - What were the most positive/negative aspects of this time and was there any effect on obtaining employment later

#### **The road to ‘now’ – Coming home –**

- What was it like coming home and making connections with the services over here
- What other supports were important at this phase  
Prompt - Family and friends, peers, role models and other
- What needed to be put into place after returning home and did these things work out for you  
Prompt – Transport, case management, communication, personal care equipment and assistive devices, accommodation

#### **The road to ‘now’ - Vocational rehabilitation –**

- What sort of help did you have to find work, retrain or study when you came home
  - How did it all happen
- Can you describe what the process was (thinking about the things that were most positive and not so helpful)  
Prompts - Case management – easy to contact – choice, complaints mechanisms, information, choices for the future/refocusing ideas on a different career, equipment and assistive devices, personal care
- Was there a possibility of return to former occupation or workplace
  - How did it happen
- Were there other influences in preparing for work or study eg. family and friends
- What kind of things prevented or made it hard for you to return to work or study eg health, access to services
  - How were they overcome
- How important were role models in thinking about future employment

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## **Back to work/study**

- How long after your injury did you return to work/study
  - Full or part time
- What things have prevented you going back to work
- What kind of employment support did you have on return to work/study
  - How did this work for you
  - Length of time support provided
  - Flexibility of return
- Networks – were these important after you returned to work/study
- Can you describe what it was like for you going back to work/study
  - Physical and emotional experience
  - How could it have been made easier – prompts -Workplace and campus access, workplace modifications, equipment, peer support
- Have you worked/studied continuously since returning to work/study
  - what kind of things disrupted work/study
- What are relations like with your employer and other employees (include after work social interaction) other students and lecturers
- Some people talk about the benefits of working and also the costs of working – financial and otherwise. What have been the costs – and benefits for you.
- Would you like to change your job/occupation or some aspect of your current position
- Are there any things happening now that make it difficult to get by at work
- If employment didn't work out, how would you go about finding another position, getting back into the system.

## **Financial effects**

- What was the effect of your injury on your financial situation
- If received compensation
  - what did this mean for you
  - what was the process like
- Are you aware of the various aspects of the Commonwealth's Welfare to Work Program

- 
- Will it affect you in anyway
  - How much has your financial situation been an element in your return or non-return to work

**General**

- Looking back over your SCI experience what things made it most difficult for you to manage
- What helped you the most to get through the experience

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## 1.2 Employer Questions – Ways to Work Project

- Do you have specific policies on employment of people with disabilities
- Are you currently employing people with disabilities/SCI
- Have you thought about how you might attract pwd to the workplace
- What kind of things would you want to hear about the disability from prospective employee
- Would you want to know a prospective employee has a disability

Prompts:

before selection

at time of interview

would you encourage the person to talk about their disability in relation to ‘doing the job’

- Would you have any concerns about employing people with disability

Prompts:

Workers comp costs and claims

Illness

Cost of modification/assistive technology

Discrimination

‘Letting down the person’ if it didn’t work out

Effect on other staff or customers

Effect on work practices and policies

- Would you have any specific concerns about employing someone in a wheel chair
- Who would you talk to about your concerns

- Are you aware of various schemes to assist employers – eg

Prompts:

Support Wage Subsidies

One off payments at commencement of employment

Apprenticeship schemes

Modification finance

Assistance with modification design

- Is there enough or the right sort of information out there about employing people with disabilities – is it easy for you to access?

- 
- Would your organization be open to allowing flexible hours and work place arrangements eg.

Prompts:

- Part time/flexitime arrangements
  - work from home
  - a carer to come to the workplace if necessary
- After the initial workplace assessment about the person's needs other things may crop up from time to time eg. heating, parking, new access issues –  
What kind of arrangements do you have that would enable employees to express their needs?
  - What kind of support would you want if you were employing someone with a disability eg vocational rehabilitation, employment agency support, occupational therapy, diversity training/
  - What would be the benefits to your organisation of employing someone with a disability?
- Prompts:
- Corporate image/good citizen/reflecting community profile
  - Economic (wage subsidy etc)
  - Increasing workplace diversity and tolerance
  - Opportunity to review workplace policies and practices
- Are there any other comments you want to make that might be useful for people with disabilities/service providers/other employers to know.